TX SenseAbilities

A PUBLICATION ABOUT VISUAL IMPAIRMENTS AND DEAFBLINDNESS FOR FAMILIES AND PROFESSIONALS

Photo: Musical Chaos by Zach

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TX SenseAbilities is a collaboration of the Texas School for the Blind and Visually Impaired and the Texas Health and Human Services Blind Children's Vocational Discovery and Development Program (BCVDDP)

Capturing the Beauty of Jayana

Shawn Piantoni, *Professional Photographer*

Abstract: A photographer describes her work in the field of DeafBlindness and the experience of doing a photo-shoot with Jayana, a young woman with albinism.

Keywords: Family Wisdom, visual impairment, photography, albinism

I have worked in the field of sensory disabilities starting when I was 12, as a volunteer at Easter Seals. After that, I worked as an Independent Living Specialist, Interpreter, Job Coach, and Technical Assistant Specialist with the The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC, which is now known as National Center for Deaf-Blindness) until I received my doctorate in Special Education and Sensory Disabilities in 2010. I now live in the Bahamas and travel internationally as a photographer. I am interested in working with families who have children with disabilities to capture the beauty they see in their children. I remember attending family workshops when I was with NTAC and the parents talking about a lack of photographs of children with sensory disabilities. This has always stayed with me and I would love to give back to the community I love!

In February, I reached out to both Edgenie Bellah, Family Engagement with the Texas DeafBlind Project, and Kathi Garza, a TVI with the Short Term Programs at TSBVI, with an opportunity for an individual with Albinism to be photographed by the award winning and internationally recognized Dutch photographer, Gemmy Woud-Binnendijk, as well as 16 other professional photographers from around the United States. As I am a long-time educator and advocate for children with sensory disabilities as well as a photographer, I wanted this to be more than a photo-shoot. I felt this could be a unique opportunity to contribute to the awareness and understanding about individuals who have albinism, using an art form that Gemmy and I hold deep in our hearts. Gemmy has photographed both children and adults with albinism before. I encourage you to view her work at https://www.gemmywoudbinnendijk.com.

We were thrilled when Jayana's mom Angela responded and said they could meet us at Railyard Studio, owned by David Parish, in El Paso, Texas.

When Jayana arrived at the studio, her nervousness was natural considering that it was her first time to model! She sat down with the makeup artist, Nadia Veenhoff, and was transformed into a little girl straight out of an old master's style painting. She became a confident young lady in front of the cameras, showing such beauty and natural talent. It was wonderful to watch her glowing smile! I am very pleased to say that Jayana's images have since been published internationally in Practical Photography magazines as well as international digital magazines.

Jayana and Angela's willingness to spend two days with us reached the outcome we had hoped for. Jayana had a unique and memorable experience. Her participation

has encouraged photographers and others to ask questions about albinism, as well as provided us with a forum to educate other photographers regarding how to photograph individuals with albinism without causing harm. Due to the lack of pigment in the eyes, any flash photography can be extremely harsh on the eyes. This is very important to understand. We asked Jayana to communicate with us when she was comfortable or uncomfortable. The picture I took of Jayana is in natural light. She is looking away from the light and not directly towards it. This was also the case when using studio lights.

We are grateful to everyone in Texas who helped spread the word and ultimately connected us with Jayana and her family! Jayana modeled all day with my daughter and I think they struck up quite a friendship out of their experience. We look forward to future get-togethers and photoshoots. I am also certain Jayana's talent will bring her more opportunities to model!

Professional photograph of Jayana by Shawn Piantoni. Jayana stands in an off-white gown on a wood floor in front of a plain, off-white wall.

After Graduation Happenings in the Life of a DeafBlind Young Lady and Her Mom

Becky Harmon, DBMAT Secretary, Ft. Worth

Reprinted with permission from In-Touch, the Deafblind Multihandicapped Association of Texas Spring 2018 Newsletter

Abstract: Becky Harmon shares her experiences of building a good life for her daughter who is a young adult.

Keywords: Family Wisdom, adult life, DeafBlind, community involvement

We are hanging in there! That's what I say when anyone asks about us since Kersten's graduation. This first year after graduation has been challenging but I figured it would be, especially since I retired from teaching (wow-31 years) at the same time to be able to take care of my daughter. Kersten has liked being at home with me, but it has been really frustrating to wait for her to do things since her last year of school. I just think of it as "Kersten time" instead of "DeafBlind time." She was really ready for school to be over! However, now she thinks that staying home is really cool and we really don't need to do or go anywhere! NOT! We have places to go and people to see. But an occasional afternoon nap is really very nice. Just sayin'...
I do think this year would have been better if I had someone who could help out.
So far, I have not been able to find anyone to work with her. Usually I find someone

Photograph of Kersten and Becky Harmon, both smiling at the camera.

from Camp Summit but this year it didn't work out. I just need someone for about 3 days a week and I can work with their schedule. I just haven't found the connection yet. I wish more signers were around our area. This is one of if not THE biggest concern and hurdle for parents: finding good help, AKA INTERVENERS!

I have signed her up for every available Camp Summit. I know she loves it, she's safe, and I get a little break from being with her…or maybe I should say she gets a little break from being with me.

She spent spring break at Camp Summit. I think she may have had withdrawal from not having her iPad for the week because of her focus (obsession) with Olympic ice skating, and of course she loves Mako Mermaids videos.
We are going to Heather's Old Skool Village in Lake Worth two days a week. It is a really unique Day Hab. She gets to hang out with kids her age and older. She plays Wii frisbee golf and bowling and usually is the best at both. It's pretty funny when she beats the boys! We work on crafts together, eat lunch, and enjoy dancing to music. Most of the activity is outside. They always have something going on! I stay with her since they don't have anyone that signs. I think they feel comfortable with her now so I may start leaving her for a short time and run an errand or two since there are several places around there to shop. She signs "school" when we talk about it. We use an app, FTVS HD (First Then Visual Schedule HD), for her daily calendar routine. She also looks at the larger calendar on her iPad. I have marked off when we have appointments and when she goes to her Dad's. For some reason she doesn't want to use the very large paper calendar from TSBVI. That's okay since the iPad is so much more portable.

I never thought about going to a Day Hab after retiring but I feel blessed to be there with Kersten. I still get to help out as a teacher by helping the others learn how to communicate and interact with her.

In the Fall I was very busy finishing my Intervener Practicum at Utah State with Linda Alsop. Documenting each of the many standards was challenging for me since I am not assigned to a specific school/teacher. I finally submitted the required portfolio so I'm just praying I pass! The Day Hab helped with providing some activities I could use for my practicum. I wish I could have done this when she was younger. I learned so much!

I want to get a better exercise program going so we have a gym membership in the works. If enough people sign up from Heather's Old Skool Village, the gym will set up a program for them. I'm looking forward to seeing what they have since Kersten is probably getting tired of jumping on the little trampoline. This has been a good routine because there is a counter that helps challenge her to increase her jumps each time.

Well, I hope you got a little taste of what we have experienced since graduation. Setting routines, no matter how small, with lots of "DeafBlind time" has helped us survive without killing each other!

Support Service Provider (SSP) Bills

Heather Lightfoot Withrow, DBMAT Board Member, Austin

Abstract: This article describes the legislative activity and community advocacy concerning the provision of Service Support Providers to people who are DeafBlind.

Keywords: Family Wisdom, Leadership, Legislation, Individualized Services for People who are DeafBlind, Service Support Providers

The state of Oklahoma has captured our attention with their governor, Mary Fallin, signing House Bill 1244 into law on April 30, 2018, also known as the Jeri Cooper Act. This is the latest and most successful of the few instances of legislative action on the state level in the past year to pass a bill to establish a support service provider program for people in their state who are DeafBlind. The other two bills are Texas' SB 1997 which died in committee and Pennsylvania's HB 2069, which is currently active in legislation with a proposed appropriation of $250,000 for a single fiscal year (H.B. 2069, n.d.).

Oklahoma's Jeri Cooper Act directs the state Department of Rehabilitative Services to establish a support service provider program, define its services, establish certification and training, and award funds through a grant application procedure. The total awarded grants cannot exceed $300,000 annually (Oklahoma H.B. 1244, 2018). While Oklahoma plans to fund their program via their Department of Rehabilitative Services, other states with established SSP programs fund them through different state departments and disbursement methods.

Today, Texas does not yet have an SSP program like our neighboring states to the north, west and east of us.

In January 2017, Texas Governor's Committee on People with Disabilities (GCPD), after hearing trends in community concerns regarding the lack of a funded SSP program and voting to recommend supporting this need, published a detailed report on SSPs and the Committee's recommendations to support this (Texas Governor's Committee on People with Disabilities, 2017).

Last year, Texas Senate Bill 1997: Pilot Program for Professional Support Service Providers for Persons who are DeafBlind was filed by Senator Kirk Watson on the last day to file: March 10, 2017 (SB 1997, n.d.). Many local DeafBlind adults, SSPs, and friends were elated with the successful filing because as a group, they've not gone that far before. However, the bill "died" in the Senate Health and Human Services committee. The DeafBlind community will need to work on having the bill ready to be filed in late fall before the upcoming 86th Legislative Session that begins on January 8, 2019. Many of us who were actively work-

ing on this last year learned lessons, and have developed materials that are ready to go the next time around. We know we must start earlier, way before the next legislative session begins, so the bill has months to move through our legislative system.

A lesson learned was that there was not enough community understanding of the distinct differences between an SSP and an intervener; how they're important, yet different skill sets support DeafBlind people, depending greatly on what the needs were. We need to create opportunities to clear up this perceived ambiguity. Perhaps this would happen through community dialogue, demonstrations, presentations and articles in the not-too-distant future.
In April 2018, the Texas Governor's Committee on People with Disabilities sent a recommendation to Texas Health and Human Services Commission (HHSC) to consider including funds in their upcoming legislative appropriations request (LAR) for supporting an SSP program. Regardless, the SSP bill filings must happen in case, in case, in case.

An email listserv regarding this bill was used last year and I'm confident that this listserv will be used for community communications regarding the new SSP bill(s). In addition to learning the latest on SSP issues in Texas, this forum is one way to learn about how to participate in efforts to educate our legislators on the needs of autonomous DeafBlind adults in our community. To visit this group, go to https://groups.google.com/a/txssp.info/group/listserv/. The direct link to join this group is https://groups.google.com/a/txssp.info/forum/#!forum/listserv/join.
A website called "TX SSP", http://txssp.info, has links to the same group as well as talking points, a downloadable text of SB 1997 and video testimony by Kim Powers, a DeafBlind leader in Austin.

I know we want to support access to services and interaction in the community for ALL Texans who are DeafBlind

References

H.B. 2069. (n.d.). Retrieved from Pennsylvania General Assembly: http://www.legis.state.pa.us/cfdocs/legis/PN/Public/btCheck.cfm?txtType=HTM&sessYr=2017&sessInd=0&billBody=H&billTyp=B&billNbr=2069&pn=3393

Oklahoma H.B. 1244. (2018). Retrieved from Legiscan: http://webserver1.lsb.state.ok.us/cf_pdf/2017-18%20ENR/hB/HB1244%20ENR.PDF

SB 1997. (n.d.). Retrieved from Texas Legislature Online: https://capitol.texas.gov/BillLookup/History.aspx?LegSess=85R&Bill=SB1997 (cont.)

Texas Governor's Committee on People with Disabilities. (2017). A Report on Support Service Providers (SSP). Retrieved from https://gov.texas.gov/uploads/files/organization/disabilities/SSP_Report_FINAL_011817.pdf

Texas legislative sessions and years. (n.d.). Retrieved from Legislative Reference Library of Texas: http://www.lrl.state.tx.us/sessions/sessionYears.cfm

SSPs for DeafBlind Texans

A Wide Spectrum of Scenarios Needs a Variety of Service Options

Vivecca Hartman, DBMAT President, Houston

Abstract: This article explores how people who are DeafBlind access their education and learn about their communities with assistance from specific service providers.

Keywords: *Family Wisdom, DeafBlind, Individualized Supports, Interveners, Service Support Providers*

What is it like to be DeafBlind? Well, that is a great question with a wide spectrum of responses based on individual scenarios. The constant amongst all individuals who are DeafBlind seems to be that DeafBlindness is a disability of access - access to visual and auditory information about people and things in the environment. Variations in the functional use of hearing and vision and other circumstances result in an array of services and support needed for each individual.

Parents of a new baby will experience shock with the realization that their child has a sensory impairment, let alone two. Very early on, these families and the professionals who work with the children need to make sure support and adaptations are available. This ensures that the student can access and take advantage of educational experiences. In this scenario, these strategies will continue to work into adulthood. Another scenario involves students who may have gone through their school years using their vision and hearing well enough to fully access educational experiences and then experienced changes in their vision or hearing later in life (i.e. near adulthood). This time of change can often be emotionally challenging for individuals who are DeafBlind and those who care about them. These are just two scenarios, but they are examples illustrating the wide variety of needs amongst our greater population of people who are DeafBlind.

On one end of the spectrum, babies who had an early onset of the dual sensory loss usually have trouble participating fully in their education. They will likely need an Intervener to support them while they are developing communication skills and learning enough life skills to make healthy choices. For example, an Intervener in the classroom can help the individual who is DeafBlind have access to clear and consistent visual and auditory information while developing their mode of communication in a reliable and trusted manner. The Intervener is also there to help support the individual who is DeafBlind with social and emotional well-being (i.e. making connection with friends on the playground and supporting the student when frustrated due to missing information).

A Community Intervener is doing much of the same access support to build independence and social communication skills, just in a different setting. This can be done by

building upon routines within the home, learning to make choices, and actively participating in self-care and domestic activities, such as meal time. Access to the community helps an individual who is DeafBlind build confidence. By going out with a trusted Intervener who provides guidance and support, they can have access to their best mode of learning, which is typically more hands-on. A person who is DeafBlind often has difficulty accessing information incidentally, or by simply observing others. They learn best with opportunities to touch and feel in order to experience things first hand. This takes time and must be led by a person they can trust, who can communicate effectively in their preferred mode of communication, and who can provide the time it takes to access information tactually. Some people who are DeafBlind continue to need this kind of support from an intervener in their adult years.

On the other end of the spectrum, there are many adults who are DeafBlind whose educational experiences have resulted in the knowledge and self-determination skills required to build a high level of confidence, self-direction and independence. For example, they may have lost their vision and hearing after their educational years or late enough in their educational career that they had already developed a fully established mode of communication, including the ability to make healthy choices on their own. These individuals often desire to be active in their communities and productive members of society. However, they also need supports to enable them to access information and the environment. What is required from another person is information gathering and communication access in an unbiased manner at the direction of the individual who is DeafBlind. A Support Service Provider (SSP) can provide this support. An SSP can facilitate communication between the person who is DeafBlind and those around them, allowing them the opportunity to interact with others. In addition, the SSP can provide safe and efficient orientation and mobility when navigating the community. The SSP respects personal boundaries, the individual's choices and their direction. The end goal is for the Deafblind individual to be able to enjoy life with greater independence.

With the opportunities a well-trained and effective Intervener provides during the educational years, my hope would be that a baby born on one end of the spectrum may get to the other end of the spectrum and only need the supports of an SSP into adulthood. Whatever the history and current situation may be, it is hoped that every person who is DeafBlind has access to the right support that meets their individual needs and goals.

Image: http://deafblind.ufl.edu/2017/05/26/support-service-providers-training-programs/

DBMAT- Early days to the Present

By Pat McCallum, Former DBMAT President

Abstract: The author shares the history the Deafblind Multihandicapped Association of Texas (DBMAT) and how they worked together to build services for individuals who are DeafBlind.

Keywords: Family Wisdom, DeafBlind, Family Organization, Systems Change, Advocacy, Education, Adult Services

Editor's Note: The following article was part of the May 2007 In-Touch issue, which is the newsletter for the Deafblind Multihandicapped Association of Texas family organization. It was edited from a National Parent Network 1991 Monograph by Steve Schoen. The National Parent Network is now known as the National Family Association for Deaf-Blind. DBMAT is an affiliate network member. We thank DBMAT for permission to reprint this article in Texas SenseAbilities.

The world-wide rubella epidemic, 1963-1965, wreaked havoc on many Texas families. Our story began with the birth of our children who are deaf-blind. At first, families struggled virtually alone with the severity of their pre-schoolers' disabilities while randomly seeking assistance. Then the Texas Education Agency (TEA) brought parents together for a series of annual conferences entitled Parent Education Project (PEP). Over 200 moms and dads were provided a vehicle through which they compared notes, commiserated, problem solved and bonded together. By 1974, with the encouragement of TEA, parents established a by-laws committee to create a mission statement and a set of guidelines for a parent support group. In 1976, we became an "official" non-profit organization with the name of Deafblind Multihandicapped Association of Texas (DBMAT).

Our early goals were geared towards ensuring the appropriate provision of educational services to our children. Parent education in understanding their child's disabilities and training in self-advocacy were also primary goals of DBMAT. As our children began to mature, the group's focus naturally expanded to include services beyond school. The parents of DBMAT considered which services were needed for adults. A decision to advocate with state agencies for quality and appropriate programming for our children was made. We wanted our family members to have a place to live, a place to work, a place to socialize and recreate and a place to receive medical care within our own communities.

DBMAT represented parent's views in a study group comprised of representatives from each state agency serving people who are deafblind and Helen Keller

National Center (HKNC). This led us to the establishment of the Interagency Task Force for Future Services to Deaf-Blind. The purpose of the task force was to work together to improve services in Texas for persons who are deafblind. This task force has continued to meet regularly since 1979. It is a clearinghouse for information, identifies service gaps, holds open discussions on issues, problem-solves and plans for improvements in the service delivery systems.

We parents were novices in the political game. Parents knew what they wanted for their children… they did not know how to get it. We brought our concerns regarding the future to the Interagency Task Force. While we explained our deaf-blind and multihandicapped children to them, the agencies informed us about their systems. They were empathic but not eager to "jump-in" with services without a legislative mandate. DBMAT developed a legislative initiative.

The Texas Commission for the Deaf (TCD) was willing to help us maneuver through the complicated legislative process. Their new Executive Director was willing to take our request to their Board for approval. Now we had our lead agency!

Simultaneously, DBMAT approached some legislators seeking a sponsor for our proposed bill. We found a newly elected and first-time congressman who agreed to help us. Coincidentally, his name was Keller! Instinctively, we made many of the right moves. Our membership wrote letters to each legislator about their children and their needs, seeking support for our legislative endeavor. We held an open house for legislators and agency personnel at the Deaf-Blind Annex to the School for the Blind. We testified at Human Services committee hearings both in the Texas House and Senate. We spoke as one voice with a single purpose – to create small group homes in Texas for persons who are deaf-blind and multihandicapped to enable them to continue learning functional living skill while accessing the community.

Our first legislative endeavor was discouraging. Although TCD received the mandate, no money was appropriated by the legislature to establish the services. During our annual conference, which immediately followed the close of the legislative session, Congressman Keller gave the membership a congratulatory pep talk. He encouraged us to continue our momentum into the next biennium. We took his advice and educated legislators regarding the needs of our children who are deaf-blind during their hiatus. We maintained our strong relationships with TCD, CTD and the Task Force. We geared up for the next session.

Additional activities took place during the interim. TCD conducted a statewide survey to locate persons who are deafblind. DBMAT gathered information from the TEA Pilot Project justifying the viability of group home living arrangements for persons who were lower functioning. This information was included in our legislative package.

On the advice of an individual who was close to the governor, DBMAT requested a Governor's Study on Deaf-Blindness. This study gathered pertinent data on needs vs. service delivery. Consumers, parents, siblings and service providers testified at a hearing conducted by the

(cont.)

DBMAT- Early days to the Present–continued

Governor's Committee for Disabled Persons. Statewide awareness and additional support for our cause was evident at this time. We had momentum!

During the legislative session, we wrote letters once again and testified at hearings. We brought our children with us for visibility. On the final day of this second session, through the tenacity of Congressman Keller, monies were appropriated from a portion of the prison system budget to establish the Deaf-Blind Program! As a low incident disability group, we had succeeded with the help of our friends. Our hope became a reality for our children.

In 1982, TEA established a "group-home living" pilot project in Dallas for students who were deaf-blind and severely multihandicapped. Six young men ages 15-19 resided five days a week in a converted two-story apartment with round-the-clock staffing. On weekends, the residents visited their parents' homes.

This three-year project set the precedent for establishing group home community-based living for individuals who are deaf-blind and multihandicapped within our state. Not only did the group home overcome community biases, but it also proved that these young men could improve their skills considerably by residing in a natural environment.

Another valuable component was ongoing parent counseling which allowed these families to share their concerns, fears, hopes and tears with each other in a supportive environment. Separation from a child with special needs, for whom you have been the primary caregiver, isn't easy. The counseling helped ease the separation pains these parents would experience as their children entered the adult service arena.

With the passage of the legislation and consequent funding, the first adult group home opened its doors in Dallas during the fall of 1984. Shortly thereafter, a group home in Houston was established. Both residences were funded from the state coffer with supplemental dollars from the Title VI-C federal dollars for those residents under age 22.

During the 1985 legislative session, it was decided to move the programs from TCD to the Texas Rehabilitation Commission (TRC) for the next funding cycle. Parents were concerned that deafblindness would take a back seat within the realm of a large rehabilitation agency. We voiced our concerns to legislators and the agency, both of which reassured us that this move would be positive and provide additional services. The third group home was established in San Antonio in 1987.

Postscript---Over time, more group homes were established. In 1995, the group homes were made part of a statewide Medicaid Waiver for people who are DeafBlind with multiple disabilities. DBMAT has played a key part in planning and implementing this program (the only one of its kind in the country) which is now run by the Texas Department of Assistive and Rehabilitative Services.

How Does an Intervener Differ from a SSP

National Center on Deaf-Blindness Home and Community Intervener Workgroup

Editor's Note: The following is an excerpt from Interveners in the Home and Community: An Under-Recognized Imperative, which was written by the National Center on Deaf-Blindness Home and Community Intervener Workgroup (2014). We are sharing this with our readers to provide more background information on individualized services for people who are DeafBlind. To read the entire document, please visit https://nationaldb.org/library/page/2458

Like interveners, support service providers (SSPs) are an emerging support service for individuals with deaf-blindness in the United States (Bourquin, et al., 2006). SSPs provide support in accessing communication, information, and environments at the direction of the person with deaf-blindness, who is the decision-maker in the relationship. The SSP model is designed for people who are deaf-blind and have the skills, abilities, maturity, and experience to independently provide direction to the SSP. The primary roles of an SSP are to provide transportation (e.g., by car or bus and as a human guide while walking) and to relay "visual and environmental information that may not be heard or seen by the person who is deaf-blind" (Bourquin, et al., 2006). A typical SSP assignment might include providing the support a person needs to fully enjoy a social event—for example, providing transportation, describing the scene and the people, and facilitating activities like mingling, getting refreshments, finding a place to sit, and participation in games. In addition to social occasions, SSPs provide support for activities like meetings, doctor's appointments, banking, shopping, travel, and reading mail.

While SSPs and interveners both provide sensory access to guide and facilitate communication, interveners provide support in many additional ways that SSPs traditionally do not. Interveners assist in the home and community by performing activities with, rather than for, the individuals they are supporting. Some people who are deaf-blind may not be comfortable with or capable of self-direction because of additional disabilities, youth, or lack of experience. These individuals may not be able to plan and initiate activities, or they may not have the knowledge and experience to take the lead and make decisions. In these cases, the intervener's role is to provide the initiation and direction needed so that the person can have more opportunities for meaningful and satisfying experiences with preferred activities. This may include assistance with making decisions if the person is unable to do so successfully on his or her own and teaching new skills to increase independence.

NCDB National Center on Deaf-Blindness

Deafblind International Network of the Americas Conference Reflections

Molly Roberts, Texas Chargers Board Member, and **Becky Harmon,** DBMAT Secretary

Abstract: Two Texas family leaders share their experience at the first Deafblind International Network of the Americas Conference held in Hyannis, Massachusetts April 15-18, 2018

Keywords: Family Wisdom, DeafBlind, Texas family leadership, Deafblind International, Perkins School for the Blind

Editor's Introduction

In April, DeafBlind individuals, family members, and professionals from across the Americas and globe descended on the beautiful Cape Cod town of Hyannis for the first-ever Network of the Americas Conference. This extraordinary event was hosted by Deafblind International (DbI) and Perkins School for the Blind with support from the National Family Association of Deaf-Blind and the Cape Cod Chamber of Commerce. The theme, Partnerships for lifelong learning was lived out during our week together

Molly Roberts, Djenne-amal Morris, and Kathi Barksdale having fun at the NFADB Mary O'Donnell Family Social

The introduction within the conference program captured the experience perfectly.

> *We're all stronger when we work together. By partnering as educators, service providers, consumers, policymakers, advocates and family members, together we can offer a lifelong array of support for the deafblind community – spanning from early intervention and K-12 education to programs, services and products for adults.*

The conference was dedicated to Dr. Jan van Dijk with these poignant reflections:

> *Dr. Jan van Dijk, who, by example, inspired us to truly seek to understand children with deafblindness. He was a masterful teacher who never failed to magically capture the interests of the children and engage with them in meaningful communication.*

Of the 400 plus participants, there were numerous self-advocates, family members and professionals from Texas. Many Texans were there in leadership roles by serving

as keynote speakers, breakout presenters, and representing various organizations. Following are reflections from two Texas family leaders who helped make Texas shine bright on an international stage.

Molly's Reflections

The theme of the first ever DeafBlind International (DBI) Conference was Partnerships for Lifelong Learning. The conference took place April 15-18, 2018 in Cape Cod, Massachusetts. It had an impressive representation of people from all over the world including state DeafBlind projects, organizations for families, educators, parents and individuals with DeafBlindness.

I had the opportunity to attend the DBI conference in two capacities, board member of Texas Chargers, Inc. and as a parent of a child who is DeafBlind. This allowed me to seek out a range of topics that applied to my particular child and those that might apply to families I encounter on a regular basis.

The experience, knowledge, and resources present were incredible. It made it difficult to choose which session to attend yet reassuring that each one would be beneficial. Topics ranged from infancy to adulthood, functional to academic skills, transition services, vocational training, parent support and many more.

While there, many conversations were started about educating our communities for the benefit of people with DeafBlindness. My own community increased tenfold from new connections with other parents, professionals and organizations. I then returned home, energized by the people I met and the

(cont.)

Texas Family Leaders and two honorary Texans take a group photo at the NFADB Mary O'Donnell Family Social.

Molly's Reflections–continued

information shared, poised to help build a bolder future for those with DeafBlindness.

I am so grateful for the opportunity to attend the DBI conference. Also, I am excited to say that once back home those conversations were continued and we have already started educating our immediate community.

I am always amazed by how the common thread of DeafBlindness binds people together as if we were family. Where all people say, "of course", in the pursuit of an authentic connection for those who are DeafBlind. The people I met at the DBI conference, the connections I made, and the resources I returned home with are priceless.

Becky's Reflections:

I had a wonderful experience attending the DbI Network of the Americas Conference as a NFADB scholarship recipient. I met so many DeafBlind parents as well as other family members and professionals who work with DeafBlind individuals from all over the world. Just to name a few…several from different parts of Africa, Norway, Australia, as well as Vermont, New Jersey, New York, Massachusetts, Utah, Oklahoma, and of course, Texas where I'm from.

There were so many of us from Texas. Most people were probably thinking they were invaded by us all! However, I believe people from Texas have a wonderful reputation of making issues of DeafBlindness important within our state. We are a very large state with over 700 DeafBlind individuals identified. We have the Texas School for the Blind and Visually Impaired that has ever changing ideas in the field of DeafBlindness, including an Outreach Program that works with parents and other organizations and professionals to increase awareness of issues.

Then we have an organization, DBMAT (DeafBlind with Multiple Disabilities Association of Texas), made up mostly of parents that work to legislate for the rights of their DeafBlind children, including the important issue of Interveners so that their children will have a connection to the world they live in.

Yes, I have to admit, I'm a little proud to be from Texas. Especially when I sat in and listened to the different sessions. The one that stands out the most was with Robbie Blaha and Matt Schultz. Robbie explained her history with the DeafBlind beginning with the Congenital Rubella Syndrome epidemic and how she realized she would have to change the way she was teaching these unique children and how she had to adapt to their individual ever changing needs. Matt and Robbie stressed how the needs of DeafBlind individuals are still changing and professionals need to communicate together to come up with new ideas. They recommended a forum for professionals to come together and discuss how DeafBlind issues need to be addressed for each student since they now need to be more fine-tuned, so to speak, because they are very different from the Rubella cases in the beginning. There are specific challenges finding what each child needs and professionals must be aware and able to advocate for more specific IEP's. Yes, I know there were other sessions but this one made me really proud to be from Texas while at Hyannis, Massachusetts.

Kathi Barksdale and Molly Roberts holding up cartoon lips and glasses in front of the NFADB banner

: Kathi Barksdale, Edgenie Bellah, and Molly Roberts smiling while standing on the beach in front of the Kennedy Compound

Four family leaders posing for a picture at the NFADB Mary O'Donnell Family Social

Controversies Surrounding Vision Therapy

Dr. Kitra Gray in collaboration with Region 11 ESC and TSBVI, January 2018

Abstract: Dr. Gray examines issues regarding vision therapy.

Key Words: vision therapy, controversy, vision training, visual training, developmental vision therapy, orthoptics, behavioral vision therapy, visual attention, binocular vision, optometric vision therapy, learning disabilities, dyslexia, related service, Local Education Agency, LEA.

If you have ever tried to find definitive answers regarding vision therapy, you might have been met with:

- Vague responses
- Inconsistent responses, depending on the source
- Emotional responses regarding whether vision therapy is a viable educational option or
- Conflicting responses regarding research and benefits of vision therapy.
- As we know, programming for children with disabilities must be addressed individually based on their own set of needs and criteria. This article will explore the controversies surrounding vision therapy and provide information so that when the topic of vision therapy arises in regards to a child, you will be knowledgeable enough to know what questions to ask, and how to interpret the answers.

Definition of Vision Therapy

The first area of controversy is understanding what is meant by the term vision therapy. Vision therapy is known by several names, including visual training, vision training, and developmental vision therapy. Some optometrists divide vision therapy into two categories. The first is *orthoptics*, which focuses on binocular vision including disorders such as strabismus and diplopia, also known as double vision. The second area is *behavioral vision therapy*, which addresses problems such as “visual attention and concentration which may manifest as an inability to sustain focus or to shift focus from one area of space to another” (Allegheny Intermediate Unit. n.d., para 3). The College of Optometrists in Vision Development (COVD, 2008), a non-profit, international membership association of eye care professionals including optometrists, optometry students, and vision therapists, does not differentiate between orthoptics and behavioral vision therapy, but simply addresses the practice as Optometric Vision Therapy. Thus, you may be confronted with any of these identifiers when someone refers to vision therapy.

No matter what identifiers are used, the overall definition of vision therapy is fairly consistent. Optometric Vision Therapy is an individualized, supervised, medically neces-

sary treatment program that is prescribed by an optometrist using neurological and neuromuscular conditioning over time to address visual dysfunctions, prevent the development of visual problems, or enhance visual performance to meet the patient's identified needs. (Hatton, D., n.d.; COVD, 2008, p. 1) "Vision therapy trains the entire visual system which includes eyes, brain and body" (Optometrist Network, 1996-2007).

What deficits does vision therapy treat?

The second area of controversy, or confusion, is what deficits can be appropriately addressed by using vision therapy treatments. The only treatment area that appears to have wide reaching consensus among optometrists, as well as ophthalmologists, is convergence-insufficiency which includes symptoms such as double vision and eye fatigue. The following citations substantiate that vision therapy can be beneficial in treating convergence-insufficiency:

- According to Dr. Jose, a well-respected Texas optometrist in the area of low vision, "symptomatic convergence insufficiency can be treated with near-point exercises, prism-convergence exercises, or computer-based convergence exercises (Jose, Rosner, & Cowan, 2012 p. 17)
- A study published in the Archives of Ophthalmology "found that a 12-week program of supervised, in-office vision therapy plus orthoptics produced a functional cure of convergence insufficiency in over half…the children with CI who received this treatment" (Heiting, G., 2017, para. 34).
- The American Association for Pediatric Ophthalmology and Strabismus (AAPOS) states that "orthoptic eye exercises as prescribed by pediatric ophthalmologists, orthoptists, and optometrists can be beneficial in the treatment of symptomatic convergence insufficiency" (AAPOS, 2016).

"Other than for strabismus and convergence insufficiency, the consensus among Ophthalmologists and Pediatricians is that visual training lacks documented evidence of effectiveness" (Allegheny Intermediate Unit, n.d., para.3). The website of the AAPOS (2016) states that:

- Behavioral vision therapy is considered to be scientifically unproven.
- There is no evidence that vision therapy delays the progression or leads to correction of myopia.

Yet, the COVD's "white paper" indicates that optometric vision therapy can significantly improve the following functional vision problems:

- Ocular motility dysfunction – eye movement disorders
- Vergence dysfunction – inefficiency in using both eyes together
- Strabismus – misalignment of the eyes
- Amblyopia – lazy eye
- Accommodative disorders – focusing problems
- Visual information processing disorders
- Visual sensory and motor integration
- Visual rehabilitation after traumatic brain injury which results in inefficient visual information processing (e.g., stroke). (COVD, 2008, para. 2).

Other deficit areas of discussion are whether vision therapy can treat learning disabilities or dyslexia. Dr. Jose indicates that through

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Controversies Surrounding Vision Therapy–continued

a number of studies, it has been determined that "readers with dyslexia have linguistic deficiencies rather than visual or perceptual disorders...Research has shown that most reading disabilities are not caused by altered visual function." Therefore "...the evidence does not support the concept that vision therapy or tinted lenses or filters are effective, directly or indirectly, in the treatment of learning disabilities. Thus, the claim that vision therapy improves visual efficiency cannot be substantiated" (Jose, Rosner, & Cowan, 2012, pps. 12,13,19). This is further corroborated by the AAPOS (2016) which notes that, "The scientific evidence does not support the use of eye exercises or behavioral/perceptual vision therapy in improving the long-term educational performance in children with learning disabilities."

In addition, Dr. Takeshita (2013), a pediatric optometrist in California who set up a foundation to assist children who are visually impaired after he lost his own sight, states that "Vision Therapy Does NOT:

- Cure medical conditions such as autism, attention deficit disorder or learning disabilities
- Strengthen eye muscles. Vision therapy increases the neuro-muscular innervation between the brain and the muscles of the eyes
- Eliminate the need for glasses" (p. 13).

While these sources concur that vision therapy cannot address learning disabilities, confusion persists for educators and parents, because other literature such as the COVD "white paper" indicates that:

"According to the American Optometric Association, 35% of all children with learning disabilities have visual problems. Specifically, at least 20% of individuals with learning disabilities have been found to have prominent visual information processing problems, and 15-20% of them have problems with visual efficiency skills (COVD, 2008, para. 8)."

The source used by the American Optometric Association is not specified and this information was written in 2008; whereas, Dr. Jose's and Dr. Takeshita's information is from 2012 and 2013 and the AAPOS statement is dated 2016. Nonetheless, you are probably beginning to see why there are very few definitive answers regarding vision therapy and why parents and educators may be confused as to the efficacy of this treatment method.

Is vision therapy a related service?

One factor that appears to be consistent in the literature regarding vision therapy is that it is a partnership between doctor, parent(s) and student. It is a prescribed treatment plan by an optometrist, or sometimes an ophthalmologist. As indicated by the COVD (2008), "Optometric vision therapy plans typically involve a programmed combination of office treatment and home therapy….As with most therapeutic treatments, the extent of the success is also linked to the patient compliance" (para. 5). Dr. Heiting (2017) states, "this therapeutic process…depends on the active engagement of the prescribing doctor, the vision therapist, the patient (and in the case of children) the child's parents" (para. 8).

According to IDEA "medical services" that are

eligible "related services" are those specific "services provided by a licensed physician to determine a child's medically related disability that results in the child's need for special education and other related services." 34 CFR 300.34 (c)(5)" (Special Education and Disability Rights Blog, 1970, para. 1). Since vision therapy is not necessary for diagnostic purposes, according to this definition it is not a related service under IDEA.

Furthermore, "the Supreme Court has adopted a bright line rule…, finding that medical services that can only be delivered by a physician are not related services and that health care support services, which can be administered by a person other than a physician are related services under the IDEA and therefore the responsibility of the school district See Irving Independent School District v. Tatro, 555 IDELR 511 (1984)" (Special Education and Disability Rights Blog, 2009, para. 2).

Therefore, as vision therapy is a service that has to be delivered by a qualified eye medical specialist, it does not appear to meet the definition of a related service.

What is the role of a Vision Therapist versus the role of VI Education Professionals?

Occasionally parents request that the teacher of students with visual impairments (TVI) or the orientation and mobility specialist (COMS) provide vision therapy without understanding that these education VI professionals are not qualified or certified to provide this medical therapy. Vision therapy is provided by Optometrists (most frequently), Ophthalmologists and certified para-optometric technicians. These eye care professionals "gain training (e.g. medical/optometric courses, clinical practicum, internship, residency, etc.) in optometric vision therapy" (Lawson, Lueck, Moon, & Topor, 2017, p. 5). They are trained to provide "medical treatment that involves neurosensory and neuromuscular activities" (Lawson et al., 2017, p. 4).

The VI education professionals are NOT vision therapists. They are education specialists trained to evaluate and provide services to IDEA eligible students with visual impairments in the school setting, not in a clinical setting. Sometimes parents, and even school personnel, mistakenly refer to the teacher of students with visual impairment as a vision therapist, but this is incorrect. They are teachers who have attended "an accredited university program, typically within a college of education" (Lawson et al., 2017, p. 2).

The role of the TVI as well as the role of the COMS are defined in the 2017 Guidelines and Standards for Educating Students with Visual Impairments in Texas. This document can be found on the Texas Education Agency (TEA) website at: http://www.tsbvi.edu/attachments/EducatingStudentswithVIGuidelinesStandards.pdf. According to these guidelines, some of the roles of Certified Teachers of Students with Visual Impairments (TVIs) and Orientation and Mobility Specialist (COMS) include:

- Assessment and Evaluation [regarding special education eligibility and educational programing]
- Direct Instruction in the Expanded Core Curriculum
- Supporting Educational Teams
- Administrative/Record Keeping Duties (Texas Action Committee for the Edu-

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cation of Students with Visual Impairments. (2017, p. 23-24).

In addition, a position paper regarding vision therapy, written by the Association For Education and Rehabilitation of the Blind and Visually Impaired (AER), Low Vision Division, explains that TVIs "are not trained to provide vision therapy services nor does vision therapy fall within the scope of the [TVIs'] professional responsibilities" (Lawson et al., 2017, p. 1). This statement is also true for Orientation and Mobility Specialist (COMS).

What is the Role of the LEA?

Of course, a child should be evaluated in all areas of suspected disabilities. The educational committee must consider evaluation information from a variety of sources (34 CFR§300.306(c)(i)) and not rely on a single source to determine eligibility. More information on eligibility for services as a student with a visual impairment in Texas is available in the Guidelines cited above, and the TEC 30.002.

Nevertheless, it is important to note that a recommendation for vision therapy by an eye medical professional does not automatically mean the student warrants an evaluation, or if evaluated, will meet IDEA eligibility criteria. An LEA should consider each case individually to determine the necessary steps to address a parent concern regarding vision therapy.

Summary

Most likely, vision therapy will continue to be controversial, or at the very least confusing to parents and educators alike because:

- there are no consistent identifiers
- the medical profession does not agree on which deficits can be addressed appropriately and
- people sometimes mistakenly refer to VI educational professionals as vision therapist without understanding the difference in focus and training.

However, the one thing that is not controversial is that since VI education professionals, TVIs and COMS, are not trained in optometric vision therapy methods, they do not play a role in the delivery of vision therapy. Their role is to evaluate and provide services for IDEA eligible students with visual impairments in accordance with the IEP.

References

Allegheny Intermediate Unit. (n.d.). BVISP FAQs, Vision Education or Vision Therapy? Vision Therapy vs Education of the Visually Impaired. [Word document]. Retrieved from http://www.aiu3.net/Level3.aspx?id=4128

Association for Pediatric Ophthalmology and Strabismus [AAPOS]. (2016). Vision Therapy. Retrieved from https://aapos.org/terms/conditions/108

College of Optometrist in Vision Development [COVD]. (2008). What is Optometric Vision Therapy? Retrieved from http://c.ymcdn.com/sites/www.covd.org/resource/resmgr/white_papers/9-_what_is_optometric_vt.pdf A "white paper."

FindLaw for Legal Professionals. Irving Independent School Dist. V. Tatro. (1984). Retrieved from http://caselaw.findlaw.com/us-supreme-court/468/883.html

Hatton, D. (n.d.). Visual Conditions and Functional Vision: Early Intervention Issues: Glossary. Texas School for the Blind and Visually Impaired [TSBVI]. Retrieved from http://www.tsbvi.edu/534-hatton-functional-vision/4627-functional-vision-module-glossary

Heiting, G., O.D. (2017). Vision Therapy for Children. Retrieved from http://www.allaboutvision.com/parents/vision_therapy.htm

Jose, R., Prof. Emeritus, Rosner, J., O.D., Cowan, C. (2012). 2012-13 Texas Focus, Vision Therapy-What is the Role of the TVI? [Word document]. Retrieved from http://www.tsbvi.edu

Lawson, H., Lueck, A. H., Moon, M., & Topor, I. (2017). The Role and Training of Teachers of Students with Visual Impairment (TSVIs) as a Special Educator and Why TSVIs Do Not Provide Vision Therapy Services. Retrieved from https://aerbvi.org/wp-content/uploads/2016/01/Low-Vision_AERBVI-Position-Paper-on-Vision-Therapy-5.4.17.docx

Position Paper from AERBVI, Low Vision Division.

Leagle. (2005). 413 F.Supp.2d 1322| Dekalb County School v. M.T.V. Ex Rel. (2005, August 19). Retrieved from http://www.leagle.com/decision/20051735413FSupp2d1322_11625/DEKALB%20COUNTY%20SCHOOL%20v.%20M.T.V.%20EX%20REL

11 Circuit Court Case

Musgrove, M. (2014). Office of Special Education Programs, Letter to Kotler. (2014, November 12). Retrieved from https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/acc-13-020197r-md-kotlereligibilitycriteria.pdf

Optometrist Network (1996-2007). What is Vision Therapy or Visual Training. Retrieved from http://www.add-adhd.org/textonly/vision_therapy_FAQ.html

Optometrists Network is a network of interconnected patient education resources and optometric websites which educate the public about visual health and unique aspects of optometric care.

Special Education and Disability Rights Blog: A2Z Educational Advocates (2009). Related Services: Medical Services. Retrieved from http://a2zeducationaladvocates.blogspot.com/2009/08/related-services-medical-services.html

Takeshita, B., O.D. FAAO FCOVD (2013). 2012-13 Texas Focus, The Neurophysiology of Reading with Low Vision [Word document]. Retrieved from http://www.tsbvi.edu

Texas Action Committee for the Education of Students with Visual Impairments. (2017). 2017 Guidelines and Standards for Educating Students with Visual Impairments in Texas. Retrieved from http://tea.texas.gov/Curriculum_and_Instructional_Programs/Special_Education/Programs_and_Services/Sensory_Impairments/Sensory_Impairments/

Now THAT'S Teamwork! My Experience as Part of the Developing District Capacity in Active Learning (DDCAL) Team

Emily Morlandt, Education Specialist: Low Incidence Disabilities, Assistive Technology, Related Services, Education Service Center, Region 20

Abstract: Ms. Morlandt shares her experience with using Active Learning for a student during and after a two-year pilot entitled "Developing District Capacity in Active Learning."

Key words: Active Learning, Education Service Center Region 20 (ESC-20), Texas School for the Blind and Visually Impaired Outreach (TSBVI), HOPSA dress, Functional Scheme.

I began my Active Learning journey backwards. I had been an Educational Specialist serving teachers of students with Low Incidence Disabilities for two years after teaching students from the same population for several years prior. I attended a conference with Ms. Patty Obrzut at Texas School for the Blind and Visually Impaired (TSBVI) to build my knowledge base about Active Learning, which had been introduced to me at the time by my partner at the Education Service Center.

I felt like a door had opened to reveal possibilities for students just like those that I had served in the classroom years ago that I had been at a loss with how to reach at the time. I had done the best that I could with what I knew at the time, and I'm proud to say that some of what my team and I had done were on the right track—but it could have been so much better. I began to wonder how I could use this invaluable information in my current role as a provider of professional development and training for teachers serving students with these significant challenges. How could I help these teachers to have this information so that they would be empowered to build instructional programs for their students who needed this approach?

I brought my thoughts forward to other stakeholders who serve the same population, and through our conversations the Developing District Capacity in Active Learning (DDCAL) Pilot was born. It was developed as a collaborative effort between the Low Incidence Disabilities Statewide Network (LID or LISN) and TSBVI. Four regions from around the state would support a district team around one student that met the criteria as a learner who would benefit from the Active Learning approach. Each team would complete the Functional Scheme assessment developed by Dr. Lilli Nielsen and submit baseline videos. The team members would

receive training through participation in ongoing consultation visits with the ESC lead and TSBVI Outreach staff and/or support to attend the 2-day Active Learning Conference. Then each district would have access to a minimum of $1000 from the LID to help them purchase materials or equipment needed for implementing Active Learning for the student.

The Pilot proposed to add 4-5 additional regions each year, with the intention for all 20 Education Service Centers to participate within four years. I volunteered to represent Education Service Center, Region 20 (ESC-20) as one of the pilot teams, and along with four other teams of my esteemed colleagues from around the state we began this two-year project.

Fast forward a few months—the first ESC-20 DDCAL team was selected and ready to go. None of us knew what to expect but all were dedicated to the idea of getting Active Learning incorporated in the school day for our student, Voozeki. At the time, Voozeki was in Kindergarten attending Maverick Elementary School in San Antonio Independent School District (ISD). Sara Kitchen, our support from TSBVI, guided the team to complete the Functional Scheme, which is the assessment tool that guides how Active Learning is implemented.

Can I say how extremely fortunate I have been to work alongside such dedicated, hard-working people? Voozeki's team took in all of the information Sara and I shared like a sponge and immediately began incorporating it into Voozeki's day. He has the most conscientious (not to mention the coolest) parents who have been there every step of the way. They

Voozeki in the HOPSA dress examining rocks in a baking pan with his bare feet.

shared the activity boards and other materials that they were using at home. They created these activities for Voozeki after they attended Active Learning training with Patty Obrzut and tweaked these learning environments with the data we gathered through completing the Functional Scheme assessment! They even invited representatives from Team Ability, which is a non-profit organization in San Antonio where Voozeki attends therapy sessions, to participate. Team Ability also utilizes the Active Learning approach. This collaboration and information sharing between school, home and this facility was incredibly

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Now THAT'S Teamwork!–continued

helpful. Team Ability not only shared information with the school team about his progress during therapy at their facility, they also allowed for our team members to visit and watch Voozeki in action.
By the end of year one, the original team had done so much—the Functional Scheme had been completed initially then was updated. The team had worked together to build equipment and gathered materials based on his preferences and what the data indicated he might need. Thanks to DDCAL support, the team was able to purchase some equipment and materials to help build on what we had begun. This included a portable tripod designed to support a hammock chair (Hammaka Tripod Hanging Chair Stand found on amazon.com), which we used to support a HOPSA (Holding Up for Standing Activities) dress so that Voozeki could explore items from a standing position.

Voozeki at the zoo touching a chime

Year Two brought a new set of opportunities and challenges. Voozeki, now a first grader, transitioned to a new school, which meant there were new team members to train about Active Learning as well as all of the other considerations when a student joins a new classroom and team. And again, the new team rose to the challenge. Voozeki's new team members jumped right in.

One of his teachers at his new campus, Crockett Elementary, has a unique classroom called the Sensory Optimal Learning Environment (S.O.L.E.), which is designed based on the Active Learning approach and philosophy. Voozeki has been able to spend part of his school day in this setting, and his S.O.L.E. teacher, Claire Heins, graciously assumed the leadership role to assist his other teachers with implementing Active Learning strategies in their classrooms. To continue moving forward, the team used an amazing and thorough online resource, Active Learning Space (www.activelearningspace.org), to provide support for new team members as well as to build his program. This website has been developed through collaboration between Penrickton Center for Blind Children, Perkins School for the Blind and Texas School for the Blind and Visually Impaired. Whenever a team member needed additional support on a particular component of Active Learning, such as the 5 Phases of Educational Treatment, they were able to visit the website to view videos that describe each phase as well as examples of implementation with students.

From year one to year two, Voozeki made progress in these skill areas: communication, fine movement, perception of objects, and spatial perception. Voozeki showed this progress through developing new skills such as purposeful acceptance or rejection of options using auditory scanning of consistent verbal labels for familiar activities. This was generalized to use either when presented by a speech output device or by a person. He showed rejection by turning away, and acceptance by turning toward a person and vocalizing. He has been vocalizing more during play and his vocalizations have become more differentiated. He also has developed specific preferences and is very clear of what he wants at various times of the day. He has grown more confident in his own ability to make choices and get information, and spends more time engaged in activities and less time taking processing breaks. He is now able to spend more time looking at his own activity with objects. He is currently experimenting with graded force of his own action, and no longer only uses large back muscles to activate arm movement. He keeps his hands in midline more often and is able to isolate the pointer finger of his right hand to spin a favored toy. Voozeki remembers where items are in familiar learning environments and returns to favored items to compare their qualities or repeat an activity with an item.

We are now approaching the end of Year Two. In a few days we will meet as a team for the final time to discuss this project: How has it benefited Voozeki, the team, what the data shows, and where we go from here? I have to say that I have no doubt about his future success. I have had the honor and privilege to work alongside these dedicated educators and family members for two years now and it reminds me of why I decided to make special education my profession years ago. I am truly grateful for the opportunity to have learned from and grown with each person on the team.

I plan on taking what I have learned from this experience and sharing it throughout Region 20 by creating workshops that will help other teams build a similar program to serve their students. TSBVI has graciously agreed to continue to support me and my partner at ESC-20, Dana Frankland, with building these new training opportunities and I couldn't be more appreciative. One new training tool is the online self-paced course, Active Learning Principles. TSBVI plans to develop 5-6 additional online modules about various aspects of utilizing Active Learning during the 2018-2019 school-year.

My ultimate goal is to share as much information as I can with school teams so that they are empowered to build meaningful instructional programs for the students in their classrooms that access the general curriculum in a very different way. My participation in the DDCAL project has provided me with the information and support to do just that. I'm very excited to see how this will grow to serve more teachers, therapists, families, and (most importantly) students.

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Texas School for the Blind and Visually Impaired Student Art Work Features in WEST Austin Studio Tour, May 2018

Gretchen Bettes, TSBVI Art Teacher, TVI

Abstract: TSBVI Art Teacher Gretchen Bettes explains the connection made between TSBVI students and the Austin art community in joining the annual West Austin Studio Tour.

Key words: WEST Austin Studio Tour, Texas School for the Blind and Visually Impaired Outreach (TSBVI), student art, creative expression.

The WEST art show is a way for the TSBVI student artists to reach out to the community and show their talents as well as help educate the public about blindness. We invite the Austin community to share in our students' talents and appreciate the expressive, creative beings they are. The students' interest is to educate those who haven't been around people who are blind and visually impaired and show that even though the students may not have sight, they are capable in whatever they choose to do. We want people to feel relaxed and so they can see that blind folks are just like everyone else, with hopes and dreams and an interior life.

"I love art. It makes me think about myself and what I feel. I pay more attention to what is going on inside." –Terynay

"It calms me to do my tape paintings and takes the anger away and makes me feel good." –Haydar

Often, people don't understand that individuals who are blind can be visual artists. Being blind doesn't mean that a person doesn't have feelings and a point of view that can be expressed through a variety of mediums, including those that are visual, as any other artist does. Students with visual impairments create ceramics, weavings, paintings, sculpture, mixed media works, etc.

"We made big huge circles, almost like a big Texas. We spent 7 Tuesdays making this. Mr. Eric Pearson brought essential oils that made it smell good while we were doing yoga and art together. We have been happy to do this. Mya says she is very proud of herself for making this. Our favorite part was working with the markers and pastels and doing savasana. We liked to joke that it's not a pasteleria, which means bakery in Spanish." —Mya, Andres, and Bethany on the making of "Yoga, Art and Language."

"Art makes me feel relaxed. It is a fun way for me to express what I think about things. I like to communicate with my art." – Mikkah

The art class is driven by the students and my job is to teach them how to express themselves using the medium that they wish to work in. Not only do the students learn the medium/mediums that they wish to work in, they learn about themselves, their feelings, and how to state that in the form of their art.

When a new student enters my art class, I start by asking what kind of experience the student has in art. Many times, their answer is "none" or "my teacher's aide usually does my art." It is often assumed that students with visual impairments have no interest in art because they can't see it, or can't see it well. This assumption is dead wrong! So they explore a little of everything to find what they enjoy and where their strengths lie. Then they explore what they want to express.

"People understand that I like horses and goats and that my dream is to have a farm because I communicate this with my art. Everything I do has to do with farms. I made ceramic goats and a hand-sewn quilt with horses and goats on it for my goats to rest on, plus a cow wind chime. It really helps me with conversation, too. " –Bethany

Students practice their craft and learn how to hone it. This involves problem solving as well as gaining awareness or mastery of positional concepts like left, right, up, down, over and under. They also tie history, math, social skills, fine and gross motor skills, etc. into weaving, sewing, working with building 3 dimensional objects with wood, clay, etc. They find that perhaps adding texture to their paintings not only makes them more interesting but is also a way for totally blind students to "see" their work and enjoy it. That is why you may touch the art at every art show they put on!

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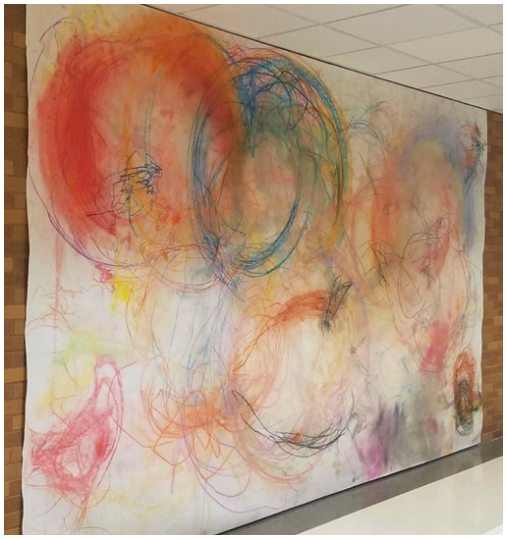
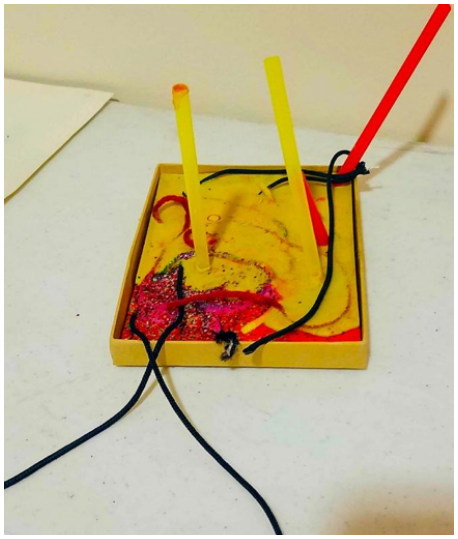


Yoga, Art and Language by Mya, Andres and Bethany

Dark Carnival by Kristina



Rays of Sunshine by Jordan

Dreaming of a Farm by Bethany

Spoons 5 by Mya

Space Debris by Adelyn

WEST occurs annually in the spring. Find out more at http://west.bigmedium.org/

Creating with Blind Abandon Goes to the Houston Art Car Parade

Katherine Trimm, TVI in Houston, TX

Abstract: Kathy Trimm describes the after-school art program she has begun with students who are blind and visually impaired, "Creating With Blind Abandon," and the group's participation in the Houston Art Car Parade.

Key Words: Community, Creating with Wild Abandon, Blind, Visually Impaired, Artist, Art, Houston, Tactile and Visual Art.

We were so excited to have participated in the Houston Art Car Parade this year! It was not a planned experience - we sort of fell into it. Read on to find out how!

In my experience as a teacher of students with visual impairments, I have found that so many of my blind and visually impaired students love art! Like many sighted people, I was surprised by this. I have encountered some very talented blind and visually impaired student artists over the years. One of the major inspirations for our art program was a student named Zack, who has very low vision, and whose art later became our group logo. More important to him than sheer talent is the real joy he finds in drawing and creating art! His interest in art inspired me to seek out art for him to experience tactually.

Living in Houston, I assumed I would find accessible art venues that my students could enjoy. I worked with Linda Brown, Braillist, to try to find sources of art for Zack and other students. Much to our dismay, all we found were dead ends. Every museum and art exhibit we could find was strictly hands-off. We knew there had to be something more for our students! That is when we got the idea for Creating with Blind Abandon –a tactile art program for students with visual impairments. With the help of some fantastic volunteers, we solicited students from multiple school districts to join our program and began meeting monthly at the local library.

During my continued quest for tactile art exhibits for my students, I came across an internet article about a local artist, Bonnie Blue, who has an art car and participates in the Houston Art Car Parade. I learned from the article that prior to the actual parade, the art cars go into the communities in the "Main Street Drag," and that Bonnie loves to be on the route that goes through the Houston Lighthouse for the Blind so she can give the patrons who are visually impaired the chance to TOUCH her car! I immediately contacted her and asked how our kids could get in on the fun. This lovely woman took us under her wing and guided us through the process of creating our own "ARTomobile" for the parade.

(cont.)

Creating with Blind Abandon Goes to the Houston Art Car Parade–continued

One of our parents, Jason Thompson, offered to let us use his truck and trailer for the parade. Students worked diligently to produce a great deal of art for our trailer in a very short period of time. We had donations of broken as well as unused musical instruments that the student artists turned into works of art including guitars, a trumpet, drum heads, and a bongo. We also had vinyl records that became art pieces. The truck was decorated to look like a guide dog, complete with Mario on the roof holding the harness! The local news, ABC Channel 13, filmed and interviewed our group in preparation for the parade.

Our entry's theme was Helen Keller's quote, "Life is either a daring adventure or nothing!" It was a mobile depiction of the "can do" spirit! This entry description explained our mission:

"Although the art community is generally closed off to those who use their hands as their eyes, we are daring to bend those rules and show the world that art can be touchable! Although art is generally considered to be a visual experience, we are daring to show that it takes more than sight to have artistic vision! Although blindness and visual impairments are considered to be limiting, we are daring to create with blind abandon!"

Two of Zack's art works: (left) Logo for Creating with Blind Abandon and a round face (right) he created for the parade.

One of the students, Madi Hayes, wanted to do something special for Bonnie Blue for helping us. We decided to decorate an album with bottle caps and rocks to make the words, "Bonnie rocks" in Braille. She presented this to Bonnie at the parade site.

The students had a great time participating in the parade! One of the students, a second grader named Caylen, said that she thought "it was really cool and fun!" She said that she would do it again because she liked "being on a trailer and having fun with [her] friends!" As for the art program itself, she liked getting to meet new people and painting and stringing beads.

Caylen turning a trumpet into a work of art

Bonnie Blue came to visit our group and let our kids tactually explore her art car

We are excited about Creating with Blind Abandon for the opportunities it gives these kids. They are forming friendships and experiencing art in a way that is all about them. They have real-life practice in multiple areas of the Expanded Core Curriculum, all while having fun in a way that makes sense to them!

Madi presenting her "Thank You" to Bonnie Blue at the parade

[Visit www.creatingwithblindabandon.com/](http://www.creatingwithblindabandon.com/)

Wildcats Win Gold at Austin Dragon Boat Races!

Scott Baltisberger, Education Specialist TSBVI Outreach, with photos by Kristine Seljenes, Adaptive PE, TSBVI Comprehensive Programs

Key Words: Dragon Boat Festival, Team Sports, Community, Race, TSBVI, Texas School for the Blind and Visually Impaired

TSBVI's Dragon Boat team logo

On April 30th the TSBVI Wildcats dragon boat team took first place in Division C of the community/corporate category at the 20th annual Austin Dragon Boat Festival, racing in three 300 meter races to capture the title. This victory was the result of regular twice-monthly training sessions which began in September of 2017, during which team members learned independent skills and aspects of teamwork that resulted in their triumph. In this endeavor, they were supported and coached by both school, residential and recreational staff as well as community volunteers.

Dragon boat racing is a 2000-year old sport that is currently having a world-wide surge in popularity. TSBVI's participation in the Austin race was a chance not only for us to mingle with the crowd and take part in the thrill of competition but also for the public at large to experience first-hand the ability, drive and goodwill of our students. Maintaining an active and engaged lifestyle can have many benefits, including physical fitness, engagement with the community and stress management and we look forward to providing another group with this opportunity during the next school year!

Gold! The Wildcats took first place in Division C.

TSBVI's Dragon Boat Team in "Paddles up" position - Ready to begin racing! (above)

Team members lining up to board the boat (left) and team members in the boat, ready to launch for our first race of the day (right).

TSBVI's Dragon Boat Team with banner.

A Braille Literacy Pilot Initiative for Young Children

William Daugherty, Superintendent TSBVI

Abstract: In this article Superintendent Daugherty discusses the new pilot program TSBVI is developing with local Independent School Districts (ISDs) and Educational Service Centers (ESC) designed to support and foster early literacy in the braille medium.

Key words: TSBVI, Braille, blind, visually impaired, Educational Service Centers (ESC), early literacy

It is widely recognized that many young children who are likely to become braille readers do not have early literacy-developing experiences similar to those of typically sighted children. Typically sighted children are surrounded by the printed word as soon as they can see, and begin to develop literacy through incidental learning and through more direct avenues such as being read to by family members. Young children with severe visual impairment often do not have sufficient, similar experiences, and may not begin to develop reading skills until formal instruction begins as they enter school. By the same age, the majority of typically sighted students have achieved a much higher level of literacy independence and are using their reading and writing skills to access the broader curriculum. The child with the visual impairment can easily fall behind.

There are certainly examples across the state where children under the age of 5 are getting an excellent early start on developing literacy in the braille medium. A commonality among these examples is a teacher who can devote sufficient time to supporting the child and their family in an organized sequence of activities in the home that build the necessary concepts and skills. For a variety of reasons, not all children have access to this type of consistent, organized instruction that finds its way into daily life routines around the home.

To try and improve this situation, TSBVI has begun creating a pilot program in collaboration with ESC 14. The target is to create a model program for students who are probable braille readers to develop braille literacy skills earlier with on-going support by educators and by family members. The age group of the children for the program will be three to five years old, with the discretion to expand that range as appropriate. This first pilot site will develop a program that we hope can then be replicated by interested regional programs and local schools. The program will consist of assessment tools, curricular materials, activities for home and a design for on-going supports utilizing families, educators and volunteers. TSBVI wants to create an early braille literacy initiative that is both effective and sustainable. We are flexible in how the program is structured and have begun working with ESC 14 on a school year model.

So far, we know we will need:

- A motivated and engaged local school administrator and/or teachers of students with visual impairments who have a strong interest in literacy
- Support for the program from the regional Education Service Center consultant
- The availability of local volunteers who are braille readers and are willing to mentor families and their children
- A package of activities, materials and supports for families that is fun, stress-free, and tailored to each child's learning needs
- Data collection and analysis leading to program improvement and justification

While the Region 14 Education Service Center in Abilene has been selected as the first pilot site, we know that several other ESCs have expressed interest and we may be able to expand our partnerships as we move forward. The goal of this first round is to figure out what approaches work best overall, with full awareness that each pilot site will likely need to be tailored to local realities. Broader goals of this initiative are to start a statewide conversation about early braille literacy needs, and to identify partners with similar interests. The desired outcome is for students entering the school system to be reading braille at their highest potential. We are excited to be part of this collaborative effort.

Rehabilitative and Independence Services within Texas Health and Human Services Commission

Keisha Rowe, Director, Office of Independence Services:
Health and Human Services Commission

Abstract: This article outlines the program services provided by the Rehabilitative and Independence Services section of HHSC.

Keywords: HHSC, services, disabilities

The Blind Children's Program is part of the Texas Health and Human Services system, which is dedicated to helping millions of people each year. For people who need medical care, food for their children, dignified care in a nursing home or an assisted living facility, or independent living resources – HHS is ready to help. More than 3.4 million Texans have a disability. HHS programs offer an array of services to meet the needs of people with disabilities, including providing guidance and referral expertise to a family whose child was just diagnosed with a disability; helping people find and secure independent housing; working with community partners to create jobs; and locating service providers who provide in-home care in order to help keep people out of institutions.

(cont.)

Rehabilitative and Independence Services–continued

HHS's Health, Developmental and Independence Services programs offer information and support in the following areas:

- Acquired brain injury
- Autism
- Blindness and visual impairment
- Comprehensive rehabilitation services
- Deaf and hard of hearing services
- Early childhood intervention
- Employment services
- How to pay for services
- Intellectual or developmental disabilities– long-term care
- Medical or physical disabilities
- Person-centered planning
- Service coordination

HDIS's Rehabilitative and Independence Services is home to numerous programs to Texans with disabilities.

Blind Children's Program

The Blind Children's Vocational Discovery and Development Program helps people 22 and younger who are blind or severely visually impaired learn the skills required for personal independence, potential employment and integration into their community. BCP's comprehensive habilitative services enhance children's ability to develop skills comparable to those of their sighted peers. It also helps children achieve financial self-sufficiency as adults. Blind Children Program's specialists serve a dual role as case managers and direct service providers

Blindness Education, Screening and Treatment Program

Blindness Education, Screening and Treatment services reduce the incidence of blindness throughout Texas. The program encourages people to protect their eyesight by seeking professional care if they are at risk for potentially serious eye conditions. The program provides medical treatment to people without health insurance, helping to prevent blindness. The BEST program contracts with the agency Prevent Blindness for screening services and collaborates with ophthalmologists for treatment services.

Comprehensive Rehabilitation Services

The Comprehensive Rehabilitation Services program fills a service gap for intensive rehabilitation services for people who have sustained a traumatic brain injury, traumatic spinal cord injury or both. The program helps people live independently in their homes and communities. It focuses on three main areas that affect both function and quality of life:

- Mobility,
- Self-care
- Communication skills

Services are provided in the consumer's home, a hospital, a residential facility, an outpatient clinic or in a combination of settings to encourage the maximum flexibility in service and independence.

Depending on the person's needs, different program services are available, such as in-patient comprehensive medical rehabilitation services, post-acute rehabilitation services -- both residential and non-residential -- and outpatient therapies and supports.

Deaf and Hard of Hearing Services

Deaf and Hard of Hearing Services oversees and manages 11 programs that advance opportunities for people who are deaf and hard of hearing. These programs reduce societal and communication barriers to ensure full and equal opportunity to participate in public life. The program also raises public awareness of the needs of people who are deaf or hard of hearing, as well as the development and coordination of programs, policies and regulations.

Guardianship Services Program

The Guardianship Services Program serves adults with diminished capacity who are substantially unable to provide for themselves and have been referred by the Department of Family and Protective Services. It also serves youth moving out of DFPS conservatorship. HHSC is appointed guardian of people affected by abuse, neglect, self-neglect and/or exploitation.

For adults to be referred by DFPS for guardianship, they must either have a disability or be 65 or older and have been abused, neglected or exploited. For youth moving out of conservatorship, they must be in CPS conservatorship and appear to meet the adult definition of incapacity.

Independent Living Services

The Independent Living Services program enhances the quality of life of people with significant disabilities, including those who are blind or visually impaired. It promotes independence in the home and community and provides access to rehabilitative services and supports. The program places special emphasis on helping people accomplish daily tasks independently; participate in their favorite activities; improve communication and transportation access and mobility; gain a better understanding of their disability; and increase their self-confidence, access to the community and participation in society.

Surrogate Decision-making Program

The Surrogate Decision-making Program authorizes family members and surrogate consent committees to provide written informed consent for people who receive community-based services, lack the capacity to make treatment decisions for themselves and have no legal guardian. This consent applies to the areas of major medical treatment, major dental treatment, use of psychoactive medication and use of highly-restrictive procedures. Volunteers make decisions for people who are living in community-based intermediate care facilities for people with intellectual disabilities or related conditions.

To learn more about these and other programs offered at HHSC, please visit the HHSC website at: https://hhs.texas.gov/

Experiencing Employment through Summer Work-based Learning Programs

Kevin Markel, Program Specialist for Pre-ETS, Texas Workforce Commission

Abstract: In this article, Mr. Markel discusses work-based learning and the impact it can have on the post-secondary education and business success of an individual with a disability.

Key words: Vocational Rehabilitation, disability, Texas Workforce Commission, Workforce Innovation and Opportunity Act, pre-employment transition services, work-based learning, Summer Earn and Learn, WACO, SWEEP, SWEAT, WALIC.

For students with disabilities and their families, achieving meaningful, long-term employment is one of the primary goals for post-school life. This goal is also shared by the education and vocational rehabilitation professionals who partner with them.

The Workforce Innovation and Opportunity Act (WIOA) requires vocational rehabilitation programs, such as the Texas Workforce Commission Vocational Rehabilitation program (TWC-VR), to provide pre-employment transition services (Pre-ETS) to students with disabilities to better prepare them for a successful transition from secondary education to postsecondary education and employment. Pre-ETS activities include five services: work-based learning, counseling on post-secondary education, career exploration, workplace readiness and self-advocacy. This article will focus on work-based learning. Future articles will provide additional information on each of the other Pre-ETS required areas.

While all of the required Pre-ETS areas are important and instrumental for transitioning students with disabilities, there is an additional emphasis on the provision of work-based learning opportunities. There are numerous studies, including longitudinal studies, that point to the positive relationship between work-based learning experiences during secondary education and successful post-school employment.

Work-based learning is an instructional approach that uses the workplace or real work experiences to provide students with the knowledge and skills that will help them connect school experiences to real-life work activities and future career opportunities. It is essential that direct employer or community involvement, within an integrative setting, be a component of the experience to ensure student engagement and assist in the learning process. Work-based learning experiences vary and are tailored to the student's needs.

These activities include:

- Job Shadowing
- Career Mentorship
- Informational Interviews
- Service Learning
- Simulated Workplace Experience
- Paid and Non-Paid Work Experience
- Volunteering, and
- Internship or pre-apprenticeship experiences

In January 2017, TWC approved the Pathways to Careers Initiative to expand opportunities for Texas students with disabilities to receive Pre-ETS. This initiative compliments and advances the Tri-Agency initiative by TWC, the Texas Higher Education Coordinating Board and the Texas Education Agency (TEA), which emphasizes the importance of applied learning opportunities. These opportunities may be through internships and work experiences, ensuring that students have better information about career pathways to promote informed choices and increase the number of Texas students who complete a postsecondary degree or credential.
One of these TWC work-based learning initiatives is called Summer Earn and Learn (SEAL), which is conducted in partnership with Local Workforce Development Boards (Boards) and their employer partners. SEAL combines essential employability skills training and paid work experience for students with disabilities. SEAL is offered across the state in each Board area during the summer months, for at least five weeks, when students are typically out of school. Through this program, students experience a real work environment, receive a paycheck, and learn valuable interpersonal and transferable skills that prepare them for their future success.

In its inaugural summer of 2017, the SEAL program assisted more than 1,500 students with disabilities with employability skills training and paid work experiences with a variety of Texas employers. TWC anticipates at least 2,500 students with disabilities will participate in SEAL in 2018.

Other summer work-based learning opportunities that have historically been available for students who are blind or visually impaired will also continue this summer. Those activities include SWEEP in Lubbock, the WACO Project at Texas A&M, and the SWEAT / WALIC programs at Texas School for the Blind and Visually Impaired (TSBVI).

On a personal note, as an individual who is visually impaired, I can point to the positive impact and integral role that summer jobs played in my readiness to face the world of work. Through these summer opportunities in high school and college, I had the opportunity to practice self-disclosure about my disability, understand how self-disclosure impacts my functioning, and determine which assistive devices and aids allowed me to complete certain tasks best. These opportunities also afforded me the chance to gain invaluable information on the type of work that I enjoyed and the type of work I did not enjoy, so I could make better informed career decisions during and after postsecondary training. For these reasons, and many others, we encourage students and their families to discuss the possibilities of work-based learning opportunities with their respective TWC-VR counselor.

Five Websites That Teach Kids about Vision Impairments

Veronica Lewis, Writer/blogger at Veronica with Four Eyes,
Excerpts from https://veroniiiica.com

Abstract: Ms. Lewis reviews 5 websites that provides information and resources that shares information about vision impairments with children.

Key Words: blind, visual impairment, Braille, low vision,
https://veroniiiica.com/2018/01/19/five-websites-that-teach-kids-about-vision-impairments/

As more and more students are diagnosed with vision impairments, kids naturally become curious about what vision impairments are and how people live with them (read more about how I answer questions children ask about my low vision here: https://veroniiiica.com/2017/08/28/answering-strangers-questions-children-edition/). Luckily, there are many kid-friendly resources online that teach about Braille, blindness, low vision, and more. In honor of National Braille month, here are five websites that teach kids about vision impairments, including blindness and low vision. These websites are targeted at sighted kids but are also great for curious kids with vision impairment.

You've Got Braille

You've Got Braille is a resource on PBS Kids that teaches young children about Braille using characters from the show Arthur. A character named Marina has a page where she talks about life with blindness and educates readers on basic adaptations such as listening to books (read more about listening to books on Amazon Alexa here), reading large print (read more about Bookshare, an accessible library here), and using screen readers. There's also a Braille translator. I love that this website is inclusive of low vision and has current information too. Check out the website for You've Got Braille here (http://pbskids.org/arthur/print/braille/).

Braille Bug

Braille Bug is an interactive resource created by the American Foundation for the Blind. On the website, kids learn about color contrast (read my post on colored backgrounds here), Louis Braille, Helen Keller, different types of Braille including music (read more about how to make music accessible for low vision here), and also has games and activities. I had a lot of fun exploring the website, especially the Louis Braille virtual museum. Check out the website for Braille Bug here (http://braillebug.afb.org/).

SeeNow Vision Simulator

SeeNow Vision Simulator was developed to teach people about navigating with a vision impairment by seeing what locations look like through the eyes of someone with uncorrectable vision loss. I used it to explain to someone why I find it difficult to navigate an area near my college and show them how it looked to me- read more about navigating college campuses here. There is also an app available, but I have not tested it. Check out the website for SeeNow Vision Simulator here (https://simulator.seenow.org/).

Kids Quest: Vision Impairment

Kids Quest: Vision Impairment is a resource developed by the Center for Disease Control. The website challenges assumptions kids may have about vision impairment and teaches them about assistive technology (read five myths about assistive technology here) as well as encourages them to research information on outside websites. There's even a section on famous people with vision loss- read my post on Buddy Holly and how he helped make glasses cool here. This website can answer most questions someone could have about vision loss. I recommend it for older kids, age 10 and above. Check out the website for Kids Quest: Vision Impairment here (https://www.cdc.gov/ncbddd/kids/vision.html).

WonderBaby

While this website isn't technically directed at kids, WonderBaby is a website curated by Perkins School for the Blind about raising children that have vision impairments and multiple disabilities. There's a lot of great projects, information and tips featured, and my mom has said she wished this website existed when I was younger because it would have been really useful. Check out the website for WonderBaby at (http://www.wonderbaby.org/).

By encouraging kids to learn more about living with vision impairment, inclusive and accessible spaces can be created and flourish. After all, kids with blindness and low vision aren't much different than other kids, which I mention in my myths about IEP students post here (https://veroniiiica.com/2017/10/30/seven-myths-about-iep-students/) – they just see things a little differently

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Boonstra-Schaaf Optic Atrophy Syndrome (BBSOAS) Family Conference

Megan Rech, Research Coordinator, Baylor College of Medicine

Abstract: Ms. Rech shares an overview of the BBSOAS Family Conference that was held in Houston in April.

Key words: Boonstra-Schaaf Optic Atrophy Syndrome, BBSOAS, Cortical Visual Impairment (CVI), optic atrophy, visual impairment, Texas School for the Blind and Visually Impaired Outreach (TSBVI)

The inaugural Bosch-Boonstra-Schaaf Optic Atrophy Syndrome (BBSOAS) Family Conference was held in Houston, Texas on April 27th and 28th. BBSOAS is a rare neurological disorder caused by a disruption in the NR2F1 gene on chromosome 5. The syndrome is characterized by a wide array of clinical features, but the most common are developmental delay, intellectual disability, low muscle tone (hypotonia) at birth, and vision impairment caused by a small and pale optic nerve and/or cortical visual impairment (CVI). There are currently about 55 known cases of BBSOAS worldwide. Though there is presently no cure for BBSOAS, with early intervention and proper management, much can be done to improve the quality of life of those affected.

The purpose of the conference was not only to provide education through presentations from leading researchers and medical professionals, but also to promote community-building by facilitating opportunities for families to get to know and learn from each other. The conference was hosted by the lab of Dr. Christian Schaaf, a Professor for Clinical Genomics and the Medical Director of Clinical Genetics at the University of Cologne in Germany and Visiting Professor at Baylor College of Medicine and the Jan and Dan Duncan Neurological Research Institute in Houston. In addition to Dr. Schaaf, several other collaborators and experts shared their knowledge with families.

Dr. Danielle Bosch (UMC Utrecht), together with Dr. Schaaf, presented on the clinical features of BBSOAS, while Dr. Fred Pereira (Baylor College of Medicine) spoke about the molecular aspects of the syndrome.

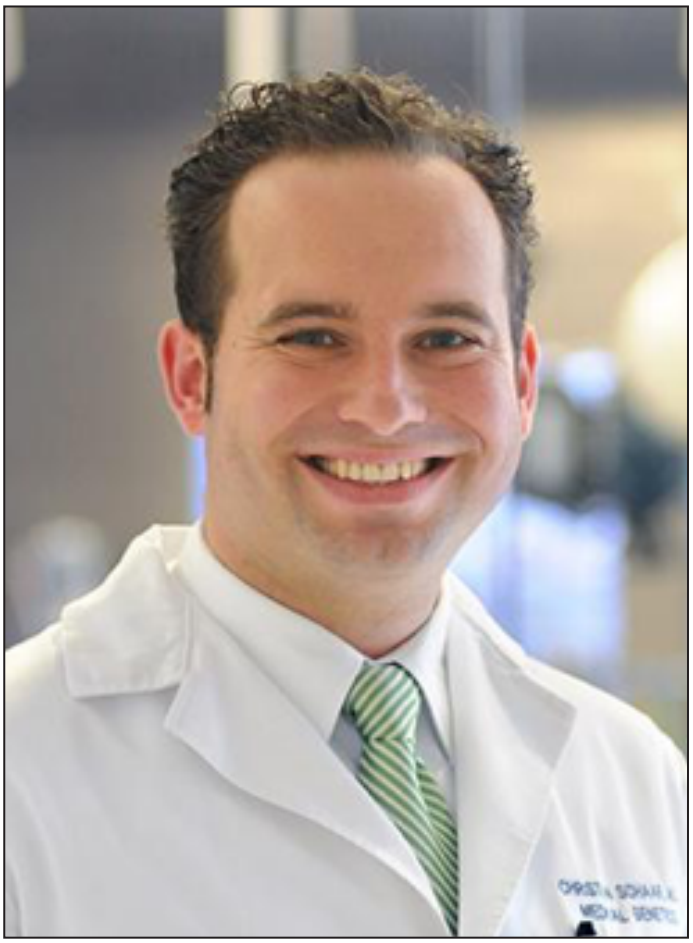
The conference also highlighted vision research, with a presentation from TSBVI Outreach Consultants Sara Kitchen and Lynne McAlister on supporting children with CVI, and a talk from Dr. Jane Edmond on the causes of visual impairment in the syndrome. Dr. Edmond is the Director of the Mitchel and Shannon Wong Eye Institute and Professor and Inaugural Chair of the Department of Ophthalmology at the Dell Medical School at the University of

Texas at Austin, and she is also an Adjunct Professor in the Department of Ophthalmology at Baylor College of Medicine. In addition, special guest Dr. Ana Treviño-Godfrey (Director of Prelude Music Classes for Children) facilitated a music activity for the group.

As part of the event, families also had an opportunity to be examined by Dr. Edmond or Dr. Veeral Shah, a pediatric neuro-ophthalmologist at Texas Children's Hospital, as well as to meet one-on-one with Dr. Schaaf. While the focus of these visits was to answer families' questions, the hope is that findings from these visits will lead to a more comprehensive characterization of the syndrome.

All in all, 27 families, or about 100 people, traveled to Houston for the conference.

To learn more about BBSOAS, please visit https://www.bcm.edu/research/labs/christian-schaaf/nr2f1.



Dr. Christian Schaaf

Dr. Danielle Bosch

The Sooner the Better: A Framework for Training Early Intervention Practitioners on Deaf-Blindness

Excerpts from the website: National Center on Deaf-Blindness https://nationaldb.org/

This framework offers state deaf-blind projects a collection of online resources that they can use to provide customized training and technical assistance to early intervention providers as well as to project staff and families. It focuses on the identification of children with combined vision and hearing loss, key instructional strategies, and the developmental domains used by early interventionists.

https://nationaldb.org/products/ei-framework

Image: https://nationaldb.org/products/ei-framework

ACBT Conference/Convention—Save the Date

American Council of the Blind of Texas
2018 Conference/Convention

Houston Marriott Westchase
2900 Briarpark Drive Houston, TX 77042

September 20-23, 2018

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For more information, you may contact Kenneth Semien, Sr., ACBT President via email
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1-877-787-8999

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