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ABSTRACT

This collection of three issues focuses on competencies for teachers of learners who are deaf-blind, living with deaf-blindness, and resources in Australia for parents and families of students who are deaf-blind. Articles include: (1) "Research-to-Practice Focus: Competencies for Teachers of Learners Who Are Deafblind" (Marianne Riggio), which discusses the development of 44 knowledge statements and 104 skills for teachers of children who are deaf-blind; (2) "Sign Language with People Who Are Deaf-Blind: Suggestions for Tactile and Visual Modifications" (Susie Morgan); (3) "What We Did for Our Summer Vacation" (Margery Sved), a parent's perspective on the American Association of the Deaf-Blind Convention; (4) "Seeing the Humor in It All: Living with Deafblindness" (Ronald Malcolm); (5) "The 1997 Amendments to the Individuals with Disabilities Education Act, Part 1: Changes to Parent Participation, Evaluations and Reevaluations, and the IEP Process" (John Killoran); (6) Part 1: "Finding a Summer Camp" (Peggy Malloy); (7) "Australia's First Deafblindness Winter School" (Mike Steer); (8) "In Australia: Placing Parents and Families at the Center of Our Planning" (Mike Steer); (9) "Research-to-Practice: Reducing Behavior Problems in Students Who Are Deaf-Blind" (V. Mark Durand); and (10) "Graduate Programs that Offer Opportunities in Deaf-Blind Education" (Peggy Malloy). (Each issue contains annotated resources.) (CR)

DEAF-BLIND PERSPECTIVES

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Deaf-Blind Perspectives

Volume 6, Issue 1 Fall 1998

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

Marianne Riggio, Project Director
Barbara A.B. McLetchie, Project Coordinator

Children 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.

In This Issue

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 individualized 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.

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).

Figure 1. Example of knowledge and skill statements

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:

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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)

Competencies for Teachers of Learners who are Deafblind was developed as a product of the Perkins National Deafblind Training Project, a three-year granted project from the U.S. Department of Education, Office of Special Education and Rehabilitation Services, Office of Special Education Programs, Model Demonstration Projects in Deafblindness, Grant Number H025D30006. The contents of this article do not necessarily reflect the opinions of the U.S. Department of Education.

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NTAC

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

Susie Morgan
Technical Assistance Specialist
National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind

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 arraignments. 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 Interpreter 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. Shahen, 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 20th 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, "21st 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 25th 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
(913) 652-9047 TTY
E-mail: jmcnam8404@juno.com.

See you in Columbus!

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What We Did for Our Summer Vacation

A Parent's Perspective on the AADB Convention

Margery Sved

My 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.

Sara Sved

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.

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."

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

DB - LINK

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 be 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 (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 Online

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
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.

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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), 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 6th 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).

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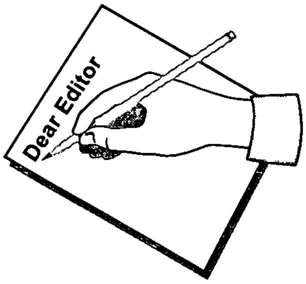

Dear Editor,

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.

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Are you...

deaf-blind?
a family member of a deaf-blind person?
a professional serving deaf-blind people?

Do you have...

ideas? hopes? facts? feelings? "bones to pick?" thoughts?
gems you've always wanted to share with people but didn't know how?

Do you want...

to contribute "food for thought" to a field *hungry* 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.

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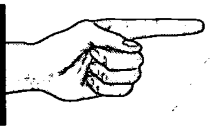

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- Share information
- Enjoy a moment of glory
- Contribute to people's thinking

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Fax: 503.838.8150

National Interpreter Education Project
National Directory of Interpreters/SSPs

The 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

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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.

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VISIT US AT OUR C·L·A·S WEBSITE!
HTTP://CLAS.UIUC.EDU

For more information about CLAS or to submit materials CONTACT

The Council for Exceptional Children
ATTN: Harriet Gray
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

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
http://www.tr.wou.edu/dblink

DB-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:

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

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Deaf-Blind Perspectives

Volume 6, Issue 2 Winter 1998-99

Seeing The Humor In It All

Living With Deafblindness

Ronald Malcolm

It's interesting how many small things we take for granted. I never realized that there were once many parts of my day that I never gave a second thought to. As a deafblind man, I experienced my deafness first and then became blind several years ago. Before I lost my vision I was able to watch a platform interpreter with ease. Glancing at my watch to see what time it was, was effortless. Reading my TTY or the captioning on the television was just an ordinary part of my day. Running to the store to pick up a simple item such as a gallon of milk was simply a part of everyday life.

Yet, my everyday life began to change when several years ago my vision began to rapidly decrease. I actually went to see my eye doctor because I thought I needed a stronger prescription. Looking back, I now recognize many of the warning signs that there was a problem with my eyes. However, a visit to the eye doctor always seemed to be put on the back burner so I could cope with my already busy schedule.

Shortly after my visit with the eye doctor my regular life came to an abrupt halt. This was followed by numerous visits to a neurologist, MRIs, Cat Scans, and of course the ever-favorite spinal taps. Just when I thought I would never know what was wrong, I received the diagnosis. My doctors told me that I had optic neuritis as well as middle artery cerebrovascular eye disease. Shortly after the diagnosis, two things occurred. The first was that my vision began to rapidly deteriorate. My peripheral vision reduced to a seven-degree field in my right eye and a five-degree field in my left eye and my night vision disappeared. The second thing that occurred is that my life came to a screeching halt in terms of my independence.

My struggle to regain my independence began to seriously affect my day. Orientation and mobility lessons began at 6 a.m. I studied braille during my lunch hour. I took computer training for the blind in the evenings and on the weekends. Combine all of this with my full-time job as a school administrator, my part-time job as a university professor, my involvement with my doctoral program, my commitment to my wife and dealing with the needs of my five children—I was beginning to feel overwhelmed.

After several months of training I began to feel that my life was mine again. I could read a braille book to my children at bedtime. I could walk my son to his karate lesson. I had learned several bus routes after realizing that driving a car was no longer an option.

In This Issue

I had some wonderful assistance from many well-meaning individuals. However, I was person who had always prided himself on his ability to be independent—it was difficult to accept such assistance. Yet, in time I learned.

One Christmas, I traveled out of state to visit relatives. Three of my younger children were with me. My only daughter Chelsea, four at the time, was playing in Grandpa's garage with her brother Joel when she fell and broke her arm. At the hospital they would not place her arm in a cast due to the swelling. I was told that we would need to wait three days before the arm could be put in a cast. Before then, we had to fly back home to Las Vegas.

When we arrived in the Las Vegas airport, I was nervous about getting Chelsea through the airport crowds without having her arm bumped. Her swelling had reduced and my primary goal was to get her through the airport and to a hospital to have her arm put in a cast.

My son and daughter always hang onto the pockets of my pants when we walk. This allows me to use my cane but also be able to feel that my children are still with me. In my rush to get through the airport, I took a wrong turn and ended up going through the line that needed to walk through the metal detector. I should have turned around but not wanting anyone to bump into my daughter with a broken arm I figured it would be just as quick to continue on. Little did I know what confusion it would cause.

As I approached the metal detector it had slipped my mind that my cane would set off the alarm. As I backed up to re-enter the detector, I suddenly felt the hands of my two children let go of my pockets. I immediately began to panic when I could not find my children. An attendant had motioned to my children to go through the detector without realizing that I was deafblind. The attendant, seeing that I was panicking, began to try to communicate with me. Of course, I couldn't understand what this woman was trying to say to me. At this point a line of other individuals was forming behind me, all eager to catch their awaiting flights. As the lady continued to try to speak to me, I finally felt the hands on either side of my pockets. Knowing my children had returned, I regained my composure. The persistent lady was now standing directly in front of me. Finally, I understood what she was saying. In order to get me through the metal detector, she loudly said to me, "Sir...please pass me your WAND!" Well, I had heard my cane called a lot of things in my day but never a "WAND."

At this point, we were almost finished with our trip through the airport. I had great hopes of getting my daughter to a local hospital. The last thing we had to do was go down an escalator and then go through a door to wait for my wife to pick us all up. As we approached the escalator, I reminded my children to hold onto my pockets. I then instructed them that we'd walk through a door and their job was to identify their mother so we could all go home. Sounded simple enough. Everyone seemed to understand his or her roles. Yet, as a deafblind adult, I have learned that nothing is easy.

As we stepped onto the escalator, I felt a hand pull away from my pocket. My son had become spooked by the escalator and let go. So, now I was carrying my luggage and a cane in one hand, carrying my daughter with a broken arm in my other arm while I attempted to go "up" the "down" escalator. As I tried to get to the top of the escalator, I noticed a person standing next to my son at the top of the escalator. Due to my limited vision I couldn't see the person clearly. As I continued to attempt to go up the escalator I began to call out to the person. I told him to take my son's hand and help him get on the

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escalator. I repeated myself several times. I became increasingly frustrated that this person was refusing to offer assistance. I continued to call out for help but to no avail. I mean after all, couldn't this person see what kind of a situation I was in?

Finally, I reached the top of the escalator. I situated both my children, put down my luggage, and took a deep breath. Then I turned in total frustration to the man standing next to my son. I wasn't sure what I was going to say to this individual. After all, he had blatantly ignored my requests for help. As I approached the man, I got the surprise of my life. The man I had been yelling at to take my son's hand to help him get on the escalator—had NO arms! Of course, with my limited vision, I was not able to see this as I was trying to get up the escalator. In return the armless man had no idea the lunatic yelling at him was deafblind. When we both realized what had happened, there was nothing left to do but laugh. In all the planning for the day's events I could never have predicted the string of events that I would be involved in for that day. I mean, how often does a deafblind guy yell at an armless man on a moving escalator.

Dr. Ronald I. Malcolm is an individual who is deaf-blind. He is the Coordinator of Low Incidence Accommodations and Alternative Assessments for the Clark County School District in Las Vegas, Nevada. He is also an Associate Professor at the University of Nevada at Las Vegas.

We want to thank Ronald Malcolm for submitting this wonderful article in response to our advertisement for writers in the previous issue. We are still looking for new writers and welcome submissions of articles on any subject related to deaf-blindness. We are interested in all types of articles including descriptions of personal experiences, professional articles, practical tips, and opinion pieces. —ED

The 1997 Amendments to the Individuals with Disabilities Education Act

Part 1: Changes to Parent Participation, Evaluations and Reevaluations, and the IEP Process

John Killoran, Assistant Research Professor
Teaching Research Division
Western Oregon University

The Individuals with Disabilities Education Act (I.D.E.A.) amendments of 1997 bring major changes to special education. To many, these changes are as revolutionary and sweeping as the original passage of the Education of All Handicapped Children Act in 1975. If fully embraced by those charged with their implementation, the amendments can enhance the lives and independence of all students, disabled and nondisabled alike. The 1997 amendments to the I.DE.A. are not simply technical; indeed they have a) reconceptualized the role of parent participation in a child's special education; b) redefined the evaluation, reevaluation, and IEP team process; and c) linked the IEP to the general education curriculum. The amendments call for planning and program development that can result in greater inclusion of students into the routine of general education, and they hold the potential to provide the supports and systems change needed to make this inclusion successful for all.

A comprehensive review of the I.D.E.A.'97 and its subsequent changes is beyond the scope of this article. The discussion in the following pages is not intended to be all encompassing. Rather, it is the first of a series of articles, that will conclude with a discussion of the re-authorization's implications for children and students who are deaf-blind and their families. The intent of this first article is to summarize those changes that immediately affect students, their families, and teachers. These include parent participation; evaluation, reevaluation, and eligibility determination; and changes in the IEP process and content requirements. Other changes will be presented in future issues.

Parent Participation

Many of the changes in I.D.E.A. '97 recognize the important role parents play in the development and education of their children. In short, Congress has increased the inclusion of parents in all aspects of their child's special education. Specifically recognized is the need for local education agencies to include parents in the initial evaluation and subsequent reevaluations of their child, as well as in the eligibility determination and placement process.

Prior to the 1997 amendments, parents were involved in the evaluation and reevaluation of their child "whenever appropriate" and often at the discretion of the multidisciplinary team or local school district policies. The changes brought about by the 1997 amendments now **require** that the child's parents are members of the multidisciplinary team that evaluates and determines their child's eligibility for special education. This involvement is not cursory, nor is it limited to a passive role. For a child referred for an initial special education evaluation and eligibility determination, parents participate in the design of the evaluation process, provide information related to their child, and participate on the team that determines if their child is a child with a disability as defined in the I.D.E.A. Parents must also be provided with a copy of the child's evaluation report and the documentation used to determine the child's eligibility.

During the reevaluation process, parents are considered to be equal members of the multidisciplinary team which reviews existing evaluation data, including evaluations and information provided by the parents to determine what additional data, if any, are required to determine whether a child continues to have a disability. Again, parents must be provided with a copy of the child's evaluation report and the documentation used to determine the child's eligibility.

Changes in Initial Evaluations, the Reevaluation Process, and Eligibility Determination

The changes required by the amendments related to initial evaluations, reevaluations, and eligibility determination are limited not only to increased parent participation, but significantly change the process previously required of schools and local education agencies.

Initial Evaluations

Similar to previous law, before a student is deemed eligible to receive special education and related services, an individualized and comprehensive evaluation of the child must be conducted. The purpose of this evaluation has been expanded by the re-authorization and now includes the following determinations:

- Whether or not the child is a "child with a disability" as defined by the I.D.E.A.
- The child's present level of educational performance
- The specific educational needs of the child

The requirement that parents of the student provide their informed consent before the evaluation is initiated remains, as do the requirements that the evaluation be nondiscriminatory and use technically sound evaluation tools. However, the reauthorization additionally requires that the local education agency use a variety of assessment instruments and that the evaluation include the collection of functional, relevant, and developmental information about the child. This information must assist the team in determining eligibility of the child for special education and in determining the educational needs of the child. The local educational agency must now consider information provided by the parent, as well as existing relevant evaluations and classroom observations.

The major additions to the initial evaluation of a student address:

- Consideration of any existing evaluation information that is available and appropriate
- Increased parent participation, input, and involvement
- Activities used not only for determining the child's eligibility for special education, but also that assist the team in determining, planning for, and meeting the child's educational needs

The Reevaluation Process

Prior to the re-authorization of the I.D.E.A., all students identified for special education were required to be reevaluated at least every 3 years. This reevaluation was to determine the student's continuing eligibility for special education.

In revising the reevaluation requirements, Congress recognized that the previous process had become an intensive paperwork process, often driven by compliance and legal concerns, rather than the interests of the child. The revisions established by Congress do away with unneeded testing and assessment if the child's disability has not changed. The intent is to reduce the time and expense associated with the reevaluation process. Under the new amendments, local educational agencies must now reevaluate identified students

- Whenever conditions warrant a reevaluation
- If the child's parent or teacher requests a reevaluation

- At least every three years

At first glance, it may appear that this change differs little from old law and actually may increase the frequency and complexity of the reevaluation process. However, in practice the amendments have substantially altered the process used in reevaluating students.

New reevaluation requirements call for the student's Individualized Education Program (IEP) team, other qualified professionals as appropriate, and the student's parents to review all existing evaluation data. This review must include evaluations and information provided by the child's parents; current classroom-based assessments, data, and observations; and teachers' and related service providers' observations and data. Based on this review, the IEP team must then determine if any additional information is needed in order to decide

- Whether the child has, or continues to have, a particular category of disability as defined by the I.D.E.A.
- The student's current present levels of educational performance
- The student's continued need for special education and related services
- Any necessary additions or modifications to the student's special education and related services to assist the student in meeting the IEP annual goals and for participating in the general curriculum

If during this review, the team determines that existing data are sufficient and that no additional data are needed, the school district must contact the parents to inform them of the decision and to notify the parents of their right to request an assessment. If additional assessment and testing are needed or requested, I.D.E.A.'97 now requires informed parent consent prior to the initiation of the additional testing. If the parents do not respond to the informed consent request, local education agencies can initiate the reevaluation process only after demonstrating that it has taken reasonable measures to obtain the consent and the child's parents have failed to respond to their request. The law also now requires that the reevaluation process be used to determine that a student is no longer eligible for services as a child with a disability as defined by the statute.

As with initial evaluations, reevaluation must also include the review of information from a variety of assessment tools and strategies to gather relevant, functional and developmental information, including information provided by the student's parents, not only to determine a student's eligibility for service, but also to assist the team in determining, planning for, and meeting the child's educational needs.

Eligibility Determination

Prior to re-authorization, parents were not required to be members of the team making decisions related to their child's eligibility for special education. I.D.E.A '97 requires that parents be included by local education agencies in all decisions related to their child and that they be included on the team of qualified professionals determining their child's eligibility.

The I.D.E.A '97 also has established a "Special Rule for Eligibility Determination." Succinctly stated, this rule requires that a student not be determined to be a child with a disability if the determining factor is a) a lack of instruction in reading or math; or b) a student's limited English proficiency.

For both initial evaluations and reevaluations, the law also requires that the local education agency provide parents with a copy of evaluation reports and documentation of their child's eligibility determination.

Changes in the Individualized Education Program (IEP)

Many of the most significant changes in the I.D.E.A. '97 revolve around the IEP team membership, the content of the IEP, and the IEP process. The IEP remains the cornerstone of educational planning for students with disabilities. Traditionally, the purpose of the IEP has been to identify the specific special education and related services a student needs in order to receive a free, appropriate public education. The I.D.E.A. '97 expands on this purpose, however, by enhancing the IEP's relationship with the regular education curriculum and by increasing the involvement of regular educators in the development and implementation of IEPs.

Team Membership

The membership of the IEP team is similar to that required by previous law. Although parents were always involved in the development of their child's IEP, the amendments now enhance the parent's role on the IEP team and the importance and value of their input. The local education representative must now also be knowledgeable about the general education curriculum, as well as special education and the resources available. At least one regular education teacher is also now required to be on the student's IEP team if the child is, or might be, participating in the general education environment. The previous law required regular education teacher participation only for students with learning disabilities.

I.D.E.A. '97 also delineates the role of the regular education teacher. The new statute specifically requires that the child's regular education teacher (as appropriate) participate in the development of the IEP. This participation includes determining the following:

- Appropriate positive behavioral interventions and strategies
- Supplementary aids and services
- Program modifications
- Supports for school personnel

Revised IEP Content Requirements

The required content of the IEP has been dramatically changed and now shows increased emphasis on the student's inclusion in the regular education environment and the relationship between the student's educational program and the regular education curriculum.

In reviewing the content requirements of the IEP established in I.D.E.A. '97, it is apparent that there is a blending of the old with the new. That is, although the concepts of present levels of educational performance, the establishment of annual goals and short-term objectives, and the dates for the initiation and duration of services remain, they each must now relate to the impact of the student's disability on his ability to be involved with and progress in the general education curriculum. Teams must now address the modifications and supports that are needed for school personnel and the student, which allow the student to be involved in the general curriculum, extracurricular and non-academic activities, and state-wide and district-wide assessments of student achievement. The IEP must now also include a description of how the student's progress will be reported to parents. This reporting must be done at least as often as parents of nondisabled children receive reports of their children's progress.

Previously, IEP teams were simply required to identify the student's participation in regular education. Teams must now explain and justify the extent to which a student will **not** participate in the regular classroom and activities with nondisabled peers.

Specifically, the IEP must now include the following:

- A statement of the student's **present levels of educational performance**. This includes how the student's disability affects involvement and progress in the general education curriculum. If the child is of preschool age, this statement must address how the child's disability affects participation in appropriate activities.
- A statement of **measurable annual goals**, including benchmarks or short-term objectives, related to
  - » Meeting the child's needs that result from the disability and enabling the child to be involved and progress in the general education curriculum
  - » Meeting each of the child's other educational needs that result from the child's disability
- A statement of the **special education, related services, and supplementary aids and services** to be provided to or on behalf of the child. This includes the program modifications or supports for school personnel that will be provided for the child to
  - » Advance appropriately toward attaining the annual goals
  - » Be involved and progress in the general education curriculum and to participate in extracurricular and nonacademic activities
  - » Be educated and participate with other children with disabilities and nondisabled children
- An explanation of the **extent of nonparticipation**, if any, with nondisabled children in the regular class and activities
- A statement of **any individual modifications needed** for the child to participate in the administration of state- or district-wide assessments of student achievement, or a statement of why the student will not participate in the assessments, including how the child will be assessed.
- The **projected date for beginning the described services**. This must include identified modifications and the anticipated frequency, location, and duration of the services and modifications
- Beginning at age 14, a statement **of the student's transition service needs**. Beginning at age 16, a statement of needed transition services. Also, a statement informing the student of any rights that will transfer to him or her upon reaching the age of majority must be included in the IEP at least 1 year before the student reaches the age of majority as defined by state law.
- A statement of **how progress will be measured** and how the parents will be regularly informed of the student's progress.

Special factors which the IEP team must consider have also been added by the 1997 amendments:

- Appropriate **strategies, interventions and supports** for a student whose behavior impedes his or her learning, or the learning of others
- IEP-related **language needs** for students with limited English proficiency
- Instruction in **braille** for students with visual impairments or those who are blind, if appropriate
- **Communication needs** of a student who is deaf or hard of hearing, including the student's language and communication needs, opportunities for direct communication with peers and professionals in the child's language and communication mode, and opportunities for direct instruction in the child's language and communication mode
- Whether the student requires **assistive technology devices and services.**

Review of the IEP

The re-authorization retains the requirement that IEPs be reviewed at least annually and additionally requires the team to address the results of a) any reevaluations; b) a student's lack of expected progress toward the IEP's goals and the general curriculum when appropriate; and c) information provided by the parent whenever the IEP is reviewed. New law also requires the student's regular education teacher, as appropriate, to participate in IEP reviews and revisions.

The second article in this series (in a future issue of *Deaf-Blind Perspectives*) will discuss mediation and student discipline, one of the more complex changes in the re-authorization of the I.D.E.A.—ED.

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Research-to-Practice: Facilitating the Self-Determination of Youth and Young Adults With Deaf-Blindness

Brian Abery, Ph.D., Project Director
University of Minnesota
Institute on Community Integration

Those who know children and youth who are deaf-blind share the goal that they lead the highest possible quality of life. In order to meet this goal we must provide support and education that will enable each individual to develop a vision for the future, to speak for himself or herself, and to effectively communicate his or her preferences, values, and interests.

Many persons with disabilities, including children and youth who are deaf-blind, are not encouraged to dream about the future. Instead, their futures are often determined by others on the basis of what is available rather than what is needed to make their dreams a reality. Enhanced self-determination provides children and youth with the tools to dream about their futures and set goals for themselves. It also actively promotes those capacities often referred to as self-advocacy that increase the likelihood that their dreams will eventually be realized.

Currently, a project designed by the author and Ann Eggebeen at the University of Minnesota is studying the issue of self-determination in order to enhance understanding of this important issue and develop educational materials to support and promote self-determination in deaf-blind youth and young adults. The purpose of this article is not to provide answers to all the questions that individuals who are deaf-blind and those who love and support them may have about self-determination, but rather to raise the issue, provide a definition, and stimulate thought about new ways to support its development in deaf-blind children and youth.

What is Self-Determination?

Self-determination is the power to make choices that reflect personal preferences, interests, and values, the prerogative to have control over one's own life, and the freedom to develop a vision for the future and to have that vision respected by others. A sense of self-determination is necessary for the development of individual identity. It is a crucial catalyst of independence and autonomy, and a fundamental component of quality of life. Characteristics of self-determination include the following:

- An awareness of personal preferences
- The ability to set goals
- The ability to use the skills one possesses to achieve goals
- The ability to evaluate progress toward a goal and learn from experience

Being self-determined does not mean that one is completely independent or autonomous. People with high levels of self-determination recognize the importance of interdependence and know they need others in their lives.

Why is Self-Determination Important?

The levels of self-determination exercised by some children and youth who are deaf-blind are considerably below their capabilities. Upon reaching adulthood they are likely to find themselves living, working, and socializing in settings they did not choose and that do not reflect their preferences or meet their needs. Enhanced self-determination can help avoid this outcome. Specific advantages of self-determination include the following:

Improved Learning

When children and youth come to believe that they have the ability to control their lives, they become partners with parents, teachers, and others both in the overall learning process and in exercising personal control. This increases their motivation, focus, and persistence and enhances the quality of their learning both in and outside of the classroom.

Enhanced Community Participation

When one talks with children and youth who are deaf-blind, it becomes clear that these are young people who have an intense desire to participate in and be a part of their communities. It is also obvious that many have an extreme distaste for being placed in the position of being dependent upon others. Self-determination skills directly enhance the ability of young persons to live independently within the communities of their choice, maintain valued employment, and develop circles of friendship and support. When children and youth who are deaf-blind are encouraged to take charge of their lives, they are also being encouraged to live as fully included members of society both in the present and the future.

Increased Personal Responsibility

The best way to teach children about responsibility is to present them with opportunities to make decisions and then allow them to experience the outcomes of their choices. In this manner, they learn to exercise control within the home, school, and community, taking into consideration not only themselves but also others around them.

Higher Self-Awareness and Self-Esteem

Students with disabilities, especially those who are deaf-blind, are often not given the opportunity to take risks, try new things, and experience the joys of success or the lessons of failure. Self-determination encourages individuals to discover their own capacities first-hand, to understand, adjust to, and accept the challenges created by their disability, and to build upon their unique talents and strengths.

How Can Self-Determination Be Promoted?

Promoting self-determination can be viewed as a process in which parents and professionals provide supports so that, as children develop, they have opportunities to gradually take greater control over their lives. These supports could entail a wide variety of resources based upon the age and unique needs of the child. Some examples include the following:

- Interveners
- Augmentative communication technology
- Mobility training
- ASL instruction for parents and family members

Most importantly, however, we need to provide children and youth who are deaf-blind with ongoing opportunities to exercise personal control so they can acquire and refine the capability to take charge of their lives. Given appropriate supports and the opportunity to gradually exercise greater control as their ability to take responsibility for their decisions increases, they will create personal visions for the future, make their own decisions, independently problem solve, and learn to advocate for themselves and others.

In summary, making it possible for children and youth who are deaf-blind to take greater control over their lives will not necessarily be an easy task. Many barriers must be overcome, including those created by the individual's limited hearing and vision and by the manner in which we currently educate persons with disabilities. Self-determination is a lifelong process to which parents and professionals, can make great contributions. By seeking new ways to support the developing self-determination of children and youth, while keeping in mind the unique skills and abilities each possesses, parents and professionals can effectively prepare young persons who are deaf-blind for their lives as adults. Supporting children and youth to build the capacities that will allow them to take greater control over their lives as they approach adulthood should be one of the foremost goals of educators and parents.

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DB - LINK

The National Information Clearinghouse On
Children Who Are Deaf-Blind
(800) 438-9376
(800) 854-7013 TTY
dblink@tr.wou.edu

Finding A Summer Camp

Peggy Malloy

Each spring, DB-LINK receives numerous requests regarding how to find information about summer camps. The resources and articles listed below will help you locate camps and also learn more about issues to consider when choosing a camp. While there are few camps available that specifically serve deaf-blind children, there are many that serve children with special needs. You may also want to locate regular camps in your community and discuss with those that interest you how they can best accommodate the needs of a particular child.

Agencies

DB-LINK

DB-LINK usually has listings for several camps that serve deaf-blind individuals in our resource database each spring. Some serve deaf-blind children and teens, while others are for deaf-blind adults. If you are aware of camps that serve either deaf-blind children or adults, please let us know so that we will have this information available to share with others.

If you need assistance finding or accessing any of the resources listed in the remainder of this article, contact DB-LINK.

State and Local Agencies

Check with the following organizations to see if they have information about camps in your area:

- State deaf-blind projects
- National Family Association for Deaf-Blind (NFADB) regional directors
- Local parent training & information centers
- Support or advocacy organizations for deaf-blind people in your state

Printed Camp Guides

Guide to ACA-Accredited Camps - A directory of over 2,000 camps throughout the United States. Cost: 19.95 (includes shipping and handling). This guide is also available in many public libraries and on the American Camping Association web site (see below).

American Camping Association
Attn: Guide Sales
5000 State Road 67 North
Martinsville, IN 46151-7902
(800) 428-CAMP (2267)

Camps for Children With Disabilities - A brochure containing tips for choosing a camp and a list of Easter Seal Societies with Residential Camping Programs.

National Easter Seal Society
230 West Monroe Street
Chicago, IL 60606
(312) 726-6200
(312) 726-4258 (TTY)
http://www.easter-seals.org

Or contact the Easter Seal Society in your community.

Summer Camps for Children Who Are Deaf or Hard of Hearing - A list of camps, family learning vacations, and remedial clinics for deaf and hard-of-hearing children.

National Information Center on Deafness (NICD)
Gallaudet University
800 Florida Avenue, NE
Washington, DC 20002
(202) 651-5051
(202) 651-5052 TTY
nicd@gallux.gallaudet.edu
http://www.gallaudet.edu/~nicd

Special Camp Guide: Camps and Summer Programs for Children with Special Needs - Lists residential camps in the Northeastern United States and day programs in the 5 boroughs of New York. A new edition will be available in February 1999. Cost is 20.00, plus 4.50 shipping and handling. Resources for Children with Special Needs will also be holding a Special Camp Fair in New York City on February 7, 1999 at the American Red Cross, 150 Amsterdam Avenue, between 66th and 67th Streets from 10 a.m. to 3 p.m., where the guide will be given away for free.

Resources for Children with Special Needs, Inc.
200 Park Avenue South
Suite 816
New York, NY 10003
(212) 677-4650

Camp Guides On The World Wide Web

American Camping Association
http://www.aca-camps.org

Easy-to-search database contains information on more than 2000 camps accredited by the American Camping Association. Includes camps that serve individuals with disabilities. Many of these camps have their own web sites that you can browse for additional information.

Kids' Camps
http://www.kidscamps.com

Provides way to search for camps by a number of different categories including residential camps, day camps, and special needs.

Super Camp Guide
http://family.go.com/Features/family_0000_01/dony/Camps/Camps.html

For Further Reading

Choosing a camp or summer program. Schleifer, Maxwell. Exceptional Parent, vol. 28, #3, March 1998, p. 28.

Provides guidlelines and suggestions for parents to consider when choosing a summer camp for their child with disabilities.

Let's go to camp. Burkhour, Cynthia Kay. Exceptional Parent, vol. 28, #5, May 1998, pp. 66-68.

Discusses strategies that allow children with special needs to attend regular summer camps. Suggests reviewing camp literature for indications of accessibility and talking personally with staff to see what kind of experience the camp has had including children with disabilities. Emphasizes the importance of communication throughout the registration process as well as during and after camp. Includes specific ideas for overcoming environmental barriers and ways to include all children in all aspects of the experience.

Selecting summer camps: Primer for parents. Bella, Margie. Endeavor, Spring 1998, pp. 20-27.

Lists tips for finding a good camp for deaf children, and important questions to ask the camp director. Included is a directory provided by Gallaudet University, listing 1997 summer camps for children who are deaf or hard of hearing.

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Books For Parents and Families

Gail Leslie

There are numerous books written from many different perspectives on the realities of living with a disability. DB-LINK is often asked to provide a list of titles useful for parents and families. Given the number of books and the difficulty in recommending just the right piece of writing for just the right set of circumstances, we rely on lists published regularly by disability related organizations or book dealers. What follows here are sources for current lists and catalogs of books that parents or service providers might find useful.

Blind Children's Fund Publications List - A catalog of informational books for parents and teachers. For a copy of the catalog: (517) 347-1357 or email:blindchfnd@aol.com.

Family Village Bookstore: Reading and Resource Lists - Online bookstore provides lists of current books by subject.
http://www.familyvillage.wisc.edu/bookstor.htm.

Good Books About Disabilities: Special Needs Project Master Catalog - An extensive catalog of books for both children and adults. The Project not only produces the list, but sells books and will locate specific titles for consumers. For additional information or a copy of the catalog: (800) 333-6867 or email: Books@specialneeds.com.

The Special-Needs Reading List: An Annotated Guide to the Best Publications for Parents and Professionals - Wilma K. Sweeney, Woodbine House, Inc., 1998. Short reviews and recommendations of books, journals, newsletters, organizations, and other information sources about children with disabilities. Part One covers topics related to disabilities in general such as disability awareness, family life, legal issues, and education. Part Two focuses on specific disabilities. Comprehensive reading lists. To order: (800) 843-7323.

1998 "Exceptional Parent" Library Summer/Fall Selections - Nearly 150 titles covering general disabilities, education, families and specific disability categories. All titles are annotated and available from Exceptional Parent. The catalog is free. (800) 535-1910. Visit their bookstore on the web at http://www.eparent.com.

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Australia's First Deafblindness Winter School

Dr Mike Steer
Senior Lecturer, Vision Impairment
Royal Institute for Deaf & Blind Children

In July 1998, Renwick College, the research and teaching arm of the Royal Institute for Deaf and Blind Children, located in Sydney's northern suburbs, offered Australia's first postgraduate program to professionals working in the deafblindness field. (*Deaf-Blind Perspectives* readers will probably be aware that in the Southern hemisphere the seasons are reversed, so that June, July and August are Australia's winter months.) This "Winter School," with the title Developing Communication Skills in Students with Sensory Disabilities, was created after a need for more training and development programs for those serving deafblind people in Australia was identified by a 1996 survey commissioned by the National Federation of Blind Citizens of Australia (now called Blind Citizens Australia). Professionals already working in the field and those wishing to work in the field were invited to attend either for postgraduate university credit or as a professional development/continuing education program without university credit.

Among the week's offerings were sessions on the following topics:

- Critical considerations in developing communication with students who are deafblind
- Defining social interaction as the basis of communication.
- Practical steps in developing communication
- Communication and behaviour
- Communication and movement
- Communication in the early years
- Communication that supports inclusive education
- Evaluating and assessing communication program effectiveness
- Assistive technology
- Interpreter skills

The Winter School was widely deemed a remarkable success, given the size of our population (17 million) and the relatively small number of deafblind Australians. A total of 45 people from every Australian state and territory gave up their school vacations or took leave from their positions to attend. Evaluations completed by participants were among the best the college has received for any of its offerings. It was generally thought that the event had given a significant boost to the field of deafblindness nationally.

Keynote lecturers included Dr. Deborah Chen, Professor of Special Education at California State University, Northridge, and Sharon Barrey Grassick, Senior Training Officer with the Western Australian Deaf Blind Association. The five-day program also featured sessions from Kirralee Lewis, Senior Training Officer with the Victorian Deafblind Association; Per Lundgren, from the Guide Dogs Association of NSW; Michelle Burdis, Rob Last, and Christine Muir from the Royal Institute; Dr Angela Wilson, Senior Research Officer of Forsight Foundation, an Australian community agency which focuses on meeting the residential needs of deafblind adults; and Trish James and Irene McMinn from Royal Blind Society and NSW Deafblind Association, both of whom are committee members of the Australian Deafblindness Council, our major national advocacy body.

Organization of an event of this type in a nation that is geographically as large as the continental United States was no mean feat. A great many people made its success possible: the institute staff who provided braille, large print and, in some instances, adaptive technology for participants, the skilled interpreters who ended each day exhausted, the institute's kitchen staff and particularly its Continuing Education staff and Research Librarian as well as Dr Greg Leigh, Head of Renwick College, who underwrote what turned out to be a relatively costly event that might, for one reason or another, have been poorly attended and result in a financial disaster for the college.

In July 1999, Renwick College plans to offer its second week-long Deafblindness Winter School, this time with a focus on *Curriculum* for students who are deafblind. The Asian economic crisis, with its impact on Australian currency, currently place our dollar at US $.59, making attendance at this event an attractive proposition to postgraduate students and other interested professionals from overseas. Added to this, Australia, with its unique scenery, flora and fauna, beautiful beaches and wide-open spaces make our country an ideal holiday destination. Further information on the July 1999 Winter School is available from:

Christine Grimmer
Coordinator of Continuing Education
Renwick College
Private Bag 29
Parramatta NSW Australia 2124
rccrg@cc.newcastle.edu.au

Meet the DB-LINK Staff

DB-LINK, The National Information Clearinghouse On Children Who Are Deaf-Blind was formed in October 1992. Since that time, the project has developed into a comprehensive information center with a large collection of materials on deaf-blindness, an extensive web site, and numerous publications. DB-LINK staff members bring a variety of backgrounds to the project, a unique blend of expertise that enhances our services. DB-LINK is a consortium of three primary organizations. Resources and staff are located at each organization: Teaching Research at Western Oregon University in Monmouth, Oregon; Perkins School for the Blind in Watertown, Massachusetts; and Helen Keller National Center in Sands Point, New York.

John Reiman, Ph.D., the Director of DB-LINK, is located at Teaching Research. Since living with a deaf/deaf-blind couple and earning his Comprehensive Skills Certificate (RID) during the mid 1970's, John has continued both personal and professional relationships with deaf/deaf-blind people. His professional experience in deafness includes directing degree programs at both Gallaudet and Western Oregon University and, since 1990, conducting multiple federal research projects. In 1992, he directed the National Symposium on Deaf-Blindness as well as DB-LINK. He also works as a professional mediator in many contexts.

Gail Leslie, also at Teaching Research is the Project Coordinator and an Information Specialist. She has been with the project since it was initially funded. Gail has a master's degree in library and information science and prior to coming to DB-LINK worked for 10 years as a public librarian.

The information specialists at Perkins School for the Blind each have master's degrees in Education and bring significant content experience in deaf-blindness to the project. **Betsy McGinnity** has been with the project since it began. She came to DB-LINK with a background in employment and transition issues for youth who are deaf-blind. She has done work nationally and internationally through the Hilton/Perkins Project. **Steve Davies** has worked in the field of deaf-blindness in many capacities including classroom teacher, itinerant teacher, transition planning specialist, and parent educator. **Lisa Jacobs** joined the project in September, 1998 and was previously coordinator of the New England Center for Deaf-Blind Services, multi-state 307.11 project. She brings to DB-LINK extensive experience working with children who are deaf-blind, their families, and school personnel.

The two remaining information specialists each have master's degrees in library and information science. **Lois O'Neill**, at the Helen Keller National Center, has been a librarian for 10 years. Her previous experience includes work as a medical librarian and as a coordinator of Project Access at New York Public library, a program which provides access to library services for patrons who are disabled. **Peggy Malloy**, at Teaching Research, is also a librarian and has worked as a medical librarian and writer. She was also a registered nurse for 10 years, working primarily in pediatrics and neonatal intensive care.

Harvey Mar, Ph.D., has been a DB-LINK staff member since early 1994. He serves as a DB-LINK consultant. Harvey is a psychologist in Pediatrics at St.Luke's-Roosevelt Hospital Center. He has been involved in several special projects pertaining to children and adolescents who are deaf-blind and have other severe disabilities.

Also at Teaching Research are several indispensable support staff. **Randy Klumph**, who joined DB-LINK in 1992 as our technical specialist, has a bachelor's degree in psychology. He brings a unique combination of skills to the project including social service experience, desktop publishing, technical illustration, and computer hardware/software technical support. **Betsy Martin-Richardson** also has a bachelor's degree in psychology and is the project's research assistant. She manages most of the office mayhem, including all of the ordering, the organization and distribution of materials, and also maintains our statistics database. **Sue Goodson**, is a part-time cataloger, who helps develop and maintain our catalog and resource databases. She is currently studying for a master's degree in information resources and library science.

1st row l to r: Sue Goodson, Lisa Jacobs, Betsy Martin-Richardson.

2nd row l to r: Randy Klumph, Harvey Mar, Steve Davies, John Reiman, Gail Leslie

3rd row l to r: Peggy Malloy, Lois O'Neil, Betsy McGinnity

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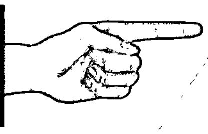

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CHARGE Syndrome Foundation, Inc.
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DB-LINK, The National Information Clearinghouse On Children Who Are Deaf-Blind is a federally funded information and referral service that collects, develops and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

Services include:

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For more information contact:

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For more information , contact:
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Deaf-Blind Perspectives

Volume 6, Issue 3 Spring 1999

In Australia: Placing Parents and Families at the Center of Our Planning

Dr Mike Steer
Renwick College
Royal Institute for Deaf & Blind Children
North Rocks, NSW, Australia

In Australia, we have learned much from our American colleagues and in particular from the 1997 amendments to the Individuals with Disabilities Education Act (IDEA). On our vast continent, with its 17 million population, children who are deafblind or have multiple disabilities (i.e., have two or more disabilities in the areas of vision, hearing, physical ability, intellect, and behavior), are at the center of what might well be the most exciting and challenging development in education today. Less than a decade or so ago, few administrators and teachers in Australian schools were concerned with the needs of children who had been so identified, and indeed neither the term deafblind nor multiple disability would probably have been widely recognized outside special education and special school circles anywhere in our country. Until relatively recently, few such children received any kind of sustained education and training outside the provisions of such charitable-sector, specialized agencies as the Royal Institute for Deaf and Blind Children in Sydney and its counterparts in the other Australian states and territories. Since the provision of "care" was the essence of the community's expectation of their developmental program requirements, such children and young adults were either kept at home or placed in settings generally beyond the responsibility of our generic school systems. Many, as is now well-known, were widely believed to be "trainable" rather than "educable," and many were deemed to be ineducable. The legacy of this perspective is, to our national shame, that in many parts of Australia, deafblind young adults and adults can still be found vegetating in nursing homes and even as residents in euphemistically named "Training Centers" for people with intellectual disabilities.

Today, the compass needle of change has swung the educationist position to the opposite pole. A dramatically different educational philosophy prevails. We now believe that ***all*** children are able to learn and that even those with the most pervasive disabilities ***can*** and ***do*** learn. In consequence, it is becoming increasingly likely that at some point in their career, every regular school teacher in Australia will encounter a student with one or other sort of significant disability in his or her class and with increasing frequency, will, for better or worse, become responsible for the education of a student who is deafblind or has multiple disabilities. Deciding ***what*** to teach this student and ***how*** to teach him or her can pose seemingly insurmountable problems for administrators, classroom teachers, and supporting specialist educators.

This is partly because the majority of children, particularly students with vision impairments, have so many things to learn that educational planning teams, whether in regular or special school, often find it difficult to decide which goals will be most important for the coming year. Other students, whose parents are increasingly seeking their enrollment in the local neighborhood school, have limited response repertoires and a variety of sensory and motor impairments, often with an intellectual disability thrown in for good measure, so that they challenge the

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creativity of both school and itinerant staff to design effective teaching strategies to meet their needs.

It is perhaps trite to state in 1999 that curriculum decisions for children who are deafblind should be based on a shared understanding of each individual student's needs, strengths, and abilities, and on the important questions families want answered. Determining just what, where, and when to teach should, however, be based on shared values about the goals of education. What do teachers, friends, and family believe the child ***should*** be doing when she or he graduates from school into adult life? What is school preparing the student for? If, for example, administrators, teachers, and parents believe that the individual will be totally dependant life-long and not particularly in need of friends or a job, then what the student is taught while at school is not particularly important. If, on the other hand, those on the educational planning team are able to share a picture in which the individual is a valued, contributing part of community life, with friends and perhaps even some form of employment in the offing, then curriculum content and teaching method become vitally important. Bearing in mind that an Individualized Educational Plan (IEP) is in Australia, as it is in the USA, at the core of the planning process and that it must reflect the input of an entire team, it becomes important to recognize (a) that each student requires individually tailored supports and resources and (b) that whatever teaching strategies are decided upon, these should be effective, inclusive, and humane.

What Should Be Taught?

The first step in deciding what to teach is to initiate a process that will discover what the child's special qualities are, what are his or her interests and aspirations, and what are the hopes and aspirations of the family and people closest to the child. A highly effective way of doing this, and one that is gaining increasing currency in Australia, is through the development of "action plans" which result from the ***McGill Action Planning System***, or ***MAPS*** (Forest & Lusthaus, 1989; Forest & Pearpoint, 1992; Orelove & Malatchi, 1996; Vandercook, York, & Forest, 1989). MAPS takes its name from McGill University in Montreal and is based to some extent on earlier "lifestyle planning" procedures developed by O'Brien & Lyle (1987) and O'Brien (1987) of Responsive Systems Associates in Georgia. It is a system designed by Marsha Forest and Judith Snow of the Canadian Association for Community Living (CACL), that grew out of the need to actively support students with severe and pervasive disabilities (Ford & Davern, 1989).

MAPS is a group, problem-solving, collaborative team approach to program planning. It is a tool, that in the hands of a creative facilitator is designed to help individuals, organizations, and families move

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into the future effectively and creatively. There are eight key questions in the process and they must all be asked by the process facilitator. The order in which they are asked may, however, be quite flexible, based on group dynamics and the flow of the planning meeting. MAPS planning sessions have been held in classrooms, school cafeterias, organizational boardrooms, small meeting rooms, community centers, church halls, and so forth. The system has been used not only with children of all ages, but also with adults (Rosenkoetter, Hains, & Fowler, 1994; Shauls, 1991). It results in a personalized plan of action that assists in bringing the student and family closer to the daily life of the school (Forest & Pearpoint, 1992). A MAP is not, however, an IEP, nor is it a substitute for an IEP. It is a process that best precedes an IEP and provides the school's transdisciplinary team with important information that will be useful when constructing an IEP. This element of the MAPS process is important because it attempts to portray the child to the best possible advantage and focuses attention on capabilities rather than deficits. The positive emphasis generates important benefits throughout the program planning and implementation phases.

How to Use MAPS

A MAPS meeting generally begins with invitees seated around a table or in a semicircle facing a wall or whiteboard. Each participant is given a notepad and pen or pencil. A facilitator (sometimes two), welcomes the group, explains the process, guides questions, and keeps the session on track. The second facilitator or an assistant serves as a "graphic guide" and records the business of the meeting, sometimes creatively and colorfully, generally on manilla or butcher's paper, which is then mounted with tacks, tape, or pins onto the walls of the room to produce a pictorial record. Sometimes meetings are audiotaped. These records, written, pictorial, or audio are essential to the process.

The facilitator attempts to generate a personal, comfortable, informal group mood and generally urges mutual trust and the avoidance of confusing jargon and acronyms. Each person attending introduces himself or herself and shares information on their relationship to the student who is the focus of the meeting. The facilitator then takes the group through a process which involves generating answers to the following eight questions:

Question #1: What is a MAP? The facilitator describes the ways in which a map is used and links the MAPS process, by analogy, to a road map that will provide directions for the student's life. The result of the meeting will be a chart which will guide that direction, so that it becomes important for participants to answer all questions.

Question#2: What is (the student's name) history? Answers to this question describe the student's life, particularly focusing on highlights or milestones. Information is included on medical, educational, communication, and social issues. It is often possible for the facilitator to collect much of this information in advance, to avoid spending too much time on the question, requiring only that group members add anything that is missing.

Question #3: What is your dream for (student's name)? Participants are asked to describe their dreams for the student for the next 5 years, 10 years, and as an adult, including dreams about where he or she will live and work, and about the various relationships in his or her life. Dreams need to be conceived as images of what might be possible.

Question #4: What is your nightmare for (student's name)? It is not possible to avoid nightmares if they remain undiscussed. It is important that participants not become despondent if the realities of institutional "care" are raised, or the threat of social isolation or poverty as an adult. Dreams and nightmares are of equal importance to the discussion. Many programs and projects fuel the nightmares rather than the dreams. The entire aim of the MAPS process is to discuss both dreams and nightmares so that the former can be realized and the latter avoided.

Question #5: Who is (student's name)? This is a brainstorming phase of the process. Everyone is invited to provide words that the facilitator records as a portrait of the person. Not merely good or bad words, but words that convey important impressions of the student's identity. The facilitator might also ask, "What other words have persons not present here today used when describing (student's name)?"

Question #6: What are (student's name) strengths, gifts, and talents? In this phase of the meeting the facilitator will record likes, dislikes, preferences, what works, successes, and so forth. The concept of "giftedness" in association with the student, is stressed not in relation to academic ability, but as one of the attributes of the student's personality.

Question #7: What are (student's name) needs and challenges? In answering this question, participants must think about the people and resources necessary to make the dreams come true.

Question #8: (a)What action plans are needed to meet these needs and avoid these nightmares? This phase requires the facilitator, working with group support to pull together finite, specific follow-up plans. These will include defining who will do what, and when and where. For example, when will the IEP session be held, who should attend, when will Circle of Friends activities begin?

(b) What would an ideal day at school look like? Using the information generated in the above process, a matrix can be constructed for use in school program scheduling.

The entire MAPS "machine" can, if efficiently prepared and managed, take about 90 minutes to conduct, with none, or few of the participants bored or overly tired as a result. In many instances, the students themselves have sat through the entire sessions. Facilitators have even invited very young children to be present for as long as they like and have arranged child care if they have decided to leave. Many have stayed for the entire session. This particular outcome merely affirms the notion that most people, including those with multiple disabilities, are vitally interested in their own lives. Those who designed the process claim that the best time to use MAPS is as part of the IEP cycle, or at crucial transition points in the student's schooling, for example, preschool to primary school, primary to high school, high school to adulthood.

MAPS can be a highly positive process through which the resources of school administration and staff, nondisabled peers, family members, and a variety of supportive people can be harnessed to develop a plan for the inclusion of children with disabilities into regular community school life. The process, which is by no means an arduous one, can be the vehicle for bringing regular and special educators together in the quest to build more inclusive school communities. MAPS has now been used with success in Canada, Britain, and increasingly in Australia for some years, generally with salutary overall impact on the lives of students and families and to the benefit of an increasingly large number of educational agencies.

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Research-to-Practice: Reducing Behavior Problems in Students Who Are Deaf-Blind

V. Mark Durand, Project Director
Christie Tanner, Project Coordinator

"If only he could talk!" Michael's mother said as she expressed her helplessness over her son's apparent frustration. Michael, who is deaf-blind, was screaming and biting his hand while his teacher tried to get him to participate in some schoolwork. "If only he could just tell us what he wants, what's bothering him!" There was no blaming here, only a feeling that Michael held the secret to satisfying his own needs—if only we could get inside his head and crack the code.

Our project is designed to "get inside" Michael's head, as well as the heads of 23 other students with deaf-blindness to determine *why* they exhibit problem behaviors such as aggression, self-injury, and tantrums. Once we determine why the students are displaying problem behavior, we attempt to teach them another way of telling us what they want, using vocal output communication aides (VOCAs) in an approach we call "functional communication training." Finally, the third stage of our project is to assess whether our efforts at teaching these students specific communication strategies in school might be effective outside the school environment.

Finding Out Why Behavior Problems Occur

It is now widely agreed that treatment efforts for behavior problems should be based on the reasons why the student is misbehaving. In fact, the Individuals with Disabilities Education Act (IDEA) now requires such assessments (functional behavioral assessments) for all students with significant behavior problems. Unfortunately, despite this widespread agreement to look at why our students misbehave as the basis for any program, many professionals continue to make such assessments in informal ways, such as through conversations with teachers and parents and brief informal observations of the student. We always begin with informal observations of and interviews with significant others, but we continue the process using *multiple forms of assessment*, including the Motivation Assessment Scale (MAS)[1] and structured observations in the student's classroom. The MAS is a questionnaire that we can give to teachers, paraprofessionals, family members, or anyone else who has a great deal of contact with the student. The MAS asks questions about where, when, and under what conditions problem behaviors occur and determines their motivations. Information from the MAS, along with other forms of functional behavioral assessments is used to design plans for reducing the behavior problems. Michael's assessments suggested that his screaming and hand biting occurred more often when demands were placed on him. This told us that he might be acting this way because his behavior sometimes got him out of tasks in his class. His teacher might end work earlier than usual if he got upset. This taught him to get upset when he did not like the work. Clearly, this information was very important to us in designing a plan for reducing his behavior problems.

Functional Behavioral Assessment Hints

- Conduct two or more *different* functional behavioral assessments for a student's behavior problems. This will increase your confidence that you have picked the right reasons the problems are occurring.
- Conduct these assessments in *all* settings where you expect to begin a program.
- Be aware that behaviors can occur in different settings for different reasons.
- Sometimes knowing what can make a student well-behaved (e.g., sitting next to the teacher) can tell you why the student is misbehaving (e.g., to get teacher attention).
- Behaviors that appear to occur for sensory reasons (e.g., repetitive behaviors) can over time be used by a student for social reasons (e.g., to avoid demands).

Using the Assessment to Design a Plan

There are many different ways to reduce behavior problems. For example, with Michael we could have simply stopped giving him any challenging class work. We knew from our assessments that making these changes in the classroom would have stopped almost all of his outbursts. But where would this have left him? Obviously, almost all educational goals would have been thwarted. Rather than remove the situations that seem to set off behavior problems, we try to teach the student how to handle these situations. Therefore, at the heart of our efforts to reduce behavior problems is the approach that teaches students other ways to tell us what they want—"functional communication training." As we saw before, our functional behavioral assessments indicated that Michael's screaming and hand biting were most likely efforts to escape work. Our solution was to teach him to use a vocal output communication aide (VOCA) to ask his teacher for help when the work was too difficult.

We taught Michael to communicate using his VOCA in much the same way we teach the other students in the project. Since we begin by placing the student in the situation that seems to be causing difficulties, we began by having Michael work on difficult tasks. *Be-*

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[1] Information about the Motivation Assessment Scale is available from the publisher; Monaco and Associates, Inc., 4125 Gage Center Drive, Suite 204, Topeka, KS 66604 (800) 798-1309, (785) 272-5501, (785)-272-5152 (fax); www.monacoassociates.com/products/

fore he had time to get upset, we would take his hand and help him press the VOCA, which was programmed to say "Help me!" We then gave him some assistance on the task to make it easier for him. Although he could not hear the voice output, it soon became clear to him if he pressed the button on the device, the task became easier for him. After a few weeks during which time we reduced the amount of help we gave him, he began to use the device with no help each time tasks became too difficult. And, when this happened, his behavior problems were reduced significantly. Although students progress at different rates, if we pick the right situation to begin teaching based on our functional behavioral assessment we are often very successful in teaching students to ask for what they want. Their problem behaviors are in turn reduced.

Reducing Behavior Problems Hints

- Always include strategies for teaching more appropriate skills in any plan to reduce behavior problems.
- Do not rely simply on avoiding situations that lead to problem behavior.
- Be sure the communicative efforts of the student are understandable to others.

Moving Out into the Community

One of the biggest challenges to designing a plan to reduce behavior problems is to create a program that will work outside special settings and with untrained persons. We need plans that will not only work with specially trained teachers and family members at school and at home, but also with the cashier at fast food restaurants, a bus driver, or the stranger on the street. To be successful in the community means that we cannot simply rely on avoiding problem situations; instead, we must teach our students how to adjust and respond to settings that are often unpredictable.

The functional communication training we just described is an ideal way to help students adapt to the community. Thus, our project extends the work in the classroom by taking the students out into their community where we identify situations that may cause them to become upset and then teach them to ask for what they might want. Because the VOCAs can be programmed to clearly communicate the students' requests, they provide a good way to bridge the communication gap between the child who is deaf-blind and the rest of the world.

Reducing Behavior Problems with Functional Communication Training is a three-year granted project from the U.S. Department of Education, Office of Special Education Programs, Model Demonstration Projects in Deafblindness, Grant Number H025D60008. The contents of this article do not necessarily reflect the opinions of the U.S. Department of Education.

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NTAC Area Updates

The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC) provides technical assistance to families and agencies serving children and young adults who are deaf-blind. NTAC's purpose is to assist states in improving the quality of services for deaf-blind individuals (birth to age 28) and to increase the numbers of children, young adults, their families, and their service providers who benefit from these services. Assistance is available to each of the 50 states and the U.S. territories and jurisdictions. Services are provided by technical assistance specialists located in four different areas of the U.S. Below are some examples from each area of current activities in which NTAC is involved.

Area 1

Hawaii and the Pacific Basin Jurisdictions - The Pacific Basin and Hawaii Deaf-Blind Projects recently worked together, in collaboration with NTAC, to present a workshop called "Communication for students who are Deaf-Blind or Multihandicapped" to teams of educators from Hawaii and several jurisdictions in the Pacific. The two deaf-blind projects, NTAC, and the workshop consultant, Terry Rafalowski-Welch, also provided ongoing support to the teams after the workshop ended to ensure implementation of the training.

New Mexico - The New Mexico Deaf-Blind Project, with the help of in-state consultants, is currently adapting training materials into an Internet course to be offered through New Mexico State University. The course, which uses the "Hand in Hand" materials published by the American Foundation for the Blind and the theories and practices of Jan van Dijk, has been presented in a traditional classroom format to local school districts and other agencies across the state for the past two years. The new web-based course will be available to all students enrolled at the university.

Utah - Beginning in the fall of 1999, Corry Hill, a Utah parent and the Family Support Specialist for the Utah Dual Sensory Impairment Project, will facilitate discussions with other family members in the state about important practices for deaf-blind individuals and how to implement those practices for Utah's children and young adults. The discussions will focus on a list of the 10 most important practices in the areas of communication, behavior, and instructional strategies that were developed by family members at the NTAC/NFADB National Parent Workshop held in July 1998.

Area 2

Iowa, Kansas, Missouri, and Nebraska - Several states in Area 2 have begun using a training model called "State and Local Team Partnership Training." This model, developed by the HKNC-TAC (Helen Keller National Center - Technical Assistance Center) Project, focuses on training teams to facilitate successful transitions from school to adult life for youth who are deaf-blind. Each state has adapted the model to fit its own unique needs. Iowa is training in-state trainers to provide ongoing support to teams within the state. Kansas and Nebraska are training teams by using a case-study approach centered around specific youth who are deaf-blind. Missouri is setting up employment teams that focus solely on placing youths who are deaf-blind in appropriate jobs that match their interests and abilities. The NTAC Technical Assistance Specialists in Area 2 and the directors of each of the state deaf-blind projects are providing follow-up support to teams through onsite consultation and training, sharing of resource information, and frequent telephone and e-mail contact.

Area 3

Florida - Florida has also developed a unique approach to the State and Local Team Partnership Model by forming a transdisciplinary state team called the Florida Network on Deaf-Blindness. The team meets regularly to provide support to local transition teams that work with individual students who are deaf-blind. Through collaborative efforts with local school districts, the Florida Outreach Project on Deaf-Blindness, NTAC, and adult services personnel, these teams are implementing best practices for transition and creating positive outcomes for students who are deaf-blind and their families. Another organization currently being established in Florida is the Family Network on Deaf-Blindness which will strive to raise awareness about issues and needs regarding deaf-blindness, and work with the state and local partnership teams to enhance transition services in the state.

Area 4

New Jersey - Several groups are working together to strengthen parent-to-parent activities in New Jersey that will provide support and empowerment for parents and advocacy on behalf of children and young adults who are deaf-blind. These organizations include the New Jersey Technical Assistance Project, NTAC, Prism Organization, Inc. (the current state parent organization), and the New Jersey Commission for the Blind and Visually Impaired. In March 1999, 15 families will meet for a weekend retreat to determine the needs of parents of children who are deaf-blind, evaluate Prism's current value and mission statements, learn about existing state and national resources, and determine next steps.

Rhode Island - In September 1998, Rhode Island held its first-ever statewide conference on deaf-blindness called "Keeping In Touch: A Statewide Conference on the Needs of Individuals with Combined Hearing & Vision Loss." The conference was supported by numerous agencies including L.I.F.E., Inc. (Living In Fulfilling Environments), NTAC, Rhode Island Services to Children with Dual Sensory Impairments, and the Helen Keller National Center. The conference was well attended by service providers from across the state.

West Virginia - West Virginia is currently in its second year of a Model Sites Team Training Project, a collaborative effort between NTAC, the West Virginia Deaf-Blind Project, and the Kanawha County School District. Its purpose is to train teams who work with students who are deaf-blind to utilize effective educational practices. The projected outcome in years three and four of the project is to have the currently involved classrooms and programs serve as model sites for teachers and service providers in the state.

Delaware - NTAC and the Delaware Program for the Deaf-Blind, in collaboration with other state agencies, are in the process of field testing a community employment initiative for persons with severe disabilities, including deaf-blindness. The purpose of this research-based initiative is to identify barriers that prevent individuals access to working in the community and to develop strategies that lead to systems change. The findings of the field test will be documented in an executive summary outlining statewide policy and procedural issues, and recommendations for personnel training and outreach.

The following is from the Jan./Feb. 1999 issue of Ragged Edge magazine. Reprinted with permission.
http://www.ragged-edge-mag.com

A Woman of Her Time—and Ours (Book Review)

Sally Rosenthal

Helen Keller: A Life by Dorothy Herrmann. New York: Knopf, 1998. Hardcover, 394 pages, $30

I know who you are. You read Ragged Edge. You're disabled and hip, a cool crip. You expect your favorite crip magazine to be just as cool. So I know what you're thinking when you see that this issue's review is of a Helen Keller biography. Yet another one. Another able-bodied dissection or sanctification of the ultimate historical icon of feminine disability. Believe me, I know what you're thinking. At best, you want to turn the page; at worst, you're already contacting the subscription department to cancel further delivery. If there's one thing cool crips don't need in the 1990s, you figure, it's another look at Keller's life.

Oh, how wrong you are.

Another look—a radically different look—at arguably the most famous disabled woman of the twentieth century is just what you do need. And you will find it in Helen Keller: A Life, a fresh, riveting interpretation of Keller's life and work by Dorothy Herrmann.

Don't feel bad, though; I almost dismissed Herrmann's book, too, when I heard the promotion of it on my local National Public Radio station. Herrmann was scheduled to be interviewed about the new biography on an upcoming talk show. This particular listener, never a fan of other Keller biographies which seemed to paint her as a saint or hopelessly enmeshed in a symbiotic relationship with her teacher Annie Sullivan Macy, wasn't overly enthusiastic about a new book. Recalling all the childhood "inspirational" accounts I had read of Keller's life (as well as the occasional adult memoirs), I wrote off Herrmann's new work before the talk show began.

Oh, how wrong I was.

Dorothy Herrmann, a biographer who did not describe herself as disabled (leading me to assume she was nondisabled—and the book information on her gave me no information to the contrary), surprised me with her insightful, new slant on Helen Keller—who emerged from Hermann's interview as more of a mover and shaker than a plaster saint. The woman Herrmann described was a staunch supporter of labor unions, the Soviet revolution and her fellow disabled comrades in arms—certainly not the heroic figure of grade-school library books who "triumphed" over her disability. Herrmann, I began to suspect as I listened to the interview, just might be on to something.

What ultimately won me over, however, was the manner in which the author spoke of Helen Keller in connection with other disabled people, disabled women in particular. The Keller she wrote about was a woman with her own deaf-blind reality, a reality Herrmann reported was just as valid as any nondisabled reality. Without denying the very real limitations of Keller's life, Herrmann was able to bring her subject to life as a passionate, vital woman, albeit one whose life might always remain somewhat of an enigma. Herrmann's astute observations and articulation of them changed my mind about her subject. No longer a shadowy disabled saint, Helen Keller became both my foremother and sister.

I picked up Herrmann's book a day later on a visit to my local bookstore. And I was not disappointed. *Helen Keller: A Life* turned out to be just as fascinating as the radio interview.

As with any biography, the basic historical facts are there: Keller's birth in 1880 in a small Alabama town, her deaf-blindness before the age of two due to a still-debated cause, the arrival of a half-blind, poverty-stricken Annie Sullivan a few years later—and, the rest, as the saying goes, is history. What amazed and intrigued me as a disabled woman, however, were the aspects of Keller's life that had never quite made it into previous accounts.

As Herrmann points out, the Helen Keller with whom most people are familiar is a stereotypical sexless paragon who was able to overcome deaf-blindness and work tirelessly to promote charities and organizations associated with other blind and deaf-blind individuals.

A recent traveling photographic exhibition sponsored by the American Foundation for the Blind, an organization for which Keller spent much of the lat-

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ter part of her life working, did nothing to dispel this common public legend (nor does the literature distributed by the AFB and other associations with whom her name and image are closely linked). Missing are the very things that those of us with disabilities would find interesting and empowering, aspects of Keller which would serve to make her a truly real and believable woman.

But Herrmann makes those missing details an important part of her book. Keller, a woman of staunch, radical convictions, supported many causes of her day. A believer in the universality of all people, Keller publicly espoused socialism, communism, radical labor unions and strikes, and spoke out against US entry into World War I. Not content to stop there, Keller managed to draw the conclusion that people of her day with disabilities were also part of the oppressed masses—and as deserving of dignity and liberation as other oppressed groups. Not exactly the stuff of which plaster saints are made—especially one who, in later life, was presented by her close circle of companions (and the organizations who benefitted from her endorsement) as a triumphant, cheerful (read: "almost normal") woman.

Keller, Dorothy Herrmann concludes, might well have been a willing accomplice in the remaking of her image. Dependent both on her companions for all daily care and communication with the outside world and with the organizations for financial support, Keller might have had no other option than to downplay the beliefs that would have made her far more human than an able-bodied public wanted.

Another event in the younger Keller's life might also, Herrmann suspects, have caused her to become more publicly compliant. Although she and a young socialist had fallen in love and applied for a marriage license, her hopes were dashed by a complicated set of circumstances—the family's disapproval, Annie Sullivan's fear of usurpation, and, possibly, the potential groom's second thoughts. The Keller who longed for sexual fulfillment and the married life expected for most women of her time rarely appears in other accounts, making Herrmann's biography the most complete and complex we have.

Complex? Yes. Admittedly, *Helen Keller: A Life* is a new look at an old subject, but the fact remains that very subject herself remains complex. Because of her very real severe disability and the historical context in which she found herself, Keller will always, to some extent, remain an enigma. Herrmann's book does much to credit Keller with striving to carve out a personal and public image for herself, no small feat for any woman of her time. The controversies surrounding her relationships with Annie Sullivan Macy, her other companions, her charitable organizations and a public both drawn to and repelled by her remain at the end of Herrmann's book.

Perhaps the task of any first-rate biographer is to ask more questions than to provide concrete conclusions. No life, especially one as singular as Helen Keller's, can be neatly parceled. Thanks to Dorothy Herrmann, however, it has emerged, thirty years after Keller's death, as a life of much more than stereotype and legend.

DB - LINK

Graduate Programs That Offer Opportunities In Deaf-Blind Education

Peggy Malloy

A number of universities in the United States offer graduate programs for training teachers to work with children who are deaf-blind. The following programs either offer degrees in deaf-blindness or have significant course content related to deaf-blindness incorporated within other degree programs. The descriptions below were compiled from information submitted by each program. Contact each program directly, for more information.

Vision Impairments-Deafblind Program
UAB School of Education
Education Building
University of Alabama at Birmingham
Birmingham, AL 35294

Contact:
Dr. Mary Jean Sanspree
(205) 934-3440
Alabama Relay (800) 251-5325 (TTY)
msanspree@icare.opt.uab.edu

The University of Alabama awards a master's degree or graduate certification in teaching students who have visual impairments. Deafblind studies are embedded throughout all subject areas. Practical experience involves clinical hours in public schools as well as optional placements, so that students receive teaching experience in a wide spectrum of classrooms. All students have individual programs designed to address their strengths and needs. Most coursework is presented during the summer and on weekends. An average of 12 students are enrolled each year. UAB also has a program in Iowa. Scholarships are available.

Teacher Preparation in Severe & Multiple Disabilities

Department of Special Education, Rehabilitation, and School Psychology
College of Education
University of Arizona
Tucson, AZ 85721

Contact:
Dr. Stephanie MacFarland, Coordinator
Dr. John Umbreit, Director
(520) 621-5165
(520) 621-7822 (TTY)
szm@u.arizona.edu

The University of Arizona offers a master's degree and certification in teaching students with severe and multiple disabilities. It includes course content related to teaching children who are deaf-blind, including the importance of assessing and developing communication systems and programs. A functional and inclusive approach to teaching individuals with severe and multiple disabilities is emphasized. Opportunities are available to pursue areas of concentration in specific subjects such as deaf-blindness, autism, and school-to-work transition. Twenty-five students are currently enrolled. Scholarships are available for full-time students.

Preparing Teachers to Educate Students with Severe and Multiple Disabilities from Diverse Cultures

California State University, Northridge
18111 Nordoff St.
Northridge, CA 91330-8265

Contact:
Dr. June Downing, Associate Professor
(818) 677-5261
(818) 677-2577 (TTY)
june.downing@csun.edu

The program at California State University, Northridge, leads to a Master of Arts degree in special education with an emphasis on severe and multiple disabilities and a certificate in deaf-blindness. Inclusive educational practices are stressed as well as working with students from a variety of diverse cultures. Approximately 15 students are enrolled in the program, which has a stipend of $6,000 per year as well as other benefits, such as monetary support for attending professional conferences.

Boston College Teacher Preparation in Deafblindness

School of Education, Campion Hall
Chestnut Hill, MA 02167

Contacts:
Dr. Barbara McLetchie
(617) 552-8431
mcletchie@bc.edu

Dr. Richard Jackson
(617) 552-8429
jacksonr@bc.edu

Boston College has operated a program preparing teachers at the master's level to work with learners who are deafblind for over 30 years. Students may choose an area of speciality such as early intervention, serving adolescents, or working with families. Varied educational practicum settings are required. Out-of-state as well as local experiences are encouraged. Scholarships are available. Fifteen students are currently enrolled in the program.

Michigan State University Master's Program in Deafblind Education

Counseling, Educational Psychology and Special Education Department
331 Erickson Hall
East Lansing, MI 48824

Contact:
Dr. Susan Bruce, Coordinator
(517) 355-1871
alonsol@pilot.msu.edu

Students enrolled in the Special Education Master's Program in Deafblind Education, at Michigan State University complete the requirements of either the Deaf Education Program or the Visual Impairment Program in addition to the Deafblind Program requirements. The importance of communication, language, and orientation and mobility to the quality of life of individuals who are deafblind is emphasized. A deafblind-specific methods course is required, as well as a semester of intern teaching. Thirty-three students are currently enrolled in the Visual Impairment Program and approximately one-third of these are going on to specialize in the

Deafblind Program. Scholarships and graduate assistanceships are available.

Hunter College of the City University of New York

Hunter College School of Education
Department of Special Education
695 Park Avenue
New York, NY 10021

Contact:
Dr. Rosanne K. Silberman
(212) 772-4740
rsilberm@shiva.hunter.cuny.edu

Hunter College offers a Master of Science Degree in Special Education with a specialization in Severe/Multiple Disabilities Including Deafblindness. The program is designed to prepare teachers to provide instruction to learners with severe disabilities, including those with deafblindness in specialized and inclusive settings. Emphasis is on collaboration between special education and general education to prepare students to improve the quality of learning and increase educational opportunities and standards for all learners. Tuition waivers and stipends are available. Thirty students are currently enrolled in the program.

San Diego State University Preparation of Teachers to Educate Children Who Are Deaf-blind

Department of Communicative Disorders, SDSU
5500 Campanile Drive
San Diego, CA 92182-1518

Contact:
Dr. Kathee Christensen, Coordinator
(619) 594-6137 (V/TTY)
kchriste@mail.sdsu.edu

The Department of Communication Disorders at San Diego State University has a graduate-level teacher preparation program which leads to the Education Specialist Credential: Deaf and Hard-of-Hearing with an optional specialization in deaf-blindness. The program combines a Master of Arts degree with the California credential. Information regarding deaf-blindness and the education of deaf children with special needs is infused across the curriculum. The specialization in deaf-blindness includes additional field work, special studies, and practicum with learners who are deaf-blind. Six students are currently enrolled in the program. Stipends for tuition and other expenses are available for qualified students.

Texas Tech University College of Education Master & Doctoral Degree Programs

Box 41071
Lubbock, TX 79409-1071

Contact:
Dr. Roseanna Davidson, Coordinator
(806) 742-2334
tdavi@ttacs.ttu.edu

Texas Tech University has had federal and private grants to train teachers since 1989. A full master's degree is offered, which can be completed in 1.5 years for the full-time student. A doctorate in education with a major in deafblindness is also available. Students are certified as teachers of the severely handicapped, and may also earn a vision credential with additional coursework. Part-time enrollment is possible. Practicum placement is possible in many sites nationally. Stipends are offered for tuition and expenses. Ten to twelve students are typically enrolled annually.

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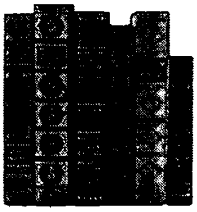
We encourage you to copy and share information from *Deaf-Blind Perspectives*, but please provide appropriate citations.

Correction

In the Winter 1998-99 issue of *Deaf-Blind Perspectives*, author Ronald Malcom was incorrectly identified as an associate professor at the University of Nevada at Las Vegas. His correct title is part-time instructor. (Ed)



For Your Library

All Kids Count: Including Students with Disabilities in Statewide Assessment Programs

Landau, Julia, J.D.;Vohs, Janet R., B.A.;Romano, Carolyn A., J.D. Boston, MA: Federation for Children with Special Needs, 1998.

Provides information about policies and practices related to inclusion of students with disabilities in large-scale assessments. Includes information on individual state policies and practices based on a survey by Parents Engaged in Education Reform (PEER) as well as an analysis of the survey results. Cost is $20.00. Order from: PEER Project, Federation for Children with Special Needs, Voice: (617) 236-7210. Fax: (617) 572-2094. E-mail: peer@fcsn.org

The Educator's Guide to Feeding Children with Disabilities

Lowman, Diane, Koontz, Ed.D.;Murphy, Suzanne McKeever, M.Ed., CCC-SLP. Baltimore, MD: Paul H. Brookes Publishing Co., 1999.

Provides educators with specific information to design and implement comprehensive feeding plans for children with disabilities. Includes a chapter on feeding issues common to children with sensory disabilities, including children who are deaf-blind. Available from Brookes Publishing Co., (800) 638-3775.

Free Appropriate Public Education: The Law and Children with Disabilities

Turnbull, H. Rutherford III; Turnbull, Ann P. Denver, CO: Love Publishing Company, 1998.

This book covers the six principles of the Individuals with Disabilities Education Act (IDEA), as most recently enacted in 1997. These principles are zero reject (including discipline), nondiscriminatory evaluation, appropriate education (including positive behavioral support), least restrictive environment, due process (including mediation), and parent participation. Also includes pre-1997 provisions of IDEA for comparison to the amended law.

Making Friends: The Influences of Culture and Development

Meyer, Luanna H., Ph.D. (Ed.);Park, Hyun-Sook, Ph.D. (Ed.);Grenot-Scheyer, Marquita, Ph.D. (Ed.);Schwartz, Ilene S., Ph.D. (Ed.);Harry, Beth, Ph.D. (Ed.) Baltimore, MD: Paul H. Brookes Publishing Co., 1998.

Focusing on issues of disability, cultural diversity, and combinations of the two, the 22 articles in this book explore the process of how children make, keep, and end friendships from childhood to early adulthood. Experienced teachers and professionals offer advice on creating positive atmospheres, supporting friendships, teaching respect, and improving behaviors. One article discusses the support of social relationships for students who are deaf-blind. Available from Brookes Publishing Co., (800) 638-3775.

Making it Happen: Student Involvement in Education Planning, Decision Making, and Instruction

Wehmeyer, Michael L.;Sands, Deanna J. Baltimore, MD: Paul H. Brookes Publishing Co., 1998.

The IDEA mandates students' participation in their education planning process. This text provides information on programs, strategies, procedures, and materials that promote students' involvement in transition planning, IEP development, and other aspects of education planning. Available from Brookes Publishing Co., (800) 638-3775.

Mosby's Resource Guide to Children with Disabilities and Chronic Illness

Wallace, Helen M., MD, MPH (Ed.) et al. St. Louis, MO: Mosby, 1996.

This book provides an overview of the different needs of children with disabilities and chronic illnesses, those of their families, and the array of services created to meet those needs. A significant portion of the book is devoted to describing services needed by children with special needs including information on the scope, objectives, skill and preparation of personnel. Designed for service providers with a strong bias toward interdisciplinary service delivery, parents, students, new team members or advocates will also find useful information here. To order, contact Mosby at (800) 426-4545.

Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction

Kranowitz, Carol Stock. New York, NY: Skylight Press, 1998.

Offers comprehensive, easily understood information on sensory integration dysfunction including identifying symptoms, characteristics and associated problems. Also includes criteria and guidance for diagnosis and treatment, and suggestions for families and teachers. Specifically recommended by parents of children with CHARGE Association. May be ordered by calling (800) 788-6262, or by visiting http://www.penguinputnam.com.

Pediatric Visual Diagnosis Fact Sheets

Blind Babies Foundation. San Francisco, CA: 1998.

This collection of fact sheets provides information on the most commonly encountered eye conditions among pediatric patients in the United States. These include: cortical visual impairment, retinopathy of prematurity, optic nerve hypoplasia, albinism, optic nerve atrophy, and retinal diseases. A seventh fact sheet addresses diagnostic tests and materials frequently used with young children. Sets or individual sheets may be ordered from Blind Babies Foundation, (415) 771-5464, Blind Children's Center, (800) 222-3566 or Hilton Perkins Program, (617) 972-7220.

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Health Information Websites

The following information is adapted with permission from a conference presentation entitled Internet Prescription for Health Information, presented at Online Northwest '99, Portland, Oregon, February 12, 1999, by Dolores Judkins, MLS, Coordinator, Consumer Health Resources, and Librarian/Web Manager for Center for Women's Health, Oregon Health Sciences University. The entire presentation outline is available on the web at http://www.ohsu.edu/women/judkinsd/consumer.htm.

There is a wide variety of health information on the web, and unlike printed materials such as books and magazines, much of the information does not go through any kind of editorial or filtering process before it is placed there. Anyone who wants to can put anything they want on the web, so it is up to the user to evaluate the information.

When searching the web for information, the reader should look at each document with the following criteria in mind:

- Authority: who is the author, what are the author's qualifications?
- Currency: how recently has the information been updated?
- Objectivity: what is the reason for the page; is it to sell a product or is it purely informational?

A good way to search for health information on the web is to go to established web pages that have gathered good information. The following websites are particularly easy to use to search for health information.

General Websites

Achoo
http://www.achoo.com

Achoo's objective is to "catalog, index, describe, and rate the mountain of healthcare information on the Net." There are both searching and browsing functions.

Dr. Koop's Community
http://www.drkoop.com/

A project of Empower Health, a company led by Dr. C. Everett Koop. It includes health information, message boards, chat rooms, and a newsletter.

HealthAtoZ: the Search Engine for Health and Medicine
http://www.Healthatoz.com/

A list of sites that are cataloged by medical professionals, their vision is to be the "starting point for all your health and medical searches on the Information Superhighway."

Healthfinder
http://www.healthfinder.gov

A "gateway consumer health information web site" produced by the U.S. Dept. of Health and Human Services. It includes information from the federal government, state and local agencies, not for profit organizations, and universities. Much of it is full text. It also includes links to organizations.

Mayo Clinic Health Oasis
http://www.mayohealth.org/

Directed by a team of Mayo Clinic physicians, scientists, writers, and educators, this site is updated daily.

MEDLINEplus
http://medlineplus.nlm.nih.gov/medlineplus/

A new resource produced at the National Library of Medicine. It contains a carefully selected list of resources on a growing number of health topics and includes links to organizations, clearinghouses, and MEDLINE (a database listing journal articles in medicine, nursing, and related fields).

NOAH (New York Online Access to Health)
http://www.noah.cuny.edu

Produced jointly by the New York Academy of Medicine and the New York Public Library. It is one of the few resources with Spanish language material.

OnHealth: Resources
http://www.onhealth.com/ch1/resource/

Includes links to Drug Database, Conditions A-Z, Alternative Practices, Herbal Index and a personal health tracker.

Government Agency Websites

Centers for Disease Control
http://www.cdc.gov/

Includes the full text of publications such as Morbidity and Mortality Weekly Report, as well as travelers' health information and data and statistics. It also has links to state health departments.

CHID: Combined Health Information Database
http://chid.nih.gov

CHID is a database produced by health-related agencies of the Federal Government. It provides titles, abstracts, and availability information for health information and health education resources in 18 different subject areas including: Deafness and Communication Disorders, Maternal and Child Health, and Medical Genetics and Rare Disorders.

Department of Health and Human Services
http://www.os.dhhs.gov

This page includes considerable consumer health information, as well as the Catalog of Federal Domestic Assistance Programs.

Food and Drug Administration
http://www.fda.gov/

Includes information on human and animal drugs, cosmetics, foods, toxicology, medical devices and radiological health and inspections and imports. It has information about current topics, including new drugs, new therapies (e.g. aromatherapy), and guidelines for drugs/cosmetics/foods. It includes the FDA Drug Approvals List and selected documents are in French, Spanish and Russian

National Institutes of Health
http://www.nih.gov

Includes links to the individual institutes and offices, health information such as MEDLINE, CancerNet and AIDS related information, and grants and contracts.

National Library of Medicine
http://www.nlm.nih.gov

This site includes information about NLM and other NIH services, research and development activities such as the Visible Human, almost 60,000 images from the Images from the History of Medicine service, the NLM online catalog, and MEDLINE.

National Center for Biotechnology Information
http://www.ncbi.nlm.nih.gov

This site has information on genetics and includes a number of databases including GenBank, a gene sequence database, and OMIM: Online Mendelian Inheritance in Man.

If you are unable to locate information on a particular health topic using any of the above sources, you may want to try searching for information using a more general web search tool. For links to these tools as well as additional websites in the areas of medicine, disability, education, deaf-blindness, and more, see the DB-LINK website. DB-LINK information specialists are also available to help you find the information you need.

DB-LINK
(800) 438-9376
(800) 854-7013 TTY
www.tr.wou.edu/dblink
dblink@tr.wou.edu

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Announcements

Camp Abilities: A Developmental Sports Camp for Children Who Are Blind and Deafblind

Lauren Lieberman
SUNY Brockport
Department of Physical Education
Brockport, NY 14420
Ph. (716) 395-5361
Fax (716) 395-2771
llieberm@brockport.edu

Camp Abilities is a week long residential summer camp held at State University of New York at Brockport. The Summer 1999 session is from July 7th to July 13th. The camp serves blind and deaf-blind children from age 8 to 18. Activities include: track and field, swimming, goal ball, beep baseball, tandem cycling, gymnastics, canoeing, judo, archery, bowling, dancing, camping and horseback riding. The camp is totally accessible for children who are deaf-blind. Early registration is encouraged.

HKNC Summer Seminar for High School Students Who Are Exploring Future Vocational and Educational Opportunities

Sue Ruzenski
Helen Keller National Center
111 Middle Neck Road
Sands Point, NY 11050-1299
Ph. (516) 944-8900 x272
Fax (516) 944-8637

The Helen Keller National Center is offering a two-week seminar, August 9-20, 1999 to deaf-blind junior and senior high school students interested in learning about vocational rehabilitation services while meeting new friends. Information and training will be offered regarding supports and services available to teens and young adults who are deaf-blind which will assist in gaining employment. Participants will also have opportunities to learn ways to do some problem-solving and self-advocacy to promote a positive college experience. Tuition: $300 per week. Room and board: $250 per week. Class size is limited to 6-8 participants.

Active Learning Conference

Patti Elsperman
Evansville Association for the Blind
500 Second Ave.
P.O. Box 6445
Evansville, IN 47719-0445
Ph. (812) 422-1181
Fax (812) 424-3154
Eabcdc@evansville.net

Dr. Lilli Nielsen, internationally known for her work with disabled children, will speak at a conference sponsored by the Evansville Association for the Blind, held at the Radisson Hotel in Evansville, Indiana. Two sessions will be offered, an introductory course scheduled for June 21-23, and an advanced course scheduled for June 28-30, 1999. The registration fee is $100.00 for each course. The seminars are of interest to parents as well as professionals who interact with children displaying various disabilities including blindness, autism, hearing impairment, and mental retardation. Dr Nielsen will lecture and provide slides, videos, and demonstrations to show care givers how to interact with special needs children using her innovative techniques. She will also work with individual families. Contact Patti Elsperman for more information.

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