

# 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  
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## Turning “Me” to “We”

By Edgenie Bellah, Family Support, Texas Deafblind Project

*Abstract: Find out about the first class of the Deafblind Family Leadership Series and how they are putting their learning into practice by being top-notch leaders within their communities.*

*Keywords: Family, blind, deafblind, leadership, training*

*Turning “Me” to “We.”* Although Dee Dee Elberle, Grant Project Coordinator with The Arc of Texas, originally shared this phrase as a definition for advocacy, twelve parents from around Texas have adopted it as their unofficial motto for the yearlong adventure they are taking together as members of the first *Deafblind Family Leadership Series*. Sponsored by the Texas Deafblind Project, the new series assists family members to hone their leadership and mentoring skills so that they can have a strong voice in the decisions being made about services and supports for their children with deafblindness.

From the moment the Class of 2005 roster was finalized, they began setting themselves apart from traditional training participants. The small class of twelve represents the diversity of Texas and the parents have already demonstrated an interest in making an impact on services and supports for children with deafblindness in their local communities as well as statewide. Nominated for the class by professionals in the fields of education and rehabilitation, and officers from DBMAT and TAPVI, each participant made a wholehearted commitment to participate in three trainings in Austin, complete Project SPARKLE, participate in a variety of distant education activities, and do three follow-up projects.



*Front Row (left to right): Denise Sewell (Gilmer), BJ Bond (Wylie), Michelle Goodwin (Ft. Worth). 2nd row: Wayne Thompson (Sweetwater), Alicia Porras (El Paso). 3rd row: Teresa Dafft (The Woodlands), Mira Lopez (Copperas Cove), LaChandra Noel (Houston), Alaine Hinds (La Porte), Yolanda Scarlett (Coppell), Edgenie Bellah (TSBVI). Back Row: Jennifer Holweger (Pflugerville), Lisa Wick (Burkburnett).*

The class came together for the first time in October. The weekend was spent studying the basics of deafblindness. Building on what they learned through Project SPARKLE, participants received training from the Texas Deafblind Project staff to broaden their understanding of deafblind issues beyond what they already knew about their own child. After the training, each of the parents completed a small follow-up assignment that demonstrated their understanding of deafblindness. Follow-up projects for the class included giving presentations to parents and teachers, writing articles, working with the media to increase awareness, and parent mentoring. Although the intent of the projects was to illustrate their knowledge, the actual outcome was a powerful demonstration of the talents of these parents!

Everyone came back together the first weekend of December to focus on understanding the community, educational, legislative, state agency and medical systems, and how to provide advocacy and leadership within each system. The follow-up assignments were designed to demonstrate the participant's leadership skills. Again, the high caliber of the class came through clearly. Emerging from the class were projects such as serving on state level workgroups, serving as editor for a special education booklet for a local school district and presenting at a family conference.

Becoming effective mentors will be the focus of the training session in late April. The best support a family receives sometimes comes from other families who have also "been there," and as leaders in their communities, class participants have already stepped up to the plate and offered this invaluable support to other families. Because this is the last training in the Deafblind Family Leadership Series, the follow-up assignment will combine all the training into a systems-change project. Again, showing their dedication to the deafblind community, several participants have already started their projects.

To accommodate the participants' busy lives while attempting to quench their continued thirst for knowledge, the training includes some distance education activities. Beginning in the fall, the class began learning more about the Special Education process by reviewing several documents and articles and going through a guided book study. Through group email discussions and a couple of telephone conference calls, everyone will have an opportunity to discuss what TEA, Advocacy Inc., and The Arc of Texas have to say about being an effective advocate for children with disabilities. Using a similar format, the class will study active learning and Orientation and Mobility more in-depth for students who are deafblind multiply disabled.

And if all this weren't enough learning to jam into one year together, the class has yet another project to complete in order to graduate. To pull everything together, each participant will be completing the *Parent Portfolio Notebook: Turning Life Experience into Credentials* workbook, a tool developed by the Family Resource Center Network of Los Angeles County. This workbook will help participants take those incredible life experiences they have had caring for their loved ones with deafblindness and turn them into credentials that open doors to leadership opportunities.

Balancing family responsibilities and leadership activities can often be hard. However, maintaining that balance is essential in order to be an effective leader and to avoid burnout. Throughout the training, participants receive information and support through telephone conference calls, group email discussions, being mentors with each other, and individual consultations to develop strategies that will help them proactively take care of their personal needs while also being leaders. This strand is affectionately called "Taking Care of Ourselves." This aspect of the training is used to remind ourselves of the importance of bringing joy into our own lives as well as the power of "we."

I anticipated being the energy and planner behind the training, but this class clearly stepped up to the task of designing their own learning opportunities. We've experienced several unanticipated outcomes of the training. The class quickly came together as a cohesive, effective group that is building upon each person's skills and talents. The degree of mentoring and resource sharing has flowed well beyond the twelve parents to benefit families across the state. The follow-up projects far exceeded any expectations we had when we wrote this activity into our state's deafblind project grant.

In the Family Section, you will be hearing from several of the Deafblind Family Leadership Series participants from this first class. This summer, applications will be going out to pull together the next group of potential leaders. So don't be surprised when one of these talented leaders taps you on the shoulder and says, "You're next!"

## How I Learned What O&M Means

By B.J. Bond, Deafblind Family Leadership Participant, Wylie, TX

*Abstract: One of the Deafblind Family Leaders share her experiences in learning what O&M means for her young daughter who has multiple disabilities.*

*Keywords: Family, blind, deafblind, Orientation & Mobility*

I'll never forget the very first IFSP for our younger daughter. Milena was only three months old and had already been diagnosed with Cortical Visual Impairment before she ever left the NICU. There was a teacher of the visually impaired present (TVI) at the IFSP and vision services were set at once a week. As we were signing the papers, she leaned to me and said, "I'm certified in O&M, so I'll be working on some of that too even though it's not in the IFSP yet." She smiled and patted my hand, so I assumed this was a good thing and smiled at her with a convincing, "Okay."

Whatever O&M was, she was welcome to do it. Milena had endured what we call "a bumpy start to life," which amounted to an extreme lack of oxygen at birth (she was resuscitated after delivery), followed by a massive cerebral stroke during her first week struggling to survive. We knew we were going to need all of the help we could get for Milena to make any progress at all. So whatever this O&M thing was that the helpful vision teacher would be squeezing in was certainly fine with me.

During that first year, I learned how to explain to my friends what the TVI does with my daughter. They would look at me puzzled, asking what on earth would be done during the times she came to our home. I finally learned to say, "the teacher of the visually impaired works with Melina on learning a particular objective through directed play with specific toys." It sounded fancy enough. But I never mentioned that the vision teacher was also doing O&M. There was no way to explain what I still didn't know. During her visits, I noticed that our TVI was using descriptive words like, "behind", "beside," and "next to," as well as colors of objects such as "the red ball" or "the pink pom-pom." I thought she was insane for using these specific terms that Milena obviously could no more understand than our cat could. Why was she so insistent on specifics?

The answer would come during our second IFSP meeting, when O&M services would actually be added in formally. It was here that O&M was spelled out for me, and I learned that it meant Orientation and Mobility. Once I had the official name, I bravely stepped in by asking what exactly would be done during the O&M session. The TVI/O&M teacher explained that she would be working on helping Milena get oriented so that

she could move about in her world. Now this really sounded crazy. Milena had just been diagnosed with cerebral palsy and wasn't even sitting up by herself, much less trying to crawl or walk or anything else. And we're talking about moving through her world? The look on my face gave me away. The O&M teacher smiled at me and said, "I know she's not moving anywhere on her own. But if we start now, giving her ideas about relations in space—directive and descriptive words—then when she is starting to move on her own, she'll already know where her left and right are, along with beside her and behind her, as well as all the colors to help her navigate. We have to plant that seed now." Okay, now this made sense. We were laying groundwork for the day she would walk and tool about on her own.

In the next few months, it became apparent that walking was a further-reaching goal than we had thought. Milena had finally just learned to keep herself in the sitting position without holding on to anyone. She made it perfectly clear that she wasn't going anywhere alone. During O&M sessions, the teacher would get down in the floor with her and try to get her in different positions: resting on her hands, kneeling, all fours. This looked like the same work that the Occupational Therapist was doing. If Milena wasn't going to walk, and everything during O&M seemed a repeat of the occupational therapist visit, why were we even keeping O&M in the mix?

It seemed pointless until one afternoon when I was playing with Milena and I tried to convince her to get on all fours to play. By this time, we could tell she could see people, and she would often look at us right in the eye. On this particular day, she began fighting me immediately so I somehow positioned myself where I could see her face better and she would hopefully see me. She looked up at me and cried out with the most pained and scared look on her face. I instantly scooped her up and held her close to let her know that she was okay. When I mentioned this the next day to the O&M teacher, she looked at me and simply said, "Well, of course, wouldn't you be scared if you had always felt something underneath you your whole life and suddenly someone was trying to take it away?" A million lights, buzzers, and bells went off right then for me—I GOT IT.

Orientation and Mobility wasn't about teaching someone to walk around in the world. It was making someone who is visually impaired want to move through the world. This explained why the teacher insisted that I carry Milena next to me as much as possible instead of in the baby carrier. It would help Milena learn the way a person moves around. Because she is visually impaired, she's not as likely to just start moving through her world on her own. To drive this home, I decided to get in some of her favorite positions on the floor and close my eyes. I imagined that I didn't know the room I was in, or anything about it, and that someone was trying to make me move. This was so scary! My heart ached for my little girl, who now, understandably, never wanted to leave the familiar confines of our living room floor.

But we worked and worked, as other parents do, and Milena did leave the living room floor. She is four years old now and will crawl from the dining room to the living room (a straight shot, but still hard to navigate) to get to her favorite toy. She also recently has begun pushing her own wheelchair, which seemed years away. She can wheel herself around the house provided someone is there to help her back up when she hits a corner, wall, or piece of furniture. She has become braver out in the world, attempting to wheel herself through school to her classroom as well as through Home Depot on those slick cement floors. (We were running to keep up!) She also discovered how the automatic doors work at Walgreen's, where her father had to chase her outside to keep her from rolling right into the parking lot. Yes, we have come a long way with O&M, and as evidenced from the Walgreen's experience, we still have a long way to go. But isn't it all about the journey anyway?

*Editor's Note: On behalf of the Deafblind Family Leadership group, congratulations to BJ, Roy, Katrina and Milena on their double blessing of twin boys, who are due this summer.*

## Time to Think – Preparing for Your Child’s Hospital Stay

By Teresa Dafft, Deafblind Family Leadership Participant, The Woodlands

*Abstract: One parent shares her pointers for preparing for her child’s hospital stay.*

*Keywords: Family, blind, deafblind leadership, hospital tips*

Our son, Travis, had a pretty rough start with life. Emergency C-section, emergency resuscitation, emergency life flight to Houston — Emergency, Emergency, Emergency. During those times, we didn’t have time to stop, think and ask questions. It just happened so fast.

That was 14 years ago, we have been fortunate that Travis has not been in the hospital since he was two. Not because he has been in perfect health but because he has a pediatrician who believes that under certain situations a child will do better at home with nursing care as opposed to lying in a strange bed in a room that actually has more germs than your home!

Then the year 2004 came rolling around and a new journey began. In January, Travis had to have bilateral hamstring lengthening. It was a fairly easy operation, which was performed in day surgery. Afterwards, he was in long leg casts for two weeks before we were able to resume our regular routine. For us, our regular routine meant a summer of fun at grandma’s farm and a growth spurt!

Travis has always been monitored for scoliosis because he is in a wheelchair and his muscles don’t work correctly. Well, this growth spurt caused his curve to go from 30 degrees to 74 degrees in 3 months. It was causing his pelvis to shift, making it harder for him to sit.

Waiting in the doctor’s office to find out what needed to be done to fix the problem, I remember thinking that perhaps the doctor would increase the support of the brace or maybe have him wear it at night. When we met with the doctor, he shared with us what was really going on. From there, everything became a blur...“surgery”...“lose ability to sit”...“50/50 chance”...“ventilator”...“ICU”...“12 hour surgery.” Words that can stop you in your tracks. The only difference this time was that the surgery was not an emergency and we could take the time to stop, think and ask our questions.

Travis came through his back surgeries with flying colors and now almost 6 months postoperative he is doing great. We know that a lot of parents will be facing the situation of surgeries and hospital stays, and as result of our experience we learned a few pointers that we would like to share with other families.

- If the surgeon is different from your regular physician, don’t hesitate to inquire about him. Ask your regular physicians, other parents and even hospital caseworkers.
- Meet with the surgeon more than once. We met with Dr. Hanson to discuss the surgery. Then two weeks later we met again with all of our questions written down for him to answer.
- Write down all your questions. **NO QUESTION IS A DUMB QUESTION WHEN IT COMES TO YOUR CHILD’S HEALTH.**
- Have the surgeon explain exactly what he is going to do step-by-step. Have him explain the possible outcomes—both the good and the bad.

- Ask which hospital your surgeon prefers. Many have privileges at several hospitals.
- Ask which anesthesiologists they like to work with and be sure to get a written list. Doctor's do not get to choose their anesthesiologist but parents can! However, YOU MUST REQUEST IT DURING THE PRE-ADMISSION BEFORE SURGERY. Travis was going to be on the table 12-14 hours. We wanted someone who our surgeon was comfortable working with.
- Ask if blood will be needed during the surgery. Call the blood bank yourself because the doctors do not know how the blood donation system works.
- Call the hospital. Most will give you a tour and arrange for you to talk with the child life specialist. Explain your child's needs. Travis was going to be in the hospital awhile so we asked about switch toys and other items he could use. We found out that at Texas Children's Hospital people could e-mail Travis every day and the hospital staff would deliver his messages to him. We sent the address out in a school memo and he got lots of email.
- Make a small laminated chart or book that explains how your child communicates. When we left him at the Operating Room doors, we knew that the nurse could at least communicate with him because of his book.
- Make a sign for the hospital room that gives people a quick reminder of how to interact with your child. We made a small sign to put on his door that said,

\*\*\*Please do not touch Travis until you have  
introduced yourself to him, then gently touch him.  
Explain what you are going to do BEFORE you do it\*\*\*  
I UNDERSTAND MORE THAN YOU THINK I DO – Travis

- Keep a scrapbook near your child to help people learn more about your child than just the medical stuff he or she is going through. We did this by placing ~his special book near his bed that has lots of pictures of Travis and all the cool things he does. This really helped to show the medical personnel that Travis was not a syndrome, but a typical teenager who did things a little differently.
- If your child has been getting his medication on a regular schedule, make sure you inform the doctor and his nurse so that this schedule will not be interrupted. Travis has been getting his seizure meds at 7am, 12:30pm and 6pm for the last 12 years. The standard hospital medication schedule is 9am, 2pm and 9pm. If we kept to this schedule, his seizures would have really been bad.
- Set up a shift system for the parents. During the surgery both of us were waiting for Travis and we were both there for him in recovery. Then we took shifts: one went home to sleep while the other parent remained at his bedside. This allowed us to not be so fatigued (yes, you are still tired) and cleared headed when doctors came in to talk to you.
- Have one person act as your information source to those who want to be kept updated on how your child is doing. This way you only have to make one call and you can focus on your child. When you get home from your shift, you can call those you would like to talk to in person. In

addition to our family and friends, we made sure we had one person designated at his school and our work to spread the word about Travis.

- And most importantly, after the surgery and hospital stay is over, drop a note to the hospital to express your appreciation and share what your child's hospital stay was like. This should include noting anything went well and that could have been done differently. In our letter, we especially thanked his anesthesiologist, because she was so good at taking care of our son. She kept him off a ventilator and made his hospital stay 10 days shorter. She also came by the floor to see him and still asks about him through our neurologists.

We hope our experience and the things we learned while Travis was in the hospital will help another family. We know they will certainly come in handy for our family when we face this again this fall when Travis is scheduled for another surgery.

### **Supporting Friends During Hospital Stays**

By Alaine Hinds, Deafblind Family Leadership Participant and TAPVI Co-Chair, LaPorte

*Abstract: Pick up on some wonderful tips for supporting parents while their child is in the hospital.*

*Keywords: Family, blind, deafblind leadership, hospital tips*

No matter how prepared I try to be before any surgery or scheduled hospital stay, I always seem to get caught off guard. There is always the unexpected stay after day surgery or the longer than usual stay in the hospital. During these times, I depend heavily on my family and friends. I find that my friends who also have children with special needs seem to be able to tune into what I most need during these trying times. Most of them have been in similar situations and can relate. Here are some suggestions on making any stay in a hospital a pleasant one for a friend and their family.

For major surgery or hospital stays, always consider what you may want and probably forgot. One of the best presents I ever received was a multi-pocketed bag put together by my Sunday School class before my daughter had hip surgery. We anticipated a 5-hour surgery followed by a 2-day hospital stay. The bag contained several bags of chips for the nervous parents who were afraid to leave to get breakfast for fear that we would miss a call from the operating room. Gum and mints were tucked inside as well as change to be used in a vending machine. Pain reliever, Tums, and chewable Pepto Bismal helped to calm our nervous stomachs and headache. A magazine and short book of "mommyisms" helped to pass the time and did not require too much concentration. Some samples of perfume and make-up helped me always appear presentable as the days wore on. A nail file was included and turned out to be the most used item. A small toothbrush and toothpaste was included. Pen and paper were handy to jot down what the doctor said and remind us of additional questions we wanted to ask. Cards of encouragement and support from members of the class reminded us that a lot of people were pulling for us and a lot of prayers were coming our way.

Additional things I would include would be a pair of socks. Is it my imagination or is it always that cold in the hospital at night? A long distance calling card comes in handy if your friends have family out of the area

that they may want to update. Hospital rules usually do not allow people to use cellular phones inside of the hospital and I find that I am always afraid to step away from the waiting area or my child's side. Cheap phone cards can now even be found in "dollar" stores.

I have found that it is difficult to eat in a hospital if your child is young and needs someone in the room at all times. I am usually reminded to eat and at that point-anything tastes good. Microwave popcorn is one of my favorites. Microwaves can be found at the nurses' stations, in waiting rooms and sometimes near vending machines. You can also buy some pretty good microwave meals that do not require refrigeration. Drinks become very expensive if you have to rely on the vending machines. A six pack of their favorite soft drink can be put over ice that is available at the nurses' station. For those who cannot function without coffee, you can purchase single servings of a variety of instant coffees or teas. Hot water can be obtained from the nurses' station or waiting rooms. Speaking of food, the quick delivery of take out to the hospital is always appreciated. Check with the nurses and they can tell you what is available and what they recommend. I have picked up food and delivered it to my friend's room or in a pinch, pulled up to the lobby and had them meet me to get their hot food. You can also prepay to some delivery pizza places and let them deliver. If the parents are in the hospital for more than a few days, food not prepared at the hospital is a real treat.

After the hospital stay, most of us will agree that it is great if someone stops by with a meal or brings a few fresh groceries. We are usually so exhausted from our hospital stay and are truly in need of quick and easy food. Even a bucket of chicken means I don't have to cook that night. Someone who offers to quickly vacuum or dust in my home is never turned down. Video or DVD rentals are also appreciated so the family can relax at home together.

Let's not forget about any siblings who may be feeling left out and confused. A small present for them helps to ease their tension. Offers to watch the siblings or bring them to visit in the hospital are greatly appreciated by the parents. If they are unable to visit, I sometimes offer to take a digital picture of the child with their parents to e-mail to the siblings to assure them that their brother or sister is doing okay. It helps them to feel included and understand what is happening at the hospital. A disposable camera can also be left at the hospital to capture and document the hospital stay. I wish I had thought to take pictures after various surgeries to put in my daughter's scrapbook later.

I think most of us always remember to bring something special for the patient. It could be a rattle or teether for a baby, a coloring book or paint with water for a child, or a book or video for a teenager. Many hospitals have VCRs and Playstation or Nintendo available to be used by the patients. For children with no vision or the ones who have had eye surgery, magnetic playsets, play dough, talking storybook or a musical toy would be appreciated.

These are just some thoughts about what you may do to help a friend through their hospital stay. You can never go wrong if you put yourself in their shoes and do what you would want someone to do for you. If their stay turns out to be longer than anticipated, stop by their house and pick up clean clothes or buy them a new T-shirt. Ask them if they need anything. Most of us appreciate the help and support our friends give us. Your thoughtfulness and kindness can make a difficult time more bearable. Your friendship is needed most during these hospital stays.

## Oh Yes You Can: How Creativity and Assistive Technology Helped My Child to Do Class Reports

By Yolonda Scarlett, Deafblind Family Leadership Participant, Coppell, Texas

*Abstract: A parent describes how her son, who is nonverbal, has limited communication skills and is not able to write or type, did both oral and written reports for class projects.*

*Keywords: Blind, Deafblind Family Leadership Series, Assistive Technology, inclusion strategies*

It is my hope that sharing and describing Isaiah's participation in class reports will inspire and encourage other parents, teachers and education teams to either open the door or open the door wider for children with significant multiple impairments to participate in class projects and activities. I also think that is important to keep in mind, that a child with significant involvement will not gain the same knowledge or have the same experience as his or her general education peers from some projects and activities. However, creativity, assistive technology, modifications and collaboration between special education teams and parents can give children the opportunity to participate and be a part of many activities and projects that their peers are doing.

Creativity, assistive technology and modifications have given my son, Isaiah, the opportunity to participate in class projects this school year. Isaiah has done not one, but two oral reports and a written report. Isaiah is currently nine years old and in the 2<sup>nd</sup> grade. Isaiah spends the majority of his school day in a self-contained environment and he spends small blocks of time throughout the day in his 2<sup>nd</sup> grade general education class. Isaiah is deafblind with multiple disabilities and he has Cornelia de Lange Syndrome (CdLS). Isaiah is significantly challenged in every area of his development. He is nonverbal, he has limited communication skills and he can neither write nor type. I affectionately refer to Isaiah as "My Little Engine That Could!"

I vividly remember the day in January when I was reading the information from the 2<sup>nd</sup> grade homework assignment envelope. The class newsletter enclosed included information about a month long focus on weather and that the students would present a weather report in class. At the time, I was not even thinking about Isaiah and doing a weather report. I just thought that would be another assignment he wouldn't be able to do. After reading the details about the report, I flipped to the next page that had the Weather Forecast Schedule—I was still not thinking about Isaiah and doing a weather report. I gasped and I believe my heart skipped a beat when I saw Isaiah's name for Thursday, Jan 27<sup>th</sup>! After I recovered, determination superseded all my doubts and I was bound and determined somehow, somehow that Isaiah would do a weather report. I didn't know how, all I knew at this point was that on Jan. 27<sup>th</sup>, Isaiah Christian Scarlett would do a weather report in class!

Isaiah did do a modified weather report in class. Isaiah's report started with a brief explanation to the class that Isaiah's weather report would be an interactive report between Isaiah and his classmates and that throughout the report volunteers would be needed to read some information. Next Isaiah started his report by pushing the button of a Big Mack and a previously recorded message played, "Today's Weather Report by Isaiah Scarlett." Isaiah's younger brother, Ervin who is in kindergarten, proudly recorded the message into the Big Mack. A Big Mack is a simple assistive technology device that allows one message to be recorded; each time the button of the Big Mack is pushed, the recorded message plays. For the next portion of the report six volunteer readers read the required elements for the weather report. For the required elements of the report my husband, Russell, cut a couple of poster boards into six strips and wrote some of the required information. For example one strip had the high and low temperatures for the day, another described the wind speed and direc-

tion, another had the forecast for tomorrow etc. Also, one of the poster board strips had written on it medium rain in the afternoon. For that Isaiah used some of his props to demonstrate rain. There was an umbrella next to Isaiah and Isaiah was holding a spray bottle filled with water and with some physical assistance Isaiah pushed the trigger of the spray bottle and water sprayed on the umbrella. Also, there was a requirement for suggestions for clothing to wear according to the next day's weather forecast. When that poster strip was being read, Isaiah with assistance held up a jacket, raincoat and umbrella. To end the report, Isaiah, with assistance, pushed the button of the small cassette tape recorder and it played "The End" which was previously recorded by Isaiah's brother, Ervin.

In February, Isaiah did both a written and oral report for his Famous American Project. Isaiah did his reports on George Washington Carver. Both reports were challenging, but the written report was more challenging. Since Isaiah is not able to write or type, I kept thinking if my husband or I wrote a report that wouldn't be from Isaiah—it would be our writing getting graded. So, for Isaiah's written report, he turned in an illustrated report about George Washington Carver. Isaiah participated in preparing the supporting materials for the report.

On the cover page of Isaiah's illustrated report, Isaiah used different colors of paint to finger-paint George Washington Carver's name. At the bottom of the page, Isaiah used his fingertips to make a multicolored design of dots. Isaiah required maximum to moderate physical assistance to finger-paint the letters in Mr. Carver's name. At the top of the next page, a simple sentence was written: George Washington Carver was born in 1864 in the state of Missouri. With a pencil 1864 was written in large numbers and glue was placed over the numbers. The plan was for Isaiah to assist with squeezing the glue, but he had different plans and didn't assist with that part. Isaiah did place gold sequins over the glue to make a shiny, gold 1864. Isaiah's hand was guided into a bag that had the gold sequins and then his hand was guided to the area where 1864 was written. A piece of construction paper was cut into the shape of Missouri. Isaiah helped to pat the paper cutout of Missouri down on the paper. On the next page at the top "Young George loved plants" was written. Isaiah, with assistance, used green finger paint to make plants. For the next page construction paper cut into the shapes of Iowa and Alabama were used to illustrate where Mr. Carver went to college (Iowa) and where Mr. Carver lived after he graduated from college (Alabama). Isaiah patted the cutouts of the states on the paper and a simple sentence was written about what each state illustrated. For the remainder of the report different things (i.e. peanuts, sweet potatoes, etc.) were cut out of construction paper, Isaiah assisted with patting the cutouts on the different pages, and simple sentences were written about his illustrations on each page. The finished product of seven pages was really awesome and impressive; and best of all, Isaiah contributed to the finished product.

For Isaiah's oral report, a written report that had a sentence for each of Isaiah's classmates to read about Mr. Carver, his illustrated report and a sequencer were used. The written report was sent to his general education teacher the day before and the 2<sup>nd</sup> graders were enlisted to support Isaiah in his presentation. Also, that gave each student the opportunity to review his or her line prior to the actual report. A Sequencer is an assistive technology device that allows a series of messages to be recorded (messages up to 60 seconds in length). Each time the button is pushed the next recorded message plays. A Sequencer can be used for so many different things such as counting, ABC's, naming classmates, phrases to a song, greeting conversation, etc. For Isaiah's report his brother Ervin again proudly recorded the messages. First Ervin's messages were recorded on a cassette tape recorder and then transferred to the Sequencer. Ervin was cued by, "1, 2, 3," before he started to record each message—the cueing really helped when the recorded messages from the cassette tape were recorded into the Sequencer.

Isaiah's oral report started by him pushing the sequencer and the message played that said, "George Washington Carver by Isaiah Scarlett." Next when he pushed the button, the message said, "George Washington Carver was born in the state of Missouri." The next message said, "Rachel next line please." Then his classmate, Rachel, read her line from the written report. Isaiah continued to push the sequencer and a message would say another classmates name followed by next line please. Isaiah had a few lines scattered throughout the report. Also during the report, my husband, Russell, showed the pages of Isaiah's illustrated report that represented the information that was being read from the written report. After the message played that said the end, Isaiah's brother, Ervin, recorded a special message to Isaiah's classmates that said, "Hi, this is Ervin. Thank you for helping my brother with his report." Also, Ervin's kindergarten teacher was kind enough to let Ervin go to Isaiah's classroom so that he could watch Isaiah do his report as well as see how much his hard work of recording messages helped Isaiah to be able to do the report. On that day I was so proud of both of my sons!

## **Sharing My Story With Those Who Need to Hear**

By Denise Sewell, Deafblind Family Leadership Participant, Gilmer, TX

*Abstract: One parent shares her experience in learning to advocate within the legislative process*

*Keywords: Family, blind, deafblind, advocacy*

This past year, my family began working with the Texas School for the Blind and Visually Impaired—both with the Outreach Department and with the Summer Program. After seeing a remarkable change in—"Blu", my child who is deafblind, I became convinced that it was important for people in decision-making positions to hear my family's story so they could make the right choices for children with visual impairments. After all, haven't we all been told that it is really parent advocacy that makes the biggest difference? It was time for me to step up to the bat, so to speak, and begin advocating myself. I started looking for opportunities and boy did I find a lot of them! The first time I decided to try my voice out was by participating in a Capital Day, sponsored by the Arc of Texas. As luck would have it, I found out that there were a group of parents from the Longview area that had chartered a greyhound bus to attend and that I could join them if I wanted to. I thought this was a great way to handle that long 5-hour drive to Austin AND meet other parents with disabilities who lived in my own back yard. A winning situation all the way around! During the drive, I found out that the primary message most of these parents wanted to deliver to legislative representatives was to decrease the waiting list for the Medicaid Waiver programs. Some of these parents were seasoned pros in talking with legislative representatives so I was sure to get as many tips from them as possible. Some of the tips they shared were:

- Be respectful of the representative's time and be precise.
- Give them a one-page flyer that has your child's picture on it as well a brief summary of your story and the points you want to stress.
- Tell a story that they will remember.
- Thank the representative for taking time to talk with you.
- Always send a follow-up thank you.

The experience was an eye opener when I realized how many people with disabilities and their families were being affected by the decisions being made at the capital.

After I had the Capital Day experience under my belt, I felt more confident and prepared to advocate for children with visual impairments in a more formal way. When I was asked if I wanted to testify on my son's behalf to the Senate Appropriations Committee for TSBVI legislative appropriations hearing, I jumped at the chance. On the way to Austin on February 8, 2005, I thought a lot about what the TSBVI Summer School Program and Outreach meant to me and my child but also what they meant to many other families and children. I had living proof that their services really work and that was my testimony to the committee. To go in front of these people and pour out my heart was difficult to say the least. But if parents do not speak up for our children then no one else will either. The committee members really listened with open hearts and minds and truly cared what my story was. I do not know if my testimony made a difference or not but the heartwarming experience it gave me was unbelievable!

I have every intention of continuing to be involved in the legislative process but I know that is only one way to advocate for children. Its important that we all add our voice to the effort to help people understand the important issues families with children who are visually impaired deal with. Whether it be through serving on committees, speaking to school boards, working with the media, writing letters or meeting with decision makers, each aspect is as essential and important as the others. So, I urge you to speak up and make yourself heard! You will be surprised who is listening.

### **Not Alone**

By Jaime Wheeler, parent, TVI, TSBVI board member <Jamie\_Wheeler@birdville.k12.tx.us>

*Abstract: A parent shares what her daughter gained from participating in an activity with other individuals who are visually impaired.*

*Keywords: Family, Blind, Braille Olympics, social*

Not alone. These two words express the one sentiment that my daughter came away with from her experience in a short-term program at TSBVI this fall. I was stunned to observe my daughter participating in the Braille Olympics this fall. I have never seen her walk tall with so much confidence, joy and pride. She participated in activities with other students her age who also read Braille, and told me more than once that at TSBVI she was no longer in the minority! What an impression that made on me, how could I have underestimated the importance of being with other visually impaired student and adults? My child who has felt alone and misunderstood at times by her sighted classmates finally felt the joy and freedom of being "like everyone else." Sometimes we forget how difficult it can be, to be the only one at school who is visually impaired. I am so thankful for the opportunity that TSBVI gave my daughter to just be a normal teenager with other teens who understood, used the same equipment and traveled with a cane. How do you assess the benefits of such an experience? Perhaps it is through the laughter and head held high for the first time in a long time. That's what I observed and it is my opinion that the program was a great success. I can only hope that every student with a visual impairment in Texas can have the same opportunity. Each child deserves to never be alone.

## **Including Braille and Literacy in the Home: Don't Let Your Summer Be a Vast Wasteland**

Holly L. Cooper, Ph.D., Assistive Technology Consultant, TSBVI Outreach

*Abstract: Suggestions for literacy activities that can be done at home. Included are Braille books, large print books, DAISY format CD's, audio books, and electronic files. Accelerated Reader booklists are discussed as a source of children's literature. Discussion of literacy related activities available in the community. Sources for books and other media are included.*

*Keywords: Programming, Braille, literacy, reading, enrichment*

Summer vacation is a time that all students look forward to with great anticipation. Days of fun and leisure can add up to boredom, however. Summers can mean long periods of inactivity and isolation for our students with visual impairments, especially those with additional disabilities. Parents, families, and friends can make summer more fun by finding and planning opportunities for kids to read and enjoy books and other literacy activities during the summer. And literacy is not just for students in a standard academic curriculum. Students who may not become independent readers can still benefit from the exposure to print or braille, the spoken vocabulary and the increased exposure to ideas and people that literacy activities provide. Parents don't have to be good readers themselves, nor do they even have to be good English speakers to help their children improve their reading skills. They just have to believe reading is an important part of a good education, and help their children find access to the books and literacy experiences that are all around them in the community.

Most classroom teachers will tell you they can see a difference between their students who read at home in their leisure time and those who don't. Kids who read at home usually are better readers, better writers and have a better vocabulary than their peers who do not enjoy reading as a leisure time activity. Often they also learn more about specific content areas in which they have particular interests, such as science or history. One of the best ways to get your kids interested in reading is to be a good role model: read yourself. Read newspapers and magazines, and read books. Use the local library, buy books at used book stores, look at thrift stores, help start a lending library at your church or place of business, and go to bookstores. When kids see their parents, grandparents, and other adults in their lives reading, they understand that reading is an enjoyable way to spend time. When your children ask questions about your book, talk to them about what you are reading at a level they can understand. Ask them about their books when they read as well.

Braille books and magazines for leisure reading are available from many sources. One of the primary sources for schools is American Printing House for the Blind (APH). APH works with a combination of funding sources that allows them to provide materials free to educational institutions through a quota point system that is tallied for each legally blind student in Texas (and other states). Private individuals can purchase books and materials from APH, but a more practical method is to give a book list to your vision teacher and ask her to request them and loan them to your child for the summer. Materials from APH obtained with quota funds are always considered loans, and books are returned and recycled for other users. Our APH quota funds in Texas are almost never used up at the end of the school year, we are strongly encouraged to use them more! Another source of books is the National Library Service for the Blind and Physically Handicapped (NLS). NLS is a part of the Library of Congress and maintains a loan program of Braille and audio books and magazines. The Texas State Library maintains a Talking Books Program which also includes Braille magazines. Braille books can be purchased from Seedlings, National Braille Press, BookShare, Braille Books Dot Com, and even Amazon. You can find links to all of these sources at the end of this article.

What books should you get? One good place to start choosing books for your child is the Accelerated Reader book list. Accelerated Reader (AR) is a commercially produced product that uses popular children's books as a source of content, and provides a test for each book on the list. Points are assigned to each book based on level of difficulty, and many schools encourage their students to read books on the list and accumulate points for reading at home. You can search the Accelerated Reader list by author, title, subject, and reading grade level. Many school districts have Accelerated Reader book lists on their websites, you can print the list and take it along when choosing books. Often these lists contain only the books that particular school has in its library, so be aware that using the AR website will give you more comprehensive lists. AR does not sell Braille books, so you must make use of other sources to obtain these.

One activity that we often omit from our lives is reading aloud. There are so many choices of ways to spend our leisure time. Often parents do not read aloud to their children. In school, teachers are under so much pressure to improve standardized test scores that enrichment activities such as reading aloud to the class are crowded out of the schedule. Reading aloud is important for many reasons. Children are less skilled readers, and benefit from the role model of an adult reading aloud to them. Instead of listening to other children read, which often happens at school, listening to adults read shows young people how more skilled reading should sound, and smooth fluent reading is easier to listen to and easier to comprehend than the broken up passages read at school by peers. Some research now indicates that children better comprehend the meaning of text they listen to when it is read by a voice familiar to them than when it is read by someone unfamiliar. Another benefit of reading aloud that we often overlook is that reading is a form of story telling and as such is a social activity. Children and many older adolescents and adults enjoy hearing a good story well told, and enjoy hearing it with others. Libraries and bookstores often have read aloud sessions for children, find out what their schedule is and mark them on your calendar. Sign up for their email newsletter to keep track of events. Some communities have story telling societies and guilds. These people meet together to tell stories, have competitions and do story telling at community events. Some storytelling societies celebrate particular ethnic traditions, such as African American or Latino culture or local folklore. Keep in mind the current popularity of book groups. Adult book groups do not typically read their books aloud, but they do read and discuss passages, talk about how the story or characters may be similar to their own lives or lives of people they know, and think about the book in different ways as a result of discussing the book with others. Consider starting a children's book club at your school or library or with a group of friends that includes your child. Parents can be included in the book group discussion or not according to the wished of the group.

To make the most of read aloud time at home, establish a regular routine with your children, usually reading before bedtime is the easiest routine to stick to. Make it a pleasant activity, sit on the sofa as a group, and tell the older kids that part of why you are doing this is to help you all to become better readers. Establish a deadline for each session, but don't be afraid to be somewhat flexible. Don't get hooked into finishing a long book if it's not realistic to do this. Part of the fun is the anticipation of returning to the book each night. Read and talk about the story. Try not to ask your child too many teacher-type questions, ask open-ended questions such as what their favorite part of the story was, who they liked best, or recall when a similar event happened to them. You can read books that are above the reading level of your children, this will encourage them to learn to follow a more lengthy story by starting chapter books that are not finished in one setting. Ask them before you read each day to recall what has happened so far.

Listening to books on tape or on CD are also literacy activities. While we generally believe that listening to a book or story is not as cognitively demanding as reading itself, students can learn skills about story comprehension, plot, setting, characters and, of course, the subject matter of the book, through listening. Many of our students with visual impairments, whether they are print readers or Braille readers, will use recorded

reading materials as they get older and the demands of reading for learning increase. At the college and university level, most books are not available in Braille, so students rely on books recorded for them. Getting the book produced in Braille is usually simply too expensive and too slow to be practical. Children will benefit greatly from learning to be active listeners of recorded content, not just passive listeners of noise. Vision teachers, and sometimes others such as speech pathologists and classroom teachers may work on teaching students to listen for content. This is typically done in a manner similar to teaching reading, the student listens to a passage and answers questions or discusses the content. When more advanced students use recorded material for their school work, they may review the questions that will be asked first before reading the content, they may review an outline provided, or make an outline or summary themselves as they go along. Most parents are familiar with “books on tape.” Our recorded books in school settings are obtained primarily from Recording for the Blind and Dyslexic (RFB&D) which is a resource individuals can access as well, but there are additional sources listed at the end of this article. With the development of technology, many audio books from RFB&D are available on compact disc. Recordings are now made according to specific standards called DAISY format. With a book on CD in DAISY format, you need a special CD player and you can scan for specific words to search for information. A listener can enter the page number and jump directly to a specific page, or paragraph or chapter. The players also allow users to speed up the speech without distorting the pitch, since a skilled listener can comprehend content at a rate much faster than ordinary speech.

Of course, listening to recorded books is becoming more popular among many who love literature but have limited time. Most major publishers now have audio recordings of their most popular books produced simultaneously with or soon after the print version. You can buy books on CD on-line, or at bookstores. You can also find them at used book stores, and at your local library. Several companies now have downloadable books that you can purchase on-line and load into an MP3 player (like an iPod). Audible.com is one such company, with a monthly cost of \$14.95 you get one book a month, plus a subscription to a magazine or newspaper from their list.

Audio books and Braille books are also available in electronic formats. Downloadable books like those from Audible.com are one type of accessible electronic format. Special exceptions to copyright laws exist in the United States which make it legal for us to put a book in an “alternative format” for people with print reading disabilities. Originally this meant paper Braille, or “talking books”. Now we also use optical scanners to scan pages and convert information to electronic text. This electronic text is simply a computer file of words. With electronic text, and special software we can convert the text to Braille and output it on paper or in refreshable Braille. We can also “read” it with voice output software such as JAWS, or with enlarging software such as ZoomText. Kurzweil reading software allows users to scan text directly into voice files. We can also download electronic files into portable notetaking devices such as BrailleNotes and PAC Mates. In addition, they can be downloaded into the BookPort from American Printing House for the Blind, and users can listen to an electronic-voice output version. Admittedly, you do not have all of this technology available at home, especially in the summer when school is not in session. But you can download a demo version of JAWS which will run for 40 minutes, this will make your computer read aloud. Also, inquire with you vision teacher about what equipment might be available for you to use with your child at home during summer break. Your district may be willing to loan less expensive devices such as the BookPort and the DAISY CD readers.

In addition to simply reading books, there are other literacy activities you can do at home. Many games are good for teaching and reinforcing literacy skills, such as Scrabble, Bingo, and Monopoly. You can purchase Braille versions of these games at the websites listed at the end of this article. Some games can also reinforce math skills, and Braille and large print versions of standard playing cards, Uno, and dominoes are all available. Tactile dice are also made. Consider the arithmetic involved in playing Yahtzee and dominoes

according to traditional scoring rules. It's fun and a challenge. Another way to enjoy reading is sending and receiving letters in the mail. Ask your vision teacher if there are other Braille reading students who will become Braille "pen pals" with your child. If your child has attended a special program at Texas School for the Blind and Visually Impaired, a local Education Service Center, summer camp, or other setting and has met other children who use the same reading medium, try to keep them in touch through the mail. Check with the other child's parent to see if they are willing to encourage and help with the correspondence process. This summer, don't let the time become a vast wasteland, plan for opportunities for reading, listening to books, discussing books with friends and playing games that practice reading and number skills.

## RESOURCES

### Games

MaxiAids

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

Braille Scrabble, Braille Monopoly, Braille dice

Card Games: Braille Uno, Braille playing cards

LS&S

<<http://www.lssproducts.com>>

Braille Bingo, Braille and large print playing cards

### Magazines and Newspapers, Book Loans

National Library Service for the Blind and Physically Handicapped (NLS)

Library of Congress

<<http://www.loc.gov/nls/bbr/2005/1-mags.html>>

Downloadable Braille files available on web-Braille

Free membership makes users eligible for free subscriptions to *Boy's Life*, *Cooking Light*, *Muse*, *Rolling Stone*, *Science News*, *Stone Soup*, *Seventeen*, *Spider: The Magazine for Children*, baseball league schedules, and many others

Texas State Library and Archives Collection

Talking Books Program

<<http://www.tsl.state.tx.us/tbp/magsrevised2.html#brkids>>

Braille magazines and books are available through their loan program

### Books

American Printing House for the Blind

<[http://www.aph.org/catalogs/cat\\_html/bkstore\\_2004.html](http://www.aph.org/catalogs/cat_html/bkstore_2004.html)>

Braille, large print, and electronic files

National Braille Press

<<http://www.nbp.org/ic/nbp/cbbc/index.html?id=MGLcTL6E>>

Children's Book Club

\$100 annual fee for 13 Braille books

Recording for the Blind and Dyslexic  
 <<http://www.rfbid.org/index.htm>>  
 Books on tape and CD in DAISY format

Seedlings  
 <<http://www.seedlings.org/>>  
 Braille Books for Children

Bookshare  
 <<http://www.bookshare.org/web/AboutBrailleBooks.html>>  
 Embossed (hard copy) Braille books, or downloadable Braille files

Amazon.com  
 <<http://www.amazon.com/>>  
 Search the site for books: Braille books  
 Many titles for children come up on a search, but most show as unavailable. Keep checking.

Braille Books Dot Com: The Braille Superstore  
 <<http://www.braillebookstore.com/>>  
 Hard copy Braille books available for purchase

International Braille Research Center  
 <[http://www.braille.org/braille\\_books/](http://www.braille.org/braille_books/)>  
 Electronic files of Braille books

### Story Tellers

Tejas Story Telling Guild  
 Statewide organization of story tellers w/listing of local groups. Fans of storytelling are usually welcome.  
 <<http://www.tejasstorytelling.com/index.html>>

### Accelerated Reader

Accelerated Reader  
 <<http://www.renlearn.com/ar/default.htm>>  
 To search by title, author, subject, or grade level go to:  
 <[http://www.renlearn.com/store/quiz\\_advanced.asp](http://www.renlearn.com/store/quiz_advanced.asp)>.

Here is a school website that has AR books sorted by title:  
 <[http://www.ashland.k12.wi.us/MVS/Book\\_Lists.cfm](http://www.ashland.k12.wi.us/MVS/Book_Lists.cfm)>

Texas School for the Blind and Visually Impaired  
 <<http://www.tsbvi.edu/braille/braillebooks.htm>>  
 Files in electronic format, AR books marked with a “\*”

Iowa Braille School  
 <<http://www.iowa-braille.k12.ia.us/library.html#braille>>  
 Files in electronic format, AR books marked with a “\*”

## Some Things to Learn from *Learning Through Touch*

By Kate Moss, Education Specialist, Texas Deafblind Outreach

*Abstract: This article shares information about the book, Learning Through Touch, by Mike McLinden and Stephen McCall. Special attention is paid to the anatomy and physiology of touch and the functions of touch.*

*Key Words: Programming, blind, deafblind, touch, tactile*

It stands to reason that children who are visually impaired or deafblind would be more reliant on touch or their tactile sense to experience the world. These children have different needs and different skills related to their use of touch in learning. Unfortunately, many of us don't know all that much about how to help these children develop better tactile skills and make better use of their tactual sense.

The work of such people as Barbara Miles, Lilli Nielsen, and Deborah Chen has made us very aware of the need to pay more attention to this sense in programming for these children. We are beginning to use hand-under-hand in our interactions with these children, and becoming more mindful of what message our touch conveys. We are providing them with a greater variety of textures and materials and giving them more time and opportunities for independent exploration of these objects. We are recognizing that hand use progresses systematically simply by the child completing constant repetition of specific hand movement schemes. We are thinking about touch as it relates to literacy and general learning. In short, we are becoming better educated about the importance of developing touch in all our children with visual impairments and deafblindness.

Recently a colleague shared a copy of a book, *Learning Through Touch*, by Mike McLinden and Steve McCall from the School of Education at the University of Birmingham in the United Kingdom. This book includes information on the anatomy and physiology of touch, the functions of touch, assessing touch, and providing instruction through touch. I was struck by a number of things I read and want to encourage our readers to try to find a copy of this book. Though the book is not readily available in the United States, it may be ordered through Amazon or on-line from Fulton Publishers at <[www.fultonpublishers.co.uk](http://www.fultonpublishers.co.uk)>.

### THE ANATOMY AND PHYSIOLOGY OF TOUCH

Our largest organ is our skin. It serves a number of purposes, such as protecting our internal organs from infections, and is also the location of the tactile receptors in our body.

The skin has an outer layer called the epidermis and an inner layer called the dermis. In each of these layers of skin are different tactile receptors or nerve endings, which seem to respond best to particular types of stimuli. These receptors are generally divided into three categories:

1. Mechanoreceptors: respond to indentations of the skin. An example of this is when a finger presses against the back of the hand. There are two types of these mechanoreceptors: those that are rapidly adapting and those that are slowly adapting.
2. Thermoreceptors: respond to temperature changes.
3. Nioceptors: respond to stimuli that damage the skin such as intense heat or the prick of a pin.

Even though each of these receptors responds *best* to these stimuli, they also respond to some degree to all types of tactual stimuli.

Tactile receptors are also located in the joints, tendons and muscles, and limbs. These help form part of the proprioceptive system. The proprioceptive system allows us to know about the stationary position of our body and also give us information about our movements. We know where our hand is and how to make it move out to reach and grasp an object because of our proprioceptive system. The visual system ties into the proprioceptive system, too, which is why some children with visual impairments have problems knowing where their bodies are located in space.

The sensations coming to us from outside our body and those coming from inside our body are experienced as two separate sensations that our brains are able to process so we can complete a wide variety of actions. When we manipulate a small object such as a pen with our hands behind our backs we know where our hands are in relation to one another, even if they do not touch. We experience the feel of the pen and can explore it, turn it, and transfer it without looking all because of the tactile sensations we experience within our bodies and from outside our bodies.

Tactile information is sent to the brain from the receptors along two main neural pathways. One pathway, called the dorsal column medial lemniscal system (DCMLS), can be thought of as a discriminatory system. It carries information we obtain through active exploration and includes such information as pressure, vibration, and proprioception. The other system, called the anterolateral system (ALS), carries information that helps our body defend itself by relaying information about pain and temperature. The DCMLS ends in the somatosensory cortex within the parietal lobe of the brain located at the top, back part of your head. The ALS appears to be a more primitive system and ends in the reticular formation that is located just above the area of the brain stem.

Although these systems are separate, they do have some overlap of function. For example, some pain information may be carried by the DCMLS, and some tactile discrimination information may be carried by the ALS. This might explain why some children avoid touching or being touched. If damage is done to one of these systems the result may be that the other system becomes more dominant. The ALS system, which handles pain, is less vulnerable to damage than the DCMLS system. Children who are tactually defensive may be responding to touch primarily through the ALS and experience its defensive function.

## THE FUNCTIONS OF TOUCH

The active use of touch to “seek out and acquire information” has been called “haptic touch.” The “haptic system” has been defined as a distinctive perceptual system, oriented towards discriminating and recognizing objects by handling them as opposed to looking at them. (McLinden & McCall, 2002) McLinden and McCall share information about the various property features we acquire through the haptic system. These include:

- Vibration
- Surface texture
- Wetness/dryness
- Surface temperature
- Shape
- Slope
- Curved
- Hardness/softness
- Weight
- Elasticity
- Pliability

Many types of touch are active, but some types of touch are not active. For example, we can experience the breeze blowing on our faces and the warmth of the sun. We can feel vibrations from the car next to us that is playing rap music too loud.

Touch can be interactive or non-interactive. Interactive touch includes such actions as hugging, kissing, or shaking hands. Non-interactive touch includes things like resting your hands in your lap, massaging a leg cramp, or bathing.

Think about the difference in the kind of information you can receive through various types of touch. For example, if you simply place your hand on a cat without moving it, what could you learn about the cat? You would feel warmth from its body and, depending on where on the cat’s body your hand was placed, some information about how soft or hard it is. If the cat is purring, you might experience some of the vibrations it makes. Passive touch like this does not provide that much information about the cat. However, if you pet the cat and examine it from head to toe by exploring it with your hands and fingers, you would find out it has fur, a tail, legs, whiskers, eyes, and ears. You might have some idea of the weight, size, and shape of the cat and whether it has short or long hair. Through interactive touch you might also learn about teeth and claws!

Hands play a leading role in touch for most of us. Still it is important to remember that we also use other sensitive parts of our bodies in touching. This is especially important to remember when we are working with children who do not have good use of their hands. A great deal of information can be gained through exploration with lips and the tongue, with feet, and with other parts of our bodies. In fact, a baby first explores with his or her mouth, and often uses his or her feet to explore things as well.

As the child’s vision and motor skills develop, a typical baby begins to incorporate more and more strategies for exploring objects with the hands. Many of these strategies are learned through watching others, but also are developed naturally by just interacting with a million different things. Think about the ways most babies spend their time. They are constantly interacting with the objects in their world — reaching and grasping, banging and batting, putting together and taking apart.

McLinden and McCall include the following chart to show the type of sensory information that can be found by various exploratory procedures we typically use on objects.

<b>Exploratory Procedure (EP).</b>	<b>Example of sensory information acquired about object through EP.</b>
Lateral motion EP (rubbing finger across surface of object).	Texture.
Pressure EP (squeezing, poking object).	Hardness.
Static Contact EP (fingers resting on object surface).	Temperature.
Enclosure EP (holding/grasping object).	Shape/size/volume.
Unsupported holding EP (holding object in hand).	Weight.
Contour following EP (tracing along contours of object).	Global shape, exact shape.

*Chart 1 – Range of exploratory procedures and examples of sensory information acquired about objects through exploratory procedures. (McLinden & McCall, 2002)*

When we think about children with blindness and deafblindness, we can begin to see how important it is to develop haptic ability (or hand use). Hand use and cognition are tied together. The more capable any child is in their exploration of objects with their hands, the better they are able to formulate concepts that are critical to learning. One researcher, Rochat, suggested that vision is the ‘organizer’ of different types of sensory information. As the child manipulates the object they view it from different perspectives and learn about its properties. So sight helps the baby make sense of what they are feeling. Stilwel and Cermak note in *Hand Function in the Child: Foundation for Remediation* (1995) in their chapter, “Perceptual functions of the hand” that young babies’ do not so much use sight as a substitute for touch but rather they use sight to guide their haptic manipulation, in order to make the sensory input more meaningful. (McLinden & McCall, 2002)

For children with visual impairments, vision may not help them make meaning from what they are experiencing. At the same time, touch may be all they have to work with to help them experience the world. When a visually impaired child’s sense of touch is also impaired because of motor problems, missing or malformed limbs, or because of prolonged restraining by IV lines and such, they are denied a great deal of information about how the world works. It is understandable that these children often show cognitive delays as well.

### WHAT CAN WE DO TO DEVELOP HAND FUNCTION?

If hand function is so important, what can we do to help our blind and deafblind children to develop these critical haptic skills? Although there is very little research-based guidance on what we should do, current best practice gives us some guidelines. These strategies include:

**Honor the child’s hands.** Do not grab or hold the child’s hands any more than is absolutely necessary. Build trust between you and the child so that he/she is inclined to trust you not to try to control what he/she does with his/her hands.

**Watch what the child does with his/her hands.** Barbara Miles reminds us this is especially important for the child who is deafblind since their hands may serve as eyes, ears, voice, and tools. When we look at what the child does with his/her hands, we can have a better understanding of what the child might know about the world.

**Use a hand-under-hand approach in guiding the child or modeling actions with your hands.** This also means offering objects to the child by bringing them up underneath his/her hand rather than taking the child’s hand to the object.

**Watch what a child can do with his/her hands.** This can be done through formal assessment and informal observation. There are a number of tools programs can use to assess the haptic sense and hand use in children with visual impairment and deafblindness. Some assessment tools that are used frequently in the United States include the Callier-Azusa Scale, Functional and Instruction Scheme, Home and School Inventories or Problem-Solving Skills, and the INSITE checklist.

**Give the child objects that encourage the development of skills.** For example, if you want the child to develop finger isolation, give him many different objects that encourage that skill, such as metal washers and nuts, wire whisks, loose knit fabric, rings or sections of tubing, containers with holes in them, and so forth. Expand skills horizontally (letting him practice this skill with many different objects) before trying to achieve higher-level skills.

**Provide the child with many opportunities each day to explore a wide variety of objects on his/her own.** These should have different textures, weights, temperatures, shapes, flexibility, and hardness. Most of the Active Learning theory focuses on this approach. If the child's hand use is limited by other disabilities, we need to make sure that things come to his hands.

**Make your hands available to the child for him/her to be able to tell you something or show you something.** A nice way to do this is to simply hold your hands out to the child with the palms facing up. Let the child take your hand and guide it where he/she wants.

**Model hand-use for the child as you do things.** This is typically done using hand-under-hand approach as you complete everyday activities such as opening, closing, twisting, rubbing, reading Braille, signing and so forth. The child can learn a great deal about hands from "watching" what you do with your hands.

**Let the child know you are experiencing the object he/she is experiencing.** Co-actively touching objects that the child is touching is the equivalent of using a pointing gesture to reference an object that the child is looking at. This allows the child to share information with you about the object.

**Play hand games with the child.** Begin by imitating what the child does with his/her hands. As time goes on and the child begins to attend to what your hands are doing introduce new actions or movements. Clap, wiggle fingers, shake hands, rub them on a surface; any interaction the child is interested in will work.

**Offer many hands-on learning experiences with real objects.** Avoid the use of miniatures or replicas.

**Provide more time for the child to explore objects within activities.** What we can quickly take in with our vision requires more time to learn with our tactile sense.

**Create object books and boxes for a child to "recall" an event they have experienced by exploring materials associated with that activity.** For example, a trip to McDonald's might be recalled by exploring a collection of objects such as a straw, a french fry cup, a toy surprise, and a sticky napkin.

## CONCLUSION

Developing the sense of touch and good hand use skills are important goals for any child who is blind or deafblind. The tactile sense often is needed to confirm what the child is seeing or hearing. Using the sense of touch to teach children with visual impairment or deafblindness may be challenging to us as sighted and hearing individuals. We must think about the child's experience of the world and find ways to enhance the use of the child's tactile sense in all the activities we do.

There are many good resources to help us learn to make better use of a child's tactile senses. Some of these are listed below. *Learning Through Touch* may not be a book that is familiar to many of us in the United States, but it is another great resource for teachers and parents alike who want to have a better understanding of the critical role touch plays in learning for children who are blind and deafblind.

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Project SALUTE. <<http://www.projectsalute.net/>>

## Accommodations for Visually Impaired Students on Statewide Assessments

By Ann Adkins, Education Specialist, TSBVI Visually Impaired Outreach

*Abstract: This article describes the accommodations that visually impaired students are allowed to use on statewide assessments in Texas.*

*Keywords: programming, visual impairment, assessment, testing, TAKS, SDAA II, accommodations, modifications*

Every year we receive many questions about the accommodations that visually impaired (VI) students are allowed to use on statewide assessments in Texas. Many of the questions seem to occur because of confusion over the use of the terms "accommodation" and "modification". An accommodation is "a change to the environment to assist a student with instruction and/or assessment." (2004-2005 ARD Committee Decision-Making Process for the Texas Assessment Program, page 114). A modification is "a change to the test itself." (page 16). Accommodations are allowed for VI students if they meet the following criteria:

1. The student **must** routinely receive the accommodations in classroom instruction and testing.
2. The accommodations **must** be documented in the student's ARD.
3. *The accommodations cannot invalidate the test results.*

ARD committees must ensure that any accommodations are based on specific student needs that are identified and addressed in the student's IEP. New or different accommodations can not be introduced or allowed on the day of testing. Because district and campus test coordinators are often unfamiliar with the needs of VI students, it is important for the VI teacher (TVI) to work closely with them before the administration of statewide tests.

Parents, teachers and districts are often concerned about the size of print used on large print versions of the Texas Assessment of Knowledge and Skills (TAKS) or the State-Developed Alternative Assessment II (SDAA II). Other common questions involve the oral administration of tests or the use of extended time, manipulatives, or calculators. Answers to these questions are provided below, as well as information on how to find the answers to any other questions about testing accommodations for visually impaired students.

1. *Print size of large print tests.* If a student needs a larger print size than the type used on the large print versions of the tests, the VI teacher or district testing coordinator should contact the Student Assessment Division of the Texas Education Agency (TEA) for permission to enlarge the test to the appropriate size, which should be documented in the student's Learning Media Assessment (LMA). According to TEA, large print versions of TAKS and SDAA II are enlarged 129% of the original print size. This means that different instructional levels of the tests are in different sizes of print. For TAKS, large print versions of Instructional Levels 3-4 are in 16 pt. type. Instructional Levels 5-10 are in 13-14 pt. type. For SDAA II, Instructional Levels K-2 are in 19 pt. type, Levels 3-4 are in 17.5 pt. type, and Levels 5-10 are in 16 pt. type. Be aware that graphs, numbering, or special mathematics symbols, such as exponents, may be printed in even smaller type than the rest of the tests. The district must get permission *in advance* to enlarge the tests further.
2. *Oral administration.* Only students served by special education or Section 504 may receive an oral administration of the TAKS. Oral administrations are allowed for math, science and social studies, but must be documented in the student's ARD. Oral administrations are *not* allowed for the reading, writing, or English Language Arts (ELA) tests. Instructions for oral administrations of SDAA II are given in the administrator's manual.
3. *Extended time.* Visually impaired students, particularly Braille readers, often need additional time to complete tests. If a student needs more than the one day designated for each subject area in order to complete the test, contact the Student Assessment Division of TEA for extended time or any special testing arrangements. Note that prior approval is also needed for some other accommodations, such as using scratch paper.
4. *Use of manipulatives.* An instruction sheet with specific information on the administration of Braille tests is included with the TAKS and SDAA II testing materials. This information includes a list of the manipulatives the VI student will need during the tests, such as coins, 3-dimensional shapes, etc. Transcribers' notes and any changes or omissions in formatting are also included in the instruction sheet. The TVI administering the test will need to review this information *before* giving the test in order to gather all the appropriate materials. The TVI should make arrangements with the district or campus test coordinator well in advance of the testing day. The TVI must also participate in all appropriate training and sign the Oath of Test Security and Confidential Integrity before administering any state assessment.
5. *Calculators.* Calculators are *not* allowed on the TAKS mathematics tests at Grades 3-8 or on the Science test at Grade 5. Students *may* use calculators on the SDAA II, Instructional Levels K-8, *only* if this accommodation is routinely used in instruction and testing, and if it is documented in the IEP.

Answers to most questions about the assessment of VI students can be found on the website of the Texas Education Agency (TEA), <[www.tea.state.tx.us/student.assessment](http://www.tea.state.tx.us/student.assessment)>. Specific information about administer-

ing tests to students with visual impairments can also be found in Appendix D of the *District and Coordinator Manual 2005*, “General Instructions for Administering Tests to Students with Visual Impairments”, pages 297-299. This manual is also available on the TEA website. An “Accommodation Request Form” is available on the website, and a copy is also provided in Appendix B of the Coordinator’s Manual (page 261). It should be mailed or faxed to the Student Assessment Division of TEA in advance of the administration of the tests.

The Student Assessment Division of TEA is very willing to answer all of your questions about allowable accommodations for visually impaired students. Teachers, parents, or district administrators are encouraged to contact them by phone, fax, email, or in writing at:

Texas Education Agency  
Student Assessment Division  
1701 North Congress Avenue  
Austin, TX 78701-1494  
Phone: 512-463-9536  
FAX: 512-463-9302  
Email: studenta@tea.state.tx.us

*Editor’s note: The months since the last edition of SEE/HEAR have been marked by the passing of two long time leaders in the field of education for students with visual impairments. Alan Koenig and Sally Mangold will be missed by the many people who knew them or were touched by their work. Dr. Phil Hatlen uses his regular “News & Views” column to share his thought on these leaders who meant so much to so many.*

## OF ALAN KOENIG

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

*Abstract: A memorial tribute to Alan Koenig by Phil Hatlen*

*Key Words: Alan Koenig, Phil Hatlen, blind, visually impaired, low vision, Braille literacy, memorial*

### ALAN AND US

Who among us in this profession has not been influenced by Alan Koenig? His very presence at a conference or meeting always brought a feeling that all is well in our profession, because we have colleagues like Alan who are doing research, writing magnificent articles and books, and developing new teachers. With his dear friend Cay, Alan gave us research and direction in Braille reading and writing instruction, a body of knowledge we have needed for a long time. With another friend, Anne, he expanded our knowledge of services for children with low vision.

But more than anything else, he was always there. There to support us, to encourage us, to be our confidante, to remind us that we are in a very special profession.

We got used to his quiet, friendly demeanor, we became his cheerleader as he and Cay opened up an entire new body of knowledge on Braille reading and writing. We were in awe of his ability to write, and those contributions will be Alan’s legacy for many generations. Whether he agreed with us or not, he honored us with his respect for our positions and our shared passion for our profession.

## ALAN AND CHILDREN

How can we think of Alan without sharing a deep and lasting appreciation for what he did for children? How many children are receiving Braille reading and writing instruction because of the research of Alan and Cay? Children are learning today because Alan cared so much that he devoted much of his life to assuring opportunities for literacy for all blind children. Mothers and fathers of school-age visually impaired children, this man gave of his heart and mind to assure that your children will receive an education that includes literacy in the media best suited for your child. What a gift to parents, professionals, and, most of all, to blind and visually impaired children!

## ALAN AND ME

I can't recall when I first met Alan Koenig, but I had heard about him many years earlier. He was described to me as a quiet, thoughtful, bright, and very interesting person who was, early in his career, already contributing to the knowledge we have about educating blind children. Then I moved to Texas. I had no idea the tremendous impact this young, gentle, kind man would have on me over a 14-year period.

Alan was part of a dynamic team at Texas Tech University, brought together and nurtured by Virginia Sowell. He and I would talk by phone from time to time and, in the early years, we would meet several times a year. There were three personnel preparation programs in Texas, and they were all very active in preparing teachers and promoting quality education for blind and visually impaired students.

I will never forget Alan's way of communicating and of being a friend. When he and I were together, I never wondered whether he was listening when I talked—I knew it by his actions. I wish I could do what Alan did so well—I wish I could give everyone my undivided attention when we are together. Do you remember, as I do, the times when you've talked with Alan, and suddenly realized that he was so interested in what you were saying that you had his complete attention? I wish I could always emulate that.

I was captivated by Alan. He was everything I wanted to be—non-judgmental, always encouraging, a good listener, never confrontational, always true to his ethics and beliefs. What more can be said about my relationship to this special man? Thank you, Alan, for the ways in which you have allowed me to grow.

## OF SALLY MANGOLD

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

*Abstract: A memorial tribute to Sally Mangold by Phil Hatlen*

*Key Words: Sally Mangold, Phil Hatlen, blind, visually impaired, memorial*

After receiving word that Sally Mangold had died, the full weight of this news is beginning to sink in, and I wanted to write a few words. I met Sally (and her husband, Phil) in the spring of 1955. The three of us were students at San Francisco State, all wanting to be teachers of blind children. Sally and Phil were both blind themselves. For 50 years we have maintained a close friendship that only the three of us fully understood. I would do anything for them, and they for me. We loved one another in a very special way. We had not only grown old together, we had shared a passion for our profession that was deep and nurturing.

A year ago I had the privilege of introducing Sally at the Migel Award ceremonies in San Francisco. Several times during this past year, Sally would call to give me news about the SAL, her very special project.

Then, I was privileged (along with a lot of other people) to hear Sally keynote the APH conference last October. She and I had several conversations in Louisville, times that I now treasure more than anyone can imagine. When I heard that Sally was gravely ill, I called and talked to her. In her usual manner, she was upbeat and certain that her inclusion in a trial at the UCLA Medical Center would be the answer to her illness. And later I talked with Phil who was also upbeat about Sally's future.

And now she's gone. And I've lost another peer colleague. It's an entirely different feeling when a mentor dies—they represent an earlier generation, and one assumes he will outlive his mentors. Now it's time that I recognize that my generation of colleagues is dying, and that is a very sobering and sad thought. My friend Karen called to give me the news of Sally's death. When we finished our conversation, Karen said "I love you, and if I never have a chance to say it again, I'm glad I could do it now". I'm glad I told Sally that I love her the last time I talked with her.

For many years, there was an office at San Francisco State University that housed Sally, Pete Wurzbarger, and me. I called Pete, who already knew about Sally's death. Pete, who is 80 years old, has his aches and pains, but he sounds strong and vital. I said "Pete, I love you" before I hung up, because maybe I won't get another chance to tell him.

Below are my words about Sally when she received the Migel Award from the American Foundation for the Blind.

FOR MY FRIEND, SALLY MANGOLD

From Phil Hatlen

(To the tune of Daisy, Daisy)

Sally, Sally, give me your answer, do  
I'm half crazy, is it Grade 1 or 2?  
It won't be a simple answer  
But I know what you say will be true  
Braille will prevail  
It will not fail  
And it's all because of you...

There are so many dimensions of Sally Mangold that I hardly know where to begin, what to stress, and what to leave out. I think, Sally, my friend, that I'll talk for a few minutes about three aspects of you.

I wonder if all of you know that Sally, her husband Phil, and I began in this profession at the same time. The three of us were among the first teachers of visually impaired children in local schools, we were a part of a tremendous evolution of services during the second half of the 20<sup>th</sup> century, and we have remained close, loyal, and loving friends for many years.

Why does Sally deserve the Migel Medal? Well, first of all, she was one of the most successful, inspired teachers I have ever known. Throughout her years as a teacher in the Castro Valley Schools, Sally developed a reputation that resulted in visitors from all over the world coming to the programs that she and Phil had developed in Castro Valley. I remember talking to Sally at some point about summer school. She told me that

she was going to teach living skills that summer. I asked her what she intended to teach. She said that she would be asking the parents of each child what skill in independent living they would like their child to learn, and that was what she would teach. Imagine that? Asking parents what they wanted their child to learn—educators never did that!! But Sally did, for she was always far ahead of others in her approaches to education.

Sally, the true master teacher of children, I salute you!!

Then there is Sally the Innovator. As a professor at SFSU, she was imaginative and creative in her approaches to providing future teachers with not only skills and knowledge, but with pride and passion. It was hard for any student in her university classes to resist the excitement Sally had for her profession, and to know that they owed it to Sally to share their skills with blind and visually impaired students. I'd venture to say that there is no one in the world who is better known for her knowledge and skill in teaching Braille than Sally. In the summer of 2002, I attended her session at a worldwide conference in Holland, and watched a roomful of mesmerized teachers from dozens of countries who knew they were in the presence of a giant.

That brings up something else about Sally the Innovator. I suggest to you that Sally is the most dynamic, inspirational, and knowledgeable speaker in our profession today. I have heard her give presentations several times in recent years, and I still find myself challenged, invigorated, and uplifted every time I hear her. Have any of you ever heard Sally give a dull and uninteresting speech? She is truly amazing!!

A teacher, a professor, a motivator, and what else? There is not a teacher in the U.S., and maybe not one in the world, that doesn't know about Educational Teaching Aids, the company that Sally and Phil cofounded many years ago, that continues to grow and flourish. Look at the catalog of this company, and count the number of products that Sally and Phil themselves invented or developed. I especially enjoyed Phil's publication entitled "The Pleasure of Eating"...

So, Sally, you are or have been a teacher, a professor, a motivator, and a business owner. But wait, there's one more Sally I want you to know, the Sally that I treasure the most—Sally the Friend.

As we grew up together in our profession, Sally, Phil, and I were never very far apart, either geographically or in our fondness for one another. Sally and Phil settled into a large, comfortable house in Castro Valley, the perfect house for quiet gatherings and noisy parties with friends. I spent many evenings with a few close friends at this home, eating, drinking, and enjoying good company. I also spent many wonderful times at noisy, crowded parties at the home of Sally and Phil. Both of them are musicians, and nothing pleased them more than to arrange a small pick-up band and spend an evening making music. The only thing they let me play was the gut-bucket, and Sally kept telling me not to play too loud!!

SFSU students looked forward to end-of-year parties with the Mangolds, and they were never disappointed! I looked forward to just being with them, where love and friendship enriched my life.

Sally, you are being honored tonight for your many significant accomplishments in your profession. You have brought the beautiful world of literacy to countless children, and your example as a teacher has brought joy and fulfillment to many, many blind and visually impaired persons. But I also honor you, my friend, for the joy and fulfillment you have added to my life. I treasure our friendship, and my life is so much richer for knowing you and Phil.

## Want to Help Blind Children Succeed? Get High!

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

*Abstract: Assistant Commissioner Barbara J. Madrigal discusses the impact that parents' expectations have on the development of children's confidence and self-esteem and the importance of "high hopes, high expectations, and high exposure" for children who are blind and visually impaired.*

*Key Words: DARS, Division for Blind Services, confidence, empowerment, high expectations, parenting, Texas Confidence Builders*

*(Editor's Note: Thanks to Barbara J. Madrigal for adapting one of her most popular presentations for this publication. Her article is directed to families of children who are blind or have vision impairments. But Ms. Madrigal suggests—and we agree—that the advice is pertinent for anyone who touches blind children's lives: rehabilitation professionals, teachers, therapists, doctors and others.)*

One of the best parts of my job is the opportunity to meet families who are determined that their blind children will grow up with all the skills they need to be confident, productive and fulfilled adults. Sometimes they ask for my advice. You might be surprised by how I respond.

I tell parents if they really want the best for their kids' futures to "get high." No, I haven't regressed to some 1960's child rearing theory. When I tell parents to "get high," I mean for them to have high hopes, high expectations and high exposure for their children. I think it's good advice for any parent—but especially for parents of kids who are blind.

Sometimes, whether or not they realize it, parents don't genuinely believe their children can excel in life because they are blind. It's a subtle thing—they don't intentionally hold their children back. Still, the parents' doubts and fears may creep into the child's subconscious and pretty soon we have a self-fulfilling prophecy.

Parents aren't the only ones who may need to tune up their expectation levels. For years, people who are blind have battled the stereotypes and stigma of low expectations from doctors, teachers, service providers and others who confuse lack of vision with lack of potential. That's not the case at the Division for Blind Services! We know that blindness itself is not an obstacle to a successful and fulfilling life. The real obstacles are negative attitudes and misconceptions about what blind people can do and achieve.

That's why I say get high if you want your child to succeed in life!

### HIGH HOPES

If parents have confidence in their children's abilities and prospects, the kids are likely to believe in themselves, too. I think most parents know this, but it's pretty easy for communicating their confidence and optimism to get lost in the hectic pace of family life.

I encourage parents to make expressing their beliefs, hopes, dreams and confidence a routine part of their interactions with their kids. Beyond that, I encourage them to express those same things to the family, friends, teachers, doctors and others who make up the child's world. Confidence and optimism are contagious and the object is for blind children to be exposed to them often!

## **HIGH EXPECTATIONS**

If you don't expect much from somebody, I believe you won't get much. So, having high expectations for children who are blind increases the likelihood they will achieve their personal goals. Kids gain confidence by succeeding at doing things. So I'm surprised when I come across families in which blind children don't have chores or responsibilities.

Families may mean well when they give special treatment to the child who is blind; but they may be sentencing that child to a lifetime of dependence and isolation. If, at home, they have not learned how to contribute to the group and take on personal responsibility, where will they get the skills they need to make friends, advance through school, hold a good job or develop hobbies or social activities?

I urge parents to set realistic, positive expectations in accordance with a child's age, development and functional abilities. Things like dressing and personal hygiene are good places to start with younger children. As they master these tasks, they're ready for more—with family members cheering them along each step.

As important as it is for families to establish high expectations for their children who are blind, I think it is equally important for them to recognize that failure is also a part of a child's development. We all learn by failing—we grow that way. Parents who overprotect their children from failure may be instilling fear and hesitancy in their kids.

## **HIGH EXPOSURE**

It's natural for parents to want to protect their children from harm or discomfort. For parents of blind children, the thought of turning their kids loose in a predominantly sighted society may be especially daunting. It's tempting to shelter them from the potential physical dangers, uninformed attitudes and even discrimination.

I propose just the opposite for parents who want their children to be confident, independent and full-fledged participants in the world around them. Blind kids need to be introduced to as many aspects of life outside their home (and comfort zone) as possible. They need exposure to new situations where they can learn to be comfortable in unfamiliar settings. They need to understand there is, in fact, plenty of danger out there; but they have the skills to get out of trouble or avoid it all together.

## **DBS CAN HELP!**

A few years ago, DBS staff began to recognize that the traditional rehabilitation practices established in the early 1900's were not keeping pace with the demands of living independently in today's society. Many folks who received traditional rehab services were just fine—until something changed (their job, vision, technology, etc.).

In response to that realization, we reexamined our philosophies and practices and made some changes. The result was Texas Confidence Builders—an approach to training and rehabilitation services intended to provide people who are blind with skills they can use for a lifetime—regardless of the inevitable changes life throws at them.

It takes a long time to introduce a new concept such as this. We're still working on implementing Confidence Builders' practices in all of our programs throughout the state. Already, though, we are seeing that this

new approach is extremely effective in helping people adjust to blindness or changes in their vision, giving them strong skills to cope in countless settings and energizing them with confidence and empowerment.

I encourage parents or anyone else who is not familiar with Texas Confidence Builders to talk to a DBS staff member to get more information. To find the DBS office closest to you, check out the Blind Services link on the Departments of Assistive and Rehabilitative Services website: <[www.dars.state.tx.us](http://www.dars.state.tx.us)>. We also have a good brochure that describes Texas Confidence Builders in more detail. For a copy, feel free to call our toll-free number 1-800-628-5115 and ask for Linda Davis.

## **2005 Texas Symposium on Deafblindness: Awards, Learning Opportunities, and Community Building**

by David Wiley, Texas Deafblind Project, TSBVI

*Abstract: A report on the proceedings of the 2005 Texas Symposium on Deafblindness and awards given to leaders among those involved with deafblindness.*

*Key Words: New & Views, Symposium, training, families, networking, awards*

On February 26-27 the Texas Deafblind Project hosted the 2005 Texas Symposium on Deafblindness. The event was attended by close to 400 family members and professionals associated with children and youth who are deafblind. The symposium provides an opportunity for Texans who are involved with deafblindness to learn from some of the nation's leading authorities in the field, as well join together to network and support one another. This year's symposium kicked off with awards presented to people who have been leaders, demonstrating a commitment to improving the lives of Texans with deafblindness and their families.

The "Trailblazer Award" is given to family members who, through their actions in meeting challenges for their own children, provide an easier path for other families follow. This year's recipients are the Welch family from Big Spring, Texas. Paul and Susie Welch worked as active partners with their son Jaceson's schools in creating a meaningful and creative educational plan throughout his school years. Jaceson and his parents were pioneers in practices such as including a student with multiple disabilities in regular education classes and community-based instruction. Jaceson became a well-known and popular member of his high school community. The Welch's will always cherish the memories of Jaeson escorting his date the senior prom, and the entire senior class rising to applaud as he walked the stage at graduation. In recent years the Welch's have become active in the Deaf-Blind Multihandicapped Association of Texas (DBMAT), and Paul currently serves as president of that family and professional support organization. Through their leadership roles, Paul and Susie work together with the DBMAT officers to organize the board of directors, plan the annual family conference, and make everyone feel welcome and involved. Paul's father, Leo Welch is a community leader through his work with the VFW, and has assisted Jaceson in doing volunteer work in the community as well. For his continuous support and involvement with Jaceson, Leo shared the award with Paul, Susie, and Jaceson.

The "Intervener Award" was presented to Helen Porter. Helen has began working as a interpreter and aide with Lee Ann Bryan in school in Amarillo in 1978, before the term "intervener" was commonly used. Lee Ann is now 40 years old, and Helen still supports her as her intervener/SSP through the Texas Medicaid Waiver for People with Deafblindness and Multiple Disabilities. During these years, Helen has also continued working in the schools with other students who are deafblind. With Helen's support, as well as the support of her wonderful family, Lee Ann is now a woman who takes full advantage of community life by continuing to learn at Amarillo College and pursuing her many interests. Lee Ann was a keynote speaker at this year's symposium,

and of course Helen was there, providing the support she needs, and providing inspiration to the other interveners in attendance.

The “Marty Murrell Award” was present to Tish Smith for demonstrating excellence in educating students with deafblindness. Tish is an SLP who has provided communication services at Texas School for the Blind and Visually Impaired for many years. During this time she has served dozens of students who are deafblind with diverse abilities and needs. She has excelled at direct services to students, consultation, and training classroom personnel on appropriate communication techniques and strategies. Among her numerous special projects is work on a process for improving the quality of interactions with students who are deafblind, which she presented with her colleagues at this year’s symposium.

The “Ann Silverrain Award” was presented to Steve Schoen for his long-term commitment to improving the lives of Texans with Deafblindness. Steve recently resigned his position with the Texas Department of Aging and Disability Services (DADS) where he served as the administrator of the Texas Medicaid Waiver for People with Deafblindness and Multiple Disabilities. Steve took over a deafblind community living program almost fifteen years ago in another agency, before moving to DADS in state agency reorganization. At that time, the program supported fewer than 30 people in three group homes. Steve had the vision and ability to convert the program to a “Medicaid Waiver”, and in doing so increased both the resources and service options available to people. The Waiver program now provides the support needed by over 140 Texans with deafblindness to live in their own homes, with their families, or in small groups in the community. Through it all, Steve has been an advocate for maintaining appropriate specialized services to people with deafblindness, and for improving community services with deafblind specific training for direct-care staff, and outcome-based monitoring of service providers. After retiring from state government, Steve has volunteered to help the Deaf-Blind Multihandicapped Association of Texas (DBMAT) as their Executive Director. He will use his knowledge and experience to assist that organization in trying to acquire additional funds for activities and a permanent paid support person.

After the awards, Joe McNulty of the National Coalition on Deafblindness, and Director of the Helen Keller National Center in New York, informed participants about recent legislative activity, stressing the need for advocates to make sure policy makers know their concerns. Our own Robbie Blaha presented a fascinating keynote on the ways children with deafblindness develop concepts, and how we can help them learn. The break-out sessions included many informative sessions by speakers from around the nation such as: Tim Hartshorne from Central Michigan University; David Brown and Maurice Belote from California Deaf-Blind Services; Sandra Davenport, a Clinical Geneticist from Minnesota; Cathy Nelson from the University of Utah; Tanni Anthony from Colorado Services for Children with Combined Vision and Hearing Loss; and Barbara Miles, a consultant on deafblindness from Vermont. The program also included numerous speakers from around Texas. The closing keynotes were again a highlight of the symposium. The Knapp family from Missouri City shared the joys and challenges they experienced as their son Christian progressed from a premature infant into a young man who is continuing to learn and grow. Lee Ann Bryan from Amarillo and Rose Yanez from El Paso shared their personal experiences and accomplishments as young women who haven’t let sensory impairments slow them down.

Over 100 people attended the Friday evening family social hosted by DBMAT. Family members got to meet and support one another, as well as tell their stories to invited legislators and other policy makers. This event epitomized a theme of the entire symposium—building communities and connections with others who have similar experiences and concerns. I spoke with many participants who can’t wait for the next symposium in 2007, for another chance to learn and touch base with this wonderfully supportive community.

## A SPECIAL REPORT: THE NATIONAL SSP PILOT PROJECT

By Kris Cué, Texas Deaf-Blind Representative for the  
National SSP Pilot Project Committee, Austin, TX

*Abstract: Kris Cué discusses the Support Service Providers Pilot Project, a program that would allow deafblind individuals increased accessibility and participation in society. Three senators, including Texas Senator Kay Bailey Hutchison, have sponsored the legislation to fund a National SSP Pilot Project, with one of the three sites to be located in Austin.*

*Key Words: Support Service Providers, SSP Pilot Project, legislation, Kay Bailey Hutchison, deafblind, Deaf-Blind Service Center*

There is a new and exciting venture about to happen in our great state of Texas involving the deaf-blind community! As the Texas Deaf-Blind Representative for this “new and exciting venture”, it is my intent here to tell you all about it! The name of this new venture is the “National SSP Pilot Project”. Allow me to give you some history regarding how this project came about and then I will give you the latest information on its progress on Capitol Hill.

Most of you reading this newsletter know, either by personal experience or by research, that there are many, many people in the United States who are deaf-blind. Deaf-blind folks are those who experience both vision and hearing losses because of various etiologies. Because of their dual sensory loss, deaf-blind people experience communication barriers and limited opportunities for employment and education in their lives. It is also difficult for a deaf-blind person to access transportation and necessary information about their environments.

A service that has proven to benefit deaf-blind individuals in Seattle, Washington (a nationally renowned deaf-blind community) is a network of skilled, trained people called Support Service Providers, or SSP’s. SSP’s are specifically trained and hired to work with persons who have both hearing and vision losses. Support Service Providers do NOT fill the roles of a personal care attendant, a sign language interpreter, or caregiver to the deaf-blind individual. They also do not make decisions for the deaf-blind person. Rather, SSP’s specifically and only provide visual and environmental information, sighted guide services and accessibility information in order for the deaf-blind individual to make his/her own informed decisions. With the assistance of SSP’s, deaf-blind people here in Texas would be able to obtain and keep a job, do job-related tasks such as reading job announcements and office memos or travel for business. They could also participate in the political process by voting, run errands, read mail, make purchases and do tasks anyone with normal hearing and sight could do. The deaf-blind people in Seattle, who have SSP services available, are no longer isolated by barriers to information and businesses, and they can participate more fully in society.

The Deaf-Blind Service Center located in Seattle, Washington has a model SSP program. Deaf-blind persons living in Seattle have received the services of trained SSP’s for the past 20 years. Research conducted by the Deaf-Blind Service Center in Seattle shows that there are only four other states that provide statewide SSP services to their deaf-blind citizens: Massachusetts, Michigan, Minnesota and Utah. Eight other states—Arkansas, Arizona, California, Louisiana, Maryland, New York, Ohio, and Wisconsin – have some form of SSP services, but only in local cities or counties. There are NO such services available in Texas.

At the 2003 American Association for the Deaf-Blind (AADB) Convention in San Diego, California, the need for SSP services became an important goal. During this particular AADB Convention, its members

informed the AADB Board about their concerns and need for SSP services nationally. The Seattle Deaf-Blind Service Center staff and Board members also approached the AADB Board about the idea of becoming partners to work on establishing national SSP services. In the Spring of 2004, Seattle Deaf-Blind Service Center (DBSC) staff and Board members met with AADB's staff and Board members and together they went to educate several members of the U.S. Congress about the need for national SSP services. The members of Congress advised them to first select 2 or 3 sites with a need for SSP services in the country, and then to set up pilot studies in those selected sites. If the results of the pilot studies show positive changes for the deaf-blind people who received SSP services in those sites, Congress might be able to provide money to help other states set up SSP services.

After meeting with members of Congress, the Seattle DBSC began putting together the National SSP Pilot Project, with the AADB in Silver Spring, Maryland and the Helen Keller National Center (HKNC) in Sands Point, New York acting as supporting partners. These partners agreed that the Seattle DBSC would be the lead agency and would also be responsible for the administration of the money for the pilot project.

As partners for this pilot project, the Seattle DBSC, AADB and HKNC agreed to then select three areas for the pilot sites, as they were advised to do by members of Congress. The first site selected was the state of Washington in order to expand their existing SSP services outside of Seattle to include all of Washington State. The second and third sites chosen were the Maryland/Virginia/Washington, D.C. Metro area and AUSTIN, TEXAS!! The criteria for selecting these two additional sites were: 1) both sites have deaf-blind leaders who have had formal leadership training during the past 2 years in Seattle; 2) both sites have a need for SSP services and a large deaf-blind community; 3) both sites have deaf-blind leaders who are familiar with and have personally experienced Seattle DBSC's SSP services and have received training from the Seattle DBSC staff; 4) both sites have deaf-blind community members ready to work on setting up SSP services and have already started volunteering their time and efforts for this work; and 5) both sites have deaf-blind leaders immediately ready to volunteer many hours for this important project. After selecting the pilot sites and the deaf-blind leaders to represent the MD/VA/DC Metro and Austin, Texas areas, the National SSP Pilot Project Committee was formed. Members of this committee are:

- Kris Cué, Deaf-Blind Community Leader from Austin, Texas
- Randy Pope, Deaf-Blind Community Leader from Washington, D.C. Metro area
- Dorothy Walt, Region X Helen Keller National Center Office and AADB Board member
- Jamie Pope, AADB Executive Director
- Elizabeth Spiers, AADB Director of Program Services
- Caryn Tenin, President of the Seattle DBSC Board of Directors
- Jackie Engler-Morris, Seattle DBSC Program Director
- Gail Ploman, Seattle DBSC Executive Director

In the Summer of 2004, the National SSP Pilot Project Committee held its first meeting in Seattle. A second meeting of the committee was held in Austin, Texas, in November of 2004 after sharing a day of training on the political process (presented by Joe McNulty of HKNC) with AADB Board members. During the last week of January 2005 the National SSP Pilot Project Committee members went to Washington, D.C. to

personally meet with their respective senators, from Washington, Maryland, Virginia, Washington, D.C. Metro area and Texas, to educate them about the project. Each committee member took with them letters of support from several major organizations and/or heads of agencies that provide community services to the deaf-blind citizen in their states. Copies of these letters of support were given to each senator that committee members met with in Washington, D.C. to show that each pilot site chosen had the support of organizations and agencies serving the deaf-blind.

Senators Murray and Cantwell from the state of Washington are the official senate sponsors of the Appropriations Request for the National SSP Pilot Project funding currently being considered for presentation to the all-powerful Senate Appropriations Committee. While in Washington, D.C., we learned early on that Texas' own Senator Kay Bailey Hutchison is a member of the Senate Appropriations Committee!

After the committee's trip to D.C. to educate senators about the project, a letter-writing campaign by the deaf-blind citizens and their family members and friends was undertaken in each state chosen to be a pilot site. These letters were written to show our senators and representatives in D.C. that we need SSP services in our state and are ready and willing to carry out the goals of the National SSP Pilot Project should it be approved for funding on Capitol Hill. These letters were, of course, sent directly to Senator Hutchison's office in D.C. ASAP!

Did our efforts pay off? Here's the good news: One week after the committee met with our senators in D.C., we got word from Senator Hutchison's office that she was joining Senators Murray and Cantwell in sponsoring the Appropriations Request for funding of the National SSP Pilot Project!! It is our hope that this Appropriations Request will earn the approval of the majority of the senators on the Appropriations Committee and continue through the necessary political process from now until October 2005 when it will be officially voted on by the U.S. Congress. When we succeed in obtaining funding for this historical project, Texas will become a pioneer state for SSP services for its deaf-blind citizens! The goal of the National SSP Pilot Project – after completion of the pilot sites' successful outcome reports in 2008 – is to establish a national network of professionally trained and skilled SSP's. For more information about this project, or if you want to know how to help, please contact:

Gail Ploman, Executive Director, Seattle DBSC  
1620 18<sup>th</sup> Avenue, Suite 200, Seattle, WA 98122  
E-mail: [gploman@seattledbcs.org](mailto:gploman@seattledbcs.org)  
Phone/TTY: 206-325-7241 OR

Kris Cué, Texas Deaf-Blind Representative, National SSP Pilot Project Committee and Facilitator, Usher Syndrome Support Group of Texas  
2113 Surrender Avenue, Austin, TX 78728  
E-mail: [kcue@sbcglobal.net](mailto:kcue@sbcglobal.net)  
Phone: 512-251-2550

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Mail or e-mail your new classified to Carolyn Perkins:

TSBVI Outreach, 1100 West 45th St., Austin, TX 78756, or <carolynperkins@tsbvi.edu>.

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

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## TEXAS FOCUS 2005

### Feeling Good and Doing Well: Self Esteem and The Child with Visual Impairments

June 9 & 10, 2005

Omni Southpark Hotel

4140 Governor's Row (IH 35 at Hwy 71)

Austin, Texas

Doing well is more than getting good grades and meeting IEP objectives. Doing well is having the confidence to make choices. Doing well is taking control of one's present and future. Doing well is about being an active member of a family, of a school, of a community. Doing well is having self-worth. Join us at Texas Focus 2005: "Feeling Good and Doing Well" as we explore these issues as they relate to children with visual impairments. Our keynote address will be delivered by Dr. Dean Tuttle, who with his wife Naomi, wrote the book, *Self-Esteem and Adjusting with Blindness: The Process of Responding to Life's Demands*.

*A general membership meeting of the Texas Association for Parents of Children with Visual Impairments (TAPVI) will be held during Texas Focus on Thursday, June 9, 2005 from 5-7pm. All interested parents are encouraged to attend.*

**ALSO:**

### **New Professional Preconference: Using the Sensory Learning Kit**

June 8, 2005

Omni Southpark Hotel

Presenter: Millie Smith

The Sensory Learning Kit is a soon-to-be released product from the American Printing House for the Blind (APH). The kit is designed for use with students with significant multiple impairments that include a visual impairment, and improves upon the old sensory stimulation kits.

This training is designed for VI professionals who have completed their training program within the last 3 years. We are able to waive registration fees and assist with travel expenses for this group. Others may register, but we cannot waive those fees nor assist with travel. Attendance is limited to the first 200 registrants.

Contacts for both events: Jim Durkel, (512) 206-9270 or <jimdurkel@tsbvi.edu>,

Paula Effinger, (512) 206-9344 or <paulaeffinger@tsbvi.edu>

## **Assessment for Students with Visual Impairments**

June 13-15, 2005  
TSBVI Conference Center  
Texas School for the Blind & Visually Impaired  
1100 W. 45th Street  
Austin, Texas

Summer workshop for assessment personnel responsible for testing students with visual impairments. Cost: \$150 per person, which includes lunch for all three days and an extensive handbook with resource materials.

Registration deadline June 1st  
Contact: Karen Scanlon at 512-206-9314, or  
<karensanlon@tsbvi.edu>

## **7th International CHARGE Syndrome Conference**

July 22-24, 2005  
Wyndham Miami Beach Resort  
4833 Collins Ave.  
Miami Beach, Florida

Speakers from medical, educational, and related professions, offering a wide range of topics from which to select. Childcare is provided during the meetings for families in attendance.

There will be a late registration fee of \$50 per registration after June 15th, and absolutely no registrations will be accepted after June 30th.

For information contact the CHARGE Syndrome  
Foundation office: 800-442-7604,  
e-mail: <marion@chargesyndrome.org>,  
or visit  
<<http://www.chargesyndrome.org/miami.htm>>

## **2nd Annual Texas Parent to Parent Conference “Our Children...Our Journey”**

July 22-24, 2005  
University of Mary Hardin Baylor,  
Belton, Texas

Texas Parent to Parent is a nonprofit organization that was created to connect families caring for children with disabilities and special health care needs.

Contact: 866-896-6001 or 512-458-8600,  
E-mail: <infor@txp2p.org>  
Website: <www.tsp2p.org>

## **Helen Keller National Center 2005 Seminars**

Leona & Harry B. Helmsley Conference Center,  
HKNC  
141 Middle Neck Road  
Sands Point, New York

Interpreting Techniques for the  
Deaf-Blind Population  
August 20-23, 2005

Enhancing Services for Older Adults with  
Vision and Hearing Loss  
September 12-16, 2005

Transformation: Person-Centered  
Approach to Habilitation  
November 14-18

Getting in Touch with Literacy Conference  
December 1-3, 2005

Contact: (516) 944-8900  
<hkncinfo@hknc.org>  
<www.hknc.org>

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## Short Classes at TSBVI

Do you have an academic student or child who might benefit from a week of intensive training in one or two vision-specific learning domains? Would you like your child or student to participate in a long weekend class focusing on issues related to vision loss? If so, you may want to read this.

### ABOUT SHORT CLASSES

TSBVI Short-Term Classes serve students who are functioning at or close to grade level. Students come from across Texas to participate in our one-week or long-weekend small-group classes. These are students whose basic needs are well met in the local school district, but who may need a short, intensive training boost in one or two disability-specific areas (e.g., O&M, independent living, technology, aspects of the braille code, math concepts or adaptations). While at TSBVI, students also have experiences related to social skill development, interactions with other visually impaired students and professionals, and independent living.

Students must be referred for a Short Class by their local school district. Students are requested to bring their week's school assignments (homework) with them. This serves two purposes: (1) the opportunity to teach new skills within the context of what students are learning at home, and (2) helping students keep up with their assignments while they are away. Before students come to a Short Class, their local VI teacher and TSBVI teachers discuss the student's current level of functioning in the skill areas selected for instruction, to maximize effective instruction as soon as the students arrive.

### SHORT CLASSES FOR THE 2005–2006 SCHOOL YEAR

Below is a listing of Short-Term Classes for next year. If you have an upcoming ARD, this could be a time to talk about a possible referral. Please call TSBVI principal, Lauren Newton, if you have any questions about the program or if you want to make a referral to one or more classes.

#### Fall Semester 2005

- September 11 - 16 Technology Week #1  
(secondary)
- September 25 - 30 Middle School IEP #1
- Oct 16 - 21 High School IEP #1
- \*October 27- 30 Middle School Independence  
Weekend
- November 6 - 11 Elementary:  
• Elementary IEP #1  
• Elementary Math Tools &  
Concepts
- Nov 27 - Dec 2 Math Tools and Concepts  
(secondary)
- December 8 - 11 "Getting There" Weekend  
(grades 9-12)

\* Long-Weekend Program

#### Spring Semester 2006

- January 8 - 13 High School IEP #2
- \*January 26 - 29 Fitness at Home & in the  
Community (secondary)
- February 5 - 10 Middle School IEP #1
- \*Feb 16 - 19 Low Vision Weekend  
(secondary)
- Feb 26- March 3 Technology Week #2  
(secondary)
- \*March 23- 26 Elementary Independence  
Weekend
- \*Mar 30 - Apr 2 High School Independence  
Weekend
- April 23 - 28 Elementary  
• Elementary IEP #1  
• Elementary Technology

\* Long-Weekend Program

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# SEE/HEAR

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Austin, Texas 78756

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

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March 1st for the Spring edition

June 1st for the Summer edition

September 1st for the Fall edition

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