This is a publication of the Council for Exceptional Children’s Division on Visual Impairments Deaf Blindness (CEC-DVIDB). Advertisements included in this issue are not endorsements of products or services, and individual views of authors are not necessarily the official position of CEC and/or DVIDB.

Ethan Wolfe (2002-2014)

In loving memory of Ethan Wolfe, 2002-2014, whose parents supported his independence, and through their leadership, the self-determination and education of thousands of students who are deafblind and their families.
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A note about the term “deafblind” versus “deaf-blind”: Sometimes the word “deaf-blind” is used in place of “deafblind”. “Deaf-blind” is an older term that is related to statute and regulation in the United States. Many in the United States are beginning to use the term “deafblind” because the combined effects of vision and hearing impairment create a unique disability. Internationally, the term “deafblind” is more accepted. Because CEC is an international professional organization, the term “deafblind” is appropriate and consistent with the trends in the United States and around the world. In this publication, “deafblind” is used; it is hyphenated when it is denoting an organization’s name or a recognized title.

Visual Impairment and Deafblind Education
Quarterly Spring Convention Issue

Are you presenting at CEC’s 2015 Convention and Expo in San Diego, CA on topics related to visual impairments and/or deafblindness? Submit a summary of your presentation to be included in the special Convention issue by April 24, 2015! Articles and pictures from convention can be submitted to Kathleen Farrand at farrand.9@buckeyemail.osu.edu.
Message from the Guest Editor

There’s No Place like Home: Growing a Professional Home for the Field of Deafblindness within DVIDB

Amy T. Parker
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When Dorothy travels through the mythical Land of Oz, she meets colorful characters along the way who teach her about brains, heart and nerve (Baum, 1900). Throughout her journey, she is reminded of important lessons that she learned from Auntie Em and Uncle Henry back in Kansas, which help her face the challenges in Oz, and which eventually, enable her to make her way back home. A professional home is a place where one belongs; where one learns about what is important in research, practice, and policy; and where one contributes to ongoing efforts within a field. A professional home provides us with resources and supports from colleagues that are engaged in a field of practice. Like Dorothy, when we are challenged with
puzzling situations on our respective journeys, we can draw from the things we have learned from our professional home to address the needs of students in complex situations. It is a place that we return to, that we protect and grow, and that helps sustain our specialized areas of focus- in this case special education for students with visual impairment and those with deafblindness.

CEC’s Division on Visual Impairment has long supported and been supported by professionals in the field of deafblindness through its conferences, competency development activities, and publications. This year the Division took another step forward in recognizing the unique needs of students who are deafblind and the special education professionals that serve them by adopting deafblindness in its name. With this new name, we have fresh opportunities to grow division membership, to ensure that the needs of students with low incidence disabilities are represented within the CEC, and to intentionally address the national gaps in special education service provision that students who are deafblind experience.

As one of the rarest of the low-incidence disability groups, students who are deafblind face enormous challenges, not only in accessing environmental information or in developing communication, but in being recognized as a distinct disability group within educational systems. Parents and family members of individuals who are deafblind often describe their ongoing efforts to educate local IEP teams about the unique instructional strategies that will support their family members with deafblindness (NCDB, 2012). Teachers of the visually impaired, who often serve students who are deafblind on their caseloads, have expressed feeling ill prepared to serve students with dual sensory impairments in the areas of literacy, assistive
technology, and in communication development (Bruce, 2007; Durando, 2008; Zhou, Parker, Smith & Griffin-Shirley, 2011). Orientation and mobility instructors have also recognized the need for creative partnerships and specialized training to be better prepared to serve individuals who are deafblind (Bourquin & Sauerburger, 2005; Huebner, Prickett, Welch & Joffee, 1994).

Because of a longstanding federal recognition of the challenges that systems face in serving students who are deafblind, technical assistance networks have been funded in the United States, now for over 30 years, to help identify children and provide resources to educational teams serving students and families (Thompson & Freeman, 1995). One of the ways that DVIDB has championed the needs of students who are deafblind is through the development of knowledge and skill competencies for teachers of the deafblind and for interveners, two direct service roles that have growing national support from family members and professionals alike (Blaha, Cooper, Irby, Montgomery & Parker, 2009; NCDB, 2012; Zambone & Alsop, 2009).

In this special issue of VIDBE-Q, we begin by listening to the stories of individuals who are deafblind themselves who are on the other side of their educational journeys reflecting on the things that helped them succeed. These brief vignettes offer us unique insights on the need for recognition of the disability for more than the sum of its parts; the need for knowledgeable teachers, and interveners; and the need for advocacy to improve our educational system, Next, we learn about the ongoing efforts to prepare teachers of the deafblind and interveners in Utah and Texas, who provide greatly needed intervention to students. We also hear about an innovative partnership between the National Family Association of the Deaf-Blind
and the National Center on Deaf-Blindness to support parents in learning more about the intervener role in educational settings. We explore technical assistance partnerships that have produced products for professionals working across state lines to advance the early identification of infants and toddlers with dual sensory impairments, as well as efforts to support young adult transition from high school into adult roles. Finally, we have the opportunity to hear from two professionals who work directly with children and young adults who are deafblind, and to receive practical advice and “pearls of wisdom” from passionate colleagues.

As we celebrate a new Division name, we realize that we don’t need to travel to Oz in search of adventures. We have plenty to discover as we work collaboratively to address the gaps that students with deafblindness and those with visual impairments face through our efforts as a professional division, within one of the most respected special education organizations in the world. We, like Dorothy, have a purpose within and an appreciation for a professional home- one where our brains, hearts, and nerve may serve students with deafblindness and those with visual impairments.

References


In my last President’s Message, I discussed the excitement a new school year can bring. Now we are nearing the end of a semester and it is time to do one final assessment of progress that has been made over the last 3 months.

Let me begin by saying how grateful I am to work with such an innovative and energetic board. They have worked very hard to maintain the momentum that we left the 2014 convention with, and have succeeded. During the past few months, DVIDB has experienced some first time achievements that we are very proud of.

- Creation and adoption of a new DVIDB logo
- The DVIDB website and social media sites now display our new name and logo
- A portal for deafblindness that includes a deafblind community Google group
- A podcast of a conversation with Mark Richert, Director of Public Policy at AFB concerning what the Cogswell-Macy Act means for students who are deafblind
• Mentorship program for first year or early career TVIs and O&Ms
• Webinar with Dr. Frances Mary D’Andrea on December 4, 2014 at 3:00 pm that is free to members and $15 for non-members
• An employment section on the website that is updated regularly
• Open contest to rename the DVIQ to include our new name

Along with these first time successes, we have also been working hard to build a high quality session line-up for the CEC conference in April, 2015. It is a very exciting time. It is my hope and charge to us all that this momentum will carry us into the CEC Conference in San Diego so that we can refuel in order to continue to grow benefits for our membership and services for individuals who are blind or deafblind.
The following are stories written by three members of DeafBlind Citizens in Action (DBCA), who recently met with several federal agencies in Washington, D.C., including the Office of Special Education Programs (OSEP), with whom they shared their stories journeying throughout the educational system. In the first section, Jamie Taylor tells us her story. In the second, Eduardo Madera offers us a window into his school years. In the third and final section, Mussie Gebre reflects on his experience with the public school system. These individuals are all deafblind. DBCA is a newly created 501(c)(3) organization dedicated to empowering deafblind people to live independent and productive lives.
Growing up deafblind was not easy, but luckily I was correctly diagnosed at 3 ½, when my patched good eye for lazy eye did not work. The doctor suspected Usher’s Syndrome because I definitely had a hearing loss. At 3 years old, I was already receiving excellent intensive speech-language therapy in a preschool for the deaf and hard-of-hearing in Kansas City, Missouri. When I moved to Minnesota in 1986, my diagnosis of retinitis pigmentosa was confirmed.

After that diagnosis, I progressed through school with some major hiccups, stalled movement in my progress in the early years, but by the time I was in 11th grade, I was thriving. What was one of the big reasons? I finally had an educational sign language interpreter/intervener. She was a certified interpreter who acted as an informal intervener. I didn’t have to focus all my energies following what the teacher said and matching it with the visuals that I couldn’t see at the same time. I now had copies printed for me and I could read the tactile sign that interpreter translated. I didn’t have to wonder where people were in the room; I could ask my intervener. She kept me informed of new information posted on the walls and helped me know if other students were paying attention to the extremely boring movie playing. This allowed me to know that I could slack off, too. I could meditate! Of course, she would inform me immediately if the teacher looked upset or reprimanded me. I trusted her to be my eyes and ears. I could fully focus on being me for the first time in my educational life and not struggle on, being just “hard of hearing”.

I also began taking some college classes at the University of Minnesota in eleventh grade. My interpreter/intervener would help me there, too. While my
Orientation and Mobility Specialist taught me how to get to my classes and my interpreter would tell me what she said, during the break in the O & M lesson and upon my request, the interpreter told me what the students were wearing, where they did/did not congregate, and their emotional appearance. Her taking on the role of an intervener, a type of environmental translator, played a critical role later when I began the classes. I had assumed everyone would be wearing dress clothes or business suits. While some did, most did not! I could blend in but use my cane, braille, etc. I could be a deafblind person and be OK! I did. What is my only wish? I wish I could have had that experience a lot sooner.

Eduardo

I have been profoundly deaf since birth. Though my vision was strong when I was young, it drastically began to diminish when I was fourteen years old. I grew up in California until I moved to Atlanta, Georgia for my education.

As I started attending Atlanta Area School for the Deaf (AASD) in Clarkston, GA, I quickly adopted the subtle differences of Georgia’s American Sign Language and made some new Deaf friends. By the time I got into the high school, I noticed that I was losing my vision. I squinted to catch a better view of my friends fanning their hands around me. I felt dazed. My counselor noticed my lack of focus and earnestly urged me to go see my eye doctor for an assessment. The day that I visited the eye doctor was the toughest day of my life. It was then that I was diagnosed with Usher Syndrome. I was fourteen years old. At the time of writing this, I cannot see in the darkness or semi-darkness, such as dusk. I have tunnel vision; that is, I can see
clearly only when looking straight ahead. In all honesty, I have struggled to accept my disabilities.

When I was in school, I missed a lot of important information the teachers gave in classes. I had a hard time keeping up, and was upset in my heart about it. I tried to ask my friends to repeat, but they often tended to say, “Oh, I forgot.” I lost many friends. The discovery of my disease changed my life forever.

I remember coming home from school one day and crying in frustration. I told my parents I wanted to move to a public school from the small deaf school. They were hesitant, thinking public school might not fit me because of my disabilities. My counselor and teachers at AASD advised me not to get transferred there because public school might overwhelm me because of my disabilities. “I want to scale the mountain beyond my ability,” I informed them confidently.

I transferred to Kennesaw Mountain High School (KMHS) from AASD. Because of my perseverance, I was able to successfully study at KMHS, and I now know better than a deaf or a normal child, how the deaf and hearing cultures and worlds differ from each other. I have adapted to the hearing world’s rapid social changes. I have experienced, understood, and am living by the maxim “Nothing ventured, nothing gained.”
Mussie

I was born in Eritrea, northern Africa. For my education, I came to California, where my parents and sister were. I have been deaf-blind throughout my life, with optic atrophy being my diagnosis.

When I immigrated to the United States with almost zero knowledge of English, I attended school in Oakland for the first time in my life at the age of 12. Communicating with teachers and getting along with peers was an enormous challenge, and learning English was difficult at Glenview Elementary School. I knew no sign language, nor could I fingerspell. Teachers had to rely on Tadoma and hearing aids, under the mistaken assumption that I would understand speech with some augmentation. But perceiving body language, aided by the use of objects for context, was my primary means of understanding teachers. Communication very rarely occurred between peers and me – and when it did, it was almost entirely gestural and basic in nature. Occasionally, teachers had to try to communicate by talking very loudly or in my ear, but it was almost completely futile, often leading to frustration. On rare occasions, I would perceive spoken words, especially when they are repeated multiple times and in a quiet setting.

When I began to learn the English alphabet depicted in rows of plastic letters laid out on a table, my teachers saw an opportunity using such letters. They would give me an embossed copy of the braille alphabet. To master the alphabet, I would touch a single plastic letter of the print alphabet, and then touch the corresponding braille letter. Once I learned uncontracted braille, my ability to communicate improved significantly, as teachers used a brailler. But I had to first learn basic English, like the meaning of “boy” and “girl”. For instance, the teacher would type...
“boy” and a sculpture of a boy would be placed in front of me. Over the months, my very basic English vocabulary base began to expand -- and so did my ability to communicate.

But it was not until high school that more attention was given to my English. After enrolling in a bottom-level ESL class in high school, I was able to compose a basic essay. But after one intermediate-level ESL class, I was placed in a regular top-level regular English class. It was in this class that I got more support from the teacher; in previous classes I rarely sat down with the teachers and hardly followed along. My signing was poor and I often had to rely on a noisy brailler so that a teacher’s aide could help me understand a bit what was going on. In those ESL classes I mostly sat through class, waiting for the time to pass or reading whatever I was given. But I had a skilled interpreter for the remaining 2 years of high school, and it was around this time that I became to notice the involvement of the California Deaf-Blind Services, which sent a representative to assess my situation and help me adapt to the larger community. But I also found some comfort in meeting a teacher who was responsible for a class with deaf and hard of hearing students, and we gradually formed a friendship and I enrolled in some of her classes.

Throughout my entire public education, I was placed in the Visually Impaired Program. None of my primary teachers knew sign language. And while I was placed in some of the classes for the hearing impaired in high school, I had trouble learning math as I was almost entirely reliant on braille. The teachers rarely had the time to sit down with me, and the school lacked sufficient resources to support me. High school
proved to be the most challenging time of my K-12 education. One reason had to do with appropriate access to communication. After I was briefly provided with an interpreter, the school refused to provide an interpreter and I, having learned for the first time that such an accommodation was required by law, had to fight for almost a year, encouraged and aided by the teacher in the Hearing-Impaired Program (HIP) class. But after learning only the basics of math, I went on to graduate with a regular high school diploma, perhaps due in part to my excellence in English and other subjects taught by regular teachers and interpreted by skilled tactile interpreters.

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**It’s Easier than Ever to Be Part of Our Family**

If you are passionate about the education of children and youth with visual impairments and deafblindness, including those with additional disabilities, please become part of our social network on Facebook. If you have a Facebook account, you can find our page and become a fan by searching for Division on Visual Impairments and Deafblindness. For those who do not have a Facebook account, you can view our page by going to the following URL: [https://www.facebook.com/pages/Division-on-Visual-Impairments-and-Deafblindness/248244976215](https://www.facebook.com/pages/Division-on-Visual-Impairments-and-Deafblindness/248244976215)
Experiences that occur during the earliest years of life critically impact children’s abilities to learn, move, and interact with others. This is especially true for children with severe sensory and multiple disabilities, for whom bonding, communication, incidental learning, social interaction, motor development and mobility are particularly challenging (Malloy et al., 2009). A National Deaf-Blind Technical Assistance Network, comprised of individual and multi-state deaf-blind projects and the National Center on Deaf-Blindness, exists to help families of these children improve early developmental outcomes. However, the expertise and resources available through this network are not often accessed during the first three years of life.

For the past 30 years, the National Center on Deaf-Blindness (NCDB) and its predecessors have conducted an annual count of children birth through 21 years of age with deaf-blindness. Over the five year span (2009-2013) the average number of children identified with combined vision and hearing loss under age three across all states and territories has been 582, which represents 6.2% of the total number. Even more significant is that on average only 76 infants under one year of age have been identified across all states and territories. This represents less than 1% of the total of
the total of children, birth through 21, identified in the National Deaf-Blind Child Count. During this same period, 47 states/territories had one or more years with no children birth-age one identified. Only 7 states identified children birth-age one each year. (Schalock & Bull, 2010, 2011, 2012, 2013, in press).

Increasing awareness about the diversity within this low incidence population is crucial in order to facilitate connections with the foundational services and interventions needed for the greatest success. This can be challenging given that:

- deafblindness can be a misleading term, since residual vision and hearing are usually present;
- families, educators and medical professionals may not recognize the impact of combined vision and hearing loss on early learning;
- more than 90% of these children have additional disabilities, including complex medical challenges; and
- due to federal regulation, programs for young children with disabilities are non-categorical.

A multi-pronged approach, undertaken by NCDB, has demonstrated positive results in the early identification and referral of young children who are deaf-blind within states. The approach employs data-based decision making, implementation of evidence-based identification and referral practices, collaboration among state deaf-blind projects, a toolbox of common materials and technical assistance delivered by an experienced Early Identification & Referral (EI&R) Team.
An online **Self-Assessment Guide** allows state deafblind projects to analyze state and national data, gather information about systems in their state serving children birth through two years old, and reflect on specific issues that impact identification and referral of infants and toddlers with combined vision and hearing loss. An extensive literature review, combined with strategies from deaf-blind projects with consistently high referral counts, has provided a set of effective practices for use by the national deaf-blind technical assistance (TA) network.

In addition, network members utilize and contribute to an online repository of resources that:

- differentiate between identification (recognition that both vision and hearing loss exist and understanding the impact on early learning) and referral (ensuring families are linked to their state deaf-blind projects and other specialized services);
- link to both an identified issue and a recommended practice;
- target a particular system (Part C programs, Early Hearing Detection and Intervention (EHDI) programs, the medical community and other programs serving children birth through two and their families); and
- provides tips and examples from colleagues who have participated in the self-assessment process and implemented recommended practices.

Currently, nearly 50% of 49 state/multi-state deafblind projects have utilized the self-assessment guide and are beginning to implement one or more of the four key
evidence-based practices recommended by the national center. The nine states participating in a pilot of this process identified 104 of the 344 newly identified infants and toddlers in 2012. Collectively, their birth through two child count has increased from 136 in 2011 to 179 in 2013.

Missouri and Tennessee are two states in which the self-assessment indicated regions within the state where no infants or toddlers were being identified. By narrowing their focus and implementing selected evidence-based practices both states have experienced a steady increase in their birth through two counts. Missouri has seen an increase from 13 to 29 in the past three years and Tennessee's count has increased from 19 to 37.

As this work continues, more state deaf-blind projects are discovering that by using data-based decision making to narrow their focus and identify the early intervention system with the highest potential and feasibility for impact their limited resources will be more effective. Through the implementation of recommended evidence-based practices related to building relationships, developing carefully targeted materials, being clear about the benefits of referral and consistently following-up with referral resources, state deafblind projects are building their capacity to increase the numbers of infants and toddlers with combined vision and hearing loss who are receiving appropriate early intervention services.
References


Schalock, M.D. and Bull, R. (in press). *The 2013 National Child Count of Children and Youth who are Deaf-Blind*. Monmouth, OR: National Center on Deaf-Blindness, Teaching Research Institute, Western Oregon University


VEDBE-Q 2015 Article and Advertisement Submission Dates:

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Children who are deafblind bring unique challenges to educational settings and specialized strategies that address communication, sensory, learning, and social needs are important components of their appropriate education. However, deafblindness is a low-incidence disability and such specialized and intensive services are not always available. This article describes the collaborative and evolutionary approaches undertaken in Utah to ensure that children and youth in the state truly have the opportunity to maximize their potential. Overviewed in this article are a brief history of statewide services provided to children and youth who are deafblind, current educational services, training for interveners, the state-recognized endorsement in deafblindness, and the University of Utah Deafblind Teacher Education program.

History

Prior to 1995, services for children who are deafblind in the state of Utah were limited to a federal deafblind technical assistance grant and an itinerant teacher of the visually impaired with training and expertise in deafblindness who served students at the Utah Schools for the Deaf and the Blind (USDB). However, a federal grant obtained by Utah State University providing interveners to young children from birth to age three with deafblindness created much enthusiasm for expansion of the
intervener model to other age groups. In 1995, the Utah State Office of Education convened a task force consisting of parents, representatives from the federal technical assistance project in deafblindness, USDB, Utah State University, the University of Utah, school districts, and the Utah State Office of Education. The task force created a state plan for children and youth who are deafblind, and task force members, particularly parents, successfully lobbied the state legislature for funding. According to the state plan, statewide services for children and youth who are deafblind consisting of interveners and deafblind specialists were to be housed at USDB along with the federal technical assistance project which became the Utah Deaf-Blind Project. Out of this statewide systems effort, more coordinated and extensive services for students with deafblindness were put into place along with the established technical assistance model for educators and families. The program has grown to include 12 deaf-blind specialists and approximately 80 interveners within USDB’s Deaf-Blind Services.

Deaf-Blind Services

The structure of the state Deaf-Blind Services continues to collaborate closely with partners that include USDB, the Utah State Office of Education, the National Center on Deaf-Blindness (NCDB), school districts, and the University of Utah, working together in a variety of ways to enhance educational services and improve outcomes for children and youth who are deaf-blind from birth through age 22. The continuum of services includes consultative support and direct services from deaf-blind specialists, family support, intervener services, and training and technical support to administrators, teachers, related service providers, and support staff in both
Part B (school-age) and Part C (early intervention) systems. Intervener services are designated as needed in Individualized Education Plans (IEP) and Individualized Family Service Plans (IFSP); interveners are then hired by USDB, supervised by deaf-blind specialists, and work under the supervision of classroom teachers.

**Intervener Training**

Training for interveners is a hybrid of face-to-face, online, and practicum trainings. Through collaboration with the University of Utah, interveners may elect to receive university credit for course and field work. The training for interveners has been approved by the university curriculum committee and a faculty member in the Department of Special Education at the University of Utah serves as a co-instructor in the training to ensure university educational standards are met. Through additional collaboration with NCDB, Utah Deaf-Blind Specialists have been involved with the creation of the Open Hands, Open Access Deaf-Blind Intervener Training modules. These modules are in the process of being added to the hybrid training as they become available. In addition, yearly trainings are provided to all interveners, as well as teachers and related service providers throughout the state. Many interveners have used their acquired training as a springboard to get further education in order to become deaf-blind specialists, special educators, occupational therapists, speech and language pathologists, and nurses.

**Teacher of the Deafblind Endorsement and Preparation**

Prior to 2012, most of the deaf-blind specialists at USDB held various special education teaching endorsements, including vision, hearing, significant disabilities,
mild/moderate disabilities, and early childhood special education. They had also acquired expertise in deafblindness though numerous trainings provided by many experts in the field and a class in deafblindness offered by the University of Utah (taught by the first author of this article). However, their expertise in the field was not officially recognized in the state. Therefore, the advisory board to the Utah Deaf-Blind Project that consists of parents, educators, consumers, and other stakeholders worked with the Utah State Office of Education to create a teaching endorsement in deafblindness. With encouragement from USDB, outlines of possible coursework were reviewed by the advisory board and parents wrote letters of support to the State Office of Education. In 2012, the endorsement became a reality. The endorsement in deafblindness is predicated on applicants holding existing licensure in special education (vision, hearing, significant disabilities, mild-moderate disabilities, or early childhood special education). It is aligned with the Council of Exceptional Children (CEC) Deafblind Teacher competencies and holders of the endorsement are designated as Teachers of the Deafblind. Teacher training programs from both the University of Utah in Salt Lake City and Utah State University in Logan received approval from the Utah State Office of Education for their coursework leading to the new endorsement. Coursework from the University of Utah is primarily on-campus and coursework from Utah State University is online. There is reciprocity of class credit for the endorsement between the two universities. The remainder of this article will discuss the program offered at the University of Utah.

When the endorsement was finally approved, the University of Utah, while long active in deafblind education and research, did not have designated funding to
implement a program in deafblind education. However, the Department of Special Education felt such a program was important to meeting identified needs in the state and thus, to that end, undertook collaborative efforts to make the program a reality. The Department of Special Education houses the state funded Multi-University Consortium Teacher Preparation Program in Sensory Impairments and it was decided that this is where the new program would best fit. Coursework from the consortium was identified in the areas of deaf/hard of hearing and blind/visual impairments that aligned with the endorsement. These classes include “American Sign Language”, “Audiology for Teachers of the Deaf and Hard of Hearing”, “A to Z Braille”, and “Ocular Disorders and Examination Techniques for Low Vision”. One class in deafblindness has long existed within the consortium and another, more advanced class was added. In addition, an Orientation and Mobility specialist from Hilton-Perkins International Programs, Dennis Lolli, was brought in to develop and teach a class called “Orientation and Mobility for Individuals Who are Deafblind”; content from this class will be added to the existing consortium class in Orientation and Mobility that will be required for endorsement. A class in the severe disabilities program called “Transdisciplinary Approaches in Severe Disabilities”, was also incorporated and the Department of Special Education provided funding for both field studies and student teaching supervision. In addition, the department provided faculty support to coordinate the programs. Further, a state grant was received that has enabled students to receive some tuition support and USDB has contributed tuition to support its Deaf-Blind Specialists in obtaining the endorsement.

The first cohort of students consisted mostly of the USDB deaf-blind specialists and the challenge was how to meaningfully add to their extensive
knowledge base. Faculty worked closely with the director of Deaf-Blind Services at USDB to ensure that course content would meet identified needs. In addition, the Utah Deaf-Blind Project collaborated with the University to bring in Dr. Tanni Anthony from Colorado Services to Children with Deafblindness to teach a class session in “Transdisciplinary Play-based Assessment for Children who are Deafblind”, and Dr. Jan van Dijk of the Netherlands met with students in the program to assist with implementation of “The Child-Guided Approach to Assessment of Children who are Deafblind” (Nelson, van Dijk, McDonnell, & Thompson, 2002; Nelson, van Dijk, Oster, & McDonnell, & Oster, 2009). Special field-based assignments in the program included a shared storybook reading assignment that students implemented in homes with parents of children who are deafblind and an arts assignment in which students paired a child with deafblindness with an artist in the community for a special arts experience. Artists included painters, musicians, and master gardeners. This assignment not only gave the children a special experience, but also afforded community artists a wonderful opportunity to work with some pretty special kids. This assignment has now been incorporated into the new federally funded Utah Deaf-Blind Project.

As of the end of fall semester 2014, eight students will have completed the endorsement program with more scheduled to complete in the next year. Several of the students also completed Master of Education (M.Ed.) degrees and their master’s projects included specialized areas within deafblindness such as literacy, technology, and cortical visual impairments. This specialized knowledge will be utilized in future university class presentations and will add to the expertise within USDB. The challenge to the preparation program going forward will be to recruit future students...
and planned recruitment efforts will concentrate on interveners and students in other special education licensure programs who may be interested in obtaining a master’s degree and adding deafblindness to their areas of expertise. Finally, in addition to efforts to train master Teachers of the Deafblind, The University of Utah is a member of the federally funded National Leadership Consortium in Sensory Disabilities (NLCSD) and is hoping to have scholars in the area of deafblindness at the doctoral level who will have the necessary skills help the teacher preparation program grow and develop in coming years and contribute much needed research to the knowledge-base in the field of deafblindness.

Collaboration has been central to the development of the comprehensive program in deafblindness in Utah and has greatly contributed to the achievement of a state-recognized endorsement in deafblindness. This endorsement has allowed for the development of sustainable efforts in deafblind personnel preparation and has led to the rich knowledge base in deafblindness that now exists within the state to meet the needs of this low-incidence but high-needs population of children and youth.

References


CHARGE syndrome is the leading cause of genetic deafblindness and this biennial conference hosted by the CHARGE Syndrome Foundation, Inc. is the largest worldwide gathering of individuals with CHARGE syndrome, their families, as well as professionals who are working in the field and conducting research. A professional day precedes the full conference, followed by 2 1/2 days of full conference, where more than 60 sessions will be presented in four topic areas: behavior, education, adult issues and medical issues. There are lots of fun evening events planned as well. The Foundation welcomes all CEC members to attend the conference to learn more and also to consider volunteering in our camp program for an unforgettable experience. All of the conference details are available at: www.chargesyndrome.org/conference-2015.asp.

See you in Chicago!

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VIDBE-Q Committee

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Are you interested in becoming a member of the VIDBE-Q committee? Do you have ideas about advertising and topics for future issues? Would you like to review newly released books in the field of VI and deafblindness? If so, then please email Kathleen Farrand and get involved today!
Teacher of the Deafblind Pilot Program in Texas: Part I

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Texas School for the Blind and Visually Impaired
TSBVI Outreach Programs

Background

Unique Needs of the Deafblind Student Population

Students with deafblindness (DB) are considered a low-incidence population nationally. These students require specialized support to access environmental information, to develop communication, and to develop concepts about the world around them due to the significant impact caused by the combined loss of vision and hearing. Although local districts may provide vision and hearing services, there is often a gap in specific planning and programming to address their educational service needs due to the lack of available professionals with training specific to deafblindness at the local level. Many districts struggle to find the internal resources to accommodate the educational needs of these students and their families (Blaha, Cooper, Irby, Montgomery, & Parker, 2009).

During the 1970s we saw the creation of regional centers for children with deafblindness. They provided a national network for program development, and sharing of information, and tended to be staffed by people with specialized training. Most importantly, the regional centers had the responsibility to develop direct service for children with deafblindness, prior to the enactment of mandatory educational legislation. While acknowledging the shortcomings of this time period – most
notably, the segregation of the deafblind student population - there were two significant characteristics that should be mentioned: the proliferation of college programs dedicated to personnel preparation specific to deafblindness, and stable funding with federally appropriated monies. These programs were able to ensure a steady supply of well-trained teachers and allowed for specific teaching practices designed to serve these students to develop within the field. (Collins, 1993).

In the decades following the 1970s we have seen a shift in educational philosophy away from centralized programming and toward more locally inclusive settings. As the population of our students with deafblindness has shifted to local communities it has presented some challenges for students with low-incidence disabilities as well as some benefits. A positive trend for students who are deafblind in being served at the local level, involves students having greater access to the standard curriculum. Recent national child count data shows over 60% of students who are deafblind are attending local schools and 26% are participating in standard instruction (Schalock & Bull, 2013). Additionally, students who attend local schools are more often able to live at home and be a part of their family's daily routines. The picture, however, of access and support for students is a complex one.

Many local school districts have difficulty providing students with access to appropriate instruction within the classroom. They may be unable to provide dedicated personnel time to a position focused on such a low incidence population. In some districts in Texas, our project has seen an increase in hiring interveners (trained paraprofessionals) to provide students with access to information, communication and social support. Although the role of the intervener is designed to provide tremendous direct support to students, it is not meant to replace the role of teacher, who is
charged with designing instruction and providing guidance to the student's entire educational team. In the rare instances when a student does have access to an intervener, our outreach staff members have observed educational team challenges when that intervener does not have access to support from qualified professionals. Such challenges include the student not having access to appropriate assessment, having a lack of DB specific IEP goals, and family members not having enough information about the intervener’s role on the team. Although such information is anecdotal, our team’s collective experiences with these challenges caused us to further examine both the need for teacher training and the role of the teacher in serving students who are deafblind.

Recently, the Office of Special Education requested that National Center on Deaf-Blindness (NCDB) engaged in a national assessment of the needs for improving intervener services in the United States. As a result of NCDB’s consultation with parents, technical assistance providers, administrators, higher education faculty members, interveners, and teachers, NCDB found that there was a need for more teachers of students with deafblindness to be able to support the intervener practice. NCDB specifically recommended that interveners have “knowledgeable supervisors and access to experts in deafblindness that may provide consulting and coaching”, thereby bolstering the intervener’s role and providing more comprehensive educational planning to students who are deafblind (NCDB, 2012).

While a handful of university personnel programs provide designated coursework for professional service students who are deafblind, currently only two states, Utah and Illinois, recognize specific licensure for a teacher of students with deafblindness. Nationally, one may assume that teachers of students with visual
impairments (TVIs) and teachers of students who are deaf and hard of hearing (TDHH) are providing much of the support for IEP development and classroom instruction. In many cases, these two teaching disciplines lack the expertise specific to teaching children with deafblindness, and local and regional support is provided by state deafblind technical assistance projects.

The field of deafblindness is currently supported, in large part, by federal grant funding to the state deafblind projects. Without recognized state or national licensure and dedicated money for well-established personnel preparation programs for teachers of students with deafblindness, our field is in a precarious place.

The Beginning: Mentor Program Teachers of Deafblind Help Define and Explore the Practice

Mentor Selection

In an effort to develop and enhance educational services to students in Texas who are deafblind, the Texas School for the Blind and Visually Impaired (TSBVI) mentor program initiated a pilot project in 2009. Five teachers were selected in three education service center regions to take part in this Deafblind (DB) Mentor Project because of their dedication to deafblind students. For the first three years of this pilot, each teacher participated in training provided by Robbie Blaha, who is a certified teacher of students with visual impairments, as well as a certified teacher of the deaf and hard of hearing. Ms. Blaha is currently a consultant with the Texas Deafblind Project with the TSBVI Outreach program. Over a three year span, the five teachers participated in training on topics such as assessment, communication for deafblind (DB) students, strategies and issues related to behavior, and sensory accommodations for the IEP. As a group, these mentors in training made inroads into
the field of deafblindness by developing and reviewing materials specific to students with deafblindness.

One of the documents developed through the mentor pilot and the Texas Deafblind Project was the “Roles and Responsibilities of the Itinerant Teacher of Deafblindness”. This document outlined eight points that were deemed specific to the job duties of the itinerant TDB and was in turn used to determine training topics specific to the TDB Pilot Program. Further refinement, discussion, and field trials of the “Roles” document was included in the TDB Pilot with later drafts being developed to include self-contained models.

**Partnership with local districts to address the challenge**

In 2010, our project began looking again at how we might address this need for a recognized teacher of deafblindness role. Through conversations with two local administrators in the Houston area, we discovered commonalities when comparing deafblind student populations and goals for each of their districts. Both administrators were invested in the idea of the best possible programming for their students with deafblindness, and were looking for innovative models to train staff.

In each district there were high numbers of students with deafblindness, which allowed for the identification of an area of need within the district. Technical assistance training topics were decided through a combination of needs assessments and pre-established roles of the TDB. This ability to channel our efforts was vital as it allowed administrators to designate and assign staff time dedicated to deafblind student caseloads. We then worked with administrators to select personnel based on
the staff’s own histories of interest and dedication to working with students with deafblindness. Out of this mutual desire to explore and define this specific role, the “Teacher of Deafblind” pilot was born.

It was decided that all teachers in the districts identified as TDB’s for the pilot, have either (or both) endorsement in auditory impairment or visual impairment. Complementary to the TDBs, teams were formed around them that included either a TVI or TDHH (depending on the TDB’s background – TDHH or TVI), and O&M. Other team members were included in the training sessions and outreach as appropriate.

In addition to the two districts in the Houston area, the Texas School for the Blind and Visually Impaired (TSBVI), Comprehensive Programs, was also approached to be included as part of the pilot. The deafblind student population at TSBVI typically fluctuates between 15-20 students annually. The model is different than that of most local districts, with self-contained, deafblind specific classrooms, low teacher to student ratios, and residential programming. It was felt that TSBVI’s “center-based” model would be complementary to the local district model and could function as a resource of practice for other pilot participants.

From June 2011 through May 2013, seven TDBs and their administrators met with our project staff to define the unique skills and practices for serving students who are deafblind. Our model for training was made up of a series of seven training workshops. The workshops were then immediately followed by direct on-to-one consultations between the TDBs, Regional Service Center 4 consultants, and Outreach staff. The follow-up consultations were meant as a way to more directly apply the ideas and concepts of our training sessions to the TDB’s deafblind student
caseload. During our workshop meetings, we often split the administrators into a separate group in order to focus on larger *systems change* topics.

**Conclusion**

Stay tuned for part II of this article in the Winter issue of the *Visual Impairment and Deafblind Education Quarterly* journal, where we describe how the Teacher of Deafblind pilot was expanded to include a new cohort of teachers to help test the model. Specifics will be given about the technical assistance provided, student, TDB, and systems outcomes, and further thoughts on how TSBVI’s Deafblind Project Outreach continued development of the Teacher of the Deafblind Pilot Program.

**References**


Pennsylvania School Teams ‘Kickoff’ Open Hands Access (OHOA) Intervener Module Training

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During the summer PaTTAN Low Incidence Conference 2014, The Pennsylvania Deaf-Blind Initiative ‘kicked off’ the Open Hands/Open Access (OHOA) Module Training for Interveners and Educational teams with six teams across the Commonwealth. As is described on the National Center on Deaf-Blindness website, “the Open Hands/Open Access (OHOA) Intervener Learning Modules are a national resource designed to increase awareness, knowledge, and skills related to intervention for students who are deaf-blind and are being served in educational settings (ages 3 through 21)”. Although “kickoff” is a word typically used in the fall to indicate the start of the football game, our team in Pennsylvania has been invested in the effort to advance the intervener practice for several years. We want to share a bit about our journey to help create and use the OHOA modules to meet the needs of students and families in our state.

The idea of intervention with students with deafblindness is not new to Pennsylvania. Since 2010, the Pennsylvania Deaf-Blind Initiative has been engaged in team training and direct technical assistance that focuses on the role intervention
for students with deafblindness and their educational teams. Our sustained effort in educating stakeholders in Pennsylvania about intervention was recognized by the National Center on Deaf-Blindness (NCDB) when they were tasked by the Office of Special Education Programs (OSEP) to create national recommendations for improving intervener services. (For a complete copy of the National Recommendations to Improve Intervener Services, please visit http://interveners.nationaldb.org/). Over the course of several months, project staff shared insights with NCDB from our efforts to take on the issue of intervention within a state with a relatively high population of students who are deaf-blind, 382 on the 2013 child count, which are spread across a geographically large area. We, like many other state partners in the national network, were challenged with providing high quality, multi-media training to all members of educational teams in a way that met the diverse and intense needs of students who are deaf-blind.

Fast forward to the Fall of 2012, and our partner NCDB was challenged to create a high quality, open access resource which would include accessible slide presentations, photographs, and learning activities that capture the best of what we know in the field of deaf-blindness. (For more information on the OHOA modules and for information on how to register please visit: https://nationaldb.org/library/page/2269). We were honored to be included as co-creators of this rich resource because we knew there was an intense practical application for such modules in our state. Staff members from the PaTTAN Pennsylvania Deaf-Blind Initiative were included in both the Advisory Committee, as well as the creator/writing teams. A teacher of the Visually Impaired from Berks
County and parents from both Central and Southwestern Pennsylvania were involved in producing videos, sharing learning resources, and creating authentic learning activities based on personal and professional experience with students who are deafblind.

When the Pennsylvania Deaf-Blind Initiative agreed to be a state to adopt these modules as outreach tools, we intentionally included all team members of the educational team in our enrollment plan. Not only did this team approach fit within the spirit of the OHOA modules themselves, we knew that for intervention to be effective, teams needed to support each other while learning to better support their students. From past efforts in intensive team-based training, we knew that we needed to enrich our technical assistance by offering participants specific instruction and resources in the areas of: planning time, resources, meaningful goals, unity of purpose, leadership, values and trusting relationships, and interdependence. One of the most vital lessons that we have learned is that collaborative teaming is essential in meetings the educational needs of a student with deaf-blindness. Finally within our year long plan that launched this summer, we have built in site visits from our project staff, from a seasoned TVI leader in our state, and from a staff member at NCDB.

The 6 teams that began the “Open Hands/Open Access” Intervener training at the Low Incidence Conference ranged from 4 members to a team of 8 members. This included Special Education Directors, Teachers of the Visually Impaired, Teachers of the Deaf Hard of Hearing, Interveners, and Paras in the role of Interveners, Classroom Teachers, and OT’s, PTs, Life Skill Support Teacher, SPL, Personal Care
Assistant/Aide, Supervisors, and Parents. All that came to the table brought their expertise and played a vital role to the team learning the intervention and the role of the Intervener in the educational setting. While at our face to face gathering the teams learned how to access and use Moodle, how to use a secure Google Drive to share student specific documents, and engaged in team building activities.

From August 2014 through July 2015 these six teams are participating in the first eight modules. In addition to the Welcome and Orientation Module, these include:

- Module 1: An Overview of Deaf-Blindness and Instructional Strategies
- Module 2: The Sensory System, The Brain, and Learning
- Module 3: The Role of the Intervener in Educational Settings
- Module 4: Building Trusting Relationships and Positive Self-Image
- Module 5: Availability for Learning
- Module 6: Understanding Communication Principles
- Module 7: Emergent Communication
- Module 8: Progressing from Non-Symbolic to Symbolic Communication and Complex Language

This year-long study will provide teams the opportunity to develop strategies based on best practices in the field of deaf-blindness. As the teams work their way through that module, each participant is required to complete several types of assignments, including; journaling, participating in discussions, reflecting on readings and slide presentations, watching videos and experiencing dual sensory loss through simulation. So far, the teams have progressed through Module 3, and here are some of the things they are sharing with us.
Concerning the Role the Intervener:

A Speech and Language Pathologist: “Interveners provide valuable information about the student; likes/dislikes, strengths/weaknesses that other team members need to know when planning lessons are making educational decisions. Interveners translate directions/instruction given by other team members so that the student understands and fills in missing information that the student needs to understand the task. All individuals working with a student should feel comfortable sharing concerns, successes, and suggestions within the team when planning instruction for the student.”

A paraprofessional in the role of the Intervener: “An Intervener helps a child experience the world by everyday opportunities in the school setting - concept development, hand-under-hand learning, modeling, waiting, doing with, not for, not forcing, establishing trust, promoting independence, consistent routines.”

A teacher of students with visual impairments: “It is vital the intervener and the rest of the team work together in providing any information they have about the child. As the child is continually learning to communicate, the whole team is continually learning more and more about the child. It is important therefore for the team to provide each other with information not only about the student’s responses and communication, but also about the content of the lessons and teaching tips/strategies that are found to be successful.”

A PaTTAN Educational Consultant: “I think the intervener and the team as a whole have to understand the importance of the two way communication which needs to occur. The intervener provides important insight to the team and the team provides the expertise in their own fields.”
Concerning a dual sensory loss simulation experience:

A parent: “I did the Optional activity for parents/family members, entitled ‘Sharing a Pleasant Activity at Home.’ I knelt beside (my child) on the couch as he held on the back and jumped. I’ve often wondered why he loves this so much...now I know. If one were to stand back and look at him doing it from some distance, one would not be overly impressed. After all, it looks like only an inch or so and he’s holding on very tightly. However, after having done it beside him while blindfolded and ear-plugged, it seems like an entirely different activity!”

A classroom teacher: “I found myself looking for other sensory input. I listened to my breathing, began rubbing my fingers together, and tapping my feet. I think it’s important to remember that without the sensory input of sight and hearing, (the student) will need other opportunities to engage in getting the input she desires.”

It is evident from the above testimonials that collaboration of teams is vital for the student with deaf-blindness. This same collaboration is best practice in our network community of deaf-blindness through the technical assistance from our National Center on Deaf-Blindness down to the state deaf-blind projects to our educational teams under the educational system. We all know that what works is a trusting relationship between the all team members involved, being available to assist when needed, and an understanding of the educational needs of children and youth with deaf-blindness.

For more information on the Open Hands/Open Access (OHOA) Modules training offered in Pennsylvania for teams, contact Sue Ann Houser (shouser@pattan.net).
References


Online Parent Training: The Role of Interveners in Educational Settings

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The National Family Association for Deaf-Blind (NFADB) and the National Center on Deaf-Blindness (NCDB) are currently collaborating to sponsor an online parent/family training called *The Role of Interveners in Educational Settings*. The training program uses Module 3 (“The Role of Interveners in Educational Settings”) from the *Open Hands Open Access (OHOA) Deaf-Blind Intervener Learning Modules*. Family/Parent participants learn about the role of interveners, the principles of intervention, and how interveners function as members of a student’s educational team.

Although the module is one of a series of modules that are being developed by NCDB to serve as a resource for programs to train interveners to work with students who are deafblind, we have found that with minor adaptations (e.g., adding information resources pertinent to family members, tailoring a simulation activity to make it family friendly) the module is also an excellent learning tool for parents and families.

The format of the course is primarily self-study, giving participants the opportunity to learn from the comfort of their own homes, at their convenience, and on their schedules. We also offer individual support via telephone and e-mail and
group support via web-conferencing. The web-conferencing meetings and discussion boards within the module also allow participants to provide support to and learn from each other—e.g., to share their experiences of interacting with school personnel and strategies to address the impact of deaf-blindness on the child and family.

A key feature of the support we offer is to reassure participants that the course is not meant to add stress to their lives. We provide them with a suggested timeline for moving through the material, but also let them know that we realize that sometimes “life just gets in the way.” Allowing for flexibility of learning has been an asset to this online learning module and is key to creating a positive experience for parents and family members who, on a daily basis, are dealing with the complexity of caring for a child who is deaf-blind.

A first cohort of family members and parents participated in a pilot program held in March and April of 2014. Two additional trainings with new cohorts have been held since that time. Recruitment involved the assistance of family specialists at state deaf-blind projects and dissemination of a flyer via the NFADB membership listserv and various social media outlets. More than 25 individuals from across the country have signed up for each cohort, indicating a clear need for the essential information provided by this training.

Based on data gathered regarding participants’ experiences, we have made minor changes to the way we offer the training over time to better meet parent and family needs. Together, NFADB and NCDB feel that this endeavor will advance our shared goals of empowering parents and increasing recognition and acceptance of the use of intervener services for students with deafblindness. We are learning together to find out what works and what does not work to meet the needs of families seeking
knowledge about intervener services.

Comments from Parents Who Have Participated in the Training:

_The concept of intervention was not new to me, but it had become dull, in need of fine tuning. This class helped me examine and see errors that had crept into my own role with my son. The examples of individual students working with interveners were very inspiring. I cannot but help feel a sense of deep gratitude for the dedication of the people who have put together this course and feel immensely privileged to have had the opportunity to participate in it._

_I would like to thank everyone who worked on this project. . . . I learned how to explain what an intervener is and even more importantly I learned how to better explain what my son's intervener needs to be. It is really important for parents to be able to specifically explain to educators what their child needs._

_The thing I found most helpful about this module was the reminder to respect my child! I know that sounds odd, but he is 17 and I’ve been through years of training. There are so many things we learn to work on, that it has been a long time since I was reminded to “respect” him with regard to not pushing him through something if he does not like it. There are so many common topics that he does not like and they are just easier to avoid than to push him through them, if they are not necessary tasks. Since doing this we’ve been getting along better!!!_

_I found the module a great reminder and refresher course on very essential basics!_
I loved video on the principles of intervention. It has helped me to understand what is missing from my daughter’s daily learning activities both at home and at school. I would like to hone my skills at using these principles so that I can use them at home and then teach them to the people who interact with my child. How thought provoking. Just when I thought I was doing everything right, a better way comes along!

If you have any questions or know of other parents in your state who may be interested in participating in this training opportunity in the future, please do not hesitate to contact:

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Editor’s note: When I asked state partners to share what they were doing to maximize resources and meet the needs of this lowest of low-incidence disability group, they shared these innovations for meeting the needs of professionals across great distances.

**Kansas Deaf-Blind Project at Kansas School for the Blind**

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In order to meet the demands of “in real time” information and idea sharing, the Kansas Deaf-Blind Project began implementing a distance mentorship model of technical assistance where password protected team collaboration sites are created for individual learner teams to share progress and information related to child outcomes. Having well over one hundred learners identified on their deaf-blind registry, the two part time staff were finding it hard to meet the individual needs of all of the teams and visit the school sites frequently enough to see consistent child and provider change. Weekly school teams are asked to supply video of the learner around targeted routines and the project staff, then view the video and give the school team input on strategies for improving the routines. Monthly the teams meet virtually through Adobe connect with the project staff to review action plans and target next steps to be achieved the following month. This process has enabled the project staff to have more consistent contact with the service providers and have also allowed the parents to be an integral part of the collaboration process. Further, the parents end up with a rich repository of video of their child’s skills that helps aid in transitions from classroom to classroom and school to school.
Virginia Project for Children and Young Adults with Deaf-Blindness

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Image: David Lojkovic and Julie Durando from the Virginia Project for Children and Young Adults with Deaf-Blindness.

The VDBP is one of more than 10 state deaf-blind projects and collaborating agencies that work together in NCDB’s Technical Workgroup on Literacy and the Common Core State Standards (CCSS). The activities of the group include updating and expanding the content of the Literacy for Children with Combined Vision and Hearing Loss website (http://literacy.nationaldb.org). Group members share their expertise with each other and the educators in collaborating states by presenting in webinars, trainings, and conferences. They are developing a library of training materials about meaningful instruction in literacy beginning at the
earliest stages and the CCSS that will be shared across the national network of state deaf-blind projects aimed at saving individual deaf-blind projects the time and resources in starting from scratch. The group continues to work in their own states to find picture and video examples to illustrate the strategies and principles. The early results of this shared work can already be found on the website which continues to expand.

In addition to collaborating on technical Workgroup on Literacy and CCSS, the VDBP takes turns hosting a series of online educational modules in collaboration with the DC/MD, RI, and WV projects. *The Open Hands, Open Access; Deaf-Blind Learning Modules* are used to provide a basic understanding concerning stakeholder roles and intervener strategies prior to receiving onsite technical assistance specific to one student. Knowledge of these fundamentals by stakeholders helps ensure that onsite technical assistance and trainings can be focused on individual needs of educators and staff rather than basic background knowledge on deaf-blindness.

We are just beginning our first cohort of participants in this multi-state cohort and registration is well over 110 participants, more than triple our target. This illustrates that there is a huge need for this type of training. By working with the other state deaf-blind projects, we hope to improve our capacity to offer more training to individuals who may have had difficulty attending face-to-face trainings offered in the past. It is our goal that these efforts will both significantly increase the number of professionals with a basic knowledge of the impact of deaf-blindness and the individualized supports as well as make the more intensive services our project provides more effective in achieving better school and post-school outcomes for the students with deaf-blindness.
Since the release of the first *Open Hands, Open Access Modules* (OHOA) in September 2013, Project Reach: Illinois Deaf-Blind Services has been hosting cohorts of learners, including teachers and other team members, who wanted to learn more about deafblindness at a distance. In July 2014, new rules came into effect in Illinois for providers of professional development credit for licensed teachers. Because of the popularity of the OHOA modules in Illinois, Project Reach is aligning the modules to fit within the standards of our system. There are a number of factors involved in the process; below we will share two factors, and our interpretation of these factors and how they relate to the OHOA modules.

1. All activities in Illinois have to align with the Learning Forward professional development standards [http://learningforward.org/standards#.VCoIIToo5jo](http://learningforward.org/standards#.VCoIIToo5jo)

   Of the seven standards, it was decided that the OHOA modules best align with “Learning Communities - professional learning that increases educator effectiveness and results for all students occurs within learning communities committed to continuous improvement, collective responsibility, and goal alignment”.  [http://learningforward.org/standards/learning-communities#.VFeeHvnF_el](http://learningforward.org/standards/learning-communities#.VFeeHvnF_el) With discussion boards and the option for student-level cohorts, the OHOA community can be expansive or specific, but provides a forum for all members to participate collectively.
2. Providers must produce a rationale for each activity on how it aligns to state standards.

*Project Reach looked to the Social Emotional Standards* [http://www.isbe.net/ils/social_emotional/standards.htm](http://www.isbe.net/ils/social_emotional/standards.htm) and under Goal 2 (“Use social-awareness and interpersonal skills to establish and maintain positive relationships”) found alignment with Learning Standard C (“Use communication and social skills to interact effectively with others”). Because of the particular challenges that students who are deaf-blind have in developing strong concepts of the world incidentally, the intervener or teacher plays a critical role as a social bridge for students- helping them first connect to people and then to concepts in the environment. When modules 1-4 are taken as a whole, student and intervener should communicate more effectively with each other at the end of the modules.

References

All Children Can Read!

Literacy for Children with Combined Vision and Hearing Loss Website

Shift Your Perspective
Find Tools and Strategies
Use the Literacy Skill Checklist

literacy.nationaldb.org

Let us show you how.

As families, caregivers, and professionals our primary role is enabling the child to ‘read the world.’

Rosenketter, 2004

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Deaf-Blindness (DB) is a disability of access to people, places and information. A person with combined hearing and vision loss may also have other disabilities. Due to the heterogeneous nature of deaf-blindness, it creates unique challenges for systems, educators and families. It is not uncommon that a young adult who is deafblind is often the only such student in their entire school district! For young adults who use sign language, reduction in visual acuity or visual fields can impact adversely on their ability to understand or be understood. Young adults who can use speech also face isolation because facilitating communication is so difficult in noisy environments.

The challenges of access to people, places and information play a major role in the lack of opportunities to make friends and establish meaningful relationships. Neighboring states discovered that the challenges young adults face could be mitigated by establishing closer connections and providing specialized services.

I learned that it is my responsibility to be my own advocate. I need to look into my future and make goals.

-Young Adult Participant
meeting the unique challenges made one thing very apparent… to effectively address this need, a collaborative relationship built on trust, shared expertise and resources was necessary.

“Exponential gains in organization effectiveness are possible at the intersection of team and spirit.” Dr. Barry Heermann, Creator of Team Spirit, a model for building high performing teams, made this statement in his 1997 publication, Building Team Spirit. His insight and model could never be more truly realized than by the teaming experience of the Southeastern Deaf-Blind Projects challenged to meet the unique needs of access for students with deafblindness and their families facing transition. Driven by this need of service, the force in Team Spirit, several states embraced the power of teaming resulting in improved service (Transition Institute) and product (The Transition Toolkit).

In 2005, the South Carolina DB Project staff had a desire to connect their young people with others with deafblindness. They were encouraged to contact the Georgia DB Project who were sponsoring an annual weekend for young adults in partnership with the Florida DB project. Together the state projects found that they could introduce young people to a greater number of peers while sharing the responsibility of identifying, training and financing interpreters, Support Service Providers (SSPs) and materials, all crucial components of making the weekends accessible. Teaming in this manner ensures young adults fully participate in the experience. (Team Spirit aspects of Initiating: building trust and belonging)
To make this happen successfully, the planning team learned how to build an infrastructure in which access was at the forefront of planning. High quality interpreting costs were expensive, tactile interpreters resources scarce, and recruiting volunteers/SSPs that had a specific skills set for the discrete needs of the young adults were even more scarce! Through teaming, the resource pool expanded by partnerships being forged with interpreting training school programs resulting in a larger network of skilled interpreters and volunteers. *(Visioning and Claiming, role clarification and responsibilities.)*

The Institute’s core ingredients:

- **Keynote Speaker should always be an adult who is deaf-blind, providing the adult role model.**

- Mentors are cultivated from previous attendees and gain leadership skills by their embedded role.

- Interactive role play, resource fair, and team building.

- Afterwards celebrate, self-evaluate and review the participants, interpreters, and volunteers’ feedback ensuring continual growth and refinement. *(Celebrating and Letting Go)*

*During the interview, the person asked me what I had hope to pass on to the kids, sorry to say I don’t think I could have given them anything, but I am telling you they gave and changed me!*  

Stephen Head,  
Father of a Young Adult
By following this recipe, the Institutes have consistently produced teens that emerge from their weekend experiences with focused action plans and renewed sense of self-confidence and direction. The families have especially remarked on the transformation occurring within themselves and their young adults from the exposure to deaf-blind role models and mentors.

As a result of the shared commitment to effort and resources, the states agreed to develop a toolkit making it possible for any organization to successfully plan an event aimed at assisting youth with disabilities to become more self-determines and help their families to become effective advocates. The product is titled “The Transition Toolkit.”

Currently, the Southeastern states are again Team Spiriting and using “The Transition ToolKit” for two upcoming 2015 Institutes, one in Alabama, June 11-14th, and the other in Kentucky, June 19-21st. In this way, additional states can participate with less cost and travel time.

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A new online community of support for professionals and family members of individuals with complex communication needs.

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Teenagers transitioning into adulthood are often presented with their first banking and budgeting experiences. They often start to be concerned about topics that they have never thought about before. These topics may include knowing how much money they have, paying for things they need or want, making purchases, and so on. These are all reasonable concerns. Through life experiences, trial and error, young adults are naturally exposed to banking and budgeting topics. Incidentally and directly, most teenagers gain the knowledge and experience they need to proceed with greater responsibilities that are demanded in adult life.

For individuals who are deaf-blind, the transition is not seamless due to lack of environmental accessibility and incidental learning. An initial financial literacy evaluation should be completed in order to determine what experiences an individual has had with managing her own finances. Banking and budgeting incorporates every area of the Expanded Core Curriculum (ECC) and therefore should be considered an integral part of a student’s high school transition plan. It is important to note that these approaches may be used by both teachers and family members who are vested in increasing the financial independence and success of young adults. It is recommended that educational and rehabilitation professionals work with the student’s family members to increase the student’s opportunities to practice skills across community contexts and in natural environments. Although there are many components of banking and budgeting, these practical tips will give you a place to begin to assist your student or family member achieve a higher level of independence.
in money management. Here are some basic steps on how to initially evaluate your student’s current level of confidence and competence in the realm of banking and budgeting.

First, determine what prior experience your student or family member has had with any banking and budgeting topics. Do they have their own accounts? Do they have their own money? Have they ever been to a bank? Have they ever independently made a purchase in a store, over the phone, or online? Once you obtain a better understanding of the individual’s experiences, ask if she can define the following terms:

- Withdrawal
- Deposit
- Insert
- Transfer
- Debit
- Credit
- PIN (Personal Identification Number)
- Savings
- Checking
- Amount
- Balance
- Budget
- Balance Inquiry
- Account
- Fee
- Expiration Date
- CVV (Card verification value, aka Security Code)
- Receipt
- Available
- Volume
Next, how does your student or family member identify her money?

- Visually identifies coins
- Visually identifies dollar bills
- Tactually identifies coins
- Uses Money Folding strategies
- Uses iBill Money Identifies
- Click Pocket Money Brailler
- Other: _______________
- Other: _______________

After the individual that you are supporting has mastered identifying money and increased her financial vocabulary, it will be time to explore other aspects of money management and explore real life implications. It is imperative to expose young adults who are deaf-blind to as many strategies as possible in order for the individual to understand which strategies will work for him. Explore the following areas:

- Can your student/family member organize and maintain his or her wallet (braille labels, dividers, tactile markings, etc.)?
- Can the individual make a purchase (in person, online, over the phone)?
- Can your student/family member manage a bank account (open the account, setup and use online banking, MoneyTalks Software, large print registries, Excel spreadsheets, bank statements, etc.)?
- Can the individual you are supporting write a check? (does she know the parts of a check, large print checks, writing guides, print a check through MoneyTalks?)
- Can your student/family member use an ATM (initiate audio, put in PIN, swipe card, adjust the volume, follow ATM prompts, navigate through screens, generalize skills to other ATMs)?
Although ATMs are not fully accessible for individuals who are deaf-blind, they do have many accessible features. As of March 2012, it has been mandated that all ATMs offer speech-enabled technology, headset jacks, and braille indicating how to initiate use of audio (ADA Standards, 2010). Thankfully, accessibility is becoming more universally applied in our society. Because of ongoing consumer advocacy, it is anticipated that a wireless blue tooth connection will be offered on ATMs so that a braille display can be utilized in conjunction with an ATM. Although there are developments of this type of technology, they have not made it to mainstream society due to security risks that have not yet been resolved (Duvey, Goyal, & Hemrajani, 2013).

Increased financial independence is possible for young adults who are deaf-blind. Through social awareness, training, and improvements in technology, financial confidence and literacy will become readily available and attainable for all students.

References


*For more information contact Dominique Neebe at d.neebe@yahoo.com.*
Sandy Kenrick uses tactile sign language to communicate with her young son, Liam.

Special thanks to : Nichole Gust Photography
I recently stopped for a moment to reflect on my journey as an educator in deafblindness. Like many who have juggled a full family, professional life, and graduate school, taking time to think - let alone reflect - seemed like a strange luxury. A friend, knowing I was at a crossroads in my journey, encouraged me to share with others the “pearls” of wisdom that I have developed as a part of my deafblind teaching experiences. Her encouragement and this brief interlude of reflection gave me the chance to capture a few of my experiences in the field of deafblindness.

Pearls are interesting things. They are created when something unexpected gets inside an oyster shell. The oyster coats the unfamiliar object with layer upon layer until it becomes smooth and lustrous, something beautiful and of great worth.

My heart has been touched by the wonderful, yet mostly unexpected opportunities that have unfolded in front of me. I can truly say my journey with deafblindness has created numerous pearls, which I can figuratively cradle in my hands, remember, and be ever so grateful for. As I examine my figurative pearls, my experiences as an intervener, as a family support specialist, and as a deaf-blind specialist, I treasure each experience. My experiences are just as precious to me as pearls of great worth.
My most recent pearls have been created by opportunities through my master’s program at the University of Utah, beginning with the opportunity to be a Helen Keller Fellow. Through this fellowship, I was afforded the opportunity to meet and interact with individuals from around the nation through enrichment trainings and internships. My fellowship experiences lead to the opportunity to participate on writing teams for the “Open Hands, Open Access” Deaf-Blind Intervener Learning Modules with the National Center on Deaf-Blindness. While participating in my graduate program, a brand new teaching endorsement for teachers of the deafblind became available in Utah. By adding some additional course work, I was able to qualify for the deafblind teaching endorsement, in addition to a master of education in visual impairments, when I graduated this past spring.

The size and quality of a pearl an oyster produces depends upon factors, such as water quality and nutrition. The richness of my deafblind experiences are due to those who have mentored, supervised, and encouraged me from the time I was first hired as an intervener until this very day. After my initial training as an intervener, the ongoing training and technical assistance provided by my Deafblind Specialist was invaluable. Because of my experiences as an intervener, I take very seriously my role as a Deafblind Specialist and now teacher of the deafblind. Interveners, teachers, and class teams can benefit if I properly do my job to help them understand and implement best practice deafblind strategies. My students with deafblindness may have a different classroom teacher each year or every few years. That can mean they start over with a teacher who has not been exposed to deafblind strategies. It is not the role of the intervener, who works one-on-one with them, to provide training
and technical assistance to the teacher. It is my role to provide the needed support to classroom teachers and other professionals; therefore, if I do my job well it is the child with deafblindness who ultimately benefits. That is what my profession is about - the children! Many of my favorite pearls are the amazing people I have met: family members, fellow graduate students, and colleagues; many of them have become treasured friends. Yet in my handful of figurative pearls, the students, and my experiences interacting with them, are my most lustrous pearls.

Looking back, not much in my personal experience with deafblindness has come easy; but when I consider the entire field of deafblindness, growth has not been easy! I don’t think it is easy for an oyster to create a pearl of worth. It requires time, effort, persistence, and patience. Likewise, effort, persistence, and patience are also necessary in order create the systems changes needed to positively impact children who are deaf-blind on national, state, local, and individual levels. Sometimes the biggest change is the change that happens within each of us. I am very grateful for the opportunities, friendships, and most of all the children with deafblindness who have so greatly blessed and changed my life. It is my sincere desire that others will grab ahold of opportunities to be an intervener or a teacher of the deaf-blind and that many others will create their own collection of precious “pearls”.
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