

Enhancing the Deaf-Blind Technical Assistance Project Network

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For over two decades, the U.S. Department of Education's Office of Special Education Programs (OSEP) has provided funding for technical assistance (TA) projects to build local, state, and national capacity to serve children who are deaf-blind and their families. OSEP currently supports 52 state deaf-blind projects (50 states, Puerto Rico, and the Pacific Basin), the National Consortium on Deaf-Blindness (NCDB), and a few targeted professional development grants to improve teacher preparation. This network of deaf-blind projects provides technical assistance, resources, data/information, and materials to states, local schools, educational professionals, and families with the overall objective to enhance educational and related services for students who are deaf-blind.

Over the past couple of years, OSEP has brought considerable focus to the TA projects it funds to construct an improved national deaf-blind network. This focus has become necessary because of the need to maximize cost efficiencies and because new technologies are available that provide opportunities for more effective collaboration and for the expansion and enhancement of the work we do. Improving connectivity and productivity among the deaf-blind projects and numerous partner organizations was a central theme for the Fall Deaf-Blind Leadership Meeting, held in Washington, D.C., on November 18–19, 2010. Dr. Anne Smith, education program specialist with OSEP and the federal project officer working with NCDB and many of the state deaf-blind projects, opened the meeting with remarks about the future with a presentation entitled "The New Normal: Doing More With Less." She emphasized the importance of recognizing the present as a time to explore alternatives to old ways of doing things and of challenging the status quo.

I recently wrote a blog post for the NCDB website (deafblindnetworks.blogspot.com) about the changes that are occurring in the network, and in this article I share my thoughts from that post with readers of *Deaf-Blind Perspectives*. I believe that, as we in the field of deaf-blind education prepare for a future of "new normal," we have a unique opportunity to refine our network of projects and strengthen services and supports for children who are deaf-blind and their families. It is critical that we recognize and capably respond both to current circumstances and to future needs. What ideals best exemplify a cohesive, mutually beneficial network for the field of deaf-blindness? I'd like to offer some thoughts about key systemic factors that, in my opinion, would promote a strong network.

First, for clarification, let me offer some descriptors that I find useful to better define what is meant by "deaf-blind network." Actually, I see two organizational layers. The first, which I'll coin as the "OSEP Deaf-Blind TA Project Network," consists of the 52 OSEP-funded state deaf-blind projects and the national center (NCDB) supported under Part D of IDEA. The second layer, which I'll refer to as the "Deaf-Blind Community Network," includes all those in the first network but extends to include parents and families and the organizations that represent them, personnel preparation projects, private organizations serving students who are deaf-blind, deaf-blind advocacy organizations, and other state and local agencies and organizations. It also includes our technical assistance partner organizations in the broader OSEP Technical Assistance and Dissemination (TA&D) network of special education projects and centers. The thoughts

In This Issue

Enhancing the Deaf-Blind Technical Assistance Project Network	1	Reflections from the Field	8
Functional Vision Assessment for Children with Cortical Visual Impairment	3	Using the Online Communication Matrix to Assess Early Communicators Who Are Deafblind.	10
Bookshare: What It Offers People Who Are Deaf-Blind	6	Research Update	13
		For Your Library	14

shared here refer to the first layer, the Deaf-Blind TA Project Network. I will address the broader Deaf-Blind Community Network with commentary in future blog posts and issues of *Deaf-Blind Perspectives*.

I believe there are six core issues that those of us in the Deaf-Blind TA Project Network must address in order to (a) strengthen the network, (b) make better use of our collective skills and talents, (c) encourage, educate and empower each other, and (d) improve the services we provide for children who are deaf-blind and their families.

1. Fundamentally, we must have general agreement on the network's common interests and values because these serve as the cornerstone for working together to achieve our objectives. While I'd argue that we already have this agreement, others may argue that we need further definition.
2. We need a comprehensive process for the network to develop and share the information and materials that we produce. This should involve collaborating with OSEP to decide collectively how products and materials are promoted and shared across the network.
3. We need an easy-to-use system for accessing quality quantitative and qualitative data on students, systems, and capacity. This system must provide a means to analyze and use relevant local, state, regional, and national data to inform our thinking about our work.
4. We need an active communication system to (a) support and encourage ongoing network-wide discussion and debate on a variety of relevant, timely issues and (b) facilitate network-wide the solicitation of help from others, simply by offering a place where one can seek assistance in identifying strategies to solve problems.
5. We need broad agreement on the types of technologies that will be employed to expand and enhance our reach. Such agreement helps ensure collaborative sharing while expanding the base of support across the network.
6. Finally, we need a mutual commitment to working together as a team to build a quality network, to utilize its resources and actively "give" as well as "take."

There seems to be agreement that mutual benefit would result from improved opportunities for connectivity and productivity across the Deaf-Blind Project Network. Indeed, many good ideas have already been identified to facilitate change. While I believe it's important that we move forward and implement these strategies, I also believe it's important to better define what we mean when we talk about improving connectivity and productivity of the network. Technology has transformed our ability to work together and successfully reach our intended audience, including students and families and those that serve them. It positions us for positive progress. While some may be wary of change from the status quo, I believe that we have reached an important milestone as a field. The premise of working under a "new normal" shouldn't discourage us. Rather, preparing for a "new normal" should challenge us and facilitate progress.

I encourage us all to engage in a network-wide dialogue about the quality and direction of our work, and I invite everyone to share their ideas and participate in an interactive process that involves listening, reflecting, responding, and sharing. Active dialogue will stimulate our individual and collective abilities to think and plan carefully and strategically for a future that is, in fact, upon us.

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Functional Vision Assessment for Children with Cortical Visual Impairment

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Visual impairment in young children can be divided into two major categories: ocular visual impairment and cortical visual impairment. Ocular visual impairment occurs when the eye structures are underdeveloped or damaged by injury, disease, or infection (Teplin, 1995). With cortical visual impairment (CVI), the eye structures are healthy but the child's brain has been injured or did not develop typically. As a result, the child is unable to interpret the information received from the eyes (Good et al., 1994). Children may have either type or both types of visual impairment (Hoyt, 2003). Recent studies indicate that CVI is now the single leading cause of visual impairment in children (Hatton, Schwietz, Boyer, & Rychwalski, 2007).

Under the Individuals with Disabilities Education Act (IDEA), children who are identified with a visual impairment are required to have an assessment to determine how it affects their educational performance [34 C.F.R. § 300.311]. Medical reports and eye test results help determine whether a child is eligible for specialized educational services, but in order to select developmental and educational modifications and accommodations that will give a child the best access to the curriculum, educational teams must also conduct assessments that help them to fully understand a child's visual functioning— how a child uses his or her vision to participate in classroom activities and accomplish activities of daily living.

For children with ocular visual impairment, there are a variety of assessment tools and a well-known framework to assess visual function, including response to light, awareness of visual input, eye muscle function, nearsightedness or farsightedness, ability to perceive colors, visual field, and visual perception (Appleby, 2002; Langley, 1998; Teplin, 1995). However, research has consistently shown that children with CVI have vision characteristics that are different from children who have ocular visual impairments (Jan & Groenvelde, 1993). In an extensive review of the literature, I found that despite the documented differences in the visual skills of children with ocular

versus cortical visual impairment, functional vision assessment tools primarily focus on the needs of those with ocular visual impairment and do not take into account the distinctive features of CVI (Newcomb, 2009).

The CVI Range

In response to the need for a functional vision assessment that meets the needs of children with CVI, Christine Roman-Lantzy, Ph.D., developed an assessment instrument called the CVI Range (2007) that is based on her own and other researchers' work identifying the characteristics of CVI (Dutton, 2003; Jacobson, Ek, Fernell, Flodmark, & Broberger, 1996; Jan, Groenvelde, Sykanda, & Hoyt, 1987; Roman, 1996).

The CVI Range is completed using information gathered from three sources: (a) parent or teacher interviews, (b) child observation, and (c) direct assessment. First, a parent, caregiver, or teacher is interviewed about the child's medical history, eye test reports, and visual behaviors. Next, the child is observed in his or her living and/or learning environments. Finally, a formal assessment of vision skills is completed by a trained evaluator. Specific directions for assessing and scoring each item on the CVI Range are provided in the book *Cortical Visual Impairment: An Approach to Assessment and Intervention* (Roman-Lantzy, 2007).

The CVI Range identifies the unique visual characteristics of children with CVI based on the following:

- ◆ *Color*: Does the child have a preference for a particular color or respond better to certain colors?
- ◆ *Movement*: Does the child need movement to initiate visual attention?
- ◆ *Visual latency*: Is there a lag between presentation of materials and the child's visual attention, and is it affected by the familiarity of the materials, time of day, or fatigue?
- ◆ *Field preferences*: Does the child respond better when materials are in a specific visual field, such as only to the right or left?
- ◆ *Complexity*: Does the child have trouble looking at an object that is complex, such as when there are many objects grouped together or when there are other things happening nearby (e.g., other sounds, sights, or sensations)?

- ◆ *Light-gazing or nonpurposeful gazing*: Does the child gaze at lights or spend time not focusing on anything at all?
- ◆ *Distance viewing*: Does the child have trouble looking at things at a distance?
- ◆ *Visual reflexes*: Does the child have typical visual reflexes, such as blinking when touched between the eyebrows or when something approaches his or her face?
- ◆ *Novelty*: Does the child show a visual preference for familiar rather than new objects?
- ◆ *Visual motor skills*: Does the child reach for things he or she is looking at, or are looking and reaching performed separately?

Research Study

In 2008–2009, I conducted a study to evaluate the quality of the CVI Range to accurately measure the presence and severity of the visual characteristics of CVI. One of the critical aspects determining the quality of an assessment instrument is its reliability (Newcomb, 2009, 2010). Reliability means consistency. If the test is repeated, are the results the same both times? If two people use the same test with the same child, do they get the same results? Another aspect of test quality is its validity. Validity means that the test measures what it says it measures.

During the study, the CVI Range was used to assess 104 children diagnosed with CVI. Of those 104 children, 57 were tested one time by a single examiner, 27 were tested by two trained examiners to see if the test gave consistent results for different evaluators, and 20 were tested two times by one examiner to see if the test gave consistent results over time. The children ranged in age from 6 months to 12 years. The assessments were done by 12 professionals, including 3 special education teachers or early interventionists, 6 teachers of the visually impaired, 2 occupational therapists, and 1 neonatologist. All had been trained extensively by Dr. Roman-Lantzy.

Study Findings and Implications

The results of the study were very positive. It found the CVI Range to be a highly reliable and valid instrument that consistently measured the characteristics and severity of CVI. This indicates that the CVI Range is a high quality instrument that can be used to assess the functional vision of children with CVI. Teachers who have children with CVI in their classrooms or on their caseloads can

use it to assess how a child uses vision and identify characteristics of CVI that may be interfering with the child's use of his or her vision. This knowledge can help determine how visual materials, home and classroom environments, and instructional strategies can be adapted to the visual characteristics and abilities of a child in order to give the child the best possible access to the educational curriculum. Each CVI characteristic that affects a child's visual functioning should be considered when developing educational strategies. For example, if a teacher discovers that a child looks only at objects that are moving or shiny, the teacher should use shiny materials in educational activities.

Another important finding of this study is that children with CVI do not have vision that fluctuates, contradicting a long-held belief in the field that children with CVI have vision that changes from day to day or even from hour to hour. When the children in the study were tested several days apart by the same examiner, in the same setting, and with the same materials, they had similar scores on the CVI Range. This was true for children with varying degrees of CVI, from mild to severe.

Although the vision of children in this study was stable, it is important to keep in mind that visual function can be influenced by many things. The more severe the CVI, the more susceptible a child is to a variety of factors that can affect functional vision. For example, if a child has stopped looking at something that he or she used to look at, it is important to consider factors that may be interfering with the ability to view the object. The child may not look at a particular toy at school that he looks at when at home because the complexity of the school environment affects his visual functioning. A child who looks at a toothbrush when positioned in an adaptive chair but not when standing at a bathroom sink may have difficulty in the latter case because the challenge of standing has increased the complexity of the task. In both cases, the conclusion could be drawn that the child looks at specific objects sometimes but not at other times, when in fact, it is a characteristic of the activity or the setting rather than the child's vision that has changed.

Personnel Training Needs

Proper training is critical for professionals who use the CVI Range. Training resources include Dr. Roman-Lantzy's book mentioned above (2007) as well as workshops offered by Dr. Roman-Lantzy and others. In addition, in West Virginia, professionals with expertise in CVI and in the use of the CVI Range have developed a website that includes video samples of parent interviews and CVI assessments (wvde.state.wv.us/osp/vi/cvi).

Another training need that emerged from this study was not related to administration of the CVI Range, but to characteristics of the children. All of the children who participated also had disabilities other than CVI and received many different services, including early intervention, special education, physical therapy, occupational therapy, speech therapy, vision services, and hearing services. Therefore, training about CVI needs to occur across disciplines, not just with vision or classroom teachers. Everyone on a child's team should understand the characteristics of CVI that affect the child's vision and know how to implement appropriate modifications to social and educational activities throughout the child's day. For example, the assistive technology specialist should understand how the child's vision can be best served by communication systems. Does he or she attend to pictures on a computer screen? How many pictures can be presented at one time? The teacher needs to know how to present materials in a group setting. Does the wall behind the teacher need to be plain? Does the child's cubby need to be outlined in a specific color so that the child can easily locate it and be successful in finding his or her coat at the end of the day?

Conclusion

CVI is the main cause of visual impairment in young children, and it is essential that they receive accurate, thorough assessments and targeted interventions to help them make the most of their visual skills. This study showed that the CVI Range is a high quality instrument and, as such, it can be used to determine a child's current vision needs, design appropriate interventions, and measure progress. The next objective in the field should be to develop and conduct research to identify evidence-based interventions that improve functional vision in children with CVI. These children can and often do show improvement in functional vision over time.

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Bookshare: What It Offers People Who Are Deaf-Blind

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Bookshare (BKS) is the world's largest fully accessible digital library for individuals with print disabilities. Print disabilities include visual impairments like blindness or low vision; physical disabilities that affect a person's ability to read print, such as an inability to hold a book or turn pages; and severe learning disabilities like dyslexia. Anyone who cannot manage a typical print book might be considered print disabled and qualify for access to print in special formats. Using BKS, individuals with print disabilities can access books electronically and use a variety of reading devices and other types of technology to read using formats that are best for them (e.g., audio, braille, enlarged print).

Historically, the best-known sources of books for individuals with print disabilities have been the National Library Service for the Blind and Physically Handicapped (NLS) and Recordings for the Blind and Dyslexic (RFB&D). NLS provides a wealth of books in braille and digital audio formats. The audio format requires use of specialized digital book players. RFB&D provides a large collection of audio books with human narration. The main difference between these services and Bookshare is that with Bookshare readers can access an ever-growing collection of books including reference materials and textbooks in digital text, digital braille, and audio formats, depending on their particular needs. These formats and accessibility options are available through a variety of types of software and devices (see below).

Since it began in 2002, Bookshare has become widely known and has more than 135,000 members worldwide. It currently provides over 100,000 books in accessible formats, and the number is growing fast. Through an award from the U.S. Department of Education's Office of Special Education Programs, BKS provides free membership to students with print disabilities in the U.S.A. and its territories. Students include those in preschool through postsecondary and adult education programs, regardless of age. Teachers have access to K-12 textbooks through the National Instructional Materials Access Center (NIMAC), and teachers and students in K-12, postsecondary, and adult

education environments are encouraged to send book requests. Deaf-Blind students are accessing BKS more and more as outreach efforts expand. Schools can sign up on behalf of qualified students who are Deaf-Blind, or their parents can sign up for them.

Students are finding the books they need for their classes at Bookshare. For example, Angela is a Deaf-Blind college student. She needed a poetry anthology that her college had available ready for conversion to braille, but when she got it, she found the book had not been formatted for poetry. She downloaded the BKS copy instead, and found the poetry formatted with ends of lines, blank lines between stanzas, punctuation, and accents in place, as well as other features that are normally present in a print copy. She was very relieved.

Qualified adults who are not students must join as individual paying members. Most Deaf-Blind (DB) people who have used BKS in school or college choose to convert to an individual paying membership. Individual memberships cost \$75 the first year: a \$25 one-time set-up fee plus \$50 annual membership. Another use of BKS is for DB adults to access books that they can read to their children. The BKS outreach team is currently making a concerted effort to reach the Deaf-Blind population. There are many books, magazines, and newspapers—something of interest to anyone regardless of English ability or etiology of deaf-blindness.

Many students who use BKS discover the joy of reading and request books that are not yet in the BKS library. BKS tries to fill those requests as quickly as possible, knowing that children's interests can be fleeting. From the time BKS acquires a new book, conversion may take 2 weeks or more depending on the difficulty of the book. The children and teens collections are very large in all genres.

The combined Deaf and Deaf-Blind (DB) collection is growing. Teen and transition-aged Deaf-Blind students are learning about their culture and history through Bookshare. Many books about deaf-blindness that are currently out of print are in the Bookshare collection. The easiest way to see the combined Deaf and Deaf-Blind collection is to go to the home page, www.bookshare.org, tab over to "Advanced Search," then enter the word "deaf" in the "synopsis" field. You don't have to be a member to use the search functions or to download public domain books from Bookshare.

How Bookshare Works

Every single BKS book is available in Digital Accessible Information System (DAISY) format and Braille Ready Format (BRF). DAISY is the global digital talking book standard that is supported by many leading libraries and by assistive technology software and hardware manufacturers worldwide who create products for individuals with disabilities. It provides the capability to distribute books digitally and uses powerful indexing and bookmarking features that make it possible to move easily and quickly from one part of a book to another. As a format, DAISY supports delivery of books that include both digital text and recorded human speech. It makes possible the adaptation of print books in multiple ways. Readers can listen to books, enlarge print, and read with braille notetakers and other assistive technology devices. The media formats and technology used to read BKS books vary. Some readers choose just one format, such as braille. Others combine a variety of formats such as sound (through speakers, headphones, or FM- or cochlear-implant patch cords) and large print or sound and braille. Some very creative combinations are being used.

BKS offers two free DAISY readers for download from the BKS website: Victor Reader Soft, (Bookshare edition) and Don Johnston Read:OutLoud. A variety of mobile devices can also be used, such as the Victor Reader Stream, the PLEXTALK Pocket, BookCourier, and Book Port. Bookshare books can also be converted to MP3 format and listened to on MP3 players. Reading software such as that on the free readers from BKS, as well as that on other devices like Kurzweil 1000, Kurzweil 3000, and OpenBook allows readers to manipulate font size and colors. It highlights words as they are being read and provides other types of reading assistance.

Text files can be processed through braille conversion programs, but BKS has also already made the files available as a separately downloadable Braille Ready File (BRF). These files can be downloaded to a computer with a braille display and read there or transferred to any current braille notetaker. (Note: the BrailleNote mPower used in HumanWare's Deaf-Blind Communicator (DBC), can be used if its back suite of programs is unlocked).

Another Bookshare accessibility feature is the new application called Read2Go, which can be used on Apple's iPhone, iPod Touch, and iPad. Using Bluetooth technology, all of these devices can also be linked to a compatible braille display.

A cautionary note at this time is that not all displays will work with the Apple products. A major advantage of the new Read2Go app is that large print readers can use an iPad to set preferred fonts and screen colors. The app offers larger font sizes than those available with the basic iPad. Finally, large-print readers have a portable solution! And don't forget, you can incorporate sound via ear-phones or hearing aid or cochlear implant systems.

Conclusion

Bookshare offers individuals with print disabilities the ability to access reading materials in formats that they can use independently for lifelong success. The Bookshare collection continues to grow, and increasingly publishers are giving Bookshare the right to make their books available internationally as well as in the U.S.A. Members in Canada, South Africa, England, Australia, and India (just to name a few) may download titles. In addition, BKS offers many books in Spanish.

To learn more about Bookshare, especially about what it offers adults, please visit the website at www.bookshare.org. The outreach group has specialists who focus on parents, K-12 programs, universities, and general adult members. And as noted above, Bookshare is currently working hard to reach the Deaf-Blind population. If you attend the 2011 AADB Symposium in June, please stop by the Bookshare exhibit table!

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Conferences and Training Events

For a list of upcoming conferences and trainings, go to nationaldb.org or call DB-LINK Information Services at NCDB. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: info@nationaldb.org.

Reflections from the Field

"Reflections from the Field" is a column in which we ask experts in the field of deaf-blindness to share their thoughts on important issues. This column features Sam Morgan, project director for the New York Deaf-Blind Collaborative, New York's state deaf-blind project. We asked Sam to tell us a little about his background in deaf-blindness and then respond to the following questions:

What is your perspective on the availability and quality of services for children who are deaf-blind and their families? How do you think things have changed, for better or worse, over the past ten years, and what, if anything, do you think needs to be done to improve services in the future?

Sam Morgan



I cannot remember a time when the pace of change in the field of deaf-blindness seemed as rapid and relentless as it does now. I originally trained as a teacher of the visually impaired in a program for children with

sensory impairments and multiple disabilities at Teachers College, Columbia University, and as an orientation and mobility instructor at the University of Northern Colorado. I subsequently became an itinerant teacher and orientation and mobility instructor serving a wide range of children with vision impairments and soon gravitated towards working with children who were deaf-blind or had multiple disabilities. From where I sit now, 20 years later, as the project director of the New York Deaf-Blind Collaborative, the challenges we face to provide high-quality education for children who are deaf-blind are real and daunting. Here are some of the forces I see operating behind many of the daily struggles and successes in providing technical assistance for children and youth who are deaf-blind:

- ◆ the impending retirement of a generation of professional and family leaders;
- ◆ a continuing need to create and sustain specialized instructional practices for children who are deaf-blind in the face of an increasingly generic educational service system;
- ◆ a push for deeper and more meaningful collaboration between organizations; and

- ◆ an increasingly rapid and technologically focused world that does not make room for those who need hands-on human relationships.

Professionals and parents from the generation of individuals who, in many ways, created the field of deaf-blindness as it exists today are starting to retire, and this is affecting our field in ways that will make it more difficult to sustain what we have. This generation worked hard to keep us on the minds of legislators and the U.S. Department of Education's Office of Special Education Programs (OSEP) by showing them why technical assistance to children, families, and professionals matters. The deaf-blind technical assistance program that many of us are part of, and for which we work hard to demonstrate effectiveness, is the result of their effort and dedication. In addition, the original group of family members that started and grew the National Family Association for Deaf-Blind (NFAADB) and many state parent organizations is moving out of positions of leadership that they have held for many years. While there are many forces that affect the survival and success of the OSEP-funded deaf-blind programs, the influence of generational change is a quiet but persistent one. This shift endangers the continuity of our field, and we need to address it directly.

A hopeful trend is that our field recognizes this and is making efforts to train new professionals and family members to assume leadership roles. Examples include parent leadership training, the Helen Keller Fellows Project, the National Leadership Consortium in Sensory Disabilities, and the intervener movement. The beauty of these efforts, if you look at them as a whole, is that they are training people at multiple levels—paraprofessionals, teachers, higher education and technical assistance providers, and families. I am not aware of any other field that has made as deliberate an effort to train people to assume such a variety of roles. These efforts accomplish the obvious goals of bringing new people into the field and training them in the specialized skill sets they will need, but just as significantly they send a message to the disciplines of special education and education at large that we, as a field, are committed to our future. The challenge for us now is to continue those efforts and create opportunities within existing organizations for newly trained individuals so they see a future in our field as well. Just as we support teachers to implement in the classroom what we teach them through training, we will need to mentor this new generation or risk losing them to

other fields that would surely appreciate their skills.

While special education services have, to some extent, moved positively towards more inclusive models of education, they have also become more generic, with fewer programs concentrating on specific disabilities such as deaf-blindness. While this may make sense for most students, it makes it very difficult to develop and sustain the specialized practices necessary for educating children who are deaf-blind. Increasingly, I see teachers trained to work with children with mild to moderate disabilities who have very limited knowledge of sensory impairments or severe and multiple disabilities. While the services of teachers of the visually impaired and of the deaf and hard of hearing may be available and do help supplement the work of classroom teachers, the services they provide are increasingly being viewed and delivered as related services or therapies rather than as primary and essential educational services. In New York, I frequently hear teachers of the visually impaired referred to as vision therapists in the same breath as occupational therapists, physical therapists, and speech-language pathologists. This trend is likely to have a significant impact on how our educational system views children who are deaf-blind. It may promote the belief that combined sensory impairment is something that can be treated through therapy rather than as a serious condition requiring program-wide implementation of significantly different instructional methodologies.

OSEP speaks to us about "The New Normal" and the importance of increasing collaboration within the Technical Assistance and Dissemination Network (TA&D). There are many good reasons for us to do this—increasing efficiency and less duplication of services, better use of existing resources and knowledge, increased awareness of what the field of deaf-blindness has to offer others, and the creation of synergistic thinking as the network moves forward. While increasing collaboration is our new reality in the TA&D Network, I think it is also true in our work with professionals outside of our network. In order for us to be effective in the current educational environment—where we ask people to do more than they have probably ever needed to with any other child, in ways that are new and foreign to them—we need to make ourselves visible and ever present. The use of technology to foster collaborative relationships in the larger special education field is critical in developing and maintaining effective programs. We need to make our small numbers seem bigger and increase our collaborative relationships with

those in the generic special education system who serve children who are deaf-blind. This can occur through social networking and information dissemination, as well as through synchronous and asynchronous training opportunities. These examples allow our small numbers to be visible on a larger scale. They allow us to span a wider area, reach a greater number of people, and help us to be present in their minds when we are not physically present. For me, the shift in knowledge and effort that this requires is something I am only beginning to understand.

There are many challenges to changing how we use technology to provide service. One of these is how we support professionals and paraprofessionals to implement instructional practices for children who are deaf-blind in classrooms and programs. As many of us know, the provision of information and training by themselves rarely, if ever, results in change in classroom or programmatic practice. Additional steps to support implementation are critical (e.g., modeling, coaching, reflection, and data collection). New ways to use technology to support implementation are emerging, and how we merge current practices and new technology to make ourselves visible and effective in a world of generic services will be critical. The number of children who are deaf-blind is too small to be self sustaining in a generic system serving literally millions of children (approximately 6.9 million children served under IDEA in 2008, compared to approximately 10,000 identified as deaf-blind). However, technology presents opportunities for us to make those children and the work that we do around them more visible and present when we cannot actually be there. When I look at special education, I think the field of deaf-blindness has made a contribution much larger than meeting the needs of 10,000 children, but we need to get better at sharing that.

In our rapidly changing world in which the pace of information exchange is accelerating, the ways people interact are changing, and there is a growing tendency to measure and value people by their achievements or how much they contribute, I fear that children who are deaf-blind will not fare well. The reality is that these children need everything and everyone to be slower-paced, deliberate, human, and meaningful in a real and rich environment. I focus much of my technical assistance efforts on communication and interaction, as I am sure many other professionals in the field do, and I believe that the biggest changes for children come about when the people who interact with them slow down, be deliberate, and be emotionally open to a child and what he or she is attempt-

ing to express or do. This takes time and singular focus, something the pace of modern life rarely allows. Is it possible to teach this through technology? I think it may be, but I am not yet sure how. I do find it odd that we expect people to use technology to access large amounts of information in an efficient manner to learn from us, but then expect them to do something very different with that information with children who are deaf-blind. I know I feel the challenge to preserve a view of children who are deaf-blind as needing something different and that, regardless of technology or changes in the system, children who are deaf-blind will always need something different.



Using the Online Communication Matrix to Assess Early Communicators Who Are Deafblind

Charity Rowland, Ph.D.
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Before children learn to speak they use a variety of movements and behaviors to communicate what they feel and want. Speech and other forms of language, such as sign language, do not suddenly appear between the ages of 12 and 24 months. They are the result of the development of

a series of increasingly complex skills that begin with early infant-caregiver relationships. Children who have disabilities, such as deafblindness, that affect how communication develops usually need intensive instruction to help them learn the early prelinguistic (prior-to-language) communication skills that typically developing children pick up naturally as they watch, listen, and interact with others.

To begin promoting early communication skills in a child who is deafblind, one first needs to determine which communication mode or system will best capitalize on the child's strengths, provide an immediate means of communication, and lay a foundation for future growth. The online *Communication Matrix* (Rowland, 2009) was developed as a free web-based tool to make this assessment task easier for parents and professionals. It provides a comprehensive picture of a child's current communication skills by identifying what a child can do, rather than focusing on what he or she cannot do (Rowland, 2005). Although this article refers primarily to children, the *Matrix* can be used by parents and professionals to assess someone of any age who is deafblind and operating at the earliest stages of communication.

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History of the *Communication Matrix*

The *Communication Matrix* is designed to pinpoint exactly how an individual currently communicates, with or without speech, and to provide a framework for determining logical communication goals. It was first published in 1990 and revised in 1996 and 2004. The original version (Rowland, 2004a) was designed primarily for use by speech-language pathologists and educators to document the expressive communication skills of children who have severe or multiple disabilities, including sensory, motor, and cognitive impairments. Its format is concise and designed for rapid administration by persons familiar with the instrument. A second, more user-friendly version was developed especially for parents in English (Rowland, 2004b) and in Spanish (Rowland, 2006). The free web-based version discussed in this article is also available in both languages (Rowland, 2009). It was developed to make the *Matrix* even easier to use, to make it widely and freely available to potential users, to encourage collaboration between professionals and parents, and to create a database of information to advance scientific knowledge about communication development in specific populations of individuals who have complex communication needs.

Organization of the *Communication Matrix*

The *Matrix* is structured around seven levels of communication (see table). Six are levels that typically developing children achieve between birth and 24 months, and one, "concrete symbols," is an additional stage that is critical for some individuals who are deafblind. The levels range from "pre-intentional behavior" (the very earliest behavior that is not under a child's voluntary control) to "language" (the ability to combine two or three words, or any type of symbol, into phrases). "Concrete symbols," the stage that is specific to some individuals who are deafblind, is Level V. In contrast to "abstract symbols" (spoken words or manual signs), concrete symbols look like, feel like, move like, or sound like the objects or concepts they represent. They include pictures, objects (such as a shoelace to represent "shoe"), meaningful gestures (such as patting a chair to say "sit down"), and meaningful vocalizations (such as making a buzzing sound to mean "bee"). For some children, concrete symbols may be the only type of symbol that will ever make sense to them. For others, concrete symbols serve as a bridge to the use of abstract symbols such as spoken words and manual signs.

The parent or other person completing the *Matrix* for a specific child responds online to 24 questions about the messages expressed by the child at each of the seven levels of communication. For example, Question C3 (Requests Attention) asks, "Does your child intentionally try to attract your attention?" The questions are answered by indicating which, if any, of a variety of communication behaviors the child uses to express a message. Behaviors are classified into nine categories: body movements, early sounds, facial expressions, visual behavior, simple gestures, conventional gestures/vocalizations, concrete symbols, abstract symbols, and language. For example, under Question C2 (Requests More of an Action), the body movements category includes the following behaviors: whole body movements, arm/hand movements, and leg movements. Three demonstration videos that explain how to use the *Matrix* and interpret its results are included on the website. A 26-page handbook may be downloaded at no cost.

Seven Levels of Communication

- I. Pre-intentional behavior—not under an individual's control, but reflects a general state (e.g., comfortable, uncomfortable, hungry, or sleepy).
- II. Intentional behavior—under an individual's control, but not used to communicate intentionally (e.g., facial expressions, eye gaze).
- III. Unconventional communication—pre-symbolic behaviors (do not involve any type of symbol) that are used to communicate intentionally (e.g., a simple gesture, such as tugging on a person). Considered unconventional because they are not socially acceptable as we grow older.
- IV. Conventional communication—used intentionally to communicate, but still not symbolic (e.g., nodding, pointing).
- V. Concrete symbols—symbols that resemble what they represent (e.g., a shoelace to represent a shoe).
- VI. Abstract symbols—speech, manual signs, brailled or printed words.
- VII. Language-combining at least two symbols of any type according to grammatical rules.

Results Generated by the *Communication Matrix*

The assessment results are generated online once the 24 questions have been completed. They are displayed in a one-page profile that reveals the individual's current level of communication function at a glance. The profile is organized by communication level and by the four major reasons that people communicate (to refuse things we don't want, to obtain things we do want, to engage in social interaction, and to provide or seek information). The profile shows all of the combinations of messages that are possible for the seven levels of communication. Color codes indicate whether the skills for each level have been mastered or surpassed, are emerging, or are not used by the child being assessed.

The report also includes a comprehensive communication skills list and an in-depth "mastery" view that quantifies the individual's range of communication skills using graphic displays. The mastery view is useful for reviewing the assessment results online with a team. A link to the assessment results may be e-mailed to others, thus encouraging the sharing of results among professionals and family members.

The *Communication Matrix* can be updated online periodically to document the communication development of a single child over time. The assessment results and demographic characteristics of children and adults who are assessed using the *Matrix* are collected and stored in a research database. Strict security measures ensure that the data cannot be linked to users.

New Report Capability

We have recently developed a feature that generates detailed individualized reports that include educational goals and suggestions for intervention. Users may specify which components to include in the report and may choose from sample goals and recommendations or generate their own ideas. This feature is in a beta-test mode and is free (although we hope that it may eventually generate funds to support the website). We are very interested in users' impressions of this new feature and will incorporate feedback from users into the final version. At this juncture, we are not able to provide the reports feature in non-English languages.

Widespread Use by the Deafblind Community

The online *Communication Matrix* is becoming widely used by the deafblind community and others. As of October 2010, over 15,400 *Matrix* profiles have been completed on more than 11,000 individuals, many of whom have been assessed multiple times. Currently, almost 300 new sets of data are entered per week. Demographic information collected through the online version shows that 11% of users are family members; 43% are speech-language pathologists; 41% are teachers, other educators, or therapists; and 6% are "other." The relatively large number of family members using the service suggests that it is encouraging parents to participate in the assessment process, as we had hoped it would. Although individuals of all ages are represented in the database, most of those who have been assessed are young children (32% between the ages of 0 and 5 years, 35% between 6 and 10 years, 17% between 11 and 15 years, and 16% above 15 years). Users come from 104 different countries, with 72% of them from the United States.

One of the expectations in developing the online version was that comprehensive data about the communication skills of children with low-incidence disabilities would be collected on a fairly large number of children. Typically, these groups of children are difficult to study because their numbers are small and they are widely dispersed geographically. This expectation is being realized. Individuals assessed using the online *Matrix* represent many different etiologies, diagnoses, and health conditions. Eleven percent have a primary diagnosis of deafblindness. As we know, deafblindness has many different causes. As of this writing, the database includes data on 835 individuals aged 0 to 21 years with a primary diagnosis of deafblindness associated with 32 specific etiologies. This is approximately 9% of the 9,131 children of ages 0 to 21 in the United States identified by the 2009 National Child Count of Children and Youth Who Are Deaf-Blind (NCDB, 2010). The value of the *Matrix* for specifically assessing individuals with deafblindness lies in the fact that it accommodates all possible communication behaviors and breaks communication development skills into smaller steps than other assessment instruments do. The information contained in the database will provide new insight into the development of communication skills in individuals who are deafblind. We plan to publish a series of scientific articles based on these data.

Future Directions

Grants from the U.S. Department of Education have supported sweeping improvements to the on-line *Matrix*. The website is now available in English and Spanish and will soon be translated into the following languages: Chinese, Vietnamese, Korean, and Russian (the languages spoken by the largest numbers of U.S. citizens who have limited English-language skills). The new language versions will encourage more parents to use the service. Although grant funds are temporarily available to support the website, this funding will end soon. Maintaining and updating the burgeoning website is not without cost. We are exploring mechanisms to support the service in the future, with the goal of continuing to offer the basic assessment as a free service. Any suggestions in this regard are appreciated. In the meantime, please use the service and feel free to offer your suggestions for improvement. It is only with the input of users that we will be able to continue to improve this collaborative website.

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Research Update

Vision and Eye Disorders in Children with Hearing Loss

Peggy Malloy
National Consortium on Deaf-Blindness

This edition of "Research Update" highlights research on the prevalence of ophthalmic (vision or eye) disorders in children with hearing loss. Over the years, a number of studies have determined that vision problems are quite common in this population of children, and in a 2007 policy statement, the Joint Committee on Infant Hearing (JCIH) recommended that every infant with a confirmed hearing loss be evaluated by an ophthalmologist to document visual acuity and rule out vision disorders (2007, p. 908). A survey of primary care physicians, however, found that only 1% reported having referred children with hearing loss to ophthalmologists (Moeller, White, & Shisler, 2006).

In 2006, a number of researchers in Europe published the results of a thorough review of articles published since 1965 on ophthalmic disorders in children with hearing loss (Nikolopoulos, Lioumi, Stamataki, & O'Donoghue, 2006). Among the articles they identified were 19 studies that investigated the prevalence of these conditions. Overall, they found that the presence of eye or vision disorders in children with hearing loss ranged from 40 to 60%. The disorders included those that are correctable (e.g., nearsightedness) or treatable (e.g., cataracts) as well as those that are not correctable or treatable (e.g., retinitis pigmentosa). There was a great deal of variation in the quality of the studies and the ways they were conducted. For example, studies used various types of diagnostic tests and defined ophthalmic disorders in different ways.

Two more recent studies found lower, but still substantial, rates of eye and vision problems. Both examined the medical records of children with sensorineural hearing loss (SNHL) who were seen at two children's hospitals over specific periods of time. The first, which evaluated the records of 226 children seen at Children's Hospital of Pittsburgh between 2000 and 2007, found that 49 (21.7%) had some type of eye or vision abnormality (Sharma, Ruscetta, & Chi, 2009). The second looked at the records of 77 children seen at the Department of Otolaryngology at the DuPont Hospital for Children in Delaware between 2001 and 2006 (Johnston et al., 2010). In order to make the results

as rigorous as possible, the researchers only considered the records of children who had had a comprehensive eye exam conducted by a pediatric ophthalmologist as well as a comprehensive genetic exam. Ophthalmic disorders were identified in 25 of 77 patients (32%) overall. When children with genetic disorders known to be related to vision loss were excluded, the percent fell to 23%.

The findings of these studies provide support for the JCIH recommendation that all children with hearing loss be evaluated by an ophthalmologist. Also, each of the articles discuss the damaging effect that unidentified vision loss can have on the development of children with hearing loss and highlight the importance of taking action to restore or improve vision problems that can be corrected and to provide adaptations, services, and supports for visually impaired children.

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Articles and Books

Practice Perspectives: College Students Who Are Deaf-Blind

National Consortium on Deaf-Blindness, 2011.

This publication, authored by Katrina Arndt, Ph.D., summarizes research she conducted on the experiences of 11 college students who are deaf-blind and provides suggestions for ways to support these students. This and previous issues are available on the web (standard print, large print, and Spanish). For free print and braille copies contact NCDB at 800-438-9376 (Voice), 800-854-7013 (TTY), or info@nationaldb.org.

Web:

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Acknowledging and Managing Stress

reSources, California Deaf-Blind Services, Winter 2011.

The effects of stress on children who are deaf-blind is an increasingly popular topic in the field. This newsletter includes articles about how stress affects children who are deaf-blind, the stress experienced by families of children who are deaf-blind, infant massage, and a new research project.

Web: cadbs.org/newsletter/resources-winter-2011

A Resource Guide for Early Hearing Detection and Intervention

National Center for Hearing Assessment and Management, Utah State University, 2011.

This free eBook includes chapters on early hearing detection and intervention (EHDI) programs, assessment of hearing impairment, the causes of hearing impairment, assistive devices, and much more.

Web: infanthearing.org/ehdi-ebook

Communication and Congenital Deafblindness

Inger Rodbroe and Marleen Janssen, The Danish Resource Centre on Congenital Deafblindness (VCDBF), Denmark and Viataal, The Netherlands, 2006-2009.

This is a set of four books (each approximately 150 pages) based on the work of Deafblind International's Communication Network. A companion

DVD is included with each book to illustrate the concepts described. Available from Perkins School for the Blind (www.perkins.org or 617-972-7308). The set of 4 books costs \$50. Individual books are \$15.00.

Media

Changing Vision, Changing Hearing: Is It Usher Syndrome? [Video Clips]

Washington Sensory Disability Services, 2011.
wsdsonline.org/deafblind/usher/index.html

This webpage includes delightful video clips of interviews with a 12-year-old and 24-year old who have Usher Syndrome. They talk about their experiences and the types of accommodations they require for school and work.

Tangible Symbols [Webcast]

Perkins School for the Blind, 2011.
perkins.org/resources/webcasts

In this new webcast, Elizabeth Torrey talks about the use of "tangible symbols," to support the development of communication in children who experience a variety of severe communication disorders and are unable to use abstract symbols. This and other webcasts on a variety of topics are available for free at the Perkins website.

Dr. Jan van Dijk Website

drjanvandijk.org

This is the website of Dr. Jan van Dijk, who has been a teacher, researcher, and advocate in the field of deaf-blindness for 50 years. The site includes information about deaf-blindness and his work. It includes a forum where professionals, family members, and others can discuss important issues and share information.

ASLdeafined [Online ASL Instruction]

asldeafined.com

This online program uses guided lessons and video demonstrations that individuals can use to learn sign language at their own pace. The cost varies depending on the subscription plan chosen. A 3-day trial period is available.

A Message from the National Family Association for Deaf-Blind

The National Family Association for Deaf-Blind (NFADB) has been supporting individuals who are deaf-blind and their families for over sixteen years and we would like to invite you to become a member of this incredible organization. NFADB offers support in a variety of ways.

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