

# Deaf-Blind Perspectives

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## Simulation Exercises to Help Stimulate Discussions about Communication Strategies Used with Students who are Deaf-Blind and Developmentally Delayed

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*Deaf-Blind Perspectives* has invited another author to respond to, and expand on this topic as it applies to students who are deaf-blind without cognitive challenges. —ED.

Communication is necessary to interact meaningfully with others. Often it is the block between students who are deaf-blind and developmentally delayed and their peers in schools. Information about various strategies can facilitate curiosity and exploration of ways to overcome these blocks. Most students in public and private schools are lacking role models of meaningful interactions between people using different communication strategies. People with developmental delays who lack a language base and use alternative strategies foreign to most outsiders are often seen as severely delayed. This, coupled with the dual sensory impairments of deaf-blindness and the lack of information about these losses, leaves huge gaps in our knowledge about how to communicate with these students. Open discussions about these issues and exploration of communication strategies can help identify solutions.

The following four simulation activities are used to introduce alternative communication strategies to general education students: (a) Toy Sculpture Descriptions (Cokely & Baker, 1980); (b) Blindfolded Art Projects; (c) Introduction to Sighted Guide; and (d) Non-language Sentences (Kettrick, 1988). Before proceeding with any activities you should clarify the students' options to participate, and provide some cautions about simulation activities. First, any student can choose not to join the activity. For non participants the only requirement is to observe and stay unobtrusive to those participating. Also, when the activity recommends a blindfold, students can choose to close their eyes if the blindfold is uncomfortable.

Second, caution students about pity. Often simulation experiences are equated with a disability. These exercises will not result in "knowing" what it's like to be deaf-blind or cognitively impaired. There is no way for

anyone to experience that through simulation. When we put on a blindfold we experience an immediate loss of a sense we are used to having. Since there is no acclimation time, our perception of the experience will differ from that of a person who has had time to adapt. A typical reaction to this immediate loss is the feeling that you would never be able to adjust. Students sometimes say, "I would kill myself if I had to live like this," or, "Oh, life must be so hard for blind people." It is good to discuss this before beginning the activities. Students should learn that pity is a common reaction. They should also know that it is a reaction that is superficial. Students should remember that they cannot experience firsthand what blindness is like. Since many of them have no role models in their lives from whom they have learned about blindness, their knowledge of blindness is abstract. Students need to learn that people with visual impairments can lead full and normal lives. Meeting people who are blind, or deaf-blind can offer more realistic perspectives to students.

### In This Issue

<b>Simulation Exercises to Help Stimulate Discussions about Communication Strategies Used with Students who are Deaf-Blind and Developmentally Delayed</b> .....	1
Jennifer White & Lyle T. Romer	
<b>From The Editor</b> .....	6
John Reiman	
<b>A Special Thanks</b> .....	7
Vic Baldwin	
<b>Hand in Hand Publications from the AFB Deaf-Blind Project</b> .....	7
<b>DB-LINK Fact Sheets</b> .....	8
<b>"Free To Be Me"</b> .....	9
Joann Twitchell	
<b>Announcements/Calendar of Events</b> .....	10
<b>For Your Library</b> .....	11

## Toy Sculpture Descriptions

### Objectives

- To sense the need for, and to utilize space in visual communication strategies by exploring the ideas of referencing<sup>1</sup> and communicator's perspective<sup>2</sup>.
- To begin to understand the differences between linear sequential communication, such as in English, where meaning relies heavily on word order, and inflective communication, such as in American Sign Language (ASL), Russian, or Latin, where affixes are often attached to words to show how symbols are related regardless of where they are placed in the sentence.
- To experience the process of agreeing on certain symbols and rules of communication without using language.

### Materials

- Bags of toys, each containing two identical sets of five toys, for example, two horses, two fences, two dice, two airplanes, two snakes.
- Dividers to place between partners. These prevent partners from seeing each other's toys. Manila folders or textbooks can be used.

### Description

Tell students to form pairs. Give each pair one bag of toys to divide between them so that each person will have the same toys as his or her partner. A divider is placed between the pair before beginning. This exer-

cise is nonverbal: No vocalizations are allowed; in fact no language is allowed, signed or spoken. (Deaf and hearing students alike are instructed to use no language.) Instead, students are instructed to use their bodies, faces, gestures, and space to communicate with their partners. The object of the exercise is for one person to arrange the toys in some order or configuration and then to describe to the partner how to set his or her toys up to look the same. Demonstrate with a volunteer and answer questions before asking students to begin.

It is very challenging for students to refrain from using their natural language during this exercise. Circling the room to remind them to think of another way to communicate is a good idea. For example, hearing students will often decide who goes first by talking about it. When asked, they can come up with several alternative ways to establish this: pointing to themselves and then holding one finger up to signify first, holding out both hands to the other person offering them the chance to begin, or pointing alternately to themselves and their partner and shrugging their shoulders while raising their eyebrows to ask who should begin.

<sup>1</sup> In (ASL) Referencing refers to setting nonpresent objects, places, and people in space. Once established, the signer can refer to these objects and people without identifying them by formal name each time. Also, referencing means the process of referring to familiar and established communication. For example, once a symbol for a toy is set in space, it can be used to show the relationship of subsequent toys.

<sup>2</sup> Communicator's perspective is the idea that all people in the communication are seeing space from the perspective of the communicator.

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Once the exercise has begun, students are to continue taking turns back and forth. Some pairs will have success from the beginning. Others will never get a completely replicated sculpture. Some pairs will increase their accuracy with each turn; others will not.

After the exercise is completed, ask the students to describe their experiences. The discussion that follows varies with each group and results in many insights about interpersonal communication skills, visual versus spoken language, the power of language skills and the frustration of losing them.

Many students have commented on the excitement of successes. When communication is smooth and they are working in a new medium, they feel thrilled to be able to get their points across. But when misunderstandings occur, or accuracy is not complete, many students resort to blaming the other person. One student put it best when quoting from an episode of the television show, *M\*A\*S\*H* in which the character BJ comments on Americans, saying, "We assume that everyone will understand English if only we speak loudly and slowly enough." It seems easy to blame the other person when we feel very clear about our own communication skills and points we are making. Discussions regarding communication as a two-way interaction usually ensue here.

Students have brought up the question of whose responsibility it is when someone doesn't understand. If another person has let us know they are confused, and we continue with the same tactic of expression, where does the responsibility lie?

## Blindfolded Art Projects

### Objectives

- To explore the differences between helping and deciding for someone else.
- To explore dependency upon another as well as another's dependency on you.
- To begin to understand tactile methods of communication.

### Materials

- Art supplies; paper, colored markers, glue, glitter, scissors, yarn, scrap cloth, and stencils.
- Blindfolds.
- Instructions written in bold print on a large piece of paper (large enough for all to see from their seats): "Help your partner make something, anything."

### Description

Have students form into pairs. One person will be blindfolded. Explain that they will be blindfolded before they get any instructions. Only the sighted people in the room will know what the instructions are. This will be a silent exercise. No talking or vocalizations will be allowed. No tactile signing is al-

lowed. The students will communicate using gestures, objects, and physical prompts.

After one person puts the blindfold on, hold up the instructions for all without blindfolds to see and say, "These are the instructions and here are the materials." Point out the materials.

Once students have completed a picture, sculpture, or other project, let them take the blindfolds off. Allow students time to talk with their partners first and then to talk as a group about this experience.

Ask the following questions to lead the discussion:

1. Did you understand what was expected of you?
2. Did you know what materials you could choose from?
3. Did you make what you wanted to make or did your partner decide for you?
4. How did your partner communicate to you?
5. If you could tell your partner one thing that was helpful and one thing that was not helpful, what would it be?

Explain to the group that this exercise was a set-up. They don't all have the skills to comfortably provide tactile information. The point is to think about why we take over for people when we don't know how to offer choices. Then discuss some successful strategies students used and offer some information regarding tactile methods of communicating: (a) letting the person know all the materials available by putting each one in his or her hand to explore; (b) letting the person set the materials down on his or her own desk or guiding them to do this and leaving materials where they are (you can't see where they've gone to when you are blindfolded); (c) making something yourself with the materials with the blindfolded person's hand placed on top of yours for them to "watch" tactually what you are doing and then offering them the materials. Those methods help orient the blindfolded person to the task and the choices available.

## Introduction To Sighted Guide

### Objectives

- To learn some techniques for safely guiding a person with a visual impairment.
- To experience the trust it takes to put your physical safety into someone else's hands.

### Materials

- Blindfolds

### Description

Depending on the school layout and weather, choose from two different exercises in sighted guide. For both give the following rules:

1. Vision and hearing are distance sensors. They supply us with information on how to react to our environment. For this exercise you will be blindfolded and will not have access to the same information you are used to getting about your environment. Because of this no horseplay is allowed. It's very tempting when your friend is wearing a blindfold to try to tease and taunt him. Don't. It is disrespectful in the deaf-blind community to surprise someone in this way.
2. There will be no talking or vocalizations allowed in this exercise. No tactile sign language or language of any kind can be used. Students must rely on tactile feedback with their partners.

Demonstrate with a volunteer the following techniques:

1. Guide the volunteer's left hand to your right elbow. The hand should be cupped around your elbow with the thumb on the outside of your arm. It should be a comfortable grip, yet one not easily broken.
2. Show that when guiding someone you become a safety block for their body. This means you must remember that you are now twice as wide as you normally are. It is your job to protect the person from objects blocking the path (open doorways, tables, shelves, tree branches). You can show this by walking through an aisle between desks, first alone and then guiding someone.
3. Always pause when there is a change in the terrain. You can show this by moving from a carpeted area to an area of tile, or something similar.
4. Doors and stairways can be very dangerous. Always take them slowly. Pause before entering or going up or down. When possible, gently guide the blindfolded person's hand to the railing of the stairway, or to the door being opened, to give him or her as much information as possible about the route.
5. Pay attention to signals from the person you are guiding. If he or she is pulling back on your arm it probably means you need to slow down. The object of the exercise is for your partner to trust that you will guide in a safe manner.

After demonstrating these techniques and answering any questions, begin the exercise. One person in each pair puts on a blindfold without getting instructions. After all the blindfolds are in place, hold up a sign with one of two directions. One option is to walk outside and pick up a small rock with the partner and return to the room. Another is to guide the partner to the water fountain and get a drink. The rock experience evokes some good discussion because it's hard to make sense of any meaning and the blindfolded person gets lost in wondering why they are doing this, similar to some students with cognitive and sensory impairments. These instruc-

tions can be varied to fit the needs of group size, age, and energy level. Generally, when the students are younger give very specific instructions such as "Go to the closet and help your partner get their coat on," or "Walk to the playground and meet me at the slide." With older students you may give more open-ended instructions: "Go outside with your partner and let him or her explore the environment, trees, and buildings."

When the exercise is completed, allow students time to talk with the partners and then talk as a group. Discuss the dependency involved in sighted guide and what it means to trust someone and be trustworthy as a guide. Also talk about how information was passed between partners. Students' comments have addressed the fear of not trusting their partner, wondering why everyone else was laughing at them, noticing the heightening of their other senses, how long it took to orient themselves, anger at the sighted partner for not providing enough information, delight at trying out a different way to take in the world, and the awkwardness of trying to make their communication clear to someone tactually. Discussing the lives of some deaf-blind people we know, or inviting a deaf-blind adult to speak with the class to answer questions about how to maneuver in the world without vision and hearing are excellent ideas.

## Non-language Sentences

### Objectives

- To experience the task of receiving and expressing abstract thought without the medium of language.
- To rely on gestures, props, and mime as the primary modes of communication.
- To begin to track one's own limits and levels of frustration when message clarity takes more effort to achieve.
- To begin to understand the notion that concepts do not equal words.

### Materials

- Paper and markers.
- Box of toy props including food items, people, vehicles, animals, atlas, and a map of the United States.
- Sets of questions found below. Have enough sets of questions so each pair of students gets a complete set. Each set consists of four slips of paper, each with one of the following sets of questions. One partner of each pair gets slips 1 and 3, the other gets slips 2 and 4.

### First Slip:

1. How do you get to school in the morning?
2. What is your favorite kind of pizza?
3. Where would your ideal vacation be?
4. Is your house one or two stories?

5. What is your favorite T.V. show?

### Second Slip:

1. Have you ever been to Paradise Lodge on Mt. Rainier?
2. What do you think is humankind's worst problem?
3. What kind of car do you drive?
4. Do you know how to sew?
5. Do you know how to change a tire?

### Third Slip

1. What is your favorite sport?
2. Where did you go on your last vacation?
3. Do you have a garden?
4. Where was your father born?
5. Are you taller than either of your parents?

### Fourth Slip

1. Where do you live now?
2. Where did you live five years ago?
3. What is your favorite ethnic food? (Chinese, Thai, Italian)
4. Do you have any pets? If yes, what are they?
5. What is your favorite holiday?

### Description

Write the following directions on the board and read them to your students:

Find out from your partner the answers to the following questions. Do not use any language. You may draw, use props, natural gestures, and mime. Explain the word "language" to mean all agreed-upon symbols. Nothing from the typewriter keyboard can be used, and no symbols for woman or man. Arrows and pictures are the only symbols allowed when drawing.

Demonstrate with a volunteer using the question "What is your favorite color?" Point to yourself and then line the markers up on the table (standing them upright so all the class can see them). Begin with the first marker in line, pick it up and raise both hands in a thumbs-up sign. Kiss the marker and hold it high. Proceed to the second marker and give it a look of approval as well as a thumbs-up. The third marker gets a so-so hand movement (hand palm face down, open five fingers, rotate right downward movement and left downward moment from the wrist). To the fourth marker give a look of "could care less" by shrugging your shoulders and using facial expressions. Pick up the fifth marker and throw it on the floor with a distasteful look on your face. Then gather all the markers together and hand them to

your partner with a shrug of your shoulders and raised eyebrows while pointing to them.

Remind the class of the instructions and add no talking to the list. Ask them how you got your partner to answer your question. They usually respond by noting that first you showed them your own favorite color then you asked for theirs. Then proceed with the exercise. Each partner takes turns asking the questions from his or her slips.

After completing as many questions as they can, allow students to talk with their partners followed by a group discussion. The group discussion involves topics such as how your life experience affects your answers. For example in the question, "Have you ever been to Paradise Lodge on Mt. Rainier?," some people who had never known about the site on the mountain thought they were being asked if they had been camping in the mountains before. Discuss the need for concrete tools with which to communicate, and how students started with the concrete and moved into abstract thoughts. Also discuss the idea of first setting up the concept and then making the point. In other words, first let your partner know you are talking about colors and the idea of favorite, then ask their opinion. Touch on the frustrations felt when we know what we mean and then expect the other person to understand us when we think we are being clear. This quickly leads us into discussing blame and how communications break down. The discussion is not closed to any one theme, as this exercise brings up all kinds of comments and thoughts to explore.

Last, demonstrate one way to conquer the question often perceived as the hardest, "What do you think is humankind's worst problem?" Explain that for a long time people thought this question too challenging to ask until one student proved otherwise. He drew five circles on the board representing faces, with two eyes and straight line mouths. He drew vertical lines between each of the faces, to indicate that each was a separate category. He then pointed to the first face and acted out an airplane flying overhead and dropping a bomb, then drew a mushroom cloud on the board. He walked over to the first face and drew four tears coming out of its eye. He then pointed to the second face and acted out a terrorist hijacking (using another student as "hostage"), and pointed on the map to the Middle East where a hijacking had recently occurred. He walked to the second face and drew two tears. After pointing to the third face, he mimed being a malnourished baby with protruding belly, who eventually dies. He pointed all over the world and drew numbers of children on the board to signify the enormity of this occurrence. He walked to the third face and drew three tears on the board. He walked to the fourth face, pointed and then drew and acted out many trees being cut down by bulldozers, factories dumping waste and killing fish, and many buildings covering the earth, crossing out the trees and animals as each building went up. He then walked back to the fourth face and drew three tears. Then he pointed back to

the first face and held his hands over his heart and made a pained face, pointing to the four tears and to himself.

Then he handed the chalk to his partner, pointed to all four faces and to the fifth space which was left blank for a new idea, shrugged his shoulders and pointed to his partner.

### SUMMARY

All four of these exercises are used to get students to think about communication in a wider range of modalities and to let them know they have the capacity to communicate in depth without the use of words or signs. Encourage students to continue these exercises, or to try them with friends or family members, to make blindfolds and practice eating or getting dressed while wearing them. Books written by Fred Gwynne (1970; 1976) illustrate beautifully the importance of clarifying your concept instead of relying on words and are excellent for continuing discussion on the role of language and communication in our relationships. His books *The King Who Rained* and *A Chocolate Moose for Dinner* are about a young girl's misunderstanding of the words used in the world around her.

Another suggestion is to invite adults who are deaf-blind as role models to the classroom. We have found that this gives students an understanding greater than any exercise we have tried. Although the students who are developmentally delayed differ in cognitive process and life experience from those who are not developmentally delayed, they share the losses of vision and hearing. Adults who are deaf-blind can offer the most useful and complete information about methods, modalities, strategies and considerations regarding the dual sensory impairment of deaf-blindness. They also can provide for the students a model of what is possible. After meeting an adult role model students could more easily envision a full and meaningful life for someone who is deaf-blind.

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Requests for reprints should be addressed to: Lyle T. Romer, Ph.D., University of Washington, College of Education; Lifestyle Planning Project, 1915 First Ave., #1, Seattle, WA 98101.

## From The Editor

John Reiman

As I move to the steward's role with this issue of *Deaf-Blind Perspectives*, I bring to friends, colleagues, and other readers of this publication my wishes for a fulfilling and abundant new year. Before proceeding with some thoughts on our future, I wish to acknowledge the extraordinary contributions to the evolution of this publication made by its first Executive Editor, Bud Fredericks. Bud's sagacious counsel and inspired leadership launched *Deaf-Blind Perspectives* and carried it forward. Were I not to have the luxury of a biweekly Scrabble game with the now retired Dr. Fredericks to discuss life and the world, I would feel terribly deprived of contact with a mentor and friend.

I envision the task ahead of us at *Deaf-Blind Perspectives* as challenging in three ways. First, I believe that the changing role of government in the lives of all Americans, not only those who are deaf-blind, compels us in this field to search out and define our mutual interests. In order to mount a common defense against governmental withdrawal of funding, this publication must present a cross-section of perspectives of all those who are deaf-blind, and, at the same time, it must not present some artificially homogenized picture. By learning to understand our different needs and interests and by acting as much as possible as one faction, we can stop competing for the constantly diminishing piece of budgetary pie allocated to people who are deaf-blind, their families, and the professionals who serve them. By working together for common needs, all will benefit.

Our second challenge at *Deaf-Blind Perspectives*, is to involve more people who are deaf-blind and their families as contributors to the publication. Nonwriters need not feel intimidated. Our editors welcome the opportunity to take otherwise acceptable (useful/relevant to the readership) pieces of writing, and adapt them to fit the style and structure of *Deaf-Blind Perspectives*'s.

Our third challenge is to achieve overall balance in the type of material we present. Our goal, even if not in every issue, will be to blend the academic with the anecdotal, the light with the heavy, the practical with the philosophical, and the emotional with the logical.

I invite the readers of *Deaf-Blind Perspectives* to tell me and our extraordinary Managing Editor, Bruce Bull, about your likes, dislikes and hopes for the future of *Deaf-Blind Perspectives*. Since we genuinely want to hear from you we have included a survey in this issue. We would appreciate your taking the time to complete and return it to us.

## A Special Thanks

A lot of very uncertain things are going on in the United States Congress. Most federal budgets are not yet approved and some categories of funding are earmarked to be eliminated. The fate of funding for the Deaf-Blind Programs is also not clear but at least they are still on the table for consideration. The fact that they have survived this long can be attributed to several factors such as lobbying by parents, pressure from organizations, and a history of an effective program. However, the single most important factor has been the relentless presence of the National Coalition on Deaf-Blindness, specifically, Joe McNulty, Director of the Helen Keller National Center and Mike Collins, of the Perkins School for the Blind. They have hardly missed a single meeting in Washington, D.C. when the deaf-blind funding was being discussed. They have not used an “in your face” approach but by their mere presence (Joe has been practically commuting) they have been “in their space”. Everyone connected with this field owe Joe and Mike a great deal of gratitude and we need to take the time to applaud them.

## Hand in Hand Publications from the AFB Deaf-Blind Project

The following promotional information on *Hand in Hand* was submitted to *Deaf-Blind Perspectives* by American Foundation for the Blind (*Deaf-Blind Perspectives* disseminates, free of charge, descriptive information on the products of relevant federal projects).—ED.

Three unique books and a videotape of essential materials for anyone who works with someone who is deaf-blind are the final result of the AFB Deaf-Blind project. This four-year federally sponsored project, conducted by the American Foundation for the Blind, was charged with developing self-study and in-service training materials to fill the existing gap in information and resources for teachers who work with deaf-blind children and youths. Under the rubric *Hand in Hand: Essential for Communication and Orientation and Mobility for Your Students Who Are Deaf-Blind*, project staff and editor Kathleen Mary Huebner, Jeanne Glidden Prickett, Therese Rafalowski Welch, and Elga Joffe focus on providing information and instructional strategies in communication and orientation and mobility (O & M) because these are the two areas most influenced by the presence of combined hearing and vision losses.

To ensure that the project was as broad as possible in scope, a national consortium with representatives from the major national service organizations concerned with the field of deaf-blindness offered guidance and worked with the project staff in developing objectives and principles. More than 30 expert au-

thors contributed to the final publications, and many more reviewed the materials. A national field test of the draft materials was conducted by more than 120 teachers and other service providers in 46 states.

The guiding principles for all the *Hand in Hand* materials reflect contemporary thought on the education of students who are deaf-blind. Primary, is the understanding that all individuals who are deaf-blind can learn, communicate, and move with purpose. Therefore, the aim of all the *Hand in Hand* materials is to help teachers maximize students' development of skills to foster their independence. In addition, the materials emphasize the inclusion of families, including the student himself or herself, as well as all members of the educational team in delivering effective and successful services.

The following four *Hand in Hand* components can be used together as a comprehensive training program for teachers and other personnel or independently to educate staff, family, and community members.

*Hand in Hand: Essentials of Communication and Orientation and Mobility for Your Students Who Are Deaf-Blind*—A two-volume self-study text providing a comprehensive curriculum that explains how students who are deaf-blind learn and provides practical strategies for teaching, focusing on essential communication and O & M skills. Self-study questions and answers, wide margins for note-taking, technical appendixes, sample forms, glossary, and an extensive resource section maximize its usefulness as a learning and resource tool.

*Hand in Hand: It Can Be Done!*—An engaging one-hour video introduction to working with students who are deaf-blind, starring deaf-blind children and young adults as well as their families and teachers. It provides a graphic illustration of many of the principles and concepts in the self-study text. It is available in closed-captioned and audiodescribed versions.

*Hand in Hand: Selected Reprints and Annotated Bibliography on Working with Students Who Are Deaf-Blind*—A two-part volume, starting with a collection of 27 classic articles on working with youngsters who are deaf-blind that supplement the self-study text. The second half is a bibliography consolidating in one easy-to-use list, descriptions of invaluable print and audiovisual resources for teachers and families.

*Hand in Hand: Essentials of Communication and Orientation and Mobility for Your Students Who Are Deaf-Blind: A Trainer's Manual*—A step-by-step guide to using the *Hand-in-Hand* materials for in-service training. This manual provides sample blueprints for workshops; hints for working with adult learners; and an overview of and sample forms for needs assessment and evaluation of workshops.

The *Hand in Hand* materials are available from the American Foundation for the Blind. For prices or to order call (718) 502-7647. For more information on the AFB Deaf-Blind Project, call (212) 502-7653.

## DB-LINK Fact Sheets

**T**he National Information Clearinghouse On Children Who Are Deaf-Blind disseminates information through two primary methods. These are referred to by the project as reactive and proactive. Reactive, refers to the information provided consumers who contact DB-LINK with specific requests. Proactive dissemination refers to information gathered, formatted, and distributed in large quantities to consumers and potential consumers.

In addition to DB-LINK's contributions to *Deaf-Blind Perspectives*, DB-LINK has developed a number of fact sheets over the last year. Below is a short description of each of these. If you are interested in receiving one or more please contact DB-LINK. Additional fact sheets are being developed. These too will be announced in *Deaf-Blind Perspectives*.

**DB-LINK**  
345 N. Monmouth Ave  
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### Overview On Deaf-Blindness *by Barbara Miles*

This overview provides fundamental information on deaf-blindness. Topics include causes, challenges, communication, orientation and mobility, education, transition, and family issues. The fact sheet is written for all audiences, especially parents, and professionals new to the field. Agency resources are listed and selected readings are referenced. (6 pages)

### Recreation and Leisure *by Lauren Lieberman*

Everyone benefits from recreation and this fact sheet shares practical information on how to get people who are deaf-blind with cognitive disabilities involved with recreational activities. The focus is on recreational activities for pre-adolescent children through adult. Included are the steps required to develop a recreational plan. Examples of recreation activities with different people who are deaf-blind. A listing of national organizations and additional readings is included. (6 pages)

### Communication Interactions: It Takes Two

*Adapted from the original written by  
Kathleen Stremel*

This fact sheet provides an overview of how to interact with children who are deaf-blind. Examples of different communication opportunities are provided. Additional resources are listed. (4 pages)

### Receptive Communication: How Children Understand Your Messages to Them

*Adapted from the original written by  
Rebecca Wilson*

Deaf-blind children communicate through a variety of receptive communication modes. This fact sheet helps the reader design a program that will assist the deaf-blind child, especially the child with additional disabilities, move up the ladder of communication complexity. Additional tips are given for sending messages and the expectations for the child's response. Additional readings are included. (5 pages)

### Expressive Communication: How Children Send Their Messages to You

*Adapted from the original written by  
Kathleen Stremel*

This fact sheet provides information on the nature of expressive communication and the value of such communication. The continuum of expressive communication modes is described with examples of behaviors often modeled by children who are deaf-blind. The progressive nature of communication is discussed and considered via sensory, motor, and cognitive development. Suggested readings and additional resources are listed. (6 pages)

### DB-LINK Family Resource Directory A Developing List of National Resources

Produced in cooperation with the National Family Association for Deaf-Blind, this is a directory of services written for families of children who are deaf-blind. National resources are described and contact information provided. Precut postcards and rolodex cards are included. (Due to printing costs, limited numbers of this publication are available. We ask that requests come only from families and direct service professionals.)

## “Free To Be Me”

Joann Twitchell

Joann is the parent of two children with Usher syndrome. The names of participants and cities have been changed to respect the privacy of participants. —ED.

### Usher Syndrome Family Weekend

2:57 a.m. Sunday Morning -

I've been awake for 45 minutes. My brain is running full power trying to sort and file the information and feelings it has experienced the past 2 days.

Family introduction session - Interpreters dressed in black. Do Marie and Alan want to use an FM trainer? Sure. OK. (They wear one every day at school “They are used to the staring people” - How do I know that? - no one stares at me - but my child is part of me and I also feel the stares.)

I feel the tenseness in the air as we wait for our turn to stand and introduce our family. Debbie and Bethany are first. I still can't believe we are both from Chicago and have to come to Tampa to meet. Bethany is confident as she signs. Each family stands. Some parents sign. Some kids sign. All interpreters sign - oops, brain says “not true.” Some whisper Spanish. Barbara waves to Gretchen from the side. It's been 20 minutes. Time for interpreters to switch. Tag in. Tag out.

Marie is antsy. She is dying to get up and tell the room who she is! Gretchen picks up on it. So much non-verbal communication going on in the room. “Who wants to be next?” Marie's hand is dancing on the air. “Marie would you like to go?” Her head bobs up and down - YES! YES! She flits up to front and center stage. The atmosphere in the room is . . . hmm . . . what's a good word . . . accepting. Marie is feeling “FREE TO BE HERSELF. Free to be me.” (It's a catchy phrase, but I wonder if it's true for me?) She's 11 years old. Will this group let me be who I am?

Parent meeting. The kids and teenagers are in separate groups in other rooms. I had to coax Marie and Bethany away from the T.V. to go to their meeting. “It's gonna be boring MOM!” “No, I saw paper and markers on the table - it looks fun!” “OK.”

The paper and markers look fun to me. Parent meeting - “It's gonna be boring.” I coax myself to go. I'm late - Doug is saving me a seat. I sit down in defiance with my arms folded across my chest. Will this group let me be me? Do they know how I feel? If they don't nobody does! I listen. It sounds familiar. One dad is explaining his personality. “I tell Alisha -Come on honey, we can do this - we can do anything.” That sounds like Doug.

Debbie is talking. Telling them she didn't want to come. She didn't want to see what her daughter would become. She didn't want to see blindness. That sounds familiar to me. The unknown is better left unknown. Right?

Gretchen asks “What were your feelings about coming to this conference?” Did she really want to know how I felt? Well, here goes - what the heck - I'll tell the truth. I blurt out - “I didn't want to come.” “Can you tell us why, Joann?” “Yeah - because they have parent meetings and ask you to tell how you feel.” As the room erupts into a little laughter I feel my tension being released into a room of understanding people. I felt understood. I was FREE to Be Me.

Break for lunch. Alan is eating with Steven and his Mom and Dad. Alan is amazing. He seems to be soaking it all in. No communication barrier is gonna stop him. I watch Julie with her tactual interpreter - Is that what he's called? Anyway, she's talking with someone. She looks so . . . “normal”. Her hair's combed, her clothes match - better than mine - she doesn't look deaf-blind. She looks . . . like Julie. I hear someone behind me saying “Who is that up there.” I look up to the 8th floor and see 4 pairs of legs dangling through the railing. Those crazy teenagers! I look closer - It's 2 teenagers, an interpreter, and . . . Grandpa Mac! He is crazy! Doug says, “That's my Father for you.” Now no one wonders why Doug and Marie are like they are. Mac is “Free to Be Me.”

Hey backup - Did I just call that girl, “an interpreter?” That sounds like what Marie and Alan hear at school. “They get called, ‘the kids with the hearing aids’.” I'm sure the “interpreter” has a name. Why are they here anyway? Is the money good? Is there a fantastic story behind the black shirt and dancing fingers? Yes, I'm sure of it.

The communication process is so alive here. I watch Seth sign. Boy - it could be dangerous to stand too close to him while he's talking. His personality jumps and stops and fly's through his fingers - through his whole body. It's such a contrast to . . . say . . . Blake. He stands, pauses, and then the signs gently flow out. Almost like he's singing. It's beautiful to watch the communication. To watch the differentness. The sameness. I look at Marie and Bethany and my brain says: Different . . . Same . . . Different . . . Same.

I watch Curtis and Alan and Steven communicate with paper and pencil. Some sign, some voice - different. All love Nintendo - same. Different. Same. It's good to be different. It's good to be the same. It's good to be . . . FREE TO BE ME!

## Announcements

### Helen Keller Art Show

This is a call for art for the Helen Keller Art Show "Washington National Cathedral Exhibit" sponsored by Very Special Arts Alabama and CEC Division on Visual Handicaps. This invitation is for visually impaired, blind, or deaf-blind youth to submit artwork from their school system. Students may select the preferred art medium. The contest is open to school children of all ages. Each school system may submit up to seven pieces of art. Winning entries will be displayed at the National Cathedral from March 7 through May 27, 1996. At the conclusion of the tour of the exhibit, the artwork will be on exhibit at the Helen Keller Festival in Tuscumbia, Alabama, June 1996, and in senate or congressional offices.

Entries to be submitted by February 1, 1996.

For entry forms, contact:

Division on Visual Handicaps  
Box 4107  
Lubbock, TX 79409-1071

### Free Information Packet

The Foundation Fighting Blindness is a national research organization that studies retinal degenerative diseases, including retinitis pigmentosa (RP) and Usher syndrome. Children with Usher syndrome are born with varying degrees of deafness and later develop RP—a degenerative disease that begins with night blindness and progresses to a loss of peripheral vision.

To request a free packet that answers commonly asked questions and provides updates on the latest research please call the Foundation at:

(800) 683-5555 or  
TDD (800) 683-5551

## Calendar Of Events

### Perkins National Deaf-Blind Training Project Schedule of Summer Institutes for 1996

**Topic:** *Strategies to Support the Inclusion of Learners who are Deaf-Blind in Schools and Communities*

Sponsoring University	Dates
Florida State University	June 23-27
Michigan State University	June 23-27
San Diego State University	July 14-18
University of Washington	July 21-25

All courses will be offered for graduate credit from the sponsoring university. For further information please contact your state Coordinator of Deaf-Blind

Services or the Perkins National Deaf-Blind Training Project, (617) 972-7226.

### 1996 American Association of the Deaf-Blind Convention

The 1996 AADB Convention will be held on the campus of the University of Tulsa, Tulsa, Oklahoma June 15-21 and hosted by the Oklahoma Deaf-Blind Sooners. The theme of for this convention is "Deaf-Blind People Can..." and will include workshops that show what the deaf-blind participants can do (dream, plan, work, etc.).

**Contact:**

AADB  
814 Thayer Ave.  
Silver Spring, MD 20910  
Voice (800) 735-2258 TTY: (301) 588-6545  
Fax: (301) 588-8705  
E-mail: ydch5849@uct.uct.edu

### Association for Education and Rehabilitation of the Blind and Visually Impaired 6th International Conference

St. Louis, Missouri is the site of AER's 6th International Conference to be held July 20-24 at the Adams Mark Hotel. Included in the topics are; assessment of infants, mobility techniques for older persons who are blind, career counseling, family intervention, literacy issues of school age children, and the latest trends in technology.

**Contact:**

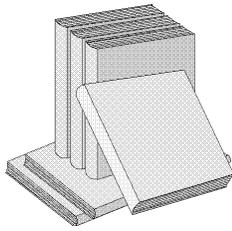
AER  
206 N Washington St. Ste 320  
Alexandria, VA 22314  
(703) 548-1884

### 5th Canadian Conference on Deafblindness

Held May 8-11 at the University of British Columbia in Vancouver, B.C., Canada, this conference offers session speakers from all over the world and includes a variety of sessions with four full day Saturday sessions. These events provide the opportunity for an intense learning experience with four six-hour workshops which require preregistration within the general registration. The conference features five keynote addresses and over 50 concurrent workshop and poster sessions.

For information and registration packet contact:

Conference on Deafblindness 1996  
Secretariat  
UBC Conference Centre  
5961 Student Union Blvd  
Vancouver, BC Canada V6T 2C9  
V/TDD: (604) 822-1050  
Fax: (604) 822-1069  
E-Mail: registration@abrock.housing.ubc.ca



## For Your Library

Unless otherwise noted, the following information may be obtained by contacting DB-LINK at: Voice: (800)438-9367 TTY: (800) 854-7013

### Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities 1992. (A Parent's Guide, Update May 1992)

The article was written to help families learn how to get help for their young children with special needs. Answers are provided for the most commonly asked questions about early intervention services for children ages birth through 2 years old and special education and related services for children ages 3 through 5 years old.

### Communication Systems and Routines: A Decision-Making Process

*Stremel, Kathleen; Molden, Vanessa; Leister, Chrissy; Matthews, Jimmie; Wilson, Rebecca; Goodall, deVergne; Holston, Jan. University of Southern Mississippi, [1990]*

The ultimate goal for children with any type of disability in the area of communication development is to assist the child, through social interactions and environmental arrangements, to be able to communicate in the most effective way possible, with a variety of people, and in a wide variety of social situations and environments. Knowing where to begin, the direction to take, anticipating some detours along the way, and knowing when when one has arrived are based on a decision-making process. This manual covers the teaching of communicative behaviors, receptive communication and expressive communication, for children with vision, hearing and motor impairments via this decision-making process. Includes diagrams, charts, examples, and an Individualized Family Service Plan.

### Dancing Cheek to Cheek : Nurturing Beginning Social, Play and Language Interactions

*Meyers, Laura; Lansky, Pamela. — Los Angeles: Blind Children's Center, [1992] 33 pages*

This booklet is based on the research findings of a four-year study of ten babies with severe visual impairment. They had differing diagnoses, resulting in varying degrees of cognitive and motor disabilities. The goal of the research was to find techniques that parents and babies can use to successfully bypass some of the obstacles to the development of social, play, and language skills that are the result of lack of vision. Includes listings of activities that were successful and those that were not.

This booklet may be ordered from the Blind Children's Center, 4120 Marathon Street, P. O. Box 29159, Los Angeles, CA 90029-0159, or by calling (213) 664-2153, (800) 222-3566.

### Interaction and Play

*Matthews, Jimmie. — Hattiesburg, MS: University of Southern Mississippi, 1992. (Adapt-A-Strategy Booklet Series) 10 pages*

Discusses interactions with people and objects at the reflexive and intentional behavior stages and encouraging social interaction through play.

### Positioning and Handling

*Yates, Cynthia. — Hattiesburg, MS: University of Southern Mississippi, 1992. (Adapt-A-Strategy Booklet Series) 10 pages*

Covers basic information about infant positioning and handling to develop motor skills. For availability information call:

University of Southern Mississippi, (601) 266-5135.

### Guiding Principles for Interaction with Young Children who are Deaf-Blind

*Anthony, Tanni; Greeley, J.; Gleason, Debbie. — Revised. 1994. 2 pages*

Eight suggestions for successfully interacting with young children who are deaf-blind. Suggestions for using toys and types of toys to use are included.

### Handbook for Parents of Deaf-blind Children

*Esche, Jeanne; Griffin, Carol. — Lansing, MI: Michigan School for the Blind, 1989 (revised) 25 pages*

The handbook deals with basic information for parents to use in raising a child who is deaf-blind and answers many questions relating to parents and family. The goal is to help parents feel more confident in assisting with the growth and development of their deaf-blind child. Contains information about mannerisms, sitting, standing, walking, eating, dressing, toilet training, discipline, speech/language, auditory experiences, play and toys, and glasses and hearing aids. Available from DB-LINK.

### Key Indicators of Quality Early Intervention Programs

*Chen, Deborah; Haney, Michele. — Northridge, CA: California State University, 1994. Length: 2*

This is a list of indicators based on a review of current literature on effective practices in early intervention. It reflect the unique learning needs of infants who are deaf-blind as well as the priorities of their families. Included is a model for promoting learning through active interaction.



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