

# Deaf-Blind Perspectives

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## Research-to-Practice Focus: Competencies for Teachers of Learners Who Are Deafblind

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**C**hildren who are deafblind require highly specialized and personalized teaching approaches because of their combined vision and hearing losses. Although children who are deafblind have the same basic needs as all children, the combination of sensory loss, accompanied in some cases by other disabilities, creates additional highly complex challenges.

The extent of vision and hearing loss varies within the population of children who are deafblind. Most have some residual use of either vision and/or hearing, while others have no usable vision or hearing. Some also have physical, cognitive, or emotional disabilities. Each child is unique, but all share communication challenges and the potential isolating effects of combined vision and hearing loss.

Teachers of children who are deafblind must have specialized competencies in order to provide their students with high quality educational opportunities. These competencies are in addition to the basic competencies required of all teachers of children with disabilities. This article provides an overview of *Competencies for Teachers of Learners who are Deafblind*, a document that lists the necessary knowledge and skills for teachers who work with deafblind children.

### How Were the Competencies Developed?

The competencies are the outcome of a collaborative process that involved the staff of the Perkins National Deafblind Training Project (a federally funded project created to improve educational practices), university level faculty who prepare teachers of children who are deafblind, and a state coordinator of deafblind services. The final set of competencies was revised based upon an extensive national review process.

### What Are the Competencies?

The competencies are comprised of 44 knowledge statements and 104 skills that are divided among the following areas: Deafblindness; Personal Identity, Relationships and Self-Esteem; Concept Development; Communication; Hearing-Vision; Orientation and Mobility; Environment and Materials; and Professional Issues. A brief example of knowledge and skill statements from the section on Personal Identity, Relationships and Self-Esteem is shown in Figure 1.

Some knowledge and skills statements, if read only at face value, could apply to teaching all children. However, knowledge and skills in these areas are especially important in teaching learners who are deafblind, since learners who are deafblind do not learn through incidental experiences. They must be carefully and thoughtfully taught what other children learn informally through overhearing and observing, and in their natural interactions with others. Each learner requires a highly indi-

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**Personal Identity, Relationships and Self-Esteem**

**11 Knowledge**

- The potential impact of deafblindness upon attachment/bonding between learners who are deafblind and their primary caregivers.

**11.1 Skill**

- Assess and explain the effects of combined vision and hearing losses upon relationships between the learner and his/her primary caregiver.

**11.2 Skill**

- Establish a trusting relationship with the learner who is deafblind by providing nurturance and consistency in people, interactions, and routines.

**11.3 Skill**

- Use touch to accommodate for lack of or distortion of visual and auditory information (e.g., use touch to substitute for mutual eye gaze).

vidualized approach depending upon his or her strengths and needs.

The knowledge and skill statements do not apply to specific ages or educational placement. They are not prioritized according to their relative importance. Some knowledge statements have no associated skills while others have several. This factor has no relationship to the importance of the knowledge statement.

**How Should the Competencies Be Used?**

There are many challenges faced by those who wish to provide high quality educational services for learners who are deafblind. More than ever before, we see children who are defined as deafblind served in districts where they might be the only deafblind child, ever. A system of support and training must be created that will not compromise the quality of the education a child receives. Support systems must be built that will encourage excellence in the kind of deafblind education that can be provided to children living with their families and attending their local public school. The specific ways these competencies will be used will vary according individual situations and needs. They may be used as follows:

Figure 1. Example of knowledge and skill statements

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**To develop personnel preparation programs.** The full range of these competencies can be used as a blueprint for courses and field experiences by those who teach and develop university personnel preparation programs in deafblindness. Qualified teachers must have basic competency in all the areas addressed in the knowledge and skill statements.

**For families and school personnel to make responsible decisions.** As family members and school personnel sit down together to make decisions, these competencies may be used as a base to evaluate the knowledge and skills that are essential to provide a rich educational experience for the individual child who is deafblind.

They can be used by parents to ask questions about the skills of the staff working with the child and to develop a plan for staff to acquire needed skills or to identify the need for additional support staff. They can also be used to educate families and other team members about the unique challenges imposed by deafblindness.

**For coordinators of statewide services to identify technical assistance and training needs.** Those who plan technical assistance on local, state, and regional levels must identify needs and devise a training plan that will develop cumulative knowledge and skills for service providers. Teachers, support personnel, and caregivers who are essential to the lives of infants, children, and young adults who are deafblind must have excellent training. These competencies can work as effective tools to identify needs and implement training in a cohesive way.

*Competencies for Teachers of Learners Who Are Deafblind may be purchased from:*

Public Relations and Publications Department  
Perkins School for the Blind  
175 N. Beacon Street  
Watertown, MA 02172 (cost: \$5.00)

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## Sign Language with People who are Deaf-Blind: Suggestions for Tactile and Visual Modifications

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Communicating with individuals who are deaf-blind is a unique experience. The language, mode, style, speed, and aids and devices used to facilitate communication are different from person to person. If you are interpreting for an individual who is deaf-blind you will need to know what adaptations will be appropriate and what additional environmental concerns you should be aware of. This article provides helpful hints about techniques that will enhance your comfort and ease your concerns when working with deaf-blind people.

The information in this article will be useful to a variety of communication partners such as interpreters, support service providers, intervenors, teachers, companions, and anyone else who is facilitating communication with an individual who is deaf-blind. It assumes that you are already fluent in the consumer's preferred sign language system and knowledgeable of cultural and linguistic differences that may affect your interaction. Due to the various etiologies, modes of communication, and cultural and linguistic differences among individuals in this population, some of these suggestions may be applicable to one consumer but not to another. It is imperative to ask the consumer his or her preferences on how the message should be conveyed and what additional auditory and visual information should be detailed.

## Expressive Communication

### Appearance/Attire

Wear clothes that provide contrast for your hands. Consider the following guidelines when selecting clothing:

- Dark colors (black, navy blue, brown, dark green, etc.) for persons with light skin
- Light colors (off-white, tan, peach, etc.) for persons with dark skin
- Solid colored clothing (avoid stripes, polka dots, etc.)
- High necklines (no scoopnecks or low v-necks)
- Professional, yet comfortable enough to allow for flexibility

Many people wear a smock over regular clothes and keep one in their office or car for accessibility.

Wear plain jewelry that is not visually or tactually distracting. Avoid rings, bracelets and necklaces that may interrupt the flow of communication. Avoid sparkling or dangling earrings as they can reflect light and cause interference.

Fingernails should be short, neat, and filed smoothly. Rough edges can be irritating. A neutral color of polish may be worn, but avoid bright reds, dark colors, French manicures, or other frills.

Due to close sharing of personal space, you need to ensure good personal hygiene.

- Avoid perfumes and scented hand lotions.
- Wash hands often or use an antibacterial lotion when moving from consumer to consumer to reduce the risk of “germ sharing.”
- Use non-oily, unscented lotion on a regular basis to avoid dry or rough skin that may cause distractions when communicating for extended periods of time.

### Distance & Seating

The distance between you and the consumer will vary from situation to situation depending on the consumer’s mode of reception. The consumer may use visual reception while you are signing in a reduced area sitting at a specified distance away. This situation may occur if an individual has peripheral vision loss and relies on central vision (also known as “tunnel vision”). Tracking is another possible visual modification. Tracking allows the consumer to keep your hands in a restricted signing space by grasping either your forearms or wrists.

When communicating tactually, close seating is necessary. There are a variety of seating arrangements. For example, when communicating with a one-handed tactile receiver, you and the consumer may sit side-by-side or at the corner of a table so that the consumer can rest his or her elbow. However, if the consumer is a two-handed tactile receiver, a

comfortable position is to sit facing each other with legs alternating. Women may want to avoid short or straight skirts as they are problematic for this configuration. Slacks or wider, full skirts allow more flexibility.

For both communicators, it is helpful if the levels of the chair seats compensate for the height differences of the signers. For comfort and in order to avoid fatigue, your bodies and signing spaces should be at similar levels.

Chairs with arm rests and back support are helpful. An additional chair may be placed next to each communicator. The back of the chair can then be used to provide support for either the signing or the receiving hand.

### Signing Space

Be sure that both you and the consumer are comfortable with the personal and signing space established. When communicating with individuals who rely on residual vision (e.g., tunnel vision), you need to be cognizant of the location of your hands in the signing space. They should be held slightly below your face in front of your clothing to allow for color contrast. When communicating tactually, it is helpful to move the general signing space down to the chest for postural ease.

During tactile signing, you must be comfortable using signs that come in contact with the body. The location of signs and consistency of placement are crucial for clear communication. Adaptations such as ducking your head to accommodate for the sign for “father” or “mother,” for example, will cause confusion because the receiver determines gender by the height of the signer. In some cases, however, to be less obtrusive, simple modifications may be made to certain signs by either lowering or raising the hand slightly from its original contact position. For example, “home” which touches the face or “body/mine” which touches the chest.

### Hand Positioning

The use of one-hand versus two-hand tactile reception of communication varies depending upon the preference of the consumer. Allow the consumer to place his or her hand(s) where he or she is comfortable and to follow your hands freely. Do not “squeeze” or pull the consumer’s hand(s) toward you.

### Conveying the Message

Whether communicating tactually or visually with someone with reduced vision, you must identify who is talking and where the speaker is located. If it

is known, use the sign name of the individual and point in the direction where they are seated. If a sign name is unknown and it is an inappropriate time to request one from the speaker, one can be created between the interpreter and consumer to save time and establish consistency.

Before the activity, if at all possible, discuss the consumer's preferred mode, style, and speed of communication. In order to convey the tone and manner in an accurate way, attempt to follow the speed and fluidity of the speaker while meeting the speed of reception and processing time of the consumer. To ensure clarity, however, fingerspelling and number production should be produced at a slower pace for both visual or tactile receivers.

One of the essential components to communicating visually is facial expression. If a consumer has tunnel vision, low vision, or complete blindness, many or all of these expressions can be lost. It is imperative that you become adept at adding facial expressions using hand and body language. Signs can be added to describe the apparent emotion of the speaker. For example, if a person is laughing, the signs for "smiling," "laughing" or "hysterically laughing" can all be added to aid in conveying the speaker's expression. If the speaker is angry, you may add the signs for "raised eyebrows," "frowning," or "mouth turned down."

When relaying facial expression, it is not necessary to constantly repeat the same expression but do convey any change in facial expression. If a person is upset, frowning, has tears in his eyes and then begins to cry, pulls out a handkerchief and blows his nose, all that information should be relayed. However, if a person is frowning and maintains this expression throughout the conversation, it does not need to be repeated more often than at the beginning and end of the speaker's monologue.

Use body language to convey the message (spoken language or body language) of the speaker whenever possible. For example, if the speaker shakes his or her head dramatically, bends over in laughter, and grimaces in disagreement, the interpreter should relay this information by replacing head movement with hand movement and arm movement to replace upper torso movement.

### **Tactile Adaptations**

When using signs that require and provide information from two hands ("highway," "garage," "meeting people," "total communication"), both of your hands should come in contact with the consumer's hand. This can be done either through a one-handed or two-handed tactile position. A skilled one-

handed tactile receiver may not need additional contact for clarity. Use your judgment about when to move to a two-handed tactile approach in order to convey the message most accurately.

Some confusion or awkwardness in positioning can occur with various signs. For clarity, additional information may need to be added or a slight variation of the sign may need to be employed. Because a consumer may not visually be able to discriminate between "understand" and "don't understand" it is imperative to elaborate the interpretation to include the sign for "yes," "no," or "not" or provide head movement in the hand. Many signs are similar and can be easily misinterpreted by the consumer. Simple additions can provide clarity. Consider the following examples:

- The word "gun" may be confused with the number "21." To avoid confusion, fingerspell "g-u-n" and add the sign "number" before "21."
- Due to body positioning the traditional sign for "dog" can be awkward. It is helpful to fingerspell "d-o-g" or use a version of a finger snap.
- To ensure clarity when fingerspelling, add the context before fingerspelling a word. For example, "city, c-h-i-c-a-g-o," "name, k-a-r-e-n," "time, 10:30."

The print-on-palm method, instead of the tactile use of numbers, is sometimes preferred when conveying numbers and/or money. Use your index finger in the palm of the consumer's hand. The letters should be in capitals (except for "I"), block format. Stay in the palm area. Do not print down the hand toward the fingers.

Be very clear about where a question is directed. Depending on the context of the question, a different sign may be employed. If the speaker is directing a question to the entire audience you could use the sign for "question/question mark" in a circular manner. If the question is directed to an individual, you should sign in the direction of the individual, adding the sign name or description of the person in question.

At times, it can be difficult to discriminate between a question and a statement. You may wish to add a question mark or question indicator after the statement to help avoid possible misunderstandings.

### **Describing the Full Environment**

When entering a new environment, be sure to explain the surroundings. If you have entered a restaurant and there is a long waiting line and the customers look unhappy, relay this information. Describe the color of the walls and things in the

room, decorative style, lighting, seating, table arrangement, and so on. Inform the consumer where things are located in relation to his or her body. For example, a chair to the immediate left, handouts on the right of the table, a pitcher of water directly in front. Use of the “clock” or “compass” concept to describe items in the environment may be helpful. You can say that the glass of water is at 12:00 o’clock or the brailled handouts are on the east end of the table.

Describe items of importance or items that draw attention such as a woman wearing a violet suit, a video camera in the corner recording the meeting, people who appear to look uncomfortable, and so on. Additional visual information should be shared such as the news that a person in the meeting has fallen asleep, a couple is fighting across the street, or a person sitting across the table keeps sneezing. To the best of your ability, try to relay what is happening in the environment without allowing your personal opinion to influence the information that is being communicated. Describe how many people are in the environment and ask the consumer if he or she would like to know, by name, who is there.

When you are describing an event, it may be helpful to move from a one-handed tactile approach to a two-handed tactile approach to allow for a fuller description. For example, if you are describing Michael Jordan getting ready to shoot a basket, it helps to add his facial expression, or that he is sweating, or his legs are in the air, and so on.

## Receptive Communication Issues

### Environmental Concerns

Numerous environmental factors can hinder the flow of communication. These include the following:

- Inadequate lighting that causes dimness or shadows. Additional floor lamps may be helpful. When establishing seating arrangements, consider where shadows will fall.
- Distracting overhead lighting such as light from overhead projectors and florescent lights.
- Glare from outside. Close the blinds or turn your seats in a different direction so that the consumer’s back faces the lighting source.
- Confusing background. It is helpful to have a solid, black or dark background behind you. This backdrop enhances visual reception for the consumer and can also provide assistance to a Team Interpreter who is feeding information and/or interpreting sign-to-voice. (A Team In-

terpreter is someone who works as a support partner to the interpreter who is currently communicating with the consumer. The Team Interpreter provides either visual and/or auditory information that may have been missed.)

### Consumer Feedback

If you are working with the same consumer over a long period of time, establish a system that works for both of you. Certain tactile feedback provided by the consumer can aid the flow of communication. Examples include the following:

- **“Keep going.”** The consumer taps one or more fingers on top of your hand.
- **“No.”** The consumer’s two fingers (“no” sign) will tap on top of your hand.
- **“Ha ha.”** The consumer may put two fingers similar to the sign for “no” on top of the your hand or may sign “ha ha” under your hand.
- **“What? Repeat.”** The consumer gently squeezes and pulls your hand toward himself or herself.
- **Facial expressions.** These vary from consumer to consumer; however, you can clarify which expressions portray specific feelings. A frown may mean “confusion,” raised eyebrows may mean “thinking/processing,” head nodding may mean “I’m following/understanding,” and so on.

### Team Interpreting/Duration of Interpreting

Due to the additional weight and unusual positioning used while interpreting tactually or communicating with visual modifications, you will want to work in partnership with someone else. To avoid fatigue or undue stress, you should switch often with your partner, approximately every 15 to 20 minutes. Try to coordinate this exchange with a natural pause to avoid interrupting the flow of communication.

Cumulative motion injuries can occur whenever there is repetition and extensive use of the hands. In addition, for consumers who receive information through tracking method or tactile sign language, taking breaks to rest and stretch the arm of the receiving hand may be necessary. Some consumers prefer to receive information in their nondominant hand to provide relief to their dominant hand. If you can perform sign communication with your nondominant hand at the same level as with your dominant hand, offering to switch hands may be greatly appreciated by the consumer.

## Additional Information

Do not consistently interrupt the dialogue to check for clarity. Instead, it is helpful to set up a system with the consumer beforehand. For example, at the start you may say, "If I am not clear, please stop me." It is then the consumer's responsibility to ask for clarification. Continually asking, "Do you understand me?" or "Am I clear?" can be disrupting and insulting.

Due to the ambulatory issues of individuals who are deaf-blind, you may be asked to "sight guide" a consumer. It is helpful to become familiar with basic sighted guide techniques.

Discuss with the consumer what symbol or sign to use in an emergency. Some consumers and interpreters are familiar with the process of printing a large "X" across the back of the consumer. An "X" is a clear indicator that an emergency situation has occurred, sudden movement is necessary, and explanations will follow. However, even though this symbol is somewhat universal, not all consumers are familiar with this method.

Remember to rely on other communication partners in the environment for additional visual activity or information that may have been missed. Teamwork is essential!

Be honest about how the environment is affecting you. A consumer can tell if you are in a hurry, frustrated, mad, lazy, tired, scared, nervous, sloppy, don't care, and so on. If you think it will affect your work, discuss your mood with the consumer. Remember to take breaks and stretch.

Finally, when in doubt...ASK!

*Special thanks and appreciation goes to M.J. Shahan, Kathy Zarate, Maricar Marquez, Stacey Sullivan, and Rich McGann. Without their expertise, experience, and support, this article could not have been written.*

## For Further Reading

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## Notes From AADB

### Report on AADB's 1998 Convention

Jamie McNamara

NTAC Technical Assistance Specialist and  
AADB Board Member

Last June, the American Association of the Deaf-Blind (AADB) held its 20<sup>th</sup> convention on the campus of Central Connecticut State University just outside of Hartford, Connecticut. The theme for this year's convention was: "Deaf-Blind CONNecTion - Expanding Opportunities."

Approximately 700 people attended, including 280 deaf-blind delegates. The remainder of the participants were support service providers (SSPs), observers, exhibitors, and family members. During the "Roll Call of the States" in the opening ceremony, people stood up, waved, yelled, and stomped when their state was called. It appeared that all but one or two states were well represented. There were also some people from far away places like England, Canada, Australia, Switzerland, and the Netherlands. Although the majority of deaf-blind delegates were adults, there were a few teens and their parents participating.

The AADB convention is the place for deaf-blind people to meet lots of others like themselves. Meeting and learning from others who are also deaf-blind is truly empowering. First-time delegates have expressed excitement at discovering they are not "alone" and have found a place where they feel "connected."

The deaf-blind delegates used many diverse communication styles. Some used sign language (tactile or sight): American Sign Language (ASL), Pidgin Signed English (PSE), or Signed Exact English (SEE). Others used fingerspelling only, or speech, lipreading, and hearing. Still others used a variety of assistive listening devices, such as FM systems, TeleBraille, large print, TTY Display, and real-time captioning on a TV screen. The diverse modes of communication made it possible for delegates to have access to and enjoy the convention activities.

The week-long convention had an abundance of activities, often occurring simultaneously, from early

morning till late at night and beyond. For many delegates, the convention is like a vacation because they are busy all day (and sometimes all night!) with interesting things going on, and they have SSPs with them all week to help them access convention activities and enjoy themselves. At this convention delegates were encouraged to help AADB by recruiting and bringing their own, as well as extra SSPs so there would be enough backup SSPs to go around.

Activities included workshops, tours, exhibits, and nightly socials. The workshops were "Fundraising Strategies," "Deaf-Blind Culture," "Political Process: What Can We Do in the Deaf-Blind Community," "Telecommunication Relay Service," and "Understanding SSP Situations." All five workshops had a full house of delegates. Summaries from the workshop proceedings will be published in AADB's quarterly magazine, *The Deaf-Blind American*.

A number of tours were offered. One was a trip to Foxwood Casino, one of the world's largest casinos. (Yes, there are some deaf-blind people who love to gamble...smile.) Other tours offered visits to a local winery, an industrial museum, a historical seaport, a garden park, an ocean beach park, a train/boat ride through the Connecticut River valley, an air museum, and shopping outlets.

Nightly gatherings had different themes: "Welcome to Connecticut," "Medieval Night," "Game and Show Night," and "1950s Sockhop." The socials had activities related to their theme for deaf-blind delegates to enjoy. For example, the Game and Show Night featured various recreational games, all of which were tactile or accessible by braille, and the New England Theatre for the Deaf-Blind of Boston gave a play on stage. Many delegates danced their legs out to rock n' roll music at the 1950s Sockhop. The Awards Banquet, a tradition at AADB conventions, was another social event that was more formal.

While there were many traditional activities at this convention, there were also a number of untraditional activities. Several activities generated increased involvement of delegates in sharing ideas, opinions, and thoughts about AADB, the deaf-blind community, and the convention. There was a "Meet and Get to Know Your Board Members" reception where delegates had an opportunity to meet with individual AADB board members. Also, there was a "Town Hall Meeting" where delegates came forward to present to the entire AADB Board their thoughts on issues affecting the deaf-blind community and AADB itself. This was setup to simulate speaking in front of legislators and other leaders in home communities. Another example of member

involvement was seen in the high return rate of evaluations.

Another example of an untraditional convention activity done in Connecticut and in keeping with the theme on "CONNECTIONS" were meetings between delegates and Helen Keller National Center Regional Representatives. These meetings gave delegates an opportunity to meet the regional representative that works with their state, meet other deaf-blind delegates in the same region, get information about what the regional representatives do, and share success stories and challenges.

All in all, the 1998 AADB convention in Connecticut was great. There was enormous diversity in the delegate ranks, their communication styles, and the recreational, educational, and networking activities. It is always wonderful, empowering, and gratifying for deaf-blind people to meet and network with others like themselves.

The next AADB convention will be held in Columbus, Ohio, July 29 - August 4, 2000 with the theme, "21<sup>st</sup> Century, the Deaf-Blind Move On!" This promises to be an exciting convention not only because it's at the start of the new century but also because it will be AADB's 25<sup>th</sup> convention anniversary.

For more information or to volunteer as an SSP at the convention, contact:

AADB's home office  
(301) 588-6545 TTY  
E-mail: aadb@erols.com  
or

Jamie McNamara, AADB Board Member  
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E-mail: jmcnam8404@juno.com.

**See you in Columbus!**



## What We Did for Our Summer Vacation

### A Parent's Perspective on the AADB Convention

Margery Sved

**M**y daughter Sara has brought much into my life that I never anticipated. I knew that adopting a then 9-year-old from overseas, especially one who'd experienced much change and loss but no formal education, would change my life. The information I had been given about her prepared me for a child who was introverted and not at all bright. My assumption that she would have normal hearing and vision was so automatic as to be unconscious. Imagine my surprise in getting to know my daughter—a sociable, bright girl. I also learned she has mild to moderate deafblindness!

I see the world a bit differently now and have been gifted over the last 3 years with many life experiences and lessons from Sara. One of the most wonderful has been what we did for our summer vacation this year, attending the week-long 1998 American Association of the Deaf-Blind (AADB) Convention.

I learned from my friend Grace, who had been to previous AADB conventions that the conventions were geared primarily toward adults. I also knew teens and young adults sometimes shied away from deafblind events. I decided that it would be better for Sara (now 12) to go sooner rather than later, so after clearing things through Joy Larson at AADB, our family made plans to attend the 1998 convention. This article describes the experiences I had hoped our family would gain from the convention and how those hopes were realized.

#### An Opportunity to See Adult Role Models Using Assistive Listening Devices

At school, Sara is the only child who uses an assistive listening device. I had visions of her at the convention's opening ceremonies surprised and excited to see many other people using assistive listening devices, but at the ceremony she had a headache and just wanted to nap. At an introductory meeting the previous night, however, I had introduced Sara to a hard-of-hearing woman with low vision, who uses voice, just like Sara. Soon, Sara was talking with

four oral, hard-of-hearing adults. All smiles, and a full part of the conversation, she held the microphone of the personal communication device for one of the adults, making sure it was aimed in the right direction as each person talked.

#### Exposure to a Range of Communication Modes and Other Tools

The diversity of communication modes and other tools at AADB was beautiful and exciting. At school, peers increasingly stigmatize disability-related differences, but at AADB the emphasis on personal interaction and access helped Sara see people using tools, rather than being defined by them. We saw people using tactile sign language, canes, interpreters, notetakers, Braille machines, dogs, Tadoma method, assistive listening devices, hearing aids, cochlear implants, lipreading, and special sunglasses. We may have created a monster though. Sara spent a long time at the booth to learn about guide dogs for deafblind people and AADB President Harry Anderson let her help take his guide dog outside. Perhaps, Sara suggested, getting a puppy would be good preparation for her to get a guide dog in the future.

#### Experience Using and Enjoying Sign Language

Sara primarily uses speech, but she has learned some sign for fun, to expand her pool of potential friends, and as a start in case her hearing worsens. At AADB, she floated between "signers" and "talkers." What seemed important to her was connection, interaction, and socializing. The communication mode was simply a vehicle to get to that. For the first time, I saw her have real conversations

with tactile deafblind people and was flooded with pride. With her diagnosis, it's unlikely she will ever need tactile sign as her primary mode of communication, but if she does, this early exposure may make it feel more natural and possible to her. A touching moment for me was watching Sara chat with a lovely senior citizen who used tactile signing. "Who taught you sign language?" asked the woman. "My mother," Sara unhesitatingly replied. She could have said the sign class at school or the sign summer camp, but she knew who started signing with her and opened up this world for her.



Sara Sved

## An Opportunity for Sara to Feel Less Unique in a Group

Almost everywhere she goes, Sara has the most sensory impairment of anyone she knows. "I just want to be like everybody else!" is an occasional refrain at our house. Being around hundreds of deafblind folks allowed her to experience herself as average for a week. She didn't feel disabled, or as if she was always trying to keep up with others. One morning, she proudly told me that she had served as support service provider for another delegate at breakfast. She enjoyed being able to help facilitate another person's activity. Of course, the next day, she expressed exaggerated relief she didn't have to do it again, but with unmistakable pride at her accomplishment.

### A Chance for Sara to Learn the Importance of Valuing Deafblind People and Events

Sara saw that going to this deafblind event was worth my time, money, energy and effort and that our family values the opportunity to interact with deafblind people. It's not something I just encourage her to do in the future, it's something in which I participate with her in the present.

### Finding Information About DB-LINK and Deaf-Blind Perspectives

I had wanted to get information about DB-LINK and Deaf-Blind Perspectives. This goal was surprisingly realized when one of Sara's delightful part-time support service providers was an Information Specialist at DB-LINK!

### Getting Information and Support

Finding out about Sara's hearing and vision conferred on me the identity of parent of a child with disabilities. At AADB, I got to experience some of the wonderful aspects of that identity, while getting encouragement and ideas for some of the difficult parts. Occasionally I felt overwhelmed, sometimes tearful. Spending time with adults who are like what Sara might be in the future triggered feelings of sadness, gratitude, fear, anticipation, and much more. From friendly exhibitors, to a delegate sharing how she started with a Braille ABC placemat while still in denial (her words) about her need to learn Braille, to a wonderful role-model mother of a 17-year-old delegate who has come to AADB since age 11, to Lauren Lieberman demonstrating fantastic adaptive physical education ideas, I repeatedly encountered gifted people who educated, inspired, and encouraged me.

## Gaining a Positive View of the Deafblind Community

More than anything, I hoped Sara would connect deafblind events with having fun, socializing, fitting in, and accessibility as she had with the few deafblind events she'd previously attended. Towards the end of the week I asked her if she'd had fun, and to tell me what had been her favorite part of the convention. "Sitting on Kim, while she was pushed up the hill in her wheelchair," she replied. What a disappointment! After a week of exposure to the world of deafblindness, *that* was the high point? But when I stopped to think about it, I realized what she was really saying was that she had experienced the deafblind community as fun and welcoming. She had hung out with Kim and other North Carolina teenagers and young adults. Some were deaf and used sign. Others were hard-of-hearing. They shared meals, compared disabilities, played pool, laughed, and danced. Riding up the hill, she was physically and socially embraced by peers (and their wonderful support service providers) who understood her experiences and included her.

What did the AADB Convention mean to Sara? She sums up her experience like this: "I felt happy and I had a good time meeting people and playing with the dog and just learning some new signs. I liked that people were there from different countries and states. My favorite thing about it was the food and the people. I would like to go next time because there may be some old people from last time and there may be some new people that I will meet."



**We encourage you to copy and share information from *Deaf-Blind Perspectives*, but please provide appropriate citations.**



## IDEA '97 - Regs on the Way

Gail Leslie

If the high point in special education for 1997 was the reauthorization of the Individuals with Disabilities Education Act (IDEA), the bright spot for 1998 will be the publication of the final regulations for the amended law. After a series of delays, congressional hearings, and cancellation of the planned regulations training workshops, the U.S. Department of Education has pushed the target release date to sometime later in the Fall. In August, the department also reopened the comment period for Part C of IDEA '97, the Early Intervention Program for Infants and Toddlers with Disabilities. With many provisions of the law effective as of July 1, 1997, and more in place as of this past July, school districts will again start the year without the accompanying regulations needed to guide them in their implementation of the revised statute.

The proposed regulations were initially published in October, 1997. At the close of the 90 day public comment period in January, the department had received more than 4,500 written comments. While responses to the proposed regulations covered a broad range of concerns, the controversies over the subject of discipline, which dominated the debate over reauthorization the year before, continued to surface. Some lawmakers, claiming frustration at having been left out of the finalizing process, called for a congressional hearing in April to discuss provisions of the proposed rules.

Since that April hearing, the Department has continued to shape the regulations while some congressional lawmakers have proceeded with legislation that would amend last year's law. In June, an amendment sponsored by Rep. Bob Livingston (R-LA), Chairman of the House Appropriations Committee, was attached to the House education spending bill. Known as the Livingston Amendment, it would remove the 45-day limitation for suspension of children with disabilities and allow school districts to remove, for unlimited amounts of time, students who exhibit dangerous or violent behaviors. A second amendment by Rep. Frank Riggs (R-CA) would allow states to stop providing special education services to youth in adult prisons. In

August, Rep. Jim Nussle (R-IA), introduced the Freedom to Learn Act. This would allow state and local school officials to establish discipline policies for all students, including special education students, moving discipline policies and provisions to the local level. These bills and amendments will come up for consideration when Congress reconvenes in September.

Special Education and disability advocates are opposed to these amendments on the grounds that they eliminate crucial provisions that guarantee access to appropriate education services. Many in the disability community fear that opening the door to any IDEA amendments creates an opportunity for dismantling a law that was the result of extraordinary bipartisan effort and cooperation.

In an effort to update states on the status of the final regulations, Assistant Secretary Judith Heumann issued a letter in July stating that districts are bound by the statute (IDEA '97) and by the existing regulations that are not inconsistent with the statute. States are also expected to conduct monitoring of local districts under these same provisions. At the same time, special education and advocacy groups have organized actions to notify consumers and to register their opposition to the newly introduced amendments.

Following is a list of contacts and websites that offer information about the statute, the regulations, and associated activities.

### Updates Surrounding IDEA and the Status of the Regulations

#### OSEP Home Page

<http://www.ed.gov/offices/OSERS/IDEA/>  
<http://www.ed.gov/offices/OSERS/IDEA/updates.html>

The OSEP web site will post any changes in the law or implementation. Any official communications will appear here and OSEP will fax a monthly IDEA '97 UPDATE to interested parties

#### Thomas Legislative Information on the Internet

<http://thomas.loc.gov/>

Comprehensive site for the status of any congressional activities, including bills or committee actions.

#### State Congressional Representative

<http://www.senate.gov>  
<http://www.house.gov>

State representatives or senators offer their constituents information about the status of particular legislation and welcome comments regarding policy. Local public libraries or DB-LINK can provide you with contact information for your state.

For teachers and districts having specific questions about implementation, contact the **OSEP** state contact for your state or **Dr. Joleta Reynolds** at OSEP, (202) 205-5507.

### Advocacy Information and Contacts

#### American Foundation for the Blind

Tel: 800-232-5463  
TDD: 212-502-7662  
FAX: 212-502-7777  
<http://www.afb.org/>

AFB's Governmental Relations Group posts updates on all legislation pertinent to persons with disabilities. They also publish *Words From Washington*, a periodic newsletter on what's happening in the Capital and maintain an e-mail listserv, AFB Watch, to send consumers updates on legislation.

#### Council for Exceptional Children

703-620-3660  
TTY: 703-264-9446  
FAX: 703-264-9494  
<http://www.cec.sped.org/>

The public policy and legislative information section covers details of federal activity and outlines CEC's positions.

#### National Coalition on Deaf-blindness

617-972-7347 (Phone)  
617-923-8076 (Fax)  
[daviess@perkins.pvt.k12.ma.us](mailto:daviess@perkins.pvt.k12.ma.us) (E-mail)

The Coalition is primarily involved with advocacy at the federal level and will be up to date on changes or actions.

#### National Parent Network On Disabilities

1130 - 17th Street, NW, Suite 400  
Washington, DC 20036  
202-463-2299 (V/TDD)  
202-463-9403 (FAX)  
<http://www.npnd.org>

A great web site with access to good advocacy information for families. The goal of NPND is to promote and support the power of parents to influence and effect policy issues at all levels. They publish the *Friday Fax*, a weekly news bulletin containing news and announcements about issues that may impact persons with disabilities and their families.

#### PACER Center

612-827-2966 Voice  
TTY: 612-827-7770  
<http://www.pacer.org>

Great section on legislative alerts with details of any changes in the law as well as advocacy information.

#### LRP Publications Education Administration On-line

800-341-7874  
<http://www.lrp.com/lrpnet/index.html>

Most of what is available at this site is fee-based, but the information about special education law is detailed and current. This website address also houses all of the information and services from National Association of State Directors of Special Education (NASDSE).

#### Washington Watch

United Cerebral Palsy  
1660 L Street, NW, Suite 700  
Washington, DC 20036  
Phone: 1-800-USA-5UCP (1-800-872-5827)  
Fax: 202-785-3508  
E-mail: [rforeman@upca.org](mailto:rforeman@upca.org)  
<http://www.ucpa.org/text/advocacy/>

This bi-monthly publication supplies the latest news on disability policy from Washington with commentary on how the legislation affects people with disabilities and their families.



## For Your Library

### Parent's Perspectives on . . . Behavior, Communication and Instructional Strategies

*NTAC/NFADB National Parent Workshop, 1998.*

A list of practices identified as the most important practices to parents in the areas of behavioral issues, communication, and instructional strategies in the education of their child who is deaf-blind. The list was developed at a national workshop called "Going for the BEST: Building Excellence and Strength Together" held July 30-August 1, 1998, attended by eighty parents and family members from across the country. The workshop was sponsored by The National Technical Assistance Consortium for Children and Young Adults with Deaf-Blindness (NTAC) and the National Family Association for the Deaf-Blind

(NFADB). The list of practices is available on the NTAC web site ([www.tr.wou.edu/ntac](http://www.tr.wou.edu/ntac)), or you can obtain a copy by calling DB-LINK, (800) 438-9376.

### Books

#### Educating Students Who Have Visual Impairments With Other Disabilities

Sacks, Sharon A. (Ed.); Silberman, Rosanne K. (Ed).  
Baltimore: Paul H. Brookes Publishing Co., 1998.

#### Foundations of Rehabilitation Counseling With Persons Who Are Blind or Visually Impaired

Moore, J. Elton (Ed.); Graves, William H. (Ed.); Patterson, Jeanne Boland (Ed.). New York: AFB Press, 1997.

### Conference Proceedings

#### Third International Charge Syndrome Conference, July 25-27, 1997, Boston, Massachusetts.

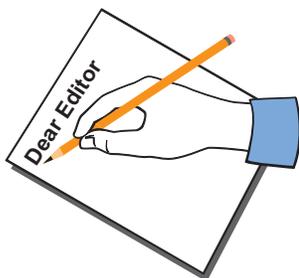
Available from DB-LINK.

#### Conference Proceedings: Mental Health and Deafblindness: A Focus on Wellness, June 5, 1997, Washington, D.C. San Diego, CA CSPP\_RRTC Publication.

Available from DB-LINK.

#### Proceedings of the 6<sup>th</sup> Canadian Conference on Deafblindness "Let's celebrate our harmony together," August 12-15 1998, Toronto Ontario.

Available from: The Ontario Chapter the Canadian Deafblind and Rubella Association, 350 Brant Avenue, Brantford, Ontario, Canada N3T3J9. Cost \$25.00 plus \$5.00 postage and handling (in Canadian dollars).



Dear Editor,

In the article entitled, "Early Identification of Infants who are Deaf-Blind: A Systematic Approach for Early Interventionists" (Chen 1998), I was surprised that there was no mention of Usher Syndrome, the most common reason for deaf-blindness in adults. Well over 50% of deaf-blind adults have Usher Syndrome (Smith et al, 1994). The only reason for its lower numbers in children is probably related to under identification.

The article did not include Usher in the list of syndromes causing deafness despite its high incidence. "Usher syndrome is the single most common identifiable cause of hereditary deafness among children who are profoundly deaf, and as a consequence the clinician must consider it as a possible diagnosis with every deaf child" (Kimberling & Moller, 1995).

Dr. Kimberling, of Boys Town Research Hospital, an international researcher of genetics and hearing loss, lists Usher syndrome as one of the 10 most common syndromes causing deafness. It is present in an estimated 6% of children with profound congenital deafness (Boys Town Research Registry for Hereditary Hearing Loss, 1995).

Early diagnosis is critical for the safety of the child. Children with Usher are night-blind as children which impairs mobility and safety; "a night-blind child is at risk" (Kimberling & Moller, 1995).

Additionally, people with Usher 1 have absent vestibular function which manifests in children "... as a delay in motor development. Affected persons are slow to sit without support and rarely learn to walk before the age of 18 months" (Smith et al, 1994).

Given the prevalence of Usher Syndrome and the fact that the early symptoms can be confusing and lead to misdiagnosis because of motor delay, keeping Usher in mind when dealing with any deaf or blind child is extremely important.

Thank you.

Sincerely,  
Ilene D. Miner, CSW

### References

- Boys Town Research Registry for Hereditary Hearing Loss (1995). *Ten syndromes most commonly associated with hearing impairment* [Online].  
<http://www.boystown.org/deafgene.reg/tensyn.htm>
- Chen, D. (1998). Early identification of infants who are deaf-blind: a systematic approach for early interventionists. *Deaf-Blind Perspectives*, 5 (3), 1-6.
- Kimberling, W. & Moller C. (1995). Clinical and molecular genetics of Usher Syndrome. *Journal of the American Academy of Audiology*, 6, 63-72.
- Smith, R.J.H., Berlin, C.I., Heijtmancik, J.F., Keats, B.J.B., Kimberling, W.J., Lewis, R.A., Moller, C.G., Pelias, M.Z., & Tranebjaerg, L. (1994). Clinical diagnosis of the Usher Syndromes. *American Journal of Medical Genetics*, 50, 32-38.



<b>Are you...</b>	deaf-blind? a family member of a deaf-blind person? a professional serving deaf-blind people?
<b>Do you have...</b>	ideas? hopes? facts? feelings? "bones to pick?" thoughts? gems you've always wanted to share with people but didn't know how?
<b>Do you want...</b>	to contribute "food for thought" to a field <i>hungry</i> for what you have to say?

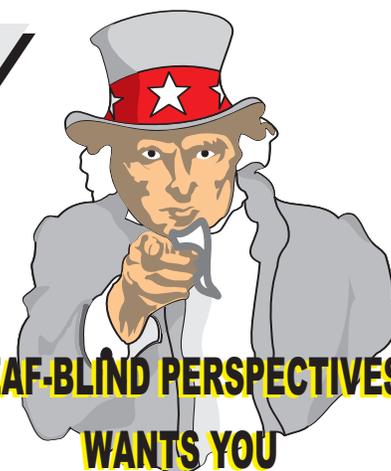
## Deaf-Blind Perspectives is looking for a few good writers!

You put it on paper – we'll take care of reviewing, editing, and possibly publishing it. Write, email, fax, or tape what you have to say—we'll take it from there (we might ask you to clarify or revise a bit). The language can be formal, fancy, formidable, funny, forceful, or frisky. The ideas don't need to be complex, compound, classy, or contorted – though we would like them to be chewy and clear.

### What's in it for you?



- Express yourself
- Share information
- Enjoy a moment of glory
- Contribute to people's thinking



**Contact**  
 Peggy Malloy, Managing Editor  
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 Monmouth, OR 97361  
 malloyp@wou.edu  
 503.838.8598 (V/TTY) 503.838.9623 (TTY message)  
 Fax: 503.838.8150

## National Interpreter Education Project National Directory of Interpreters/SSPs

**T**he National Interpreter Education Project would like to get "IN-Touch" with interpreters and/or SSP's who are skilled in working with deaf-blind individuals! Be a part of a national listing which will be made available to all deaf-blind persons. First printing is projected to be in December, 1998. Send in your application and copies of your credentials today to:

National Interpreter Education Project  
 NCCTC  
 Park Place East  
 Winsted, CT 06098

If you would like to be listed in this national directory, or if you need more information contact

Janet Faccinto  
 (860) 738-6371 (V/TTY)  
 E-mail: NW\_faccinto@commnet.edu

The application is also available via FTP from DB-LINK [ftp://tr.wou.edu/dblink/dir\\_app.doc](ftp://tr.wou.edu/dblink/dir_app.doc)

**AN EMERGING RESOURCE****CLAS needs you!**

The CLAS Institute seeks your *early childhood materials* to compile a practical, user-friendly resource bank. This growing collection will span cultural and linguistic backgrounds and contain both English and translated materials.

Funded by the U.S. Department of Education, CLAS is collecting print-based, video, audiotape, and multimedia materials. The materials will be in such areas as behavior management, IFSP/IEPs, second language acquisition, deaf/blind, and transition.

The resources will be available nationwide both in print and on the Internet.

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- Child Find Materials
- Child & Family Assessment Tools
- Resource or Curriculum materials

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Acquisitions Coordinator  
1920 Association Drive  
Reston, Virginia 20191-1589

Phone: 703.264.9488 (voice)  
703.264.9449 (TTY)

Fax: 703.260.2521

E-Mail: [harrietg@cec.sped.org](mailto:harrietg@cec.sped.org)



## Do You Need Information and/or Referrals Regarding Children and Youth Who Are Deaf-Blind?

### Contact DB-LINK

(800) 438-9376 Voice  
(800) 854-7013 TTY  
[dblink@tr.wou.edu](mailto:dblink@tr.wou.edu)  
<http://www.tr.wou.edu/dblink>

**D**B-LINK, The National Information Clearinghouse On Children Who Are Deaf-Blind is a federally funded information and referral service that collects, develops and distributes information to help improve the education and lives of children and youth who are deaf-blind

*Services include:*

- Information Center
  - » Information specialists are available to respond to individual requests for information, including in-depth research.
- Referrals to other organizations
- Web site
- Short topical publications (some available in Spanish)

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| <input type="checkbox"/> Administration (e.g., Dept. of Ed., project director) | <input type="checkbox"/> Teacher trainer                   |
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**Please send my copy in:**

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 Division 345 N. Monmouth Ave. Monmouth, OR 97361 or  
 call Randy Klumph (503) 838-8885, TTY (503) 838-8821,  
 Fax: (503) 838-8150, E-mail: dbp@wou.edu

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