

Deafblindness: Educational Service Guidelines: A Product of Our Strengthening Field

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In the middle 1970s, the field of deafblindness was young, as was the special education system that required that all students receive a free and appropriate public education. During that time, the federal program that supported the development of specialized teaching approaches, personnel preparation, and associated programs to serve students who were deafblind focused almost entirely on the needs of students born with Congenital Rubella Syndrome. Teachers who were trained in specialized university programs typically obtained work teaching classrooms of children with deafblindness in schools for the blind or in state schools for children with cognitive disabilities. They also moved into jobs in amply funded regional centers offering services to children and youth with deafblindness.

Over the next three decades many significant changes influenced the services that were provided for students who are deafblind. The two most pronounced changes were a widening diversity within the population of children and youth with this disability and an increased emphasis on serving children in programs closer to their homes. Also during this time span, more of the financial responsibility for educating students with deafblindness fell on states and local education authorities, and less of this funding was directed toward personnel preparation. The federal program rightfully shifted to a model of technical assistance and information sharing.

During this period, we struggled as a field to provide students and their families with quality educational programs. A severe shortage of skilled professionals in deafblindness made advocating for children's rights to these services complicated, and creating a system to facilitate educational teams' access to experts in deafblindness was seen as a luxury that few states could afford. Ironically, graduates of personnel preparation programs in deafblindness often had difficulty finding jobs in the field. So, we were in a real Catch-22 situation.

During the past several years, however, we have seen a wonderful coalescence in our field, largely because of the commitment of professionals at state, regional, and national levels who represent students with deafblindness and of students' family members and strong family organizations, who have become very articulate advocates for the rights of students with this disability to a truly appropriate education. Through efforts such as intervener training programs, the creation of endorsements in deafblindness in some states as a part of their credentialing systems, the formation of Council for Exceptional Children specialized professional associations (SPAs) in deafblindness, and the establishment of the Helen Keller Fellows Program, our field has risen to face the challenges inherent in providing special education services to students with one of the most complex disabilities. Providing a free and appropriate public education to students with deafblindness requires that state and local education agencies recognize their unique educa-

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tional needs and put into place systems that will ensure access to a quality education that is equal to that of their sighted-hearing peers.

The publication *Deafblindness: Educational Service Guidelines* (Riggio & McLetchie, 2008) was developed collaboratively by leaders in the field of deafblindness who represented state deafblind projects, university training programs in deafblindness, the National Family Association for the Deaf-Blind (NFADB), the National Consortium on Deaf-Blindness (NCDB), and the National Association of State Directors of Special Education (NASDSE). Its purpose is to serve as a best-practice guide that educational administrators at state, local, and program levels can use to better understand the impact of combined vision and hearing losses on learning and to respond to the need for specialized assessment, program planning, and service delivery.

Many people are familiar with the publications *Meeting the Needs of Students Who Are Deaf or Hard of Hearing: Educational Service Guidelines* (2006) and *Blind and Visually Impaired Students: Educational Service Guidelines* (1999). Both of these are best-practice documents that present foundational knowledge about the nature and needs of students with hearing and vision losses, personnel issues, assessment methods, programs, services, and placement options, as well as administrative considerations. *Deafblindness: Educational Service Guidelines* (Riggio & McLetchie, 2008) addresses the same topics. Key themes are emphasized throughout the book:

- ◆ Deafblindness is a unique and complex disability. Educators who serve students who are deafblind must have the necessary

knowledge and skills to provide adequate services.

- ◆ Students and educational teams require the guidance of a deafblind specialist who has the knowledge and skills necessary to guide planning and to provide technical assistance and direct services.
- ◆ Communication, the foundation for all learning and the building of social relationships, is a primary need that must be addressed in a thoughtful and comprehensive way in the development and implementation of individualized educational programs for students who are deafblind.
- ◆ Most students require one-on-one communication support in order to access their learning and social environments. This may be in the person of an intervener, who is a paraprofessional with specific training to meet the needs of students who are deafblind.
- ◆ Students who are deafblind require unique and creative skills on the part of assessment team members, who must understand the impact that deafblindness has on students' development. They must also understand and be able to use communication forms that are appropriate for students who are deafblind, and they must be willing to work cohesively on teams to share information that will result in fair appraisals of students' abilities, challenges, and priorities for instruction.

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- ◆ While every special education team must by law include parents and other family members as central team members, this is especially critical for students who are deafblind. Family members possess a unique understanding of their children's communication and learning abilities that educational teams must tap in order to complete appropriate assessments and to deliver appropriate educational services.
- ◆ The design of services and placement for students with deafblindness requires very thoughtful and personalized decision making. The goal of placement in the least restrictive environment (LRE) will only be realized when students have full access to the curriculum and educational environment in their own communication forms, engage in authentic interactions with both peers and professional personnel, and achieve according to the highest possible performance standards. Services must be well coordinated and implemented in a collaborative manner to meet the identified needs of students.
- ◆ It is important that state and local administrators work collaboratively and creatively with existing resources and develop new resources when necessary to expand state capacity and to ensure that students who are deafblind receive the specialized services necessary for equal access to education.

It is critical that the information contained in this publication be supplemented by training for state and local service providers to guide the development of services. Currently, representatives from state deaf-blind projects, Perkins School for the Blind, NCDB, NFADB, and NASDSE are working together to develop training modules on issues that must be addressed by state and local systems. There is a focus on building a pool of trainers who have expertise in the field and who are able to share their knowledge effectively. Over the next several months, all of the partner agencies in this project will work closely with the Department of Education's Office of Special Education and Rehabilitative Services and the field, to develop an implementation plan that will carry the message forward.

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Home Visits with Families and Their Infants Who Are Deaf-Blind

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Families of infants and young children who are deaf-blind are likely to receive home visits from multiple service providers representing a variety of agencies. The main purpose of home-based early intervention is to help families promote the development of their children who have complex learning needs. To meet this goal, home visitors individualize home visits according to each family's priorities (Ridgley & O'Kelley, 2008), coach family members to use strategies that help their child learn and develop (Chen & Klein, 2008), and provide information and support (McWilliam & Scott, 2001).

Home visiting is a complex process that requires thoughtful planning and skilled practices to ensure effectiveness. According to a recent survey in California (Klein & Chen, 2008), early intervention professionals use a variety of strategies when making home visits, including providing information about learning strategies, child development, characteristics of disabilities, and resources; listening to family members and offering emotional support; working directly with children and demonstrating specific techniques and interventions; and coaching caregivers as they interact with their children. A survey of early interventionists in Australia revealed that similar strategies were used in serving families of young children with visual impairments and multiple disabilities (Chen, Griffin, & Mackevicius, 2009). In this article we describe important elements of these home-visiting practices and review research findings and current recommendations on conducting home visits with families and their infants who are deaf-blind.

Promoting Learning and Development

A focused interview with mothers of infants with sensory impairments and additional disabilities revealed they felt that learning specific strategies to promote their children's development was the most helpful part of home visits (Klein & Chen, 2008). Similarly, parents of young children with visual impairments and additional disabilities identified "getting suggestions that fit the home environment" as most helpful (Chen et al., 2009). Effective teaching of these strategies to parents and other caregivers involve ensuring that professionals from different disciplines work together, making use of items already found in the home, embedding learning activities into everyday routines, and supporting infant-caregiver interactions.

Interdisciplinary collaboration. Professionals from different specialty areas should share their expertise with the family and with each other to effectively support an infant's learning within the context of family life. They should work together to identify effective strategies and use them consistently when interacting with the infant and family members. This is known as interdisciplinary teaming, and it is essential for high quality, coordinated services (Horn & Jones, 2004; Rapport, McWilliam, & Smith, 2004). For example, the intervention team for an infant with low muscle tone, moderate hearing loss, and total blindness may include service providers who are certified in the areas of hearing loss, visual impairment, occupational therapy, and physical therapy. The provider certified in hearing loss should help the family learn about the type and severity of their infant's hearing loss, available communication options and amplification devices, and ways to facilitate his or her listening skills. The service provider certified in visual impairment should share information about the infant's visual impairment and teach the family how to encourage the use of other senses and provide tactile input. The physical and/or occupational therapist should provide information on the infant's motor problems and skills, appropriate positioning and handling techniques, and strategies to encourage movement and physical development.

Use of materials found in the home. Current literature recommends using items and materials during home visits that families already have at home, instead of the "toy bag" containing toys and other items that many early interventionists have traditionally used when working directly

with infants. McWilliam (2007) has clearly articulated the following problems associated with the "toy bag" approach:

1. A professional toy bag sends the message that the family does not have useful items at home and that special materials are needed.
2. It gives the appearance that early intervention occurs only when the home visitor "works" with a child using specific toys.
3. It may lead families to incorrectly attribute their infant's progress solely to the time and effort of home visitors.

Routine-based interventions. Embedding interventions within everyday family routines takes advantage of natural learning opportunities to help children develop skills within the context of meaningful activities (Chen et al., 2009; Chen, Klein, & Haney, 2007; Dunst, Trivette, Humphries, Raab, & Roper, 2001). For example, one of the desired outcomes on the individualized family service plan (IFSP) for 34-month-old Henry is for him to walk independently. The home visitor asks his mother, Jen, to describe times when Henry seems motivated to walk. Jen tells her that Henry loves to eat and will often move toward his high chair. Together, Jen and the home visitor develop a routine for Jen to use at mealtimes that will help Henry achieve the goal of walking about 3 feet to his high chair. They place a dark, high-contrast mat under his high chair to help him see the chair better. When it is time to eat, Jen puts Henry's bib on him and says "time to eat" to cue Henry that it is time to find the high chair. When he reaches the high chair, she says "up, up, up" and touches his shoulders before putting him in the chair. Before feeding Henry, she touches his lips and does oral-motor stretches around his mouth as recommended by his occupational therapist. During the meal, she says "Henry, look! Find the spoon!" holds the spoon about 9 inches in front of his face, and waits for him to look at it before she moves it to his lips. She also says "take a bite" and waits to see if Henry opens his mouth. When the meal is finished, Jen says "all done," signs "finish," and waits for Henry to respond by putting his arms up to be removed from the high chair. By using the routine consistently, Jen is able to promote Henry's development by integrating strategies related to physical and occupational therapy, use of vision and hearing, and communication into a common everyday activity.

Caregiver-infant interactions. Home visitors should promote a family's confidence and competence in interacting with their child who is

deaf-blind and encourage a parent's or other caregiver's use of specific strategies to support these interactions (Chen et al., 2007). The caregiver-infant relationship is strengthened when the caregiver recognizes, interprets, and responds to an infant's communication efforts (Dunst & Kassow, 2004; Kassow & Dunst, 2004), but caregivers need assistance to recognize their infant's subtle and unique signals and to respond in a meaningful way. Thus, a significant focus of home visits should be to facilitate caregiver-infant interactions and promote the child's participation within the family routine (Chen & Klein, 2008; Keilty, 2008).

Providing Information

When an infant has both visual impairment and hearing loss *and* other special needs, initial home visits usually involve sharing information about relevant medical issues, explaining the causes of the infant's sensory impairments, and helping the family to learn about their infant's particular visual, auditory, and communication needs. The home visitor may also provide information about agencies and professionals that conduct evaluations (e.g., audiological, ophthalmological, or physical therapy).

Most families of infants with combined visual impairment and hearing loss will be unfamiliar with the term *deaf-blind* and may not view the label as appropriate for their infant, particularly if he or she has some functional vision or residual hearing. Home visitors should explain the range of combined sensory impairments described by the term and how this relates to educational strategies, specialized services, and accommodations needed for a particular infant. Families should also become familiar with relevant resources such as state deaf-blind technical assistance projects, the National Consortium on Deaf-Blindness (NCDB; <http://nationaldb.org>), and the National Family Association for Deaf-Blind (NFADB; <http://www.nfadb.org>).

Use of functional vision and residual hearing.

If the infant wears glasses or contact lenses or hearing aids, the family may need assistance to learn about the care and management of these devices, how to introduce them to the child, and how to help the child make sense of what he or she sees and hears. Families may also have questions about cochlear implants. Depending on the infant's sensory status, home visitors should help families create opportunities for their infants to move towards sounds (e.g., searching for a family member who is calling the child's name or locating a toy that makes a sound), to visually locate

preferred items and people (e.g., looking around the room for mother or searching for a favorite blanket), or to tactilely search for a favorite toy kept in a consistent place.

Communication options. Development of communication skills is a primary need for infants who are deaf-blind. Families may need encouragement to observe, interpret, and respond to their infant's communicative efforts. They will have questions about options in communication modes (e.g., combined oral/aural, total communication, or American Sign Language) and wonder if their child will be able to read print or Braille. Families may ask whether their child will learn to speak and will need assistance to develop and use concrete communication methods such as touch and object cues and adapted sign language. Home visitors with expertise in deaf-blindness should schedule joint visits with other service providers to share information and strategies and to develop consistent use of communication methods to encourage the infant's communication development.

Supporting Families

Home-based early intervention services must be family-centered and tailored to each family's unique characteristics (e.g., beliefs, culture, language, composition, social-economic level, attitudes toward disability) and the infant's developmental needs. The home visitor should create ways to engage everyone who is involved in an infant's care. In a large extended family in which there are several caregivers, for example, the home visitor should ask who should be involved in home visits rather than make assumptions. If appropriate, siblings should participate in the visit and be invited to share their points-of-view about the infant's likes, dislikes, and strengths.

Information should be offered in a format that the family understands and prefers. Some individuals like print materials, while others prefer online resources or DVDs. If the family and home visitor do not share a common language, an interpreter familiar with terminology related to early intervention and the child's diagnoses should be used to translate discussions. However, a common language, while essential, is not all that is required to help families support their child's development. In a study of non-English-speaking Mexican-American mothers of infants with developmental delays, Perez (2000) found that even when home visitors were bilingual, they tended to work directly with children rather than modeling and coaching fami-

lies in ways to promote their children's communication development.

Home visitors should recognize that families are likely to experience a range of emotions associated with the birth or diagnosis of an infant with a disability. Feelings like shock, anger, and sadness have been associated with adapting to having a child with a disability (Anderregg, Vergason, & Smith, 1992; Moses, 1983). Home visitors should be sensitive, compassionate, active listeners and understand that each member of the family may experience different feelings at different times. These are natural feelings that serve a healing purpose (Gallagher, Flalka, Rhodes, & Arceneaux, 2002). Home visitors should also assist families to identify and obtain the kinds of informal support (e.g., extended family members, friends, or spiritual leaders) and formal help (e.g., parent mentors, mental health professionals, or family support groups) that are likely to be needed.

Transition to Preschool

As a child approaches 3 years of age, families have questions about preschool options and concerns about moving away from home-based early intervention services. This transition is likely to be an emotional and anxious time for families as they leave the security of family-centered home visits and familiar service providers for unknown, child-centered preschool services. Home visitors should assist families to learn about the transition from the individualized family service plan (IFSP) process to the individualized education program (IEP) process, their rights under the Individuals with Disabilities Education Improvement Act (IDEA), advocating for their child, and what they can expect when their child goes to preschool.

General Tips for Home Visiting

Although the nature and content of a home visit will vary according to each family's priorities and concerns, the age and needs of their child, and a variety of other factors (e.g., program policies or state requirements), service providers must be prepared to make the best use of the family's time. The following are general suggestions to guide home visits:

- ◆ Remember that you are in the family's home; be respectful, compassionate, and nonjudgmental.
- ◆ Explain that family involvement during home visits is essential.
- ◆ Be flexible, listen to the family, and follow their lead.
- ◆ Follow-up on issues raised during previous visits.
- ◆ Focus on the infant's and family's daily activities and interests and provide suggestions that fit into their routines.
- ◆ If the child wears a hearing aid or amplification device, check to make sure it is working.
- ◆ Discuss ways to promote the child's communication development.
- ◆ Consider recording videos of learning activities if the family is comfortable with this (viewing videos provides great opportunities for observation, learning, and discussion).
- ◆ Offer to make family-to-family connections if the family is interested in meeting other families of infants who are deaf-blind.
- ◆ Find enjoyment in learning together.

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Just Say No to Drive-bys

Debra Garvue

I am tired of “drive-bys.” I’ve had enough. I am the mother of a 6-year-old deafblind daughter. Since entering the public school system, she has been bombarded with drive-bys. What are drive-bys? The term “drive-by” is my way of describing the school system’s solution to her education. A deafblind child is placed in a classroom full of children with multiple disabilities, where he or she is usually the only deafblind child in the room. Then the drive-bys begin. A vision teacher will drive by and spend 30 minutes with her, then a hearing teacher will drive by and spend 30 minutes with her, and on and on. My daughter’s day is fragmented by various therapists and their minute requirements.



My question is this, do drive-bys work? Is this the best a deafblind child can hope for? Wouldn't my daughter be better off in a room full of her peers with like disabilities? As I delve into these questions, please remember that these are the opinions of a mother, and a teacher with 15 years of experience.

There are schools for the deaf and schools for the blind. Where are the schools for the deafblind? This is a question that I have often asked. The public school system always gives the same answer—there aren't enough deafblind children to start a classroom of their own. Is that to say these children are insignificant? Even though they are few in number, do they not deserve the same consideration as other children? Many children who are deaf are immersed in language and communication all day. And many children who are visu-



ally impaired are put in classrooms with like peers and surrounded by the tools they need to succeed. But children who are deafblind are placed in classrooms with children who have multiple disabilities and receive drive-bys. As a mom and an educator, I believe that students who are deafblind should be placed with their peers and immersed in language, communication, and vision instruction for the entire time they are at school.

My daughter, Maddie, has light perception only and some peripheral vision, but no central vision. She also has a cochlear implant. When she was ready to begin kindergarten, I toured public school classrooms and was offered the same option in all of them. They could serve my child in a classroom (where there were no other deafblind children) and make sure she was seen by their specialists (drive-bys), but I had finally had it. I did not want a fragmented education for my child. Fortunately, I am blessed to live in a city that has a very good private school for children with hearing and language impairments, and the public school system offered this as one of my choices.

Usually, any student with visual impairment is considered for the vision impaired class, but since my daughter had multiple disabilities, this was not an option for her. This led me to think, yes, my daughter is deafblind, however, because of her cochlear implants, hearing is one of her strengths. It dawned on me that it made sense for her to attend a school that could help her to hear with her implant and to communicate better. I loved the school, but I was worried that a private school would not take a deafblind child. Would they agree with my belief that deafblind children who have cochlear implants or hearing aids should attend schools for children who are deaf or hard of hearing? Luckily, they did. They had reservations because they had never taught a child with such a severe visual impairment, but they accepted my sweet daughter and have met all of her needs head on. Not only did they accept her, but they have agreed to look into beginning a regional deafblind program for children like my daughter because they see the amazing progress she is making.

My daughter is being educated with her peers. No, they are not deafblind, but they are deaf, and there is another deafblind child in her class. To me that is definitely a step in the right direction. The school has agreed to look into opening a pilot program for students who are deafblind and have implants or hearing aids, and they will provide all-day instruction by a teacher who specializes in children who are deaf or hard of hearing. No more

drive-bys! The children will also have the services of an intervener and be immersed in language and communication all day. And the school will hire a vision consultant to train the staff to teach visually impaired children.

How did all of this happen? Well, I don't like to brag, but it was me, a parent who had had enough. A parent who knew her child like no other and was certain that a few minutes of instruction and support here and there would not make enough of a difference. A parent who knew that if she searched long enough, begged and pleaded, and finally got mad enough, she could achieve her vision of deafblind education.

But, I can't take all the credit. In fact, my daughter's school deserves most of it. They agreed to everything I suggested. They are dedicated to building a quality program for students who are deafblind. What more could a parent and teacher ask for? Finally, a place where deafblind children will be with their peers and immersed in learning that is focused on them for the entire school day. I believe every deafblind child deserves to be educated by a certified deaf educator, and if possible, a deafblind educator. Can you imagine the progress these children are going to make? Can you imagine the self-confidence and acceptance they are going to feel? I can.

As a parent, empower yourself. You know your child, and you know what they deserve. Seek it out. Make it happen. Say it right now. Out loud. *No more drive-bys!*



From Ignorance to Understanding: Adventures in Deaf-Blind Interpreting

Robin Van Dusen

Six months ago I was a typical interpreting student doing what I needed to do to become the best interpreter I could be, when an opportunity arose to become a student worker for DB-LINK at the National Consortium on Deaf-Blindness. DB-LINK is a center for information on deaf-blindness, and I thought it would be a good place to work part-time while I was going to school at Western Oregon University (WOU). I liked the fact that the job related to my major, but I had already made up my mind that I would never go into deaf-blind interpreting. I am sometimes uncomfortable having people in my personal space, and I thought that the close proximity that is

required for deaf-blind interpreting would be difficult for me. My feelings about that would soon change.

Not long after I began working at DB-LINK, I learned of an opportunity for students fluent in American Sign Language to volunteer at the 30th Annual Deaf-Blind Retreat, a camp for adults who are deaf-blind held every summer in Seabeck, Washington. The camp features many fun activities such as bicycling, paddleboating, canoeing, rowing, and parasailing. There are also arts and crafts activities, workshops on topics of interest to deaf-blind individuals, and day trips to local attractions such as the Seattle Lighthouse, the Seattle waterfront, and a local mall. Deaf-blind individuals are matched with support service providers to ensure that they have the support they need to participate in all of the activities that interest them. When I first heard about the retreat, I wasn't sure if I wanted to volunteer, but after much contemplation I decided that I would at least give it a try before I completely dismissed the possibility of deaf-blind interpreting. I put my whole heart into my application and the essay questions that went along with it.

While I was waiting to hear if I had been accepted as a volunteer, I found out there would be a workshop on deaf-blindness at the Oregon School for the Deaf. A friend and I decided to go. Ten minutes after the workshop began, a deaf-blind woman arrived. The workshop paused while the interpreters, the deaf-blind participant, and the deaf-blind presenter worked together to create an environment that would provide equal access to information for everyone. Chairs were moved, backgrounds changed, window blinds closed, and the signing space was tested. After about fifteen minutes, everyone was settled, and the workshop continued. I watched in complete awe as the interpreters adapted their skills to their consumer's needs, and I came home with a completely different perspective on deaf-blind interpreting. I had noticed that the deaf-blind individual did not use tactile sign language, but instead sat a couple of feet from the interpreters for close vision signing. This was a new concept to me. I had thought that deaf-blindness meant profound deafness and total blindness. I hadn't realized that people who are deaf-blind have a range of vision and hearing losses and use a variety of communication methods. That day was a huge turning point for me, and I came home from that workshop intrigued by deaf-blindness. In fact, I was convinced that deaf-blind interpreting is the most challenging and rewarding setting in which to interpret. Two weeks after attending the workshop, I was accepted to volunteer at Seabeck.

In the spring of 2008, a group of 13 WOU students who planned to volunteer at Seabeck, and two faculty advisors, met weekly to learn from each other how to work with deaf-blind individuals. Together we practiced tactile sign language and discussed assigned readings from the book *Guidelines: Practical Tips for Working and Socializing with Deaf-Blind People* (Smith, 2002). We also practiced sighted-guide skills around campus, and we gained experience by volunteering at a retirement community for deaf and deaf-blind individuals. At our last meeting, the group held a deaf-blind simulation activity at a local pizza parlor. Half of the group wore ear plugs and goggles to simulate loss of both hearing and vision, while the other half served as SSPs. Those in the SSP role guided the group members who were simulating deaf-blindness into the pizza parlor and provided visual information about the surroundings for the first half of the meal. Halfway through the meal, we switched roles.

At the end of spring quarter we went our separate ways, reconvening via conference calls twice over the summer to make sure we were all on track getting ready for the retreat at Seabeck. During the summer, I also had the experience of taking a deaf-blind man grocery shopping. This experience affected me greatly. I had read that deaf-blind people often function at a slower pace than hearing and sighted people, but I didn't exactly know what that meant until I spent the afternoon with this man. I came to realize how much longer it can take for deaf-blind people to do some of the tasks that I take for granted everyday. I tend to be on the go all the time and to try to squeeze more and more into my day. But when I went shopping with this man, the experience was not about me. It was about him and making sure that he got everything he needed, whether it was a can of olives or genuine friendship and conversation. While I was with him, time wasn't important.

Before I left for the retreat, I felt I had done everything I could to prepare. I continued to read about deaf-blindness, to practice tactile sign language and guiding, and to practice strategies for interacting respectfully with deaf-blind individuals. Despite my preparation, I was nervous about whether my skills were good enough to enable the deaf-blind campers to enjoy their vacation. However, as soon as I met the first camper I was assigned to, my worries were alleviated.

I had a great experience at the Deaf-Blind Retreat. I learned and experienced things that could not have been taught to me in any other way. Before I left for the retreat, I had become book-smart, but once there, I obtained hands-on experience and was able to ap-

ply many of the concepts I learned from my reading. When I first started working with people who did have some vision, I struggled with knowing exactly how much visual information to share. There were so many things happening around us, and I felt it was my responsibility to share everything I saw and heard. I soon found out that not every deaf-blind person wants to know every single little thing that is happening. I learned to ask questions and find out what each person wanted to know. By asking about their needs and interests, I was able to become confident in my ability to offer the right kinds of support.

One of the women that I worked with used a combination of ASL and the Rochester Method, which involves the use of fingerspelling. I had never interacted with anyone who used this particular combination of communication methods, and it took me a while to realize what I was seeing. I was concerned that some of my signs might not be clear and that the reason she fingerspelled some words to me was because she could not always understand me. Despite our initial struggles to communicate, by the end of the week I was able to interpret for other SSPs who wished to chat with her. It made me feel good that I was able to get past the communication barriers that existed when we first met.

While I was at the Deaf-Blind Retreat I met many people who live isolated lives, and for them the retreat is very important. It provides an opportunity to interact and socialize with people who understand and who have experienced the same things they have. But it is an opportunity that only comes around once a year, and many deaf-blind people are turned away each year because there are not enough volunteers.

The most difficult, and yet most rewarding, part of the camp was the last day. Saying goodbye to the wonderful people I worked with all week was truly bittersweet. When I said goodbye to one of the women whom I had grown to love over the course of the week, I put my hand over hers to let her know I was there, and she signed my name before I could even identify myself. It was so touching that she knew exactly who I was without my telling her. We gave each other a huge hug, and neither of us wanted to let go. Unfortunately, letting go also symbolized what might be another year of isolation for this amazing woman. I will be volunteering at Seabeck for years and years to come if only to make sure that more people are able to attend and experience the sheer joy of connecting with people similar to themselves.

Since returning from Seabeck, I often catch myself touching people on the shoulder more often or touching the top of someone's hand to let them

know I want to tell them something. Clearly, I no longer have a problem with people in my personal space. The experiences I have had in the past six months have changed me as a person and pointed my professional life in a new direction. I now know that I will always be involved in deaf-blind interpreting.

Reference

Smith, T. B. (2002). *Guidelines: Practical tips for working and socializing with deaf-blind people*. Burtonsville, MD: Sign Media, Inc.



Outreach to Improve Early Identification in Kentucky

Gail Leslie

National Consortium on Deaf-Blindness

Many children who are deaf-blind have additional disabilities and complex medical needs and often begin their lives receiving services from physicians and other health-care providers. Recognizing the importance of medical professionals in the lives of children with disabilities, the Kentucky Deaf-Blind Project developed an outreach program targeting these professionals in an effort to increase their referrals of children who are deaf-blind to the project.

The outreach program had its genesis in 2002 as part of a broader Kentucky Department of Education (KDE) initiative to improve educational services for children with sensory disabilities. The Kentucky Board of Education invited the American Institute on Research to evaluate the state's current services and provide recommendations. As a result, the Kentucky Deaf-Blind Project was asked to take the lead on initiatives to implement recommendations specific to early intervention and early childhood services for children with complex needs—deaf-blind, deaf-blind with other disabilities, deaf or hard of hearing with other disabilities, and blind or visually impaired with other disabilities. Two workgroups were formed, and the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC) played an integral role in facilitating group discussions to identify needs and generate solutions related to the recommendations.

The need to improve early identification was one of the first problems identified. Diane Haynes, the Kentucky Deaf-Blind Project coordinator as well as the state's coordinator, at that time, for Part C (Program for Infants and Toddlers with Disabilities) of

the Individuals with Disabilities Education Act, says, "I just knew that while there were ongoing efforts to address this issue, there were significant pieces of information and resources at our disposal that were not being used efficiently or were not giving us maximum results." One untapped resource was the medical community. Haynes wondered if improved outreach to health-care providers would increase the number of referrals of children who are deaf-blind to Part C early intervention services and the state deaf-blind project.

Initially Haynes spent a great deal of time reviewing Kentucky's Part C Established Risk list. The list includes approximately 300 conditions that, once diagnosed, identify a child as immediately eligible for early intervention services. In studying the list, she recognized many conditions that placed a child at risk for vision or hearing loss, and after reviewing the list with physicians from the Department of Genetics at the University of Kentucky (UK), she learned that far more conditions were associated with a risk for vision and hearing loss than she had originally assumed. After reviewing files of children currently receiving early intervention services, she found that many children diagnosed with these conditions were not receiving services related to their hearing or vision and those with combined hearing and vision loss were not always referred to the Kentucky Deaf-Blind Project. She also became concerned, especially after speaking to Dr. Neelkamal Soares—a developmental pediatrician at UK, that pediatricians might not be aware that sensory losses were associated with these conditions unless they specialized in genetics or other specialty areas.

Forming Partnerships

Haynes and Soares both felt that a partnership between educators and health-care providers was needed, not only for early identification purposes, but also to enhance the overall delivery of educational services for children with sensory losses. Together they began to discuss the identification activities targeted by one of the KDE workgroups, as well as additional activities on which educators and health-care professionals could collaborate.

Haynes also met with Dr. Harold Kleinert, who, as director of the UK Interdisciplinary Human Development Institute (IHDI), oversees programs offering educational and medical services for individuals with disabilities. He agreed that increasing health-care professionals' awareness of the distinct needs of children with sensory disabilities could positively impact both their health and educational outcomes. To assist with her outreach and networking efforts, Kleinert introduced Haynes to a member

of his staff who served as the liaison between his program and the UK College of Medicine.

Dr. Sarah Cawthon, a physician and parent of a young child with deaf-blindness, suggested that Haynes give a presentation on deaf-blindness during grand rounds at the UK College of Medicine. Grand rounds are a form of continuing education for doctors, residents, and medical students. "It seemed to me," says Cawthon, "that grand rounds presented an opportunity to share information with the pediatricians of tomorrow." She had specific recommendations regarding the presentation. It would be important to place the information in the context of the medical system—details about children who are deaf-blind, why they need services, and why early identification of hearing and vision loss is important. She also felt that the presentation would be strengthened by the participation of someone with a medical background. Haynes realized that Cawthon herself was the perfect partner in this endeavor because she understood on both a professional and personal level the significance of appropriate services for children who are deaf-blind. In the spring of 2005, they made their first presentation at grand rounds at the medical school at UK.

Outreach Strategies

In addition to the grand rounds presentation, the Kentucky Deaf-Blind Project incorporated a number of other strategies into their medical outreach endeavors. Many involve direct contact and collaboration between project staff and physicians, which have been found to be the most effective means of increasing physician referrals, particularly when they include "ongoing and frequent face-to-face contact" that is paired with written program materials to reinforce verbal information provided during personal visits (Dunst & Clow, 2007). Specific outreach strategies include:

- ◆ Production of a brochure designed for annual mailing to health-care providers and for use as a hand-out at presentations. It focuses on the risk factors and implications of hearing and vision loss and includes Kentucky Deaf-Blind Project information and other resources. A template is available from the NCDB Web site (www.nationaldb.org/ISKyBrochure.php).
- ◆ Development of a presentation with information targeted to health-care providers. The PowerPoint slides used in the presentation are available from the NCDB Web site (www.nationaldb.org/ISKyMedOutreach.php).

- ◆ Presentations to medical school personnel and students during grand rounds as described above.
- ◆ Presentations as part of a monthly “brown bag” lecture series sponsored by the Interdisciplinary Human Development Institute (IHDI) at UK, to which are invited students from the College of Social Work, the College of Medicine, and the IHDI. Haynes has made two presentations on meeting the needs of families who have children with disabilities. One presentation was entitled “Delivering Holistic Services in a Fragmented Service System,” and the other “Addressing the Unique Needs of Families Who Have Children with Disabilities.”
- ◆ The development of opportunities for medical school students to observe Kentucky Deaf-Blind Project staff members as they work with children.

Since initiating these activities in 2005, the number of children referred to the Kentucky Deaf-Blind Project by health-care providers and Part C programs has increased by 40%. In the spirit of true partnership, the state deaf-blind project is now recognized by the UK College of Medicine as a valuable resource for its shadowing program for 3rd and 4th year medical students. Within a year of the first grand rounds presentation, nine students had chosen to shadow state deaf-blind project personnel on their visits to children. These students visited homes and schools, problem-solved with educational teams and families, and saw, first hand, what life is like for children with complex disabilities outside of a medical environment. Many medical students have reported that the shadowing experience has been one of the most beneficial and enlightening of their program.

Recognizing that both education and medicine share the goal of enhancing the lives of all children is the key to improving the quality of early intervention and educational services for children with disabilities. “If we are going to work collaboratively,” says Diane Haynes, “we must build a bridge between the two disciplines.” Part of building that bridge involves understanding problems, priorities, and concerns from the perspective of both educators and physicians and other health-care providers and identifying and sharing methods and solutions. “It is important,” Haynes continues, “to come to the table with a clear understanding that both parties have something to offer and that each share a concern that once children are identified as deaf-blind, it is absolutely critical that they receive the services they require and deserve.”

Reference

- Dunst, C. J., & Clow, P. W. (2007). *Public awareness and child find activities in Part C early intervention programs*, *Cornerstones*, 3(1), 1–7. Retrieved March 3, 2009 from www.tracecenter.info/cornerstones/cornerstones_vol3_no1.pdf.



What’s New at AADB?

Elizabeth Spiers
American Association of the Deaf-Blind

Maybe you are a long-term member of the American Association of the Deaf-Blind (AADB) and want to know the latest happenings. Or perhaps you’ve heard about AADB but are not sure who we are or what we do. Then this article is for you! AADB is a consumer advocacy organization of, by, and for people who have both hearing and vision loss. We have been growing and changing quite a bit within the last couple of years. Here are some updates.

Lower Membership Dues

Any individual (including those outside the U.S.) can now join AADB for \$10 a year, down from \$25 in the past. We also have new dues for organizations: \$50 a year for nonprofit organizations and \$75 a year for businesses and for-profit organizations. People who wish to join AADB can go to our web site at www.aadb.org to print a membership form to send us, or contact our office. We hope to have online membership registration available later this year.

Outreach to Teens and Young Adults

Are you a teen or young adult who is deaf-blind, or do you know someone who is? What can AADB do for you? We can offer you the chance to meet other teens and young adults who have both vision and hearing loss. One exciting way is through AADB’s profile on Facebook. As of this writing, 369 members have joined us. To find AADB, just go to www.facebook.com and type “AADB” in the search engine after you log in. There, you can find other people, including teens and young adults, who are also deaf-blind, as well as friends, supporters, and professionals. We also have a new brochure describing our services to teens and young adults. Just contact the AADB office to obtain a copy. In addition, we have a teen program at our national conferences, where teens can meet and connect with each other.

Support Service Provider and Technology Summits

AADB is focusing on two top needs that members identified at our two most recent conferences: a need for more support service providers (SSPs), and a need for affordable, accessible technology. With the help of support service programs and technology providers we are exploring how AADB can help make these services more accessible to Americans who are deaf-blind. When we gather our findings, we will also include input that we received from our deaf-blind members during the SSP and technology forums held at the 2006 AADB Conference.

Publications

AADB offers two major publications—our e-newsletter, “AADB Today,” and our magazine, *The Deaf-Blind American*. These publications have changed recently. “AADB Today” was formerly “AADB E-News.” It has expanded to include more news, and it spotlights people who are deaf-blind who are making a difference in their communities. “AADB Today” is free to anyone. People can go to our web site at www.aadb.org to sign up or contact the AADB office to be put on our distribution list. We also provide print and Braille copies to our members upon request.

The *Deaf-Blind American*, available to AADB members, is published twice a year. It focuses on specific hot topics in the deaf-blind community, such as interpreting, support service providers, technology, and employment. This year, we will have a summer issue focusing on teens and young adults.

We are now, for the first time, accepting ads in each publication. For more information on how to place ads, please contact the AADB Office at aadb-info@aadbd.org. If anyone wants to contribute to or be interviewed for our publications, please contact Elizabeth Spiers at elizabeth.spiers@aadbd.org.

Outreach and Advocacy

AADB strives to educate the public about the needs of people with both vision and hearing loss by presenting, exhibiting, and networking at national conferences, including those for teens and young adults who are deaf-blind. AADB has been working with other disability organizations to make sure that new legislation and initiatives include the needs of deaf-blind people. For example, AADB participated in an Obama-Biden transition team meeting in December 2008, along with other organizations such as the National Association of the Deaf and the Hearing

Loss Association of America. Each organization was given two minutes to comment on top issues. AADB advocated for national SSP services and accessible technology and submitted written recommendations on how deaf, hard-of-hearing, deaf-blind, and late-deafened people can be included in all aspects of civil rights, housing, employment, health care, telecommunications, and transportation.

These are just a few highlights of what is happening and what AADB can offer you. If you want more information, please visit our web site at www.aadb.org, e-mail the AADB office at aadb-info@aadbd.org, or call us at 301-495-4402 TTY or 301-495-4403 Voice. You can also contact us by VP at 301-563-9107 or 866-761-5768, or write to AADB, 8630 Fenton Street, Suite 121, Silver Spring, MD 20910. We would love to hear from you!



For Your Library

You Make the Difference: An Educator-Oriented Process for Supporting High Quality Interactions with Students Who Are Deafblind [DVD]

Craig Axelrod, Kim Conlin, & Tish Smith. *Texas School for the Blind and Visually Impaired*, 2008.

The interaction training process presented in this DVD is designed to help educators learn how to improve the quality of their interactions with students who are deafblind, by changing their own interactive behaviors and by adapting the circumstances in which interactions occur. Cost: \$50.00. Available from the Texas School for the Blind and Visually Impaired. Phone: 512-206-9427.

Web: www.tsbvi.edu/publications

Assessing Communication and Learning in Young Children Who Are Deafblind or Who Have Multiple Disabilities

Charity Rowland (Ed.). *Portland, OR: Oregon Health & Science University*, 2009, 59 pages.

This guide is designed to help professionals conduct meaningful assessments of young children who are deafblind and have additional impairments. Parents may also find it helpful. The emphasis is on assessing communication as the foundation for learning. Available on the web:

www.ohsu.edu/oidd/d21/com_pro/db_assess_ab.cfm.

Print copies will be available from DB-LINK as long as supplies last. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: info@nationaldb.org.

Data Summary: Validation of Evidence-based Assessment Strategies to Promote Achievement in Children who are Deafblind

Portland, OR: Oregon Health & Science University, 2009, 68 pages.

This document describes the major activities conducted under the auspices of Grant #H324D030001, "Validation of Evidence-based Assessment Strategies to Promote Achievement in Children who are Deafblind." Data collected through the grant's activities are summarized. Available on the web: www.ohsu.edu/oidd/d2l/com_pro/db_assess_ab.cfm.

Teaching Children with Visual Impairments (an online video on teaching physical activity)

Camp Abilities, The College at Brockport, State University of New York, 2008.

This 35-minute-long free online video on physical activity instruction for students who are blind, visually impaired, or deaf-blind, includes information about instructional techniques, safety considerations, running techniques, and equipment and game modifications. It is available online in 2 parts from: www.campabilitiesbrockport.org/Camp-Video.html. The information on deaf-blindness is included in the second part.

Suddenly Slow: Poems

John Lee Clark. Handtype Press, 2008.

Suddenly Slow: Poems, is a limited edition chapbook that showcases sixteen poems by the award-winning deaf-blind poet, John Lee Clark. Clark was born deaf and became progressively blind beginning in early adolescence. Cost: \$8.00. Available at www.handtype.com or www.amazon.com.

Practice Perspectives: Transition

The National Consortium on Deaf-Blindness (NCDB), January 2009.

This publication describes the importance of in-depth transition planning to meet the unique needs of children and youth who are deaf-blind and the requirements of the Individuals with Disabilities Education Act as measured by Indicator 13. Standard and large print versions are available on the NCDB Web site (nationaldb.org/NCDBProducts.php?prodID=62). Print and Braille copies are available by contacting NCDB (800-438-9376 V; 800-854-7013 TTY; info@nationaldb.org).



Conferences and Events

Pacific Rim Conference on Disabilities

May 4-5, 2009

Honolulu, Hawai'i

The PacRim Conference has several topic areas including native and indigenous education and health issues, disability rights, youth leadership and advocacy, autism, and universal design for learning. For more information, visit www.pacrim.hawaii.edu or e-mail cccrocke@hawaii.edu or 808-956-7539.

Idaho Project for Children and Youth with Deaf-Blindness Summer Institute

June 18-19, 2009

Boise, Idaho

The theme of this institute is "The Emotional Heart of the Child: Why 'Self-Regulation' Matters So Much." The presenter is David Brown, Educational Specialist, California Deaf-Blind Services. Cost: \$30.00. Web: www.idahocdh.org/dnn/cydb/SummerTraining2009/tabid/286/Default.aspx.

TREDS Summer Institute

July 8-10, 2009

Nashville, Tennessee

"Emerging Literacy for Children with Multiple Disabilities Including Deafness: Techniques, Strategies, Interventions and Implementation," is the topic of this summer institute, featuring guest speaker Robbie Blaha from the Texas School for the Blind and Visually Impaired. The program is open to all. For more information contact Jennifer Vick (jennifer.vick@vanderbilt.edu).

Registry of Interpreters for the Deaf National Conference

August 1-6, 2009

Philadelphia, Pennsylvania

This conference, hosted by the Registry of Interpreters for the Deaf (RID), will include several presentations on deaf-blindness. RID's Deaf-Blind Member Section (DBMS) will also meet to review its achievements, make plans for the future, and elect new officers. Web: www.rid.org.

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