What Can CDBS Do For You?
By Maurice Belote, CDBS Project Coordinator

As CDBS enters the fifth and final* year of our funding cycle from the U.S. Department of Education, Office of Special Education Programs, we want to provide a brief overview of CDBS activities between now and next September. All CDBS services are provided at no cost. Despite the fact that we are a small project with only four full or part-time field staff members, we provide services everywhere throughout the state. Here is what we can do for you this school year:

Technical assistance

Technical assistance is a term used in many arenas including education, government, and business and typically refers to external consultants providing help of some kind. CDBS offers two basic kinds of technical assistance (we usually shorten it to just “TA”):

**Focused TA:** This is for addressing one or two basic issues and would be help for one person or a small group. It is conducted online using Zoom meetings and might also include Skype or FaceTime (or similar platforms) if we need to take a quick look at the child/student, the environment, or a specific piece of equipment. Focused TA typically includes one or two TA activities over the course of one or two months. Access to the Zoom meeting platform is provided by CDBS at no cost to training participants.

**Comprehensive TA:** This is for more complex issues or multiple issues and is typically conducted onsite — in the home, school or both — and also using Zoom, telephone and email as required. Comprehensive TA is typically a commitment of at least one year of CDBS TA activities with the educational team and family.

*Final is used in the writing to indicate that this year is the last year of funding for the project.*
It is important to know that CDBS can only provide TA to people who have asked for it. We do not have the authority to provide school-based TA at the sole request of a family member, and likewise we cannot provide TA to a family if the request comes solely from the educational team. Please remember that we are not advocates and that if you are looking for an advocate, check with your local family resource center or parent training and information center for referrals to educational advocates. If you’d like TA, complete the TA request form that you’ll find on our website at http://www.cadbs.org/how-does-technical-assistance-work/.

We will continue taking comprehensive TA requests for school-age children and youth until January 31, 2018 for this school year. Requests for comprehensive TA for infants and toddlers, as well as requests for focused TA, can be submitted to CDBS at any time between now and the end of the funding cycle next September.

**Remember, it is okay to ask for help.** Deafblindness is a complex disability and you are not expected to have all the answers. That’s why there is a federally funded project like CDBS in every state in the U.S. We are here to support you!

**Training**

CDBS staff can provide training to educational teams, school systems, family organizations, and others. Training is most effective when it is paired with technical assistance or when it is longitudinal (i.e., multiple training activities over a period of time) but there might be situations when single training activities might be effective. You can get information about CDBS training at our website (http://www.cadbs.org/services-servicios/trainings/) and here is some basic information:

**Onsite training:** CDBS staff can provide workshops and other inservice training for districts, SELPAs, county offices of education, family resource centers, parent training and information centers, family empowerment centers, and regional centers. Training can be conducted in English or Spanish.

**Preservice training:** CDBS can guest lecture in personnel preparation programs at any of the 23 campuses of the California State University system. This training is typically conducted in programs for the following California credentials: moderate/severe disabilities, vision impairment, orientation and mobility, Deaf/hard of hearing, and early childhood special education.

**Online training:** Training can be provided using the Zoom meeting platform. Again, access to Zoom is provided by CDBS at no cost to training participants.

**Open Hands Open Access (OHOA):** OHOA includes 27 online modules that can be accessed by anyone at anytime. CDBS staff can host OHOA cohorts if you have a group of people that want to go through one or more of the OHOA modules as a group. For more information about the modules, go to https://moodle-nationaldb.org.
**Family Support**

In addition to Myrna Medina, our CDBS Family Engagement Specialist, we also maintain a network of trained volunteer family members throughout the state who are available to provide family-to-family support. You might be linked to a family support provider based on your geographic location, age of child, or etiology (e.g., CHARGE syndrome, Usher syndrome, etc.). For information about the CDBS Network of Family Support Providers, go to [http://www.cadbs.org/family-support-providers/](http://www.cadbs.org/family-support-providers/).

**How To Stay Connected.**

The best way to stay current on upcoming CDBS activities and relevant information specific to deafblindness is to follow us on Facebook and Twitter:

[https://www.facebook.com/California-Deafblind-Services-179838528705916/](https://www.facebook.com/California-Deafblind-Services-179838528705916/)

[https://twitter.com/cadeafblind?lang=en](https://twitter.com/cadeafblind?lang=en)

**Questions??? Contact anyone at CDBS by phone or email and we will be happy to provide more information about what CDBS offers!**

• We are a federal project for the benefit of the people of the state of California and are funded for 5-years by a federal grant from the Department of Education. We hope to be able to continue providing services and are cautiously optimistic about applying for another grant to do so. When we say that this is our final year in this funding cycle, it means that we will be applying again in 2018 in the hopes of being funded for another 5 years to continue similar services for individuals from birth through age 21 who have both hearing and vision problems, with or without additional disabilities.
Promoting Literacy for All: Thinking Beyond Just Reading & Writing
By Julie Maier, CDBS Educational Specialist

“Each person who is deaf-blind—whatever her sensory, mental, and physical abilities—deserves the opportunity to become literate in all the ways of which she is capable. Reading and writing are especially crucial for one whose world is narrowed because of vision and hearing losses. Literacy can enable such a person to exchange information and ideas, and develop relationships that would otherwise be out of reach.”
~Barbara Miles (2005)

Abstract: This article shares information about the importance emergent literacy development for those children and youth who are deafblind and not yet proficient communicators and/or learned that symbols have meaning. In addition to discussing the purpose of emergent literacy instruction for all learners, suggestions for when and how to plan and provide meaningful literacy instruction both at school and home will be offered. The article also includes links to multiple literacy resources available on the internet.

There are few things I enjoy in life as much as spending time reading a good book or article in a favorite magazine. A smile crosses my face whenever I happen across a child reading or listening to someone read. I still clearly remember the sound of my mother’s voice as she read books to me before I could do it myself and reading books with my own children was one of sweetest parts of my day when they were young. When I begin to think of all of the times and ways we use literacy skills each day to complete a myriad of tasks and chores at work and home, as well as, to share our thoughts, opinions, ideas and feelings with others through texts, social media posts, notes and letters, the list seems never-ending. It’s no wonder that literacy remains such an important targeted focus in areas of child development, education, and career preparation.

I believe that literacy development should be a targeted focus for all children, including those who don’t demonstrate a discernible interest or the prerequisite skills for reading and writing, and it is a constant focus in my work supporting school teams and families. In my work I find that the topic of literacy and children and youth with deafblindness, especially those with additional disabilities, usually brings up many questions and reveals many assumptions about the relevance of literacy development for ALL children. These questions and assumptions are understandable given the unique learning profiles, skills, interests, and needs of these learners. Some of the questions I hear relate to ways of providing relevant access to similar literacy activities as same-age peers. Others focus on identifying meaningful access points and opportunities for practice. Finally, many center on how to practice communication skills and build social connections through literacy development. This topic and these questions have been pondered and discussed in depth and with great clarity and creativity by Barbara Miles (2005), and Phil Hatlen (2004; 2010) and I encourage you to read their classic articles. (Links to both articles appear at the end of this article)
In this article I’d like to share my own thoughts and some suggestions for meaningful ways to promote literacy skill development, both at home and school, for children and youth with additional disabilities who need direct experience within the context of meaningful routines to develop a stronger understanding of symbolic communication. There are many wonderful, helpful resources related to this topic on the internet (articles, videos, webcasts, checklists, photo examples) and it’s my hope this article will steer you towards some of them.

How do we define literacy? In 2005 Barbra Miles shared this definition: “Literacy generally refers to the ability to read and write. Reading and writing are symbolic systems that allow people to receive and send information across distances of time and space.” In my mind it’s important realize that at its base, literacy is a form of communication. It serves as means to share ideas, information, opinions, and feelings. In fact, research has demonstrated a strong correlation between the development of literacy and communication skills especially for learners who use augmentative or alternative systems of communication (Downing, 2005). Miles (2005) also pointed out that the educational research field is equally interested in emergent literacy, which recognizes that literacy development is a process, typically occurring in childhood, that involves cognitive, social, psychological, and linguistic processes (Bloom & Green, 1984). Emergent literacy allows you to understand that even a learner who doesn’t yet understand symbols have meaning can participate in carefully planned literacy-based activities that will promote the development of symbolic representation in both literacy and communication and provide meaningful contexts for the development of social relationships.

Phil Hatlen explained in his article Literacy According to Phil (2010), that media literacy – instruction in interpreting the images and sounds of our multi-media world – is also a highly relevant educational practice due to the ever-increasing use of digital media and image-based printed information children and youth are exposed to today. When one considers literacy from the viewpoint of both emergent literacy and media literacy, it is much easier to recognize that putting together a daily schedule of tactile objects or photos, or sharing a remnant or souvenir from a weekend activity in memory book, or exploring and categorizing objects covered in different textures is evidence of meaningful literacy skill development.

Why is literacy important for children who are deafblind with additional disabilities?

Miles (2005) explained beautifully in her article, Literacy for Persons Who are Deaf-blind, the need to adopt an expanded notion of literacy beyond simply reading and writing when instructing these learners. Emergent literacy focuses on the social, psychological and linguistic benefits of literacy instruction which can help families and educators to connect various literacy activities to the unique, and likely, multiple modes of communication of a child. I agree with Miles that promoting literacy is essentially important as an issue of access to information about our world as well as access to the people in it. Helping students to understand that objects, photos, and pictures convey meaning and can be used to gather or share information is extremely powerful and certainly fits into an expanded definition of literacy. This wider umbrella of literacy allows you to better understand why literacy goals and activities should be included in every child’s daily home routine and school program.
How will I know a child is ready for literacy instruction and experiences?

In my experience working with teachers and service providers who support learners with more complex support needs who do not effectively use a symbolic communication system, it often seems that “readiness” appears to be a criteria for considering literacy activities. I personally find this is a very limiting view. I always encourage school teams to identify multiple ways to promote interest in literacy for these students and to think of ALL of the possibilities to promote literacy skills. Hatlen expressed in 2004, “If we think that literacy is only demonstrated through skills in reading and responding to print or braille text, then we are denying access to literacy instruction to countless children and youth” (Hatlen, 2004; 2010). This seems to me a very dangerous path to follow and instead we need to assume these learners can find enjoyment and develop skills in literacy, even at an emerging level, that will enhance their understanding of their world and connect them to the people, places and things in their world.

So, when is a child ready? As soon as you have engaging activities and materials prepared to share with them. Preparing the right activities and materials rests upon a good match between the learner’s current skills and interest levels related to literacy and the planned activities and prepared materials. A good place to start with determining those skills and interest levels is the All Children Can Read: Literacy Skills Checklist (B. Purvis & N. Steele, 2016) found on the Literacy for Children with Combined Vision and Hearing Loss website. This easy-to-use checklist will give you a snapshot of their skills, which can then be paired with these Steps to Literacy (Deaf-Blind Network Literacy Work Group, 2014) to identify potential learning targets and literacy activities. This website is a goldmine for educators and families looking for ideas for activities and additional links to resources specific to the child’s literacy skill level.

When should I plan literacy instruction?

Barbara Miles (2005) reminded us of the simple fact that literacy is a social endeavor when she wrote, “We know literacy goes far beyond the reading and writing done in class. Each of us engages in and practices meaningful literacy in a variety of pragmatic ways everyday, many of them for social reasons.” For a child who is deafblind literacy activities will most often be shared with another partner. Some activities naturally necessitate a partner such as a bedtime story routine, story time in school, or buddy reading. At other times engaging in a “conversation” about a prior shared experience creates a literacy experience that also promotes communication and social skills practice. Examples of these conversations include: creating and then exploring an experience book together; or joining the child’s in assembling their schedule using objects or photos or pictures at the beginning of the day.
There are many pragmatic functions of literacy that all children are introduced to and practice each day. As you plan your literacy instruction and activities for the day, ask yourself “How can I offer a learner who is deafblind, especially one who has not yet developed a symbolic level of communication, similar meaningful opportunities?” Start with listing all the daily routines of your class or family, and which of these routines include potential literacy activities; then look for specific tasks or roles in which the child could participate, such as turning pages of a book or pushing switch that says “turn the page”; feeling a tactile marker on each student’s name card during attendance; using tactile objects to make choice or offer response during reading center or at when reading at home; collecting leaves and acorns on walk to create journal entry or collage. Many teachers and families wisely focus on goals that promote a child’s independence and participation in daily life activities. Here again there are multiple opportunities to practice literacy skills. Some examples include: using a tactile or photo checklist or guide to complete a class activity or routine at home or shopping trip to the store; helping complete their home-school journals; or following a recipe card of photos or objects to make a simple snack or meal.

How should I adapt my instruction and materials to ensure accessibility?

This is probably the most essential question to ask yourself when planning your class activities for the day or home routines for a learner who is deafblind. A good first step is consider employing universal design for learning (UDL) principles: representation (the “what” in learning); action and expression (the “how” in learning); and engagement (the “why” in learning). I can’t think of better resource for explaining and illustrating the use of UDL than Elizabeth Hartmann’s brief, informative article Universal Design for Learning (2011) and accompanying webcast from the Perkins e-Learning site.

Another resource I often share with teachers, service providers, and families is the Paths to Literacy website and listserv. This website holds a treasure trove of ideas and personal stories – many that provide specific directions and with photos for creating and using materials, activities and games. New stories, activities, resource ideas are updated constantly and as parent or teacher of a child who is deafblind this would be high on my bookmarked list of websites.

Certainly you will consider the child’s hearing and vision losses or limitations when planning and developing adaptations, but it’s also important to match the instruction and materials to the learners’s
level of understanding and individual interests. When a child has difficulty accessing books and other print or digital materials through vision and hearing, it can be more difficult to interest the child in literacy activities. I think the best approach here is to build the literacy activities and materials around the child's interests. An example I often share with teachers and families is a wonderful video, called *He Likes Wheels, not Books*, created by the Washington Sensory Disabilities Project, illustrating an experience book for a little boy who loved to spin wheels on toy cars but showed no interest in books. His team created a book that included different types of spinning wheels within the pages of the book that sparked his interest and allowed them to introduce books and early literacy skills to him.

It's also important to ensure the materials, vocabulary and concepts are well matched to the child's level of conceptual understanding. This does not mean material or content need to be watered down or that you use materials designed for younger children. In fact, extra care must be taken to ensure the materials and content are age-appropriate, relevant, and as much as possible, connected to the child's real life. We need to ensure that the information shared in literacy activities has relevance for the child based on their personal direct experiences and the people, places, and things in their world. Some examples of relevant literacy activities and materials to try include: memory boxes or books; experience (or object) books; assembling journal entries through collage of objects; creating a personal dictionary; and exploring books through use of *story boxes* or multisensory books with that include multiple ways to interact with the material such as through touch, movement, and perhaps even smell.

I hope the thoughts and suggested practices and resources I've shared have encouraged you to try to incorporate more literacy activities in your class or, if you're a parent, at home. On the following pages I've provided a list of online literacy resources specific to deafblindness that I think you'll find helpful.

I'd love to hear your thoughts, comments, or questions about this article and I'm always interested in learning about new ideas, activities, and resources for literacy development, so please contact me at jmaier@sfsu.edu to share anything you'd like.
Literacy Resources for School Teams

We’re fortunate that many knowledgeable, experienced, and dedicated educators in the field of deafblindness have been developing and sharing useful and relevant information about literacy development and instruction with others in the field for many years. The collaboration within the network of various deafblind projects across the country has also led to the development of wonderfully rich resources. Here are some of our favorite literacy resources:

Paths to Literacy: “This website is a joint project between Perkins School for the Blind and Texas School for the Blind and Visually Impaired and is intended to be an online hub for information related to literacy for students who are blind or visually impaired, including those with additional disabilities or deafblindness. It includes original content, as well as links to other sites and resources available on the web. Some materials have been summarized, with a link to the full resource. In cases where information is available free of charge on the web, they have linked directly to articles and other resources. In cases where information is sold, they have linked to the web address or URL where more information can be found. Some of the information and photographs have also been posted with permission.” [From Paths to Literacy website]

Paths to Literacy website: http://www.pathstoliteracy.org/

Link on Paths to Literacy site regarding students with vision impairments and additional disabilities: http://www.pathstoliteracy.org/multiple-disabilities

Link on Paths to Literacy site regarding importance of routines for teaching concepts and emergent literacy through establishment of routines: http://www.pathstoliteracy.org/developing-routines

Link on Paths to Literacy site regarding creating and using story boxes for literacy development: http://www.pathstoliteracy.org/storybox-ideas-norma-drissell

Link on Paths to Literacy site regarding creation and use of tactile schedules: http://www.pathstoliteracy.org/strategies/tactile-schedule-students-visual-impairments-and-multiple-disabilities

TWO OF MY FAVORITE CLASSIC ARTICLES ON LITERACY


**Literacy for Children with Combined Vision and Hearing Loss:** “This site is for individuals interested in beginning or enhancing literacy instruction for children with combined vision and hearing loss. Its content is also designed to improve literacy instruction for children with multiple disabilities and other complex learning challenges. Our contributors include State Deaf-Blind Project staff as well as teachers who want to give back to the field and help more families play a role in educating children with complex learning challenges. The instructional techniques and tips provided on this site include evidence-based practices for increasing literacy skills. It is recommended that you visit the Shifting the Perspective page for an explanation of literacy from a broader view. If you are looking for resources for a particular child, completing the Literacy Skills Checklist provides guidance in determining which area of the website will be most helpful.” [From Literacy for Children with Combined Vision and Hearing Loss website]


**Perkins e-learning Webcast: Accessible books and literacy:**
**Supporting and encouraging a love of literacy**

1 hour webinar from Perkins School by Sandy Kenrick, parent

“Sandy Kenrick is the mother of two young boys. Liam, her six-year old son, became deafblind at the age of two and a half after an illness. In this webinar, she describes how she helps develop her son’s literacy skills and his love for books through making tactile, accessible books to support his interests, concept development, IEP goals, and general love learning. Sandy shares her rich ideas about how to support literacy for the individual child and also within her whole community.” [From Perkins e-learning website]

Washington Sensory Disabilities Services: Experience Books
This site offers an introduction, a series of videos that explain how to make and use experience books and show unique examples of books, an FAQ page, and additional resources and links:

“Experience books differ from traditional books in that:
• Experience books are created with a specific reader in mind.
• The story is based on an experience or interest of the target reader.
• The objects included in the experience book are particular to the experience or interest of the student for whom the book is made.
• The words written (and, when appropriate, brailled) on the pages are chosen for a particular student.

There are many different ways to make experience books. Several examples appear in the videos on this page. Identifying the desired outcome (for example: communication, structured interaction, consistency of vocabulary, reinforcement of familiar routines) will help to determine the appropriate format and content.”
[From Washington Sensory Disabilities Services website]
http://www.wsdsonline.org/video-experience-books/

Making Object Books by MaryAnn Demchak from Nevada Dual Sensory Impairment Project Newsletter
This is a wonderful one-page article describes types of object, or experience, books and provides tips on how to make and use an object book for a child with accompanying photos examples.

Project SALUTE: Emergent Literacy for Children Who are Deaf-blind
This information sheet includes practical and relatable suggestions for multiple activities that include direct experiential learning to build a learner’s literacy and communication skills.
http://projectsalute.net/Learned/Learnedhtml/EmergentLit.html

Texas Deafblind Project: Creating and Using Tactile Experience Books for Young Children with Visual Impairments
This resource offers a detailed information about many levels of adapted books for learners with vision and hearing loss, including specific descriptions of several tactile experience books.
References:


Early Tactile Communication: Touch, Cues, and Signing
By Stacy Aguilera, CDBS Educational Specialist

A question that is often asked when it comes to students identified as deafblind is, “What type of communication should be used and how do I get started?” Often the misconception is, if a student is identified as deafblind they should automatically be taught to use tactile sign language (signing using touch, usually by touching and making signs in the other person’s hand) as their first form of learning to communicate. However, this is not always the case. Most often, other forms of tactile communication need to be introduced first and then build up toward tactile sign language.

In this article, I will explain the different forms of tactile communication used with students who are deafblind and when it may be appropriate to use each form of communication. Please keep in mind this is just a guide and may not apply to each individual student in the same way, but hopefully will give you an overview and starting point. It is good to refer to the deafblind project in your state and request technical assistance if you want a more in-depth approach to helping your student with deafblindness.

It is important to understand that even though our goals and expectations should be to reach the highest form of communication, not all students with deafblindness will become complex communicators (OHOA, module 8). It is important to keep in mind the individual needs of the student when developing a communication system.

Two terms we will refer to in this article are Receptive Communication (how the child receives communication) and Expressive Communication (how the child expresses or shares desires, emotions, or ideas to others).

Nonsymbolic/Presymbolic Communication

During this stage, a child communicates through behaviors that usually reflect a general state of being such as that they are comfortable, sleepy, upset, etc. It is up to the caregivers to apply meaning to those behaviors in order to interpret what the child needs or how they are feeling. Children who are deafblind may be very subtle in the expressive behaviors, and those closest to the child will need to bond with them and observe carefully to be able to interpret and discern the child’s needs or desires being expressed. The child’s body movements, facial expressions, or sounds are the behaviors that need to be interpreted to understand what the child is trying to let us know. Pointing, nodding, waving, hugging, looking for a person or desired object, and other non-signing simple physical gestures are still considered forms of presymbolic communication (OHOA, module 8). Presymbolic communication in this situation means that the communicated behaviors are directly related to the emotions and actions being felt right then and do not represent other separate concepts.

TOUCH CUES defined

“Touch cues are physical cues that are used in a consistent manner on the child or adult’s body to give a specific message about what is about to happen to the person. In most cases, the touch cue will be at or near the body part that will be affected and if the touch cue is used to prepare the child for movement, the touch will give the child information about the direction their body will move” ~ (Belote, Fact Sheet) Please refer to the fact sheet for a more detailed explanation and examples.
The first form of tactile communication that should normally be introduced is called Touch Cues. Touch Cues are a form of receptive communication that gives the individual with limited or no functional use of their vision and hearing an indication that something is about to happen to their body. For example, to indicate to a child that they are about to be picked up from a chair, the caregiver may give two or three gentle taps in the armpits in an upward direction (Belote, Touch Cues Fact Sheet). Often, touch cues are used for individuals at a presymbolic language level. Touch cues should be introduced and used consistently from the very beginning of any communication, especially if the child has little to no usable vision and hearing.

It is important to remember during the nonsymbolic and presymbolic stages of communication that the child’s expressive communication will likely be subtle and usually exhibited through behaviors. An indicator that the child understands the information that is given to them (receptive communication) is if they change how they then respond to the action that occurs after the touch cue communication. For example, if in the past every time they were picked up and moved they responded by tensing up, crying, anxiety, etc. and now they are calmer and seem to have less anxiety and tension, that is an indicator that they understood the touch cue indicating that they were about to be picked up and moved. Touch cues allow the opportunity for the child to understand ahead of time (anticipation) of what will be happening to him or her before it happens.

Concrete Symbolic Communication

The use of concrete symbols is the beginning of symbolic communication. Concrete symbols would include pictures to represent the objects pictured within (if the child has functional vision), objects, iconic gestures (pat chair to mean sit), and sounds (buzz sound to represent bee). These symbols have meaning to the child in their immediate physical environment. This means the symbols will look, feel, move, and sound like what they represent to the individual with deafblindness (OHOA, module 8). It is important to keep in mind that the perception of the same object by a child with deafblindness will be different from a peer who has full use of their hearing and vision. For example, a miniature replica of a bus (visual perspective) would have no meaning to an individual who is deafblind and had not seen a whole bus before, but a piece of the seatbelt (tactile perspective) that he or she wears on the bus would have meaning representing the idea of “bus” because that is what he or she feels when they are sitting on the bus.

Each child is different and close observation of the child’s actions, movements, and expressions is needed to understand what they are trying to tell you. One individual being observed had exhibited self-abusive behavior so other similar motions were assumed to be related and the child trying to share that his leg hurt was being missed. The self-abusive behavior was hitting his leg with a closed fist. In contrast, his way of expressing discomfort was by grabbing his leg open handed and pulling on it. After the difference was pointed out to the caregivers, they were able to respond differently and the child then stopped crying because they were able to understand the message and fix the problem. The differences are subtle but they are there.

NAME CUES defined

“Name cues are a physical touch cue that an individual with deafblindness uses to identify the important people in his or her life” ~ (Belote & Rodriguez-Gil, 2005, p. 3). Please refer to the article for detailed information on selecting an appropriate name cue.

OBJECT CUES defined

“Objects that can represent activities, places, and people. They can be used alone, or together in a calendar or schedule system” ~ (Belote, 2005, p. 5). Please refer to the article for detailed information on getting started with object communication.
During this stage, the individual with deafblindness would be learning (receptively) all the common symbols that represent meaningful activities and people in his or her life by using name and object cues. Building off the step of Touch Cues that let a child anticipate an activity, Name Cues can help identify the person who is there with them and help them start identifying different people with different activities.

Introducing name cues and object cues provides opportunities for a child with deafblindness to communicate in a more effective manner instead of just through behaviors such as pushing things away, throwing a tantrum, etc. However, please keep in mind that the student still may not be able to use expressive communication in the way we perceive or expect language to happen. For example, he or she may be able to understand the activities and recognize who is working with them based on the name and object cues, but that does not necessarily mean they can take those same objects and mirror it back in the same way expressively it was presented to them. His or her expressive communication may be as subtle as change in behavior, facial expressions, expressing emotion (crying) etc.

The first step to initiating expressive communication with objects is to use two objects to represent a choice between two activities and see if they select one. If the child has limited movement, his or her choice making may be as subtle as eye movement towards the object they chose.

With some individuals who are deafblind, concrete symbols may be the only type of symbols that make sense to them; however for others it may be a bridge to using abstract symbols such as coactive and tactile signing.

**Abstract Symbolic Communication**

Abstract symbolic communication is a higher form of communication because the symbols may not be physically similar to what they represent. Examples of abstract symbols are speech, manual signs, (like ASL or tactile) and Braille or printed words (OHOA, module 8). With individuals who are deafblind, coactive and tactile signing would be a form of abstract symbolic communication. Some examples of a combination of concrete and abstract symbols would be 2-3 word phrases such as “want-eat” or “me-go-home”. The development of abstract symbolic communication (expressively) can be difficult for individuals with deafblindness. Concept development is necessary for the child to use abstract symbols and will take time with a great deal of assistance (OHOA, module 8).

**WHAT IS COACTIVE SIGNING?**

“Coactive signing involves taking the child’s hands and, in a respectful way, molding the child’s hands through the signs, so that you are helping the child make the signs” (Rodriguez-Gil & Belote, 2005, p. 1). Please refer to the article for detailed information on understanding coactive signing and when it should be used.

**WHAT IS TACTILE SIGNING?**

“Tactile signing is used when the person places his or her hands under the child’s hands to express something to the child” (Rodriguez-Gil & Belote, 2005, p. 1). Please refer to the article for detailed information on understanding tactile signing and when it should be used.
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The contents of this newsletter were developed under a grant from the U.S. Department of Education, #H326T130031. However, these contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer: Jo Ann McCann.
On Saturday, November 4th CDBS held their 6th Annual Deafblindness Symposium at San Francisco State University. This annual autumn event serves as both a reunion and an opportunity for ongoing professional development training for current students and past graduates of the San Francisco State University Specialization Program in Deafblindness program. This collaborative personnel preparation project between Moderate-Severe Disabilities Program at San Francisco State University and CDBS provides additional specialized training in the education of students with deafblindness to student teachers working towards their moderate-severe teaching credential. Through this partnership close to 50 student teachers have graduated with additional specialized competencies to assess, teach and support students who are deafblind, with eight more graduates expected next summer.

In its reunion function, our annual symposium gives graduates a chance to reconnect and provides current students the opportunity to meet these fabulous former graduates who are now teaching in the field. It’s become a tradition to invite a former graduate to welcome the new cohort to the small, but mighty, field of deafblindness. This year Edith Arias, a special education teacher supporting transition-aged youth in San Francisco Unified School District and a parent of a young man with significant support needs, provided the official welcome to the eight students in our current 8th cohort in the Specialization in Deafblindness program and shared some of her special memories and important takeaways from her experiences in the specialization program.

Based on feedback gained from past symposiums, the topics selected for this year’s symposium were customized employment and self-advocacy. Ellen Condon from the University of Montana Rural Institute and Marc Gold & Associates, as well as coordinator of the Montana Deaf-Blind Project, was all set to provide the first presentation, Competitive, Integrated Employment for ALL: Strategies that will help us get there, when an unexpected snowstorm grounded her at home in Montana. Yikes!
We needed to quickly think outside the box and to get creative this year with distance technology, which thankfully worked out without a hitch. Ellen provided a wonderful presentation and compelling examples of customized employment, which can be described as “competitive integrated employment, for an individual with a significant disability, that is based on an individualized determination of the strengths, needs, and interests of the individual with a significant disability, is designed to meet the specific abilities of the individual with a significant disability and the business needs of the employer” (Workforce Innovation Technical Assistance Center, 2017).

In particular her presentation focused on using a “process of discovery” to determine an individual’s strengths, needs, and interests and motivation towards work based on in-depth, qualitative, ecologically-based assessment approaches. We were really intrigued by Ellen’s presentation and the positive perspective she offered about this process to determine and negotiate individualized, integrated job opportunities for individuals with significant support needs in which the interests, goals, and support needs of the job seeker and the benefits for the employer are equally considered. This process is very much aligned with the familiar “follow the child” assessment and person-centered planning approaches. It’s encouraging to learn of this unique approach to finding meaningful employment opportunities for individuals who have been excluded from interesting employment because they are not well matched to the competitive job market. To learn more about the essential elements of customized employment, here is a helpful article: [http://bit.ly/WINTAC_Cust_Employ](http://bit.ly/WINTAC_Cust_Employ)

After connecting and catching up over lunch, our second presenter, Mussie Gebre, the president of Deafblind Citizens in Action (DBCA), as well as a fellow SFSU student, shared some stories of his journey through the local public school system and what he learned about essential supports and accommodations for students
who are deafblind. Mussie emphasized the importance of providing assistive technology and appropriate related service providers in order to meet the unique needs of individual students who are deafblind. In Mussie’s case, this meant the services of tactile interpreters and opportunities to try many different braille devices, which could provide fuller access to the school curriculum and environment. Mussie shared that as he gained more knowledge of availability of assistive technology devices and the services of tactile interpreters he began to feel more empowered to advocate that he had an educational right to these supports and services. Since high school he has continued to advocate for himself and other individuals who are deafblind or blind and their access rights and needs in schools, workplaces, and all parts of the community. He pursues this advocacy through his work as an assistive technology consultant and as a contractor for the National DeafBlind Equipment Distribution Program (NDBEDP), and a leading member of Deafblind Citizens in Action. Mussie shared Deafblind Citizens in Action’s current goals and work and encouraged us to continue to reach out and learn about lives, goals, contributions, and unique support needs of individuals who are deafblind. Each us learned so much from hearing the story Mussie’s journey of empowerment and goals for the future. To learn more about Deafblind Citizens in Action and Mussie Gebre and the other members and activities, check out their website www.dbcitizens.org.
All parents play many roles but now let’s think about those same roles for parents of children with deafblindness. Those roles can seem endless at times, and trying to prioritize all the demands might appear impossible because they are all important.

During a parent training I facilitated an icebreaker activity that brought the group into a discussion about what struggles parents face in their daily lives of parenting children with disabilities. When planning this activity I took into consideration a couple of things. First, who are the participants in my audience? Second, what were my goals for this training? I knew the audience was parents of children with special needs and the outcomes were for them to leave with a) an understanding that parenting a child with special needs includes stressful demands; b) how to identify these potential stressors; and c) learn about some strategies for coping and maintaining the balance.

For this activity I laid out a great amount and variety of hats of different sizes, shapes and colors on the table. Each hat was labelled and represented a different role that the person might have to perform in their day-to-day activities (parent, spouse, chauffeur, etc.). I asked them to grab a hat for each role that they play daily, and to start writing the different activities they have to do in order to fulfill those demands. During the first minute or two, I noticed the almost all the hats were gone and that each participant had many hats by their side and they were still writing. Once I started going around the table asking everyone to share and present about their hats, it was not surprising that almost all of the participants shared the same common daily roles.

Once they completed the first part of the activity, I explained for the second part of the activity, they would sort their hats (roles) from the highest priority to the lowest priority. It was amazing to discover their responses confirmed what I already knew from my personal experience. The most important roles in our lives were placed on the lower end of the priorities’ scale. Important roles such as being a “parent” (including parent of other siblings) “husband or wife,” “sister or brother” and even a “friend” are taken for granted, and many times overlooked and little or nothing is done to nourish them. These roles are set aside until we have the time for them or raised red flags are screaming for attention and impossible to ignore.

This activity had led us to a very rich discussion. Parents were able to open up and share their feelings and frustration of not being able to handle these demands to maintain a healthy family balance while performing these different roles. Even though there is no strict definition for “special needs” there was a clear consensus that a “special needs child” means “many needs” and meeting these needs takes extraordinary time and effort and the accompanying emotional and physical stress can extend not just to the parents, but to the whole family. (https://www.psychologytoday.com/basics/stress).

During my almost 18 years of professional experience speaking with parents of special needs children, I have learned a lot from the many things parents have shared about parenting and raising a child with complex needs whether that includes medical, physical or mental health needs. The greatest lessons have come from my personal experience of being a mother of a child with special needs.

There are many factors of parenting a child with special needs. It gives you the joy of being a parent, but on the other hand, sometimes those joyful moments are overtaken by inevitable reactions to stress from all the demands that come with parenting a child who needs so much support and time. Often times, there is hardly
a moment of peace, until bedtime. In my experience it is also true that our marital relationships and caring for other children are placed in a paused mode. Our social life and self-care needs are neglected until we see that everything is “under control”, and until then, we maintain ourselves at a simple survival level.

I would like to share some strategies that have worked for me and other parents as we’ve coped and to find the balance in the difficult situations and with different roles we play everyday. Please remember that just as every child has different needs, every parent also has their own definition of needs and what works for one parent might not work for other parents.

The following are strategies to consider when trying to balance your daily demands…

1. **Acceptance** - Accepting and recognizing that caring for a child with special needs is physically and emotionally draining, even when we know that we can do everything and at any time. We have to be careful and understand that when we take care of ourselves, our performance will be much better in caring for our love one.

2. **Delegate responsibilities to other family members and friends** — Often times there are people near us who are willing to help. Family members and friends can help with making a phone call for you, run errands, carpool, and organize a get-together.

3. **Use available respite care services** — Using respite services will give you extra hands and free time that you may need to rest or do other important things.

4. **Allocating quality time to other children** — Setting aside 10-15 minutes a day to spend with other children will be beneficial to you and your children. You will experience other type of childcare needs other than “special needs” and your children will know that they are also important.

5. **Be a parent** — It is understandable that all the daily demands of having a child with special needs (medical, educational and physical needs) are great, so it is important not to forget to see them as our children, not clients, patients or students.

6. **Be a wife or a husband** — Many times our marital life suffers tremendously, due to the many demands of our daily life, so it is important to set aside time to spend together for “a date” at least once a month in which you can have some quality time together that you will look forward on a regular basis.

7. **Be yourself** — Most of the time as parents we put our own needs in the back burner and think that self-care is selfish. Understanding our own needs are important and taking the responsibility to make these needs a priority can help achieve balance in our lives.

8. **Have a life** — As mentioned in the previous suggestions, the concept of having your own life might seem selfish to you or others. However, acknowledging that you need to make time for yourself might help you reset and make changes in your routine. Try to restructure your schedule to allocate small amounts of time at first to do the things you like, such going out with friend or doing a hobby you enjoy.