Kersten’s Story

By Matt Schultz, DeafBlind Outreach Consultant, TSBVI

Abstract: In this article, Matt Schultz explores the journey of one student who, as a result of her instructional team’s use of a relationship-based educational approach, had a life-changing breakthrough. This approach is an example of the work of Dr. Suzanne Zeedyk, a Developmental Psychologist who presented at the December 2017 Studies in DeafBlindness for the Advanced Practitioner. For this year’s Advanced Practitioner Day, TSBVI will host Barbara Miles on December 11, 2018. Please see the News and Views section of this newsletter for more information.

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Dr. Zeedyk’s Work

In December 2017, a community of practitioners and families hosted a weekend at TSBVI for families and a day of training for educators with Dr. Suzanne Zeedyk. Dr. Zeedyk is a Developmental Psychologist and founder of Connected Baby, an initiative and website formed in response to the last two decades of scientific study on how human brains develop and function. Dr. Zeedyk’s research and work provide insight into how crucial relationships are for human health, happiness, and well-being.

Dr. Zeedyk traveled to TSBVI from Dundee, Scotland for the Annual Event Series: Studies in DeafBlindness for the Advanced Practitioner. Her one day presentation was titled The Biology of Connection: How Relationship-led Teaching Changes Brains, Bodies and Behavior. The themes of her presentation centered around the critical roles that positive relationships play in supporting our students’ emotional growth and general well-being. Dr. Zeedyk helped the audience understand how early experiences shape a child’s biology and their ability to self-regulate. She encouraged participants to make a shift in thinking. This shift is from characterizing moments when our students are “displaying challenging behavior” to framing events with biologically accurate language, such as “experiencing moments of distress”. In other words, the focus moves to the perspective of the student, who is having a rough time (the cause), instead of the perspective of those who are inconvenienced by the manner in which the student expresses their distress (the symptom).
How Does This Apply?

Sitting in the audience, I found my thoughts drifting to a former student. Her name was Kersten and when I met her, she was most certainly a person in distress. In fact, the people closest to Kersten, those who loved and adored her, would sometimes describe her in true southern vernacular, as “a hot mess”. During a typical school day, Kersten could be observed kicking chairs, throwing calendar boxes and classroom materials across the room, hitting staff members and attempting to pull their hair, headbutt them, or bite them. Kersten also engaged in self-injurious behavior: banging her head on desks and tables, hitting herself in the face, legs and head, and scratching her face and nose, causing bleeding and scarring. Transitions from one classroom to another would often take 45 minutes and require the support of 3 adults to keep Kersten and near-by students safe.

Changes In Kersten’s Behavior

Fast forward several years later. After not working with Kersten for a few years, I stopped by her classroom to say hello. I was astounded to see this young girl who, just a few years prior, was hurting herself and others in ways that not only interfered with learning but demonstrated intense moments of distress. I saw no kicking, no hitting, no throwing or scratching. Kersten was happily going about her classroom routines. She was communicating easily and proficiently with her teachers. She was completing steps within her routines with very little adult support and a noticeable sense of confidence. She was participating in long, in-depth conversations about enjoyable activities that she had done earlier in the week. She discussed details about what she was scheduled to do that day, asking specific questions about who she would be doing them with and where they would occur. She was delighted to talk about an upcoming farmer’s market at which she and her classmates would be working.

Kersten was also deeply engaged in a discussion about an upcoming doctor’s appointment. This topic seemed to be causing a mild amount of stress. She would occasionally halt the conversation by taking her gaze away from her conversation partner, rocking back and forth while placing her hands in front of her face. However, after a brief pause, she was able to work through it. She asked for confirmation about the date of the appointment, whom she would be traveling with, and what specific steps the appointment would entail. She looked like a totally different kid.

I turned to her teacher and with raised eyebrows and mouth agape asked, “What happened?” Her response was simple. “Kersten has become a mature young lady”. She went from a “hot mess” to a “mature young lady”. Wow.
What Happened to Cause the Change?

This tale of transformation and growth begs an explanation. That explanation is rooted in (1) her team’s understanding of the impact of DeafBlindness on Kersten’s social, emotional and communicative development, and (2) their quest to better understand challenging behavior as an expression of emotional distress. The team’s ability to comprehend the value of relationship-based and child-led educational programing was crucial to this transformation.

Additional Background

I left out a few important details in my introduction of Kersten. When I first met her, she was a new student at TSBVI. TSBVI is a residential school. Kersten had left the community in which she grew up. She was away from her family and friends for the first time in her life. She found herself in a new school, in a strange city surrounded by people she did not know, who could not anticipate her thoughts or immediately provide her with a sense of safety and connection. Unfamiliar surroundings and faces were everywhere. Kersten was legally blind with poor acuities and distance vision as a result of bilateral corneal transplants. The transplants took place at a young age and did not heal well, resulting in corneal scarring and chronic dry eyes. Kersten had a profound sensorineural hearing loss that prevented her from gathering environmental and speech sounds. To expressively communicate, Kersten used a combination of facial expressions, gestures, pictures and sign language.

New environments and unfamiliar people can be a source of stress for any of us. Imagine how stressful these circumstances might have been for a 15-year-old girl with limited vision, hearing and conceptual understanding of the world!

Trust and Accurate Information

In addition to feeling homesick, Kersten experienced a great deal of stress for another reason. As an individual with DeafBlindness, Kersten had difficulty gathering trustworthy and accurate information that was critical in allowing her to feel safe and secure. Any person would want to know when finding himself or herself suddenly in a new place:

- Who are these people?
- Where am I going?
- What is happening around me?
- What do these people want from me?
- How can I make sense of all this?
- Why am I here?

These are all questions Kersten may have been asking herself. Her ability to gather and receive information that would help answer these questions was compromised by her partial vision, hearing loss, and incomplete conceptual understanding. Without answers to these questions, how could she feel safe? How could she feel connected?

Progress

After a few months in her new surroundings, Kersten began to develop positive relationships with her teachers and some of her peers, and to settle into her new routines in the classroom and in her dorm. Within the support provided by her daily calendar, Kersten was able to
participate in conversations that allowed her to anticipate activities throughout each day. She learned to use a weekly calendar to have back and forth conversations with trusted adults. During these meaningful conversations, she began to get answers to the questions that were of vital importance to her.

Do I have to go to the health center today?

With whom will I be painting my nails?

On what day?

When do I get to talk about my experience books?

Kersten was able to take the conversational lead by simply looking at a picture of interest. Her teacher would follow her lead by adding information about the picture and topic of Kersten’s choice. Slowly, through these reciprocal and child-led conversations, Kersten’s world became more predictable and a little less scary.

New Concerns

However, a new and concerning pattern emerged in her interactions with peers. During transitions to classes, Kersten would travel in hallways and sidewalks alongside her schoolmates. On occasion, and seemingly without warning, Kersten would toss her walker aside, lunge toward another student, raise her arms over her head, and attempt to strike the other students.

Team Efforts to Observe and Plan

Kersten’s team gathered to discuss a plan to better support her, a plan based on understanding the root cause of her distress in relation to this behavior with her peers. They considered the impact of DeafBlindness on her ability to connect to the people in her environment. One team member mentioned that Kersten had very few social interactions with peers, that she really only conversed with adults. Another pointed out that when she had observed Kersten in these distressed interactions, she did not seem angry at all. Instead, she seemed excited to have an opportunity to connect with a peer. She recounted that Kersten would smile widely when moving toward the other student and that it wasn’t until she was very near that she appeared frustrated and lashed out. The team began to wonder what this could mean. They began to re-evaluate their previous hypothesis: did she intend to hurt her peers, or was this entirely something else?

As the team reviewed documentation of these distressed moments, gathered during a Functional Behavior Analysis, it was revealed that Kersten was having difficulty regulating her emotions when she came into contact with other students using walkers or wheelchairs. Could it be that the true function of her aggressive actions was that she wanted to talk with them about their shared topic of walkers and wheels? That she wanted to say “Hey, I have a walker too. Mine is blue!”? Despite her desire to say these things, she found herself unable to do so. Could it be that these feelings of inability and disconnection were the cause of her frustration and aggression?

A Shift in Perspective

As consensus was built around this root cause of the behavior, her team began to view her not as a child that displayed bad behavior or was unable to follow the rules but instead as a child that was in need of various kinds of help, including:

Help from her teachers in the form of information and instruction
Help to experience success in her attempts to make connections with other people, and help to practice and develop the communication skills needed to make friends.

Creating a Behavioral Intervention Plan

Kersten’s team made a plan to better support her desire for social connection. They set out to create an instructional routine that would allow her to successfully practice her conversation skills. Kersten already had a daily living skills routine that involved making breakfast tacos on Friday morning. The team wondered if she would enjoy making a few extra tacos to sell to her peers. They set up a table in her classroom and placed it just inside of the entryway. The table would provide a natural barrier between Kersten and her customers for extra support, “just in case”. Kersten’s teacher created a script made of three blank index cards with drawings of sign language hand shapes for “Hello”, “One dollar, please”, and “thank you”. The script was designed to help Kersten have a successful interaction even when she felt excited, anxious or unsure.

When the first customer came, Kersten’s teacher modeled how to use the script to greet and ask the customer for the correct amount of money. After the money was handed over, the teacher handed the customer a taco before signing “goodbye”. When the second customer arrived, it was Kersten’s turn to act!

She smiled widely as the customer approached the table. Her teacher directed her attention to the first part of the script by pointing. Kersten closely looked at the sign drawing for “Hello”. She began to laugh as she slowly raised her hand in the air to sign “Hello”. When the customer signed “hello” back, she let out a shriek of delight. Her eyes lit up as she looked back at her teacher, seemingly in disbelief at what had just occurred.

Her teacher, trying not to act like this was anything out of the ordinary, directed her attention with a little smile to the next card in her conversation script. Kersten’s facial expression turned serious as she focused her vision on the card. She brought her gaze back up to the customer and slowly began to sign “One dollar, please”. She was hesitant and looked to her teacher for support. Her teacher calmly shook her head up and down, indicating an encouraging “yes”. The teacher modeled the sign language and Kersten mimicked the signs. The customer, after receiving some coaching of his own, slowly reached out, offering a dollar bill. The two students looked at each other as their hands met and the dollar bill moved from his hand to hers. Kersten placed the dollar in a cash box, grabbed a foil wrapped breakfast taco and handed it to her young customer.

With a look of slight concern, Kersten quickly looked to her teacher for the next step. Her teacher calmly responded by looking at the next card in the script sequence and signed “Thank you”. Kersten brought her attention back to her customer and signed “Thank you”. As her customer walked away, Kersten looked again at her teacher, the palms of her hands gently resting on her cheeks. Her face lit up in a wide smile and her body began to shake with excitement. For a second time, she let out a loud shriek of joy.

Her teacher reflected the excitement back to Kersten with her laugh and smile. Moving closer to Kersten while reaching out her hand, she touched the side of Kersten’s arm and moved it quickly back and forth in a rhythm that mimicked the excitement that they both felt over this transformative moment: The moment when Kersten was able to experience the feeling of success in having a conversation with a friend. The moment when Kersten was able to regulate...
the strong emotions she feels in social situations and become flush with pure excitement in the success of learning how to feel connected to the people around her.

**Impact of Systematic Support**

This very moment led to thousands of similar moments when Kersten was able to experience the type of social and emotional growth that many of her peers who are hearing and sighted experience without direct instruction and practice. As a result of that growth, Kersten’s moments of distress involving peers in the hallways declined and eventually became a thing of the past. Kersten was provided with opportunities for this growth by a team who took the time to create an individualized program and an Individual Education Plan that considered the impact DeafBlindness has on a person’s social, emotional and communicative development.

The team considered the possibility that her actions were not those of a misbehaving child but instead the actions of a child experiencing deep distress, that she was not a child giving them trouble, but a child having trouble. Their ability to focus their time and attention on a relationship-based and child-led educational program created an environment where Kersten was able to experience regular and consistent feelings of success, independence and connectedness - joy, the essence of a happy life. These are feelings that each and every young girl must feel to become that “mature, young lady” that her teacher described.

Please tune into the next issue of Texas SenseAbilities to read Part II of this story, a deep dive into why relationship-based intervention works! Also see the News and Views section of this newsletter for information on this year’s Studies in DeafBlindness for the Advanced Practitioner on December 11, 2018 when TSBVI will host Barbara Miles for Genuine Conversations: A Path to Lifelong Learning for Both Partners [https://txtsbvi.escworks.net/catalog/session.aspx?&session_id=39651](https://txtsbvi.escworks.net/catalog/session.aspx?&session_id=39651).

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