

TX SenseAbilities

A PUBLICATION ABOUT VISUAL IMPAIRMENT AND DEAFBLINDNESS FOR FAMILIES AND PROFESSIONALS



Ki and her family at the 2019 International CHARGE Syndrome Conference – see page 5

Family Wisdom

Austin All-Stars	3
Connecting with My Granddaughter	5
Texas Fellows	8
CHARGE Syndrome Conference	9
Summer Send-Off.....	11
Usher Syndrome Conference	15

Effective Practices

Active Learning: Documenting Progress ...	17
Teaching Braille to the Whole Child.....	21
Accessing Self-Determination	25
Specially Designed Instruction, Part 2.....	31

News & Views

The Texas Perspective	33
Success Stories of SEAL Initiative	35
Navigate Life Website.....	37
Case of the Mysterious Missing Dog	39

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

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Thank you for reading *TX SenseAbilities*!

Texas School for the Blind and Visually Impaired, the Texas Workforce Commission, and the Texas Health and Human Services Commission are proud to provide our readers with the latest stories about the worldwide community of students who are blind, DeafBlind, and visually impaired.

We strive to reach out to people in our areas of practice who are at the forefront of education, culture, and family experiences. By providing these stories in print and on our website, <https://www.tsbvi.edu/tx-senseabilities>, we hope to inspire and engage our audiences of teachers, professionals, families and the public at large.

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Austin All-Stars Albinism Awareness Picnic

Kathi Garza, Family Engagement Coordinator, TSBVI Outreach Program

Abstract: This article describes an event hosted by the author to bring those in the albinism community together on behalf of NOAH, the National Organization for Albinism and Hypopigmentation.

Keywords: albinism, National Organization for Albinism and Hypopigmentation, NOAH, families, community, awareness

For the last 14 years, the National Organization for Albinism and Hypopigmentation (NOAH) has rallied its members to participate in an annual fundraising event. Members across the country organized Bowl-A-Thons raising money and awareness to help NOAH with its mission to provide accurate information about living with albinism and offer a place where people with albinism and their families can find acceptance, support, and fellowship. Albinism is a rare, genetic disorder that impacts the body's ability to produce pigment. The lack of pigment in the eyes causes varying degrees of light sensitivity (photophobia), nystagmus, and poor visual acuity. Albinism occurs in about 1 in 17,000 individuals across all races and ethnic groups.

Since 2010, I have worked with various individuals and agencies to host events in Austin. This year, we decided to ditch the bowling shoes and have our event at a local park. On July 27th, the Austin All-Stars slathered on sunscreen, grabbed our hats and sunglasses, and connected with each other for our Albinism Awareness Picnic. Although it was the middle of summer, we were fortunate to have lots of shade and a nice breeze.

Five families and two sets of grandparents attended the event where the kids enjoyed the playscape, played lawn games, and listened to a peer with albinism play the fiddle. The adults connected with one another on topics related to albinism and parenting, or grandparenting, in general. At noon, we were treated to a delicious pizza and popsicle lunch donated by Dr. Laura Miller and her team at Northwest Hills Eye Care.

Over the years, these events have meant a great deal to me and to the families who have attended. Watching children with albinism light up as they realize there are other kids “just like them” in the world is magical. Connecting with families as an adult with albinism is so rewarding. It allows me to feel that my experiences, the good, the bad, and those between, are relevant and can help other families with their own children. Now, as a parent to a young child without albinism, I have the opportunity to educate my son about albinism and visual impairments. These events are exciting for him, but to my surprise, meeting others “with white hair like mommy,” isn’t anything out of the ordinary. I also love when my mom can attend with me because

(cont.)

FAMILY WISDOM

Albinism Picnic—continued

I enjoy seeing her interact with families while talking about the way she approached raising a child with albinism. I'm so thankful to NOAH for encouraging members to host these events. I feel like I'm hanging out with family I never knew I had but that I can't imagine being without. NOAH events really make 1 in 17,000 feel like a small world!



Kathi, mom Beatrice, and son Keegan, enjoy coming together with others in the albinism community.

Below are a few thoughts from attendees about their experience at the picnic:

Mom Beatrice shared,


"These events are great because they are like little family reunions. Everyone gets to talk and catch up on what's been going on in our lives since the last event. I feel such pride as I witness my daughter, Kathi, an adult with albinism, encouraging attendees with her knowledge of resources, experiences, and personal thoughts. It's nice that this can be done around the picnic table in an informal way."

Nancy, grandparent to a young toddler with albinism, shared,

"It was wonderful to meet adults and children with albinism. It was reassuring to see the kids playing normally and happily together. I enjoyed getting the chance to talk with other parents and adults who were wonderful resources."

Mom Irene shared,

"This was our first albinism awareness event. My daughter, Anabelle thought it was nice to talk to other people with albinism. It was also helpful to talk to someone who wears bioptic lenses."

For more information about albinism, or to get involved with NOAH, visit www.albinism.org. 



Anabelle, Kathi, and Areya at the 2019 Austin All-Stars Albinism Awareness Picnic.

Discovering How to Connect and Communicate with My Granddaughter

LeAnn Pressler, Grandparent of a child with CHARGE syndrome

Abstract: This article discusses connection and communication between a grandparent and her grandchild with CHARGE syndrome. The author discusses the benefit of attending conferences and how implementing the “Triple C Concept” has improved her communication and relationship with her granddaughter.

Keywords: CHARGE syndrome, grandparents, families, connection, communication, DeafBlind, Triple C Concept, choice

As a grandparent and caretaker of my granddaughter with special needs, I often ponder what I can do to help her live a full and happy life. Ki (pronounced “Kee”), who has CHARGE syndrome, is now six years old and thriving in more ways than we ever imagined. I used to wonder how it would even be possible to connect with this person that seemed to be so locked up in her own little bubble and hard to reach. I’ve discovered that attending conferences focused specifically on Ki’s challenges and needs has been very helpful. Bonds are built and much is learned through sharing experiences and having conversations with other families in the same situation.

Recently I attended a conference to learn more about how to communicate and connect with my granddaughter. Ki is non-verbal but rapidly learning how to sign. She expresses frustration in her face and with body language when I don’t understand her or provide what she wants. Ki, like any other person on this planet, wants to be heard and feel validated. At this particular conference, I learned some things that resonated with me.

Giving choices and waiting for responses has greatly improved our communication, and inherently, our relationship. I’d like to share a few more ideas that seem to be working very well.



Ki brushes her doll's teeth.

(cont.)

FAMILY WISDOM

Connecting With My Granddaughter—continued

How can we connect and communicate with someone who may seem unreachable? There are three things that can help promote progress in our quest to include these special people in our lives and build their confidence: **C**reate Opportunities, **C**hallenge the Individual, and Offer **C**hoices. (We could call this the “Triple C Concept”).



Ki and her mom pose for a photo at the International CHARGE Syndrome Conference 2019 in Dallas, Texas.

Create Opportunities

Create opportunities to communicate with the person. It can be mimicking their sounds and/or movements, using gestures and signs, holding their hand, talking to them as if there are no barriers, or any other respectful action to help them react to your effort. Ki loves it when I mimic her sounds and movements. In her world, I am speaking her language, and she feels connected when I notice her and what she's interested in. When I gently touch Ki's chin, she realizes

it's time to focus and pay attention to what I am saying. When I need her to do something, I take her hand and she automatically knows to follow. She appreciates being spoken to at her age level. Since she looks like a three-year-old and often doesn't make eye contact, I catch myself speaking to her as if she's a toddler. It's important for me to remember that her brain is most likely functioning as the six-year-old that she is.

Our favorite “created opportunities” each day are made by including Ki in practically everything we do. We make sure to find ways that she can participate in what's going on, even if it means just having her in the same room so she is exposed to new activities. This helps Ki know we love her and that she is part of our family. Taking Ki to playscapes and kid-friendly events sparks a lot of excitement, and her spunky personality just beams. She tries to keep up by pushing herself to do things that the other kids are doing. Her mobility and social skills improve with every outing because she's motivated and happy. ◆



Ki and her dad at home

Challenge the Individual

Challenge the person with things to improve their coordination, speech, knowledge, creativity, etc. This gives them opportunities to feel important and proud of themselves as they accomplish new skills. Ki loves when she is the designated person to push buttons for the elevator, be the “light switch flipper,” or pull the chain for the ceiling fan. Asking Ki for help with chores like unloading the dryer and putting groceries on the pantry shelf makes her feel like she has important jobs like everyone else in the family. While these jobs improve her sense of belonging within the family, they also challenge her coordination and communication skills.

Playing games and watching educational programs on technology are a great way to promote creativity and challenge problem-solving skills to increase knowledge. One of Ki’s favorite activities is playing Mahjong on my iPad. Our little genius can find matching patterns almost as fast as I can. I also like to record Ki echoing words that I prompt her to say, and in turn, she’s infatuated with viewing these videos over and over. While watching her videos, Ki gets so much joy out of mimicking herself and practicing the words again and again. I’m constantly surprised to find selfies, fun photos, and entertaining videos on my phone that our Little Missy has taken or created when I wasn’t looking.

Having moments to be creative with crafts or playing with water encourages endless discoveries. It can be messy but well worth it. Ki’s favorite water activities include swimming, playing with bubbles while washing her hands, and standing on a chair next to Nana to rinse and stack the dishes. Of course, there’s more playing in the water than stacking dishes!



Ki and her doll sit together to play on her iPad.

Choices

Choices are extremely important and give a person a chance to feel like their opinion matters. Susan Bashinski, Associate Professor of Special Education at East Carolina University, teaches us that too often WE make choices for people with special needs. This doesn’t give them a chance to think for themselves. Chris Sense, who also has CHARGE, taught us that, “we should always assume that special needs people CAN communicate.” We want to acknowledge our children with special needs, give them chances to make decisions, and allow them to explore options. It’s up to us to learn what a non-verbal person’s responses are through their own sounds and movements. Don’t forget that in most cases, response time is different for everyone. WAIT for that response! Refrain from rushing to move on and making the decision for the individual. If you find that you get a response different from what you expected, honor that decision. Eventually, the individual will learn through their own trial and error what they really do like and prefer. People need to feel validated and know that their choices matter.

(cont.)

Connecting With My Granddaughter—continued

Honoring her choices makes Ki happy and boosts her cooperation and confidence. The motivation to progress improves immensely. Some of the simple choices that can set Ki's mood for the day are choosing her outfit and hair accessories when getting ready in the morning. She also likes to have a say in what foods are put on her plate for her swallowing therapy and which bites she will take next. This stimulates her brain through problem-solving and presents her with opportunities to communicate. Most importantly, this gives her a sense of control and helps her realize she is being heard and that she has worth.

I hope this information is helpful for other parents, grandparents, and caregivers. When my granddaughter was born six years ago, I wondered if this would even be possible.

It IS possible! I truly believe in my heart that we CAN connect and communicate with these tender beautiful angels on earth. Through trial and error, we discover daily what works and what doesn't. We are amazed at how much we are still learning as Ki gets older. Thank heaven for conferences! These events are rich with information and support and improve our ability to "understand her" along our journey as we help raise such a complicated and yet sweet spirit. For us, the Triple C Concept makes so much sense. It results in giving our loved ones with special needs a voice and a chance to feel loved and validated. These individuals do notice the time we invest in them, and hopefully feel valued. They deserve as much of a chance to belong in this world as we do and long for it! Let's be proactive and help them to not only be seen, but heard. ♦

TSBVI Outreach Program Honors Texas Fellows

*Recognizing VI Professionals
in their Role as Recruiters*

The Texas Fellows program acknowledges the individual recruiters (Texas Fellow) and welcomes the new VI professional (Candidate) to the field. You are eligible to be a Texas Fellow if you were a significant person in the candidate's recruitment. To be eligible for the program during the 2019–2020 school year, candidates must have started their training after May 15, 2019.

Texas Fellows and Candidates receive the following recognitions: The names of the Texas Fellows and the candidates are published in the *Texas SenseAbilities* newsletter. Texas Fellows and the candidates receive special acknowledgement at all statewide TSBVI-sponsored activities. Texas Fellows receive TSBVI's most popular publications OR Registration assistance for an upcoming TSBVI sponsored conference.

2018–2019

<u>Texas Fellow</u>	<u>Candidate</u>
Gabriella Ortuno-Haywood	Emma Reese
Mari Garza	Amy Reyna
Mari Garza	Dahlia Rivera
Tracy Fletcher	Brenda Blum
Tracy Fletcher	Amanda Garcia
Emily Calvert	Candi Stilts
Tracy Hallak	Gina Zavorka
Scarlett Bayard	Debbie Fussell
Cathy Edwards	Jo Ellen Fisk Cloyd
Barbie Priest	Amanda Campbell
Yevernett Anderson	Pamela Jackson
	Thomas

For more information about the Texas Fellows Program or working as a VI professional contact: Mary Shore at shorem@tsbvi.edu; 512-206-9156.

Connecting with a Community: International CHARGE Syndrome Conference 2019

Callie Sutcliffe, Parent, Dallas-Fort Worth Area

Abstract: The author discusses her family's experience at the International CHARGE Syndrome Conference in Dallas. Callie gives her perspective about resources shared and the wonderful community in which her family was immersed. She also discusses the special memories she was able to create with her family over the weekend.

Keywords: CHARGE syndrome, National CHARGE Conference, parents, family, community, connections, sensory integration, family leadership, advocacy

Community Connections

This past summer was our family's first time to experience the International CHARGE Syndrome Conference. We were excited this year because it was held in our home city of Dallas, Texas. We were also excited because we had always wanted to meet the CHARGE community in person. Hannah is our six-year-old daughter with CHARGE syndrome. We've spent the past six years forging special bonds and friendships with others in the CHARGE community all over the nation, and even the globe. However, until now, it had all been online.

Seeing so many faces for the first time in person was an amazing experience. It filled us with hope and empowerment as we mingled and connected with others from all over. We were also thrilled to make many new friends and build deeper connections. Whether it was a guy's night/girl's night out, the swim party, or just hanging out between sessions and mealtimes, the bonds of the CHARGE community became stronger and more evident.



Hannah had her face painted during one of the evening activities.

(cont.)

CHARGE Syndrome Conference—continued

Perhaps the greatest aspect of our time at the CHARGE conference was all the fun our little Hannah had! Hannah is never one to be shy. She boogied and danced her heart out one night during the Texan classic hoe down! She pulled other friends into her circle and danced with as many people as she could. The camp was incredible. The kids got their faces painted, saw live animals, played games, participated in arts and crafts, and got to meet Disney princesses! What an amazing adventure for her!

Resources and Speakers

The quality and quantity of resources available to families at the National Conference for CHARGE Syndrome were invaluable. Regardless of how long we've been a part of the CHARGE community and how much research we've encountered, we find ourselves always needing to learn so much more. This year, the conference provided our family with strategies to help work through sensory issues at home and at school.


Hannah's biggest needs as a DeafBlind child are strategies for relating and responding to her world appropriately. Some sensory issues and behaviors we encounter with Hannah are hitting, throwing, the inability to sit still (ever!), and her aversion to heat and anything hot. Unfortunately, these things can occur at school too. The strategies, lessons, and materials presented at the conference gave us hope for the home and school environments.

When I returned home, I sat down with my husband to go over everything we learned and made notes about what we wanted to

present at Hannah's ARD meeting when school was back in session. We felt more equipped to handle IEP goals and create a plan with her educational team that would benefit Hannah. Of course, nothing is perfect. We still have to remind her educators when issues arise. No matter what, we are always Hannah's advocates first, but having a wealth of resources and research to back up your claims goes a very long way in advocating for your child, on the front lines at home and at school.

Family Time

In the midst of all the excitement and activity, we also made time for our own family to enjoy a mini-vacation at the five-star Hotel Anatole in Dallas. We managed to wake up early on Sunday morning and sneak away to the hotel's pool, themed after a water park. We ate brunch at the hotel buffet and walked around enjoying some quality time together. Apparently, we were not the only ones! We saw many families making special time for each other around the hotel. It was quite beautiful!

Family time was an essential aspect of the conference. Every evening, the board hosted a fun-filled night of entertainment. Families gathered together and bonded with one another, as well as with the community. Our family's favorite night was the hoedown, Texan style! We danced, rode on an indoor train, and ate dinner together. By the end of the night, our hearts were as full as our stomachs, and we left with huge smiles on our faces. We definitely created memories that will stay with us forever. 

Summer Send-Off

Kathi Garza, Family Engagement Coordinator, TSBVI Outreach Program

Abstract: This article, compiled by a former Summer Programs Coordinator, provides information about Summer Programs 2019 at Texas School for the Blind and Visually Impaired. Parents and students offer insight into the impact of their experiences with Summer Programs.

Keywords: TSBVI, Summer Programs, summer, parents, ECC, Expanded Core Curriculum, testimonial

What are some thoughts that come to mind when you think about summer programs or summer camp for your children? When considering Summer Programs at TSBVI, some families wonder about inclusivity, safety, meals, and homesickness. Other families wonder about the activities. Will they be enriching, engaging, adapted to my child's needs? During my time as a Summer Programs Coordinator, it was no secret around campus that summer is my favorite time of the year simply because of the energy and engagement that Summer Programs brings.

This past summer, TSBVI served 177 students in five different programs. From work programs and a PE class for credit to programs focusing on enrichment and exploration of the Expanded Core Curriculum (ECC), students of all ages conquered new challenges, experienced new activities, and forged new friendships.

Here's what some of our great students and families had to say about TSBVI Summer Programs 2019:

"I am one of the biggest Momma Bears when it comes to my daughter, Ally. Thinking about letting her go to camp for a WEEK

and 6 hours away was a BIG "NO" the first year we heard about the camp. How could I leave my tiny, low vision child for a week without her momma? The second year came around, and I was going to be in the area for school myself, so we decided to let her go. After visiting the facilities and seeing how organized it was the day of drop off, I felt so much better about leaving her. The school has registration down to a science. Everyone was so welcoming and helpful. I was scared about her leaving campus for activities, but I felt like she would be taken care of by the staff I met. The dorms appeared very secure. On the day of pick up, Ally was so excited about her experience that she didn't want to leave. She couldn't stop talking about the places she went and the things she learned to help her live independently in a world she has trouble seeing. Ally met some great friends, exchanged phone numbers, and they still communicate today. I wouldn't hesitate to send her back!"—*Chaz Baker, Parent*

"TSBVI Summer Programs is something I look forward to every year! They have fantastic activities that are so fun, but it's not really about that for me. It is more

(cont.)

Summer—continued

about the amazing community you experience there. Unlike my school, when I am at TSBVI everyone relates to you and you feel like you truly belong.”—*Sarah Menefee, High School Student*



Ally and Sarah ride the city bus for an off-campus outing during Summer Programs 2019.

“Sarah has participated in TSBVI Summer Programs since the summer before 6th grade. It is a safe, supportive community where she feels like she fits in. She always comes home having learned new skills as well as a BIG boost in confidence.”—*Nickie Menefee, Parent*

“As a parent, I feel that it’s very important for a visually impaired child to get the opportunity to interact with other children his own age who have similar challenges. It’s also important for them to be able to learn how to be independent and take

care of themselves and their belongings when away from home and parents. TSBVI provides an ideal environment for this to happen. I feel that we are very fortunate to have such a school available to us. My child, Mustafa, has definitely benefited from his experiences during summer camp at TSBVI.”—*Fehmida Vejilani, Parent*

“Our son Drody has been attending TSBVI Summer Programs for the past few years. Drody attends as a day student for the week long summer camp program where he learns daily living skills, practices traveling with his cane, and participates in social activities. Drody enjoys going to Summer Programs for the week. He meets new friends every year and enjoys getting to know the teachers and staff. They take him to shop in grocery stores where he learns how to pick



Drody and his teacher grab a bowling ball for his upcoming turn. He won the game!

out items & place them at checkout counter, bowl with friends, ride the metro train into town, eat out in restaurants, and go to the pool for swimming. Drody also gets to make lots of crafts and participate in activities in the classroom. Music class is another fun activity he enjoys while at TSBVI! Drody looks forward to going every summer to make new friends and experience new activities. Our son has some medical needs, and the Health Center staff on campus is excellent in providing his medicine on schedule while being adequately prepared for emergencies. Everyone knows the sensory issues involved with Drody's eating and is professional in their treatment of him during meal times! TSBVI Summer Programs is a great place to go where the school and staff are well trained and familiar with the issues we go through on a daily basis!"—*Jackie and Mitchel Pitre, Parents*



Drody uses a blender to make himself a smoothie.



Mila mixes the ingredients to make soap.

"TSBVI Summer Programs forever changed how we view summer! It's a time for Mila to look forward to camp, just like our other child. They both go to the most fun camps where they try new things, meet life-long friends, stay up late bonding with peers, and develop the skills needed to be away from home. TSBVI has provided us with a wonderfully planned camp, with first class staff trained to help our visually impaired child. We feel Mila is not only thriving and extremely happy, but incredibly safe with the staff and medical personnel ready to assist at any point. Mila has met her closest friends through TSBVI Summer Programs, which provides us with year-round play dates and other parents to share any joys or concerns with. Above all, we have gained further involvement with other TSBVI programs that help our daughter as we navigate her school years. We are forever grateful."—*Shelley Berger, Parent*

(cont.)

Summer—continued

“Summer camp is really fun because I get to see all my Braille friends. I really like the rec center because that's where we do talent shows and play games. We also get snow cones at special events! I like spending the night at the dorm because it feels like my home, except I have a roommate, so it feels like a sleepover!”—*Mila Berger, Elementary Student*

“We adopted our son several years ago from China. He had received no vision services at all. He is legally blind and hadn't had access to glasses, optical devices, a cane, or anything else. That was in 2014. Joseph was able to attend Summer Programs in 2019 after showing the ability to voice his feelings, concerns, and be a self-advocate. Initially, I was concerned about whether he would be ready for a camp away from home. Would he do well without me around? I suspected he would be fine, but the moment I met TSBVI staff, I was sure he would be fine. I could not have been more pleased and assured that our son was safe and in capable hands. Joseph attended camp where he was able to make food, meet friends, and come away feeling confident. In fact, Joseph had such a wonderful time that he would love to attend the school full time. The classroom environment was so conducive to learning. Joseph showed his art projects to everyone and greeted his teachers and staff enthusiastically. Joseph was a little nervous at first, but by the end of the program, he was familiar with the campus and could show us where to go. His favorite part of

the program was learning about the eye, especially the optic nerve. He had a great time with his roommate, telling stories and laughing together. The whole experience left me feeling encouraged and excited to see if we make the list for next summer.”—*Casey Powers, Parent* ◆



Joseph uses a coding app on the iPad to fly a drone during Summer Programs.

If you are considering referring your student to TSBVI Summer Programs, please refer to the helpful tips provided in this issue of *TX SenseAbilities* on page 20!

Usher Syndrome Coalition USH Connections Conference - Perspectives from a First-Time Parent Attendee

Angela Anker, mother of a 6-year-old boy who has Usher Syndrome

Abstract: The author describes her experience at the 2019 Usher Syndrome Coalition USH Connections Conference held in Philadelphia this past July. This conference provides an opportunity for those impacted by Usher Syndrome to learn about the latest developing treatments from leading USH researchers while connecting with hundreds of impacted individuals, their families, and professionals serving the DeafBlind community. There were over 300 attendees.

Keywords: Usher Syndrome, community, knowledge, conference, DeafBlind, family

This past July, we attended our first Usher Syndrome Coalition USH Connections Conference. As first-time parent attendees of this conference, my son's dad and I, like others, came for answers. We were relatively new to our son's diagnosis and hoped we would make some new connections and gain knowledge about Usher Syndrome. We had no idea what to expect.

When we first got our son Michael's diagnosis of hearing loss, we wasted no time learning as much as possible so we could make educated decisions for our baby boy. We worked our tails off advocating for his needs and ultimately found a new normal. It wasn't until four years later, when we got pregnant with his little brother Austin, that we decided to go ahead and run the newest set of genetic tests for hearing loss. Our older son, Michael, in addition to deafness, had always had a more challenging vestibular system than most deaf kids but we never considered another condition. The genetic testing came back, and Michael was diagnosed with Usher syndrome type 1C, which we discovered was causing his balance issues. When we learned of his Usher

diagnosis, we sat on this information for a while. It was like understanding a foreign language filled with undesirable outcomes. This became an emotional secret we shared with no one because, let's face it, you can't fully understand the idea of the unknown. We grieved separately and silently. We kept thinking, "What now . . ."



The Anker Family

(cont.)

Ultimately, the idea of “no known cure” sank in. I would stay up late researching and networking on Facebook and online. When I learned about the conference, I knew we had to go.

We attended the USH Connections Conference knowing we had to bring home strength for our family. We found that and more. It was exactly what we needed. As a result of the conference, we were able to really accept a fulfilling future for our boy. Meeting people and feeling a part of a larger community made this process less scary for us, similar to how we found a “new normal” after the hearing loss diagnosis. It’s one thing to research and network online, reading about the science and the hope, but meeting people in person, hearing

face-to-face how parents ahead of us in this journey have dealt with things, was priceless. It was calming, inviting, and so informative.

Our big takeaway from the conference was, “Talk about it (Usher Syndrome) a little, a lot”. We don’t know if we’ll be able to attend the conference in Austin next year, but we hope to. If you haven’t attended before and have the opportunity, I highly recommend it. Hopefully, like us, you’ll leave with more connections, information, and hope. Michael has blazed his path through deafness and I know with the right support team, he can be ready for what comes his way. It is still scary, but now we know that we are not in this alone. ◆

USH2020 IN AUSTIN, TEXAS

12th Annual USH Connections Conference

Friday and Saturday, July 10–11, 2020

The Usher Syndrome Coalition's annual event, the USH Connections Conference, is the largest gathering of our global Usher Syndrome community.

Join us for this invaluable opportunity to learn the latest on developing treatments from leading USH researchers while connecting with hundreds of affected individuals, their families, and professionals serving the DeafBlind community.

NEW: We are adding Friday programming to give you a chance to make even more connections at the USH Connections Conference! Hotel group rates will be available Thursday through Sunday. Details to follow.

WHEN:

Friday and Saturday, July 10–11, 2020

WHERE:

Omni Austin Hotel at Southpark
4140 Governors Row
Austin, Texas 78744

Stay tuned for Conference Registration and Hotel Reservation Details!

QUESTIONS? CALL US!

Toll Free: 1-855-998-7437 (1-855-99-USHER)

Toll: 1-978-637-2625

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Documenting Progress in Active Learning

Kate Hurst, Education Consultant, TSBVI Outreach Programs

Abstract: Kate Hurst explores the difficulties surrounding documenting progress for students whose educational team members use an Active Learning approach, a technique for teaching students who are learning skills within the range of 0–48 months in child development. She explores what documenting progress means according to IDEA, and offers simple solutions for measuring and reporting progress as exhibited by these students.

Keywords: Active Learning, Lilli Nielsen, IDEA, tracking progress, IEP, benchmarks, diagnostic teaching, portfolio, Functional Scheme, assessment, evaluation

Educational teams must document skills in a student's IEP and may also track skills not specifically noted in a learner's IEP goals. This may present a challenge when a child has significant and multiple disabilities. If the team is using the Active Learning approach developed by Dr. Lilli Nielsen, tracking progress is sometimes even more challenging, as growth can occur in tiny steps and may take many months to become evident. This is why documentation is so important for these students. They don't have time to waste on ineffective programming.

IDEA and Documenting Progress

The Individuals with Disabilities Education Act (IDEA) provides clear information about what should be the focus of documenting progress in the IEP for students with disabilities.

IDEA states that each child's IEP must contain:

(3) A description of—

(i) How the child's progress toward meeting the annual goals described in paragraph (2) of this section will be measured;

and

(ii) When periodic reports on the progress the child is making toward meeting the annual goals (such as through the use of quarterly or other periodic reports, concurrent with the issuance of report cards) will be provided...[§300.320(a)(3)]

This means that specific skills that are included in the IEP must be measured through periodic reports, report cards and review as part of the IEP meeting. This information informs the IEP team about the effectiveness of their instruction.

If no progress is being made, it might be that the skills targeted in the goal are not appropriate for the learner. It might also mean that the instructional strategies that are being used simply aren't working. It also might indicate regression which could occur as a result of problematic aspects like medical issues or emotional challenges. If the student demonstrates a skill in only one environment or activity and not anywhere else, perhaps the less successful learning environments or activities need to be re-examined.

(cont.)

It is also important to develop goals and benchmarks appropriately for all students. Teams must ensure that these are written clearly so that everyone knows the exact skills on which to focus during instruction. For example, "Joey will use a visually directed reach" references a specific skill that can be demonstrated. A statement such as "Joey will use a Little Room", does not specify a skill that the student can perform. To ensure that the Little Room is provided as a necessary way to access information for a particular student, include it as part of that student's Assistive Technology in the Accommodations and Modifications section of the IEP.

Benchmarks (or objectives) take the larger goal for the school year and break it down into much smaller steps. Children who benefit from Active Learning typically are slow to make progress, and those smaller benchmarks help to chart the important little steps they make. These steps are invaluable in documenting progress. They also serve to help the team evaluate instruction so they don't waste time on activities that are not helping the learner make progress. Diagnostic teaching, which is tied to the monitoring of ongoing progress, allows the team to make adjustments to the program quickly as the need arises. Benchmarks indicate a clear timetable throughout the year for reviewing progress.

A form is available on the Active Learning Space website that can be used to document progress towards IEP goals and objectives. To view the form and/or download a blank copy go to <http://bit.ly/ALDocument>.

Documenting Progress Using the Functional Scheme

The Functional Scheme is a checklist developed by Dr. Lilli Nielsen that helps to determine developmental skill levels across

all areas. We recommend that the student's Functional Scheme be updated at least annually. After the initial assessment, the columns for *Learning has begun*, *Performed in favorable conditions*, and *Performs spontaneously* provide important information about a student's progress in attaining skills. The team may want to review the Functional Scheme more frequently, especially if they see new skills emerging or notice regression.

We also encourage the educational team to work in pairs to score and update the Functional Scheme. The entire team can then review the results and reach agreement on the scores. The parents or primary caregivers are critical to this process. They know the child best and are likely to be the only individuals who are consistently in the learner's life as he or she progresses through school.

To learn more about how the Functional Scheme can be used to track student progress, visit Active Learning Space at <http://bit.ly/ALFunctionalSchemeTips>.

Student Portfolios

Another way to document progress is a Student Portfolio. A Student Portfolio contains examples of what the student does.

Examples could include videos of a student in a learning environment, an observation form related to skills demonstrated during observations, artifacts such as art activities, anecdotal information from the members of the student's team, photographs, and charts documenting the student's biobehavioral states (alert, sleepy, etc.) throughout the day or medical challenges (seizures, medications) that seem to impact performance. It could also include an ongoing list or pictures of new objects the child interacts with, examples of an increased interest in exploring an environment, or connecting with a peer.

Below are some of the things we suggest including in a student's portfolio:

- Active Learning Materials and Activities Planning Sheet <http://bit.ly/ALPlanning-Sheet>.
- Functional Scheme summary page and other assessment summaries (OT, PT, and communication reports, Functional Vision Evaluation, Learning Media Assessment, eye doctor's report, audiological report, etc.)
- Video clip examples of the student in each learning environment (be sure to include short clips showing changes throughout the school year and throughout his or her educational career)
- Photos that show the student participating in activities; include examples of skills, important people in the individual's life, and other information that will provide insight about the learner
- Information about how the student communicates including the forms (speech, gestures, behavioral state changes, object cues), topics (people, places, actions, emotions), and functions (requesting, rejecting, commenting, questioning, expressing emotions, greetings) of the communications
- Important medical information (what people who don't know the child need to know such as how to respond to a seizure, signs of problems with a shunt, list of medications and possible side-effects to watch for)
- Copy of IEP goals/benchmarks and progress reports

Tools like LiveBinders, Google Drive or Dropbox can be used to upload items for sharing with the entire team. Be sure to check features to protect student confidentiality before using online resources.

Parents, caregivers, and staff may want to compile a sample of photos, videos, and observation forms into a PowerPoint presentation to share with a new educational team entering the student's life. These are also great for service providers outside the educational system (babysitters, respite providers, home nurses, etc.) to help them understand the student better.

Conclusion

Children who are involved in Active Learning may take a long time to show big changes, but little changes are worth celebrating. Documenting progress is an important part of any instructional program.

To learn more about documenting progress for students using an Active Learning approach, please visit the Active Learning Space website at www.activelearningspace.org. ◆



A student uses a "Position Board" to explore the qualities of objects.

TSBVI Short Term Programs Information: Continued from page 14.

If you are considering referring your student to TSBVI Summer Programs, here are some things to remember.

- If you're curious about the TSBVI campus, we are happy to take you and your family on a tour of our campus and the areas specific to Summer Programs. Please reach out to Sara Merritt, Principal of Short-Term Programs merritts@tsbvi.edu, or Kathi Garza garzak@tsbvi.edu, Family Engagement Coordinator, for more information and scheduling.
- Summer Programs serves students who are blind, visually impaired, DeafBlind, and those who may have additional disabilities.
- Applications for Summer Programs will open on the TSBVI website in January of each year. The deadline for applications to be received for consideration is February 14th.
- Students who attend Summer Programs typically stay in the dorm to participate in residential programming with peers, but we do consider applicants who wish to only participate as day-students.
- During Summer Programs, families are expected to provide transportation for their children to and from TSBVI.

For more information about TSBVI Short Term Programs, visit:

<https://www.tsbvi.edu/short-term-programs>

TAER 2020: Envisioning Our Future

April 2–4, 2020

Embassy Suites, San Marcos, TX

1001 E McCarty Lane

San Marcos, TX 78666

Phone: (512) 392-6450

<http://www.txaer.org/conference.html>

Registration: <http://www.txaer.org/registration-638115.html>

LOW VISION CONFERENCE 2020: Accessing 21st Century Tech: What's Applicable, Available, and Affordable

Friday, May 1, 2020

**James C. Durkel Conference Center,
TSBVI, Austin, TX**

Keeping up on the ever-present impact of technology in regards to vision has become a critical part of the VI professional role. This extends beyond task completion in the classroom and workplace. This conference will present a range of topics related to current and evolving technologies.

REGISTRATION COMING SOON!

Teaching Braille to the Whole Child: Considering the Impact of Social and Emotional Development on the Acquisition of Braille Skills

Scott Baltisberger, Education Consultant, TSBVI Outreach Programs

Abstract: In this article, Scott Baltisberger offers teachers and families ideas for alternate routes to take when braille instruction isn't going well.

Keywords: social-emotional development, braille instruction, behavior, prompting, play, child-guided, self-directed, self-regulation, developmental approach, behavioral support

Some time ago, a Teacher of Students with Visual Impairments (TVI) shared information about one of her students. This child was eight years old, identified as visually impaired (VI) with no additional handicapping conditions, and enrolled in a general education second grade class. Her early educational experiences had been disrupted but she had made progress in braille and knew all the whole word contractions. In addition, she demonstrated good comprehension and verbal communication skills. Her reading rate was well below average, however, and she did not maintain focus on an assignment unless closely monitored and constantly prompted by an adult. The TVI expressed some confusion as to why this student, who seemed to have all the prerequisite skills, was unable to work at a level commensurate with her peers. The teacher was very concerned with this apparent lack of motivation or interest in learning and felt that this behavior was further distancing the child from both classmates and teachers. The last statement caught my attention. When we spoke, the teacher shared that the student was very immature for her age; she did not independently initiate or maintain

age-appropriate interactions with her peers, her topics were generally self-centered and focused on limited topics, and when left to her own choices, she typically played alone and chose activities that were more typical of a much younger child. She also had frequent bouts of disruptive behavior that the teacher characterized as “tantrums.”

I've found this profile—that of a student with all the prerequisite skills in braille but whose marked lack of participation and engagement in class has limited his or her progress—to be fairly common. Often, the situation is viewed as a “behavior issue” with the implication that it is the result of certain attitudes and choices on the part of the student. The “behavior issue” is often addressed by setting expectations that grade-level assignments will be completed and by providing rewards and/or consequences for compliance. For the student and for the teacher, the approach is not successful; student behaviors become more pronounced or extreme and there is a corresponding increase in the level of the teacher's response. All parties continue to escalate and the problem is worsened instead of alleviated.

(cont.)

In these situations, it may be helpful to view things from a developmental rather than a behavioral standpoint. Using this approach, we consider that there is always a functional aspect to a child's actions. What the child does or doesn't do communicates information about their needs, about what they are ready to do and what they are not ready to do. This directs us to provide instruction that targets the child where he or she is developmentally. Targeting skills at higher developmental levels will not be effective because skills develop sequentially. Earlier skills provide the base upon which higher skills are built. Higher skills cannot be built if foundational skills are not in place.

With braille instruction, we typically look at the development of skills and knowledge in the cognitive and physical areas. However, one factor often overlooked is that of the child's social and emotional development. This goes beyond simply identifying a child as being immature or having behavior issues and looks at actual assessment of the child's level of social and emotional development. Literacy instruction is organized to accommodate for needs at that level. The types of things in which a student likes to engage independently, without support or prompting, is a good indicator of his or her social and emotional levels. Observe the child during unstructured time and note their behaviors and choices. Notice how the child responds to or initiates social interactions. These can be compared to developmental scales to determine the current level of needs. It also helps to simply provide more of what the child is seeking.

Like other developmental areas, skills in the social and emotional domains occur sequentially, with beginning skills creating a

platform from which later, more sophisticated skills grow. If, for some reason, a prerequisite skill is inadequately or incompletely developed, the child will have difficulty acquiring the skills that are appropriate for his or her age. A student may be cognitively and physically capable of engaging in third-grade classroom activities but not be emotionally ready. Third-graders, for example, are expected to engage in topics that are of the teacher's choosing and to do so for extended periods of time. Students read passages and respond extensively to questions about the content. For a student functioning emotionally as a two-year-old, this would be confusing and exhausting.

In the scenario described at the beginning of this article, we determined that the student's behaviors were more typical of a two-year-old. For a typical two-year-old, successful activities are child-centered and child-led; they must be of high-interest and self-referential. A two-year-old is in the sensorimotor and preoperational stages of learning and is typically engaged in self-directed, exploratory activities. A two-year-old is not yet socially ready to be responsible for their own learning. It is critical that the adult spends time in bonding and interaction activities with the child who is at this emotional developmental level in order to develop a trusting relationship and to build basic self-regulation skills.

Using this developmental approach, the teacher began to spend a great deal of time playing games and engaging in topics of the child's choosing. Doing this required that the teacher expand her concept of what constitutes "teaching." While these interactions did not look like typical instruction for a second-grader, they were setting the developmental stage for more age-appro-



Left: Drawing of a sad braille reader. **Right:** Drawing of a happy braille reader.

priate learning to occur. Novel activities and topics were offered and the child was allowed to reject them. Braille instruction was slowly brought into the mix by incorporating it into the games and topics the child had self-identified as important. Support was also provided by the school's "Intensive Behavioral Continuum" classroom, which further focused on the student's emotional and social needs in a consistent and ongoing manner.

Two comments made by the teacher stood out to me: First, she mentioned that she realized how little she knew about her student before and that she had never really taken time to get to know her as she was, rather than as she wanted her to be. Second, while the amount of braille work the student produced independently was initially quite low, it was actually on par with the output she had previously achieved through prompting and support. In addition, the amount of indepen-

dent braille production increased substantially over time. The takeaway, for me, was that a more positive relationship between a teacher and student, combined with the student's experience of interest and success, resulted in higher levels of achievement and readiness for more challenging goals.

One and a half years after beginning to implement this approach, the TVI reported: "She is doing fantastic, and is now reading and writing on grade level, and participating in grade level math lessons! Math calculation is still way below grade level, but she is making progress with the abacus. Resource has been removed from her services. It's been amazing how her academics have grown since her emotional needs have been addressed. . . . Of course, we do have set-backs. . . but overall she is doing super great. We can teach her so much now!" ◆

SPEDTEX Special Education Information Center

Visit the SPEDTEX website for information and questions about special education. Information and resources are provided for anyone committed to the success of children with disabilities. Navigate through various sections such as Frequently Asked Questions, Educator's Corner, and Child Find. There is also a chat feature for immediate help.

The SPEDTEX website is a collaborative project between the Texas Education Agency and Region 10 Education Service Center.

More information is available at:

www.spedtex.org

1-855-773-3839

inquire@spedtex.org



Accessing Self-Determination Through a Creative Process

Kathi Garza, Family Engagement Coordinator TSBVI Outreach Programs

Chrissy Cowan, Mentor Coordinator, TSBVI Outreach Programs

Abstract: The authors describe a process for creating an informative product which will support students with low vision in advocating for visual needs in the home, school, and community.

Keywords: low vision, self-determination, self-discovery, instructional strategy, lesson ideas, self-advocacy, peers, accessibility, visual strategies, Short-Term Programs, Universal Design

For a student with low vision, navigating various environments and social situations can be difficult because he/she is not completely sighted but also not completely without vision. Teachers, peers, and family members might be confused when, at times, the student appears to be able to complete one task without any support, but then needs significant accommodations to complete another task. Eye fatigue, visual stamina, preferred optical devices or seating, and travel skills are just a few things that can vary by day, or even by class period, for a student with low vision. Additionally, seeking adult support when a student's needs aren't being met can be difficult. Peer situations can be challenging as well because the student lacks the language or self-determination to answer questions or stand up for themselves when peers ask questions about or "test" the student's vision, tease the student, or handle their devices without permission.

All of these challenges were taken into consideration when elementary-aged students with low vision attended a week-long Short-

Term Programs (STP) class at Texas School for the Blind and Visually Impaired (TSBVI). The goal for this class was for the students to build self-determination by creating an informative product to share with adults and peers in their school and community regarding their specific needs as an individual with a visual impairment. Self-determination includes choice-making, decision-making, problem-solving, personal advocacy, assertiveness, and goal setting. Students with visual impairment often have fewer opportunities to develop and practice the specific skills that lead to self-determination. People who know and value themselves and have self-determination skills can become effective advocates for themselves and therefore have more control over their lives.

Students who attend the STP class typically need guidance before they are ready to fully explain their visual preferences. The class objectives translated into activities that contributed to a self-discovery process which helped the students communicate about their visual needs.

(cont.)

EFFECTIVE PRACTICES

Self-Determination—continued

Class Objectives:

- Identify parts of the eye, visual impairment, and etiology-specific health concerns
- Discuss the impact of impairment on visual performance in the classroom and home environments
- Generate a list of low vision-specific tools and strategies that can be used to support visual access to instructional programming

The concept of creating a product was chosen because it is an informal and creative way to express information about the student's visual impairment and personal preferences. A product can be customised with relevant information for the intended audience: parent/caregiver, teacher, peer, or potential employer. Possible product formats include:

- Collage or Poster
- Informative Business Card
- Brochure
- Picture Book
- PowerPoint or Google Slides
- Song or Poem
- YouTube Video
- Documentary (e.g., *A Day in the Life*)

When teachers create a product with their student, mastery of technology is not the focus. Teacher support with typing, researching, and using desired programs or applications may be necessary, but students should be responsible for designing and selecting the appropriate information to include in their products. It's not necessary for the student to commit to a specific product format



Cameron proudly shares information about her eye condition using the poster she created as a guide.

before the process begins. A product format will emerge as students explore feelings about the constant need for self-advocacy and how they are perceived by others.

The STP class objectives and activities detailed in this article can easily be replicated by itinerant TVIs with a single student over an extended period of time. This allows the TVI and student time to individualize the activities and develop specific skills needed by the student.

Eye Condition

Learning about the eye and their specific eye condition can support students in advocating for visual or access needs. During class, students participated in the activities on the next page to help improve their understanding of how the eye works.

Student Activities:

- **Model Eye:** Students used common objects to represent each part of the eye and read a script that contained information about the function of each part. A favorite was the use of gelatin to represent the vitreous humor.
- **The Visual System:** Using diagrams and a video from the National Eye Institute, students reviewed the name and function of each part of the eye and participated in a discussion on the process of seeing. Students were later tasked with ordering each step in the process.
- **Edible Eyeball:** Using the information they had gained throughout the week and some common food items such as twizzlers, campfire marshmallows, and gummy Life Savers, students created an Edible Eyeball model to enjoy for a snack.

Students also had the opportunity to re-search their visual impairment and ask any specific questions they might have. They often reported that talking about their visual impairment is “annoying,” but in many cases, students lacked the knowledge and language to explain their condition and how it relates to visual functioning in terms that peers and teachers can understand. The information about their eye condition was used as a component of the final product.

Impact of Impairment on Visual Performance

Before a student can create a product that communicates visual needs and preferences, they have to understand the impact of their vision on daily tasks across environments. The following activities were used to clarify the impact of impairment on visual performance and to develop self-determination and



Front view of edible eyeball showing a green gummy Life Savers iris attached.



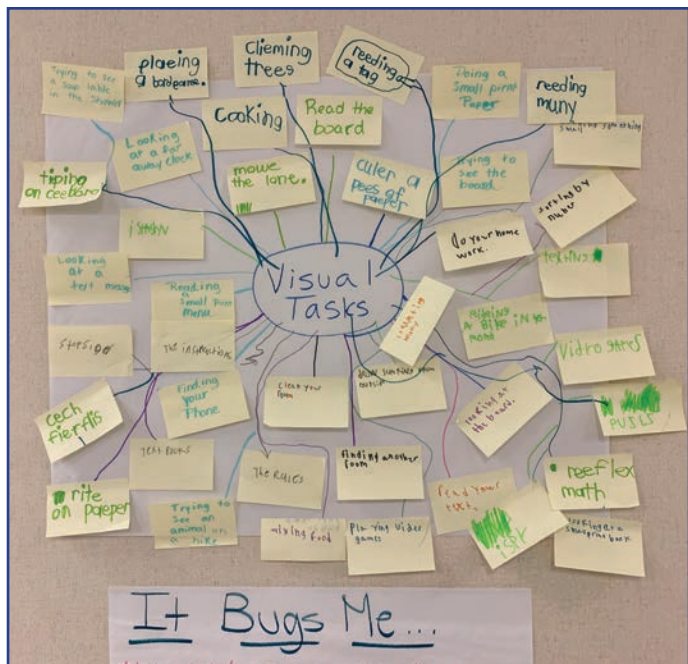
Back of edible eyeball shows a sour belt retina with a licorice optic nerve sticking out.

(cont.)

EFFECTIVE PRACTICES

Self-Determination—continued

problem-solving skills to use when facing challenges in the home, school, or community environment.



*Students collaborated to create
this Visual Tasks Web.*

Activities to support this objective included:

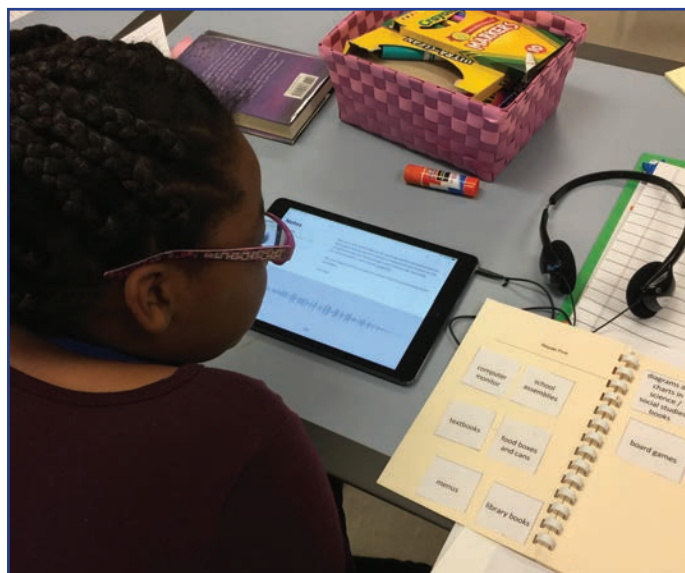
- **Creating a Current Access Book:** To begin this activity, students generated a web of visual tasks required in home, school, and community environments. Some examples of visual tasks included reading soap labels in the shower, playing video games, reading the board, completing homework, seeing math, reading websites at school, and identifying plants and animals in nature.
- After activating prior knowledge of visual tasks, optical devices, and low vision strategies, students were asked to sort some typical tasks, printed on strips of paper, into categories that indicated how they gained access to those tasks. Pages in the Current Access Book were labeled with the headings regular print, large print, optical devices, ask for help, or cannot perform. The students glued

the strips onto the page that indicated the access strategy that they used for that task. As the week of instruction continued, students revisited the books and discussed ways to move tasks into different access categories by using a learned strategy.

Tools and Strategies

As they move through school, students with low vision may have experimented with an assortment of technology and strategies for access that may or may not work for them. Another objective of this class was to assist them in creating a list of practical low vision-specific tools and strategies that can be used to support visual access and to communicate preferences.

The following activities center around the topic of tools for access, as well as exploring strategies for improved performance and clarifying their visual needs for others:



Tylar refers to her Current Access Book and selects relevant information to add to her final product.

- **Exploring Assistive Technology:** Completing an assistive technology (AT) survey is an activity that helps clarify current strategies for access. It helps students consider challenges presented by some tasks and the tools used to navigate them. The Google Forms application was used to create a simple digital survey with questions about how vision affects the student's access to information at home, in school, and in the community (a copy of this survey is available on the website version of this article). The survey required students to select examples of tasks for which they use AT. In addition, students were given a list of different types of AT they might use and asked to select all that apply. Examples included low tech (e.g., bold-lined paper and flair pens), middle tech (e.g., optical devices, talking or large print calculators, and adapted science equipment), and high tech (e.g., video magnifiers, tablets, smartphones, and screen magnification software).
 - **Accessibility and Universal Design:** As students seek to educate others about their visual needs, an important concept for them to understand is the role that universal design plays in accessibility. For example, lighting, signage, font, contrast, marked steps, and positioning of furniture and materials are all elements of universal design for students with low vision. An activity was created that included a discussion about design, what it means, and the people it benefits. The class discussed universal design—that is, designing things so that most people can use them—and how someone with a disability accesses or benefits from something that is designed for increased access.
 - **When I Can't See. . . :** This problem-solving activity was designed to help students identify reasons why they hesitate to speak up when they cannot see in class or other locations. The activity was introduced by asking: "Are there times when you are asked to complete an assignment or do something that you can't see clearly? Can you give me some examples of these things?" Some student examples included:
 - Drawing an object viewed outside the window
 - Reading a story from the board and answering questions within a limited amount of time.
 - Taking a timed test
 - Ordering from a menu in a restaurant
 - Finding friends in the cafeteria or playground
 - Watching an assembly
- Once these examples were generated, the students were asked, "Why do you think you are hesitant to say anything about not being able to see clearly or complete the task?" Some reasons reported by students included not wanting the other kids or teachers to think they are stupid, not wanting to be teased, not wanting to get anyone in trouble, and not wanting to make the teachers frustrated by making their jobs harder. After students had the opportunity to feel heard, they began to generate a list of strategies to use to advocate for themselves. A popular solution was a combination of ideas where students would request to meet with the teacher privately and develop a secret signal to use in class to show that he/she needed some additional support.

(cont.)



This 'When I Can't See' poster demonstrates how students navigated through the problem solving process as it related to visual access.

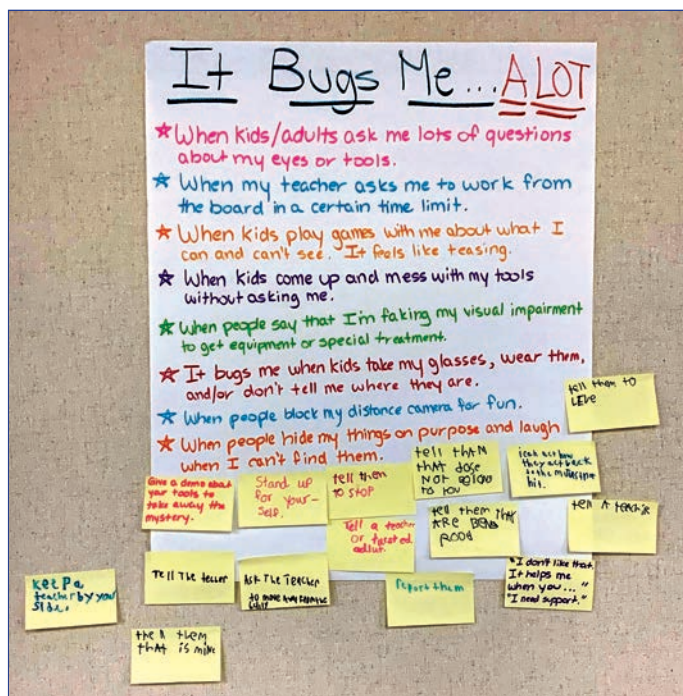
- It Bugs Me: It is not uncommon for a student to feel annoyed by assumptions made about their vision and/or negative attention to the way they complete visual tasks. This empowerment activity was designed to encourage students to share their feelings about frustrating or uncomfortable situations they encounter. To end on a positive note, this activity required them to identify solutions so that, going forward, a student could take control over his/her own feelings and situations at home, school, and in the community. Some examples of situations that bugged students included times when:
 - kids ask lots of questions about their vision and tools
 - kids take/hide their tools without asking

- kids play “can you see” games with them
- people accuse them of faking their visual impairment
- parents won’t let them cross the street or use the stove

Some solutions included talking to trusted adults, talking to the class about your impairment or tools, standing up for yourself, and using “I statements.”

- **Life Goals:** A nice addition to the student's product is a bit of information about his/her personal goals. For this reason, a lesson was created to address this topic. During this activity, students discussed their dreams and goals. They wrote down 1–3 personal goals, then discussed how their vision may impact the process of achieving each goal, what steps they need to

Continued on page 34



'It Bugs Me' poster with shared ideas for how to handle intrusive comments from others.

What is Specially Designed Instruction for Students with Visual Impairments? Part 2

Dr. Kitra Gray, sponsored by Region 11 Education Service Center

Abstract: The Summer 2019 issue of *TX SenseAbilities* introduced an article on specially designed instruction (SDI) for students with visual impairments. The excerpt below explains the first component of IDEA's mandate, adapting the content, and how it may differ for students with visual impairments. The other two components of SDI, adapting the methodology and the delivery of instruction (IDEA § 300.39 (b)(3).), will be featured in future issues of this newsletter. Dr. Gray's entire article can be viewed at <http://bit.ly/DrKitraSDI>

Keywords: specially designed instruction, SDI, local education agency, LEA, unique needs, Expanded Core Curriculum, ECC, IEP

Component I: Adapting the Content

Usually when educators think of adapting the content, they focus on the state curriculum content standards. However, the Texas Education Agency (TEA), *2017 Guidelines and Standards for Educating Students with Visual Impairments in Texas* (2017, p. 6) state that "In addition to the general education curriculum all students with visual impairments, starting at birth, also need an **expanded core curriculum (ECC)** to meet needs directly related to their visual impairment (TEC 30.002, Subsections (c-1) and (c-2))." Thus, when considering adapting the content for students with visual impairments, the ARD committee must consider two content areas:

1. General education curriculum
2. Expanded core curriculum (ECC).

This additional content area, known as the Expanded Core Curriculum, is essential for students with visual impairments so they can graduate ready for further education, employment and/or indepen-

dent living as required by the purpose of IDEA. Meeting this IDEA purpose "is a key role of the TVI [teacher of students with visual impairments] and the Expanded Core Curriculum for Students with Visual Impairments..." (AFB, n.d., p. 5).

According to the *2017 Guidelines and Standards for Educating Students with Visual Impairments in Texas* (TEA, 2017, p. 6), the Expanded Core Curriculum includes:

- Compensatory skills that permit access to the general curriculum (such as braille and concept development, tactile graphics, Nemeth Code, and specialized communication skills)
- Orientation and mobility skills
- Social interaction skills
- Career education and planning
- Assistive technology, including optical devices
- Independent living skills
- Recreation and leisure skills
- Self-determination, and
- Sensory efficiency (including visual, tactual and auditory skills).

(cont.)

The guidelines do not indicate that one area of the ECC is more important than another area. They are all equally important for students with visual impairments. Therefore, for the ARD committee to appropriately develop an IEP for a student with a visual impairment, the committee must have access to four types of evaluation/assessment data:

1. Functional vision evaluation (FVE)
2. Learning media assessment (LMA)
3. Expanded core curriculum (ECC) assessments (in all areas)
4. Orientation and mobility (O&M) evaluation.

“The FVE, LMA and ECC assessments are the main specialized assessments for students with visual impairments that form part of a comprehensive evaluation for eligibility” (Zebehay, et.al. 2017, p. 39). In addition, in Texas, the Orientation and Mobility Evaluation is also a requirement of the initial and continuing eligibility of a student with visual impairments (SBOE § 89.1040 (12)(B).). So, all four evaluations/assessments are required both at the initial evaluation and at the three-year evaluation. IDEA is clear that a comprehensive evaluation must address both eligibility and “content of the child’s IEP” (IDEA § 300.304 (b) (ii).). Furthermore, “these specialized assessments should be considered a ‘living document,’ meaning that they should be updated frequently enough to maintain a record of the student’s functioning and to assess current and future needs that may change with age, grade level, or visual prognosis” (Zebehay, et.al. 2017, p. 39).

Therefore, specially designed instruction for students with visual impairments must consider “two equally essential and interrelated curricula, the general curriculum and

the expanded core curriculum. . . . The first is the core curriculum which consist of all skill areas that are common to all students” (Holbrook & Rosenblum, 2017, p. 205). The second curriculum, the ECC, is important because “after analysis, there is evidence that there are numerous significant relationships between the receipt of instruction in expanded core curriculum (ECC)-like content areas and meaningful outcomes, such as employment, postsecondary training, and engagement in social activities” (Wolffe & Kelly, 2011). Thus, the expanded core curriculum is an “integral and indispensable component of the [general] curriculum, not skills that are considered extra or for enrichment” (Holbrook & Rosenblum, 2017, p. 205).

When devising an IEP for a student with a visual impairment, the ARD committee needs to address both curricular areas because one area can impact the other. For instance, the general curriculum may need to be adapted because the braille reading curriculum is commonly not aligned with the general education reading curriculum. Braille instruction includes learning symbols and contractions of words that frequently need to be introduced in a different order than letters and words in the traditional reading curriculum.

Another example is sometimes a student with a visual impairment may not be reading on grade level because of proficiency with braille, not because of the student’s ability to learn. Braille takes more time and practice than visually reading print. Learning braille can also be impacted by other disabilities or the age when the student’s vision was impaired. So consideration of adaptations of both curricula, general curriculum and braille curriculum (part of the ECC), must be addressed simultaneously as one can impact the other.

The Texas Perspective

Emily Coleman, Superintendent, Texas School for the Blind and Visually Impaired

Abstract: Superintendent Emily Coleman shares her insights and introduces Kate Borg, newly appointed TSBVI Outreach Director.

Keywords: outreach, student support, statewide, independent school district, ISD, education service centers, ESCs



Superintendent Emily Coleman (left) with new Outreach Director Kate Borg (right)

On August 1st, I moved from the position of Outreach Director into the role of Superintendent at TSBVI. My entire career to this point had been spent focusing on students who were visually impaired (VI), blind, or DeafBlind served in local independent school districts (ISDs). Starting as an itinerant teacher of the visually impaired, those were my roots. Therefore, my perspective has always been statewide, and that hasn't

changed with my new office setting. Let's call this the "Texas Perspective," because it requires big thinking.

Regardless of the department at TSBVI, or the programs housed within, we work for the benefit of all students in Texas. We're providing research-based academic and enrichment programs for students who are here all year or just for a week. If we don't have

(cont.)

students physically on our property, we're collaborating with experts outside of TSBVI to develop strong programs for them in their home communities. We're solving problems that will be shared with our field and creating trainings that will meet the needs of teachers and families. We are here when any of the almost 11,000 students identified as blind, VI, or DeafBlind in Texas need us for any level of support.

Luckily for TSBVI, our new Outreach Director, Kate Borg, also has the "Texas Perspective". Kate is coming to us from the Utah Schools for the Deaf and the Blind where she most recently served as Director of Blind Educational Services. Kate has also worked as a university instructor, instructional coach, classroom teacher, itinerant teacher, and in a family support

role. She's leading the Outreach department with a heart and background for each of the almost 11,000 students with visual impairment or DeafBlindness in Texas.

Kate joins a team of individuals at TSBVI that is dedicated to Texas and to our students. As we continue through the 2019–2020 school year, we'll be thinking more about each of those 11,000 students, as well as the ones we may be missing, and working to determine what is needed to make sure they are set up for success. We're lucky to have statewide partners within universities, ISDs, and ESCs that have extensive expertise, and we benefit from our collaborative efforts. Together we're all building a culture of improved student outcomes, not only with a Texas Perspective, but also with a Texas Passion. ◆

Self-Determination: Continued from page 30

take first, and who may be able to help them. For example, one student wanted to be a collegiate gymnast, so she included the UCLA logo with her text about how she could achieve this goal. Another student's goal was to be a performer, so she created and performed a rap as the format for her entire product. These kinds of discussions can lend themselves to future lessons related to the access tools and strategies the student will need to achieve their life goals.

Each of these activities was designed to contribute to a comprehensive product that the student can use to communicate their challenges and preferences for visual ac-

cess across environments. This product is designed to grow and change with the student throughout their years in an educational system, and even into a work environment. Before launching their product with others, students should first practice with their TVI and family. The goal is to empower the student in a fun, creative, and individualized way. ◆

References:

<https://www.perkinselearning.org/accessible-science/activities/edible-eyeball>

Success Stories of the Texas Workforce Commission's Summer Earn and Learn Initiative

Tammy Winkenwerder, Program Specialist for Transition, Texas Workforce Commission

Abstract: The Texas Workforce Commission's Summer Earn and Learn (SEAL) Initiative provides work readiness skills training and work experiences for students who are blind and visually impaired. Employers who participated in SEAL also benefited by becoming aware of how a person with a disability can contribute to the production and goals of their business.

Keywords: Texas Workforce Commission, TWC, Vocational Rehabilitation, VR, employment, work-readiness skills, training, work experience, SEAL program, work experience trainer, job skills trainer, advocacy

In 2017, the Texas Workforce Commission's (TWC) Vocational Rehabilitation (VR) program launched an initiative for students with disabilities called Summer Earn and Learn (SEAL). SEAL is a partnership between the VR program and the 28 Local Workforce Development Boards around the state of Texas. During SEAL, students with disabilities learn work-readiness skills and obtain work experience through various summer job placements. Here are a couple of examples of students who are blind and/or visually impaired who benefited from their participation in SEAL as well as how SEAL benefited an employer.

Savannah

Savannah attended SEAL in summer 2019. She loved her summer job at True Value in Sinton, TX. She was there for 5 weeks. When she told her mother about her work day, she used the word "we" when talking about selling a lawnmower and Weed Eater

to a customer. She felt like part of a team. Her job duties included sweeping, mopping, cleaning and stocking shelves and helping customers. She learned where products were in the store and was able to direct customers to find the products they needed. She reported that staff treated her well and she was thankful for getting the opportunity to participate in SEAL. She also learned how good it felt to earn a paycheck and she used the money to treat herself to clothes and breakfast!

Maycie

Maycie has participated in SEAL for the past three years. In 2017, she worked as an administrative assistant for United Way. Although she had a difficult first day at work trying to find her way to her work site, everything else went smoothly thanks to the help of a work experience trainer. She learned to advocate for herself, and she changed the staff's percep-

(cont.)

Summer Earn and Learn Initiative—continued

tions of people who are blind. In order to show their appreciation of her work, they gave her a surprise going-away party when she left the program that summer.

In the summer of 2018, Maycie worked for the food bank in Houston, TX. She greeted everyone at the front door and continued to ask for additional job duties. She also worked in their cafeteria and call center. In 2019, she worked for the Young Men's Christian Association (YMCA). She greeted customers and cleaned equipment. At each job site where Maycie worked, the staff was amazed by her abilities. She gained various skills in these work experiences which contributed to her setting future goals of attending college and being a Business Enterprises of Texas (BET) manager.

SEAL is not only a benefit to students with disabilities but to employers as well. The

Golden Crescent Workforce Board placed three SEAL interns at the United Postal Service (UPS) Store and Rapid Printing in Victoria, TX. The UPS Store and Rapid Printing are two small businesses that share the same owner and are side-by-side in a location. The students split their time between the UPS store and Rapid Printing. They were also provided job skills trainers through a TWC provider, G.R.A.C.E (Getting students Ready for Advanced and competitive Careers through transition Employment training) Transition Education Services. This was the first time the UPS store and Rapid Printing hosted a work site for SEAL. Pete Muñoz, the general manager for both locations, took the interns under his wing and provided mentorship and training to each. In addition to training on the customer-service-related duties at the store, the interns received training on how to operate the in-house advertisement design software. The interns used this skill to design flyers, posters, and event tickets for an event called *Small Business Night at the Park*. Pete reported that the interns have been an excellent addition to the store and that "the Summer Earn and Learn interns are willing to do anything that they can do to help."

SEAL has proven to be a life-changing program for students with disabilities and employers around the state. It has helped students gain skills needed for successful future employment and has helped employers see the benefit of giving people with disabilities a chance to contribute to the job market. If you would like to know more about the Summer Earn and Learn program, please contact your local Vocational Rehabilitation office and speak to a Vocational Rehabilitation counselor. Your local office can be found here: <https://twc.texas.gov/offices/vr-general-services.html>. ♦



Maycie at her desk as Administrative Assistant at United Way during her SEAL placement.

Navigate Life Texas Website

Debbie Bridge, Office of Primary and Specialty Health, Health and Human Services Commission

Abstract: The Navigate Life Texas website is a valuable resource for parents of children with disabilities.

Keywords: parent support, Navigate Life Texas, NLT, HHSC, disabilities, DeafBlind, empowerment, resources, special healthcare needs

The Navigate Life Texas (NLT) website www.navigatelifetexas.org, a project supported by the Texas Health and Human Services Commission (HHSC), launched June 2015. It was created to inform and empower parents of children with disabilities or special healthcare needs. Healthcare, education, insurance, medical diagnoses, transition to adulthood, and how to connect with other parents are among the many topics found on NLT. Here, parents share their perspectives on challenges and rewards they have faced, revealing their valuable first-hand experiences.

Navigate Life Texas was developed by parents for parents. Most of the content is written by parents of children and adults with disabilities or special healthcare needs. There are blogs of personal experiences, along with videos of parents and their families. Sign up today to receive Navigate Life Texas newsletter.

Here are some articles and resources on the site with content related to blindness/visual impairment:

- Support for Families of Children Who Are Blind or Visually Impaired
- DeafBlind with Multiple Disabilities (DBMD)
- Funding and Grants for Children with Disabilities
- Find Services, Groups, and Events - Enter "blind", "visually impaired", or "DeafBlind" in the keyword searches to see relevant resources and events. Results can then be narrowed down by entering a ZIP code. 📍



A young girl uses a cane and holds her mother's hand to explore a park with her parents.



Navigate Life Texas
For families raising children with disabilities

Texas Focus 2020

Self-Determination: Building Positive Futures for Every Child

February 27–29, 2020

Join us for Texas Focus 2020 as we explore tools and strategies to empower all children with visual impairments. Sessions will focus on ways to provide children with greater voice, meaningful options, and increased participation in their lives.



Learning Objectives:

- Participants will develop strategies that will assist their students in advocating for their unique needs.
- Participants will increase their knowledge of effective strategies for students with complex communication needs.
- Participants will explore ways to enrich students' lives through involvement in creative arts.

For more information regarding Texas Focus, please visit the Texas Focus web page.

<https://www.tsbvi.edu/tx-focus-info>

REGISTRATION OPEN NOW!

SDI -Continued from page 32

What is Specially Designed Instruction for Students with Visual Impairments? Part 2
by Dr. Kitra Gray

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ANNOUNCING: *Tomás and the Case of the Mysterious Missing Dog*

Scott Baltisberger, Education Consultant, TSBVI Outreach Programs
Chrissy Cowan, Mentor Coordinator, TSBVI Outreach Programs.

Article Illustration: Scott Baltisberger

Abstract: The authors describe a new book and video available as free downloads from the Publications page of the TSBVI website. Created for elementary students, Tomás relates how a young student uses his low vision devices to join friends in the search for his missing dog. Teaching strategies and accessible drawings are also provided.

Keywords: optical device, low vision device, magnifier, monocular, low vision, elementary

Inspired by the *Monocular Mac* booklet created by Dr. Anne Corn in the 1970's, *Tomás and the Case of the Mysterious Missing Dog* is an illustrated narrative story intended to inspire students with low vision to explore the many possibilities in which their optical devices and strategies can be helpful, not only in the classroom, but in real-life settings and situations. Intended for elementary readers, the tale relates the adventures of Tomás and his friends as they search for his beloved dog who has escaped the yard. Tomás is able to fully participate in this adventure with the magnifier and monocular skills he has learned from his TVI and COMS.

Forty-two cleverly detailed ink-pen drawings by Scott Baltisberger are visually accessible to students with low vision and bring the story to life. Teachers can use the booklet as a teaching device, guiding students through the process of using a magnifier to locate some of the picture details mentioned in the story, and expanding on the concept of monocular use in their own community.

The book is available for free download in digital format, with an accompanying dramatic

reading production (video) of the complete story. Lowell Bartholomee with TSBVI Outreach produced the video, directing students from TSBVI through an upbeat and lively performance of the story, complete with lots of expression and sound effects. The book and video can be found on the Publications page of the TSBVI website <https://www.tsbvi.edu/publications/6025-tomas>. The original webinar presentation from May 2019 with Scott and Chrissy describing the project and the actual video performance can be found at <https://library.tsbvi.edu/Player/18691>. ●

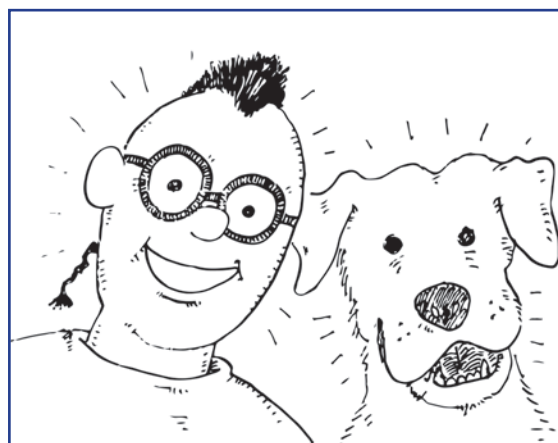


Illustration: Scott Baltisberger

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www.tsbvi.edu/tx-senseabilities

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To request a notice by email when a new edition is published on the web or to unsubscribe by mail, please contact Melanie Schacht at schachtm@tsbvi.edu

If you have an idea for an article that you think would be great for *TX SenseAbilities*, please send an email to one of the section editors. We would love to hear your ideas.



Texas School for the Blind and Visually Impaired Outreach Programs

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Texas Health and Human Services Blind Children's Vocational Discovery and Development Program

<https://hhs.texas.gov/services/disability/blind-visually-impaired/blind-childrens-vocational-discovery-development-program> 1-877-787-8999



Texas Workforce Commission

<https://twc.texas.gov/> 1-800-628-5115



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The opinions expressed here are those of the authors and do not necessarily express the position of the United States Department of Education.