

## Central Auditory Processing Disorders An Overview of Assessment and Management Practices

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**H**earing is a complex process that is often taken for granted. As sounds strike the eardrum, the sounds (acoustic signals) begin to undergo a series of transformations through which the acoustic signals are changed into neural signals. These neural signals are then passed from the ear through complicated neural networks to various parts of the brain for additional analysis, and ultimately, recognition or comprehension. For most of us, when someone talks about hearing abilities, we think primarily of the processing that occurs in the ear; that is, the ability to detect the presence of sound. Likewise, when someone is described as having a hearing loss, we assume that this individual has lost all or part of the ability to detect the presence of sound. However, the ability to detect the presence of sounds is only one part of the processing that occurs within the auditory system. There are many individuals who have no trouble detecting the presence of sound, but who have other types of auditory difficulties (e.g., difficulties understanding conversations in noisy environments, problems following complex directions, difficulty learning new vocabulary words or foreign languages) that can affect their ability to develop normal language skills, succeed academically, or communicate effectively. Often these individuals are not recognized as having hearing difficulties because they do not have trouble detecting the presence of sounds or recognizing speech in ideal listening situations. Since they appear to “hear normally,” the difficulties these individuals experience are often presumed to be the result of an attention deficit, a behavior problem, a lack of motivation, or some other cause. If this occurs, the individual may receive medical and/or remedial services that do not address the underlying “auditory” problem.

### What Is Meant By the Term “Central Auditory Processing?”

Katz, Stecker & Henderson(1992) described central auditory processing as “what we do with what we hear.” In other words, it is the ability of the brain (i.e., the central nervous system) to process incoming auditory signals.

The brain identifies sounds by analyzing their distinguishing physical characteristics—frequency, intensity, and temporal features. These are features that we perceive as pitch, loudness, and duration. Once the brain has completed its analysis of the physical characteristics of the incoming sound or message, it then constructs an “image” of the signal from these component parts for comparison with stored “images.” If a match occurs, we can then understand what is being said or we can recognize sounds that have important meanings in our lives (sirens, doorbells, crying, etc.).

This explanation is an oversimplification of the complicated and multifaceted processes that occur within the brain. The complexity of this processing, however, can be appreciated if one considers the definition of central au-

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ditory processing offered by the American Speech-Language-Hearing Association (ASHA).

Central auditory processes are the auditory system mechanisms and processes responsible for the following behavioral phenomena.

- Sound localization and lateralization
- Auditory discrimination
- Temporal aspects of audition including
  - » temporal resolution
  - » temporal masking
  - » temporal integration
  - » temporal ordering
- Auditory performance with competing acoustic signals
- Auditory performance with degraded signals

These mechanisms and processes apply to non-verbal as well as verbal signals and may affect many areas of function, including speech and language (ASHA, 1996, p. 41).

This definition acknowledges that many neurocognitive functions are involved in the processing of auditory information. Some are specific to

the processing of acoustic signals, while others are more global in nature and not necessarily unique to processing of auditory information (e.g., attention, memory, language representation). However, these latter functions are considered components of auditory processing when they are involved in the processing of auditory information.

## What Is Central Auditory Processing Disorder (CAPD)?

CAPD can be defined as a deficiency in any one or more of the behavioral phenomena listed above. There is no one cause of CAPD. In many children, it is related to maturational delays in the development of the important auditory centers within the brain. Often, these children's processing abilities develop as they mature. In other children, the deficits are related to benign differences in the way the brain develops. These usually represent more static types of problems (i.e., they are more likely to persist throughout the individual's life). In other children, the CAPD can be attributed to frank neurological problems or disease processes. These can be caused by trauma, tumors, degenerative disorders, viral infections, surgical compromise, lead poisoning, lack of oxygen, auditory deprivation, and so forth.

The prevalence of CAPD in children is estimated to be between 2 and 3% (Chermak & Musiek, 1997), with it being twice as prevalent in males. It often

### *Deaf-Blind Perspectives*

Volume 7, Issue 1

Fall 1999



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co-exists with other disabilities. These include speech and language disorders or delays, learning disabilities or dyslexia, attention deficit disorders with or without hyperactivity, and social and/or emotional problems.

## What Are Some of the Behavioral Manifestations of CAPD?

Below is a listing of some of the common behavioral characteristics often noted in children with CAPD. It should be noted that many of these behavioral characteristics are not unique to CAPD. Some may also be noted in individuals with other types of deficits or disorders, such as attention deficits, hearing loss, behavioral problems, and learning difficulties or dyslexia. Therefore, one should not necessarily assume that the presence of any one or more of these behaviors indicates that the child has a CAPD. However, if any of these behaviors are noted, the child should be considered at risk for CAPD and referred for appropriate testing. Definitive diagnosis of a central auditory disorder cannot be made until specialized auditory testing is completed and other etiologies have been ruled out.

- Difficulty hearing in noisy situations
- Difficulty following long conversations
- Difficulty hearing conversations on the telephone
- Difficulty learning a foreign language or challenging vocabulary words
- Difficulty remembering spoken information (i.e., auditory memory deficits)
- Difficulty taking notes
- Difficulty maintaining focus on an activity if other sounds are present (i.e., child is easily distracted by other sounds in the environment)
- Difficulty with organizational skills
- Difficulty following multistep directions
- Difficulty in directing, sustaining, or dividing attention
- Difficulty with reading and/or spelling
- Difficulty processing nonverbal information (e.g., lack of music appreciation)

There are a number of behavioral checklists that have been developed in an effort to systematically probe for behaviors that may suggest a CAPD (Fisher, 1976; Kelly, 1995; Smoski, Brunt, & Tannahill, 1992; Willeford & Burleigh, 1985). Some of these checklists were developed for teachers,

while others were designed for parents. These checklists can be helpful in determining whether a child should be referred to an audiologist for a central auditory processing assessment.

## How Is CAPD Assessed?

CAPD is assessed through the use of special tests designed to assess the various auditory functions of the brain. However, before this type of testing begins, it is important that each person being tested receive a routine hearing test for reasons that will become obvious later.

There are numerous auditory tests that the audiologist can use to assess central auditory function. These fall into two major categories: behavioral tests and electrophysiologic tests. The behavioral tests are often broken down into four subcategories, including monaural low-redundancy speech tests, dichotic speech tests, temporal patterning tests, and binaural interaction tests. It should be noted that children being assessed for CAPD will not necessarily be given a test from each of these categories. Rather the audiologist will select a battery of tests for each child. The selection of tests will depend upon a number of factors, including the age of the child, the specific auditory difficulties the child displays, the child's native language and cognitive status, and so forth. For the most part, children under the age of 7 years are not candidates for this type of diagnostic testing. In addition, central auditory processing assessments may not be appropriate for children with significant developmental delays (i.e., cognitive deficits).

Space limitations preclude an exhaustive discussion of each of the central tests that are available for clinical use. However, a brief overview of the major test categories is provided, along with an abbreviated description of a few tests that are considered representative of the many tests available for use in central auditory assessments.

### Electrophysiologic tests

Electrophysiologic tests are measures of the brain's response to sounds. For these tests, electrodes are placed on the earlobes and head of the child for the purpose of measuring electrical potentials that arise from the central nervous system in response to an auditory stimulus. An auditory stimulus, often a clicking sound, is delivered to the child's ear and the electrical responses are recorded. Some electrophysiologic tests are used to evaluate processing lower in the brain (auditory brainstem response audiometry), whereas others assess functioning higher in the brain (middle latency re-

sponses, late auditory evoked responses, auditory cognitive or P300 responses). The results obtained on these tests are compared to age-appropriate norms to determine if any abnormalities exist.

### Behavioral tests

**Monaural Low-Redundancy Speech Tests:** Due to the richness of the neural pathways in our auditory system and the redundancy of acoustic information in spoken language, a normal listener is able to recognize speech even when parts of the signal are missing. However, this ability is often compromised in the individual with CAPD. Monaural low-redundancy speech tests represent a group of tests designed to test an individual's ability to achieve auditory closure when information is missing. The speech stimuli used in these tests have been modified by changing one or more of the following characteristics of the speech signal: frequency, temporal, or intensity characteristics.

An example of a test in this category is the **Compressed Speech** test (Beasley, Schwimmer, & Rintelmann, 1972). This is a test in which the speech signals have been altered electronically by removing portions of the original speech signal. The test items are presented to each ear individually and the child is asked to repeat the words that have been presented. A percent correct score is derived for each ear and these are compared to age-appropriate norms.

**Dichotic Speech Tests:** In these tests different speech items are presented to both ears either simultaneously or in an overlapping manner and the child is asked to repeat everything that is heard (divided attention) or repeat whatever is heard in one specified ear (directed attention). The more similar and closely acoustically aligned the test items, the more difficult the task.

One of the more commonly used tests in this category is the **Dichotic Digits** test (Musiek, 1983). The child is asked to listen to four numbers presented to the two ears at comfortable listening levels. In each test item two numbers are presented to one ear and two numbers are presented to the other ear. For example, in figure one, 5 is presented to the right ear at the same time 1 is presented to the left ear. Then the numbers 9 and 6 are presented simultaneously to the right and left ears. The child is asked to repeat all numbers heard and a percent correct score is determined for each ear and compared to age-appropriate norms.

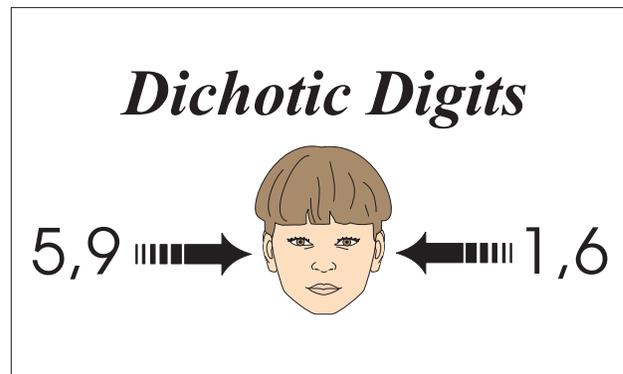


Figure 1. Dichotic Digits

**Temporal Patterning Tests:** These tests are designed to test the child's ability to process nonverbal auditory signals and to recognize the order or pattern of presentation of these stimuli. A child can be asked to simply "hum" the patterns. In this case, the processing of the stimuli would occur largely in the right half of the brain. If on the other hand, the child is asked to describe the patterns using words, then the left side of the brain is also involved, as well as the major auditory fibers that connect the auditory portions of both sides of the brain.

The **Frequency Pattern Sequences** test (Musiek & Pinheiro, 1987) is one of the temporal patterning tests used frequently with children. The test items are sequences of three tone bursts that are presented to one or both ears. In each of the sequences two tone bursts are of the same frequency, while the third tone is of a different frequency. There are just two different frequencies used in this test: one is a high-frequency sound and the other a low-frequency sound. The child therefore hears patterns, such as *high-high-low* or *low-high-low*, and is asked to either hum or describe the patterns heard. As with other central tests, the test items are presented at levels that are comfortable for the child and percent correct scores are obtained and compared to norms.

**Binaural Interaction Tests:** Binaural interaction tests are sometimes referred to as binaural integration tests. These tests tap the ability of structures low in the brain (brainstem) to take incomplete information presented to the two ears and fuse or integrate this information in some manner. Most of the tests in this category present different parts of a speech signal to each ear separately. If only one part of the signal is presented, the child usually cannot recognize the test item. However, if the two different parts of the stimuli are presented simultaneously, with one portion going to one ear and the other portion to the other ear, the child with normal processing abilities has no difficulty recognizing the test item. This is because the two parts (which are unrecognizable if

presented in isolation) are integrated into a single identifiable stimulus by the auditory nervous system.

An example of a test in this category is the **Rapidly Alternating Speech Perception** test (Willeford, 1976). For this test, sentence materials are divided into brief segments which are alternated rapidly between the two ears. The example below is a rough approximation of what happens to a sentence when it is segmented in this manner. In this example, the first sound in the sentence (represented by *pu*) is presented to the right ear, then the *t* sound is presented to the left ear, and so forth and so on. If the child hears only the segments presented to the right ear or left ear, he or she is unlikely to be able to recognize the sentence. However, if the right ear and left ear segments are presented in a cohesive fashion to the child, sentence recognition improves dramatically as long as this particular function of the brain is intact.

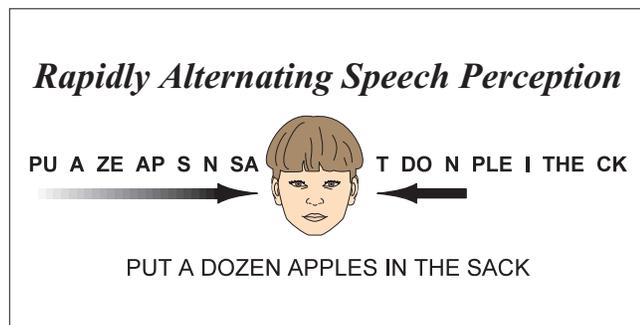


Figure 2. Rapidly alternating speech perception

## What Are the Educational Implications of CAPD?

The list of behavioral observations provided earlier in this article highlights many of the academic and/or speech and language problems that might be experienced by the child with CAPD. Since speech and language skills are developed most efficiently through the auditory sensory modality, it is not unusual to observe speech and language problems, as well as academic problems (many of them language-based), in children with CAPD. If a child experiences difficulty in processing the brief and rapidly changing acoustics of spoken speech, he or she is likely to have problems recognizing the “speech sounds” of language. If problems are encountered in recognizing the sound system of language, then additional problems are likely to be encountered when the child is asked to begin to match “speech sounds” to their alphabetic representations (a skill that serves as the foundation for the development of subsequent reading and writing skills). This in turn can lead to comprehension prob-

lems and poor academic performance. It is worth reiterating at this time that not all children with CAPD will experience all of these problems. There is a wide range of variability in the problems experienced by children with CAPD; however, it should be recognized that the presence of a CAPD places the child at risk for developing many of these language and academic problems.

## What Management Strategies Can Be Used To Remediate CAPD?

There are several different ways to help children overcome their CAPD. The exact procedures or approaches used will depend upon a number of factors, including the exact nature of the CAPD, the age of the child, the co-existence of other disabilities and/or problems, and the availability of resources. In general, the approaches to remediation or management fall into three main categories: (a) enhancing the individual’s auditory perceptual skills, (b) enhancing the individual’s language and cognitive resources, and (c) improving the quality of the auditory signal.

The following discussion presents some of the procedures that may be used with a child with CAPD. More detailed information is beyond the scope of this article, but may be found in the various resources listed at the end of this article.

Many children with CAPD will benefit from auditory training procedures and phonological awareness training. Intervention may also involve the identification of (and training in the use of) strategies that can be used to overcome specific auditory, speech and language, or academic difficulties. A number of actions can be taken to improve the quality of the signal reaching the child. Children can be provided personal assistive-listening devices that should serve to enhance the teacher’s voice and reduce the competition of other noises and sounds in the classroom. Acoustic modifications can be made to the classroom (e.g., carpeting, acoustic ceiling tiles, window treatments) which should help to minimize the detrimental effects of noise on the child’s ability to process speech in the educational setting. Finally, teachers and parents can assist the child in overcoming his or her auditory deficits by speaking clearly, rephrasing information, providing preferential seating, using visual aids to supplement auditory information, and so forth. The program should be tailored to the child’s individual needs, and it should represent an interdisciplinary approach. Parents, teachers, educational specialists, and other professionals, as appropriate, should be

involved in the development and implementation of the child's management program.

## Do Children With CAPD Have Hearing Loss?

Children with CAPD do not have hearing loss if the term is used to refer to a loss of hearing sensitivity. Most children with CAPD have normal hearing sensitivity and their auditory difficulties will not be detected during routine hearing testing unless some of the special "sensitized" tests (see discussion above) are administered. These children, however, have hearing loss in the sense that they do not process auditory information in a normal fashion. They have auditory deficits that can be every bit as debilitating as unidentified hearing loss. If the auditory deficits are not identified early and managed appropriately, many of these children will experience speech and language delays, academic failure and/or underachievement, loss of self-esteem, and social and emotional problems.

## Can a Child Have Both a Hearing Loss and a CAPD?

Children can have both a hearing loss and a CAPD. Fortunately, most children seen for central auditory testing have normal hearing (i.e., detection) abilities. However, children with hearing loss can also have a CAPD. In fact, the presence of a hearing loss may place a child at risk for CAPD. This is because the auditory pathways and centers in the brain develop as they are stimulated with sound. The presence of a hearing loss may limit the amount and type of auditory stimulation that is necessary to promote optimal development of the auditory nervous system. If this happens, then auditory deficits are likely to result.

A question frequently asked of audiologists is "whether or not a child with a hearing loss can be tested for CAPD?" The answer is not a simple "yes" or "no." Many children with hearing losses can be tested as long as they have some hearing (i.e., detection) abilities. Interpretation of the test results does become somewhat more difficult for the audiologist who is conducting the testing if a hearing loss is present, but there are distinct patterns of test results that can indicate the presence of a CAPD. Moreover, there are certain tests that the audiologist can use that are not affected to the same degree as other tests by the presence of a hearing loss. These tests should be used whenever feasible. Unfortunately, there are some individuals with losses so severe that testing

cannot be completed. As a general rule, central auditory testing cannot be done if the individual being tested has a hearing loss falling in the severe-to-profound range.

## Where Can I Go For Additional Information?

The books listed in the reference section are good sources of information. In addition, we have provided a list of web sites that you may find helpful.

### Selected Web Sites for Teachers and Parents

<http://www.kidspeech.com/tips.html>  
<http://www.ldanatl.org/factsheets/Auditory.html>  
<http://www.healthtouch.com/level1/leaflets/aslha/aslha024.htm>  
[http://www.ldonline.org/ld\\_indepth/process\\_deficit/tab\\_le\\_deficits.html](http://www.ldonline.org/ld_indepth/process_deficit/tab_le_deficits.html)  
[http://www.ldonline.org/ld\\_indepth/process\\_deficit/pro\\_deficits.html](http://www.ldonline.org/ld_indepth/process_deficit/pro_deficits.html)  
[http://www.Kidshealth.org/parent/healthy/central\\_auditory.html](http://www.Kidshealth.org/parent/healthy/central_auditory.html)

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Musiek F.E., & Pinheiro, M.L. (1987). Frequency patterns in cochlear, brainstem, and cerebral lesions. *Audiology*, 26, 79-88.

Smoski, W.J., Brunt, M.A., & Tannahill, J.C. (1992). Listening characteristics of children with central auditory processing disorders. *Language, Speech and Hearing Services in Schools*, 23, 145-152.

Willeford, J.A., & Burleigh, J.M. (1985). *Handbook of central auditory processing disorders in children*. Orlando, FL: Grune & Stratton.

Willeford, J. (1976). Differential diagnosis of central auditory dysfunction. In L. Bradford (Ed.), *Audiology: An audio journal for continuing education* (Vol. 2). New York: Grune & Stratton.

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## Book Review

By

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*Remarkable Conversations: A guide to developing meaningful communication with children and young adults who are deafblind*. Barbara Miles and Marianne Riggio (Eds.) Watertown, MA: Perkins School for the Blind, 1999.

**R**emarkable Conversations does not read like a typical, academic textbook; it pulls the reader into (remarkable) conversations with the authors who share their wisdom, philosophies, and experience in educating learners with deafblindness. Theory is embedded in the examples and case studies, but it is not the thrust of the book. The book is refreshing and revitalizing. In fact, I easily read this book, like a good novel, for hours, without feeling the input overload that occurs when reading more technical writings. It is a practical text from the perspective of practitioners trained in deafblindness and who have taught children with deafblindness for many years. As a result, *Remarkable Conversations* provides readers with examples they can relate to and learn from.

The 14 chapters of *Remarkable Conversations* address a full spectrum of important issues relating to communication and language with learners who are deafblind, including partnering with families, conversations, environments that encourage communication, assessment, communication modes,

beginning communication, teaching basic sentence patterns, complex language, adolescents with multiple disabilities, building toward adult life, and creating a vision of services. Some of these topics are ones we would expect to see addressed in such a book, but there are also some novel perspectives. Each chapter flows smoothly into the next, creating a progression from early communication to complex language with many related issues woven in between. The amount of information provided is broad but not overwhelming, due mainly to the user-friendly style.

Within the first chapter of *Remarkable Conversations*, I knew I was going to like the book. The tone immediately conveys respect for individuals with deafblindness and the unique ways they learn and understand their environments. Involvement with individuals who are deafblind is presented as an opportunity, albeit at times a challenging one. Such an opportunity affords hearing-sighted people the chance to “see” the world differently. This chapter clarified for me the importance of communication, prelinguistically (before formal language begins) and as a part of formal language. It also discusses literacy as part of language, the sociolinguistic importance of communication in relationships, as well as the responsibility of educators. To personalize the information, the authors introduce us to some individuals with deafblindness. Stories about these children and young adults, appear throughout the book to support the information. As I read about these individuals I found myself thinking about the many children I have worked with, noting the similarities and wondering if I might even know the child they were describing.

The concluding chapters of the book do an excellent job of both tying the book together and also guiding us as we build visions for quality services. In Chapter 13, the authors reinforce the idea that there is no single model of service that can meet the diverse needs of learners with deafblindness; each program needs to be individually designed, based on each child’s uniqueness. The educational assessment, when conducted by qualified individuals, plays an important role in defining the foundation of the child’s program and enables the educational team to develop the educational plan. This includes prioritizing areas for instruction and identifying goals, objectives and interventions, as well as considering options for least restrictive placement.

Chapter 14, the final chapter, compares the educational needs of children with deafblindness with those of other children to illustrate that there really should not be a significant difference. However, there is a difference because the general education

system is geared to meet the needs of the majority, not those with very low-incidence needs. This chapter challenges the reader to create a vision of high quality services. It lays out essential elements of a good system as well as ways to advocate for and develop such a system. Services and expertise typically will not be readily available; however, with a vision as to what might be needed, resources can be identified and developed.

*Remarkable Conversations* is not a theoretical textbook full of research and extensive citations. Instead, *Remarkable Conversations* is a practical guide that will inspire its readers, shift perspectives, and validate the significant role that families and educators have with children who “see and hear” the world differently.

ED Note: Remarkable Conversations may be ordered from:

Perkins School for the Blind  
175 North Beacon Street  
Watertown, MA 02472  
Attn: Public Relations & Publications  
Tel: (617) 972-7328  
Fax: (617) 972-7334  
The cost is \$35.00 (add \$5.00 if overseas).



## Supporting the Involvement of Deaf-Blind Individuals in Meetings About Deaf-Blind Topics

By Jamie McNamara  
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Individuals who are deaf-blind have much to offer meetings that focus on deaf-blindness related services or projects. The unbeatable first-hand perspective of a deaf-blind person gives other participants insights into deaf-blindness that will help them carry out meeting tasks and achieve goals more effectively. Deaf-blind people benefit as well. Participation gives them an opportunity to gain respect and increased confidence from networking with others, as well as to make a contribution to improve the quality of life of other deaf-blind people.

Many different types of meetings focus on topics important to deaf-blind people. These may be one-time meetings or an ongoing series of meetings. Examples include advisory board meetings for state deaf-blind projects, state level meetings involved in developing deaf-blind services, and meetings focusing on specific topics such as planning for an Usher syndrome screening program. Another type of

meeting is an IEP (Individualized Education Program) meeting for teen or young adult students in which the student may participate.

At times, I've attended meetings where there were no local deaf-blind people present to give their perspective. When I've asked meeting organizers about this lack of involvement, they've told me that either they were unable to find deaf-blind people interested in attending or that they needed more information about how to support a deaf-blind person's involvement. The suggestions below address each of these issues. They are based, in part, on my own experiences as a deaf-blind person.

### Locating Interested Deaf-Blind Individuals

**Contact the American Association of the Deaf-blind (AADB)** — AADB publishes the Deaf-Blind Contact Directory. This directory lists services for deaf-blind people, deaf-blind organizations, and contact information for some deaf-blind people by state.

**Contact state or local deaf-blind associations and agencies** — Helen Keller National Center (HKNC) Regional Offices, HKNC affiliates, other agencies that serve individuals who are deaf-blind, associations of deaf-blind people, and state deaf-blind projects may be able to connect you with interested individuals. For confidentiality reasons, agencies cannot give out names and contact information unless the person gives consent, but they may be able to have interested individuals contact the meeting organizer directly. Contact DB-LINK for a list of organizations and agencies in your state.

#### Contact Information

American Association of the Deaf-Blind  
814 Thayer Ave, Ste 302  
Silver Spring, MD 20910-4500  
(301) 588-6545 TTY  
E-mail: aadb@erols.com

DB-LINK  
Teaching Research  
345 N. Monmouth Ave.  
Monmouth, OR 97361  
(800) 438-9376  
(800) 854-7013  
dblink@tr.wou.edu  
<http://www.tr.wou.edu/dblink>

**Post an announcement to an e-mail discussion group** — E-mail discussion groups specific to deaf-blindness include the Deaf-Blind Mailing List and the Usher List. Both include a variety of subscribers who share information about deaf-blindness with each other. Subscribers include deaf-blind teens and adults, family members, and professionals. Send an announcement seeking deaf-blind people in your area who may wish to participate in your meeting.

### Subscribing to E-mail Discussion Groups

#### *Deaf-Blind Mailing List*

Send a message to [listserv@tr.wou.edu](mailto:listserv@tr.wou.edu)

In the body of the message type:

“Sub deafblind” *first name last name*

(note there is no “i” in deafblind)

or contact [owner-request@tr.wou.edu](mailto:owner-request@tr.wou.edu).

#### *Usher Syndrome Mailing List*

Send a message to [Ushers-subscribe@onelist.com](mailto:Ushers-subscribe@onelist.com)

If you have difficulty subscribing contact the list-owners at [Ushers-owner@onelist.com](mailto:Ushers-owner@onelist.com).

**Publish an announcement in a newsletter** — Newsletters produced by organizations that focus on issues important to deaf or blind individuals in your region may also have deaf-blind subscribers on their mailing lists.

## Supporting Involvement

Once you’ve located interested individuals for a meeting, it is important to fully support them so they can be actively involved. The following are suggestions for providing support both before and during the meeting.

### Before the meeting:

**Learn about preferred methods of communication** — Deaf-blind people use a variety of communication methods. The first and most important preparation necessary to support an individual’s involvement in a meeting is to find out his or her preferred communication method in detail in order to make arrangements necessary to provide optimal communication during the meeting. These arrangements may include hiring interpreters, obtaining an assistive listening device such as an FM system, choosing a meeting site with good sound acoustics and minimal background noise, or making modifications to the environment that enhance visual reception. For example, for an individual who uses sign language, find out the type of sign language used (e.g., American Sign Language, Pidgin Signed

English, Signed English) and whether he or she uses tactile or visual modifications. Some individuals communicate tactilely, while others have enough vision to sign visually, but require modifications such as smaller signs produced in a smaller space or closer positioning between the signers. This information will help you hire interpreters who best match the individual’s style. For more information about communication systems used by deaf-blind people, see the reading list at the end of this article.

**Ask about print or alternative media preferences** — Deaf-blind individuals also use a variety of print and alternative media formats including Braille, standard print, large print, audiotape, or diskette. Make sure all materials associated with the meeting such as the agenda and any handouts or other materials are converted into the individual’s preferred format and send this information in advance so that he or she can review it prior to the meeting. Being able to review materials in advance benefits all participants, but may be especially helpful to deaf-blind people. It is difficult, for example, for a person who uses sign language to both watch an interpreter and read materials handed out at the time of the meeting.

**Find out about transportation needs** — Check with the deaf-blind person to see if transportation assistance is needed to and from the meeting.

**Arrange for consultant fees** — Depending on the type of meeting, deaf-blind individuals should be paid as consultants when they are giving their time and expertise to be involved in a meeting. This is especially important when the individual is attending on his or her own time or doesn’t have a full-time job while other participants in the meeting may have their time covered by their employer. It sends the message that his or her input and involvement is equally as important as that of professionals in the field.

**Meet one-on-one prior to the meeting** — It is helpful if the meeting organizer meets with the deaf-blind participant individually prior to the meeting to review the meeting’s purpose and activities and answer any questions or discuss concerns the participant may have. A prior understanding of background information will make it easier for the deaf-blind person to participate effectively during the meeting. This is important if the rest of the group has met previously. It is sufficient to do this once before the start of involvement in ongoing meetings.

**Come early before the first meeting** — Meet again early on the day of the first meeting to provide orientation to the building (e.g., room setup, restrooms, elevator, stairs, drinking fountain) and make sure

everything is set-up to provide for good communication. Check the room for lighting and best seating. Set up the FM system or other equipment and/or meet with the interpreters. All of this takes time and can't be done adequately during the meeting.

### At the meeting:

**Establish communication rules and set a reasonable pace** — Set communication rules for the group at the start of the meeting. It may be difficult for the deaf-blind participant to follow the flow of the conversation if people talk fast, interrupt each other, or jump in quickly to speak immediately after another person has finished speaking. To prevent this, pause between speakers and have people raise their hands when they wish to speak and say their names (and sign their names if the deaf-blind person uses sign language) before speaking. Another good technique is to go around the room one by one, giving each person a chance to speak.

**Include activities that promote teamwork** — Arrange activities that promote a spirit of teamwork, such as icebreakers at the beginning of the meeting or small group activities or discussions. These types of activities help all participants feel involved and included. They not only help the deaf-blind individual get to know others in the meeting, but also help other participants feel comfortable with the deaf-blind individual.

**Actively encourage participation in the discussion** — Check in with the deaf-blind participant from time to time by asking him or her to comment on the topic at hand. It is also helpful to have a list of the specific questions and outcomes to be discussed at the meeting sent to participants ahead of time. This helps everyone prepare in advance and is more effective than "on the spot" questions. Review the discussion during breaks and after the meeting.

**Provide a means for translation of visually presented information** — Establish a method to help the deaf-blind individual keep up with information that is visually presented via flip charts, chalkboard notes, and overhead transparencies. Some deaf-blind people prefer to have visual information copied for them when it is presented, while others prefer to have the information read or interpreted for them. Others may be able to read it for themselves if they have enough vision. Find out from the individual which method he or she prefers. It may also help to move visually presented information closer or to a well-lit location.

**Assign tasks for future meetings** — When assigning tasks to group members in preparation for further meetings or activities, be sure to ask and

encourage the deaf-blind participant to take the lead or work on designated tasks.

## Summary

As I mentioned in the introduction, the suggestions listed in this article are based, in part, on my own experiences. I have attended meetings where no communication rules were established at the beginning of the meeting. The frequent interruptions and rapid pace of the meetings on these occasions made it difficult for my interpreters to keep up with the flow of the discussion and made it nearly impossible for me to participate. I have also been to meetings for which I did not receive materials in advance. This prevented me from participating fully because I had to choose between reading the materials or watching the interpreter while other participants who could hear and see, were able to scan the materials while listening to the speaker. In these situations, I did not have the same access to information as everyone else. I have also experienced being asked "on the spot" questions without having been given information prior to the meeting that would have allowed me to give thought to the issues and prepare in advance. And, at times, I have had interpreters who were not skilled at meeting my interpreting needs, making it difficult for me to follow and contribute to the discussion. My own experiences and the experiences of other deaf-blind people have shown me what does and does not work to enhance the participation of deaf-blind individuals in meetings where most of the participants are hearing and sighted.

It is always a thrill to see deaf-blind people participate equally and fully alongside their hearing-sighted peers in meetings about deaf-blind related topics. Deaf-blind people CAN do it with the right support for their involvement.

## For further reading:

Atwood, A. A., Clarkson, J. D. & Laba, C. R. (1994). *Being in touch: Communication and other issues in the lives of people who are deaf-blind*. Washington, DC: Gallaudet University.

Bagley, M., Mascia, J., & Rothstein, R. (1996). Facilitating oral communication with adults who are blind and severely profoundly hard of hearing. In *Proceedings of the fifth Canadian conference on deafblindness: Living & learning: A lifelong adventure* (pp.54-65). [Available from DB-LINK.]

Cooper, S. B. (1997). A glossary of some communication methods used by deaf-blind people. *Views*, 14 (11), 6-7.

Devich, J. (1997). Definitions of alternative communication styles with deaf-blind people. *Views*, 14 (11), 15.

Morgan, S. (1998). Sign Language with people who are deaf-blind: Suggestions for tactile and visual modifications. *Deaf-Blind Perspectives*, 6 (1), 3-7.

Rothstein, R. (1998). Alternative communication methods for AADB conventions. *The Deaf-Blind American*, 36 (2), 19-22. [Available from DB-LINK.]

Smith, T. B. (1991). *Guidelines for working/playing with deaf-blind people*. Monmouth, OR: Teaching Research. [Available from DB-LINK.]

Smith, T. B. (1994). *Guidelines: Practical tips for working and socializing with deaf-blind people*. Burtonsville, MD: Sign Media, Inc.



## With and Within Us: The DeafBlind Gift

John Lee Clark

*I am John Lee Clark.  
Then I am DeafBlind.*

One can be Deaf and Blind with any asymmetry, but it is only through embracing oneself that one can be truly DeafBlind. My aspiration here is to share with you what all DeafBlind children and the people who live with and around them must fathom. I hope what I extend to you is a sagacity in which you can absorb the beauty of DeafBlind culture, life, and people that is here with and within us.

Let me unravel a part of my personal history that helped me learn what many DeafBlind children need to create in their lives. Then I shall probe the striking value of DeafBlind children's true selfdoms.

When I was younger, my classmates found me as their most compelling target. For that, I hated being DeafBlind. I felt worthless and I often reflected *I am a freak mutated from a human infant into what nobody likes*. Naked under the rage of my rancor, I became an unruly artist in denying who I was. Until later, I did not know that my frugal camouflages failed to shroud my DeafBlind self. I did not fool anyone, least of all myself.

Realizing that I could never sprout into my future in disguise, I—with a jolt—understood why I was a frustrating creature to my peers. My DeafBlind state was never a magnet for their creative mockery like I first believed. It was how I dyed myself that made

me a vagabond on the land of peer friendship. I openly did not like the fact that I was DeafBlind and that made me odious to others. One can be amazingly exasperating when one perpetually pretends. Abruptly, I stopped blaming my being DeafBlind for all my encumbrances.

I then learned what being DeafBlind meant. By magnifying my familiarity with the arcane universe of only touching, tasting, and smelling, I became complete. I took Braille classes, oriented myself in the art of sauntering with my white cane, and plunged myself socially within the DeafBlind community. I emerged as a character who loves who and what I am.

I want all DeafBlind children to learn that hiding and masquerading is a no-no. There is nowhere one can savor life without a concrete "I am" that is one's very own.

Because of insensitive conventions in our world, innumerable children grapple with their DeafBlind lives. This results in the practice of denial. Denial, in turn, spawns the rejection of their own existence. If you work with DeafBlind children, please understand that their problems are there not because they are DeafBlind, but because of their repudiation of the DeafBlind badge. The DeafBlind label cannot be evaporated as long they breathe. Trying to peel it off squanders time and everything that time can offer.

I know some DeafBlind adolescents who try to stomach the problem of being rejected in sundry designs. Reacting to social isolation, they often view themselves as an obscure species. Believing in this (how can they not, being in their position?), they author many solutions for themselves—some rather ingenious, others highly perilous.

Some dangerous "solutions" involve flirting with death. One girl, under the notion that she could not live a DeafBlind life, attempted suicide on three separate occasions. She attended a mainstream school in her hometown. All her childhood, her family and school pedagogues were preoccupied with her eyes and her ears; every month she would be dragged through the "rounds," four eye doctors and two audiologists. Her parents and her teachers hoped to glean medical wizardry from the experts.

Her classmates, like my own, bombarded her with insults and punches. She became more and more depressed after each sneer, every visit to the white-coated doctors. It all became too much and she resolved to kill herself. However and happily, her efforts in exiting our world failed. She is now recovering from substance addiction, depression, and suicidal compulsions in a halfway house.

You have just read a sketch of countless DeafBlind adolescents' experiences. The plot is same for many, but with varying situations, scenes, and endings. The story evolves like this: People behave strangely around a DeafBlind child. DeafBlind children are, for innumerable people, a rarity and something of a freakish nature. This is shown in peer enmity and the negative mentality harbored by that child. The child then naturally hates being DeafBlind. Attempting to blast out of the mess, that child will often crash into amplified self-exile. Self-exile created from how people respond to the first stratum of that child's self-loathing grows. This could go on in circles, increasing in inclemency each time around. The realization and love for oneself can come in any time or never. Self-acceptance can be born only when one dislodges others' opinions and develops an esteemed view for oneself OR when someone helps that person learn about the power of "I am who I am, and I love who I am" by treating that person ingenuously.

In preventing any harm, parents and teachers must regard every DeafBlind child as who they are—exquisite and singular human beings—before they meet their needs as DeafBlind children. Too habitually, people who surround DeafBlind children first look upon them as DeafBlind, and then vaguely, as who they are. Hazardous inclinations such as these stifle the emotional and intellectual growth of children because the heart of a child is how that child understands the concept of "myself" through others.

An old adage construes how people interpret themselves:

*I am not what I think I am.*

*I am not what you think I am.*

*I am what I think you think I am.*

If a person approaches a DeafBlind child's life as a problematic case that demands intervention, the act of "curing" will be the problem. Imagine what a DeafBlind child thinks—judging from other people's behavior—on what is being thought about that child. Yes, it is devastating for that child and for anyone. I can assure you that DeafBlind children who allegedly have "certain limitations" do not have those limitations because they are DeafBlind. Rather, the culprit is—with all being equal—the limited recognition that DeafBlind children gain for being normal and simply human. Children will successfully, even exultantly, relate to their DeafBlind reality if teachers and parents respond to who they are before anything else.

I hope more and more children will be known as who they are so that they can cursorily correlate themselves with the layers of identity—from oneself to one's culture. DeafBlind children, like each and every child, must not be denied the freedom of "Yes, I am!"

*John Lee Clark can be reached by e-mail at johnadrean@uswest.net*



## Helen Keller National Center National Registry

Nancy O'Donnell  
Coordinator of the National Registry

As a professional in the field of deaf-blindness, one of the first questions I am often asked is, "How many deaf-blind people are there in the country?" For those under 22 years of age, national demographic information has been available since the mid 1980s through the efforts of Dr. Vic Baldwin at Teaching Research, Western Oregon University. For many years, though, there has been no good way to answer this question for the "over 21" population other than educated guesses. We are pleased to report, however, that during the most recent reauthorization of The Helen Keller National Center (HKNC) Act, HKNC was given the charge to maintain a national registry of those who are deaf-blind. As a result of this registry, more information will become available about the adult population.

### Who Is Considered "Deaf-Blind?"

The answer to this question is somewhat sticky due to discrepancies in definitions between the education system and the rehabilitation system.

As found in the HKNC Act, the term "individual who is deaf-blind" means any individual:

(A)

(1) who has a central visual acuity of 20/200 or less in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both these conditions;

(2) who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing

loss having a prognosis leading to this condition; and

(3) for whom the combination of impairments described in clauses (1) and (2) cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation; or

(B)

who, despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining vocational objectives (United States Code, Title 29, Chapter 21, Section 1905)

Although the definition contained in the HKNC Act has been commonly accepted by the state vocational rehabilitation (VR) agencies, the VR system uses its own formal coding system (RSA 911) to identify clients by disability category. Using this system, the deaf-blind population has been consistently under-reported. For example, in fiscal year 1996, only 437 individuals were identified as deaf-blind using codes 290-298 (deaf-blindness) on the RSA 911. A look at the breakdown of some of the other categories indicates that the VR counselors need a good amount of training in the use of the codes. For example, there are an additional 207 individuals having "blindness" as a major disabling condition. Of those 207 individuals, 95 have "deafness" as a secondary condition, 4 have "hard-of-hearing" as a secondary condition and 108 have "deaf-blindness" as a secondary condition!

## Establishing a Database

Over the years, HKNC has collected data on the clients we have served through our programs at headquarters, in the field, through our affiliated agencies and from other cooperating organizations. This information, however, has not been available on a national basis. This summer we have enthusiastically started the process of compiling a national database. Beginning with records stored in our archives, we are entering data on thousands of individuals, including their etiologies, severity of hearing and vision losses, methods of communication, residential situations, employment status, training needs and the like.

When this information has been entered and cleaned up, we will be able to answer such questions

as the following: How many people in the registry are reported to have Usher Syndrome? Congenital Rubella Syndrome? CHARGE Association? What is the most common age of onset of vision loss reported by those with retinitis pigmentosa? What types of communication methods are most commonly used? How many people use hearing aids or FM systems? What services are available and what services are needed? All this information will be accessible in national, state, and local profiles. Cross-tabulation of data will also be possible, answering questions such as, How many females with congenital rubella syndrome are employed competitively? or How many people who are totally blind and profoundly deaf live independently?

Our demographic information will be helpful to agencies planning adult services for this population, to university programs preparing teachers to work with those who are deaf-blind, to agencies providing residential and employment services, and to the federal government as it develops initiatives and priorities for funding.

The registry will not replace the current comprehensive system of collecting census information for children aged birth to 21, collected by Teaching Research in cooperation with the State and Multi-State Deaf-Blind Projects. However, although HKNC serves those who are 18 years of age and older, we will include anyone who is deaf-blind, of any age, on our registry. If you would like to register yourself or obtain an application for someone you know, you can request a copy of the registry form from your Helen Keller Regional Representative or from HKNC headquarters at 111 Middle Neck Road, Sands Point, NY 11050, Attention: Nancy O'Donnell. All personal information will be kept in strict confidence.

**Ed note: There is also a registry in Canada for deaf-blind Canadians. For more information, contact:**

National Registry of Persons Who Are  
Deaf-Blind in Canada  
Canadian Deafblind & Rubella Association  
1658 4th Avenue West  
Owen Sound, ON N4K 4X4  
Phone: (519) 372-0887  
Fax: (519) 372-0312  
E-Mail: stan.munroe@sympatico.ca







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*Deaf-Blind Perspectives* is a free publication, published three times a year by the Teaching Research Division of Western Oregon University. The positions expressed in this newsletter are those of the author(s) and do not necessarily reflect the position of the Teaching Research Division or the U.S. Department of Education. DB-LINK and NTAC contribute staff and resources for content, editing, and publication.

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