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Photo Caption: Joe Paschall, a coach at the Texas School for the Blind and Visually Impaired, completes his first Ironman in hopes of exemplifying a limitless lifestyle for his students. Read more about fitness opportunities for people with vision impairments in the Family Wisdom Section.

A collaborative effort of the Texas School for the Blind and Visually Impaired and the DARS Division for Blind Services
"Dad, Where’s the Plunger?"

By Richard Holloway, Vice President, Georgia Organization of Parents of Blind Children
www.gopbc.org

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Keywords: Family Wisdom, blind, independent living skills, non-visual strategies, concept development, self-determination, home life.

Abstract: The author shares the practical and meaningful approach he took helping his daughter have hands-on exploration with everyday objects so she could increase her understanding about the world around her.

From the Futures Reflections Editor: It is often said that 80 percent of all learning is visual. For a totally blind child, however, 100 percent of learning occurs nonvisually. Given plenty of opportunities for hands-on exploration, a blind child can acquire most of the information about the world that sighted children possess. In this article, Richard Holloway describes how he helped his blind daughter, Kendra, fill in some important information gaps.

"Dad, do we have a plunger?" my daughter asked one afternoon. "Where's the plunger?"

I was a little concerned. Why would my eight-year-old daughter possibly need a plunger, after all? This just couldn't be good!

"I want to know what a plunger feels like!" she explained.

Wow! I had done it again. I pride myself on describing the visual world to my blind daughter, but there it was—another little hole in her understanding. Did we have a plunger? Sure. Was I going to let her explore it with her hands? Well, no, that didn't seem the best plan. You might find ours to be as well-washed as any slightly used plunger anywhere, but I'm not going to put it into a child's hands for tactile exploration. "I'm sorry," I said, "we don't have a plunger that you can touch. It isn't clean enough. But what if I take you to the store and let you explore a new, clean plunger?"

Kendra was delighted with the idea. That's how I came to take her on her first Home Depot expedition.

Adventures at Home Depot

There was nothing I needed to buy. This was an outing of exploration, a true quest for knowledge. We made our way to Home Depot's plumbing aisle. Not only did Kendra get to look at a plunger. She soon learned that there are different styles of plungers, made from different materials, and that they come in various sizes. She was fascinated and full of questions.

After a while we moved on. I had blocked several hours of the day for this outing, just in case. Where should we head next? Toilet seats! There was an entire wall of them only a few feet away. Standard length, elongated, with lids, without lids, plastic, wooden, hard, padded, even some with a cutout in
The greatest fascination for my daughter was why the seats were arranged vertically on the wall that way. I began to realize how much information she was missing, information that most kids pick up without any special effort on anyone's part.

What about whole toilets? We have never encouraged Kendra to explore toilets with her hands, but brand-new ones are as clean as anything else in a store. We checked out the toilets, then moved on to tubs and showers. Next we found sinks for both the bathroom and the kitchen.

Before long, we had examined all the plumbing supplies we could find. We began to roam the store's other aisles. Appliances, Carpet and Flooring, Lumber, Fencing, Landscape. Kendra hates the noise of lawnmowers and other loud machines. In the store she understood that they were turned off and would make no frightening sounds, so she explored them freely.

Kendra seemed to enjoy hardware a lot, too. She was fascinated to learn how small and how large nuts and bolts can be. Tools were also fun. The many shapes and sizes of hand tools and power tools were quite new to her.

Shoes, Balls, Motors

The Home Depot outing left me exhausted. It involved several hours of intense describing and explaining, but the effort was well worthwhile. Not long after that Kendra had a question about shoes for sports. The concept of cleats seemed bizarre to her. We headed to Sports Authority and went straight to the shoe racks. I showed her baseball cleats, soccer cleats, football cleats, turf shoes, golf shoes, and any other unusual shoes I could find. I also let her explore more conventional tennis shoes so she could compare them to basketball shoes and running shoes.

Many questions followed, and ideas started popping into my head. Did Kendra have any idea that a baseball glove is a giant oversized thing nothing like the gloves she'd seen before? Did she know that there are different kinds of gloves for baseball and softball? Had she ever heard of a catcher's mitt? Did she know what a wooden bat was like compared to an aluminum bat?

We explored baseballs, softballs, and footballs. Kendra was surprised to learn that some balls aren't even round! She wondered why some balls have laces or seams. How many kinds of balls were there? We found tennis balls, soccer balls, golf balls, and bowling balls. We compared inline skates with roller skates. We noticed that skateboard wheels felt a lot like skate wheels. We compared different kinds of life preservers and various wet suits. We found the weights department and felt
weights from one pound up to twenty pounds or more, one pound at a time. We compared the shapes
of the weights and how hard they were to lift. We examined barbells, dumbbells, ankle weights, and
free weights. Who knew there were so many kinds of weights to choose from? I could sense the
wheels turning in Kendra's mind. Pieces were coming together for her about a lot of things.

Since then, we've made trips to a lot of different stores. Bass Pro Shops was especially interesting,
with row after row of boating and camping supplies. In the boating area Kendra learned what an
anchor is like. She discovered that anchors come in assorted designs and sizes. Outboard motors,
too, come in a wide range of sizes. We examined little electric motors and gas engines from two
horsepower up to 350. My five-year-old son could just about lift the smallest engines, but the big
ones are over seven feet tall and weigh over 800 pounds. Fortunately, the store had a
rack with at least a dozen engines of various sizes for Kendra to touch and compare. I
took her to the back of a boat with a 350-HP engine. She
studied it from the ground up. It was taller than she could reach, so I lifted her on my shoulders
until she could touch the very top.

We've searched the auto parts store for all things automotive. We've compared many wheels
and tires at a tire store. They come in lots of sizes, but the different tread patterns on tires seem to be
the most interesting feature. We've explored all sorts of electronics at stores such as Best Buy and
Fry's, though feeling the internal parts of an old junk computer at home seemed to be more
interesting than exploring new machines on display.

It may be easier and faster to get through the supermarket if we don't discuss every item on each
shelf. However, when time allows, grocery shopping certainly can be a fascinating opportunity. We've
found a lot to explore in the produce section--that's one part of the store where most of the products
are out in the open, not encased in plastic wrappings or cardboard boxes.

Up on the Roof

When Kendra was six years old, we took her with us to pick out a Christmas tree. Kendra helped us
make our selection, so she knew what the tree looked like. As we drove home, Kendra wondered
aloud where we had put the tree; she knew there was no room for it inside our van. Where did the
tree go? How did it fit?

"We put the tree on the roof of the van," I explained. I showed her the roof from the inside and said
the tree was on top of that.

My answer didn't seem to help much. "How can it be outside the car?" Kendra asked.
As soon as we got home, I grabbed a ladder. I invited Kendra to climb up as I stood behind her. Standing on the top rung didn't help a lot either. A sighted person can easily see the entire roof of a van from a ladder, but only a small portion was within Kendra’s reach.

Finally I guided Kendra to move from the ladder onto the roof of the van. She sat and explored all she wanted. The tree was still tied to the roof rack, so she could find out how it stayed on in the wind. I remembered the little pocket camera on my belt and snapped a quick photo. I still smile when I see that picture, thinking of that day and that moment of learning.

Perhaps my daughter is not quite old enough yet, but I think we’re not far from a walk on the roof of our house. A model of a house would be a great learning tool, of course. But if she can explore the roof safely, there's nothing like firsthand experience!

Closer to the ground, we've examined a lot of plants over the years. As a gardening enthusiast, I've maintained a sensory garden with interesting plants that have distinctive textures and scents. When she was quite young, Kendra enjoyed having a number of interesting (and relatively safe) plants to explore. They were all within reach from one location that she thought of as hers.

**Surprises from Santa**

Since Kendra came into our lives, Santa seems to bring us more things to explore, such as extra musical instruments. We have acquired a variety of ukuleles, guitars, keyboards, synthesizers, a small harp, and even a drum set. We also have some unusual pieces, such as a Native American flute; a jaw harp; and a kalimba, or African thumb piano. We even have a Theremin, the only electronic instrument you play without touching it. You vary the sounds by moving your hands closer or further from a pair of antennae.

I've bought these instruments because nothing beats unlimited exploration time. We've also taken quite a few trips to large music stores such as Guitar Center, where we can roam the aisles for free. In a music store you can explore hundreds of instruments under one roof. They also have plenty of recording gear and PA equipment, always a great fascination to my child. She especially loves all the faders and knobs on audio consoles.

Last summer, on the way to the NFB convention in Dallas, we stopped overnight in Vicksburg, Mississippi. As we headed out in the morning, I saw some Civil War cannons in front of the hotel. Kendra was curious. We didn't hesitate to delay our departure. She got out of the car and felt all the parts of a cannon or two.

**Close to Home**

Chances to supply missing information are almost everywhere. We've found many of them close to home. Not long ago Kendra's cane bumped into a guy wire at the edge of our front yard. We had passed within inches of that wire hundreds of times. Actually, we made a pointed effort to avoid it. It was a trip hazard, after all. Kendra had no idea that the wire was there, but one day she found it with her cane. What was it for? "It helps hold up the phone pole," I explained. I anticipated the next question, "What's a phone pole?" There it was again, information that Kendra's sighted peers took for granted. My explanation led to details about how electricity and cable TV, phone service and the
On a drive soon after this discussion, I spent several minutes telling Kendra every time we passed a phone pole. She couldn't believe there were so many of them. I realized how many other things we passed while she was unaware. From time to time I'd pick something else to tell her about in quantity as well as specific detail—houses and traffic lights, for example.

Some things, such as traffic lights, are hard to explore hands-on. I've bought some decommissioned traffic lights for a playhouse I built, so they were available for Kendra to touch. As parents we've had to be creative and proactive to provide Kendra with opportunities to examine things tactiley. Still, hands-on exploration is so valuable that it is truly worth the effort. We have learned a lot together, but a great deal remains for us to explore. This learning process is never really finished.

What, you may ask, does Kendra consider the most meaningful of all these adventures? Home Depot, she will say, without a doubt. At the end of that first adventure she talked me into buying her—you guessed it—her very own plunger! It is a joy to watch our daughter discover the world in her own unique style!
Being Included Is Priceless

By Jean Robinson, TSBVI Outreach

Keywords: blind, visual impairment, adapted sports, triathlon, family wisdom

Abstract: Parents of children with visual impairments including additional disabilities approached community organizers so their children could participate in a local triathlon. With the help of sighted guides the children ran the course alongside their peers.

Editor’s note: This event happened in the Houston area but you can give your child the same experience in your part of the state. Talk to the organizers and learn how to get started. Contact your local running, bike, swim or triathlon clubs. C-Different has volunteers in Austin, Lubbock and Houston to support you. It’s great for your child’s health and self-esteem to be active and involved in the community. Have a fundraiser for your favorite cause or C-Different. Find out how to get involved at <www.cdifferent.org>.

Like the familiar Nike ad: Just do it! That’s exactly what a few moms did. They took the initiative to involve their children in a local triathlon. They believed the event was an opportunity to encourage their children with blindness and visual impairment including other conditions, to get active. Lauren did the 200 meter Fun Run, and Madi did the 5K. Way to go, Lauren and Madi!

“"It was also a chance to show the community how to include our kids in typical ways, even when the task seems challenging”, explained Michele Chauvin, mother of Lauren. Michele and another parent of a child with a visual impairment, Leigh Ann Cloutier met several times with Patty Godfrey from Sugar Kidz Triathlon and Marrielle Monte from C-Different. Both are committed to do whatever is necessary to include any athlete who has blindness and/or a visual impairment with or without additional disabilities. "Whatever it takes" was their comment regarding accommodations, so they are willing to be creative.

Patty said, “If your child would like to “try a tri”, we can work with you and your child to accommodate certain needs. Also, your child can choose to compete with a guide. This guide may be a parent or another child. We have children of all different levels from our Triathlon Club able to compete with your child.” The Club also sets up specific training days with guides.

For more information contact us at: Patty Godfrey, Race Director, Sugar Kidz Triathlon, 281-491-6579, <patty@firsttri.org>. Patty is a member of The Fort Bend TriPsyclones Club that organizes these events for children ages 5-12. Check out their website <www.tripsyclones.org> and register for their newsletter to get dates of future events.

Photo Caption: Lauren with her mom Michele and Madison with her mom Alison at the Sugar Kidz Triathlon.
Ironman, Texas Style

By Jean Robinson, Family Specialist, TSBVI Outreach with Joe Paschal, Lead Teacher, Physical Education Teacher, TSBVI, Austin TX

Abstract: Learn how people with blindness and visual impairment can compete in athletic events. The C-Different Foundation inspires athletes, educates communities and changes perspectives by connecting sighted guides to blind athletes. Find out about the five blind athletes that participated in the Ironman Texas.

Keywords: Ironman, triathlon, adaptive sports, blind, visually impaired, family wisdom

Have you heard of Ironman? It is a triathlon that began in Hawaii in 1978. Participants swim 2.4 miles, bike 112 miles and run 26.2 miles. It is the world’s most prestigious one-day endurance event—an athletic accomplishment, few people can claim. A bigger challenge is competing in this event without sight, and five people recently did so in Texas. C-Different Foundation athletes inspired participants from every state, 11 countries and thousands of spectators at the inaugural Ironman Texas in May of 2011.

The C-Different Foundation was founded to inspire people with visual impairments to lead active and healthy lives. In order for someone with a visual impairment to participate in many of the athletic competitions in their community they typically need a guide that is tethered or running next to them. That means the guide must be at least as athletic and in-shape as the blind athlete so the competitor is not held back. Usually the competitor and his or her sighted guide spend hours together training for the event.

When talking about his Ironman experience Joe Paschall, Lead Teacher, Physical Education Teacher, and coach at TSBVI, stressed the importance of having another athlete encouraging you along the way. Joe, who has albinism, has been a fast runner since childhood. Growing up he participated in athletics, but remembers not being able to fully participate on his high school football team because he couldn’t follow the football at kickoffs. Now he knows that if the ball had been florescent instead of the traditional brown he would not have lost sight of it.

Sharing his experiences and teaching students how they can become athletes have been passions for Joe. He started his own training with the Houston triathlon and then the New York triathlon working his way to the next level until he was ready for the Ironman. He plans to participate in the next Houston triathlon in January 2012.

Matt Miller, the founder of C-Different, contacted Joe to organize a mini-triathlon for TSBVI summer school students. Later C-Different athletes helped a group of residential students to participate in the Houston triathlon. The
involvement Joe had with C-Different inspired him to establish Team Vision to support individuals in making a lifestyle change. The focus of Team Vision is on fitness, nutrition and emotional wellbeing. Their mission is to provide young adults with visual impairments exposure to recreational and fitness programming, help them learn to access public and private community facilities, to network with peers, to plan trips and travel independently to the site and to establish good health habits to maintain emotional well-being. Joe welcomes your interest and he can be contacted at 512-206191 and <paschallj@tsbvi.edu>.

The C-Different Foundation makes the connection between the person with a visual impairment and the sighted guide. Anyone can sign up on the CDF website. Becoming a guide is a great experience and takes no experience. Maybe you want to find an exercise partner near you with similar capabilities and skills. Complete a profile online and you will train, exercise and race with a partner with equal or less experience than you.

CDF also seeks to inspire and educate others through the telling of the stories and circumstances of the athletes and their guides. Below are pictures of some of the blind participants in the Ironman Texas. To find out more about their amazing experiences, sign up for the CDF newsletter, or get involved, go to <www.cdifferent.org>. Their next fundraiser is the Chevron Houston Marathon and the Aramco Half Marathon in January 2012. Look for C-Different on Facebook for more information.

Photo Caption: Patricia Walsh now holds the record for the fastest blind athlete to complete an Ironman with a time if 11 hours 50 minutes. Patricia is in the center with her two guides.

Photo Caption: Brandon Adame completed his first Ironman with guide Nigel Willerton. Nigel gives an insider's view of the experience on his blog at www.facebook.com(note.php?note_id=178841872173397)
Texas Boy Learns to Maneuver with Limited Vision

By Marc Ramirez, Dallas Morning News, Dallas, TX
Reprinted with permission of Helping Hands, Macular Degeneration Association
www.maculardegenerationassociation.org/resources/information.aspx?category=Helping Hands
Monday, June 27, 2011. Originally published Jun 19, 2011; Dallas Morning News

Abstract: A description of how an eight-year-old boy with deteriorating vision learns to use echolocation to identify objects in his environment. His family organizes a soccer clinic for children with visually impairments so others can learn how they can play sports.

Keywords: rod-cone dystrophy, low vision, visual impairment, adapted soccer, echolocation, family wisdom

Editor's note: I met Zach’s mom in early spring and admittedly did not fathom how she could organize a soccer clinic for children with visual impairments by the summer. Thankfully Johanna was not deterred. She got friends, family and the community on board and solicited donations for snacks and water. She ended up with getting shirts, adapted soccer balls and hot dogs! The passion and determination of one person made a difference in the lives of so many families. One of the most impressive sights at this soccer clinic was a number of teen volunteers from a local soccer team. They were all eager to offer one-on-one help. They, along with some siblings didn’t hesitate to try playing blindfolded. Families of children with similar conditions and age networked while watching their children learn new skills both on and off the soccer field.

Does anyone really like tiramisu? Why are there so many Chinatowns? These are the questions on the mind of an 8-year-old boy.

But early one June afternoon, a different puzzle was at hand as 8-year-old Zach Thibodeaux walked, blindfolded, down his suburban street, his white cane only partly guiding the way. Making intermittent clicks with his tongue, he traced the sidewalk, his instructor just behind. He paused, unsure. then reached out with the cane and found one of the stout, stone mailboxes common in his Lewisville neighborhood.

"Good," said Daniel Kish, founder of World Access for the Blind <www.worldaccessfortheblind.org>, placing a hand on the arched structure. "We don't have mailboxes like these where I come from. These are brick bunkers."

Last fall, Zach — who just finished second grade at Mary Immaculate Catholic School in Farmers Branch — was diagnosed with cone-rod dystrophy, a degenerative eye disease that will ultimately render him blind. This month, he spent several days working with Kish, whose 10-year-old organization, based in Long Beach, Calif., aims to teach the blind not just to be functional but to feel able to pursue their dreams.

As part of his training, Kish and his crew teach a disciplined form of echolocation — what bats use to "see" in the dark. By sending out sound waves in the form of carefully honed tongue clicks, Kish said, the blind can effectively sense what's around them, taking acoustic imprints of their surroundings as waves echo back. "It's like putting clay into a mold," Kish said. "The sound is taking the shape of the environment."
Down the street, Zach — whose task was to note nearby objects — paused again. "There's something to your right," Kish told him, guiding him back a few steps toward a rail-thin sign post. "You heard it after you passed it."

Kish himself is blind, though you'd hardly know it to see the confidence with which he moves around. He's hiked alone, mountain biked, gone solo-camping for days at a time. At 45, he travels the world, teaching and speaking about his craft.

We live in a visual society, where the idea of sound-oriented mobility is hard to envision. Kish's training, then, is about more than getting around obstacles; it's about overcoming them — as well associated attitudes that put limits on blind kids' potential.

"We see it a lot," said Juan Ruiz, one of two instructors who work with Kish. "Blind people have things handed to them. If I say, 'Where's the trash can?' — odds are somebody will say, 'I'll do it for you.' That's the reality of the world these kids live in."

Kish also encourages risk — the willingness to suffer bumps and bruises en route to independence, an attitude he said parents must foster in their blind children. He wants to give students the skills to move about as freely as he does. Advocates for the blind caution that not everyone can be as uniquely talented as Daniel Kish. Echolocation should not take the place of a cane or guide dog, they say — but used in tandem with those methods, it can be a valuable tool.

Austin software developer Nolan Darilek, blind since birth, said Kish's training is almost martial arts-like in its discipline, unlike any he's ever experienced. Until he began working with Kish, he'd consigned himself to striking objects with his cane, drawing attention as he gets around. "I don't want to bludgeon my way through life," said Darilek, 30. "I want to move through it gracefully."

Many blind people develop some system of auditory navigation, but few have perfected and contemplated it as much as Kish, who lost his sight to retinal cancer as an infant. His prosthetic eyeballs are as lifeless as a wax figure's. Still, he said, "my mom's biggest goals were that I get out of the house and pay taxes. In order for me to be like everyone else, I had to be treated like everyone else."

The clicking came as naturally as blinking, he said, and he recalls a childhood free of limitations. He ran around with other kids and rode a bicycle, even joining other kids in a sort of bike destruction derby. "I was fearless, and I had the best bike — a BMX," Kish said, "We'd go to an open space and all crash into each other and see who was the last one standing. These days, there'd be some old biddy coming out and telling us to stop because someone was going to get hurt."

Get hurt he did. Occasional run-ins with slides or poles required medical attention. But he was a regular kid, and he would go on to do his thesis on echo location for a master's program at California State University, Los Angeles. He'd planned on being a psychologist, but frustration over how few blind people moved as freely as he did drove him to want to do more. In 2001, he launched World Access for the Blind.

Kish's goal is to rewire the brain to rely on sound and touch, rather than sight, to construct images. More than 500 blind or low-vision students in 18 countries have gone through his program, which urges families to be active supporters.
"There are people who want echolocation as a miracle cure, relieving them of responsibility," Kish said. "In some ways it is magical. You're freeing the brain — but it has to be supported."

Zach's sight has worsened since his diagnosis: By early last month, he'd lost 80 percent of his sight; now he can see just two feet in front of him. But he's excelled at Braille, and his mastery of the abacus has revived his math prowess. After his mother, Johanna Uek, read about Kish in Men's Journal, she arranged to bring Kish to Dallas to work with Zach and to conduct a soccer clinic for local blind and low-vision children. "This is going to help Zach be more social," Uek said. "I want him to know — you gotta deal with what you got."

Zach's training included outdoor exercises in which Kish positioned objects — a cutting board, a Styrofoam plate — near, or away from Zach's blind folded face to develop his perception of them as he clicked. Now Kish held the plate about a foot to Zach's left. "Tell me which side it's on," he said. Zach clicked in either direction, then reached to his left and found it there. Before long, he was getting the hang of it. "He wasn't able to hear the plate at all yesterday," Kish said, after they were done. "That's how quickly this can develop."

But using it to get around is something that will take time. Along with their neighborhood walk, Kish had Zach practice getting around a roller rink, a car-filled superstore parking lot, the labyrinth of a college campus building.

Darilek, the Austin software engineer, said Kish's methods have inspired him to consider activities thought to be limited to sighted people, even as some find it hard to imagine. "That's one thing I'm encountering with my friends. I tell them I want to ride a bike, and they're freaking out about that. . Maybe it's a horrible idea. I hope not. But to live your life a slave to fear and horrible things that might happen to you is not the way I want to live."

Zach and 14 other blind and low-vision kids attended Kish and Ruiz's soccer clinic at a Farmers Branch park on a hot afternoon. The balls were filled with rattling beads that allowed players to track them as long as they kept rolling. Afterward, as worn-out kids and families gathered for hot dogs in the shade, Zach described what he knew about echolocation and the technique behind a good click. "The brain lights up when it gets all that information," he said.

And a smile as you click produces one that is higher-pitched, he explained, reaching greater distances. Still, he knew he had a long way to go. "I can't bike yet," he said. "I'd freak out." Kish had already made a mental picture of the park on this, his first visit, using barely audible clicks and his cane to get around, occasionally walking off to take calls on his cellphone. Now, sitting nearby, he asked where the ice chest was, because he could use another bottle of water. He got up to go get it, but as he did, he found someone had already gotten one for him.
TAPVI TALKS
By Jean Robinson, Family Specialist, TSBVI Outreach

Abstract: TAPVI, an association of Texas parents with children who have visual impairments, participated in a statewide family event at Morgan’s Wonderland in San Antonio.

Key Words: Family Wisdom, TAPVI, Family Organization, Morgan’s Wonderland

When agencies and organizations collaborate great things happen for a larger number of families. TAPVI jumped on the bandwagon as soon as they heard the whispers of a possible statewide event for families, knowing it would be a great opportunity to network with other families. TAPVI volunteered to sponsor a sensory station in San Antonio during Destination: Morgan’s Wonderland. Families were given the chance to learn about TAPVI while their children searched tactually to find hidden treasures and to identify different scents. Each child went away with small prizes. Families that came by the station entered a drawing for a large gift basket filled with goodies. Anyone joining or renewing their TAPVI membership earned extra chances to win. Working together on a mutual project provided time to enjoy each other’s company and laugh out loud. The parents had as much fun as our children did!

To find out more about TAPVI contact Alma Granado at 956-735-9247 or alma.granado@yahoo.com
To join TAPVI and NAPVI go to www.spedex.com/napvi/chapters.html#5
To join TAPVI on Facebook contact Michele Chauvin at 832-2486703 or michelechauvin@yahoo.com
To join the TX VI Family Network list got to: www.topica.com/lists/txvifamily
For more resources go to www.familyconnect.org

Photo Caption: Isela Wilson, President, helping to hang the new TAPVI banner.

Photo Caption: Meeting new friends from across the state was a big part of the day.
What I Learned at the CHARGE Syndrome Foundation Conference:
P is for Pain

Holly Cooper, Ph.D. Outreach Deafblind Educational Consultant, Texas School for the Blind and Visually Impaired (hollycooper@tsbvi.edu)

Abstract: The author discusses research about pain and CHARGE syndrome presented at the 2011 National CHARGE Syndrome Foundation Conference by Kasee Stratton.

Keywords: CHARGE syndrome, pain, medically fragile individuals.

This summer I had a first-time experience: I attended the National CHARGE Syndrome Foundation Conference, which occurs on alternating (odd-numbered) years. I’ve been particularly interested in individuals with CHARGE syndrome for a number of years, and since joining the team of the Texas Deafblind Project, I’ve had the opportunity to learn a lot about it. I have been able to attend the statewide Texas CHARGERS Annual Retreats several years in a row, and have met new students with CHARGE every year. I had heard many times that attending the national conference was an experience you can never forget, and where you can learn new information about CHARGE that can be found from no other sources. These are the people doing the research, and some of the studies they present have been conducted at these very conferences. Of course, if you’re a parent or family member of an individual with CHARGE, it’s a life-changing experience. You can hear geneticists from the Netherlands and the U.S., and meet the researchers who identified the genetic source of CHARGE syndrome. You can learn about medical issues, potty training, communication, cochlear implants, and so much more. I think I talked to almost everyone there who was a family member of a CHARGEr from Texas, and I’m a pretty introverted person! It was a wonderful experience, and there was so much information. Even as a professional who frequently attends conferences, this conference felt different. The emotional component, the joy and relief people experienced from sharing their knowledge and experiences, was everywhere in conversations and exchanges.

P IS FOR PAIN

Much of the information available about CHARGE syndrome is written for medical and psychology professionals and families. There is a substantial amount of information relevant to educators, but sometimes the reader must sift through a lot of information to figure out how to apply it in their own classrooms. But presentations at this conference included a lot of practical information of use to teachers and others in educational settings, so I wanted to bring some of it back to share with Texas teams. One topic that I found of particular interest was the issue of pain. Because individuals with CHARGE have a lot of complicated medical issues, they may have frequent pain experiences. Some specialists in the CHARGE field believe that due to the complications of the sensory system, individuals with CHARGE may have a high pain threshold, that is, they may not feel pain as acutely as other people (Davenport, 2002). Also, when the pain finally gets intense enough to be felt, the individual may be completely overwhelmed by it and unable to function in other ways for a time. This can result in behaviors like tantrums or crying spells. Individuals with CHARGE typically have difficulties with self-regulation, so once such a behavioral event begins it may continue for a long time before the individual is able to stop and reorganize his or her emotional state. Such behavior state breakdowns and the fatigue that follows can cause hours of the school day to be lost for instructional purposes. Less intense pain can be a source of other less severe behavior and manifest as self-abuse. Self-abuse may cause injury, but even if it doesn’t cause injury, self-abuse interferes with the student’s availability for learning, communicating, and interacting with others. Kasee Stratton, a
school psychologist and doctoral student at Central Michigan University presented a session on her survey about pain in individuals with CHARGE called “Identifying the ‘P’ In CHARGE” (Stratton, 2011). As you may know CHARGE is an acronym for what was originally believed to be the major anomalies present in the syndrome. Stratton’s contention was that pain, the “P” was such a pervasive component of the CHARGE experience, that it was every bit as important as the other major anomalies.

Stratton’s study included 58 individuals with CHARGE syndrome. The most common sources of pain identified by the participants or their caregivers were ear infection, sinus infection, gastric reflux, constipation, after-effects of surgery, tactile defensiveness, migraine headaches, problems with the stoma site (the surgical opening where the g-tube enters the body) and abdominal migraine. As an educator, I was aware of the complications of CHARGE ears, which with their atypical structure are more susceptible to ear infections. Chronic and recurring ear infections are a major problem, particularly for younger children with CHARGE. The nasal and throat problems can make children susceptible to respiratory and sinus congestion which can lead to infection. I was not aware of the impact of CHARGE on so many different complications of the digestive system as sources of pain. Stratton’s research indicated four of the top major causes of pain were related to the digestive system. Since educators do not see their students around the clock, we are less aware of problems like reflux, constipation, and stomach pain.

I was not aware that migraines are a common problem of individuals with CHARGE, and I had never heard of abdominal migraine. WebMD describes abdominal migraine as a variant of migraine headaches that occur in children (WebMD, 2011). Children with abdominal migraines do have a high likelihood of having migraine headaches when they grow up. Abdominal migraines involve severe abdominal pain and nausea, vomiting, and loss of appetite. Such pain does not have a clear cause such as gastric reflux or constipation, although in some cases it may be triggered by the consumption of certain foods or stress and anxiety. Treatments include antidepressants and other serotonin influencing medications used with migraine headaches. Most treatment focuses on prevention through stress management and healthy lifestyle choices. Such treatment is complicated by CHARGE syndrome issues, such as high anxiety levels experienced by many children and youth.
Stratton’s study involved a survey of parents, 75% of whom said they could tell when their child was experiencing pain, although none said they could tell if they had chronic pain. As educators, we have classes full of students with many distractions, so awareness of the issue of pain for a child we are responsible for may be inconsistent at best. Individuals with CHARGE often have facial palsy which may cause them to be unable to smile, or make their facial expression difficult to read. In addition, their visual impairment may cause them not to appear to be attempting to make eye contact because of their visual field loss, so their attempts to initiate or maintain communication may go unnoticed. Some have difficulty communicating expressively, especially about topics which have no visual reference. In Stratton’s survey parents cited behaviors or actions that indicated pain. Such behaviors included vocalizations, changes in social behavior such as withdrawal, and being difficult to console. Grinding teeth, frowning, being less active or restless, rubbing the area of pain, spasms and seizures were also cited as indicators. Even changes in skin color and breathing were noted as signs of pain. More extreme behaviors included aggressive or destructive behavior, and self-injurious behavior. Some individuals with CHARGE are put on medication for challenging behaviors and anxiety. Although we cannot always do anything to stop their pain, Stratton suggested changing the expectations and reducing the demands on an individual with CHARGE when they are in pain. She also encouraged teaching communication strategies to the student so they may have ways to discuss their experience of pain.

I have had the opportunity to observe many different strategies for teaching students with limited communication skills to make statements about their emotions or physical state in constructive, socially appropriate ways. Some teachers incorporate statements about emotion into their language circle time, in a similar manner as discussions about the weather. Although this isn’t a very natural context in which to express one’s feelings, it is a good opportunity for students to observe others who may be more skilled communicators. As teachers and other adults in the lives of individuals with CHARGE, we can insert comments about our own emotions and physical state into conversations and ask questions during natural opportunities during the day. If a student is absent or goes home sick, this can be a good opportunity to talk about feeling ill or being in pain, and distinguishing “feeling bad” or ill, from “feeling sad.” Many students may benefit from the use of picture symbols depicting facial expressions. One strategy that health care providers use is to ask patients to rate their pain on a scale of 1 to 10, with 1 being little pain and 10 being the worst pain. A pain rating system was developed by Wong and Baker (Wong, et. al., 2001) using simple line drawings of faces to indicate severity of pain. This system, for those with vision and understanding of symbolic depictions of faces, gives the opportunity for more detail and gradations of pain than simpler picture symbols such as Meyer-Johnson pictures used in communication systems.

![Wong-Baker FACES Pain Rating Scale](image)

The Wong-Baker FACES Pain rating scale.
Used with permission.
Conclusion

I believe most of us educators recognize the importance of considering the whole child, but doing so is not always an easy thing. Time constraints limit what we can fit into the usual school day. However, behavior and attention problems that teachers must manage are so ubiquitous in children and adolescents with CHARGE syndrome that we cannot address them without considering the physical conditions inside the bodies of these complex children and youth. I hope this article will help you understand some of the complexity of the medical and physical issues involved in CHARGE syndrome and the challenges these individuals face on a daily basis. Sometimes I hear teachers say the student with CHARGE should be expected to behave like everyone else, but it is important to consider the difficulties they are coping with which far exceed those of other students.

References


Assistive Technology Evaluation – Part 2

Pat van Geem, TSBVI Outreach Assistive Technology Consultant

Abstract: In Part 2 of his article, the author presents guidelines for assistive technology evaluation, training and skills acquisition documentation, and implementation for students with visual impairment.

Keywords: blindness education, visual impairment, assistive technology evaluation, technology

Introduction

Part 1 of this article, in the previous issue of TX SenseAbilities, covered the evaluation establishing and documenting the need for technology. Up to this point, student information, the interview process, and assembling a team of experts have all been discussed. Now in Part 2 the question becomes: how do I use this information to determine an assistive technology solution for my student?

What to do with the Information

First, send each member of the assistive technology team short summaries of student information, observation findings, and interview answers. Then schedule a team meeting a week later to give them time to read the summaries. Keep a tight agenda and limit meetings to an hour. Here’s a suggested meeting agenda:

- List the student’s abilities and difficulties.
- List key aspects of the student’s environment.
- Identify the tasks the student is asked to do in his learning environment.
- Prioritize the tasks.
- Brainstorm all possible access solutions.

During the brainstorming process, keep in mind the student, the instructional environment, the tasks, and the tools already used, (SETT). For more information, see the website by Joy Zabala, Ed.D. At: <www.joyzabala.com/Documents.html>, containing guidelines and forms on the SETT process. It addresses considerations, data collection, tool selection, and implementation follow-through.

Determining the Assistive Technology

At this point, you should have clues of possible solutions for your student, and thoughts of devices, adaptations, computer access, and modifications that could factor in for successful outcomes. These questions to consider when selecting assistive technology are based on information from the Wisconsin Assistive Technology Initiative (WATI).

- Will it help the student access information?
- Is it needed for reading, writing, listening?
- How complicated is it?
- Will the professionals be willing to learn how to use and maintain it?
- Is it expensive?
- Is there a low-tech solution?
Always start with simple solutions. Usually the areas to begin finding solutions are with adaptations and modification. If assistive technology is the determined as a need, low-tech solutions are the starting points. Once you decide on a particular device or software application the problem becomes “where or how do we get this equipment?”

**Procuring the Assistive Technology**

Software vendors usually offer timed or feature-limited demos. For instance, ZoomText (screen magnification) offers a 60-day demo. MAGic (screen magnification) offers a full feature product for 45 minutes at a time before needing to restart the computer. JAWS (screen reader) offers the same features as MAGic. NVDA (screen reader) is an open source application and is free to download and install. SeroTek, the developers of System Access also have several inexpensive alternatives.

Hardware devices are a different story. Many vendors will offer demonstration service or they may loan a device for a short period. Education service centers (in Texas) can agree to loan out a device. The Texas School for the Blind and Visually Impaired Outreach Department offers a tech loan program. Check this web link for further details: <www.tsbvi.edu/technology-loan-program>.

**Trial Runs**

Once the assistive technology has been determined and obtained, activities that incorporate its use are planned out in order to determine whether the solution is appropriate for your student. Use entry level skill sets associated with task objectives when developing activities for evaluation. Activities should be short and measurable. You also may need to do more than one activity just to make sure this is the right choice.

In 2006, Cecilia Robinson (visual impairment specialist at Region 4 Education Service Center) and Debra Leff (visual impairment specialist at Region 13 ESC) made a presentation called “Merging an Assistive Technology Protocol with Teaching Materials for the Visually Impaired” at the CSUN Assistive Technology Conference in Los Angeles, California. In the packet of handouts are documents on assistive technology evaluation procedures for various devices and software applications. Here are a few examples of devices and software assistive technology activities taken from their handouts.

**Procedure for Computer Access: Screen Magnification Software**

The first task is to evaluate the student using the normal (default) settings. If there are some difficulties, evaluate the student using the built in computer accessibility features like enlarged fonts and cursors, monitor modifications, and screen enhancements. If the student is still struggling, screen magnification software should be considered for further evaluation.

Once it has been determined that screen magnification software might be the solution, an activity is developed to evaluate how well the student interacts with the software application. After the student is shown how to use the basic features, he is evaluated using these features independently. These features are in a list of skills needed to perform the most basic tasks of the application. Based on how well the student interacts with the software application, a determination is made on the appropriateness of the assistive technology for the student.
The basic skill set for evaluating screen magnification applications include this list of tasks:

1. Turn on the computer and the application.
2. Activate/deactivate the application.
3. Set color combinations (screen and text contrast).
4. Adjust for magnification.
5. Use key combination commands for navigation.

**Procedure for Video Magnifiers (formally CCTV’s)**

A reading rate needs to be determined without using assistive technology. Do an Independent Reading Inventory to determine reading rate and accuracy. Repeat the above procedure using a video magnifier.

1. After demonstrating the features of the device, see if the student can do these tasks:
2. Adjust image size.
3. Focus image.
4. Use the XY table.
5. Write a simple sentence.

**Procedure for Computer Access: Screen Reading Software**

Prepare a short reading sample for the student for interaction on a computer. After the student has been shown the features, see if he can do these computer access tasks:

1. Activate the screen reading application.
2. Use the arrow keys to navigate through the document.
3. Use key combination commands to do unique operations.
4. Edit content within the document (cut, paste, copy, etc.).

**Procedure for Portable Electronic Note-taking Devices**

Evaluate how the student handles the device (carefully vs. carelessly). Note whether the student prefers a QWERTY or a braille keyboard. Below is a list of the typical basic skills for most electronic note takers.

Tasks for evaluation and determination of whether these devices are appropriate for the student, should come from this list of skills.

1. Identify the functions of certain keys.
2. Turn on/off the device.
3. Set the preferred speech setting.
4. Navigate through the menu items.
5. Open a word processing document.
6. Type in a word processing document.
7. Close the document.
Sample Activity Planning Outline

The following is an example of an activity planning document to determine if a screen magnification software application is an appropriate solution for a low vision student.

Using Screen Magnification Software to Activate a Word Processing Application.

Materials:
ZoomText 9.1 (60 day demo edition)
PC Windows XP or 7 operating system.

Objective:
With the assistance of screen magnification software, the student will independently learn how to open a word processing document.

Activity:
The student will follow the complete process from activating the computer to having an opened word document. She will have three trials.

Procedure:
- Turn on the computer.
- Turn on the screen magnification software.
- Set the preferred magnification setting.
- Locate the word processing icon with the keyboard commands.
- Placing the mouse cursor on the icon.
- Double click on the word processing icon to activate the application.

Keyboard Commands to Learn
- Opens an application/program, Ctrl+Alt+Z
- Activate application, Alt+NumPad Insert
- Deactivate application, Alt+NumPad Delete
- Increase Magnification, Alt+NumPad +
- Decrease Magnification, Alt+NumPad -

Observation
Assistance during these steps varied each time she performed them. She knows how to turn on a computer. The three key combinations to turn on the screen magnification always required assistance. The student did set the magnification level independently. She also located the Word icon. She moved the mouse on the icon with minimal assistance. Double clicking was understood, but the action itself required some assistance.
Data Collection

Collect data on all evaluation tasks. Data must be measurable and collected from functional, meaningful activities. There are a number of ways to measure student performance.

When preparing to gather information you need to ask yourself the following questions:

- What does the student need to do?
- What kind of change could there be in the way the student completes that particular task?
- What aspect of the student's performance will change (speed, accuracy, etc.)?
- What is the best way to gather data to show that change?
- What change is realistic?

Here are some general types of data collection to measure student performance.

1. **Speed/frequency**: How many times did an action occur in a given time period? What is the reading rate on a video magnifier? How many times does the student push the button in a given time period?
2. **Accuracy**: What is the number of correct responses? "Johnny completes steps 1-3 with 100% accuracy in a five minute time period."
3. **Spontaneity**: Does the student know when to perform the action/behavior?
4. **Duration**: How long does the student stay on a task? How long did a certain behavior take in the context of time?
5. **Latency**: How long did it take a student to respond to a request/motor planning/cognitive/ wait time 0-3?
6. **Quality**: How was the writing (legible)? How was the reading (comprehension)?
7. **Quantity**: What is the percentage of the work completed? What is the reading rate? How much time did the student pay attention to task?.

Other ways of gathering information:

- Interview the student to get an opinion on the device or software.
- Review the finished products created by the student.
- Observe the student's performance during the task.
- Video tape (one of the best ways to evaluation).

Other Things to Observe:

- Motivation/Interest Level
- Anxiety Level
- Handling of the Device
- Ease of Use

Writing a Report

An actual report does not need to be the final outcome of an assistive technology evaluation; however, any report (as well as an assistive technology report) is helpful to all paraprofessionals, professionals and parents working with a particular student. It is important to have something written
down if you want to convince your special education director to buy a piece of equipment that could cost as much as your car. It is also important to have written documentation if there is some controversy centered on assistive technology.

An assistive technology report should include in the following:

- Student name, date of report, birthday, school, grade, and date(s) of assessment
- Environment(s) where assessment took place
- Background information on student, family, school settings
- Reason for assessment
- Summary of procedures, activities, and findings
- Recommendations:
  - Implications of findings
  - Student preferences
  - Concerns
  - Strategies and non-technology adaptations
  - Services and features of technologies recommend for trial
  - Types of technologies
  - Potential for training

Be sure to elaborate on these points:

- Provide recommendations that are based on the student’s strengths, needs, and the instructional value of the technology.
- Indicate whether devices and services have potential for improving access to curriculum.
- Indicate what training may be necessary in order to use the technology equipment (IEP goals and objectives).
- Specify all services that the IEP team determines are needed to support the selection, acquisition, and use of assistive technology devices. It needs to be designed in the IEP.

**Range of Service and Responsibilities**

It is very important to emphasize range of service and responsibilities. If this is not stated, then the technology may not be used appropriately. According to Quality Indicators for Assistive Technology Services (QIAT) by Joy Zabala, <www.qiat.org>, responsibilities are made very clear. Below are three major components taken from her website.

- Persons supporting the student across all environments in which the assistive technology is expected to be used share responsibility for implementation of the plan. All team members who work with the student should know their roles and responsibilities, and be able to support the student using assistive technology.

- Persons supporting the student provide opportunities for the student to use a variety of strategies, including assistive technology, and to learn which strategies are most effective for particular circumstances and tasks. This assures that, when and where appropriate, students are encouraged to consider and use alternative strategies to remove barriers to participation or
performance. Strategies may include the student's natural abilities, use of assistive technology, other supports, or modifications to the curriculum, task or environment.

- Training for the student, family, and staff is an integral part of implementation. Determination of the training needs of the student, staff, and family is based on how the assistive technology will be used in each unique environment. Training and technical assistance are planned and implemented as an ongoing process based on current and changing needs.

**Conclusion**

The purpose of an assistive technology evaluation is to determine the most appropriate solution for a student with a visual impairment. Proper consideration and determination is important because it will impact how the student will access information in his or her instructional environments. Though this imposes yet another task on we teachers for students with visual impairment, it is not more difficult than having a student struggle through classes due to inappropriate access of instructional materials.

**References**

Georgia Project for Assistive Technology (GPAT), www.gpat.org.


Tech Loan Services, Texas School for the Blind and Visually Impaired Outreach Department, www.tsbvi.edu/technology-loan-program.

Texas Assistive Technology Network (TATN), www.texasat.net.


**Resources**

JAWS Screen Reading Software Application,

MAGic Screen Magnification Software Application,

NVDA Screen Reading Software Application, www.nvda-project.org.


TSBVI and Read Naturally

Sue Mattson, Braille Specialist, Texas School for the Blind and Visually Impaired

Abstract: The author describes implementing the use of the Read Naturally program with selected students at TSBVI.

Keywords: braille literacy, education visually impaired

The Read Naturally program was first used at Texas School for the Blind and Visually Impaired (TSBVI) in 2006 by Jerri Cleveland, a Braille and Reading Improvement Teacher for high school students. Ms. Cleveland had very specific goals and looked for a program that met the following criteria:

- Used audio output with a slower rate of reading
- A program that "students were willing to do"
- Helped students understand how practice could improve their reading performance
- Helped students to achieve and experience success
- Nonfiction
- Predictability of program

The Read Naturally program met all her criteria, and as her students met with success other teachers began to use it too.

A Brief Description of the Process

The Read Naturally program implements three research-based elements of success—Teacher Modeling, Repeated Reading, and Progress Monitoring—to help students become proficient readers. (Read Naturally) Students listen to a recording while reviewing key words and reading the story. Next they continue to practice reading until they have reached a pre-determined goal, and participate in recording their progress after completing each story.

Teachers can determine which level is appropriate for their students by following the guidelines in the placement package. The placement package contains a worksheet, directions on how to use it, and examples. The initial assessment will determine the word count per minute.
Once a level has been determined, students select a story and read the key words and definitions while listening along to the audio compact disc. They are asked to write a prediction of what they think the story will be about. The first time the students read the story, they time themselves for one minute and mark words they have difficulty with. This establishes a cold timing used to measure improvement after further practice. The students read the story along with their teacher on the recording, and are encouraged to 'subvocalize', thus practicing the phrasing and pronunciation. They continue to practice and time themselves without the recording, working toward their goal. Questions at the end of each story are designed to gage students’ comprehension. When the students are ready, the teacher times them as they read. Errors are subtracted from the number of words read in a minute to determine the correct words per minute. There are 24 stories in each level with interesting topics ranging from people, like Booker T. Washington, Martin Luther King, Magic Johnson and Beatrix Potter (the author of The Tale of Peter Rabbit) to animals, fish, insects and snakes.

**Examples of Student Achievement**

The following is a small sample of the progress two TSBVI students made. Both were 4th graders at the time.

First, student A is a girl who lost her vision at age 6 due to a shunt malfunction which created papilledema (swelling of optic nerve). Through an assessment at TSBVI, it was determined that she had dyslexia. At the time these scores were recorded she was a beginning braille reader, reading uncontracted braille, double-spaced.

<table>
<thead>
<tr>
<th>Fall 2009 Level 0.8</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Story</strong></td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>6</td>
</tr>
</tbody>
</table>

*Word count per minute

The word count per minute is established by following the process in the placement package. The cold rate is determined as the student times herself for one minute the first time she reads the story, and the pass rate is the student's word count after reading the story with 3 or less errors, while being timed by the teacher, and answering the comprehension questions.
The next table shows the scores of student B, a boy with retinopathy of prematurity and retinal detachment in both eyes. He read contracted braille.

<table>
<thead>
<tr>
<th>Story</th>
<th>Start Date</th>
<th>Goal WCPM*</th>
<th>Cold Rate</th>
<th>Pass Rate</th>
<th>Pass Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5-4-10</td>
<td>50</td>
<td>37</td>
<td>51</td>
<td>5-4-10</td>
</tr>
<tr>
<td>2</td>
<td>5-11-10</td>
<td>50</td>
<td>30</td>
<td>50</td>
<td>5-11-10</td>
</tr>
<tr>
<td>3</td>
<td>5-14-10</td>
<td>51</td>
<td>36</td>
<td>57</td>
<td>5-14-10</td>
</tr>
<tr>
<td>4</td>
<td>5-19-10</td>
<td>----</td>
<td>35</td>
<td>53</td>
<td>5-19-10</td>
</tr>
<tr>
<td>5</td>
<td>5-24-10</td>
<td>60</td>
<td>58</td>
<td>65</td>
<td>5-24-10</td>
</tr>
<tr>
<td>6</td>
<td>5-15-10</td>
<td>51</td>
<td>31</td>
<td>56</td>
<td>5-25-10</td>
</tr>
</tbody>
</table>

*Word count per minute

The data sample of the two TSBVI students in this article, although a small sampling, clearly demonstrates improvement.

**Benefits to Students**

In addition to improved reading fluency and comprehension, the desired goals of the program, there are added benefits to students with visual impairments. First, the reinforcement of important technology skills achieved while using a CD player to listen to the audio files and a Braille Note or other device for writing responses to questions. The second was reinforcement of organizational skills. Students were expected to set up their own work areas to maximize success while reading, working with the CD player, and recording responses. For blind students this meant arranging a BrailleNote or Perkins Braille Writer, braille version of the Read Naturally story, and the CD player.

**Benefits to Teachers**

Since 2006, continued use of Read Naturally and positive student results has led TSBVI to work with Tom Ihnot, CEO, and Karen Hunter, Director of Curriculum and Professional Development, to format the Read Naturally material in braille and text files. Lanie Molinar, a TSBVI student with exceptional braille skills, was hired by Read Naturally to proofread the braille files. Read Naturally then put it all together in an accessible document in portable document format (PDF). The result was a reading curriculum that comes with ready-to-emboss braille files and plain text files that can easily be converted to large print, or loaded into a braille note-taking device. Benefits noted include:

- Access to the same research-proven, quality materials sighted students use.
- Time savings: braille files are embosser-ready in Duxbury and Braille 2000 file formats.
- Plain text files for easy formatting for large print readers.
- Each CD contains a help file with tips to assist teachers or others involved in production.
- A note to the teacher file including information to alert teachers to the use of Transcriber's Notes.
Conclusion

According to the National Federation of the Blind studies conducted during the 1990's, 70% of blind people were unemployed. Of those who were employed 80% used braille in their day-to-day lives. These studies reported that reading braille, literacy, educational achievement, employment, and independence were connected (National Federation for the Blind). The cooperative relationship between TSBVI and Read Naturally has resulted in the production of a significant educational resource for improving literary skills for students who are blind or visually impaired.

References


Hustle and Bustle in the TSBVI Construction Zone

By Bill Daugherty, Superintendent, Texas School for the Blind and Visually Impaired

Abstract: In this article, Superintendent Daugherty discusses how the changes on campus and new students are shaping the look of TSVBI.

Key words: TSBVI, visually impaired, blindness, students, comprehensive program

The Texas School for the Blind and Visually Impaired is starting the 2011-2012 school year with the largest August enrollment in well over a decade. The 56 new students joining us have adjusted well to the construction dust and the ever-changing pedestrian routes around campus. The Main Education Building that has stood in the center of our campus since 1916 is now just a large hole that is rapidly being backfilled and will soon become “The Lawn”. Of course, it will be planted with low maintenance, drought-resistant turf and plants. For the new students, the state-of-the-art campus that is taking shape will be how they will remember their TSBVI experience, much like students who first arrived at what was the new campus in 1916.

This large influx of new students has noticeably energized the campus. They have a great deal of camaraderie among themselves and have blended well with the current students. Our staff is excited about the challenges and opportunities each of these students bring to the mix. In our quest to continually examine and improve upon our contribution within Texas’ fine network of ISDs, ESCs, DARS/DBS and the luxury of two personnel prep programs (TTU & SFASU), we are refining our processes to help ensure that these new students we are serving at our campus K-12 program truly require the intensity of our specialized services at this time in their lives in order to receive an appropriate education. There is now an increased focus on our part to also make sure all students have multiple access points to our services, be it with our short courses during the school year, a wide array of summer program offerings, and statewide outreach services collaborating with students’ IEP teams for improved outcomes at home. Additionally, there is a DARS/DBS partnership to provide a post-secondary experience on our campus that has a heavy emphasis on Adult Daily Living Skills in an apartment setting.

For those students being referred by local ARD committees to our K-12 campus-based Comprehensive Programs, our referral committee is closely examining the reasons for referrals and the degree to which a student might already be receiving an appropriate education in their local school district. Our reference point is the federal law IDEA, and the key components are referred to as a Free and Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE). The LRE is always considered to be the placement where a student has the most contact with non-disabled peers as far as IDEA goes, but there is also legitimate discussion that such environments may in some cases impose other significant restrictions such as access to sufficient supports. Both FAPE and LRE have standards that provide guidance to how and where students are educated, but admittedly, they are complex and sometime contentious in practice when ARD committees are considering an individual student. We also consider whether or not our outreach services or our short-term or summer programs might be the missing piece(s) that can help a student or their school to be more successful locally.

Ideally, the balance we are seeking is for our intensive campus K-12 program to be primarily reserved for students who, for reasons closely tied to their visual impairment, need to spend as little as six months or as much as three years at TSBVI in order to gain the skills, confidence and knowledge to successfully return home to their local schools. When the formula works right, these students can
receive an appropriate education (FAPE) in the least resource-intensive environments more typical of public schools (LRE). To work well, this is a partnership between the school district, the family (and student), and TSBVI. Even the ESCs and DARS/DBS can be critical players, and in cases where there is no Teacher of the Visually Impaired or Orientation and Mobility Specialist, or there is insufficient access to these personnel, our university partners at TTU and SFASU can help train locals who will stay local.

TSBVI’s overriding concern behind the increased attention to this approach to our role within the state is driven by three primary concepts, given here in order of priority. First, our experience tells us that, all other things being equal, students with strong ties to their family and their home communities tend to have the best life outcomes. Second, we believe that it is important to follow the law as set forth in IDEA, and to make that law work to the advantage of every student. To that end, the K-12 Comprehensive Program, Short-term Programs, Summer Programs, the Post-Secondary Program and our Statewide Outreach Program provide multiple, high quality avenues for students to benefit from what TSBVI has to offer throughout their educational career. And third, with over 8,000 students with visual impairments in the state, TSBVI has to have multiple ways to deliver its services. Students accessing those services offered on our campus, particularly the K-12 Comprehensive Programs with its residential component, need to be rotating in and out as soon as it is appropriate so that other students can share this limited resource.

As I see this happy and energetic group of 56 new students running around our campus, it presents a vision of TSBVI and its role within the state, where 56 or more new students are arriving every year and 56 or more students, having gotten what they needed from us at a particular time in their educational career, are taking their new skills, attitudes and knowledge back home to their families, schools and communities. A vision where students come back time and time again for short-term and summer programs, and where TSBVI outreach services in partnership with schools, organizations and family advocacy groups help build communities that strive to continually improve their local services to students. As with most visions, the reality is imperfect, and no plan or approach will work with every child in every situation. But as you interact with TSBVI now and in the future, I think you will see these themes continually moving strongly to the forefront. It is a work in progress and always will be. Your feedback and guidance, be it encouragement or constructive criticism, has always informed and enhanced TSBVI’s improvement efforts and will continue to do so.

In two years the construction project will be completed and perhaps enough time will have passed for the new grass, shrubs and trees to have settled in a little. If you have never visited our campus, or it has been a long while, 2013 on a cool fall day might be a good time to come and see this statewide resource that belongs to you. The incredible investment Texans put into the rebuilding of TSBVI with the passing of bonds at an election years ago is an opportunity to make sure we maximize the return. What you see above in this article represents our best thinking on that opportunity so far. Much of it is informed by what you have told us over the years, and much of it is informed by our careful observation of the experiences and outcomes of students who have come through TSBVI. It has also been informed by hundreds of visits to your communities and schools across the state to work with you on our common goal of seeing that all students have access to a good education and that they are able to take advantage of it.
Change is in the Air for CCRC

by Barbara J. Madrigal

Abstract: In this article Ms. Madrigal describes the changes in programming at Criss Cole Rehabilitation Center.

Key Words: DBS, Criss Cole Rehabilitation Center, Blindness, Visually Impairment, Confidence, Skills, Application of Skills

We'd like to be able to use the expression “fall is in the air,” but I’m not sure this record-setting hot Texas summer is ever going to end. I can announce, however, that “change is in the air” for programming offered through our Criss Cole Rehabilitation Center (CCRC). So, why are changes being considered and how would these benefit Division for Blind Services’ consumers? Let’s take a look.

One of the ways to implement continuous quality improvement or quality assurance is to periodically check the pulse of your constituents. Early on in this process, we surveyed the Center’s primary customers—consumers and field staff—as well as Center employees. Feedback from field staff and from consumers indicated a desire to produce quicker results, increase program intensity, optimize technology throughout the program, enhance employment focus, enhance individual customization of programming, and increase partnerships with field and consumers. Feedback from CCRC indicated a need to increase the quality of the experience, maximize the use of consumer time, decrease cost per graduate and training hour, increase referrals, maintain full capacity, increase marketing and communication with field, integrate technology in all areas, and sequence classes to build capacity. So, the goal was to create programming that would be more responsive to individual needs, more flexible in terms of specific areas the consumer would participate in, and faster in terms of the time spent by consumers at the Center. And all of this while maintaining or increasing quality.

The proposed CCRC program structure is designed to incorporate all of this feedback in its new model of service delivery. Using the Admissions office as the point of coordination for referral information, continuing dialogue with the field, and for tours, it is now possible for consumers to enter the program through any one of three programming areas. While a more traditional training sequence would begin with confidence building, followed by proficiency training, and culminating in the career focus training program, consumers will be able to select the areas that match their individual needs. The purposes of the three program areas are:

- **Confidence Building Program [Confidence]**
  - Overcome fears
  - Learn basic blindness skills
  - Increased problem solving and decision making

- **Proficiency Training Program [Skills]**
  - Hone or develop skills
  - Longer-term, in-depth training
  - Master blindness skills
  - Advanced problem solving and decision making
• Career Focus Training Program [Application of Skills]
  o Self-directed training activities
  o Work, Internships and Networking (WIN) program
  o Employment focus training and practice

Regardless of which area or areas the consumer participates in, the goals of each program supports employment and/or independence for the individual. And, of course, the Center staff and management recognize those accomplishments through a graduation event at the conclusion of the training.

Behind the scenes, the instructional staff will be optimizing the classroom experience through a teacher-consumer, results-based Partnership (and yes, that’s Partnership with a capital “P”). Classroom activities will be goal oriented, will challenge consumers through experiential activities, will welcome increased oversight for class and learning standards, and will ensure that teachers are trained in effective classroom management.

This new model promises to:

• Produce quicker results by allowing consumers to graduate sooner
• Increase program intensity so that consumer gains confidence, skill building and application sooner
• Optimize technology throughout program by encouraging consumers to use technology sooner, independently, and effectively
• Enhance employment focus by training consumers to become better qualified applicants
• Enhance individual customization of programming by requiring consumers to demonstrate an understanding of relationships between training activities and their individual vocational goals and to increase their commitment to training
• Increase partnerships with field and consumers by increasing referrals and achieving increased field and consumer satisfaction measures

As of mid-September, CCRC management has just completed presentations and discussions with field staff and consumer groups to describe this new model of services. Once final adjustments are made and my executive team is satisfied with the redesign and all of its details, we expect to roll this out in early 2012 to our consumers. We look forward to continuing to serve Texans who are blind through the Center's new programming choices in the very near future!
Career Clusters: Use AFB CareerConnect in a whole new way!

By Joe Strechay & the AFB CareerConnect Team <jstrechay@afb.net>
Permission to reprint from American Foundation for the Blind

Abstract: This article describes AFB’s Career Connect program and its new option on exploring careers and connecting with mentors through Career Clusters.

Key words: AFB, blindness, visually impaired, Career Connect, mentors

Can you remember thinking about careers while growing up? I can remember wanting to be a marine biologist or park ranger. AFB CareerConnect (www.afb.org/cc) has always offered persons the opportunity to connect with their mentors, but now they are offering something brand new.

CareerConnect launched the Career Clusters in late spring, a new option on exploring careers and connecting with mentors. Career Clusters allows a much more user-friendly experience when navigating careers and connecting with mentors. Connect with mentors specific to the fields via message boards. These message boards are associate to the field and monitored by mentors working in that career field.

I can't say that we have marine biology or park ranger as a field, yet, but we started by launching law, counseling, health, and education. CareerConnect plans to launch more "clusters" in the near future. If you don't find the career that you are interested in the Career Clusters, you can always check out our other career exploration options. Go explore these Career Clusters and let us know what you think!

If you haven't had the opportunity to check out the free, self paced, online, employment process course called The Job Seeker's Toolkit. This is a great resource to utilize with students and clients with visual impairments who are interested in employment. Plus, professionals can be associated with users, enable users to send their assignments to an associated professional.

The July issue of AccessWorld, a themed issue specific to "Back to School" with some amazing resources for teachers, professionals, and students. There is a great article about STEM (Science, Technology, Engineering, & Mathematics) filled with resources and great content. Check it out in the "Back Issues" section of AccessWorld or the link will be in the list below.

Career Clusters Link: http://www.afb.org/CareerConnect/users/browse_by_cluster.asp
Other ways to explore careers:
http://www.afb.org/Section.asp?SectionID=7&TopicID=209&SubTopicID=63
Job Seeker's Toolkit:
http://www.afb.org/Section.asp?SectionID=7&TopicID=209&DocumentID=5319
July Issue of AccessWorld
AccessWorld
www.afb.org/aw
Abstract: Hadley School for the Blind has a program that can be customized to help students graduate from high school.

Key Words: blind, visually impaired, Hadley School for the Blind, High school diploma, “Graduate Texas Initiative”, DARS, TSBVI

A teacher with the Colorado School for the Blind and Deaf recently emailed Hadley with a thank you for helping one of her students earn a high school diploma. She wrote, “My student had enrolled in an online school last fall to obtain some high school credit, and things unraveled quickly and it didn’t look like that would work. We tried to set up a distance learning course in braille, and the next day I wondered why we were attempting to create a course when I knew Hadley existed for this purpose!”

Since the 1930s, The Hadley School for the Blind has offered an accredited High School Program to students with visual impairments age 14 and up who live in the United States. Hadley customizes a student’s high school program to his or her needs, and instructors and student services representatives are available for support via email and a toll-free phone number. Learning materials are accessible in a variety of formats including braille, large print and audio and online, and students study at home, at their own pace. Best of all, courses are free of charge to people with visual impairments.

Like the student from Colorado, many turn to Hadley because they have had challenges fulfilling high school requirements through their local school district. According to the American Foundation for the Blind, five million people with visual impairments over the age of 25 have not completed their high school degree. To help students obtain the skills they need to succeed, Hadley not only fulfills the requirements for a diploma but offers award-winning braille instruction and courses focused on access technology and independent living skills, among others. Students may receive their diploma directly from Hadley or they may apply Hadley course credits toward graduation from their local high school. Homeschoolers can also supplement their educational program with courses from Hadley. Students who complete Hadley’s High School Program are invited to a commencement ceremony each June in Winnetka, Illinois, where the school is headquartered. Hadley even pays the travel expenses.

In Texas, Hadley is collaborating with DARS Division for Blind Services and the Texas School for the Blind & Visually Impaired on a “Graduate Texas Initiative” to reach out to anyone desiring a High School Diploma in Texas. We are looking at the possibility of holding the graduation ceremony right here in Texas. If you know of anyone who might be interested in completing their High School Diploma, please contact Billy Brookshire, Hadley Texas Outreach, at 512-565-9690 or email bbrockshire@austin.rr.com for more information. And please encourage all teachers, counselors, or others who work with blind or visually impaired high school students to visit www.hadley.edu or call 800-323-4238 for a more detailed description of the Hadley High School Program.
Seminars@Hadley: The Fast, Convenient, and Free Way to Learn

By Billy T. Brookshire

Abstract: This article describes how to take advantage of seminars offered by Hadley School for the Blind.

Key words: Hadley School for the Blind, blindness, visually impaired, seminars

Did you know that The Hadley School for the Blind offers two FREE web seminars a month? That’s right. From the convenience of your office or home, you can listen to recognized experts in the blindness field talk about the issues of the day.

The seminars are fast: 1 to 2 hours in length with ample time provided for question and answer. And it’s easy to register. Just go to www.hadley.edu and follow the Seminars@Hadley link. On the day of the seminar, simply enter your name and password and you’ll be admitted into the seminar.

If your busy schedule makes it impossible to attend a seminar, no worries. All Seminars@Hadley are archived. You can find them organized by category under “Access Past Seminars” on the Seminars@Hadley web page. You have the option of listening to them real time or downloading them to disk or other device and listening at your convenience.

Some seminars are approved for Continuing Education Credits. To obtain CEU’s you have only to complete a short quiz and pay approximately $25 U.S. This is true for both “live” seminars and those that are “archived”.

Upcoming Seminars@Hadley include: Powerpoint for Blind Presenters; The Cookie Exchange (blind & visually impaired cooks share cookie recipes), Dancing Dots & Other Innovations (Bill McCann shares electronic innovations for blind musicians).

So, want to learn more about what’s coming up on Seminars@Hadley? Check the website (www.hadley.edu) or subscribe to Hadley News and Announcements at: http://www.hadley.edu/9_a_mailingList.asp.
Bureau of Engraving and Printing Launches EyeNote™ App to Help the Blind and Visually Impaired Denominate US Currency

Press release from the Bureau of Engraving and Printing, U.S. Department of the Treasury

Abstract: This article provides information regarding a free downloadable application (app) that will recognize the denomination of US currency.

Key words: Bureau of Engraving and Printing, Us Dept of Treasury, blind and visually impaired, US currency, apps

The Bureau of Engraving and Printing (BEP) has developed a free downloadable application (app) to assist the blind and visually impaired denominate US currency. The app is called EyeNote™. EyeNote™ is a mobile device app designed for Apple iPhone (3G, 3Gs, 4), and the 4th Generation iPod Touch and iPad2 platforms, and is available through the Apple iTunes App Store.

EyeNote™ uses image recognition technology to determine a note’s denomination. The mobile device’s camera requires 51 percent of a note’s scanned image, front or back, to process. In a matter of seconds, EyeNote™ can provide an audible or vibrating response, and can denominate all Federal Reserve notes issued since 1996. Free downloads will be available whenever new US currency designs are introduced. Research indicates that more than 100,000 blind and visually impaired individuals could currently own an Apple iPhone.

The EyeNote™ app is one of a variety of measures the government is working to deploy to assist the visually impaired community to denominate currency, as proposed in a recent Federal Register notice. These measures include implementing a Currency Reader Program whereby a United States resident, who is blind or visually impaired, may obtain a coupon that can be applied toward the purchase of a device to denominate United States currency; continuing to add large high contrast numerals and different background colors to redesigned currency; and, raised tactile features may be added to redesigned currency, which would provide users with a means of identifying each denomination via touch.

More information is available at http://www.eyenote.gov/ or through email at eyenote@bep.gov.

More information can be found also at: http://www.bep.treas.gov/uscurrency/meaningfulaccess
Abstract: This article describes the Rose Project that provides free World Book Encyclopedia articles in Braille to blind children in grades 1-12.

Key words: Blindness, visually impaired, Seedling Braille Books for Children, literacy, education

We are very pleased to announce that Seedlings’ Rose Project received a grant from Delta Kappa Gamma which will allow us to continue to provide Free World Book Encyclopedia articles in braille to blind children grades 1-12.

Students from across the United States contact Seedlings via the web, by telephone or email and provide the subject(s) or topic(s) of interest for which they would like information. A staff member produces the articles and sends them to the student’s home or school, via UPS, free-of-charge within five business days.

Every year we have requests from new students and/or students that have recently been diagnosed as visually impaired. The Rose Project allows us to continue to fill a need in their lives so they can continue to grow and learn and become independent and successful individuals.

Seedlings Braille Books for Children is a non-profit, tax-exempt organization based in Livonia dedicated to increasing the opportunity for literacy by providing high quality children’s literature in braille. For more information on the Rose Project, or to request an article, please visit http://www.seedlings.org/rose.php or contact us at (800) 777-8552.

Seedlings Braille Books for Children
14151 Farmington Rd.
Livonia, MI 48154
www.seedlings.org
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.
An up-to-date Statewide Staff Development Calendar is posted at www.tsbvi.edu/Outreach/vi.htm.

Short-Term and Summer Programs at
Texas School for the Blind & Visually Impaired

The TSBVI department of Special Programs provides a range of short-term classes throughout the year for students in elementary through high school: during the school year (Short-Term Programs) and during the summer (Summer Programs).

Short-Term Programs (Sep-May)
Classes of 3-5 days duration designed to provide Expanded Core Curriculum to students functioning at or close to academic grade level.
These students typically take regular TAKS (or accommodated) and typically passed at least one test.
Requires referral from local school district, usually the teacher of the visually impaired.
All costs covered by TSBVI, including transportation
How to Refer” described at: http://s22318.tsbvi.edu/special/InterestForm_J.asp

Summer Programs (Jun-July)
Wide range of classes for students -- on academic grade level through Life Skills curriculum levels and all levels in between.
Classes range from 1-5 weeks.
All costs covered by TSBVI, except transportation which is not provided
Referral from local district preferred but not essential
Applications available online January 9 – February 14: http://s22318.tsbvi.edu/special/Login.asp

For additional information go online at: www.tsbvi.edu

Or contact: Lauren Newton, principal newtonl@tsbvi.edu 512-206-9119
Teaching Braille Music
Sharon Nichols, Outreach Technology Consultant, and Brian Sobeck, BA in Music Composition
December 1, 2011 at the TSBVI Outreach Conference Center

Want to help your student learn to read braille music? This hands-on workshop will provide you with strategies and resources for doing just that. Audience: Teachers of the Visually Impaired (TVIs), Music Teachers.

Interesting Facts About Skin and the Importance of Good and Safe Touch in Brain Development
Gigi Newton, Early Childhood Consultants, TSBVI Outreach Program
January 13, 2012 at the TSBVI Outreach Conference Center

Studies have shown how important good and safe touch is for an infant’s survival, growth, and development both emotionally and physically. Information will be shared why good and safe touch is vital for all human beings and what techniques promote this type of touch. Audience: Early childhood instructors, Teachers of the Visually Impaired (TVIs), Teachers of the Deaf, Certified Orientation and Mobility Specialists (COMS), parents.

Assessment of Students with Visual Impairments: New Tools, Successful Strategies
Marnee Loftin, Psychologist, Texas School for the Blind and Visually Impaired
January 20, 2012 at the TSBVI Outreach Conference Center

Blindness is a very low incidence disability area, and most evaluation staff have irregular opportunities for assessing students with visual impairments. Time-tested tips and strategies will be shared. A new braille edition of the Woodcock Johnson and a new tool from Dr. Joan Chase offer improved options. Audience: School psychologists, Diagnosticians, TVIs.

Save the Dates

TAER/Texas Focus
March 29-30 and 30-31, 2012
Omni West Hotel, Houston, TX

This year, in an effort to make both events more convenient and cost effective, TAER and Texas Focus have collaborated to host a combined conference. A single registration site is established so you may opt to attend all or part of the event and pay accordingly.

More information and online registration will be available later this fall on the websites for either TAER <www.txaer.org> or TSBVI Outreach Programs <www.tsbvi.edu/outreach>.
TX SenseAbilities

Published quarterly: February, May, August, and November

Available in Spanish and English on TSBVI’s website at <www.tsbvi.edu>.

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

Items to be considered for publication should be submitted by email to the section editors at the addresses listed below, or mailed to:

TSBVI Outreach
1100 West 45th Street
Austin, Texas 78756

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

The audio version of TX SenseAbilities is provided by Recording for the Blind and Dyslexic, Austin, Texas,

This project is supported in part by the U.S. Department of Education, Office of Special Education Programs (OSEP). Opinions expressed herein are those of the authors and do not necessarily represent the position of the U.S. Department of Education. TSBVI Outreach Programs are funded in part by IDEA-B Formula, and IDEA-D Deaf-Blind Federal grants. Federal funds are administered through the Texas Education Agency, Division of Special Education, to the Texas School for the Blind and Visually Impaired. Texas School for the Blind and Visually Impaired does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.