Frequent Breaks: Fact Sheet  
by Stacy Aguilera, CDBS Educational Specialist

The term ‘frequent breaks’ is another term for sensory breaks most commonly seen in children with CHARGE syndrome. Sensory breaks are often mistaken as a negative behavior instead of a way one uses to self regulate themselves. Self-regulation is one’s ability to adjust or regulate the level of alertness depending on time of day and stimuli presented (asensorylife.com). Demands on the nervous system such as attention to task, cognitive demands, and motor tasks (gross, fine, visual motor) can create significant levels of stress, which is often seen in a school setting.

It is important to remember that all behavior has a purpose and to identify that purpose instead of just seeing it as a negative behavior that needs to be eliminated. Look for patterns of how often, where, when and with whom. Always consider the context of what is happening and what happened after. According to David Brown, “For children with CHARGE, even if they ‘perform’ well in structured activities, the activity can create significant levels of stress if they continue for too long a period of time, or if the child’s positioning becomes uncomfortable or insecure”. During my observations in the past, this has always been the case when I saw a pattern occur of a specific behavior. The child was expected to attend to a task for an extended amount of time in a sitting position while utilizing the functional vision and hearing they have; which lead to a pattern of behavior seen as a frequent break.
An example from a student I observed was her frequent trips to the water fountain during instruction. The student was attending to the teacher while she was direct teaching and then all of a sudden she would get up to get a drink from the sink and then return to her seat. When she returned to her seat she was back on task and focused on the teacher. During my observation I noticed a pattern. It would happen about every 10-15 minutes within an hour of being required to sit and attend to the teacher’s lesson. Her trip to the sink was brief and with intention. It was determined that these multiple trips to the water fountain gave her a break from the sensory input long enough to allow her to continue to attend to what the teacher was saying. When I spoke to the teacher later and went over the observation, the teacher noted she thought this behavior was negative and needed to be eliminated. In her efforts to eliminate the behavior she had a water bottle placed on her desk in hopes that she would not get up multiple times to get a drink of water. However, this strategy did not work because the intention of getting water was not to get a drink but instead to self-regulate so that she could attend to the task required of her.

This is just one example of many. Students with CHARGE will find a way to self-regulate when they are overwhelmed by the sensory input they are receiving. This is different from other type breaks in the sense that it does not need to be a long break unless they are not given the opportunity to self regulate. If given the opportunity to take frequent breaks, the break should last anywhere from 30 seconds to 2 minutes and it usually has a pattern to it.

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<th>Here are some examples of frequent breaks:</th>
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<td>Going to the sink and wiping it down with paper towels</td>
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<td>Getting up to throw away trash</td>
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<td>Close eyes</td>
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Children with sensory differences (such as CHARGE) quite often have a difficult time with self-regulation due to various factors. When children have a difficult time with self-regulation, we observe maladaptive behaviors or responses to the environment and sensory stimuli. It is important to identify those signals of self-regulation before jumping to conclusions it is behavior driven (asensorylife.com).

Once a repetitive behavior is identified as a frequent break and understood, it is important to identify what leads to the child having to self-regulate and adjust the environment if possible. David Brown explains that an activity-based approach to curriculum can often help to keep stress levels and arousal levels down. “Many children with CHARGE enjoy and respond well to moving around and physically ‘doing’ things, and can learn a lot of the curriculum while they are doing this” (Brown, 2011).

References:

Tricia Houlihan: California’s First Credentialed Intervener
By Maurice Belote, CDBS Project Coordinator

Everyone at California Deafblind Services is pleased to salute Tricia Houlihan from Blind Children’s Learning Center in Santa Ana (Orange County). A few months ago, Tricia became the first credentialed intervener in California. The national credential requires two semesters of university coursework, which Tricia completed at Utah State University. In addition to the coursework, the credential requires 100 hours of supervised practicum and the submission of a portfolio to demonstrate knowledge and skills. The national credential is granted by the National Paraeducator Resource Center.

Interveners are one-on-one paraeducators who have specialized knowledge and skills specific to deafblindness and work under the direction of classroom teachers and/or related service personnel. The National Center on Deaf-Blindness lists the following as the primary roles of the intervener:

- Provide consistent access to instruction and environmental information that is usually gained by typical students through vision and hearing, but that is unavailable or incomplete to an individual who is deaf-blind;
- Provide access to and/or assist in the development and use of receptive and expressive communication skills;
- Facilitate the development and maintenance of trusting, interactive relationships that promote social and emotional well-being; and
- Provide support to help a student form relationships with others and increase social connections and participation in activities.

To read the entire description of intervener services, go to: https://nationaldb.org/library/page/2266.

Tricia serves students at Blind Children’s Learning Center, including the development of receptive and expressive communication systems for their young students. She also supports other paraeducators at the school on issues specific to deafblindness. We asked Tricia to write something about her work:

“I am very honored and proud to be the first credentialed intervener in my great state of California. This educational achievement has come through a very long time of efforts, passion and most importantly my belief in the abilities and potential of the incredible population of young individuals that I interact and work with on a daily basis.”

Tricia has also been a longtime member of the CDBS Advisory Committee and was part of the California delegation to the Deafblind International Network of the Americas Conference this past April in Hyannis, Massachusetts.

In addition to the National Intervener Credential, the National Center on Deaf-Blindness has developed the National Intervener Certificate E-portfolio system (NICE) as an alternate path to certification. And CDBS is working in partnership with Dr. Chris Brum at San Diego State University to launch an online intervener training program that is scheduled to begin in Fall 2018.

For more information about any of these intervener initiatives, contact anyone at CDBS.
Preparing Teachers for the Field of Deafblindness:
The story of our collaborative personnel preparation projects with San Francisco State University’s Credential Program in Moderate-Severe Disabilities
Julie Maier, CDBS Educational Specialist

In California there are three credentials that authorize a teacher to teach students with deafblindness — Visual impairments, Deaf/Hard of Hearing, and Moderate-Severe Disabilities credentials. CDBS has always kept teacher training with numerous teacher credential programs around the state as a central focus of our work. Over the past 10 years, we’ve been lucky enough to dive deep into pre-service teacher training with two separate OSEP funded personnel preparation projects directed by Dr. Pam Hunt, coordinator of the Moderate-Severe Disabilities Program at San Francisco State University. Both projects were four-year projects that provided interested and qualified students from the Moderate-Severe Disabilities program with a generous stipend to complete additional deafblind specific courses and fieldwork and to participate in internship activities and travel with CDBS staff. The most recent project, Specialization in the Education of Students Who are Deafblind, was implemented from Oct. 2014-July 2018 and provided 28 student teachers the opportunity to greatly increase their knowledge and skills in deafblindness through seminars, course assignments, completion of some of Open Hands, Open Access modules, fieldwork in local school serving learners with deafblindness, and participation in internship activities with CDBS staff. The most recent eight graduates of this project each wrote an article for this issue of reSources about one of the most meaningful internship activities they experienced over the past semester and we hope you enjoy reading all that they have to share.

During our seminars the students met with different members of the CDBS staff, as well as guest presenters from the fields of early intervention and visual impairments, to learn about topics such as types of visual impairments and interventions and access to the curriculum; hearing loss, signed communication, and assistive listening technology; communication; concept development; the sensory system and self-regulation; partnerships with families and early intervention service providers; social relationships and positive self-image; orientation and mobility; and interveners and access to general education curriculum and settings. The knowledge gained from these seminar discussions was expanded during fieldwork visits and through active participation in internships activities. Some of the internship activities included accompanying CDBS staff on technical assistance visits; attending state and national conferences related to deafblindness; volunteering at a family camp for young children with vision loss or deafblindness and the Blind Babies Foundation annual Beeper Egg Hunt; assisting in person-centered planning meetings and district staff trainings; meeting board members from Deafblind Citizens in Action; and much more.

In addition to training these new teachers we also strive to keep them connected to each other and to other teachers and professionals in our field. Our annual CDBS Fall Symposium began during the previous personnel preparation project as a way to bring in nationally recognized experts in deafblindness to share their expertise and experiences and to give the students a chance to meet members of other cohorts. Some presenters have included Robbie Blaha, Anindya “Bapin” Bhattacharyya, Amy Parker, David Brown, Ellen Condon, and Mussie Gebre. This annual fall event will continue to live on as an ongoing professional development opportunity and a reunion for these teachers of the deafblind that we’ve helped to train. We are very excited to learn about “Literacy for All” from this year’s presenter, Nancy Steele, in just a few weeks.

We want take this opportunity to congratulate our final cohort of scholars from the OSEP funded four-year personnel preparation project, Specialization in the Education of Students Who are Deafblind. We are immensely proud of and excited for these 8 new talented and committed teachers, just as we are for each of the graduates of the
prior cohorts, who are making a difference in many schools and programs across the state. These teachers have the knowledge and skill competencies to not only effectively serve the students with deafblindness and multisensory needs in their programs and schools, but to provide much needed mentoring, coaching, and consultation to teachers in their regional districts and we look forward to our continued professional partnerships as we work to expand knowledge and recognition of the important role of the teacher of the deafblind in our state and at a national level.

CONGRATULATIONS
to our SFSU Cohort 4 Graduates for completing their work in the
SPECIALIZATION IN THE EDUCATION OF STUDENTS WHO ARE DEAFBLIND

Reflections from the Field
Julie Maier, CDBS Educational Specialist

In this edition of reSources we are proud to feature articles written by the most recent graduates of our Specialization in Deafblindness teacher preparation program. The following eight articles describe some of the most meaningful experiences these teachers encountered during their spring internship with California Deafblind Services. You will notice that some of the articles highlight collaboration with other agency partners, school teams, or families, while other articles focus on the new knowledge and insights gained by attending sessions at Deafblind International Network of the Americas Conference and learning from influential researchers, other deafblind state project partners, and families. The final article in this series was written by a graduate of our first Specialization in Deafblindness cohort and tells a bit of her journey from an intervener to a classroom teacher and the important lessons she learned from the student who changed her life. We hope you find these articles helpful and inspiring as you move forward in your work teaching, supporting and celebrating the children and youth with deafblindness and their families.
By Claire Pohle, Intern in the SFSU-CDBS Specialization Program for Learners with Deaf-Blindness

This April I attended the first-ever Network of the American Conference in Cape Cod, Massachusetts. The conference, hosted by Deafblind International and Perkins School for the Blind, brought together in partnership educators, service providers, policymakers, advocates, and family members from around the world. The conference offered so many interesting and important workshop sessions ranging in topics from tactile signing to integration of the arts in the education of learners who are deafblind that it was difficult to choose which to attend.

Facilitating Inclusion into Physical Education, Recreation, and Sport for a Lifetime, presented by Lauren Lieberman and Melanie Perreault inspired me to think more broadly about how I can integrate physical activities into my students’ school routines. I teach at a non-public school in the Bay Area that serves students with movement disorders such as cerebral palsy. So, although I do not teach students with deafblindness, I do work with students who have cortical vision impairments and multiple disabilities. I found that many of the teaching strategies I’ve learned about for students with deafblindness are applicable to the students with whom I work.

It is inspiring to know that within the field of special education there is a growing body of research and best practices on how to include students of all ability levels in the activities which are enjoyed the most. My big take-away from Lieberman and Perrault’s session is that a little creativity goes a long way when designing physical games for students ranging in ability levels. For example, basketball can be made more accessible by simple hanging a hula hoop from the basketball hoop! This simple adaptation provides a larger visual cue and makes putting a ball through the hoop more manageable for those with mobility issues.

Over the summer I will be volunteering at Enchanted Hills Camp during a weekend family camp program for children with visual impairments and deafblindness. I’m excited to see how the campers enjoy outdoor activities. What a pleasure it will be to play in the outdoors with these kids! I imagine that after attending Facilitating Inclusion into Physical Education, Recreation, and Sport for a Lifetime, and then Enchanted Hills Camp, I will have a rich body of knowledge and experiences from which I can create meaningful physical and leisure activities for my students.

Lauren Lieberman and Melanie Perreault shared several resources which include curriculum, philosophy, and best practices for including students with deafblindness and other disabilities in physical activities:

- Transition Guidelines for Community-Based Physical Activities for Students Who Have Visual Impairments, Blindness, or Deafblindness, written by Lauren J Lieberman, Ph.D., Scott J Modell, Ph.D., Paul Ponchillia, Ph.D., and Lleah Jackson, B.S.
- Physical Education for Children with Moderate to Severe Disabilities, edited by Michelle Grenier and Lauren J. Lieberman.
Moments from the DeafBlind Conference of the Americas
by Nicholas Leung, California Deaf Blind Services Intern
and Special Education Teacher, AP Giannini, San Francisco, CA

A string of moments characteristic of my internship, occurred during the DeafBlind International Network of the Americas Conference held in April when, as an intern student with California Deafblind Services, I shuttled off to the other end of the United States to take part in this event. One session that opened my mind to possibilities that I had not considered before was in Dr. Susan Bashinski’s Beginning of a Lifeline presentation. It was not the first time I had heard of Dr. Bashinski. Due to my internship’s other components, I had previously watched some of her webinars and selected her session on that basis.

Dr. Bashinski’s presentation was called a Lifeline and it was unlike most studies I had previously encountered. It was unique in that it was a combination study focusing on one child over a period of 14 years. Most studies that I have read in education are usually short in span, over a significantly shorter period of time, one or two years, and designed to isolate one variable or theme. Her study, facilitated by strong personal connection, strong parental advocacy, and an element of random chance was much more like a deep dive into the Life/Timeline of one student.

One of the best parts of being a special education teacher in my opinion is the ability to stay with your students and grow with them over multiple years. This gives the educator a deeper understanding of the child, where they started, and possibilities of where they are headed. Still, this study was even more than I imagined could be possible. Typically, when a student graduates from 8th grade, you are not able to keep up with what they are doing years later. Dr. Bashinski’s study helped give me more of an overarching perspective as to the length of interventions, how progress is measured, and a more holistic view of a child than most teachers are often able to experience.

The student, whom we will call Larry for confidentiality purposes, was born with CHARGE syndrome. Larry has a visual acuity loss yet can see clearly within 6 inches with corrective lenses. He also has a profound hearing loss, a G-tube, and tracheostomy. When he was 4 years old, he received a Cochlear Implant, and could walk upright immediately after, but still did not display discernible responses to auditory input until in 5th grade, nearly 5 ½ years after his implantation. Dr. Bashinski’s initial study looked at an intervention teaching communicative gestures.
Three Key takeaways stood out to me after learning about Larry’s 14 year journey.

1. Larry’s expressive and communicative progress after demonstrating response to sound mirrored the developmental time for typical children. Rather than measuring Larry’s progress by what he couldn’t do, Dr. Bashinski measured using his “Time-in-Sound”, or the amount of time he had been receiving auditory input, and it was comparable to typical children of that age development. When Larry was chronologically 10, but his “Time-in-Sound” was 65 months, his development mirrored children of 55 months age in social adaptation, exploration of the environment, etc.

2. A singular intervention at a key point within Larry’s life, not only set the stage for him to develop symbolization, but provided the base for his communication modes a decade later. When Dr. Bashinski reunited with Larry 14 years after the initial study, he was still using the gestures he had learned from that intervention to communicate both at school and home.

3. Although Larry primarily utilized gestures, he also made use of a variety of other communicative modes, which expanded over his educational journey, from picture symbols to manual sign to a high-tech Speech Generating Device, illustrating the need for people with CHARGE syndrome to utilize different communication modes for receptive and communicative purposes. Some modes took years for Larry to acquire proficiency in.

I was quite fortunate to be able to take part in the Deaf Blind International Network of the Americas Conference as well as learn more about Larry’s life. As an educator, it gave me perspective as to the importance of teaching communication, how it will change over time, as well even more motivation to look at my students as whole people. The defining feature of my student internship with SFSU-CDBS has been acquiring new perspectives and ways of understanding. Prior to beginning my coursework in deafblindness, I had never considered the possibility or the implications of a person being both deaf and blind. I consider myself fortunate to be able to have had these experiences over the course of this year-long university program and am extremely grateful to my mentors and cohort family for their guidance.
Reflections on “Empowering the Deaf-Blind: Accessing Information Through Touch.”
by Tesha Henderson, Intern in the SFSU-CDBS Specialization Program for Learners with Deafblindness

While attending the Deafblind International (DbI) Network of the Americas Conference, I had the opportunity to observe a session titled, “Empowering the Deaf-Blind: Accessing Information Through Touch,” facilitated by Marilyn Trader and Maricar Marquez. The purpose of this session was to provide awareness and information about Haptics, a formalized structure that utilizes specific tactile signals to provide both environmental and interactional information.

One of the most fascinating observations I made during this session was the various modes of communication occurring around the room at any given moment. Whether it was sign language interpreters translating for audience members, tactile sign provided for individuals in the audience or those presenting on stage, speech translated into sign, sign translated to tactile sign, or tactile sign translated to speech — everyone was communicating in an individualized way. Everywhere in the room there seems to be someone either providing or receiving information other than standard verbal speech. The most noteworthy observation I made was watching those receiving this environmental information through touch while simultaneously communicating via tactile sign language — something that certainly takes a large degree of focus, attention, and practice.

A key point made in the session was that Haptics is not at all associated with American Sign Language (ASL), or even considered a language at all. The goal of Haptics is to provide “equal access to all information” that may otherwise be missed by an individual with deafblindness. This information is relayed by various forms of pressure or contact on the arms, top of the hand, or on the back. Some of the information received includes name signals, facial expressions, the layout of the room, food and drink in the vicinity, actions of individuals in the immediate area, and directional cues. Haptics can be provided in many situations including; 1-1 interactions, and

educational settings, social engagements, Orientation and Mobility instructions, and interactions with family members. This system can provide any environmental information in all scenarios and can be personalized and individualized to meet the needs of the person receiving.

Another point of discussion in the session was that, although most environmental information can be relayed to the individual, “not everyone wants the same information.” The provider must modify the use of touch signals and prioritize the visual and environmental information according to the individual needs of the receiver. This is because not all information is as important to the receiver, and some information may not be as relevant to one person as it is to another. For example, the receiver may not be interested in knowing about every person that enters the room, but only those with a significant relevance — perhaps someone they know or wish to speak to. It is for this reason that the receiver and the provider must first communicate to determine what levels of information the receiver would like exposure to.

Prior to this experience, my exposure to tactile communication was minimal. Upon reflecting about this session, I realized the importance of environmental information as it relates to day to day living. It’s critical to know what’s happening in your immediate environment and to consider that this information that is not accessible to some. Haptics provide that access, which is often overlooked by those with functioning sight and hearing. Overall, I found this session extremely interesting and valuable because I learned much about accessing environmental information through touch and the importance of providing that access to all.
Beep! Beep! It’s the Annual Beeper Egg Hunt!
by Yasmir Navas, Intern in the SFSU-CDBS Specialization Program for Learners with Deafblindness

Blind Babies Foundation (a program of Wayfinder Family Services) hosts an event every year that is very special to all families who receive services from them or have in the past. This event is not only accessible for children who are blind or visually impaired, but also to their siblings and other kids with different abilities, so the whole family can come along and take part in all of the fun! An annual Beeper Egg Hunt is held in Fremont at the California School for the Blind and a Central Valley Beeper Egg Hunt is also held at AgVentures! Learning Center and Tractor Museum. I was one of the lucky interns fortunate enough to serve as volunteer for the Beeper Egg Hunt. I was very excited and curious about what this looked like since I had heard so many good things about this event.

Taking place at the California School for the Blind campus, the majority of the activities were being held in the school gym, recreation center, and theater. Families were told to sign in at the theater and then guided to the recreation center. Once inside the gym, children were greeted by volunteers at different activity stations. Parents and children had the freedom to walk around and take part in any of the fun activities. Some of the activities stations were:

- **Face Painting**: There were 5-7 volunteers at two different tables with different examples face painting designs.
- **Plant Potting**: Kids were able to pick a plant of their choice, scoop up dirt (fun and messy!) into a pot, put their plant in it, water their plant and then take it home.
- **Cookie Decorating**: Kids could pick a cookie, top it with icing, sprinkles, etc.
- **Exploring Musical Instruments**: Instruments were laid out on mats. Kids could go on the mats, explore the instruments, and play with them, etc.
- **Arts and Crafts Table**: Decorate a bird or an animal with feathers, googly eyes, glitter, beads, etc.
- **Ball Pit**: A small ball pit was available for kids to go in and explore/move around in it.
- **California Guide Dogs for the Blind Photobooth**: Take your picture with one or all of the amazing Guide Dogs and Guide Dogs in training!
- **Meet Newfoundland Dogs**: Come and hug, squeeze, touch and play with the Newfoundland dogs!
- **Sensory Painting**: Use bubble wrap, paint (with your hands or brush) and create a masterpiece on your own!
- **Decorate a Picture Frame**: Grab a foam frame, put stickers on it, glitter, shapes, etc!
After families walked and explored the fun activity stations, lunch was provided by Blind Babies’ Foundation. Shortly after was when the big event was to occur: THE BEEPER EGG HUNT. This was the most exciting part of the day. The Beeper Egg Hunt was held in the school’s theater, away from the activity stations. There was green turf laid out on the ground, eggs (small and big ones) on the turf, and a white fence around the eggs. A few feet behind the fence, was a large walk-through tent with baskets dangling off the canopy. At first, I didn’t understand why there was a separate section with baskets hanging and I waited to see what they were for.

The announcer, Mike Nicco from Bay Area Channel 7 News, got on the microphone to start the countdown for the first round of kids to start their egg hunting. He reminded all the participants that the smaller eggs were for kids who are not visually impaired or blind. The larger ones were for the kids who are blind or visually impaired. That is when you started to hear it — BEEP! BEEP! It was a piercing sound, but one that almost everyone could hear, which was a good thing. Then, the countdown started- 5, 4, 3, 2, 1! Go! And off the kids went.

I saw siblings picking up the smaller eggs, and kids listening for the sound. I saw a little girl with bunny ears pick up a big egg, examine it, hold it up to her ear to confirm it was beeping and then put the egg in her basket. Once baskets were full, they were able to switch out the eggs they collected for prizes. Kids kept coming into the area where the eggs were and kept collecting more eggs. I didn’t realize how inclusive this event was until I finally had the opportunity to see what was happening in the tented area. The tent area was designed for kids using wheelchairs! Basically, kids were able to move through the tent and collect eggs out of the hanging baskets.

I loved how this event was made for kids with so many abilities in mind. There were so many different activities and entry points for all kids. This event was truly inclusive. It was amazing to see all the kids smiling with their faces painted, prizes from their egg hunt, plants that they potted themselves, and their crafts that they made from the activity stations. All kids were welcome at the Beeper Egg Hunt!

Blind Babies Foundation is an awesome organization that supports kids and families. They serve babies and toddlers up until the age of 3 years old with vision loss and many with additional disabilities. What Blind Babies Foundation offers for families are: weekly in-home visits; play skills practice; individualized family support plan (IFSP) support; support with communication skills; activities that involve physical, visual, auditory, social and emotional development; and access to parent support groups among other services. Blind Babies Foundation is program of Wayfinder Family Services which strives “to empower individuals, support families and strengthen communities through our four overlapping areas of service” which are: special needs services, vision loss, foster care and adoption services, and mental health services. [www.wayfinderfamily.org](http://www.wayfinderfamily.org)

There is more information on the Blind Babies Foundation website about the Beeper Egg Hunt and other services: [https://www.wayfinderfamily.org/news-and-events/annual-events/beeper-egg-hunts](https://www.wayfinderfamily.org/news-and-events/annual-events/beeper-egg-hunts)
Reflections on Parent-Teacher Relationships in the School Setting
by Mary Spaulding, Intern in the SFSU-CDBS Specialization Program for Learners with Deafblindness

The most impactful experiences I have had in the SFSU-CDBS Specialization in Deafblindness program were when learning directly from parents with children who have been diagnosed with deafblindness. This reflection serves to summarize what I have learned from these individuals who continue to love and improve the lives of their children.

One family’s journey with a child with deafblindness is not identical to another family’s journey. This point seems simple and obvious, however, when this truth is dissected, it has complex implications for educators. It is important to take the time to get to know the whole family: who they are, what they do, what they believe, and how they feel. All of this information will help me understand and work with families to teach their child in a way that is relevant and useful for him or her. If I limit what I know about the family, I ultimately will limit their child’s education. These experiences have taught me to listen first and integrate that information into the collaborative education for the child.

Attending the Deafblind International Network of the Americas Conference allowed me to attend a panel about family partnerships with schools. On the panel was a mother of a child with deafblindness who had faced hardships in the school system trying to have her son fully included in general education classrooms. When referencing teachers and administrators she had faced she said, “People don’t care how much you know until they know how much you care.” As an educator, this statement immediately had me reflecting on my own teaching practices. I had always wanted strong, collaborative relationships with parents, but was I truly communicating my concern for their child or was I communicating what I felt was best for their child?

Another parent shared how families have different “cycles of needs”. Educators are often so used to checking in with families during limited meetings like progress reports and IEPs (Individualized Education Plans), that we forget to go at the family’s pace. Too often, instruction is centered around what we as educators think the child should learn without also considering what is happening at home or in their community. From this parent’s presentation I learned how educators need to look at the child from a holistic perspective to see how school can improve the quality of life at home and not just the other way around.

The experience that brought me not only mindfulness around parent-communication, but empathy and perspective (although I use this word in caution as I can only understand so much not having a child with deafblindness), was a parent who came to our class to bravely share her family’s experience of raising a child with deafblindness. This mother shared how she and her husband experienced grief over the deafblindness. This was still their child, but he was nothing like they had expected. The loss of the dreams they had planned for their child was unbearable at times and both she and her husband coped with this in varying ways. She explained that grief does not occur in stages. Rather it is disorganized and fluctuates in duration, emotion, and intensity. She went on to share how her family grew to accept deafblindness and enjoy life with their son. She shared proud moments of accomplishments and family vacations which taught me that what may be most important to families is what they learn on their journey as family from diagnosis to acceptance. As an educator, I now understand the need to ask about and listen to the stories family have to tell.
Reflections on Donna Snyder’s “Experiences of Families Raising A Child Who is Deafblind and Teacher Response to Those Shared Experiences”  
by Adrian Adair, Intern in the SFSU-CDBS Specialization Program for Learners with Deafblindness

While attending the Deafblind Network of the Americas 2018 Conference I had the pleasure of taking part in a session lead by Donna Snyder, the State Coordinator of the Kentucky Deaf-Blind Project with the University of Kentucky. In this session, Snyder presented on her dissertation, which is concerned with the experiences of families raising a child who is deafblind, as well as subsequent teacher responses to those shared experiences. In this presentation, Snyder shares about an idea she put into practice that effectively deepened participating teachers' understandings of their students with deafblindness. Her methodology consisted of inviting families of students with deafblindness to self-select sets of 20 images of their child. Snyder proceeded to interview the families about these photos, record those interviews, and eventually set the photos and family commentary to a short video montage to later share with these students’ teachers. The monumental impact that this endeavor had on the teachers’ view of their students convinced me that this is a practice that is worth spreading the word about and one that we as educators and service providers should adapt into our own repertoires when considering how to bridge the understanding gap between educators and their students.

In embarking on this project, researcher Donna Snyder explained that she initially predicted that there would be common threads that would arise throughout the interviews between families as they walked her through their selected photos of their child with deafblindness. Indeed, Snyder notes that the interviews she conducted with families uncovered five overarching themes including: “medical, positive descriptions, family and community, likes/don’t likes, and parents’ love.”

As Snyder shares about her experience of families discussing medical issues that took place throughout their children's lives, she notes that when families do choose to include an image of their child in a hospital setting such as the NICU, their accompanying descriptions of these photos focused on the resilience and strength their child had in order to overcome medical obstacles, rather than the potentially limiting nature of the obstacles themselves. In one case, Snyder describes a situation in which a family shares a photo of their child standing up on a wakeboard. The family uses positive terms to describe just how hard he kept trying to stand up until he eventually did. This student’s teacher had originally used words like “hard-headed” or “stubborn” to describe this student, but in listening to this family’s testimony, she began to see those characteristics of determination as an asset for the student rather than a character flaw.
Through this activity, teachers also went on to learn about some of the likes and dislikes of their students that can be crucial for a teacher’s understanding of how to motivate a student in their class. Teachers also were able to bear witness to just how full these students’ lives were outside their classrooms in terms of how they impacted their communities and just how much love and support they were surrounded by outside of school.

When Snyder began her work on this project, she hoped that “teachers would begin to see the students as not a static being in time, but an ongoing developing young mind” (20). Snyder interviewed teachers both before sharing the video montages complete with family interview commentary as well as after. Snyder found that after she shared the video montages, there was a major shift in perception and the way that these teachers spoke about their students. Teachers’ descriptions of their students changed from a focus on what students couldn’t do to what they could do. Teachers exhibited a higher degree of connection to the family rather than the initial disconnection they described feeling. Teachers’ medical descriptors of the students shifted toward a focus on using human descriptors. Finally, and perhaps most importantly, teachers’ views of their own capabilities to teach these students changed from a feeling of can’t do to can do (Snyder, p 84).

Perhaps what I like best about this intervention is that it requires a relatively small degree of work to implement while at the same time yielding huge results. Something as simple as asking a family to collect photos and then speak about those photos for ten minutes can open a window of understanding in a teacher’s perspective on their students. I believe this tool could be useful in transitioning a student to a new school or new classroom, training staff about an individual student, and any other scenario in which an educator can benefit from learning a little more about a student and their family. I am happy that I had a chance to see Donna Snyder present on this and am indebted to her as I begin to use this tool within my own educational practice.

References

Using technology to enhance engagement for all learners
by Charles Beavis, Intern in the SFSU-CDBS Specialization Program for Learners with Deafblindness

Access for all students

I have had the honor and privilege to listen to Elizabeth Hartmann speak both at the Council for Exceptional Children (CEC) Convention and the Deafblind International (DbI) Conference. During both of these sessions, Hartmann discussed the use of Universal Design for Learning (UDL), and how, when using this framework, teachers can create an environment for learning not just for students with disabilities but for all students (Hartmann, 2018). Technology is an important resource for implementing the framework of UDL.

CAST UDL Model

In her session at the CEC convention, she outlined the original thoughts and structure behind the CAST model for UDL. I will briefly discuss this model. The CAST UDL model focuses on three key principles/guidelines for learning: multiple modes of representation, multiple modes of expression, and multiple modes of engagement (CAST, 2018).

- **Representation** refers to the way that the students’ access the lesson or learning objective: the *what* of learning. Teachers need to think of multiple ways to represent the same idea.

- **Expression** refers to the way students are expected to respond and communicate their knowledge: the *how* of learning. Teachers need to provide students with multiple means of expression.

- **Engagement** means exactly what it sounds like: making the lessons meaningful and relevant so the student is motivated to be engaged in the lesson: the *why* of learning.

Originally this model argued a linear progression from representation to expression to engagement, but the researchers realized that even if you have multiple modes of representation and expression, if the student is not engaged or motivated, then the lesson is already lost. The original progression of the three key areas has now changed. The framework for UDL should actually **start** with engagement, **then** teachers should think about representation and expression. This is represented by the following graphic.
So, learning starts with the why. It starts with engagement and being motivated. But this doesn’t mean teachers shouldn’t think about representation or expression if the child is not engaged. In fact, it is the exact opposite. If the student is not engaged, teachers need to think about the different modes of representation and expression they are using. They need to change these modes in ways that better motivate and engage their students. The bottom line, however, is this: without motivation or engagement the lesson is never going to be as meaningful as the teacher or the student want it to be.

**Tech in the classroom: A three-tiered framework approach.**

During Hartmann’s workshop at the DbI Conference, she asked the question: “How can we use technology to better design and implement curriculums and instructional supports for students who are deafblind?” (Hartmann, 2018). Sadly, there are no evidence-based practices for using technology for curricular purposes when working with students who are deafblind. She argues that educators need to organize their best practices into a succinct framework. Otherwise, teachers and educators have to sort through all of these practices, which can take time. And time is something that teachers and educators have very little of. Hartmann proposes a three-tiered framework approach to ensure the success of students who are deafblind.

The following three-tiered framework helps organize some of the current best practices: Universal Design for Learning (UDL), Student Environment Task Tools (SETT), and Substitution Augmentation Modification Redefinition (SAMR) (Hartmann, 2018).

**UDL**

I have already discussed UDL, so I will not elaborate too much. I will mention, however, that at its core UDL is looking at reducing barriers and adding supports within the curriculum (Hartmann, 2018). When we think of reducing barriers, we are often talking about the actual curriculum in classrooms and how this curriculum doesn’t always consider how students with multiple disabilities learn. By adding more supports for a focus student, teachers are providing a better means for the student to have access to the content and learn important life skills. These supports should be embedded in all three steps of UDL.

Some important questions to ask when implementing UDL are:

- Is the lesson meaningful and engaging to the student?
- How can we optimize the representation of the content?
- How can we optimize the way the student expresses their knowledge?
- How can we change the curriculum?
- What supports that we are using for a focus student could we use for their peers?
SETT
Student Environment Task Tools (SETT) refers to the assistive technology and tools used to support the student throughout the lesson (Zabala, 2012). Teachers must first think of the particular student and the supports that already work for them. They must then consider the environment in which the student is learning and whether this environment is one of optimal learning. Teachers must also consider the specific task the student is expected to complete. By looking at all three of these categories (student, environment, and tasks) teachers can make an informed decision about the tools the student will need in order to successfully complete and remain engaged in the lesson.

Some questions to consider when implementing SETT are:

- How does the student express themselves?
- What is the environment of the lesson?
- What are the expected tasks?
- What tools or assistive technology can be used to make this lesson accessible?

SAMR
Substitution Augmentation Modification Redefinition (SAMR) looks directly at the technology being used throughout the lesson. It is essentially a check on the implementation of the curriculum. When implementing SAMR we are trying to enhance the technology (substitution and augmentation) and then transform it (modification and redefinition) (Walsh, 2015). In other words, how do teachers change their lesson to better suit a particular learner. And how can these changes help all learners throughout a given lesson?

Hartmann uses the metaphor of ocean exploration to describe this process (Hartmann, 2018). When we are standing on a beach and looking at the ocean, we are exploring the ocean using no technology. Teachers can enhance this technology through substitution (building a canoe and looking at the water from on top) and augmentation (use a snorkel to explore in the ocean). In this light, the teachers have used technology to give their students better access to the insights that the ocean holds.

Teachers can transform this technology through modification (by taking the idea of a snorkel and designing a scuba diving suit, explorers are exploring the ocean in a similar way to a snorkel, but the time they can spend in the ocean has increased as well as the depth they can go) and redefinition (by exploration using a submarine. In order to do this, we pulled technology from many different areas and created something with almost endless possibilities for exploration) (Hartmann, 2018). While these last two steps are hard to implement because they take time and effort, the difference teachers see in their students’ engagement and expression will be paramount.
Some questions to consider when implementing SAMR are:

- What kinds of technology will enhance the lesson?
- What kinds of technology will transform the lesson?
- What kinds of technology are the student and his or her peers already using?
- How can we use this information to benefit all students?

**Checklist for Technology in the classroom**

Based on Hartmann’s presentation (Hartmann, 2018), I have created a checklist to help teachers and educators assess their lessons and figure out ways to make these lessons more accessible for all students. I tried to make the format user friendly and simple to navigate. You will notice the third column: the benefit to the focus student and the other students in the class. One of the beautiful things about this three-tiered framework is that when it is implemented well, all students have better access and more opportunities for engagement and learning.

I have filled in the boxes with the following case study, but you are more than welcome to take this checklist and use it in your classrooms. The suggested supports are by no means exhaustive, but simply a few examples we came up with during our workshop discussion with professor Hartmann.

**Case Study**

*Example Lesson: Write informative text about animals of student’s choice.*

Sammy is a fun and silly third grader who is fully included in a general education classroom. She has a strong support team consisting of an intervener, a speech language pathologist, an occupational therapist, an orientation and mobility instructor, and parents who are very active in her education. Sammy has low vision and she benefits from enlarged and high contrast font. She can communicate using AAC, adapted ASL, or verbally. In her classroom, she has access to tablets, laptops, and different APP’s. Sammy has everything she needs to access the lesson. Some supports work well in multiple areas, which is what makes them effective supports. Using the three-tiered framework approach we can ensure she is accessing and learning during the lesson.

**References**


Hartmann, E. (2018, April) Technology implementation and curriculum engagement for children and youth who are deafblind. Paper presented at meeting of the Deafblind International Conference, Cape Cod, MA.


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<thead>
<tr>
<th>UDL</th>
<th>Suggested Support</th>
<th>Benefit to focus student and other students</th>
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<tbody>
<tr>
<td>How can we make the lesson meaningful and engaging to student?</td>
<td>Bring real life animals to school: pets, SPCA, etc. Take a field trip to a petting zoo.</td>
<td>Get to share with Sammy and other students their interests and their pets. Opportunities for social communication are more likely because this sharing creates a warm community.</td>
</tr>
<tr>
<td>How can we optimize the representation?</td>
<td>Pair her with preferred adults and/or peers. Text-to-speech, videos on blogs or YouTube, real life animals.</td>
<td>Sharing interests. Exploring interests. Hands on learning benefits everyone.</td>
</tr>
<tr>
<td>How can we optimize the way the student expresses their knowledge?</td>
<td>act out animal movements, make a video, talk about animals using AAC or voice.</td>
<td>Other students can choose their own expression too, which lead to more engagement.</td>
</tr>
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<th>SETT</th>
<th>Suggested Support</th>
<th>Benefit to focus student and other students</th>
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<tr>
<td>How can we make the lesson accessible? What tool should we use? Think student, environment and task.</td>
<td>Write blogs, make a video, invite professionals from community, present about animals using AAC or voice.</td>
<td>Blogs or videos can be engaging for all students.</td>
</tr>
<tr>
<td>How can tech help us do this?</td>
<td>Access to computer or text-to-speech.</td>
<td>More advanced students can help other students edit or create blogs.</td>
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<th>SAMR</th>
<th>Suggested Support</th>
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<tr>
<td>What kind of tech could enhance the lesson?</td>
<td>Blog websites, iMovie, microphone, school-wide survey of animal preferences.</td>
<td>Most kids like to have multiple means of expression.</td>
</tr>
<tr>
<td>What kind of technology can transform the lesson?</td>
<td>Visits to the local zoo or petting farm</td>
<td>All kids love field trips!</td>
</tr>
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Who is ‘Awesome Student’?  
Observations & Reflections after assisting CDBS staff with a MAPS (Making Action Plans) Person Centered Planning Meeting  
by Charli O’Malley - Intern in the SFSU-CDBS Endorsement Program for Learners with Deafblindness

As a student at San Francisco State University, I was taught about Person Centered Planning in the context of multiple classes I have taken and even practiced writing up an entire person centered plan. The knowledge is something I planned to apply to my teaching, and assisting as a recorder for a young man’s person centered planning meeting really helped me visualize the experience even more. Most importantly, it was a positive and meaningful meeting for everyone involved, especially the young 21 year old man with CHARGE syndrome who is transitioning to adult services.

Many things made this experience more substantial for me. The MAPS (Making Action Plan) process is a collaborative and a very visual process of detailing the team’s vision for the individual and allows for creativity, flexibility and it is just way less sterile than a standard IEP meeting. There were no formal assessments, no talking about what ‘Awesome Student’ couldn’t do and the team and family felt empowered to effortlessly share their vision for this young man. I am going to review over a few characteristics of the MAPS process.

How do you know you’re attending a MAPS meeting?
• The atmosphere will be more relaxed and comfortable. These meetings are typically held in places such as the local coffee shop, a close friend’s living room, etc.

• Besides the facilitator and recorder, the attendees are people who are close to the individual and their family. They care about the person’s future and well being. This can include immediate family, extended family, friends, neighbors, coaches, employers, teachers, service providers, interveners, etc.

• The language is less formal. Details from the meeting are recorded in an organized, story format with visuals.

• Everything is laid out on the table. The meeting is very positive and you will leave feeling good, because you will leave the meeting with an obtainable action plan as well as a follow up contingency. That does not mean fears are overlooked either! All important issues are addressed:

What do you talk about at a MAPS meeting? The meeting is very individualized, but I will provide some examples:

1. The Story - On paper, the story is displayed like a winding road starting with the individual’s birth. The family and individual share major events in their life. They may share about a tough pregnancy, difficult birth, retinas detaching and surgeries. They may talk about family vacations, when they met certain service providers, major transitions such as starting a new school, interveners, moving to a new town, when a communication mode was learned. It’s a very unique family story that draws a foundation to continue planning for the individual’s ‘story’ throughout the meeting.
2. What is the dream? - They sky is the limit! The student and team share their dreams for the individual. This can include things like friendship, sensory experiences, good food, more peers who know ASL, living with family, a good intervener, recreation opportunities, etc.

3. What is the fear? - Everybody has fears and it is an important part of planning to address those fears so they can be avoided. Fears can include: being in an environment where the individual can’t communicate, abuse, finding a bad adult day program, being stuck indoors, not having friends, etc.

4. Who is ‘Awesome Student’? - Team members will write characteristics of the individual on colorful post it notes and paste them on a large figure outline of a person. This will help paint a picture of who this person really is at their core. Some examples include: loving brother, fun, makes people around him better, athletic, happy, silly, and loves good food!

5. What is ‘Awesome Student’ good at? Enjoy? - There are four subcategories, and possibly more if the team has a different idea: Relationships, Activities, Places, and Strengths.

6. What does ‘Awesome Student’ Need? - Taking into account the individual’s strengths and dreams, the team will brainstorm what supports the person will need in order to be successful.

7. FINALLY, the Action Platform - Team members discuss, list and take responsibility for specific actions in order for the individual to be successful on his or her future path. This component is broken down into 3 months, 6 months, and 1 year.

Conclusion
My hope is that any family or person who cares about an individual with deafblindness in their life reading this article will feel inspired to have a MAPS meeting for their loved one. MAPS meetings are a great way to fulfill IDEA’s requirement that all individuals 14 and older, or as needed, who have IEP’s also have a transition plan. Your first step is to find a 3rd party facilitator who can help run the MAPS meeting. Fortunately families of students who are served by California Deafblind Services can always request this service through technical assistance. I also found a great website for families who want more information on MAPS planning: https://inclusive-solutions.com/person-centred-planning/maps/
Sammy’s Lessons
by Kayla Kenton

Every educator has at least one special student who changed their career path for the better. A student who tests your patience, but genuinely loves you. A student who gives you challenges you couldn’t even expect, but then cries when you leave at the end of the day. Sammy is my special student.

I met Sammy at the beginning of first grade in Ms. Kim’s class. Sammy is a happy little boy, who loves dancing, loves people, and loves being a part of his community. Sammy is also deafblind. With visual and hearing impairments we were encouraged to get creative to successfully communicate to each other. As his one-on-one aide, we used total communication, which means I spoke to him while also using American Sign Language and he communicated back to me using an AAC device or sign language. We quickly formed our own secret language. When you spend 6 hours a day with someone, they don’t need words to tell you how they are feeling.

Being Sammy’s one-on-one aide also made me his translator. Every day at recess Sammy would roll his walker around to meet other students at our school. When he was ready to introduce himself to someone he would roll up to the student, grab their hand, and start swaying back and forth (showing off his dance moves) or he would stand in front of them, start squealing and laughing with his arms crossed in front of him. This was when I would come in and say something like “Hi! This is Sammy!” turn to Sammy and say “Can you sign Sammy?” turn back to the student “I think Sammy wants to know your name! What’s your name?” while helping Sammy practice his Sign Language. It was sloppy and confusing at the beginning, but introducing yourself to a new friend is never easy.

I was not prepared for where these conversations with his new friends might go. Most children in elementary school are curious and would ask “Why does he look weird?” or “What’s wrong with his eyes?” and that’s when I had to teach students about children with disabilities and teach them how to phrase questions in a more polite way. I quickly became very interested in teaching students without disabilities about students with disabilities. Just because Sammy can’t verbally say “Hi, do you want to play?” to a friend, doesn’t mean he doesn’t have the desire to do so. My next two years with Sammy were focused on mainstreaming, making friends, and finding a successful way to communicate with his community.

First and second grade for Sammy (and I) was filled with friends, field trips, mainstreaming, talking in an assembly, learning to walk without a walker, and forming genuine relationships with people in Sammy’s community. Sammy was not a lazy little boy. If he wanted something, he would do whatever he could to get it. He did not need to verbally tell us what he wanted for us to understand what he wanted. If he didn’t want to do work, he would throw his pencil away from us: can’t do work without a pencil. If he wanted to see a friend, he would push me aside and bolt over to the lucky individual on the other end of his gaze. If he wanted to dance, he would find your hand and start dancing. Sammy had ways of communicating successfully; it just took patience from his community for him to be heard.
I quickly learned that Sammy was as well renowned in his community as he was at school. Soon after meeting Sammy and his amazing family, I started caring for Sammy and his brother during the weekends. We would go to therapists, after school programs, and go out in their neighborhood. Sammy LOVES hot chocolate. One time when Sammy and I were heading to Starbucks, Sammy kept looking up at me to sign “chocolate” and I would have to keep reaffirming “yes, yes we are going to get hot chocolate.” The second I opened the door to Starbucks, Sammy let out a loud scream of excitement that had everyone looking our way. I quickly made some joke about how excited we both are for Starbucks and quickly got in line, slightly embarrassed. Once we were in line, the person in front of us turned around and started to greet Sammy. They held his hand, had a conversation, and then went to order. I couldn’t believe it! Sammy knew someone in his own neighborhood. Then once we were ready to order, I discovered that all of the baristas already knew Sammy and his order. I was extremely happy to learn that what Sammy and I were working on at school was something his parents constantly worked on in their community too!

After my two years of working one-on-one with Sammy, I made the transition to my new job as a Special Education teacher. Grad school and my experience with Sammy made me well prepared for new students who needed a teacher to help them successfully communicate to their peers, feel included, and form relationships within their community. In my first year I got all of my students mainstreaming 30 minutes a day, buddies coming into our room and reading together, and normalized the idea that the Special Day Classroom should be included in every activity happening at our school. Every student of mine is different and special in their own ways, but the one student I think about when I am having a challenging time with one of my own students, is Sammy. I think back to when I first met him and how frustrated Sammy would get when I couldn’t figure out what he wanted. Or that time he was so excited we were going on a field trip that he pulled a clump of my hair out. These experiences taught me so much about non-verbal communication and I use this knowledge every day.

Four years later in the same teaching position, I still compare every student to Sammy. I use what I learned those two years with Sammy on every student that comes into my classroom. I ask myself what can that behavior mean? What do they want? What are they trying to get to that I am not seeing? I am always following the child to figure out what they want or need. I still teach Sign Language to help my students communicate, I use AAC devices and visual boards even if a student is verbal, and I always encourage community involvement for everyone. Sammy taught me more than any class could ever teach and I still enjoy watching him grow into the middle schooler now!! I am so proud of the teacher I have become today, but I wouldn’t be half the teacher I am without students like Sammy.

Kayla Kenton is a middle school special education teacher in the Newport-Mesa Unified School District and earned her teaching credential and masters degree from the Department of Special Education at San Francisco State University. She was a member of the first cohort in the SFSU-CDBS Specialization in the Education of Students Who are Deafblind. She previously worked as an intervener in San Francisco Unified School District and as an elementary special education teacher in South San Francisco Unified School District. You can keep up to date with her teaching journey and tips at her website http://www.inclusionstartsnow or follow her @inclusionstartsnow