

TX SenseAbilities

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This holiday season, are you looking for gift ideas for a young person with a visual impairment? *TX SenseAbilities* editor Holly Cooper created “Gifts to get Kids who are Blind, Visually Impaired or Have Additional Disabilities” beginning on page 14.

Celebrating Life

By Janie Carrillo, Grandmother, McAllen, TX

Abstract: The author shares how she celebrated her granddaughters life through planning a cultural tradition ten years early.

Key words: Family Wisdom, Grandparents' Perspective, Cultural Relevance, Quinceañera, Cincoanera, Family Traditions, Deafblind, Multiple Disabilities.

As my granddaughter, Alexena at the age of seven months, laid there in the hospital bed defenseless, with fear of not knowing what was going on or even what the doctor was saying, I begged God to please let me trade places with her. After seizing for twenty five minutes, I was finally told that she had a rare brain disorder called Open Lid Schizencephaly and would need medical attention immediately. Throughout the years many other obstacles were added on; seizures, microcephaly, epilepsy, developmentally delayed, aspiration, cerebral palsy, legally blind, deaf, having a G tube placement and a VNS. It was just a lot to take in within such a short period of time; but with God's help we faced it head on.

Many doctors and nurses would constantly tell me to give up—that Alexena was shutting down and needed to just be put in hospice; that she would not live till the age of two and would just be suffering. Determined I traveled back and forth from McAllen to Corpus and even Dallas, in search of a doctor who could find a medication that would work. The same speech from every doctor was given to stop wasting my time and just to enjoy the time I had with her before she left. The medication that she was taking would bring her down, to where she was sleeping about twenty hours a day and spent

the other four too tired from vomiting her meals. A miracle finally happened when I found a neurologist that was willing to give her a quality way of life over quantity. The doctor lowered her amount of medication and just told us to be prepared for the worst. She may have about a hundred seizures a day but she can now stay awake like a normal child and play. Despite all the many bumpy roads that she has faced since then, whenever a smile shows up on her face it reassures me that I made the right decision.



Photo caption: Janie and Alexena

Alexena is now a five year old little girl who cannot sit or stand, who cannot walk or crawl, who cannot say a single word or have the possibility of hearing what we are saying; but she is a little girl who will always have a smile on her face and has not given up the fight to live. She enjoys life. She is someone who enjoys laughing and playing with her brother and sister. Not once has she ever been treated as someone with a handicap or as different. She is just like any other normal child who enjoys getting into trouble and throwing a tantrum now and



Photo caption: Alexena enjoys the party!

again. Every time I want to give up I see her smile, and I know I am her voice, her legs and her arms.

As the months passed Alexena got sick again, and again the hospital recommended that maybe it was time to enroll her in hospice. I argued that she was not ready to give up, that she enjoyed playing tricks on people, that she could be severely sick one minute and the next be getting into trouble. She may have difficulties seeing and hearing but she also enjoyed watching cartoons and would laugh when something funny happened. With the help of mechanical devices she has been able to stand and take baby steps with assistance. I always knew that with the help of family, friends and

God anything was possible. On that day I was asked to consider hospice, I determined I was going to throw her a celebrating life party.

I started to make phone calls asking around if anyone knew how I could even make such a huge celebration happen. Working with family members, private home nurses, and her home school teacher, we came up with an idea that went full speed. We did not slow down till the day of the celebration. We were going to celebrate Alexana by having a cincoanera!. It was going to take a lot of help from family and friends but it was going to happen. I figured that if doctors said she was not going to make to her fifteenth birthday, why not go all the way out now.

First thing I had to do was to find her an escort. I thought of having her brother, but we had a volunteer. A little boy who knew her since before kindergarten, and has always been by her side, volunteered to escort her to church and the dance. Her home school teacher made a skit. Her teacher of the visually impaired baked her cake. Her provider made the decorations. Her nurse made the pictures and invitations. So many other family members, past nurses and therapists assisted in making Alexena's day a dream come true. I made it a point to invite other children with disabilities to the celebration because they understood in a way others cannot, what they shared with Alexana.

Many prayers were made in hopes that God would grant her one day without seizures or vomiting so she could have the same experience as other children do on their birthdays. Alexena was awake at eight in the morning to begin her normal routine, but this time to be dressed in a white dress and escorted to church by her escort and god parents. A beautiful mass was given in her name while the priest blessed her for another year of life. The church was filled with family and friends despite that it was being held on a Friday during work hours. Everything went perfect; she had a smile bigger than she has ever had and did not have one seizure. I could not have asked for a greater gift, but her day was not yet over.

Alexena rested in bed awaiting her big night while her nurse styled her hair and put her tiara on her head. Waiting beside Alexena were the two dresses picked especially for her. We all arrived at the dance hall and prayed once again to God to grant her just a few more hours without seizures or vomiting.

As her hour finally arrived, Alexena was wheeled in by her escort while “Somewhere Over the Rainbow” was played. There was powerful meaning found in the words of the song. Somewhere, over the rainbow, way up high, and the dreams that you dreamed of, once in a lullaby. Oh, somewhere over the rainbow, blue birds fly, and the dreams that you dreamed of, dreams really do come true. Seven sets of girls and boys entered the dance hall with her and then danced their skit to perfection—Alexena, in the middle laughing and smiling. As the song came to an end everyone clapped and she was escorted off the dance floor.

Her night was not yet over; she had a mother-daughter dance. As everyone stood, the music once again began to play, “If you knew how lonely my life has been and how long I’ve been so alone. If you knew how I wanted someone to come along and change my life the way you’ve done”. Tears began to fill my eyes when I saw Alexena being carried and danced on the dance floor.

Throughout the rest of the night Alexena was taking pictures with all her guests and enjoying herself. Alexena continued to stay in perfect health; without a single seizure or looking tired. As the night’s celebration came to an end, I sat there holding Alexena. She looked up at me and smiled. Right then and there, I knew all the hard work was worth it.

To this day she continues to be a very happy little girl with the same huge smile. I will never give up as long as she continues to fight. I believe Alexena was put here for a purpose: to show me that life goes on, and to not let little things stop me from enjoying my life. I have made a promise to Alexena to never treat her different or to exclude her from our family. As part of that promise, I try to make sure she gets to do everything other children would get to do, just with a few minor adjustments. She has completed my life and has taught me many lessons.

On the invitations to Alexana’s cincoanera was a picture of her in the grass surrounded by butterflies with the following words printed below: “A child is like a butterfly in the wind. Some can fly higher than others, but each flies the best it can. Why compare one against the other? Each one is different, each one is special, and each one is beautiful.”

Alexena is such a butterfly.



Photo caption: Alexena taking pictures with her guests in their elegant party attire.

Travels to St. Louis

By Andrea Arena Wade, Parent, San Antonio, TX

Abstract: A mother shares her family's experience attending the 2012 National Organization of Albinism and Hypopigmentation (NOAH) conference in St. Louis.

Keywords: albinism, low vision, family wisdom

My name is Andrea Wade and my husband, Sean, and I have a three-year-old daughter, Elizabeth, who has albinism. Albinism is an inherited condition in which people have little or no pigment in their eyes, skin and/or hair. They have inherited genes that do not make the usual amount of a pigment called melanin. About one in 17,000 people in the US have some type of albinism. Although Elizabeth was born with a head full of white hair, we didn't learn that she had albinism until she was about six weeks old. We understood that we needed to take necessary precautions to protect her while she was out in the sun by wearing sunscreen, sunglasses and protective clothing. One issue that we were completely unaware of is that people with albinism always have a visual impairment and it is not something that is correctable with glasses. The degree of visual impairment varies, but many people with albinism are considered legally blind. At our most recent visit to the eye doctor, Elizabeth's vision was 20/300.



Elizabeth and her mom, Andrea in a picture taken by her dad, Sean.

Soon after learning about Elizabeth's diagnosis, we did like most people do and scoured the internet for information. We discovered a wonderful organization called NOAH (National Organization for Albinism and Hypopigmentation). We joined NOAH and in a short amount of time received a "welcome" box with sunscreen, sunglasses, and an informative book called "Raising a Child with Albinism." We also received a call from a trained "first responder" who was a fellow parent with two children with albinism. She was there to listen, answer questions and give support. Since joining NOAH, we have had the opportunity to listen to teleconferences and watch webinars on various topics related to the issues surrounding albinism. We also receive a quarterly magazine, *Albinism Insight*. NOAH hosts a biennial national conference, and their most recent one was in July of this year in St. Louis. We agreed that attending the NOAH conference would be a very valuable trip for our family to make.

The NOAH conference consisted of a variety of workshops for the adults to attend. They also had a wonderful children's program where

Elizabeth got to play and spend time with other children her age. Some of the sessions we enjoyed the most were Advocating for your Child, Dealing with the Negative Comments, Building Self-Esteem in your Child, the Joys and Challenges of Parenting, the Genetics of Albinism, Latest Research in Albinism, and Assistive Technology. I was also able to attend a workshop specifically for mothers of children with albinism. It made such a positive impression on me. Although I had never met any of these people before, there was just a natural feeling of understanding and knowing that you have been through some of the same triumphs and challenges. It is amazing how having one thing in common with a complete stranger can make you feel so connected and so at ease.

The course that interested my husband the most was the Assistive Technology Seminar. The presenter was Ike Presley who works for American Blind Services. In his seminar we discussed all different types of assistive technology and the most affordable and beneficial devices. Mr. Presley spoke about how important it is for anyone with a visual impairment to use a large enough font size to make reading easier. Aph.org is a great resource for getting the larger font types for free on your PC. Mr. Presley also recommended lighting with 2700 Kelvin to 3500 Kelvin light bulbs with reddish to yellow tint to help reduce glare on a screen. He discussed why having the proper lighting can help visually impaired individuals reduce glare, which helps minimize eye strain and fatigue.

The last part of his presentation focused on practical and cost effective non-optical devices to make a visually impaired individual's environment more adaptable. Using an articulated arm for book reading, computer screens, and typing can help reduce neck strain, eye fatigue, and shoulder stiffness. Using spot readers and keyboard commands are also keys for success in a sighted world. By teaching my child keyboard commands, she will be able to maneuver a PC without really even using a mouse. Most of us are mouse dependent and we can be more efficient in our computer skills if we take the time to learn keyboard commands.



Andrea and her daughter, Elizabeth, at age 3 years. Picture taken by Sean Wade.

When we first joined NOAH we knew attending this conference would be a valuable experience for our family and we were right. Over 850 people traveled from all over the country and the world to attend this conference. We met so many adults and children with albinism and enjoyed participating in the informational sessions and social activities with our new friends. We normally stand out in a crowd, but at the NOAH conference, we fit right in and it was very comforting.

One final point that really made an impression on me was that when something negative happens, whether it's someone saying something mean or doing poorly on an exam, it is important to not let that one moment define you. I think of that often with Elizabeth, in relation to her albinism and what some may see as the negative effects it has on her and her everyday life. Elizabeth has albinism, but it doesn't define who she is --- it is simply a part of who she is.

Climbing the Advocacy Ladder with Other Family Leaders

By Vivecca Hartman, Parent and Family Leader, Houston, TX

Abstract: The author reflects upon her participation in the National Family Association for Deaf-Blind Family Leadership Symposium, which was held in Austin, TX this past July.

Keywords: Family Wisdom, family leadership, Intervener, NFADB, systems improvement, deafblind

Editor's Note: The following article was written by one of the Texas family leaders who were invited to participate in the National Family Association for Deaf-Blind (NFADB) Symposium this past July. The NFADB Symposium was designed to be an initial step towards partnering with other national entities to effectively advocate for a continuum of individualized supports for people with deafblindness.

Vivecca's article focuses on Intervener services. In the Winter, 2012 and Spring, 2013, we will feature articles that focus on Support Service Providers (SSPs) and qualified Interpreters for individuals who are deafblind. To learn more about the NFADB Symposium, please turn to "National Family Association for Deaf-blind 2012 Symposium" in News & Views on page 36.

The National Family Association Deaf-Blind (NFADB) Conference this summer was a wonderful opportunity to join with other families across the nation! We got to say hello and put faces with names we have seen in emails and rekindle relations made long ago. It was such a reassuring atmosphere of belonging and being part of a bigger group ~ THANK YOU NFADB!



Photo Caption: Vivecca Hartman speaking at the NFADB Symposium in July.

I was also excited to participate in the opportunity to help motivate other families with our personal family journey that led us to be so driven in the Intervener movement. I cannot reiterate enough, how our lives improved after learning from having a well-trained Intervener stay in our home for a few months. She taught us and set up routines that we have kept in place over 5 years later!

Quite honestly, having chosen the path to stick with staying in our local school district has been good for our family and we have benefited from our district's realization that a stronger commitment to deafblind training was needed. I did not get to expand on this during the presentation due to time restraints, but I did open my story by saying that I am extremely grateful to the TSBVI Deafblind Outreach team for being a lifeline for us over the years! TSBVI Deafblind Outreach is the Texas Deafblind Project that offers technical assistance and outreach to individuals with deafblindness and their families. We also had successful state level advocacy through my involvement with the Deaf-Blind Multihandicapped Association of Texas (DBMAT), my state's family organization that is also an affiliate of NFADB. When my district was ready to make a stronger commitment, the Outreach Team were there and ready to

offer more help and support to our educational team! As some of you know now, at age 15, things are going very well at school for Christopher ~ Thank you Outreach for getting us where we are!

I want all families that could benefit from a well-trained Intervener to have the same opportunities early on in their child's life!

During the Saturday afternoon portion of the NFADB Symposium , family leaders attended breakout session where the choices were focused on advocacy at the school district Level, state level, national level , and adult services. Having had successful opportunities thus far on the school district and state levels in my child's 15 years of life, I chose to attend the national level session. It was so informative. As with anything, you have to start with the basics. You have to learn about a system before you can start planning a strategy to help educate yourself as well as others about how to effect a change in a positive and diplomatic manner. I learned so much and yet, it was a seed to help me realize how much more I have to learn! Fortunately, they gave many resource ideas of places to find more information.

Shortly after the NFADB Symposium, the National Coalition on Deaf-Blindness (NCDB) announced their plan to start collecting information in the development of a national Intervener college level curriculum! I look forward to helping in any way possible so that our nation has this readily available to all!

I am so excited about the national plans for establishing Interveners as a recognized support for people with deafblindness, which NFADB has the opportunity to support! We're one step closer to making more information and training opportunities available to not only the families, but also the professionals that work with our loved ones!

NFADB – You Rock in keeping us all connected for the betterment of our national Deafblind Community! I look forward to a gathering of celebrations of our stories and successes someday soon!

Advocacy Tips for the Long Haul: It's Not a Race – It's a Journey!

By Cynthia Carr Falardeau, Parent, and Executive Director, Education Foundation of Indian River County, Vero Beach, FL

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Abstract: The author shares 10 evidenced based strategies for parents to be successful advocates for children with disabilities.

Key Words: Family Wisdom, advocacy, family leadership, school involvement

Editor's Note: We've recently discovered Parenting Special Needs Magazine and have found it to be quite a treasure trove for the families we partner with. We especially enjoyed reading the following article, as Ms. Falardeau's 10 tips for successful advocacy are key components in the Texas Family Leadership we've had the pleasure of being part of for many years. Thank you, Parenting Special Needs Magazine, for sharing your wonderful article with us!

Recently I talked to my son's first elementary school Principal. She marveled at the progress he had made from his first days in the Pre-K ESE (Exceptional Student Education) program. He was three, non-verbal, crippled by sensory input, and miserable. We would begin each day with me literally dragging him through the parking lot. He would cling to my leg screaming. When I would finally arrive at the classroom door I would have to peel him off my body. He would then run and hide under a table and cover his ears and scream and cry. In a word it was AWFUL!

I felt like I was part of comedy parody. I had a new teacher, a student resource coordinator who didn't understand Autism and a behavior analyst whose idea was to "man handle" my child into the cafeteria. The Principal said, "I was always so worried that you would put him back in the car and never return!" For a moment I was speechless. Then I laughed out loud and replied, "I never knew I had that option!" I almost started crying but then cracked up again.

The truth was, I knew the situation was bad but I felt comfort in the fact that the Principal helped me network with school district leaders. She also gave me her commitment to try to fix the challenges that impeded my son's progress. I trusted her. I knew I had to work with her, not only for my child, but the others in the classroom.

I didn't know it then but I was becoming an advocate.

Now 6 ½ years later the same person who was once a Principal is now a key administrator for our school district. She observed my son in a summer general education science and math camp. Her remark made my heart sing, "I can't get over how social your son is!"

We had come a long way from being a scared child who chewed the arms off his shirts out of fear. It took a lot of hard work. Most of all, it required me to become an advocate.

I have made plenty of mistakes along the way. But here are my top 10 tips to help any child thrive.

1. **Have a Clear Vision:** The key to achieving any goal is to have a clear picture in your mind of what success looks like. You need to be able to define it and to give specifics of how you will know you have arrived. It sounds simplistic but visioning is the process of goal setting. So often I talk with families and they want someone to offer them a "menu option" to help them to identify the path. The truth is that every child is different and the gateway to success depends on each child's strengths and weaknesses. Bottom line: there is no "one size fits all" approach.
2. **Identify the Cast of Characters:** Even when you think everyone is against you, there is always one person who identifies or understands what you are trying to achieve for your child. Ask for their input and help to refine your approach and to engage supporters. One mom put it best, "Be focused in your goal, be consistent in your messaging, build consensus with a core group to move forward." I couldn't have said it better myself!
3. **Determine the Best Way to Unite the Decision Makers:** You may need to, "divide and concur," by having lots of, "meetings before the meeting." This is the stuff that sends working mothers into overdrive, and non-working mothers to feel like they need to be paid for their time! The reality is that if you want to achieve different results – you need to challenge yourself for a new outcome through an innovative path that you have not traveled before. Building relationships takes time, but it delivers the greatest return on your investment.

4. Gather Data: “Emotion muddles the water,” that being said you need to boil your case down to numbers. Statistics speak volumes. It’s a great strategy for overly emotional beings like me, “the Ubber Mommy Bear!” When you can present information in a numerical manner it takes the drama out of the situation and brings clarity to the problem that needs to be addressed.
5. Rally the Troops: Often children with special needs show their talents to different people and in varied settings. It’s best to bring as many folks to team meetings and IEP’s (Individualized Education Program) as possible. The “more the merrier.” This gives the team a more comprehensive view of the child and the potential for a more innovative and successful plan. It also helps to feel supported when you, the parent, are nervous. I don’t care how confident you are – parents often feel like they are being judged by the school team. To some extent they are – but by bringing a group of experts about your child – shows them that you mean business and are serious about advocating for your child’s success.
6. Have a Plan for You – The Caretaker/Advocate: Quite simply, I am a mess! I have learned that when I take time for myself through exercise and/or prayer, I am a better person, and therefore, a better advocate. It’s really hard when every emotional and financial splinter of your life goes into helping your child try to succeed. I have found my greatest success is when I am rested and rejuvenated. This is not always easy for parents of special needs children as we are, by nature, jugglers. So it is essential that you find an outlet to center yourself. This time allows for you to reflect and think. For me, it’s all about the process of triathlon: swim-bike-run. I love it and it releases all of my angst. It also gives me a means to generate new ideas and feel recharged. Whatever release you choose, know that you have made the choice, to do something for you and your child’s future.
7. Keep it all: It’s a good practice to keep everything that comes home from school until the next IEP. Always keep a few examples of work for each school year. This is especially important during the elementary school years. This practice will allow you to be prepared with examples of work to back up your point of advocacy. For example, having dated writing and drawing samples can document progress/no progress. Being prepared with a neat folder shows your level of absolute awareness. It can be very powerful.
8. Confirm the Communication Plan: We have used notebooks, agendas, email and charts. They all work as long as everyone agrees on the process and the frequency. At the team meeting each year, we determine what will work for all. It’s important to have a focus that relates to specific goals. This way everyone is working together.
9. Determine the Follow Up Strategy: It’s always a great feeling when you reach a moment when everyone is united in the effort. You need to decide when the next meeting will be or how will the group resume conversation to talk about the student’s progress. It seems simple but often this step gets lost in what I refer to as a “celebratory moment.” Use the time when everyone signs on the dotted line of the IEP to confirm when the group will meet again.
10. Seek Best Practices from Other Parents and Professionals: There is no “one size fits all” strategy. So it’s important to commit yourself to being a “lifelong learner.” Advocacy is not a race; it’s a journey, so the more you learn, the more you grow. Networking through parent groups, blogs, Facebook or other social networks is a great way to exchange ideas and encourage each other. Some things I try and others I just think about. The key to being the best advocate for your child is to have an open mind.

The Braille Challenge® Reading, Writing and Spelling Contest

By Beth Freeborn, Harley's Mom, Austin, TX

Abstract: A mom describes the impact of her son competing in the Braille Challenge, a national reading and writing contest in braille that is sponsored by the Braille Institute of Los Angeles. Check out their highlight video at <www.brailleinstitute.org/Services/The_Braille_Challenge.aspx>.

Keywords: braille, visually impaired, blind, competition, Braille Institute

Editor's note: Competing in the Braille Challenge is a great way to motivate students with blindness and visually impairments to practice their literacy skills. The competitors range from 1st to 12th grade. Students must first compete in a Regional Preliminary event which has been held at the Region 13 Education Service Center in Austin. Contact your Teacher of the Visually Impaired (TVI) if you are interested in this academic competition designed for braille users.

I'm writing this because my son, Harley Fetterman, has been to the Braille Challenge national academic competition 6 out of the last 9 years. We met Merlyn Hilleman and her family there. Merlyn now lives in Round Rock and has gone to the Braille Challenge 8 out of the last 9 years.

The Braille Challenge is a wonderful event that the Braille Institute in Los Angeles, CA holds every year. It is wonderful from many perspectives.

First, it gives the kids something to compete in. Competition is good for everyone because it makes us all strive to do better, to improve our skills. Sighted kids have many opportunities to compete with each other. It's not always easy to get visually impaired kids involved with competitions. This is one event that is for visually impaired kids, and it helps them improve on a skill they will use all of their lives.

Second, the whole event is designed to instill pride in those kids that participate. The notice that the kids receive tells them that their scores were the best amongst over 800 people that submitted their scores. Only 60 kids (5 levels with 12 kids each) make it to Nationals.

The day of the event, the kids are met by cheering supporters as they reach the Braille Institute. The opening ceremony is a grand event, starting with the USC Trojan Marching Band that comes in playing rousing music as the contestants march in. The emcee announces each contestants name and they stand up to be acknowledged by all of the fans.

And when it is over, the Awards Ceremony is a spectacular event. Each contestant can invite 5 members of their family or friends to the formal sit down event. The show is emceed by a celebrity. This year it was Danny Jacobs, best known to kids as the voice of King Julien on Nickelodeon's popular television show, *The Penguins of Madagascar*. Even though the awards banquet is about the winners, it is all designed to make each contestant feel good just to make it to the contest.

Last, and most importantly, it provides a special environment for these kids to expand their world by meeting people from different cultures and places, and make new friends that are visually impaired just like them. The night before the competition, there is a get together where the kids can meet each other, talk, sometimes swim, sometimes dance, and do a little karaoke. We've met people from New

York, Missouri, Massachusetts, Hawaii and Canada there. We still keep up with some of the families that we met there years ago.

But the Braille Challenge national competition is just part of the story. The best part is that it provides a reason to have regional Braille Challenges. Regional Braille Challenges are wonderful for all of the same reasons that the national Braille Challenge is wonderful – minus some of the flare and sparkle. It is a lot of work, but it is so beneficial for the kids to meet at a regional level and to share experiences and solutions to problems, and to support one another. In so many ways, the regional competition is more important than the national level. They actually meet friends that live close enough so that they can see them more often than once a year. I hope we will see the Texas Regional Braille Challenge thrive and grow long after Harley and Merlyn are no longer eligible. All our kids should have the opportunity to compete and meet new friends.

What Is The Braille Challenge?

By Jayme Alexander, M.Ed., CTVI, Education Specialist for Students with Visual Impairments Region XIII ESC

Abstract: The 2013 Texas Regional Braille Challenge will be held in Austin, Texas

Key Words: braille, literacy, Braille Challenge, blind, visually impaired Braille Institute

What is the Braille Challenge? It's Braille Institute's national reading and writing contest in braille and a great way to motivate blind and visually impaired students to practice their literacy skills. Contests include reading comprehension, braille speed and accuracy, proofreading, spelling and reading tactile charts and graphs. More than 800 students from first through twelfth grades participated in the Preliminary Round last year.

The top-scoring 60 came to Los Angeles in June for the Final Round—two days of competition, camaraderie and fun! Last year, we had 40 students compete at the Texas Regional Braille Challenge and three of our competitors went on to compete at the National Level in California.

Beyond the competition, participants also enjoyed time with friends they have made from past Braille Challenges and participated in an art workshop by John Bramblitt, a talented artist from the Dallas area who is blind. For more information about the 2013 Texas Regional Braille Challenge, please contact Jayme Alexander at (512) 919-5170 or jayme.alexander@esc13.txed.net. Registration forms are released in mid September and the registration deadline will be December 5th.

TAPVI Talks

By Isela Wilson, President, the Texas Association for Parents of Children with Visual Impairments (TAPVI) and Jean Robinson, TSBVI Outreach, TAPVI Advisor

Abstract: The Texas Association for Parents of Children with Visual Impairments (TAPVI) is a nonprofit organization for parents of children with visual impairments including those with additional disabilities and for the professionals that work with them. TAPVI Board of Directors made changes to simplify bylaws and reduce membership dues. Hosting regional family events are in the planning stages.

Keywords: Family Wisdom, family organizations, visual impairments, TAPVI



In the last few months, the TAPVI Board had two face-to-face meetings to organize efforts to make TAPVI membership more meaningful and valuable to its members. The bylaws have been restructured and the membership dues reduced to ten dollars, per family, per year. This is for TAPVI membership only. NAPVI membership is an additional \$25 and as a member, you will receive the Awareness magazine.

Both the TAPVI Spanish and English applications are updated to include contact information for our current board members and can be emailed to you electronically. Please send requests to lhulett9804@yahoo.com. Feel free to make copies and distribute them to friends, families and professionals.

Anyone interested in supporting our organization can join TAPVI by mailing a check payable to TAPVI to our treasurer Linda Hulett, 12 Rocky Ln, Houston, 77040. Another option is to pay online using

PayPal™. TAPVI has a PayPal account which makes it easier to join and to donate to our group. Create and login to your PayPal account, click on the Send Money tab and enter TAPVIFamilies@yahoo.com in the email box. Please indicate your name and contact information in the blank text box.



Photo Caption: 2012 TAPVI Board and Advisors, Linda Hulett, Isela Wilson, Jean Robinson, Joe Paschall, Cyral Miller, Alison Brown

Along with increasing membership, the board wants to create opportunities for families to meet each other. The board is in the planning stages for a new project: hosting regional events. These events would include the entire family and focus on recreation and leisure activities. If you are interested, TAPVI will help you host a family event in your area. Just contact our President: Isela Wilson, 956-778-1142, [<iselawilson@yahoo.com>](mailto:iselawilson@yahoo.com), or any of our board members

Gifts to get Kids who are Blind, Visually Impaired or Have Additional Disabilities

Holly Cooper, Ph.D. Deafblind Educational Specialist, TSBVI Outreach

Abstract: toys and recreational items for students with visual impairment of all ages

Keywords: visually impaired, blind, toys, recreation

I often have people ask what to get as a gift for Christmas or birthday or other special occasion for a child who has a visual impairment. Sometimes people tell me about gifts they have given and I wonder what they were thinking. Every child is unique and has their own interests, preferences, and abilities so any advice must be considered with the logic of what the particular child would like. Having said that, ideas are always good, and we who work in schools get a first-hand look at what makes our students excited and happy to use or play with.

Infants

Infants who are visually impaired may be premature or medically fragile, and so may not be interested in reaching out and exploring the world at the same age as other babies. Sometimes friends and



Photo Caption: look for baby toys of various materials with diverse attributes.

family members give them visually cute soft plush toys because they are soft and safe. For little ones with vision this is fine, but babies who are blind may not like such toys. An occupational therapist once told me that it's the indistinct tactile boundaries of such toys that is aversive to them. For a tactile explorer, reaching for and knowing where the object is when it's furry and soft is confusing. Having soft things around is fine, but look for variety.

Another issue for infants and kids of all ages is plastic toys. Plastics are good, they're generally safe, sturdy, brightly colored, and easy to clean. But being surrounded by items which are virtually all plastic doesn't provide the developing mind with enough variety. Lily Neilson in her Active Learning literature tells us to look for items of different sizes, weights, and types of materials. Having more than one item of a kind is also good. So look for safe, sturdy items made of metal, wood, and cloth. As babies gain more fine motor skills, look for items with internal movement, parts that twist, bend or spin. Most people know to look for toys that make noise, but also look for noise producing toys which are not electronic, to provide different experiences and fine motor challenges.

Because our babies with visual impairment may have spent much time in the hospital and may be at risk of health problems at home, they may have spent a lot of time on their backs. So look for blankets and baby items that they can lay on to have "tummy time" where they practice pushing up against gravity and reach for toys

and interact with people. These pushing up movements are the first steps to sitting independently and later to walking. Consider these items an infant may find interesting:

- Wooden toys
- Plastic links to keep dropped toys nearby.
- Wind up or battery operated musical toys
- Cloth books, board books
- Safe everyday objects



Photo Caption: a cloth book is one item that may encourage an infant to explore

Toddlers

Typical children reach the age and have the motor coordination to begin to walk around 12 months of age. Our students with visual impairment may reach this stage later due to medical issues, additional disabilities, or delays due to the unique effects of blindness on the developmental milestones of early childhood. As youngsters begin to move about more independently, gross motor play dominates their time and their fine motor and communication skills may plateau for a while. Toddlers with cortical visual impairment may make rapid gains in their visual processing skills as they move about more and gain more experience interacting with objects in space.

To encourage functional gross motor skills such as crawling, cruising and walking, avoid prolonged use of devices such as baby “walkers” or standing play stations. Also avoid over use of equipment

that confines them to a space such as the “Johnny Jump Up” or “Sit ‘n’ Spin.” These devices may keep a young child safely contained, and safety is important; but experienced vision professionals have had many experiences trying to break self-stimulatory habits such as jumping and spinning that young children with blindness may have.



Photo Caption: a push toy such as this will encourage a toddler to move, and build skills leading to future cane use.

So look for items such as riding toys that the young child can self-propel, and toy grocery carts or lawn mowers which give youngsters some support in standing and a “bumper”

to provide good experiences to build on for cane use. Think about these items such as these for your toddler:

- Riding toys
- Nesting/stacking cups or blocks
- Safe small blocks
- Duplo blocks
- Balls: koosh balls, nerf balls
- Large cars and trucks
- Buckets, shovels, scoops for playing in a sandbox, water table, or outside in the garden
- Toddler books



Photo Caption: riding toys and items such as large cars and trucks encourage movement.

Ages 3 to 5

Around the third birthday, children usually begin to focus somewhat less on gross motor play and settle down with longer attention spans and more imaginative play. More significant gender



Photo Caption: as children get older, items like this train encourage longer attention spans.

differences are evident at this age, with many boys interested in vehicles and things that move, and many girls interested in imaginary play, dressing up, playing family roles, and socializing.

Move away from the push button light and music show toys. Consider items like:

- Blocks and Legos
- Smaller cars and trucks
- Fire trucks
- Trains or cars on a track
- Dolls (for both boys and girls)

- Play dishes and tea sets: made of tin, plastic, or ceramic if you dare
- Metal pots and pans
- Real food on a temporary basis: apples, pears, carrots, potatoes, onions,
- Crackers, cookies
- Clothes and old costumes to dress in (Goodwill and thrift stores)
- Wearable accessories such as purses, tote bags, coin purses, hats, jewelry, cell phones, make up mirrors, combs, belts, scarves
- Baby dolls and child dolls
- Play characters and props such as Play Mobile sets, doll houses with small dolls
- Books



Photo Caption: dress-up clothes and costumes are great for imaginative play.



Photo Caption: elementary-aged children like science kits and things to build.

School Aged: Elementary

Elementary school is a busy time for young minds and for families at home. Many of us who are teachers see children who don't have enough leisure time and don't get enough sleep. It is common for typical elementary aged children to be involved in a variety of lessons, sports, and programmed activities during their after school hours. Our students with visual impairment may spend many more hours completing their homework than their peers.

However, it is very important for young children to have unstructured leisure time. Such time allows them to play and engage in social and creative activities, to read and

investigate interests of their own and to develop and practice using new skills. Look for engaging toys to keep them occupied and to minimize "screen time," time watching television, playing video games or texting friends. Items such as these can be interesting for elementary kids:

- Science kits, robot kits, electronics kits
- Microscope, magnifying glasses, telescopes, binoculars
- Lego sets
- Art sets: paint, markers, crayons with paper or canvas
- Beading, knitting, crochet or weaving supplies
- Train sets
- Model cars or planes
- Kid proof camera
- Digital audio recorders
- iPad, iPod or other digital music player
- Books, audio books, ebooks
- Ebook reader such as the Kindle
- Library card
- Board games, playing cards, dice

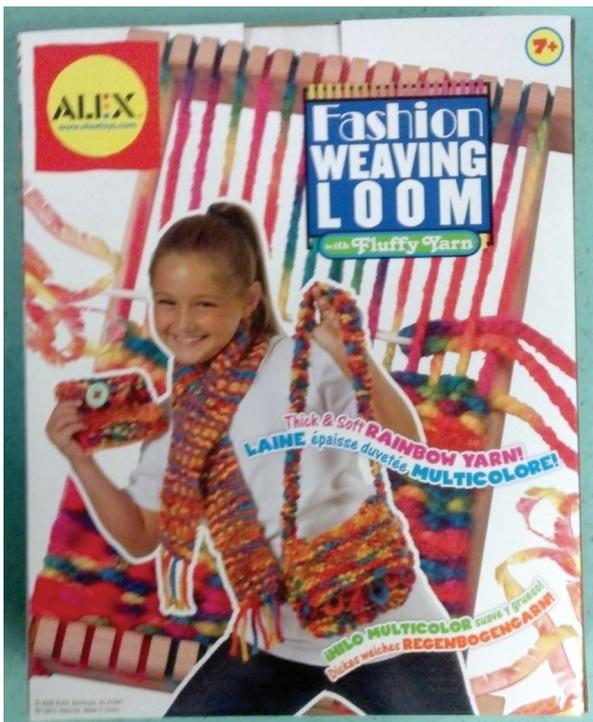


Photo Caption: a loom can build creativity.

Middle and High School



Photo Caption: the iPad Shuffle is an inexpensive electronic device.

- Laptop computer
- iPad or other tablet computer
- iPod touch (It has all the features of the iPad, but smaller. Good for kids who are blind.)
- Cell phone (check for accessibility)
- iTunes card
- Karaoke machine
- Books, audio books, e books
- Hobby and craft related supplies
- Science kits, robot kits
- Mass transit (bus) pass if available in your area
- Skateboard or non-motorized scooter
- Flash (digital storage) drives

In middle and high school, if kids don't already have electronic devices, it's time to get them. Check around with teachers and parents of students who have visual impairment, and others to find out about electronic devices which are accessible to students with visual impairment. Most Apple devices have built in voice output capability without adding software like JAWS. Many other recreational activities are also appropriate, but actual "toys" generally are less of an interest. For young people who may still like to have their toys, collecting toy items such as dolls or model trains is a way for them to enjoy their favorite things and expand their interests in an age-appropriate way.

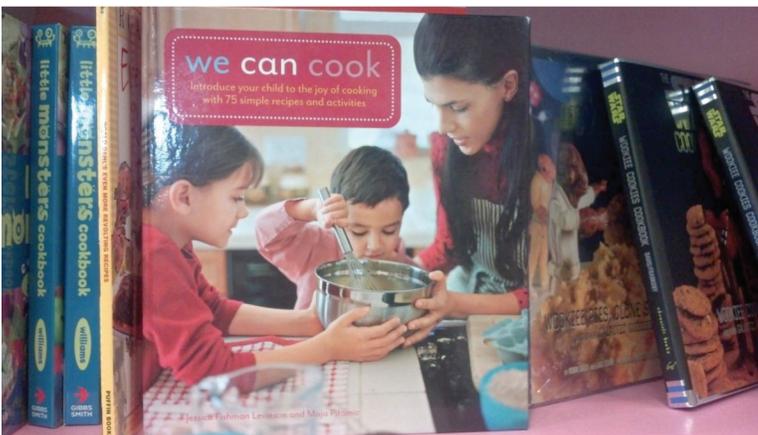


Photo Caption: as students get older they become more interested in hobbies, like cooking.

Accessible Hobbies

As students get older, they may be less interested in toys and more interested in other things. It can be challenging for adults who are not their parents to come up with ideas. Most kids do get involved in hobbies or sports, and if they do not, then encouraging these activities is a good thing. Do you worry about teenagers who sit around and watch TV and play video games all day? Help them find alternatives

by showing them the things you enjoy, taking them on outings related to your interests, and making things with them. Here are some activities which can be accessible even to totally blind individuals. Young people with vision will be able to enjoy a broader array of choices.

- Playing a musical instrument
- Beading
- Crochet or knitting
- Weaving
- Pottery
- Gardening
- Cooking
- Short wave radio listening
- Ham radio operating

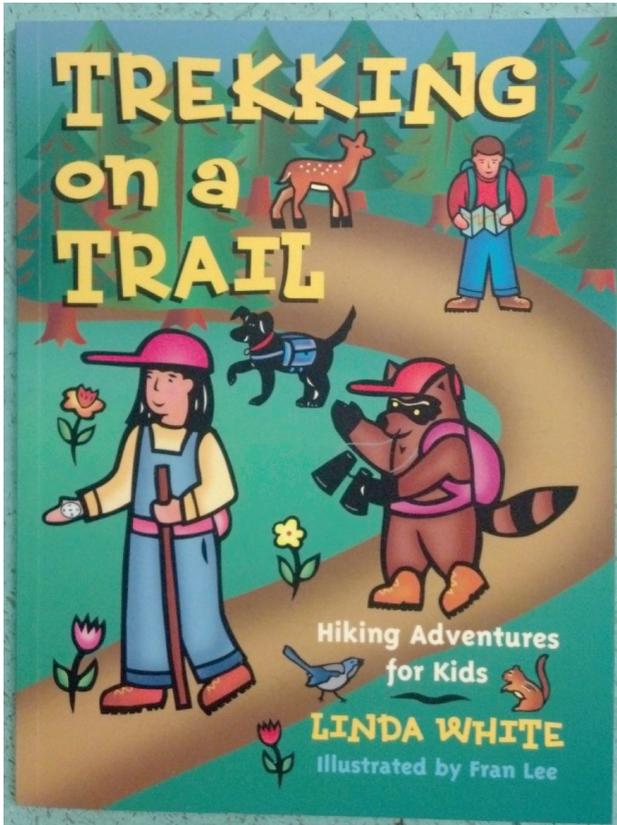


Photo Caption: gifts can encourage physically active pursuits, like hiking.

Accessible Sports & Athletics

- o Running, walking
- o Hiking
- o Camping
- o Swimming
- o Wrestling
- o Gymnastics
- o Cheerleading
- o Dancing
- o Goal ball

With a partner or guide

- o Bicycling (on a tandem bicycle)
- o Rowing
- o Rock climbing
- o Geocaching
- o Horseback riding



Photo Caption: gifts like a tandem bike a great to use with a partner or guide.

Thanks to Terra Toys of Austin for tolerating me while I stalked around taking photos of their many wonderful toys!

Editor's note: For more ideas of meaningful, creative gifts, read about the importance of using the real object and common household items to develop concepts and life skills.

Resources

Creating Educational Toys And Activities For Children Who Are Blind Or Visually Impaired:
<www.tsbvi.edu/instructional-resources/1913-creating-educational-toys-and-activities-for-children-who-are-blind-or-visually-impaired>

Let's Play: <www.tsbvi.edu/tx-sensabilities/2681-lets-play>

Early Tactile Learning: <www.tsbvi.edu/resources/3096-early-tactile-learning>

To explore store-bought toys that look like typical toys for sighted children, the Toys"R"US Toy Guide for Differently-Abled Kids can be downloaded in English and Spanish at the Toys R Us website <<http://www.toysrus.com/shop/index.jsp?categoryId=3261680>> or by going to this link: <<http://trus.imageg.net/graphics/media/trus/2012-DAG-English.pdf>>

Games

MaxiAids: <www.maxiaids.com> Braille Scrabble, Braille Monopoly, Braille dice, Braille Uno, Braille playing cards

LS&S <www.lssproducts.com> Braille Bingo, Braille and large print playing cards

Books

American Printing House for the Blind <www.aph.org/catalogs> – Braille, large print and electronic files

National Braille Press <www.nbp.org/ic/nbp/programs/cbbc/cbbc.html> – Children's Book Club: \$100 annual fee for 13 Braille books

Seedlings <www.seedlings.org> – Braille Books for Children

Bookshare <www.bookshare.org>

Embossed (hard copy) Braille

Students with Vision Impairment Forge New Learning Pathways with Reading Technologies

Valerie Chernek, disability advocate, with Roger Price, CTVI Keller ISD

Abstract: A teacher describes how his students benefit from new reading technologies

Keywords: visually impaired, reading, accessibility, adaptive technology

Roger Price is a Texas teacher in Keller Independent School District, part of Fort Worth and the town of Keller. He recalled many years of observing his students who were blind or visually impaired struggle to keep up with their reading assignments. In the past, these students were routinely burdened with heavy volumes of printed textbooks. Images and photos were low quality, text was black and white, and students would straddle their desks to read the large print – requiring extra space to accommodate their learning needs; indications of being labeled ‘different’. Mr. Price says, “Advancements in reading technologies and the availability of accessible educational materials in digital and audio formats have given students more freedom to forge new learning experiences.”

“The Keller school district has made technology and digital accessible books a priority for students with qualifying print disabilities,” said Jill Ross, Special Education Coordinator for the district. “Today, many of our students are comfortable using MacBooks, iPads, laptops and desktop computers to download and read digital text. Some use smart phones and devices such as the BrailleNote Apex, PlexTalk audio and Bookport Plus.” Mr. Price wants his students to read in braille first and then use digital text so they can hear information read aloud through text-to-speech. “This reinforces tactile learning and also enables students to improve their reading comprehension, spelling and grammar,” he said.

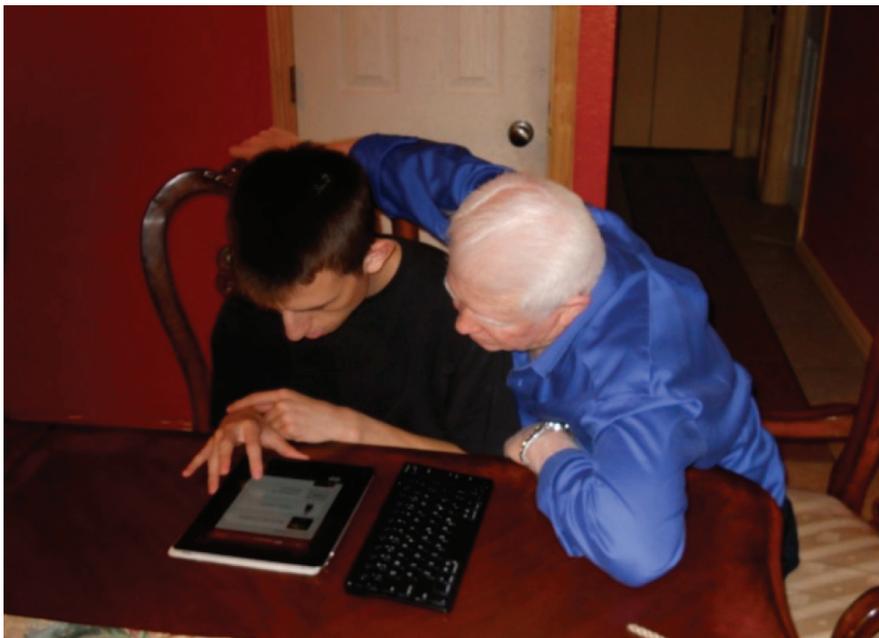


Photo caption: Roger Price, Texas VI Teacher (blue shirt) works with student Juan on his iPad.

Students Forge New Learning Pathways

Mr. Price shares the following stories about his students using digital books from Bookshare and reading technologies. Bookshare is an online accessible book library, free for students living in the United States with print disabilities who qualify through federal awards from the U.S. Department of Education, Office of Special Education Programs.

Juan came to Keller five years ago. He spoke no English and was on the verge of retinal detachment failure. Eventually Juan lost his

sight. Through the efforts of Mr. Price and teachers at the Texas School for the Blind, Juan became an avid reader of digital books. He learned how to use many electronic devices and is now very tech savvy. Juan is at the top of his class in academics, speaks English and is learning French. In general education classes he signs on to the Bookshare website and downloads literature in English and Spanish to his iPad, MacBook or computer. Juan is an inspiration to all of us!" said Price.

Amber is an incessant reader and a graduate of Keller ISD. In the fall, she will attend the University of Texas, San Antonio. Amber uses a top-of-the-line BrailleNote Apex. It's a small and lightweight electronic device that she carries on her shoulder. She finds the digital books she wants to read on this device at Bookshare. In high school, she took advanced literature classes and kept up the reading pace through the use of digital books and technologies. "Many students with vision difficulties get stumped when teachers give impromptu assignments, but not Amber," said Price. "She is comfortable using the refreshable braille device and downloading digital books, just as a sighted student is in opening a hardback book or a technology device."

Sean is a 10th grader who has severe cerebral palsy and low vision. He uses a motorized wheelchair to travel to his classes. "He only types with one finger, but can quickly whip out his MacBook and navigate through digital text," said Price. "Accessible formats enable him to more easily change font size, set color contrasts, and modulate speech. They are an equalizer for him!"

This year, Mr. Price and Ms. Ross watched Emily an 8th grader with Stargardt's Disease or juvenile macular degeneration, a condition that causes extremely low vision, receive six distinguished learning awards in school. She took all advanced placement classes and read digital books on her Plectalk, iPad and Kindle Fire. "Without Bookshare and the portable technology devices, this student would not have kept pace with her peers in school," said Price. "It's such a contrast now from the days of learning with closed circuit televisions (CCTV's). My students are tech-savvy. They use the latest technologies and digital books and are the students who carry flash drives, download MP3 formats, use braille and text-to-speech. These advancements help them fit into a social norm and for the first time, the stigma of being labeled 'different' is finally fading."

Resources

Bookshare <www.bookshare.org>



Photo caption: Emily, a student with Stargardt's reading a digital book on her iPad

The World of Digital Talking Books

Patrick Van Geem, TVI, Assistive Technology Consultant, TSBVI Outreach

Abstract: a summary of currently available audio and visual electronic reading options

Keywords: digital talking books, BARD, electronic media, DAISY, EPUB

The digital age is not approaching, it already is here. Yet, changes are still coming, especially in the delivery of instruction, instructional materials, and support applications and programs. The development of digital talking books (DTB) is one of the significant landmark innovations of information access. Many textbooks, novels, newspapers, and magazines, are in some type of digital talking book format.

Braille and Audio Reading Download (BARD)

At the Texas Talking Book Program, digital talking books are the successors to vinyl records and cassettes tapes. Typically they are produced in what is now known as linear audio format files. This means that reviewing and searching is accomplished by fast forwarding or rewinding. The Talking Book Program loans out books in this format by using USB digital cartridges for playback in a specialized device. It is called the Braille and Audio Reading Download (BARD) Program of the National Library Service for the Blind and Physically Handicapped.

Textbook CD Companions

Other digital talking books are textbooks. Sometimes, textbook will include a CD companion. These multimedia productions can vary from only digital text to digital text enriched with multimedia productions (usually videos). Some will also include a text-to-speech component that will play in a computer. Many textbook publishing companies will include some type of digital information with the hardcopy book.

Linear Audio Digital Talking Books

Commercial audio books use a more linear (fast forward or reverse) digital format. These digital talking books are mainly for leisure reading activities, although some are informational. Almost all are read by either a professional reader or the author of the book. Some have music in the background during transitional periods (between chapters). Audible.com is a website repository containing a large source of audio “digital talking” books.

DAISY Formatted Talking Books

So what is a digital talking book? According to the Digital Accessible Information System (DAISY), a digital talking book is a “multimedia representation of a print publication”. DAISY books contain:

- One or more digital audio files read by a human or computer voice narration of part or all of the source text;

- A marked-up file containing some or all of the text (strictly speaking, this marked-up text file is optional);
- A synchronization file to relate markings in the text file with time points in the audio file;
- A navigation control file which enables the user to move smoothly between files while synchronization between text and audio is maintained.

Navigation features offered by DAISY formatted information have made review, bookmarking, annotating and searching similar to hardcopy information. Not only is it easier to learn and review information, they also can promote the development of study skills. The technology used to access DAISY books includes portable standalone devices, desktop devices, and computer playback software. The versatility of being able to play on so many devices has made DAISY a commonly used format in most classrooms. Teachers of the Visually Impaired regularly recommend their student use some type of DAISY playback device or software.

A study from the Canadian Institute for the Blind involved testing participants on a series of tasks using a stand-alone player and a software application installed on a computer. The tasks came from a checklist developed by the project team who took information from user manuals created by HumanWare (maker of some DAISY playback devices and software).

For the purpose of analysis, the project group categorized the tasks into three groups.

- Navigation of book: included tasks related to moving to the different access points within a book (for example, “Navigate by heading level”).
- Operability of book: included tasks that controlled playing a book (for example, “Play” or “Stop”).
- Operability of player or software: which included tasks required to operate the playback equipment (for example, “Turn on the player” or “Load the software”).

Their report indicated:

- By exploring the experiences of participants with DAISY Talking Books, this study not only discovered how people who are blind, visually impaired, and/or print-disabled read DAISY books, but also identified participants’ perceptions of DAISY as being particularly useful in their educational, professional, and social lives.
- Specifically, participants noted the usefulness of DAISY technology with regard to educational and work-related materials, as it allows students and working-age adults to move more easily within a textbook or reference manual, and gives them the option of placing bookmarks throughout a document.
- Participants saw advantages, as well, in the fact that more than one book can be recorded onto a single CD, and in the digital media’s superior navigation and sound quality when compared to analog cassettes. Many participants mentioned that, as a result of this project, they will continue to use DAISY books to ensure better access to the information they require.”

Along with stand-alone devices and computer software, DAISY books can be loaded to tablets and smart phones. Learning Ally (formally RFB&D) and Bookshare both have Android and iOS apps that will play DAISY format books. The Learning Ally app, called Learning Ally Audio, uses recorded human speech. Volunteers will read the text in “chunks” recorded as mp3 files. It is then compiled

into a series of files that is set to a XML codes called SMIL files. This gives the listeners navigation options, such as searching by chapters, headings, or page numbers. Bookshare has an app called Read2Go. Bookshare DAISY books use a text-to-speech synthesized voice output, and similar coding and mp3 file series to enhance navigation, searching, and reviewing.

There are some things to consider when selecting playback for DAISY format talking books.

- When selecting a computer playback software application, does it have an easy to use key command system for navigation, annotation, bookmarking, etc.?
- You may need to consider synthesized speech as opposed to human speech.
- Ease-of-use needs to be considered when selecting a playback device.
- Will the student always have access to a computer?
- How well is the speech output on playback devices and software?

Electronic Publication (EPUB) Books

EPUB is short for electronic publication. It was standardized with guidelines by the International Digital Publishing Forum (IDPF) in September 2007. The format was designed for reflowable content. Reflowable content is the hallmark feature of an EPUB book. Having reflowable content means that the text display can be optimized for a particular device. It means that the same text information will keep the layout format the same on a Kindle Touch, an iPad, an Android smart phone, a tablet, or an iPhone 3-5. It also means that the user (not the developer) chooses the font style, size, margin size, line spacing. These are important features for individuals with print impairments.

EPUB books also have some limited text-to-speech voice output but have fewer features than DAISY formatted materials. If an individual user requires voice output materials, DAISY formatted materials are usually preferable.

Like DAISY, EPUB book and material also offer study skill features. Depending upon the device, EPUB features include:

- Annotation: produces a sticky note for entering own information (writing in the margins).
- Bookmarking: marking a page that keeps a list for recall later.
- Highlighting: underlining some information that keeps a list for recall later.
- Navigation: movement by page number, bookmarks, highlights, or chapters
- Referencing: highlight a word, then activating a dictionary or Wikipedia

Conclusion

Within a ten year period digital talking books have revolutionized reading material. There are a large number of playback devices and software applications. They are becoming common place in general education secondary instruction. In some districts, EPUB textbooks have replaced hardcopy textbooks. iPads and other tablets are widely used in classrooms. Distance learning courses and classes have mainly gone digital especially with reference materials and textbooks. Most academic student with a visual impairment now use some type of DAISY playback device or software.

A new and exciting area of digital materials development are DAISY format authoring tools such as Dolphin's Easy Converter, Word-to-DAISY add-in, OpenOffice conversion add-in, and eClipse Writer. Now teachers for the visually impaired or braille production personnel can develop their own DAISY materials for their students. EPUB materials can also be developed by using software that start with free open source tools to commercial third-party applications.

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Audible.com is a website repository of digital talking books. <http://audible.com>

EPUB Overview Web Site <http://idpf.org/epub/30/spec/epub30-overview.html>

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Teachers' Influence Lasts Forever

Kristie Smith, CTVI, Mesquite Independent School District

Reprinted from a column which appeared in the Dallas Morning News on August 22, 2012. Original location: www.dallasnews.com/opinion/local-voices/headlines/20120822-kristie-smith-teachers-influence-lasts-forever.ece

Abstract: An educator discusses the rewards teachers receive from influencing students

Key Words: visually impaired, teaching,

Henry Adams once said, "A teacher affects eternity; he can never tell where his influence stops." Judy Bryant, my favorite teacher, taught me that. There are very few teachers who go to work just for a paycheck. Most teachers have chosen one of the most important careers to make a difference in the lives of children.



Last school year, I was checking on one of our visually impaired students in Mesquite ISD when I walked into a portable building. The young teacher stood behind the desk, teaching the paint off the walls with so much passion. Suddenly, she yelled, "Ms. Smith! Is that you?" Only when I looked more closely did I remember her from my fifth-grade classroom long ago.

Photo caption: "Amber, I am so proud of you!" I beamed. "You are an amazing teacher!"
Kristie Smith

She smiled and whispered to me, “I was going through a rough time in my life the school year I had you, but you taught me to love reading for the first time.”

Since I did not want to break down and cry in front of her class, I repeated how proud I was of her, and how she just made my year. This sort of thing happens to teachers from time to time.

My mother, also a teacher, bumped into the mother of one of her former students while we were out shopping.

“Oh, my gosh! You are Mrs. Smith. You were Todd’s favorite teacher,” the woman said. Todd was a young boy who overcame his shyness in my mother’s classroom and began doing reports in front of the class.

“I loved him,” my mother said. “He overcame so much that year.” She loves all of her students so much that they are frequent conversation topics when we train other educators.

“Todd is now becoming a paramedic,” his mother said. “You made a difference in him. You helped his confidence and were what we called our angel teacher.” The woman in the store then showed us a picture of a young, handsome man with a movie-star smile. My mom had tears in her eyes.



A good friend of mine — who’s also a teacher — one day showed me a note she received from a student. When she took the worn note out from her desk, she sobbed.

“What’s wrong?” I asked as I began to read. “He says that he will never forget you and how you made his life better. That is something to be proud of, so why are you crying?”

“When my student wrote the note, he was dying of cancer,” she cried. “Read the last sentence.” The note continued, “When you read this note I will have gone to heaven, but I will always remember the difference you made in my life. You made me laugh and have something to look forward to every day.” My friend reads that note the first day of every school year. She doesn’t teach for the money. She teaches because she knows her influence can affect eternity.

Photo Caption: Kristie Smith with her student Austin Ziegler

Follow the Bright Spots

KC Dignan, PhD, Professional Preparation Program Coordinator, Texas School for the Blind and Visually Impaired, Austin, TX

Abstract: stories of professionals in education for students with visual impairment

Keywords: visually impaired, O&M, teaching

Times are changing in education. Budgets are being cut, experienced staff are retiring, caseloads are changing, families face increasing challenges and performance evaluations are about to have a radical change.

With so many complex challenges it is tempting to focus on the problem: to dissect it and analyze it to the smallest degree; to look for blame and/or cause, as if knowing more about the problem will automatically lead to a solution, a positive change, a growth moment.

Dan and Chip Heath, experts in change, suggest just the opposite: focus on what works. They call it “Finding the Bright Spots”. The bright spots are those parts of the situation, the emotions or the people that are working, that have strength. We learn from our strengths, not from weakness. It is by focusing on what is working that we will find a path for the future.

This column will be about Bright Spots. It will be a collection of short stories, stories from parents, students and professionals in the field of visual impairment (VI). It will showcase those moments when the students, parents or professionals could see their way to the future, when a dream was realized, when a student or child connected with the world.

The stories are presented just as they were sent to me. In some cases I may edit for length and remove or alter names. These are the stories of VI professionals. I look forward to more stories from parents, VI professionals and (hopefully) students.

Our Stories

1. There was a kid who transferred into my class and the paperwork said he was: visually impaired, deaf, had CP, was microcephalic and was a behavior problem. But then there was the day he realized that by moving his hands he could “communicate” with someone. To see his eyes lit up and the great big smile on his face. WOW!!! (Anonymous)
2. I recall going to pick up a child for O&M instruction. She was about 8 years old. As soon as we opened the exit door of the school campus, a burst of fresh air filled us. She exclaimed, “What is that on my face” with a big smile. I looked at her smiling, joyful, astonished face. I said to her that it was a strong breeze of air and that the wind was very strong today. You see, she was blind and needed to know what wonderful thing was touching her face! I’ll never forget that beautiful expression. (from G.F.)
3. I think the best thing that happened to me this year was when I brought a father to tears. He was observing his daughter’s O&M lesson and watched her cross two residential streets to find her bus stop and interact with her peers while waiting for the bus. Finally the bus arrived

and she got on the bus and rode off to school—all independently! (I was watching from across the street.)

As I turned to ask him what he thought about the lesson, he was wiping tears from his eyes. He said that he never thought that she would be able to do anything like this. :) (from D.F.P.)

Bright Spots

So what are the bright spots in these stories, at least as I see them? You may find other bright spots, but to me the brightest spot is the huge power of experiential or “real world” learning. Consider:

- Explaining to the father that his daughter could travel independently just wouldn’t have had the power of actually seeing her travel, talk with chums and get on the bus. Expectations changed that day.
- You can talk about the wind, a breeze or a draft, but only by experiencing it will it have meaning. The world expanded that day.
- Learning that you can have an impact on your world is a potent lesson, regardless of your cognitive ability. Power increased that day.

Each of these stories demonstrates the power and impact VI professionals, parents and students have on each other. Each is just a beginning. Each shows what can happen when students and parents learn in real settings.

This column is also just a beginning. Please send your stories about a Bright Spot in your world. I am hoping to hear from parents, students and VI professionals. The stories can be short, just like the ones above, or more comprehensive. Go to www.tsbvi.edu and look for the Bright Spots announcements, or you can email me at kcd@tsbvi.edu

Please take the time to share your Bright Spots!

Reference

Heath, D & Heath C., 2012. *Switch: How to Change Things When Change Is Hard*. Broadway Books. New York.

TSBVI Opens New Career Education and Transition Building

William Daugherty, TSBVI Superintendent

Abstract: In this article, Superintendent Daugherty shares information on the new Career Education and Transition building at TSBVI and how it provides students with hands on job training and experiences.

Key Words: TSBVI, Career education, Exit Program, blind, visually impaired, job skills

After a very long wait caused by construction delays, TSBVI opened its Career Education and Transition Building this September. The facility has classrooms for the EXIT Program, a call-center and office technology lab, a large Family and Consumer Science classroom, a work skills room for production activities, a coffee and snack bar and a training area for hospitality services, including six small guest quarters rooms and a lounge area. Sure, the roof is leaking, but we are in and glad to be there, and a roof fix is in the works.

Several years ago, federal stimulus funds under the control of the Texas Workforce Commission were made available to TSBVI, and we have been very pleased with the decisions we made on how to use it to improve our curricular offerings. New areas of training were designed, and equipment was purchased to provide entry-level skills training in a variety of jobs commonly found in the towns and cities where our students reside. After many years of focusing primarily on general job-getting and job-keeping skills, TSBVI students now have the opportunity to walk into several types of businesses with real skills and experiences that can help land that very important first job.

It has been said that the coffee shop is the new Dairy Queen, and if so, we have several barristas in training who can turn out a very fine cup and could do so in every medium sized town in Texas. A computer-assisted monogram machine has proved to be fairly accessible for students, and they have produced some finely finished products. A class that covers the technology and processes in common use in office-clerical environments such as call centers ties into a growing industry, and a training package using the Statler Center curriculum is being used for training in hospitality services in the guest quarters area. Among the other offerings are screen printing, horticulture, pet care, culinary and a combination of sound engineering and advertising—think the jingle business.

Competition for all jobs is tough these days, but it is our goal to ensure that TSBVI students have both some marketable skills as well as experiences that can spark an interest in a career path. We all know that we are unlikely to continue working in our first job forever, but each of the jobs we have helps us better choose the next one, and makes us better at it because we learn to be on time, to be productive and to get along with our coworkers as a member of a team.

Dress for Success = Confidence for Our Younger Consumers

by Barbara J. Madrigal, Assistant Commissioner, DARS Division for Blind Services

Abstract: The author describes a Group Skills Training that enabled DBS consumers to learn new skills and increase their level of self-confidence.

Key Words: Dress for Success, blind, visually impaired, DBS, confidence,

One of the special programs that the Division for Blind Services has offered to consumers is Dress for Success activities. Coordinating these programs with community partners and local business is an effective way to work with our adult consumers on job readiness skills. So, while this concept is not new to DBS, some of the innovative approaches used by our team in the San Antonio office are really having a profound effect on our service delivery. I'm quite proud of what the staff is doing and impressed with the way they have introduced this concept to young consumers in that area of Texas.

This recent Dress for Success program for children in the Division for Blind Services' Blind Children's and Transition programs was held on August 1 in San Antonio. Coordinated by Blind Children's Coordinator Mayra Lopez, this one-day program was fast paced and full of confidence-inspiring activities for a group of 15 energetic young consumers. "This was the third year for the program," explained Mayra, "and the ages ranged from age seven all the way to age 12." The makeup of the group was nine boys and six girls. The younger nine participants were consumers in the BCP, while the other six were involved with our Transition program. What a great way to involve consumers in two separate programs around some common areas of interest.

When asked why she offers this type of program, Mayra said, "The first time we did this, we kept seeing children who were lacking skills. Their involvement in this program helped them with overall confidence. Something as simple as learning personal grooming skills helped them with other core areas. They not only looked at themselves differently, but they made an effort to present themselves more positively every time they would leave the house—even for church or for other social activities." In other words, the kids became more aware of how others viewed them and they established higher standards for themselves.

So, Mayra and team of expert co-workers began the day by giving specific tips for dressing on a budget. VR Teacher Myra Garza was on hand to teach grooming skills and to help the children make the connections between good grooming, appropriate dress, and how those things contribute to a positive appearance and, thus, to one's confidence. Other coaches or subject matter experts teamed up with the kids to offer direct feedback and suggestions. A bus trip to the local mall delivered the group to J. C. Penney's, where that retailer participated by providing free haircuts to the consumers. Each child had a shopping budget of \$125, which was to include everything from accessories to shoes (and the main attire) that would dress them for an interview in a job for which they were interested.

Even the lunch break in the middle of the day—a short 45 minute intermission—helped prepare the consumers, as they had to make their own sandwiches and they got to network with the adult coaches at their tables. After the lunch break, the consumers got to hear from several "success ambassadors," who were participants from the original program three years ago. They challenged

the group to “don’t be afraid; just do it” when referring to the confidence walk that was coming later in the afternoon. What was the “confidence walk”? It was literally a walk on stage in the form of a fashion show held at a local hotel. To prepare for this walk, it took up to two hours of practice for some of the children—along with a rule that canes were required because of safety concerns—to get ready to strut their stuff (i.e., show off their new attire and image in front of friends and family members). Mayra explained that the funniest thing that happened all day involved a child from the Fredericksburg area who was a self-proclaimed cowboy. He was wearing a pair of quite nice orange and brown boots and informed Mayra earlier in the day that, “You can do anything you want, but these boots are not coming off!” So, it made selecting clothes a little more of a challenge, but he did it and was able to model his boots during the confidence walk.

Mayra also reported that the seven year old consumer—the youngest in the group—had been quite apprehensive about some of the activities, especially the confidence walk. It turned out that his family was running late and missed the fashion show. This child insisted that he be allowed to do an encore performance to be sure his family was able to see his big debut. He got his wish and was once again able to demonstrate his newly found confidence on the walkway! Audience members seemed to experience a wide range of emotions—from beaming with joy to tears of pride and astonishment—as these consumers did what many thought was not possible.

Organizers for the conference reported that it is a tremendous amount of work to plan all the logistics with the staff, volunteers, consumers, family members, former participants or mentors, and the transportation needs. But it provides a concentrated opportunity for these young consumers to learn things—and try new things—that would otherwise take many months or even years to experience. The transformation that begins during this special day provides the groundwork for a lifetime of memories, usable skills, practical tips, and just plain confidence that is a measure of the program’s success. Over the years, the size of the group has doubled, the age range of the consumers has expanded, and the pace of the day’s agenda has accelerated. So, what’s in store for next year? Mayra reports that the next one will probably be about a year and half away and she hopes to build on the tremendous success of these first programs.

This program is one of many dress for success opportunities that DARS DBS offers its consumers around the state. Whether done through the Blind Children’s Program, the Transition Program, or Vocational Rehabilitation, activities such as these help consumers establish a solid foundation that inspires confidence and opens up so many other doors and opportunities down the road.

Distance Learning - distance.tsbvi.edu - at TSBVI

By Mike Bicknell, Web, Media, and Distance Learning Developer, TSBVI Outreach

Abstract: the author describes TSBVI's distance learning program, the subject headings and how to access the programs.

Key Words: TSBVI, TSBVI Outreach, blind, visually impaired, distance learning, tutorials

This article is about the free distance learning opportunities available at the Texas School for the Blind and Visually Impaired Distance Learning website: <http://distance.tsbvi.edu>. TSBVI creates videos, courses, and blogs for teachers, instructors, other professionals, paraprofessionals, family and community members, and even students to watch, read, or to interact with online at their own pace and schedule.

The main page of the Distance Learning site lists our current subject headings: Accessibility, Assistive Technology, Deafblind and MIVI (Multiply Impaired, Visually Impaired), Family Matters, Literacy, Math, Media, Orientation and Mobility, Physical Education, Project Share, Teachers, Therapists, Transition, and Video Conferences. The Assistive Technology section, for instance, is further subdivided into "Blog," "Courses," and "Videos." We're hoping to add new material every week or so, including new subject headings. "Transition" is a new one, for example, and we hope to add "Interveners" and more soon. Even though much of this material is spread across various websites, the Distance Learning site organizes all of these offerings under one roof, so to speak.

The Distance Learning site started as an extension of TSBVI Outreach Programs, because Outreach Consultants for the Visually Impaired and the Deafblind encountered a repeated need for presentations across several topics around Texas. Some of these topics are particularly suited to web based instruction. So as resources and time permitted, these consultants began creating distance learning material with the assistance of Media and Web Developers from Outreach.

This new phase of distance learning at TSBVI started in 2008 when we created a You Tube channel at <http://www.youtube.com/VideoTSBVI> to hold tutorials or How-To videos. To date, this channel has 98 subscribers and nearly 75,000 video views. While You Tube is a great resource, not all school districts and places of employment allow access to You Tube. This fall we launched an additional media library that is hosted on our school servers with a friendlier web address for access in the workplace: <http://library.tsbvi.edu/>. Soon we hope to cross-list most of our videos in both locations, as appropriate.

From the Distance Learning site, you can also find links to our social media presence on You Tube, Facebook, and Twitter. You can Like, Follow, or Join Us. And please give us your feedback as we continue forward.

Contact:

Mike Bicknell

Web, Media, and Distance Learning Developer

bicknellm@tsbvi.edu

Braille Letters From Santa Program

Excerpt from the NFB website www.nfb.org

Abstract: NFB is once again helping Santa get Braille letters out to girls and boys. This article provides information on how to your child's name on Santa's list.

Key Words: National Federation of the Blind (NFB), blind and visually impaired, literacy, letters from Santa

Once again, Santa has enlisted the help of the elves at the National Federation of the Blind (NFB) Jernigan Institute to get Braille letters out to hundreds of blind boys and girls this Christmas season. Between November 15 and December 20, parents can go online at www.nfb.org and fill out a Santa Braille Letter request form. The form can also be printed and faxed to (410) 685-2340. Beginning December 1, the Braille letters from Santa will start going out to boys and girls around the country. The Braille letter will also be accompanied by a print copy (for mom and dad to read), and parents can choose the contracted or uncontracted form of Braille for the letter. Requests for letters must include the writer's name, the child's name, birthday, gender, mailing address, and a telephone number or e-mail address in case Santa's helpers at the National Federation of the Blind have questions.

CHARGE Syndrome Foundation, Inc. – National Tele-Support Group

By Sheri Stanger, Director of Outreach with the CHARGE Syndrome Foundation

Abstract: This article provides information on a tele-support group parents/guardians of children with CHARGE syndrome.

Key Words: CHARGE Syndrome, tele-support group, blind, deaf-blind

In January, I started a national CHARGE tele-support group for parents/guardians of children with CHARGE syndrome. This support group is offered to families through The Jewish Guild for the Blind's National Tele-Support Network for Parents of Children with Visual Impairments in collaboration with the CHARGE Syndrome Foundation. I facilitate this weekly support group at no cost to the participants on Tuesday's at 1pm eastern standard time. The group can last from 1-2 hours with a predetermined topic discussed each week. Guest speakers are invited to join us from time to time. Calls are conducted in English and are open to families in the United States and Canada. While I have a steady group of participants, I have room to accept a few more dedicated individuals. This new venture has been an exciting experience and a wonderful way for parents/guardians to discuss shared experiences, challenges and achievements. If you are a professional, please distribute this information to your families that have a child with CHARGE syndrome. If you are a parent and would like to join or simply want more information, please contact me, Sheri Stanger, Director of Outreach with the CHARGE Syndrome Foundation at 1-855-5CHARGE (1-855-524-2743) or at sheri@chargesyndrome.org. I am excited to add a few more parents/guardians to this national call. I look forward to hearing from you.

National Family Association for Deaf-Blind 2012 Symposium

Press Release from the National Family Association for Deaf-Blind (NFADB)

Abstract: This article is an overview of the 2012 NFADB Symposium, Preparing Leaders for Today and tomorrow: Family Leadership in the 21th Century.

Keywords: Deaf-Blind, family leadership, TSBVI,

The National Family Association for Deaf-Blind (NFADB), originally started by and for families of individuals who are deaf-blind, now extended to all persons and organizations that wish to support individuals and families who are deaf-blind, held its first National Symposium July 13-15, 2012 at the Texas School for the Blind and Visually Impaired in Austin, Texas.



Fifty-one family leaders and four self-advocates from 24 states, Washington, DC and Puerto Rico attended the 2012 NFADB Symposium, "Preparing Leaders for Today and Tomorrow: Family Leadership in the 21st Century." The overarching goal of the Symposium was to give family leaders the understanding and knowledge needed to be effective in advocating for individualized communication supports. These supports are necessary to allow individuals with deaf-blindness equal access to auditory, visual and environmental information that is often not accessible to them.

Photo caption: The NFADB featured presenter from around the country.



The leaders were given information on three crucial individualized supports for those with deaf-blindness: Interveners, Interpreters and SSP's (Support Service Providers) and how when properly trained, these supports can dramatically enhance life for someone with deaf-blindness. At the end of the Symposium, the family leaders were asked to identify their vision for individual supports for a person with deaf-blindness. They addressed not only their personal vision, but also

Photo caption: Students and adults with deafblindness were among the presenters at the NFADB symposium.

what they would like to see happen at the local, state and national levels. The theme of collaboration and leading other parents in advocating for individualized supports became universal at the NFADB 2012 Symposium.

The National Family Association for Deaf-Blind is a nonprofit 501(c)3 organization which exists to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs. If you would like more information regarding NFADB, or are interested in membership, please contact NFADB at 800.255.0411, NFADB@aol.com

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For more information about becoming a Texas Fellow or working as a VI professional contact KC Dignan at <kcd@tsbvi.edu>.

Bulletin Board

Announcements/Regional, State, National Training and Events

Mail or email your items for the Bulletin Board to Beth Bible:
TSBVI Outreach, 1100 W. 45th Street, Austin, TX 78756; or bethbible@tsbvi.edu.
A link to an up-to-date Statewide Staff Development Calendar can be found at
<http://www.tsbvi.edu/workshops>

2013 Texas Deafblind Symposium Hands Matter

**February 22 – 23, 2013
Austin, TX
Omni Austin Hotel in South Park**

This year our theme is “Hands Matter” will focus on the importance of developing the tactile sense and hand-use in students with deafblindness. Of course, there are many other topics in the breakout sessions, including student and family issues, orientation and mobility, communication, transition, self-determination, behavioral challenges and mental health concerns, and the impact of pain.

TSBVI Outreach Programs is pleased to announce that Barbara Miles and Paul Hart will be the keynote presenters at the 2013 Texas Deafblind Symposium. Paul has collaborated with Barbara, and others, as a part of the Tactile Communication Network for Deafblind International, and has worked for Sense Scotland for many years. We are very excited to hear them co-present at our general session, The Landscape of Touch, and we look forward to the opportunity of spending time with each of them during breakout sessions. Other international guests include Ricard Lopez, a parent from Spain, and Guido Dettoni, a sculptor who created Deafblind Shape. Please be sure to read more about Guido on the Handsmatter tab of our website.

In addition to information from Jay Gense, Director of the National Consortium on Deaf-Blindness, we will have presentations from individuals who are deafblind such as Kim Power-Smith, Divya Goel and Ashley Jackson. We have sessions by and for family members including presentations by Marlyn Minkin, Brownie Shott, the Daley family, and Jennifer Tumlin-Garrett. Tim Hartshorn, parent and psychologist, will share information about self-regulation and Kasee Stratton, post-doctoral fellow at the Kennedy Krieger Institute and John Hopkins School of Medicine, shares information about pain and its relationship to behavior.

For more information on all of our speakers, sessions, special activities and other pertinent details, please browse all the tabs in our registration website. Link to the registration site from the TSBVI site at www.tsbvi.edu.

For more information contact Brian Sobeck: sobeckb@tsbvi.edu (email); 512-206-9225 (phone).

TAPS: An Orientation and Mobility Curriculum for Students with Visual Impairments, 3rd Edition (2012)

NOW AVAILABLE!!!

Authors: Rona Pogrund, Debra Sewell, Heidi Anderson, Lisa Calaci, Mary Faith Cowart, Carolina Gonzalez, Ruth Ann Marsh, & Burnsteen Roberson-Smith. Major contributors include Ryan Conlin, Carol Dancey and Christopher Tabb.

TAPS has been one of the primary resources in O&M instruction for nearly twenty years. This curriculum has been used throughout the United States and the world by many O&M specialists and university preparation programs. As terminology, philosophies, and practices have evolved over the past few decades, it became apparent that there was a need to update, revise, and expand the TAPS curriculum.

Additional goals, objectives, and teaching strategies have been included in this 3rd edition as well as an entire section on the use of ambulatory devices. Information and instructional strategies to support students who have other multiple impairments have also been added.

The Appendices have been updated and expanded to include research information on evidence-based practices, movement and yoga activities, O&M terms in Spanish, strategies for students with deafblindness, and a sample O&M evaluation template and reports.

The four-part curriculum set includes:

Part 1: The Curriculum

Part 2: Comprehensive Initial and Ongoing Evaluation

Part 3: Appendices

Part 4: Supplement: Street Crossings for Travelers Who Are Visually Impaired

For ordering information, check the TSBVI website, <www.tsbvi.edu/curriculum-a-publications>.

Short-Term Programs at TSBVI

Referrals are being accepted for TSBVI's Short-Term Programs, held at various times throughout the year. Short-Term Programs provide short-term services to visually impaired students who attend their local districts during the school year. It is best to apply 3 months before a class begins.

More information Short-Term Programs and class offerings for Spring 2013 can be found at:
<www.tsbvi.edu/short-term-programs>;

or please contact:
Dr. Lauren Newton, Principal of Special Programs
(512) 206-9119
newtonl@tsbvi.edu

TX SenseAbilities

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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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Production Staff

Editors-in-Chief

David Wiley (512) 206-9219
<davidwiley@tsbvi.edu>
Holly Cooper (512) 206-9217
<hollycooper@tsbvi.edu>

Editor's Assistant

Beth Bible (512) 206-9103
<bethbible@tsbvi.edu>

DARS-DBS Editor

Gay Speake (512) 533-7103
<Gay.Speake@dars.state.tx.us>

Website Editor

Jim Allan (512) 206-9315
<jimallan@tsbvi.edu>

Spanish Edition Editor

Jean Robinson (512) 206-9418
<jeanrobinson@tsbvi>

Section Editors

Family Wisdom Editors

Edgenie Bellah (512) 206-9423
<edgeniebellah@tsbvi.edu>
Jean Robinson (512) 206-9418
<jeanrobinson@tsbvi.edu>

Effective Practices Editors

Sharon Nichols (512) 206-9342
<sharonnichols@tsbvi.edu>
Holly Cooper (512) 206-9217
<hollycooper@tsbvi.edu>

News & Views Editor

Gay Speake (512) 533-7103
<Gay.Speake@dars.state.tx.us>

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