

Moving Forward Together

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In the Spring 2011 edition of *Deaf-Blind Perspectives*, I penned an article entitled “Enhancing the Deaf-Blind Technical Assistance Project Network.” In it I shared my thoughts about strategies and system-wide infrastructures that I believe will strengthen services for children who are deaf-blind, primarily through refinement of the ways that deaf-blind projects and organizations collaborate within the network. I offered five characteristics of an improved system-wide approach:

1. coming to a general agreement on the deaf-blind network’s common interests and values;
2. formalizing the process to propose, produce, and share products, information, and materials;
3. developing and implementing a system for providing access to and enabling use of quantitative and qualitative data, including student and systems data;
4. developing and implementing an active network-wide communication system to support dialogue and provide opportunities to solicit help from others;
5. embracing a mutual commitment to work together based on recognition of the inherent value of working as part of a larger team across the entire deaf-blind community.

Since this article was published, much has transpired that has begun to move the deaf-blind project network in directions that reinforce implementation of these principles. Last October, the National Consortium on Deaf-Blindness (NCDB) received a two-year project extension that charged us to bring focus to “deaf-blind network systems development.” A primary goal of the extended project period is to develop and implement tangible infrastructures and systems that can be used by the network, as well as the broader deaf-blind community, to improve services and supports for children who are deaf-blind and their families.

In this edition of *Deaf-Blind Perspectives*, you will find articles that highlight work implemented in response to these new charges and built upon the five points listed above. Jamey McVicker, the father of a child with deaf-blindness, shares his experience of serving on a State Special Education Advisory Committee, describing the benefits of helping to educate others about the unique needs of deaf-blindness. Jon Har-

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ding discusses strategies to use distance technology to form quality connections within the deaf-blind network and, more specifically, with individual teams serving children. Gail Leslie describes how a planned redesign of the NCDB website will, similarly, offer new opportunities for our community to work together. The intent of the new site is to shift from an online environment that is static and primarily one-sided to one that is dynamic and interactive. Heather Herbster discusses the importance of partnerships to ensure that children with deaf-blindness are identified and referred to state deaf-blind projects as early as possible. Kathee Scoggin, a noted and respected leader in the field of deaf-blind education, offers her perspectives on serving children who are deaf-blind in today's educational climate. Peggy Malloy, Amy Parker, and I provide information about an exciting new effort to create a series of open-access modules that can be used to support intervener training. This effort capitalizes on bringing together numerous stakeholders across the deaf-blind community, all in service of creating resources for mutual benefit. Betsy McGinnity shares details about the remarkable and exciting new National Deaf-Blind Equipment Distribution Program, just getting underway.

Each of these contributions articulates a purposeful action to design and implement tools, resources, and strategies that tap the collective expertise of the deaf-blind community and expand local, state, and national capacity to increase and make the most of needed services for children who are deaf-blind. The activities they describe very much align with the five characteristics that I believe can enhance our national service delivery model.

Finally, we remember four of our colleagues who have passed away in recent times. Jim Durkel, June Downing, Diane Kelly, and Harvey Mar made enormous contributions to the field of deaf-blindness and to the lives of children and their families. They will be missed.

A number of the articles in this issue emphasize how technology has transformed our ability to work together. By truly embracing the new opportunities that technology provides, we can significantly enhance the quality and availability of services for children who are deaf-blind and their families. This new work will stimulate our individual and collective abilities to think, plan, and carefully and strategically work together to create a future that is, in fact, upon us.



Do you have questions about anything you have read in *Deaf-Blind Perspectives* or need other information about deaf-blindness?

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One Dad's Nuts and Bolts of Advocacy on the State Level

Jamey McVicker

Editor's note: During NCDB's current two-year extension, a major focus has been placed on increasing the capacity of family members to form collaborative relationships and to develop leadership and self-advocacy skills. One very practical opportunity for collaboration can be found on state special education advisory panels. IDEA [Sec. 612(a)(21)] requires that each state establish and maintain an advisory panel for the purpose of providing policy guidance with respect to special education and related services for children with disabilities in the state. As part of its overall family engagement initiative, NCDB is working to build the capacity of parents of children who are deaf-blind (as well as deaf-blind project personnel) who serve on these panels. This article highlights the perspectives and experiences of a father serving on the Missouri Special Education Advisory Panel.

In this article I aim to share my family's path and experiences, as well as my role as a dad, husband, firefighter, teacher, and activist. First, let me introduce myself and my family. My name is Jamey McVicker. My wife, Amy, and I were high school sweethearts and have been married 14 years. We have 3 children—Aiden (11), Avery (8), and Addison (5). Aiden was born with bilateral anophthalmia (the absence of eyes) and has profound bilateral hearing loss and other health and development issues. We live in Cameron, Missouri, a rural farming and bedroom community just north of Kansas City and east of St. Joseph. I am employed with the St. Joseph Fire Department as a fire captain.



Captain Boyd Alldredge, Aiden McVicker, and Jamey McVicker.

Like every newly married couple, we had dreams of the perfect family, the perfect life. When our son was born, we were headed down that perfect avenue. My how our lives have changed . . . and we wouldn't have it any other way. Aiden has introduced us to a world we may not have otherwise seen and passionate people we may not have met. He embodies values and characteristics that we hope to emulate. The time I have had with Aiden has helped me develop into a "Man" more than any other experience in my life. I owe it to him, and a strong faith, for making me the better person I am today.

Living in a rural town, it is difficult to acquire the necessary resources to best serve Aiden and his educational and medical needs. This past year, we as a family decided it would be best to educate Aiden at home. With the help of the Missouri Deafblind Project, we pursued a "future planning" approach. Our lesson plans are primarily life-skill based and incorporate community activities and social functions.

The staff with the Missouri Deafblind Project witnessed our passion for the deaf-blind community and encouraged us to participate at the state level, advocating for this population. Thoughts and prayers were given to the idea of serving on the Missouri Special Education Advisory Panel, which advises and recommends policies, procedures, and practices for the Missouri Department of Education, concerning special education. It is comprised of individuals with a disability, parents of individuals with a disability, educators, and administrators. I concluded that it would behoove our family, and others, to fill this need. I applied for a position on the panel and was appointed by the Commissioner of Education the next month.

This position was outside of my comfort zone, but I was willing to step out for my child. I have never been one to put myself in the public spotlight. I do not have a master's degree in education, but I do have a passion for my child. The time requirements were minimal. The panel meets quarterly, and the meetings run approximately 5 hours. Transportation and meals are provided. Going into the first meeting, my stomach was in my throat because of anxiety and nerves. What can a firefighter bring to the table? Firefighters, and dads, fix things. It's just what we do (with a manly grunt). We use our practicality, experience, innovation and our hands. Our family had been thrust into something I couldn't fix. But I felt I could play a role. I could help "fix" the way people think about disabilities and help policymakers better meet the needs of children with disabilities.

Much to my surprise, I found my niche quickly and took a leadership role on the panel. I do have a lot to offer, and it is experience-based. No one knows what families need better than the families themselves.

My experience serving on Missouri's Special Education Advisory Panel has been highly enlightening. I've learned about educational techniques, state and nationwide trends, and new, innovative adaptive equipment and technology. I'm now learning about new legislation coming down the pike. It is very rewarding to receive this knowledge and be able to provide a credible influence for children in our state—all because I was able to step out of my comfort zone. I would encourage anyone who has an interest to pursue a position on their state's panel, and to do so wholeheartedly. Deaf-blind awareness-raising and legislation to benefit children who are deaf-blind need all the advocates they can get because of the low incidence of dual sensory loss. It is a very exciting time for deaf-blind education, particularly involving the development and recognition of interveners—individuals with special training in deaf-blindness who work with children who are deaf-blind and provide access to the environment, communication, and other people. We owe this progress to all the activists who travelled this road before us. Now it is our turn to take the torch and run.

If I had one wish for Aiden's education, it would be for him to have had intervener services at an early age and continuing into adulthood. My hope for all individuals who are deaf-blind is to mimic Minnesota's intervener programming inside the schools and within the community. The intervener role is on the verge of breaking out nationwide, and I hope we all share the same values as the Minnesota deaf-blind community leaders. Should you have questions, concerns, or anxiety about playing a role on your State Special Education Advisory Panel, please do not hesitate to contact me. Wouldn't it be amazing to have at least one representative for the deaf-blind community on *every* State Special Education Advisory Panel? Together, we can collaborate; share our experiences, successes and failures; and make great strides forward for future generations.

Thank you for taking the time to read about my family and our experiences. I know we all have many trials and tribulations, but I wish to share our successes and smiles as well. Too many tears have been shed through the years. Many of them could have been prevented if only we had opportunities to collaborate on effective strategies, as

well as to learn from each others' failures. I would also like to thank NCDB for allowing me this opportunity to share and hopefully motivate others. I have failed many times and in many different capacities in my life. I hope that I have learned from these times and that they have made me grow to know what it takes to be a better dad, husband, firefighter, teacher, activist, student, and son. I would like to share with you a thought of mine that I feel is very true to all life experiences, whether they be academics, athletics, or any other endeavor:

Only failure can leave the motivation to fuel the hard work that produces success. To have had success means to have known and understood failure.

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Improving Connections among Professionals in Deaf-Blind Education

Jon Harding

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Being a connected educator is not simply a desirable add-on to the real work of helping students learn. It is integral to the future of the profession.

—Darren Cambridge (2012)

Recently the U.S. Department of Education sponsored Connected Educator Month (see www.connectededucators.org/cem). Through this month-long initiative, teachers were asked to contribute and engage with other teachers and administrators using Web 2.0 tools such as blogs, Nings, web-conferencing software, wikis, and social media. Why? Because to be effective professionals in the twenty-first century, educators need to learn and support each other by connecting and building shared knowledge. Our children are now part of a global community connected through technology. Professionals need to engage in that world too.

Since 1968, the federal government has funded programs that support educational services for children with deaf-blindness (Thompson & Freeman, 1995, p. 22). Currently, the Office of Special Education Programs funds 52 state deaf-blind technical assistance (TA) projects and one national TA project (National Consortium on Deaf-Blind-

ness). Their purpose is to strengthen the capacity of state educational systems to serve the population of children and youth who are deaf-blind, aged birth through 21, and their families. Although the structure of federal support for this population has evolved over the last 44 years, the importance of keeping educators and technical assistance providers connected has remained constant. However, the ways that they connect, the means by which they connect, and the impact these connections have are changing dramatically.

Aren't Professionals in Deaf-Blind Education Already Connecting?

An argument could be made that our deaf-blind network has been *connecting* for years. Indeed, there are myriad examples of state deaf-blind projects collaborating with one another—holding meetings, sharing resources, developing products, and solving problems of common concern. Project collaborations have most often emerged within geographic regions of the country as, in the past, NCDB structured technical assistance according to four distinct areas of the U.S. In recent years, examples of multi-state cooperation have included a focus on strategies for cortical visual impairment assessment and intervention and a compilation of instructional strategies that are considered to be the best practices for children with deaf-blindness.

These examples are laudable, but large segments of the deaf-blind network still operate largely autonomously and independently of one another. Connecting is something that happens in defined parameters, when schedules, time, and interests are aligned. Many of us connect only when an urgent problem or need is present. We connect to fix our own immediate issue, but often do not see a purpose for connecting with others beyond addressing that immediate need.

The type, intensity, frequency, and method of our collaborations will need to shift dramatically in order to meet the challenges of the future. Specifically, these challenges include increasing demands for accountability; budgetary constraints at local, state, and national levels; an increase in the number of children with sensory losses; the complexity of integrating children with deaf-blindness into inclusive settings; and a loss of expertise in deaf-blindness and leadership caused by retirements.

Connecting now needs to be viewed as an everyday necessity for our work rather than a periodic luxury. Connecting in this new era means

building collective knowledge and experience regardless of geographic location.

Developing Online Models

If we are to redefine how we interact with one another, it is necessary to create models that can be emulated. One example is the Distance Mentorship Collaborative, a connected work group that NCDB has been facilitating for the past six months. The members of this community are personnel from the state deaf-blind projects in Georgia, Kansas, Idaho, Texas, Vermont, Washington, and the New England Consortium states. They are asked to contribute to the development of distance mentorship practices by sharing what they learn *as they implement practices* in their respective states using videos, wikis, and web-conferencing tools to build the capacity of local teams working with children who are deaf-blind. It is an intensive, technology-driven model, and its success is predicated on the development of relationships, the use of proven deaf-blind instructional strategies and content, and the empowerment of parents and local educators. The state deaf-blind projects that are part of this community “meet” asynchronously (at different times) via a Google site that serves as a cloud-based repository for collected wisdom (e.g., experiences, beliefs, questions, discussion, training activities, resources). The projects also meet synchronously (at designated times), via monthly web conferences, to provide updates and share best practices. In this way, a model of collaboration is emerging to address the demands of the future for accountability, efficiency, and knowledge retention.

Members of this community document and share their successes, gain experience in providing TA remotely, and build a collective body of knowledge that can be shared with the rest of the field. Although the projects are required to give more to the community (e.g., time, products) in this new model, they also *receive more* (e.g., affirmation, support, ideas, and resources). By sharing and engaging regularly and intently in a community, they are able to help themselves and others to improve practice and outcomes.

As this community model for connecting emerges, NCDB anticipates facilitating numerous communities that are of interest and concern across the deaf-blind network. NCDB's focused initiatives—Family Engagement, Intervener Services, Early Identification and Referral, and Tech Solutions—are logical starting points, but other communities can emerge from the field. Hosting

these communities in one online location makes it easy for projects to determine where and how they might best contribute their knowledge, experience, and resources. The online community models encompass more than just content or knowledge. They also promote and share the implementation of good content. Examples of best practices can be showcased and provide other practitioners with activities to emulate.

Facilitating and Supporting Online Connections

Creating active, viable, meaningful online connections requires active facilitation, especially in the beginning. As online communities form and develop, NCDB proposes to take an active role in creating spaces where members feel welcome to contribute. The presumption is that everyone has something to add to a safe, community space where dialogue and respectful debate are encouraged. As communities evolve, facilitators may emerge from within. Participants can contribute on different levels, in different ways, and at different times, but there should be a sense of commitment to contributing to the advancement of the community.

There is a reward in belonging, in having an identity, and in contributing to a larger effort. We no longer need to operate independently, autonomously, or anonymously. In fact, if we are to improve practice and outcomes in deaf-blind education, we must find ways to extract, catalogue, and facilitate our collective knowledge and expertise across the network.

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NCDB Plans for A New Nationaldb.org Website

Gail Leslie

National Consortium on Deaf-Blindness

When we turn on our computers, launch our browsers, and head out to the Web, we enter into an environment that is constantly evolving and changing. Each year, new technological innovations produce dramatic changes in the look and function of what is offered on the Internet. Cloud technology, mobile applications, social media, and the ability to deliver highly personalized experiences of the Web create new possibilities for our personal and professional online spaces. In 2013, NCDB will launch a new website at nationaldb.org. Consistent with the Office of Special Education Programs' emphasis on the development of a more efficient and collaborative network of deaf-blind technical assistance projects, this new site will be interactive and user centered. It will offer our community more opportunities to work together to develop and share resources and practices.

The new site will still house the deep content knowledge in deaf-blindness gathered by DB-LINK and NCDB over many years, but the presentation will have a different look and feel. Front and center, the homepage will sport a prominent invitation to create a user profile. While it will not be necessary to have a profile to access much of what is available on the site, users who do have a profile will be able to keep track of network contacts, post user comments, participate in forums, forward information to social media accounts, join in on online collaboration workspaces, and bookmark their favorite resources. With bookmarking, users can tag articles, videos, and web links and organize them in their profile space. This will allow them to curate a personal collection of site resources and share them—via email or a URL—with others such as colleagues and family members.

The new website will also take a big step forward in offering a selection of tools for use in online collaboration workspaces. These tools, including forums, wikis, walls, and file managers, will help individuals who are part of the deaf-blind network to maximize resources as they work to meet the needs of children and their families. These tools have the potential to create a new kind of democracy across the network. Users move from simply being consumers of informa-

tion to being producers of information, sharers of experience, and shapers of perspective. Potentially our traditional boundaries of geography, time, and affiliation may fade away, equalizing not just access to information about deaf-blindness, but access to working communities of users—parents, practitioners, and students. One of our site reviewers, when asked how she might describe the new site prototype, responded, “I like that I can access not just materials, but other people’s brains.”

If We Build It, Will They Come?

These innovations and changes come with challenges. This is not just the transformation of a national project website. A cultural renovation must take place as well through the cultivation of an online community. For the network to develop, people must be willing to engage as participants who together create a vibrant culture of exchange and take seriously their responsibility to share their knowledge and experience. With already busy schedules, how do we build relationships online that make a difference in addressing national needs? The U.S. Department of Education is involved in similar efforts to engage educators in online communities of practice. The Connected Educators Project (www.connectededucators.org) and the IDEA Partnerships with SharedWork.org (www.sharedwork.org) are trying to inspire educators to get connected, improve educational practice, and share their experience and expertise. Both argue that utilizing technology to expand connections among educators is integral for the future education of all students.

The constellation of individuals and organizations that is the deaf-blind community has shifted and redefined itself over the course of many years. In the 1970s it was a network of regional centers, which became a network of state projects in the 1980s and then expanded with a national clearinghouse, research projects, and family organizations in the 1990s. Over the last 10 years we have added a growing cadre of students and practitioners. It remains part of our history and part of our cultural evolution to take advantage of new technologies to move forward and improve the lives of children. In 1992 at the National Symposium of Children and Youth Who Are Deaf-Blind, Mike Collins spoke eloquently about the educational needs of children who are deaf-blind and the national supports needed for adequate service. He called for the formation of a national network, grounded by a national clearinghouse that would “become a pivotal point in our relationships

across state boundaries” (Collins, 1992, p. 174). This must, he continued, “become a vehicle by which professionals, parents, and consumers can be linked together, informed of each other’s efforts, updated about literature in the field, and galvanized to act in mutual support.” Twenty years ago, Mike Collins was talking about the value of a network when our tools for galvanizing were face-to-face meetings, a toll-free telephone number, a clearinghouse to organize our knowledge base, and something on the horizon known as e-mail. We have come a long way, and technology is offering us new opportunities to galvanize to even greater effect. Let’s promote and use our new nationaldb.org website to travel even further down the road.

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Early Identification and Referral: Partnerships in Action

Heather Herbster

Ohio Center for Deafblind Education

Editor’s Note: The Ohio Center for Deafblind Education (OCDBE) was one of ten state deaf-blind projects that participated in a field review of the *Early Identification and Referral Self-Assessment Guide*, a tool developed by NCDB to assist state deaf-blind projects in the evaluation and planning of their efforts to identify children who are deaf-blind from birth through age 2. The feedback provided by the state projects played a critical role in ensuring the guide’s quality and relevance for use by the national deaf-blind network. The NCDB Early Identification and Referral Team thanks Heather Herbster for contributing this article that describes the OCDBE staff’s experiences using the guide.

For the past several decades in the U.S., the process of identifying children who are deaf-blind has been a driving force in the provision of high quality services for them. Child count data collected by state deaf-blind technical assistance (TA) projects guide service delivery and provide important information about this population of children at the state and national levels. Each year, the network of state TA projects works to improve its data reporting processes so that the variety of characteristics of children with combined vision and hearing loss

can be reflected in the most accurate way. And, in an effort to continue improving upon this process for young children with deaf-blindness, NCDB has adopted early identification and referral as one of its national initiatives.

As project coordinator of the Ohio Center for Deafblind Education (OCDBE), I understand the challenge of identifying children with deaf-blindness. OCDBE has made great efforts to increase awareness of deaf-blindness among individuals who work within state systems and local communities, to help them better understand what the term *deaf-blindness* means and the impact that deaf-blindness has on a child's life. We were thrilled to be approached to be a review state for NCDB's new data-based *Early Identification and Referral Self-Assessment Guide*, which was developed as part of its Early Identification and Referral Initiative.

The guide is based on prior work by NCDB—in collaboration with state deaf-blind projects—that involved careful review of existing evidence-based practices regarding early identification and referral and formation of focus groups composed of state deaf-blind project personnel. With the aid of state-specific data collected over the span of 5 years, a state deaf-blind project can use the guide to determine whether young children who are deaf-blind are being adequately identified and referred to their project. For our staff, the self-assessment design offered a new perspective on existing data that had been collected over a number of years.

The guide consists of six parts that collectively comprise a detailed framework for understanding and addressing early identification and referral challenges. The following discussion of each part provides an overview of the process from OCDBE's perspective as a review state.

Part 1: Review of Data

Part 1 of the guide consists of five tables. The first four are used by state deaf-blind projects to compare their own state's deaf-blind child count data for children from birth through 2 years with (a) national deaf-blind child count data, (b) federal and state counts of all young children with disabilities (Part C counts), (c) their own state's child count across age groups, and (d) their own state's count of young children over time. The tables allow for simple calculations and comparison of data over the previous 5 years. The fifth table is designed to aid in the examination of regional data to assess whether children are being identified and referred from all geographic areas within

the state. We used the table to evaluate differences among regions within Ohio's established regional educational service delivery system.

Part 2: Determination of Need for Improvement

In this section, data from Part 1 is used to ascertain whether a state's deaf-blind project staff believes there is a need to improve identification and/or referral within that state. Using seven indicators of potentially low counts of young children, users of the guide are asked to reflect on the question "Does it seem that the Deaf-Blind Child Count for age groups less than 3 years is lower than it should be?" Based on the criteria offered within the guide, we were able to affirm that a number of indicators associated with possible under-identification and under-referral are present in Ohio.

Part 3: Review of State Systems

Part 3 is used to examine current early identification and referral efforts conducted by a state deaf-blind project and other entities within a state. The other entities are programs and services that have been identified by previous research and practice as important partners in the identification and referral of young children who are deaf-blind or have other disabilities. They are part of existing state systems that focus on infants and toddlers, such as Part C programs, the medical community, Early Hearing Detection and Intervention programs (EHDI), and other community outreach programs. For each, the guide asks open-ended questions about factors that are likely to influence identification and referral efforts. For the Ohio self-assessment, this subjective section required the most time to complete because we contacted representatives from each group via phone and e-mail to verify that we were reporting accurate information.

Part 4: Under-Identification Analysis and Part 5: Under-Referral Analysis

Parts 4 and 5 focus on identifying possible causes of and solutions for under-identification and under-referral. Each includes three subsections that examine (a) whether under-identification or under-referral is a challenge in the state, (b) whether each of the systems reviewed in Part 3 is adequately identifying children with combined vision and hearing loss, and (c) potential challenges that could be the focus of future identification and referral efforts by a state deaf-blind project. The latter subsection utilizes a matrix that lists potential

systems to target across the top and potential explanations for under-identification or -referral down the left-hand side. For each entity, the user is asked to indicate whether a number of potential explanations for under-identification are applicable. The possible response options are “yes,” “no,” and “unsure.” Because we felt somewhat uncomfortable with the subjective nature of the questions, our staff at OCDBE completed the matrix separately and then met to compare our responses. It was, after all, these responses that would be totaled to develop our action plan.

We shared the matrix with our state project’s advisory board for review and discussion. I recommend this approach for all future users of the self-assessment guide because it allows for broad stakeholder input into the review. We had previously provided the board with materials about our partnership with NCDB’s Early Identification and Referral Initiative and they had attended an online presentation by the initiative’s team leader, Barb Purvis. As a result, our meeting to discuss identification and referral of young children with deaf-blindness in Ohio was very lively. Based on agency affiliation, board members were assigned to one of two discussion groups. This allowed for broad representation across the potential systems to be targeted, including Part C early intervention programs, hospitals and medical centers, EHDI programs, and community programs serving children from birth through 2 years of age. We compared our own responses with those of the board members and prioritized the areas that could be addressed in the future.

Part Six: Developing an Action Plan

The final section of the self-assessment framework provides step-by-step instructions for developing an action plan using the information generated in Parts 1 through 5. A nice feature of the action plan is that it allows users to develop state-specific strategies to address under-identification and under-referral with evidence-based methods identified by the Tracking, Referral and Assessment Center for Excellence (TRACE; www.tracecenter.info).

The opportunity to be a partner in the NCDB Early Identification and Referral Initiative has been an honor for OCDBE and a pleasure for all of our participating staff members. The guide’s data-based model framework enabled our project to conduct a comprehensive review of our child count data and caused a shift in perspective toward a more targeted approach to early identification and referral efforts. As a result, our staff has

been able to work efficiently with key partners in Ohio on efforts to achieve this shared goal that will improve the lives of the children and families that we serve.

The Ohio Center for Deafblind Education is a project of the University of Dayton School of Education and Allied Professions Grant Center.



Reflections from the Field

In this column, we ask experts in the field of deaf-blindness to share their thoughts on important issues. In this issue, we feature Kathee Scoggin from Washington State Services for Children with Deaf-Blindness. Kathee graduated from the Deaf Education Program at the University of Cincinnati in 1966 and later obtained a master’s in education degree from the University of Arizona. She has worked as a teacher of children who are deaf and deaf-blind, a principal at the Arizona State Schools for the Deaf and Blind, and was an instructor in the area of communication for students with deafness at the University of Arizona. For the past 19 years, she has been at Washington State Services for Children with Deaf-Blindness as an educational consultant and co-director. We asked her to respond to the following questions:

What is your perspective on the current 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?

Kathee Scoggin

There is one change that I have seen over the last two years that concerns me greatly. Because of changes in school funding in this time of economic difficulty, I have seen services for children who



are deaf-blind decrease, especially services provided by highly qualified paraprofessionals. There is more information for schools about the needs of children who are deaf-blind than ever before: resources provided by the few existing training programs for interveners and teachers, live and

recorded webinars on many websites, a myriad of information and links on the National Consortium on Deaf-Blindness website, and videos demonstrating strategies for working with deaf-blind children. School staff members have the desire to use this knowledge to work effectively with their students who are deaf-blind, but the amount of individualized time they have available to spend with students has lessened.

As I reflect on these last ten years, however, I have also seen many positive changes. It occurs to me that in the field of deaf-blindness we make progress by working as though we are running a marathon, not a series of 50-yard dashes. I am speaking as one humble person among thousands of more highly skilled and committed people serving the needs of children who are deaf-blind. As I think about the current status of the field, my "filter" is as a lifelong learner, a teacher, an assessment specialist, a university instructor, a principal, and, currently, as a deaf-blind specialist. I have had the good fortune to know and work with children, families, and service providers who have the creativity, desire, skills, and heart to carry on the marathon. As a result of this collective marathon we are all running, I think that there have been many positive changes for children with deaf-blindness and their families over the past decade. Here are some that I've observed:

1. Because of the increase in the number of students with disabilities who attend public school, there are many more young people today who have known a child with deaf-blindness. I meet them in the community as adults. I know of a produce manager at a grocery store, for example, who provided a student with deaf-blindness with a vocational training opportunity that became a job after graduation. Individuals like him may not have all the techniques that educators or rehabilitation specialists have to help an individual with deaf-blindness achieve his or her potential, but they have the heart to welcome those children or adults into the community as full members, not with pity but with expectations.
2. More families of children with deaf-blindness have knowledge about deaf-blindness, are involved in their children's education, and understand their children's needs. I have seen an increasing number of families visiting other school districts to look at education program options.

The Internet and programs like Skype and GoToMeeting allow families to connect with each other and share photos and videos. This

has required a change in the attitude of some professionals who are most comfortable in the role of "expert." A skill all professionals need to master is how to listen and how to ask questions that get to the heart of a child's needs. Sometimes we are afraid of quiet spaces during meetings, but they provide opportunities to reflect on what a family member or professional is saying. Removing the word *but* from all discussions would be a good start. I think there are more professionals listening closely to the needs of children and families than ever before. I know that if I don't listen, my arrogance can be damaging to a child's future.

3. More families understand the joy of communicating with their children in a variety of ways that may not yet be considered "language." When IEP goals are developed, a family may know more about their child's communication than the professionals and be able to better describe how he or she communicates and relate that to suggested IEP goals. I've noticed that more parents come to meetings these days already prepared with goals of their own. A parent recently said to me, "Now that my son is losing skills, I just want to be able to communicate with him, know how he feels, and know that he knows I am here with him."
4. There are many knowledgeable people in this field who share their expertise with others through their teaching, writing, research, and leadership, and they are leaving a legacy for all who follow. Collectively the field of deaf-blindness has developed an extensive body of knowledge that is the result of decades of work with children, youth, families, and service providers. This collective body of knowledge has a firm basis and is continually changing and growing.
5. There are more educational service providers asking questions about communication for children who are deaf-blind. As a result, I see many children communicating at a more complex level than before. Communication development continues to be the focus for these children because it is the basis for learning.
6. There are many professionals who have taken on learning how to work with children who are deaf-blind with great enthusiasm and intelligence. The progress of their students shows that clearly. Many are also learning the value of distance technology and share videotapes of their students to learn how to improve or change strategies so that the student can prog-

ress, as a whole person, not just one IEP goal at a time.

My life's goal has been, and still is, to assist individuals who are deaf-blind in reaching their potential. Sometimes I know that I and others have made a difference. Even when I didn't have the "data" to show it, many of the children and adults I've worked with or observed have been successful and made progress almost no one expected *as long as* they had people surrounding them that they could trust who were consistently connected with them, open-minded, using instructional strategies that work, and doing no more for an individual than he or she needed.

My own role as a deaf-blind specialist has changed over the last 5 to 10 years, and that means I've had to change. I review my purpose each time I provide technical assistance on site or at a distance. I always ask myself, "What will move the student's educational team forward so that the student can make progress?" If the same IEP goals have been repeated month after month and year after year, I become a historian, reminding the educational team and family that in order for a child to learn he or she needs meaningful, achievable goals that lead to progress.

I've also changed the way I conduct training activities. I am still changing and know that more changes are in store for me, especially now that I am providing technical assistance from a distance. Large group workshops or presentations can capture an educator's attention and motivate him or her to try new ways of working with a child, but that is only the beginning. Without follow-up from someone who can help that educator use instructional strategies correctly and consistently, we may hear him or her say later, "I tried that, but it didn't work." I still do training, but attempt to do it more often with smaller groups who have a mutual topic, and often through a distance technology program. When several teams participate in training at the same time on a topic that is relevant to each of their students, cross-pollination occurs that strengthens all of the teams and ultimately the children who are deaf-blind.

At a broad level, I and many others work for all children with deaf-blindness who are in this marathon. At the same time, I do my best not to lose sight of individual children, families, and service providers. There are times when I falter, especially when I encounter barriers to a child's progress that dampen my enthusiasm. However, I simply need to remember the children who are deaf-blind that I am serving and the assistance that helps them progress, and I am back in the race.

I want to thank the many children and adults who are deaf-blind, their family members, and professionals in this field for their encouragement and generosity in teaching me over the years. June Downing, Jim Durkel, Diane Kelly, and Harvey Mar are four people who have run the marathon and will continue to influence how we assist children who are deaf-blind. Though they have hit their own finish line with arms raised and joy on their faces, they offered many of us encouragement along the way and even a "kick in the pants" when we needed it. We all know the stakes are high and the children deserve our best.



Moving Forward with Intervener Services Recommendations

Development of Intervener Training Modules

Peggy Malloy, Amy Parker, and Jay Gense
National Consortium on Deaf-Blindness

In recent years, the provision of intervener services to young children and students with deaf-blindness has been an important topic of discussion and the focus of advocacy efforts across the nation. The purpose of these services is to provide access to sensory information that would otherwise be unavailable to individuals whose vision and hearing are severely limited or absent. Although people who are deaf-blind may benefit from intervener services at any age and in any setting, the growth of these services in the U.S. over the past two decades has focused primarily on their use in promoting a child's learning and development in educational settings. A skilled intervener—an individual who has received specialized, in-depth training in deaf-blindness and works one-to-one with an infant, child, or youth who is deaf-blind—can facilitate a child's access to environmental information, support the development and use of communication, and promote social and emotional well-being (Alsop, Blaha, & Kloos, 2000).

In July 2012, the National Consortium on Deaf-Blindness (NCDB) released recommendations for improving intervener services for children and youth who are deaf-blind from birth through age 21 in the United States (NCDB, 2012a). These recommendations, developed in re-

sponse to a request from the U.S. Department of Education's Office of Special Education Programs, were based on information gathered from an extensive data collection process and from NCDB-facilitated discussions with multiple stakeholders—family members, state deaf-blind project personnel, interveners, teachers, university faculty members, and administrators.

Now that the recommendations have been completed, the next step for NCDB, state deaf-blind projects, other professionals, and family members is to join forces to make the achievement of the recommendations a reality. One of the first major activities addresses the third of the ten recommendations, the development of open access intervener training modules that can be used to increase the number of high-quality intervener training activities across the U.S. The modules will be aligned with the Council for Exceptional Children's (CEC) Specialization Knowledge and Skill Set for Paraeducators Who Are Intervenors for Individuals with Deaf-Blindness (2009). They are likely to be most useful to colleges or universities as they begin, update, or expand intervener training programs and also to state deaf-blind projects who can use them to enhance their ability to (a) develop in-state intervener training programs, (b) conduct activities to supplement university training programs, and (c) provide continuing education to interveners.

Why Training Modules Are Needed

Prior to developing the recommendations, NCDB conducted a number of surveys and interviews to gather data about the current status of intervener services across the country. One of the things we learned is that there are currently a number of excellent intervener training programs in the U.S., including two university-based online programs. Both universities offer distance-learning courses and are available to out-of-state students for a relatively low cost. At the time we collected data, approximately 20 state deaf-blind projects reported that they provide support via tuition stipends, on-the-job coaching, and annual face-to-face workshops to some interveners-in-training who are enrolled in one of these university programs. In addition, six state deaf-blind projects reported operating their own in-state training programs. Each of these training models—online university courses with local support from state deaf-blind projects and comprehensive programs operated by state deaf-blind projects—are highly valued in the field (see table).

Percent of Survey Respondents who Rated the Following as Effective Training Methods		
Type of Training	State Deaf-Blind Project Personnel (n=58)	Educational Administrators (n=32)
Child-specific training for intervener & team + large group training	78%	83%
University or college coursework + support from state deaf-blind project	72%	66%

Despite the existence of these programs, there is still a crucial need to expand opportunities for intervener training in the U.S. Our data indicate that approximately one-half of states do not have formal intervener training programs, either operated by the state's deaf-blind project or in collaboration with one of the online university programs as described above, and only small numbers of interveners have been trained in the majority of states. In our survey of state deaf-blind projects, NCDB asked respondents how many children on their state's count of children with deaf-blindness receive intervener services. Of the 42 states that responded, 9 reported that they did not know the number with another 7 states identifying that no children had interveners. The total number of children reported to have interveners in the remaining 26 states was only 391. Currently, approximately 10,000 children (from birth through age 21) have been identified as deaf-blind in the U.S. (NCDB, 2011).

State deaf-blind projects have limited resources to develop intervener training materials. Only 15% of the project representatives that responded to our survey reported that their projects had sufficient funding for this purpose and only 20% that they had enough time. They also indicated a strong need for these types of materials:

- ◆ 46% rated having a "standardized training program that our state deaf-blind project could use for intervener training" as very important, and
- ◆ 78% rated having "easily accessible online intervener training modules on a variety of topics" as very important.

Module Development Process

In order to meet the ambitious goal of providing all states with access to high-quality intervener training materials, NCDB is partnering with members of the deaf-blind network, as well as experts outside the field of deaf-blindness who have expertise in module development, to produce and evaluate a foundational set of training modules by the end of June 2013. Using a participatory development process, NCDB will collaborate with university faculty, state deaf-blind projects, family leaders, interveners, teachers of the deaf-blind, and young adults who are deaf-blind who have been involved in supporting and sustaining the use of intervener services.

NCDB has built a coalition of teams of advisors, module leaders, and module contributors to share their expertise regarding how individuals gain the knowledge and skills needed to become effective interveners. By building modules based on the rich and collective knowledge of those who have a history of investing in intervener training, we aim to create materials that synthesize the network's best practices at this time. Alignment of module content with the nationally recognized CEC standards (2009) will help ensure that they incorporate skills and knowledge that interveners need to work effectively with children who are deaf-blind. After the draft modules are completed, NCDB will partner with field participants and field reviewers to evaluate the modules and further refine and revise them.

Our hope is that the open access training modules will provide an important resource for the expansion and development of intervener training programs so that a sufficient number of well-trained interveners become available for children who need intervener services.

Responsible Use of Modules

NCDB's initial data collection process also identified potential challenges associated with the development of open access training modules, and concerns about these challenges have been echoed by a number of stakeholders since the recommendations were released. First, there is the potential for inadequate implementation of the modules if they are used by individuals, agencies, or organizations that lack expertise in deaf-blindness. To minimize this possibility, the training modules will be accompanied by a companion document that (a) includes advice about the expertise required of instructors who use the modules, (b) describes how they should be used, and (c) provides

tools for trainers to measure the quality of implementation. Additional ideas such as the creation of tools to support local instructors, the building of new modules based on emerging evidence from the field, and work by the deaf-blind network to guide individuals who are new to deaf-blindness to in-state experts or resources will all be a part of the ongoing dialogue within the network about module development and use.

Second, as noted above, at the present time there are essentially two accepted intervener training models:

1. programs operated by state deaf-blind projects that typically train interveners to serve in their states and
2. online programs offered by universities that are available to out-of-state students.

The training modules being developed will be a useful resource for both. However, because deaf-blindness is an extremely low-incidence disability and children are widely dispersed, it will be important to ensure that new programs, particularly any programs available to students in more than one state, attract a sufficient number of students to make the programs sustainable. Professionals within the field of deaf-blindness will need to collectively plan new programs to avoid weakening the current excellent programs that serve as an important resource for many. As new programs become available, a challenge will be to make sure there are enough, but not too many.

Conclusion

As recognition of intervener services increases, their use is likely to expand dramatically. It is crucial that the field of deaf-blindness prepares for this increase by strengthening the current system of intervener training. National open access training modules, created by leading experts in the field of deaf-blindness, would support the consistent expansion of training opportunities across the country.

Development of training modules is just one of ten recommendations found in the report *Recommendations for Improving Intervener Services* (NCDB, 2012a). Collectively, the ultimate goal of the recommendations is to promote positive developmental and educational outcomes for children and youth who are deaf-blind, from birth through age 21, by improving both the availability and quality of intervener services throughout the United States. Recommendation 3 asserts that an essential component of these services is the sufficient avail-

ability of high-quality training opportunities. Its goals are for every child who requires intervener services to have them available and to receive them from interveners who have a core set of knowledge and skills obtained through a high-quality training program. The process of developing intervener training modules represents an opportunity to work together to create a resource that can support all states in meeting current and increasing demands for interveners. We support inclusion of intervener services as a related service under IDEA and believe that intervener preparation is best approached using our collective strengths to address national training needs. Many students who are deaf-blind need interveners as a support for participation in schools. To paraphrase Helen Keller, NCDB looks to the participation of contributing partners so that we can all accomplish more together than we may do alone.

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“I Can Connect!”

The New National Deaf-Blind Equipment Distribution Program

Betsy McGinnity
Perkins School for the Blind

Sending an e-mail or text, checking the weather forecast online, or searching for the best price for that new gadget are things that most of us do each day without much thought or effort. It's just part of life in the 21st Century. For individuals with combined hearing and vision loss, however, these tasks may not be so easy. In order to successfully access the same distance communication technology and services as hearing-sighted people, those who are deaf-blind often require specialized equipment and training. The equipment is often expensive, and the training can be hard to find in many areas. Fortunately, there is a new program to address these challenges—the National Deaf-Blind Equipment Distribution Program (NDBEDP), sponsored by the Federal Communications Commission (FCC) to help people who are deaf-blind achieve their distance communication goals.

The NDBEDP was established as part of the landmark 21st Century Communications and Video Accessibility Act (21st CVAA), a wide-ranging law passed by Congress in 2010 that is designed to ensure access by people with disabilities to all aspects of modern communication. Recognizing that deaf-blindness leads to significant barriers in communication and video access, the framers of the 21st CVAA included a section mandating the FCC to establish the NDBEDP and authorized spending up to \$10 million annually for equipment and training for individuals who are deaf-blind. The funding is allocated to states based on population.

It took several years and leadership from Congressman Ed Markey and other lawmakers to pass the 21st CVAA. Advocates, including individuals who are deaf-blind, were intensely involved in persuading Congress to pass the law and also provided input to the FCC as it developed the rules that will govern the NDBEDP. To their credit, staff at the FCC conferred with individuals who are deaf-blind and other interested parties for months to develop the rules and carefully considered the feedback they received from consumers, families, and service providers. Because there was no precedent for such a program and there were a num-

ber of issues upon which no real consensus could be reached, the FCC decided to initiate the NDBEDP as a 2-to-3-year pilot program. Final rules will be established after the pilot phase has been completed.

As part of the pilot program, the FCC invited organizations and agencies in each state to apply for certification as the state entity that distributes equipment for the NDBEDP. Although only one entity in each state could be certified, applicants were encouraged to form partnerships to carry out the program. Applications were submitted in November 2011, and the equipment distribution entities were selected on July 2, 2012.

The FCC also invited applications for participation in a national outreach program to raise awareness of the benefits of this new initiative throughout the U.S. Perkins School for the Blind (Perkins) in partnership with the Helen Keller National Center for Deaf-Blind Youth and Adults (HKNC) was awarded this grant, which began July 1, 2012. NDBEDP is being marketed as iCanConnect (www.iCanConnect.org). Perkins, in partnership with HKNC, took a leadership role in helping a large number of states develop their applications and deciding how best to establish the deaf-blind equipment distribution in their states. Perkins and HKNC are also designated as the certified equipment distribution entity in 10 states, Puerto Rico, and the U.S. Virgin Islands, and they serve in a supportive role in 18 additional states.

Through iCanConnect, eligible individuals can get equipment that enables them to use telephone communication, access the Internet, and use what the FCC refers to as “advanced communications” (e.g., Internet-based voice communication, e-mail, instant messaging, and video conferencing services) (FCC, n.d.). Equipment covered includes hardware and software applications that may be either specialized equipment or “off-the-shelf” items, such as smart phones and iPads. The FCC did not establish a list of approved types of equipment, but any equipment provided must support distance, not face-to-face communication. It is anticipated that most solutions will be customized for each eligible individual. The type of equipment needed by a specific individual will be determined through an assessment of his or her communication goals. As technology changes, more effective and creative solutions will be incorporated.

In order to be considered eligible to receive equipment and training, an individual must meet the following definition of deaf-blindness as established in the Helen Keller Act: “In general, the individual must have a certain vision loss and a

hearing loss that, combined, cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation (working)” (FCC, n.d.). Individuals must also have an income that does not exceed 400% of the federal poverty guidelines. There are no age restrictions or work requirements. It is important to remember that the equipment is to be used only by individuals who are deaf-blind, not by their family members or service providers. For a detailed description of the program see <http://www.fcc.gov/guides/national-deaf-blind-equipment-distribution-program>.

In some instances, if an individual has significant vision loss, the ability to read Braille may be necessary. That said, it is important to note that a person who uses pictures or gestures to communicate and who is able to use a service like Skype to chat with a distant family member may be eligible. In establishing the rules for the program, the FCC sought to include as many eligible consumers as possible. It is expected that one of the largest groups that will benefit is that of individuals who have lost hearing and vision as a result of aging. They may be experienced in using advanced telecommunications technology but have been cut off from using it because of sensory loss.

Distribution entities in several states have already started to process applications for equipment from individuals with deaf-blindness and verify their eligibility. Once an individual is deemed eligible, he or she will meet with an assessor to discuss his or her communication goals. The assessor will help individuals identify equipment to support those goals and test sample equipment. When the assessment is complete, the equipment will be ordered. When the equipment is delivered, a trainer will be sent to install it and train the consumer to use it. Recognizing the great diversity in the population of individuals with deaf-blindness, the FCC did not set any limit on the number of training hours.

In recent decades, technology has vastly expanded the way most people communicate through voice, data, and video services, but the high financial cost of this technology and associated training for individuals with combined vision and hearing loss have prevented equal access to it for people who are deaf-blind. The goal of the National Deaf-Blind Equipment Distribution Program is to address this imbalance by ensuring that every person with combined hearing and vision loss has access to modern telecommunication tools and the training necessary to use them, thus granting each the opportunity to interact with the

world as an involved, contributing member of society. To learn more about this program, visit iCanConnect.org or call 1-800-825-4595.

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Remembering Colleagues Who Passed Away in 2011–2012

Editors' note: In 2011 and 2012, the field of deaf-blindness in the U.S. lost four amazing individuals—Jim Durkel, June Downing, Diane Kelly, and Harvey Mar. All died much too young, but while they lived each had a profound impact on children who are deaf-blind and their families. Each has left a legacy that will inspire and inform their contemporaries in the field of deaf-blindness and generations to come. We asked colleagues and friends to write remembrances.



Jim Durkel

By Cyral Miller

On Monday, May 28, 2012, Jim Durkel passed away from multiple myeloma cancer. Jim worked at the Texas School for the Blind and Visually Impaired

(TSBVI) for more than 20 years. He held numerous positions at TSBVI including classroom teacher, deafblind outreach teacher, and statewide staff development coordinator. He was also the coordinator of American Printing House for the Blind materials for TSBVI, the annual registration of children with visual impairments in Texas, and the Texas Deafblind Census. These many roles and titles, however, do not fully reflect the countless ways he assisted children, families, and his colleagues at TSBVI and across the country. He was a frequent presenter at conferences and workshops, a collaborator on the development of web-based

training materials, and a go-to resource for people across the country.

Jim had deep knowledge of an impossibly wide range of areas. He was an accomplished audiologist and speech language pathologist before he joined the field of visual impairments and deaf-blindness, where he became an outstanding resource on language development and communication issues. His talent for synthesizing complicated information to increase understanding of children's needs was awe-inspiring. He wrote numerous articles for the *Texas SenseAbilities* newsletter and created TSBVI's first online training module (www.tsbvi.edu/course), which was designed to help new mentors of teachers and orientation and mobility specialists develop basic mentoring skills prior to engaging in direct training. Jim also shared his knowledge widely beyond TSBVI via modules now posted on the Perkins website, the NCDB website, and others. He was instrumental in developing the Pathways to Literacy website co-produced by Perkins and TSBVI (www.pathstoliteracy.org).

Jim was a wonderful colleague who made extensive contributions to the field of deaf-blindness. His friendship and professional expertise will be sorely missed.

June Downing

By Stephanie MacFarland



June Downing lived and taught by example. She held high expectations for all, from students with multiple disabilities and deaf-blindness, to students in her teacher preparation programs, to her colleagues in the field, and to the many people to whom she presented nationally and internationally. June exuded optimism and fortitude and was passionate about, and a strong advocate for, educational practices that presumed learner competence, inclusive education, family involvement, collaborative teaming, and positive behavioral support. She always saw opportunities for learning for every student and asked "Why not?" when barriers or challenges arose. And if the question "Why not?" was answered with more excuses, "I don't know" or "cannots," she creatively and mindfully gave ex-

amples to show how something could be done with dignity, meaning, and timely humor.

We are fortunate that June was an educator as well as a scholar because she published 9 books, 13 monographs and curricula, 14 book chapters, and over 38 articles. She left us a rich collection of systematic instructional strategies to teach students with multiple disabilities and deaf-blindness how to communicate, learn academic and social skills, and become self-determined. She gave us clear pictorial and descriptive examples of how to adapt core curriculum and teach literacy skills that parents, teachers, and other practitioners could collaboratively and individually implement. June was greatly appreciative of the families she came to know and the teachers who graduated from the special education preparation programs she directed at the University of Arizona and California State University, Northridge, during her career. They directly impacted the ultimate goal of education in June's vision for students with severe and multiple disabilities: "to have the highest quality of life with friends and meaningful activities."

Diane M. Kelly

By Peggy Lashbrook



Diane Kelly, project director of the Maryland state deaf-blind project, Connections Beyond Sight and Sound, passed away on August 21, 2012, following a courageous and inspiring 2-year battle with small cell neuro-endocrine cancer. Diane's

generous and gracious spirit, evident in all of her efforts for children and youth with deaf-blindness, their families, and supporting professionals had a profound and lasting impact on many in our field.

Diane, an alumna of Penn State and the University of Maryland, joined the Maryland project in 1990 as its project coordinator and became director in 2001. Those close to her work from even the earliest years talk of her passion and expertise in providing child-focused and family technical assistance and her ability to garner collaborative support and respect from team members with diverse points of view. She managed to skillfully balance the roles of foot soldier and administrator, both so crucial in the provision of quality technical assistance, and she gave generously to the field of

deaf-blindness, sharing her time, energy, and skills on many national and regional initiatives.

As people learned of Diane's passing, her legacy became immediately apparent. Hundreds of individuals from across the country shared stories of her impact on their work, both professionally and personally. Many spoke of her genuine welcoming and supportive spirit, her expertise, her incredible work ethic and sense of humor, and her unwavering commitment to making the lives of children and youth with deaf-blindness and their families better. To her very last days she was actively engaged in that pursuit. She is survived by her parents, siblings, and two children—Lauren and Brendan, the absolute lights of her life—and by many friends.

While our friend and colleague was taken from our midst far too soon, her gifts to all of us far outweigh the years we shared. Even in her untimely illness she gracefully and quietly continued to teach life lessons about being positive, grateful, and inviting, as well as about sharing and celebrating community. As we move forward, may we, as a community, honor Diane by supporting each other and continuing our work on behalf of children and youth with deaf-blindness, a passion that fed her very soul.

Harvey Mar

By Nancy Sall



Harvey Mar was many things to many people. He was a brilliant and insightful psychologist, a dedicated researcher and eloquent writer, and a quick-witted and caring friend.

As a professional, he aimed for perfection in his work—from evaluations to grant applications and everything in between. And he expected the same from everyone around him. His perfectionism affected my work very directly. Years ago, I worked with him on deaf-blind projects while also working toward my degree. I had already jumped through all of the required hoops with the readers of my dissertation, and then . . . enter Harvey. On the day of my dissertation defense, he came in with his copy, marked with Post-it® notes indicating changes he thought were necessary. After it was over, one of the other readers came back to me and said not to bother, the changes were so miniscule that they wouldn't matter; that he wouldn't read it again and he would never know.

But I knew that he would, in fact, read it again. It was the difference between something being really good and something being really great, and I made those changes.

Harvey had the same influence on the field of deaf-blindness. He raised the bar with regard to dynamic assessments, understanding children, and collaborating with parents and educators. Many parents talk of his calming influence and the tireless passion with which he approached his work.

Harvey also had a passion for life. After cramming to get grant proposals in before midnight deadlines (running to the post office on 34th Street in Manhattan at 11:45 pm), he was known to play hooky the next day. At conferences or project director's meetings, he always ended up in the bar with a group of colleagues followed by dinner where he delighted in the likes of escargot. He took great joy in these and other simple pleasures.

His greatest joy, though, came in being a father. It changed him, and changed his priorities. He was an exceptional father who always made time for Julia and Tessie, whether for pick-ups from piano lessons or drop-offs at violin lessons, making dinner, or helping with homework.

Harvey was a stalwart mentor and friend. He led by example (how I sympathize with my students when I see their eyes widen as I return their papers with Post-its on far too many pages). Harvey died suddenly on May 17, 2012, taken too quickly for anyone to understand. He touched the lives of many, and we are all better people for having known him.



For Your Library Publications

Recommendations for Improving Intervener Services

National Consortium on Deaf-Blindness, 2012.
interveners.nationaldb.org

These recommendations for improving intervener services for children and youth who are deaf-blind in the United States were developed in response to a request from the U.S. Department of Education's Office of Special Education Programs. They are

based on information gathered from an extensive data collection process and from NCDB-facilitated discussions with multiple stakeholders.

Free Training Materials from NCDB

DB-LINK, the information services arm of NCDB, can provide bulk copies of fact sheets on a variety of topics (e.g., communication, assessment) free-of-charge. This includes most (but not all) of the publications on this web page:

<http://www.nationaldb.org/NCDBProducts.php?prodCatID=84>. Contact us and let us know the titles and quantity of the documents you desire and we will do our best to fill your request.

Phone: 800-438-9376 (Voice); 800-854-7013 (TTY).
E-mail: info@nationaldb.org.

A Family's Guide to Interveners for Children with Combined Vision and Hearing Loss

Linda Alsop, Clara Berg, Vivecca Hartman, Melanie Knapp, Kimberly Lauger, Cheryl Levasseur, Mike Prouty, & Sally Prouty. Logan, UT: SKI-HI Institute, Utah State University, 2012.

intervener.org/wp-content/uploads/2012/06/A-Familys-Guide-to-Interveners.pdf

This booklet includes information about deaf-blindness, effective intervention for children who are deaf-blind, the role of interveners, and determining the need for an intervener through the Individualized Education Program (IEP) process.

Invisible: My Journey through Vision and Hearing Loss

Ruth Silver. Bloomington, IN: iUniversere, Inc., 2012.

The memoir of a woman who is deaf-blind. She shares her life experiences and her struggles to accept blindness and later hearing loss.

AIM: Assessment Intervention Matrix

Enid G. Wolf-Schein & Jerome D. Schein. Three Bridge Publishers, 2009

The Assessment Intervention Matrix (AIM) is a curriculum for teaching individuals with significant communication or sensory impairments (including those with severe auditory and visual problems or autism) to develop communication and daily-living skills in realistic, meaningful contexts, at school and at home. For more information, go to www.AIMcurriculum.com

Multimedia

Perkins Webcasts

www.perkins.org/resources/webcasts

The Perkins series of on-demand webcasts, presented by experts in the field of visual impairment and deaf-blindness, continues to grow rapidly. Categories include assistive technology; CHARGE Syndrome; curriculum, instruction, and mentoring; deafblindness or visual impairment with additional disabilities; help for families; independent living skills; and social skills and sexuality education.

Communication for Children with Deafblindness, or Visual and Multiple Impairments

Texas School for the Blind and Visually Impaired (TSBVI)

<http://distance.tsbvi.edu/communication>

This website, developed by Chris Montgomery, a deafblind outreach specialist at TSBVI, offers a place for sharing strategies and ideas in the design and use of communication systems. Current sections include interaction and bonding, assessment, routines, and calendars. Video clips are used to illustrate interactions and instructional strategies. There are many additional great resources at the TSBVI Distance Learning website: <http://distance.tsbvi.edu>.

Literacy for Children with Combined Vision and Hearing Loss

www.nationaldb.org/literacy

Provides strategies, practical examples, and resources that provide expanded learning opportunities to children with deaf-blindness, multiple disabilities, and complex challenges.



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Deaf-Blindness

Announcement

Seeking Special Education Teachers and Speech Language Pathologists for Communication Research Studies

Study 1

Special education teachers and speech-language pathologists are needed to participate in a study funded by the U.S. Department of Education. Participants must:

- ◆ Currently serve at least one student with complex communication needs at any grade level, including early intervention/early childhood special education.
- ◆ Be responsible for developing communication-related IEP/IFSP.
- ◆ NOT currently use the Communication Matrix to evaluate students.

Participants will receive an honorarium ranging from \$200-\$350. For further details, please email quinnem@ohsu.edu.

Grant #H327A110010

U. S. Dept. of Education

Dr. Charity Rowland, P. I.

IRB #1517

Study 2

A Research Project, "Using the ICF-CY to Guide Communication Instruction for Learners Who Use AAC" (Augmentative and Alternative Communication), is seeking special education teachers and school-based speech-language pathologists who:

- ◆ Currently work at least weekly with one student with complex communication needs in grades K-12.
- ◆ Are responsible for developing communication-related IEP goals for the student.

It should take no more than two hours to complete the requested activities. All participants will receive \$150 Target gift card upon completion of study tasks. For further details, please e-mail: ICFAAC@ohsu.edu

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Institute of Education Sciences

U. S. Dept. of Education

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