

Deaf-Blind Perspectives

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Tactile Learning Strategies for Children who are Deaf-Blind: Concerns and Considerations from Project SALUTE

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Without reliable access to clear visual and auditory information, children who are deaf-blind must rely on additional modes of learning, such as learning through touch. For many of these children, touch is a primary mode of communication. Although a variety of tactile strategies are frequently used with children who are deaf-blind, there is little research-based evidence that validates their use. Identifying effective tactile strategies for deaf-blind children who also have cognitive or physical disabilities is particularly challenging. Project SALUTE (Successful Adaptations for Learning to Use Touch Effectively), a federally funded model demonstration project, is addressing the need for a more informed approach to the use of these methods. The goal of the project is to identify, develop, and validate tactile instructional strategies for children who have hearing loss and no functional vision, plus additional cognitive and physical disabilities.

This article discusses key issues and concerns regarding the use of tactile strategies based on Project SALUTE's initial activities—a review of publications and input from focus groups. This preliminary examination has identified that there are large gaps in what is known about tactile methods and has revealed more questions than answers regarding the use of touch with children who are deaf-blind. For example, what are the most effective ways to present information in this mode? How should children be taught to use their hands for exploration, learning, and communication? What adaptations are needed for the child who requires tactile information, but has severe physical disabilities and cannot easily control hand movements?

The following literature review and focus group findings serve as a basis for the work of the remaining three years of Project SALUTE. We hope that it also stimulates discussion and sharing of ideas and resources among families and professionals who are interested in this topic and encourages those who are using tactile strategies to analyze their use in a systematic way.

Literature Review

We identified a number of tactile strategies commonly used with children who are deaf-blind by reviewing publications in the areas of visual impairment and blindness, deaf-blindness, occupational therapy, developmental and biological psychology, and related topics. For the most part, these strategies are not based on research, but rather on the experiences or opinions of the authors or on anecdotal reports. Few research studies have focused on tactile adaptations for children who are blind with additional disabilities (one exception is Rowland & Schweigert, 2000). Consequently, there is little empirical evidence validating tactile strategies that are used frequently with children who are deaf-blind. These specific strategies we identified are discussed below.

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Hand-over-hand guidance. Hand-over-hand guidance is a common strategy in which an adult puts his or her hand over a child's hand to help the child explore an object, act on an object, or make a gesture or sign (Free man, 1985; McInnes & Treffry, 1982). This hand-over-hand

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strategy should be used only when necessary and with sensitivity to the child's reactions. Some children dislike having their hands manipulated and feel threatened by the lack of control. Others become passive and prompt-dependent. They learn to wait for an adult's hand on their own as a prompt to initiate an action (Downing, 1999; Miles, 1998). However, hand-over-hand guidance may be an essential strategy for children who have severe physical disabilities because they often need assistance to manipulate and explore objects.

Hand-under-hand guidance. This is an alternative to hand-over-hand guidance. Using this method, an adult places his or her hand slightly under the child's as they explore objects together (Dote-Kwan & Chen, 1999; MacFarland, 1995; Miles, 1998). The adult may also gently rest a hand underneath the child's and wait for the child to initiate an interaction. One strategy for introducing unfamiliar objects using the hand-under-hand method involves placing the child's hand on top of the adult's hand while the adult grasps an object. The adult then slowly rotates his or her hand so that the child is gradually introduced to the shape of the object. Another strategy involves gradually withdrawing the adult hand until the child's fingers touch the surface of the object or texture being explored (Dote-Kwan & Chen, 1999). In order for hand-under-hand strategies to be effective, the child must be willing and

able to keep his or her hand on top of the adult's hand.

Adapted signs. Adapted signs are tactile adaptations of visually-based manual signs (Chen, 1995). Adaptations involve how the sign is made (hand shape, orientation of the hands in relationship to the body, movement of the hands from one point to another, and area of the body where the sign is produced) and received by a child who is deaf-blind. This is a developing area of knowledge and the terminology can be confusing. Some methods of adapting signs include the following:

- ◆ **Tactile signing.** The receiver places his or her hands on the signer's hands in order to perceive the signs (Reed, Delhorne, Durlach, & Fisher, 1995). This is a hand-under-hand method. It is also called interactive signing (Alsop, 1993; Watkins & Clark, 1991). Tactile or interactive signing provides a means of communication input (receptive communication) for the child who is deaf-blind.
- ◆ **Coactive signing.** A type of adapted signing in which an adult physically guides the child to produce signs using a hand-over-hand method (Watkins & Clark, 1991). This is a means of communication output (expressive communication).

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- ◆ **Body signing.** The signer produces signs on areas of the child's body other than the hands (Joint, 1998). For example, the sign for EAT may be placed against the lips. Body signs are based on manual signs that are symbols or words. The child may perceive the sign as a touch cue, however, and not recognize a particular sign as a word.
- ◆ **Key word signing.** The use of selected signs (e.g., nouns and verbs) to communicate main ideas or messages (Chen, 1999). Many children who are deaf-blind with additional disabilities have very short attention spans and limited communication. The majority of hearing adults who communicate with them are usually limited in their sign language skills unless they have a background in deafness. For these reasons, most children who are deaf-blind who have additional disabilities are exposed to key word signs rather than to American Sign Language (with its own grammar) or manually coded English (uses English syntax). For example, WANT PLAY are key word signs for "Do you want to play?"

A common terminology and systematic study of the methods used to adapt manual signs for children who are deaf-blind is needed. Questions that need to be answered include: How should manual signs be adapted to encourage receptive and expressive communication? What criteria should guide decision-making when considering whether adapted signs are an effective communication option for a particular child?

Tactile representation. Tactile representations must make sense to a child in order to convey meaning (Downing & Eichinger, 1990; Rowland & Schweigert, 1998). For example, using a toy car to represent "going for a ride in a car" may be completely nonsensical from a child's tactile point of view. A seatbelt may be a more meaningful association based on the child's experience. Adults should think from a tactile rather than a visual perspective when selecting tactile representations.

Touch cues. Touch cues or tactile signals are an important communication strategy to use with young children who are deaf-blind during the early stages of communication development (Klein, Chen, & Haney, 2000; Rowland, Schweigert, & Prickett, 1995). The intended meaning of a touch cue is derived from the specific context and situation. The use of touch cues should be consistent. A child will not be able to decipher the meaning of a touch cue if

different people use it for a variety of messages. For example, patting or tapping a child on the shoulder may express any of the following:

- ◆ positive feedback ("Great job")
- ◆ a request or directive ("Sit down")
- ◆ information ("Your turn")
- ◆ comfort or reassurance ("Don't cry, you're OK")

A child will not be able to discriminate the meaning of a touch cue if there is competing tactile input or if he or she does not like being touched. For example, touching a child's lips while patting his or her hand is confusing if the message is "here is your drink." Touch cues should be used selectively, conservatively, and consistently so that the child can develop an understanding of what they represent. Our literature review and focus group discussion raised a number of questions regarding touch cues. What is the difference between a touch cue and an object cue from the child's perspective? Is touching the child with the nipple of a bottle a touch cue or an object cue if what the child perceives is pressure on the lip? What is the difference between a touch cue and a body sign from the child's perspective? Is making the sign for CANDY on the child's cheek a body sign or a touch cue if what the child perceives is pressure on the cheek? How should touch cues or body signs be made (place on the child's body, type, and duration of touch) to help the child associate a cue with its meaning?

Object cues. Object cues are objects or parts of objects used in activities or associated with a particular person. They are used to give information, make requests, and provide feedback. Initially object cues should be used during activities and selected so that the child can easily make an association between an object and the activity it represents (Chen, 1995; Rowland, Schweigert & Prickett, 1995). For example, a small cardboard container of juice may be used to represent "time for snack." As the child learns to associate an object with an activity, object cues can become smaller and more abstract. An object other than the one used in the activity (e.g., an empty juice container), a piece of the object (e.g., lid of the container), a partial representation of the object (e.g., piece of cardboard), an associated object (e.g., a straw), or a model of the object (e.g., a miniature juice box) may be used instead.

Object cues are meaningful only if the child can recognize what they represent. For example, miniatures usually provide visual representations that cannot be seen by a blind child. In addition, very small objects provide limited tactile information

and may be more difficult for a child who has a physical disability such as cerebral palsy to handle and explore. Sometimes arbitrary object cues are used if there is no logical object related to a specific activity. For example, if a child changes from one classroom to another every day, a piece of felt on the classroom door may be used as an arbitrary object cue. With experience, the child learns to associate the piece of felt as a landmark for that particular classroom (Rowland, Schweigert & Prickett, 1995).

Essential considerations in selecting objects, symbols or tangible symbols (Murray-Branch & Bailey, 1998) include the following:

- ◆ Tactile saliency (ease of recognition)
- ◆ Types of objects preferred by the child (encourages exploration)
- ◆ Whether the objects or tangible symbols can be reduced in size so that they are portable and can be used in a variety of settings
- ◆ How easily the object or texture can be discriminated from others used in a group of tangible symbols

Textured materials such as sandpaper or bubblewrap, are often used as abstract tangible symbols to promote communication with nonverbal children and adults who are blind or deaf-blind (Murray-Branch & Bailey, 1998; Rowland, Schweigert, & Prickett, 1995). These tangible symbols are used on communication boards to give information, elicit requests, and provide choice making opportunities. Selection of materials is typically based on the saliency of tactile characteristics. Little is known about effective strategies for assisting a child who is deaf-blind with additional disabilities to associate meaning with abstract tactile symbols.

Focus Group Findings: Current Practices and Issues

Four focus group meetings were conducted in California. The 33 participants included English-speaking and Spanish-speaking family members and service providers (both English-speaking and bilingual) of children who were deaf-blind or blind with additional disabilities. Although SALUTE focuses on children who are deaf-blind with additional disabilities, we also wanted to learn from individuals who interact with children who are totally blind and have cognitive or physical disabilities.

Participants were asked to identify the tactile strategies that they use and to discuss their successes,

challenges, and needs. Many of the strategies and issues identified by the literature review were also raised during the focus group meetings. In addition, the participants shared their own experiences and suggestions for enhancing tactile methods of teaching and communication. They also identified areas where more information, guidance, and clarity regarding this topic are needed.

Individualized approach. Each child who is deaf-blind has unique needs and preferences. Participants stressed the importance of using an individualized approach when determining the best teaching practices and when selecting specific activities and materials. Several reported that children preferred tactile input that had a functional purpose, a simple design, and a concrete form (e.g., a wooden box with a lid or uncooked beans). Many reported that in general, their children tended to dislike tactile input that was unpredictable, indistinct, complex in form, light, sticky or that was extreme in temperature or texture (e.g., sand, feather dusters, water paint). On the other hand, a few indicated that their children liked to handle these types of materials. Overall, participants said that they used a trial and error approach to determine what works best for a particular child. They identified a need for the development of guidelines and other tools to help them determine effective tactile strategies.

Meaningful instruction. The importance of meaningful instruction emerged as another overriding theme. Participants felt that children who are deaf-blind learn most effectively when instruction occurs within familiar routines, activities, and environments. The use of real items that have a useful purpose instead of fabricated or artificial ones (e.g., a real orange rather than a plastic one) was mentioned repeatedly as essential for enhancing concept and language development.

Supportive and positive instruction. The importance of using a very positive and respectful approach when interacting with children who are deaf-blind was also emphasized. Participants felt that children should not be forced to manipulate objects or engage in other tactile learning activities. They should be approached with sensitivity and given ample time to receive tactile information. Repeated use of words such as rapport building and non-intrusive underscored the importance of this approach.

Awareness of what motivates a child and how to pair that motivation with an unfamiliar tactile item was identified as an effective strategy. For example, some children are motivated by an activity such as music or movement, in which the tactile exploration of objects could be encouraged. Preschoolers who

have some hearing and enjoy music may cooperate with handling play dough if the adult sings. This is the way we roll the playdough, roll the playdough, roll the playdough... Consideration regarding the type of touch and where on the body the child likes to receive tactile information was also stressed. Instead of demanding that a child hold and examine an item, participants felt that they should follow the child's lead, offer opportunities for the child to come into contact with materials, and invite the child to handle items in shared activities.

Systematic instruction. Participants stressed the importance of routines and repetition to support learning. Consistency in the presentation of information across different settings (e.g., both at home and at school) enable children to generalize concepts and skills. They seem to better understand activities that have a clearly marked beginning, middle, and end. Participants also indicated that the use of instructional prompts (e.g., holding the child by the wrist to encourage exploration of an object) and cues (e.g., touching the child's hand with an object) help children use tactile strategies. Prompts should be withdrawn gradually as the child learns to respond to natural cues.

Adapting from the visual to the tactile mode. Despite their acknowledged expertise, comments from most participants suggested that adapting visual materials is very challenging. It is difficult to convey adequate information about many concepts or objects through tactile adaptations alone. For example, information about objects that are very large (e.g., a car) or very small (e.g., an ant) or that move quickly (e.g., a bird flying), require explanation. Participants indicated that in these cases they provided a spoken or signed explanation about the tactile adaptation to the child.

Concepts that are easy to understand when seen, such as identifying facial expressions or recognizing feelings, are much more difficult to recognize through touch. The imitation of physical actions is another visually-based learning strategy that is difficult to adapt to a tactile mode. Typical tactile adaptations in these situations are to guide the child through specific actions or movements (hand-over-hand guidance) or to let the child feel another person's movements or actions (hand-under-hand guidance). At best, these strategies provide tactile modeling or demonstration. Imitation requires that the child use tactile information to mimic what he or she has experienced.

Although tactile learning often refers to the use of one's hands to learn, focus group participants viewed this as a very narrow interpretation. They advocated an expanded definition to include the use

of the feet, chest, stomach, face, and the whole body in addition to hand use. While this may be particularly critical for children with significant limitations in hand use, participants also indicated that learning through other body parts was helpful for children whose hands were hypersensitive to tactile input.

Confusing terminology. Throughout the focus group meetings, participants used many different terms to describe tactile strategies. Some terms such as tactile signals, touch cues, motoring, physical prompting, and tactile signing were defined in different ways. This variety and confusion in terminology also emerged from the literature review. For example, as broadly defined by Rowland and Schweigert (2000) the term tangible symbols includes both two- and three-dimensional symbols (pictures, textures, and objects). However, in the traditional augmentative and alternative communication literature, tangible symbols are restricted to those symbols that can be discriminated on the basis of shape, texture, or other tangible properties; therefore excluding pictures and other two-dimensional symbols (Beukelman & Mirenda, 1998; Downing, 1999). The use of vocabulary from multiple disciplines has produced similar terms with different meanings and multiple terms with similar meanings. This is an area where standardization is needed.

Conclusion

Our review of the literature and comments from focus group participants have raised complicated questions regarding the use of touch with children who are deaf-blind. In the next three years, SALUTE will address these questions through the systematic use of individualized tactile learning strategies with children who are deaf-blind and have additional disabilities. We would like to invite readers to share their questions, concerns, and resources related to the use of tactile strategies with children who are deaf-blind.

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Project Information

Working with a National Advisory Committee, focus groups and selected children in California, Project SALUTE staff will identify, develop, document, and validate tactile learning strategies for children, infants through elementary school age. One focus group was conducted with Spanish-speaking families in order to produce materials that are culturally responsive. Materials will include a manual and videos (closed captioned and in English) demonstrating activities in both home and school environments. The video of home activities will also be in Spanish. Project SALUTE is a model demonstration project funded by the U.S. Department of Education grant #H324T990025 to California State University, Northridge.

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Web Site for Post-Secondary Deaf-Blind Students

<http://www.peersupportdb.com>

This is a resource for students who are deaf-blind attending post-secondary institutions, such as colleges, universities or technical schools. It is primarily intended for students in British Columbia, Canada, but contains information that may be of use to others as well, including causes and types of deaf-blindness, how to access post-secondary services, funding, an overview of resources, and using adaptive technology.

Research-to-Practice

Parents Use a Research Technique to Help Their Children with Cortical Visual Impairments

Karen Goehl
Georgia Hambrecht

In the truest sense of the idea of research-to-practice, the Indiana Deafblind Services Project developed and co-sponsored a program to train parents to use a single-subject research design to improve specific skills of their children with cortical visual impairments (CVI). The single-subject design is a research method well known to behavioral scientists and clinicians. It is used to examine a specific behavior of an individual (the subject), introduce some form of intervention, and evaluate any resulting change in behavior. This design is often used in situations where it is important to reduce or eliminate behaviors that interfere with a student's ability to function, such as self-stimulation or hitting others. Alternatively, it may be used to increase desired or useful behaviors such as paying attention to tasks or participation in social activities.

There are several different types of single-subject designs. One common type, applied behavior analysis, begins with taking baseline measures. A baseline is the frequency (e.g., number of times in a day) or intensity that a target behavior (e.g., tantrums) occurs prior to any intervention. An intervention strategy (e.g., communication training) is then implemented. Target behaviors continue to be charted on graphs during and after the period of intervention. The graphs depicting behavior change are reviewed to determine whether a change occurred due to the introduction or withdrawal of the intervention strategy.

Sixteen families (28 family members) participated in the Indiana project. All had children with CVI who were six years old or younger. Eight of the families had deaf-blind children. The family members attended a workshop where they learned about new strategies to promote the development of functional vision that are proving to be effective when used with infants and toddlers who are visually impaired. Family members were also taught to use a formal process to select and apply these strategies to help their children acquire specific skills and behaviors. Essentially, the families learned to become active participants with research teams.

Several weeks prior to the workshop, eight education professionals received training as facilitators. The role of each facilitator was to help family members take their ideas and turn them into doable single-subject studies. They helped each family interpret technical language, go through the process of designing a study, develop an intervention, understand how to observe their children's behaviors, and develop a method to collect and record data.

Facilitator training was conducted by Georgia Hambrecht of the Department of Communication Disorders and Special Education at Indiana State University, and Karen Goehl, Project Director of the Indiana Deafblind Services Project. They reviewed several topics with the facilitators including single-subject research designs, data collection methods, and strategies for encouraging use of functional vision in young children with CVI.

During parent training, the 16 families were divided into 8 groups (2 families per group). Each was assigned to one of the facilitators. Most of the families were accompanied by one or more of the service providers who worked with them (e.g., developmental therapist, occupational therapist, speech therapist). Parents were guided through a specific process that began with describing their children's vision and hearing abilities, and concluded with a description of their baseline and training procedures.

Each family submitted a completed research design by the end of the workshop. Parents and family members determined which behaviors of the child were important to focus on (e.g., visual tracking, reaching, lifting head, scanning objects, attending to other people), and specific tips or procedures to use at home to help improve or change the behaviors. Family members had to describe how they would record the targeted behaviors, and what form of data (percentages, rates) they would use to examine changes over time. *(See next page for an example of a design created by one family—the child's name and other identifying information have been changed).* The families then used specific data reporting forms to chart their children's progress.

Family-centered programs such as this one give parents and care providers a sense of control and involvement, realistic expectations, and the direct experience of shared success. This project provides an example of a commitment to empower families by giving them access to tried-and-true methods to promote skill development in their own children. The Indiana Deafblind Services Project is continuing to gather data that family members submit about their progress. For additional information, contact Karen Goehl at 800-622-3035.

Cortical Visual Impairment: Linking Information to Strategies

To Do Form

Name of Child: *Kevin*

Age of child: *2 years 6 months*

1. Write a brief description of your child's vision and hearing abilities.

- ◆ **Vision:** *Light sensitive, more in left eye; seems to turn to light, no tracking, no functional vision. Right eye too damaged.*
- ◆ **Hearing:** *Mild loss left, moderate right. He can localize; discriminates words, voice discrimination.*

2. Expand the definition of the behavior you wish to change.

- ◆ **Behavior:** *Roll to favorite toy (Elmo toy squeaky worm) and reach for it.*
- ◆ **Definitions:** *The care giver will be 3-5 ft. from Kevin and the toy will be presented visually & auditorily and with verbal encouragement; with tactile cue/sign.*
- ◆ **Example:** *Kevin will roll to the toy when it is presented visually and auditorily and with verbal encouragement and he will reach for it.*
- ◆ **Iffy instances:** *Auditorily or visually at tends, or complains without moving toward the toy; rolls in wrong direction.*

3. Write the three tips you are considering.

- ◆ *Facilitate graduated steps through the activity.*
- ◆ *Use song/exaggerated intonation when we describe his act.*
- ◆ *Allow him time to process auditory information.*

4. Write the one tip you want to try.

Sing command to London Bridge Tune, You are rolling to the toy.

5. What are some reasons (examples or facts) why you picked that tip?

He loves music.

6. Write your Best Guess idea. (Start with a general Best Guess idea in the following form: If I use (tip) then (child's name) will (behavior).)

If we use this individualized song, Kevin will localize and roll & reach for the toy/person.

7. Decide how you will count the behavior.

Rolls to toy and reaches for it (3-5 ft).

8. Select the data form (percentage, duration, rate).

Percentage.

9. Describe in detail how you will implement your Best Guess idea (who, what, when).

10. Describe your procedure for Baseline and Training including time for each (number of days you plan to do old way and with new tip).

- ◆ **Baseline** *3 consecutive days lay him down, squeak toy 3 ft away and observe response.*
- ◆ **Training**

11. Identify who will be responsible for sending the data to the Deafblind Project.



A Special Library

Gail Leslie
Peggy Malloy

Susan is a special education teacher. In two weeks, a 5-year old deaf-blind boy will be enrolled in her class. She has never worked with a deaf-blind child before. She is anxious to learn as much as she can about deaf-blindness and teaching strategies for this student.

David is 17 and has Usher syndrome. He is planning to go to college and needs information about how to make sure the school he attends is able to meet his needs.

Annette and Robert are the parents of a 3-month old son, Danny. Danny was born prematurely and has severe vision and hearing loss. They want to make sure that Danny gets the best possible education and know how important it is to start early. They need information about early learning and communication.

Jennifer is a graduate student. She is writing a research paper about the impact of deaf-blindness on learning. She needs help locating what has been written on this subject.

These examples show the range of information requests that DB-LINK staff receive on a typical day. When the federal government launched plans for a clearinghouse specific to deaf-blindness in 1992, its intent was to make information about this disability widely available. Today, DB-LINK responds to requests from people throughout the United States and is nationally recognized as the central source for the collection and distribution of information about deaf-blindness.

Two aspects of information management have been essential to our success. First, DB-LINK was designed to combine features of both clearinghouses and libraries to create a service that makes us unique among information providers. Second, we were fortunate that our development occurred at the same time that information technology was expanding. This made it possible for us to take full advantage of computers and the Internet.

Clearinghouse/Library Design

A clearinghouse is an information center that traditionally functions by making general information about a specific topic available to any one. Clearinghouses usually maintain a small selection of publications and resource lists, and are often expert at

providing their customers with referrals to meet more specific needs. As a clearinghouse DB-LINK has developed topical publications that meet the general needs of our customers and we maintain information about a network of service providers for referral. These include agencies, support groups, schools, and consultants. We have also developed a level of service and a focused, deep collection of materials that is not typical of most clearinghouses. In this way, DB-LINK functions more as a special library.

A special library is a library that has a unique focus and develops a comprehensive, in-depth collection of materials about a specific topic. Special libraries are found in government agencies, private companies, museums, hospitals, and other similar organizations. The mission of a special library is to organize and manage a body of information not readily available anywhere else or to meet the needs of a particular group of people.

Prior to the establishment of DB-LINK, it was hard to find in-depth information about deaf-blindness. State deaf-blind projects had small resource libraries, but they were not comprehensive or widely available to parents and teachers. Because deaf-blindness occurs in a small number of people, it is a topic rarely included with the education or disability information found in most libraries. Before DB-LINK, much of what was written about educational methods and research in the field had no visible network for distribution. For these reasons, it was important that DB-LINK comprehensively collect all available useful information about deaf-blindness and make it easily accessible.

Currently, our library includes books, articles, videos, newsletters, conference proceedings, research findings, and catalogs. By using such standard library practices as collection development, database creation, centralization of resources, and reference service, DB-LINK has created greater visibility and accessibility for information about deaf-blindness. We also collect information from other subject areas that deepen our ability to support the specific informational needs of our customers. Topics in these areas include special education, disability law, medicine, assistive technology, and funding opportunities.

Most important to our customers, is the responsive nature of our service. DB-LINK information specialists research and deliver specific responses to questions. We provide articles, resource and curricula lists, and locate information online. Our customers include parents, deaf-blind individuals, teachers, researchers, IEP teams, and technical assistance providers. We support families and teachers with infor-

mation that can make a difference for their child or student. Our ability to respond uniquely to each request makes it possible for anyone, regardless of geographic location, to access our library.

The Influence of Technology

Emerging technologies have allowed us to format information and provide a range of services that were not even a twinkle in the federal government's eye when they initially planned this project. We were fortunate to begin in 1992, when few people were anticipating the information explosion that would follow in the next few years. As we developed, the fact that we were unburdened by a history of established practices made it very easy to take advantage of computers and advancing technologies.

Timing, knowledgeable staff, and supportive institutions have been key to integrating our use of technology, affording us the opportunity to move information into the hands of a much wider community of users. Our web site offers full access to our databases and publications, and current information about research projects, training opportunities, and conferences. It also provides a starting point for locating additional information on the web. Familiarity with computers and the Internet is not necessary to access DB-LINK, however. The majority of our customers still contact us by phone.

DB-LINK also uses technology to manage a variety of e-mail discussion groups. These give families, professionals, and consumers an opportunity to exchange personal experience and knowledge via e-mail.

Additionally, technology has made it possible for DB-LINK to operate as a consortium. Three primary agencies work together on DB-LINK: Teaching Research at Western Oregon University, Perkins School for the Blind, and the Helen Keller National Center. Electronic databases, a rotating 800 telephone number, and the ability to move large amounts of information via the Internet has made it possible for us to remain geographically separate, yet provide unified service delivery.

Technology has helped to create a network that extends the impact of information and is transforming the field of deaf-blindness. DB-LINK is now part of a community that is developing information resources and increasing awareness about deaf-blindness throughout the world.

What You Can Do

At DB-LINK, we collect information in a variety of ways. We subscribe to journals and newsletters. We attend conferences and collect proceedings. We

search online databases and the Internet. We collect information produced by research projects and state deaf-blind projects. At every step of the way, your partnership is critical to our mission to provide service and access to quality information. You can help. Send us notices or copies of new products such as books, articles, manuals, and videos, so that we can add these to our collection and publicize their availability. Send us materials you develop for training programs or conferences. If you run support groups or work for schools, agencies or organizations that provide services to deaf-blind individuals, help us keep our resource database up-to-date. Call us or check the resource database on our web site to see if your organization is currently listed and the information is accurate. Contact us if you have expertise in deaf-blindness and are interested in being listed as a consultant in our database.

Think of us as your special library and spread the word about DB-LINK. Let families, teachers and other people who work with deaf-blind children and youth know that we are available by phone, TTY, e-mail, fax, and on the web, to assist in meeting their information needs. Tel: 800-438-9376, TTY: 800-854-7013, dblink@tr.wou.edu, <http://www.tr.wou.edu/dblink>



Personal Perspectives

Peggy Malloy

With this issue of *Deaf-Blind Perspectives* we begin what will hopefully be an ongoing column about deaf-blind people, their families, friends, and the people who work with them. In each column we will profile one to two individuals to find out about their lives, their work, and what they think is important for the field of deaf-blindness. The purpose is to give readers an opportunity to learn more about each other and to give individuals an opportunity to share their personal views about deaf-blindness. I want to thank Barbara McLetchie at Boston College for suggesting this idea. For this first column, I talked to Barbara Miles, a private consultant who specializes in communication issues, and Janie Neal, a private consultant, teacher, and speaker in Seattle.

Barbara Miles

Through her work as a consultant, teacher, and writer, Barbara Miles helps deaf-blind children learn and communicate by teaching their parents, teachers, and other professionals effective teaching methods. As a private consultant with expertise in

communication issues, she provides training about individual deaf-blind children to teachers and parents. Her goal is to inspire the people that she works with and give them perspective on their teaching methods. She sees her role as supportive and says that the real heroes are the parents, and the teachers who work directly with deaf-blind children. Barbara also does presentations at conferences and workshops and works for the Hilton/Perkins Program in Asia (mainly Indonesia and Malaysia) and Latin America, helping to establish classrooms for deaf-blind children.

Prior to starting her consulting business, Barbara was a teacher of deaf-blind children at Perkins School for the Blind. She developed an interest in deaf-blindness when working as a volunteer at a school for disabled children in Rutland, Vermont. She was fascinated by the challenge of making genuine contact with deaf-blind children and found that she needed to learn to experience the world differently in order to communicate with them. This experience inspired her to obtain a master's degree in deaf-blind education at Boston College.

Barbara told me that her work is very important to her because she believes that deaf-blind children have important things to teach us about ourselves. She said that deaf-blind children, Teach me to value every person, to slow down, to notice really small things, to pay attention to my hands and their hands, to value nonverbal communication, to be aware of the miracle of language, and to not pity myself. She quoted Martin Prechtel, a Mayan teacher, who spoke at a workshop she recently attended. He said, If you want to be blessed, you should go to a person in the society who is shunned or discounted and ask them to bless you. Barbara says that every time she meets a person who is deaf-blind, she receives a blessing.

Barbara is a wonderful writer. She has written three fact sheets for DB-LINK: *Overview of Deaf-Blindness*, *Talking the Language of the Hands to the Hands*, and most recently, *Literacy for Persons who are Deaf-Blind*. She said that writing *Talking the Language of the Hands to the Hands*, about how deaf-blind children learn about the world and communicate with their hands, was particularly important to her. It gave her an opportunity to express her feeling that hand-over-hand teaching techniques don't work. She believes that controlling children's hands is not helpful. Writing the fact sheet gave her an opportunity to think and write about alternative teaching methods. Along with Marianne Riggio, Barbara also edited and contributed to a book called *Remarkable Conversations: A Guide to Developing Meaningful Communication with Children and Young Adults who are*

Deafblind, published in 1999. She is grateful to have had the opportunity to work with Marianne on the book. She also wanted to mention that she is also grateful for the influence of Sara Gaar who first made her aware of the importance of genuine conversations with deaf-blind children.

When asked how educational and other services for deaf-blind children and adults could be improved, Barbara said that as a society we need to show that we value deaf-blind children. One way to do this is to start paying teachers, paraprofessionals, and all other service providers excellent salaries. Good support services for parents, families, and teachers are also important. Additionally, professionals must really listen to deaf-blind people, ask them again and again what they need, and question assumptions that professionals know what is best for deaf-blind people.

Barbara has a dog named Rosie who has been with her to many important deaf-blind events. Barbara wanted to take this opportunity to say thanks to Rosie, Uncle Steve, Marianne, and all of Rosie's friends in the deaf-blind community. She says that the community of deaf-blind people and the people who work with and for deaf-blind people is really amazing and she feels fortunate to have met so many wonderful people.

Janie Neal

Janie Neal, a consultant, teacher, and speaker, has been incredibly active in raising awareness about deaf-blindness and improving services for deaf-blind people. She was diagnosed with Usher Syndrome Type 1 when she was 13 years old (six of her cousins also have Usher 1). She attended the Tennessee School for the Deaf and then went on to receive a bachelor's degree in psychology from Gallaudet University and a master's degree in special education from Georgia State University.

In the past, Janie worked as a teacher for deaf children. More recently, her efforts have focused on deaf-blind issues. She has taught workshops at schools, colleges, and conferences about communication methods and adaptive equipment used by deaf-blind people and has spoken to interpreting students about deaf-blind interpreting. She also consults with agencies that need information about deaf-blindness and provides peer support to other people with Usher syndrome. She has worked as a vocational rehabilitation teacher, was Project Coordinator for a Seattle Deaf-Blind Service Center recreation and leisure project, and twice served as Director for the Seattle Lighthouse for the Blind annual Deaf-Blind Retreat. She currently serves on the board of the American Association for the

Deaf-Blind and is a member of numerous committees for agencies such as Seattle Deaf-Blind Service Center, King County Sound Transit, and Helen Keller National Center. She is a past president (two terms) of Washington State Deaf-Blind Citizens.

Janie believes that deaf-blind adults can serve as role models for deaf-blind children and that it is very important for deaf-blind children to be in contact with deaf-blind adults on a regular basis. Parents of deaf-blind children can also benefit from socializing with deaf-blind adults. She also has a number of suggestions for improved education for deaf-blind children. She suggests hiring deaf-blind adults familiar with educational objectives as consultants to assist with Individualized Education Program (IEP) development for deaf-blind children. She advocates the use of intervenors and/or support service providers beginning early in life to help deaf-blind children develop their potential to the fullest. She encourages parents to explore the use of all types of communication including sign language (visual and tactile) to communicate with their children.

Janie says that she uses humor to deal with the minor and major challenges that deaf-blind people face every day when encountering things that other people take for granted. She believes that it is important to enjoy your life to the fullest and never lose your sense of humor.



NTAC Parent and Family Activities

Kathy McNulty
NTAC Associate Director

One of the main objectives of NTAC (The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind) is to provide technical assistance to parents and families. During the past 4 years of our current 5 year funding cycle, this objective has been met in several ways: an annual national parent workshop in collaboration with the National Family Association for Deaf-Blind (NFADB), cooperative work with key groups and agencies on activities that provide parent and family related technical assistance in specific states, and production of resource materials designed by and for parents and family members.

With the requirements set by the Individuals with Disabilities Education Act (IDEA 97) regarding par-

ent/family participation in all aspects of the education of children who have disabilities, the year 2000 found NTAC searching for ways to maximize and expand its parent/family technical assistance activities. This article summarizes these efforts and hopefully captures our strong commitment to working with and for families of deaf-blind children and youth.

Workshops

NTAC supported three family-focused workshops in 2000. The first, *Family Specialists: Self-Discovery - Impact on Families*, was held June 24-25, in Minneapolis. This workshop, jointly sponsored by the Hilton-Perkins National Program and NTAC, was designed for family specialists who work for state deaf-blind projects and the 10 Regional Directors of NFADB. The Regional Directors are parents who sit on the NFADB board and are responsible for working with families and parent organizations in their assigned regions. The primary planners and presenters of the conference were Marlyn Minkin (deaf-blind consultant), Cathy Kirscher (Helen Keller National Center Regional Representative), Nancy O'Donnell (Helen Keller National Center), and Steve Perreault (Hilton-Perkins). The goal was to help each participant gain knowledge and awareness of conflict resolution strategies and greater understanding of the interrelatedness of power and position in relationships. Viewed as a follow-up to a family specialist workshop offered in 1997, it helped to enhance and strengthen an emerging network among the participants.

The second workshop, *Negotiating the Maze: Strategies for Effective Family Technical Assistance*, also in Minneapolis, was held June 26-27. The need for this workshop, attended by professionals from state deaf-blind projects throughout the United States, was identified by a survey of state project personnel earlier in the year. The program agenda included a strong blend of related topics that artfully combined the academic and human aspects involved in delivering technical assistance to families. Gwen Beegle (Beech Center, University of Kansas) spoke about how to translate current research on parent and family issues into effective practice. Kate Moss (Texas Deaf-Blind Outreach Project), Kathy McNulty (NTAC), and Sally Prouty (Minnesota Deafblind Project) gave a presentation on the who, what, where, when, and how of providing technical assistance to parents and families. Minnesotan parents Susan Smith, Liz McDevitt, Karen Wojcik, and Sally Prouty, and Arizona parent, Kim Lauger, participated in a panel presentation on parent perspectives. Gwen Whiting, family trainer and mental

health consultant, spoke about grief and how to maintain both professional and personal balance when working with families.

The third workshop, *Transitions-They Happen All the Time*, held August 10-12 in Salt Lake City, was co-sponsored by NTAC and NFADB. The topic, transition planning, was chosen based on the results of a national parent/family interest survey conducted by NTAC during the winter of 2000. The term transition is most often associated with young adults preparing to leave school, but NTAC and NFADB recognized that there are additional, equally important stages of transition. We designed a workshop to address different types of transitions throughout the educational years of children with deaf-blindness. The agenda focused on: issues that arise and stresses that may be experienced during any time of transition, strategies to alleviate stress and conflict, IDEA and effective transition practices for different age groups, and resources and services needed for a successful transition. To make the workshop more meaningful for parents, participants were divided into groups according to the age of their child: Early Intervention to Early Childhood, Early Childhood to School Age, School Age to Secondary, and Secondary to Adult Life.

To help offer training on transitions across a variety of age ranges, we assembled what we considered the dream team of presenters: Marlyn Minkin, a deaf-blind consultant on mental health issues; Dr. Gene Edgar, a consultant on transition and special education and a professor at the University of Washington; Linda Alsop, an early childhood consultant from the Ski-Hi project at Utah State University; Sue Olsen, an early intervention specialist in Utah; David Wiley, a transition specialist with the Texas Deaf-Blind Outreach Project; and Dr. Jennifer Grisham-Brown, a consultant on alternate assessment and functional curriculum for students who are deaf-blind, and a professor at the University of Kentucky.

The results of the workshop were extremely gratifying. Nearly 100 parents from over thirty states and staff from twelve state deaf-blind projects attended. Networking among parents began almost immediately and, with the knowledge and guidance provided by the excellent presentations, action plans were developed by each parent before leaving for home. As one parent wrote on an evaluation form, I loved the networking with other parents! I learned so much. I can hardly wait to take it back to my state.

State-Specific Technical Assistance

In addition to conducting workshops during the past year, NTAC has also worked cooperatively with people involved in deaf-blind education in numerous states to provide parent/family related technical assistance. This included such activities as working with parent/family organizations, helping individual state deaf-blind projects provide effective family technical assistance, and encouraging the inclusion of parents in state-wide training events that involve NTAC participation.

Resource Materials

NTAC has developed a number of resource and training products during the past year. Two were specifically designed by and for parents and families, *Communication at Home and in the Community: Helpful Strategies and Suggestions from Parents and Families with a Child who is Deaf-Blind* and *Transition Tool Kit for Parents*.

Future Activities

As NTAC moves into the fifth and final year of the current funding cycle, new activities under the parent objective are already under way. Work within individual states will continue and it is anticipated that a workshop for new family specialists will be offered. A set of communication fact sheets for parents and a fact sheet on family issues are in progress and scheduled for distribution this year. And last, but not least, something new and exciting is being planned for the National Parent Workshop in 2001. On August 2-4 in Miami, Florida, NTAC, NFADB, and the Hilton-Perkins International Program will host an International Parent/Family Workshop. Thirty parents from Latin America will join parents from across the United States to share their experiences of parenting and educating a child who is deaf-blind. As always, this coming year will find NTAC continuing its efforts to provide technical assistance to parents and families.



Looking for information about conferences?

We ran out of room in this issue. Please contact DBLINK for a current listing. Tel. 800-438-9376, TTY 800-854-7013, dblink@tr.wou.edu, or go to <http://www.tr.wou.edu/dblink/data>

Book Review

Charlotte Cushman, M.Ed.

Catholic Charities Maine/New England Center
Deafblind Project

Creative Constructions: Technologies that Make Adaptive Design Accessible, Affordable, Inclusive and Fun. Molly Campbell and Alex Truesdell, 2000.

Think creatively. Plan collaboratively. Build economically. That's the philosophy of the authors of *Creative Constructions*, a new book that offers a wealth of practical information about creating adaptive materials and equipment for individuals who have special needs. This helpful book is a resource for therapists, teachers, parents, and others looking for light technology options to solve problems or create opportunities for individuals who have disabilities. The authors share their views about working as members of a team, assessing assistive technology needs, and establishing adaptive design workspaces. The materials and techniques used to make customized assistive devices are described in a clear, straightforward manner. Topics include cardboard carpentry, paper-based technology, woodworking, fabric and foam use, plastic construction, and basic electronics. Examples of successful projects from their personal experiences are included to stimulate the reader's own creative ideas.

Alex Truesdell and Molly Campbell have extensive experience in the field of adaptive design. Both have worked as coordinators of the Adaptive Device Center at Perkins School for the Blind in Watertown, Massachusetts. Each brings a different perspective to their work. Alex is an education consultant specializing in teaching adaptive design. Molly is an occupational therapist with extensive experience in pediatrics, developmental disabilities, and adaptive design. They have taught workshops on the basic techniques of adaptive design around the United States and abroad.

Creative Constructions contains something for everyone. Educators and speech therapists will be interested to find information about tangible symbol cards based on the ideas of Dr. Jan van Dijk and the tangible symbol systems he developed for deafblind children in the 1960s. The purpose and function of tangible symbol cards are included as well as specific directions on how to make them.

There are numerous ideas for seating and positioning equipment that physical and occupational therapists will welcome, such as step-by-step instructions for building a corner chair. There are suggestions

for sensory motor equipment including sensory exploration boards and weighted blankets. Orientation and mobility instructors will find directions for making the Connecticut pre-cane. A range of activity centers are described, using many different types of materials. The authors outline some of the therapeutic benefits students gain from inviting and stimulating environments.

One of the greatest qualities of *Creative Constructions* is a friendly and approachable style that makes it easy to use. It is full of clear line drawings, lists of suggested tools and equipment, and photographs of materials and projects. The tone is inviting. It empowers the reader with a can-do attitude. This book is equally valuable to novices needing gentle encouragement and to more experienced readers needing a quick review or suggested resources.

Creative Constructions is a practical, straightforward resource book that is a must for anyone looking for creative, low-cost ways to design and make customized materials for individuals with disabilities. It is a welcome addition to the field and highly recommended for anyone with an interest in adaptive design.

Creative Constructions is available for \$24.95, plus \$5.00 shipping and handling for one book and \$2.00 for each additional book. Make checks payable to Molly Campbell.

Creative Constructions
659 Green Street
Cambridge, MA 02139
617-972-7520
mollycampbell@mediaone.net



For Your Library

Tangible Symbol Systems, 2nd Ed.

Rowland C. & Schweigert P., Portland, OR: Oregon Health Sciences University, 2000.

Describes how to teach people who are unable to communicate using speech, manual sign language or other abstract symbol systems to use two- and three-dimensional symbols to communicate. The book has been revised based on recent research involving individuals with deafblindness, mental retardation, autism spectrum disorders and multiple disabilities. A companion 75-minute video (2nd ed., published in 1996) is also available. Order via the web at <http://www.designtolearn.com> or contact Mayling Dixon, OHSU Center on Self Determina-

tion, 3608 SE Powell Blvd., Portland, OR 97202; Tel. 503-232-9154, ext 108, dixonma@ohsu.edu Cost: \$25.00 (book); \$15.00 (video).

The Intervener in Early Intervention and Educational Settings for Children and Youth With Deafblindness (NTAC Briefing Paper)

Alsop, L., Blaha, R. & Kloos E. Monmouth, OR: NTAC, The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind, 2000.

This paper includes: a discussion of the needs of children who are deaf-blind and how interveners can meet those needs; how to determine the need for an intervener during the IFSP or IEP process; logistical issues such as training, supervision and support; and commonly asked questions. Available on the web (<http://www.tr.wou.edu/ntac/publications.htm>) or through DB-LINK: Tel. 800-438-9376, TTY 800-854-7013, dblink@tr.wou.edu

The Preemie Parents Companion: The Essential Guide to Caring for Your Premature Baby in the Hospital, at Home, and Through the First Years

Madden, S.L. Boston: The Harvard Common Press, 2000.

This book includes information about caring for premature infants, parenting in the hospital, home care, infant development, and financial issues common to premature births. It also reviews common medical complications and discusses how to cope with difficult situations. Appendices include growth charts, infant CPR, immunization schedules, and other resources for parents. Available through bookstores.

Where Do I Begin? Developing Communication With Children Born Deafblind (Video)

Open-captioned. 23 minutes. West Australian Deafblind Association, 2000.

Focuses on key communication development strategies including making contact, building rapport, acknowledging communication efforts, tactile cues and symbols, tactile signing, routines, and choice-making. Available in both PAL (Australian format) and NTSC (US and Canadian format). Available from: WA Deafblind Association, 6th Avenue and Whatley Crescent (PO Box 14), MAYLANDS, Western Australia 6051, Australia; Tel. (08) 9 272 1122, TTY (08) 9 370 3524, wadba@nw.com.au Cost: \$27.50 (PAL) plus \$5.00 postage within Australia or \$10.00 outside; \$35.00 (NTSC) format, plus \$10.00 postage outside Australia. Checks or money orders in Australian currency only are accepted.

Charge Syndrome: A Management Manual for Parents

Hefner, M. & Davenport S.H.L. (Eds.) Columbia, MO: CHARGE Syndrome Foundation, Inc., 1999.

Contains a history of the CHARGE Syndrome Foundation, stories from families, a brief section on de-

velopment, extensive information on the medical problems of CHARGE, a glossary, and resources. Available from: CHARGE Syndrome Foundation Inc., 2004 Parkade Blvd., Columbia, MO 65202-3121, Att. Marion Norbury; Tel. 800-442-7604 or 573-499-4694, <http://www.chargesyndrome.org>, marion@chargesyndrome.org Cost: \$20.00 (includes postage).



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