In an ideal world, all infants would receive screenings for their vision and hearing with coordinated follow-up services as needed. Indeed, universal infant screening for hearing loss has been recommended nationally (Mauk, Barringer, & Mauk, 1995; National Institutes of Health, 1993); however, few states have implemented this recommendation. Likewise, both the National Academy of Ophthalmology and the National Academy of Optometry have recommended a comprehensive visual examination for all infants (American Academy of Ophthalmology, 1992; American Optometric Association, 1994), but this is not common practice.

As a result, the professionals who work in early intervention programs either as direct service providers or as consultants, play an important role in the early identification of vision impairment and hearing loss. These professionals may include physical therapists, occupational therapists, nurses, speech and language therapists, audiologists, orientation and mobility specialists, psychologists, social workers, and teachers certified in the areas of early childhood special education, vision impairment, hearing loss, deaf-blindness, or severe disabilities, as well as other specialized consultants. An early interventionist is thus any professional who provides direct services to infants (birth through 36 months) with disabilities and their families. Unfortunately, national estimates indicate that more than 95% of states have shortages of qualified early intervention personnel, particularly in specialization areas, and that approximately 80% of states anticipate that these shortages will continue to the year 2000 (Klein & Campbell, 1990). These statistics indicate that many programs serving infants with severe or multiple disabilities may not have easy access to educational professionals who know how to screen infant vision and hearing. Further, socioeconomic and other conditions may restrict a family’s access to such medical services (Halpern, 1993; Lewit, 1992) as audiology, ophthalmology, or optometry.

Given this lack, it is imperative that people who work with infants who have disabilities (a) are familiar with the high risk factors and signs associated with vision and/or hearing loss, (b) are skilled in gathering information about the status of an infant’s vision and hearing, (c) are familiar with procedures for making referrals to audiologists and ophthalmologists or optometrists, and (d) know how to access the services of consultants or teachers certified in vision impairment, hearing loss, or deaf-blindness.

Identification of High Risk Factors

Many high risk factors are associated with both a visual impairment and a hearing loss as shown in Figure 1. Vision and hearing are such primary avenues for learning that infants who have vision impairments combined with hearing losses should receive specific supports to promote development. In most cases, visual impairment is identified first, so the hearing of these infants must be tested and monitored closely. Because language is developed during infancy, even a slight, transient, or unilateral hearing loss can distort speech input and impede the speech discrimination and comprehension abilities of infants (Kile, Schaffmeyer, & Kuba, 1994; Nozza, 1994). Early interventionists working with infants who have severe disabilities, infants who are visually impaired, and
<table>
<thead>
<tr>
<th><strong>High Risk Factors Associated with Hearing Loss</strong></th>
<th><strong>High Risk Factors Associated with Visual Impairment</strong></th>
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<tbody>
<tr>
<td>Family history</td>
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<tr>
<td>Prenatal exposure to maternal infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, herpes)</td>
<td>Prenatal exposure to maternal infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, herpes, chicken pox, HIV)</td>
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<td>Prematurity</td>
<td>Abnormal prenatal brain development</td>
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<td>Hypoxia</td>
<td>Prematurity</td>
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<td>Cleft lip and palate</td>
<td>Hypoxia</td>
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<td>Craniofacial anomalies (malformations of pinna, ear canal, absent philtrum, low hairline)</td>
<td>Certain syndromes (e.g., CHARGE, cri du chat, Down, Fetal Alcohol, Goldenhar, Hurler, Lowe, Marfan, Norrie, Refsum, Trisomy 13, Waardenburg)</td>
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<td>Hyperbilirubinemia level requiring transfusion</td>
<td>Other congenital ophthalmological syndromes (optic nerve hypoplasia, Leber's)</td>
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<td>Apgar score of 3 or less at 5 minutes after birth</td>
<td>Bacterial meningitis</td>
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<td>Prolonged use of ototoxic medications</td>
<td>Head trauma</td>
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<td>Prolonged medical ventilation (10 days)</td>
<td>Cerebral palsy</td>
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<td>Certain syndromes (e.g., CHARGE, Down, Fetal Alcohol, Goldenhar, Hurler, Norrie, Refsum, Trisomy 13, Waardenburg)</td>
<td>Certain neurodegenerative disorders (e.g., neurofibromatosis, Tay Sachs)</td>
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<tr>
<td>Childhood infections (bacterial meningitis, mumps, measles)</td>
<td>(Northern &amp; Downs, 1991; Teplin, 1995)</td>
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<tr>
<td>Head trauma</td>
<td>(Joint Committee on Infant Hearing, 1991; Northern &amp; Downs, 1991)</td>
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Figure 1. High Risk Factors Associated with Hearing Loss or Visual Impairment in Very Young Children (Chen 1997).
infants who are deaf or hard of hearing should be aware that certain etiologies are associated with vision impairment and hearing loss.

Children who are developmentally delayed or who have cerebral palsy, and those with Down syndrome have a higher incidence of refractive errors and other ophthalmological problems than nondisabled peers (Capute & Accardo, 1991; Hoon, 1991; Wesson & Maino, 1995). At least 78% of children with Down syndrome have a hearing loss (Northern & Downs, 1991). There are over 70 syndromes in which hearing loss and visual impairment are likely to occur together (Regenbogen & Coscas, 1985). Research also indicates that 42 to 90% of children with severe or profound disabilities have visual impairments (Cress et al., 1981; Jacobson & Janicki, 1985). At least 20% of children who have severe and multiple disabilities have a hearing loss and over 33% of children with hearing loss have an additional disability (Sobsey & Wolf-Schein, 1991). Indeed, infants with severe and multiple disabilities are more likely to have a vision impairment or a hearing loss than any other group of children. They are also likely to require early intervention services to facilitate their learning and development.

**A Systematic Approach**

Early interventionists play an important role in identifying infants who should receive clinical hearing and vision evaluations. They should review the infant’s medical reports, gather information from parents, conduct structured observations of the infant’s response to sound and reactions to visual stimuli, and assist parents in obtaining a referral to an audiologist, ophthalmologist or optometrist, and educational services as needed.

**Review medical records**

With consent of the family and program approval, early interventionists should examine medical reports to identify the etiology of the infant’s disability and tests which have been conducted. The following procedures provide a systematic approach:

1. Review the audiological report to identify the types of hearing tests that were conducted, the results, the reliability of the results if indicated in the report, and the recommendations of the audiologist. Was a hearing loss identified? If so, what is the type and degree of loss? Were hearing aids recommended? If so, is the infant wearing them? If not, what is the reason? If hearing aids were not recommended, why not? When was the last hearing test conducted? When should the infant receive another hearing test? Were any recommendations made regarding specific interventions to assist the infant’s use of hearing or communication development? How have these recommendations been implemented?

2. Review vision evaluation reports to identify the types of vision tests that were conducted, the results, the reliability of the results if indicated in the report, and the recommendations of the ophthalmologist or optometrist. Was a visual impairment identified? If so, what is the type and severity of the visual impairment? Were corrective lenses recommended? If so, is the infant wearing them? If not, what is the reason? When was the last visual evaluation conducted? When should the infant receive another vision test? Were any recommendations made regarding specific interventions to assist the infant’s vision use? How have these recommendations been implemented?

**Gather information from families**

Frequently, parents are the first to notice that there is “something wrong” with the infant’s vision and/or hearing. Early interventionists should find out whether parents have any concerns about their infant’s vision or hearing and what they have been told by medical or other professionals about their infant’s vision and hearing status.

1. Ask specific questions about the infant’s response to sound. What have parents observed about the baby’s responses to their voices, household noises, and other sounds? How loud are these sounds? How close do they have to be to the baby to get a response? Does the infant seem to prefer certain sounds? Does the infant demonstrate better responses to sounds presented from particular directions (e.g., to the left, right, above or below the infant’s ears)? Does the infant seem to understand any spoken words?

2. Ask specific questions about the infant’s reaction to visual stimuli. What have parents noticed about the infant’s visual attention and responses to their faces, familiar objects, and bright or shiny toys. What seems to get the infant’s visual attention? How close do they have to be to the baby to get a response? Does the infant seem to prefer certain types of visual stimuli? Does the infant demonstrate better visual responses in certain lighting or to stimuli presented at particular positions (e.g., to the left, right, above, or below the infant’s eyes)?

**Conduct systematic observations**

Observe the infant during everyday activities as well as during activities specifically structured to engage the infant’s attention to visual and auditory...
High Risk Signs of Hearing Loss

Atypical appearance of the face or ears:
- Cleft lip and palate
- Malformations of the head or neck
- Malformations of the ears including lack of opening at ear canal (atresia)
- Frequent earaches or ear infections (otitis media)
- Discharge from the ears

Atypical listening behaviors:
- Has few or inconsistent responses to sounds
- Does not seem to listen
- Does not respond to caregivers calling his name
- Shows a preference for certain types of sounds

Atypical vocal development:
- Has limited vocalizations
- Has abnormalities in voice, intonation, or articulation
- Shows a delay in language development

Other behaviors:
- Pulls on ears or puts hands over ears
- Breathes through mouth
- Cocks head to one side

(Chen, 1990; Gatty, 1996; Fewell, 1983; Joint Committee on Infant Hearing, 1991)

High Risk Signs of Visual Impairment

Atypical appearance of the eyes:
- Drooping eyelid which obscures the pupil
- Obvious abnormalities in the shape or structure of eyes
- Absence of a clear, black pupil
- Persistent redness of conjunctiva (normally white)
- Persistent tearing without crying
- High sensitivity to bright light indicated by squinting, closing eyes, or turning head away

Unusual eye movements:
- Jerky eye movements (nystagmus)
- Absence of eyes moving together or sustained eye turn after 4 to 6 months of age

Unusual gaze or head positions:
- Tilts or turns head in certain positions when looking at an object
- Holds object close to eyes
- Averts gaze or seems to be looking beside, under, or above the object of focus

Absence of visually directed behaviors:
- Eye contact by 3 months
- Visual fixation or following by 3 months
- Accurate reaching for objects by 6 months

(Chen, 1997; Calvello, 1990; Fewell, 1983; Teplin, 1995)

Figure 2. High Risk Signs of a Hearing Loss or Visual Impairment in Very Young Children (Chen 1997).

stimuli. Pay attention to the position of the infant and where the stimuli is presented in relationship to the infant’s eyes and ears. Note the distance (12”, 3’, 5’, 10’) between the stimuli and the infant. Observe the infant’s characteristics, in terms of state, attention and interest.

1. Structured observation: Hearing screening. Are the infant’s face and ears typical in appearance? What responses to sound does the infant demonstrate? What types of vocalizations does the infant produce?

What types of sounds elicit the infant’s response?
- Type (vocalization, speech, sound toys, music, environmental sounds).
- Intensity (loud, conversational, whisper/soft).
- Duration (length of stimulus).
- Position (of the sound source in relation to the infant’s ears).

2. Structured observation: Vision screening. Are the infant’s eyes typical in appearance? Are there unusual eye movements?

Does the infant have an atypical gaze or head position? What visual attending behaviors does the infant demonstrate? Does the infant orient towards or reach for a desired person or object? What types of visual stimuli elicit the infant’s response?
- Type (familiar face, lights, colored objects, black and white objects, toys, familiar objects).
- Size and background (e.g., Cheerio® on dark placemat, bottle on high chair tray, brown labrador walking across room).
- Duration (length of presentation).
- Position (of the visual stimuli in relation to the infant’s eyes).
- Lighting conditions.

Is the stimulus meaningful and familiar or novel? Is the environment quiet and free of distractions? What type of activity was observed? How many trials were conducted? What are your impressions of the infant’s responses to visual and auditory stimuli? Look for high risk signs of hearing loss or visual impairment as shown on Figure 2 by observing the infant’s appearance; looking and listening behaviors; vocalizations; and eye-hand coordination.
The early interventionist should document and analyze the collective findings from the infant’s medical reports, information from the family, and from structured observations to determine whether or not clinical tests may be warranted. Findings and observations should be discussed with available program staff such as the nurse, speech and language therapist, and teachers certified in visual impairment, deaf and hard of hearing, or deaf-blind specializations. If the infant responded to visual or auditory stimuli, the team should discuss the type of responses that were observed. For example, responses may be reflexive or awareness behaviors (i.e., eye blinks, limb movements, or body startles); attention or alerting behaviors (i.e., looking, reaching, searching, smiling); or discrimination, recognition, or examining behaviors (i.e., differential responses to auditory and visual stimuli and indicating preferences) (Barraga, 1976; Chen, 1990; Flexer, 1994; Gleason, 1984; Hall & Bailey, 1989; Leuck, Chen & Kekelis, in press; Northern & Downs, 1991). Even the latter set of responses does not ensure that the infant has normal vision and hearing. If the infant demonstrates high risk indicators or signs of vision impairment or hearing loss, if the family has concerns, or if infant responses to visual stimuli or sounds are questionable, then the early interventionist should assist the family in seeking a referral for a vision and/or hearing test. If possible, referral should be obtained to a pediatric audiologist and pediatric ophthalmologist or optometrist who have expertise in evaluating infants—preferably infants who have multiple disabilities.

### Conduct Follow-up Services

Once evaluations are completed, families and other members of the early intervention program team should discuss test results and recommendations. It is essential for early intervention professionals to consult and collaborate with other professionals who have expertise in working with infants who are visually impaired, deaf or hard of hearing, or deaf-blind. All professionals involved with the infant should participate as members of a coordinated transdisciplinary team to avoid subjecting families to fragmented services involving multiple professionals.

Educational resources are available for deaf-blind infants and children. Each state has a federally funded deaf-blind project which serves as a valuable resource for early intervention programs and families to obtain technical assistance regarding relevant strategies and other resources. The federal government also sponsors DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind). To locate the deaf-blind project for a particular state and other information resources call DB-LINK (800) 438-9376.

Teachers certified in the areas of vision impairment, hearing loss, or deaf-blindness can explain terminology and diagnoses and suggest environmental adaptations, activity modifications and other specific interventions. For example, families and other professionals may question the terms ‘deaf,” blind,” and “deaf-blind” if the infant reacts to some sounds and visual stimuli. Caregivers may also need information about ways to develop communication with their infants who are deaf-blind. If the infant is diagnosed as having a vision impairment and/or hearing loss, recommendations should be reviewed and families should make decisions regarding their implementation. Specific interventions should then be developed to address the infant’s needs. These interventions need to fit within the family’s routine and culture. An individualized approach is essential for establishing collaborative relationships with families from diverse cultural and linguistic backgrounds.

### Summary

Vision impairment coupled with hearing loss profoundly affects a child’s ability to learn. Early identification of vision impairment and hearing loss is the essential first step in making sure that infants who are deaf-blind and their families receive appropriate support and early intervention services. Early interventionists should be aware of high risk factors associated with hearing and vision loss, use a systematic approach to screening, and have knowledge of available medical and educational resources in order to identify and obtain services for deaf-blind infants as early as possible.

### References


Research-to-Practice Focus:
FM Systems For Children Who Are Deaf-Blind

Barbara Franklin, Ph.D.
Megan Jones, M.A.

Public areas such as auditoriums, theaters, and restaurants provide poor acoustical environments for people who have a hearing loss. In such places, echoes and reverberations, as well as “background noise,” can greatly interfere with a person’s ability to hear what someone else is saying, even with the use of a hearing aid. Children who are deaf-blind may face similar difficulties hearing their teachers or peers in the school and classroom. “Assistive listening devices,” however, can improve students’ abilities to hear others by reducing acoustic problems.

This information sheet provides an overview of assistive listening devices for children who are deaf-blind. It explains what these devices are, describes how they work, considers potential problems and solutions, and reviews current technology. This information sheet is based upon the work of Dr. Barbara Franklin who, with the assistance of Megan Jones, M.A., conducted a federally funded research project entitled “FM Systems with Children who are Deaf-Blind.” The project, now in its final year of funding, is being conducted at San Francisco State University.

Types of FM Systems

The most typical assistive listening devices are personal FM systems and FM auditory trainers. Both work by providing the user with a constant “sound pressure level” of the speaker’s voice. With a personal FM system, a speaker’s voice is sent through the hearing aid(s). The speaker (e.g., teacher) wears a microphone transmitter that sends his or her voice to a receiver. The receiver is attached by a loop or cord to the microphone of the listener’s hearing aid(s). With an FM auditory trainer, the speaker similarly wears a microphone transmitter, and his or her voice is sent to a microphone in a receiving unit that the listener wears on the body. The components for either the personal system or the auditory trainer are contained in a rather bulky case, which is placed on the child’s chest or back.

New FM System Technology

A newer type of FM receiver is now available which combines the hearing aid and FM system in a single behind-the-ear unit (BTE/FM). This new BTE/FM eliminates the body-worn case, as well as all loops and cords. The unit operates as a hearing aid alone, an FM system alone, or a hearing aid and FM system simultaneously. Several companies have produced these units, including Phonic Ear, AVR Sonnovation (a company in Israel), and Telex. A BTE/FM unit for individuals with severe to profound hearing loss who need to communicate in noisy environments is being jointly developed by Sonnovation and Unitron. The latest advance comes from Phonak, which has developed the world’s smallest FM microchip ever designed for spoken communication. The device, called a Microlink, is about one third of an inch and is attached to a plastic boot that slips over the end of the over-the-ear hearing aid.

Considerations for Purchasing an FM System

Several questions might be considered when purchasing an FM system:

- Does the degree of amplification which the FM system provides match the degree of amplification the user needs? A child with a mild hearing loss, for example, might be “overpowered” by a system with a great amount of amplification, while a child with a severe hearing loss will be underserved with a system that does not provide enough amplification.

- How might the sound provided by the FM system change when the system is connected to a child’s hearing aid? The addition of a hearing aid to the FM “loop” can alter the nature of the sound provided by the FM unit, which may result in problems.

- Will the child be able to regulate the microphone on the FM receiver or access the on-off switch?

- What is the most effective input mechanism for the individual? In general, earphones are only appropriate for children with little hearing loss who do not use hearing aids. “Teleloop inducers” can be used by most children with a telecoil switch on their hearing aids, but may be less useful for those with more than a moderate hearing loss because the sound signal tends to fade in and out when the user changes head position. Direct audio input cords provide the greatest de-
gree of sound delivery, but they are more delicate than headphones or teleloops—a consideration for younger or very active children.

- Are the new BTE/FM units appropriate for the child? One drawback to this type of unit is that it may have an easily broken external antenna on the hearing aid. Another drawback is that these combined systems do not as yet deliver the same quality of sound as do other FM systems currently on the market.

Potential Problems in FM System Use

Just because a student uses an FM system does not necessarily mean that his or her hearing has improved. If your child or student uses an FM system, you should be aware of several potential problems:

- The microphone might be too close or too far from the speaker’s mouth. Six inches from the mouth is optimum placement. Make a fist under the chin and attach the microphone to the clothes at the resulting distance.
- Be careful that the speaker’s jewelry and clothing do not cause static.
- A speaker might hold the microphone instead of clipping it onto clothing. Fidgeting with the microphone hand may cause the speech signal to fade in and out.
- Many users lack the basic knowledge to troubleshoot the systems or to operate the more complex units.
- The type of microphone used can have a significant impact on the FM signal. Omni-directional, conference, or environmental microphones are effective where there is little background noise, such as in classroom lectures or small group discussions. On the other hand, they may not be effective in a noisy classroom, cafeteria, or playground. Uni-directional and “boom” microphones are more effective for noisy environments. It is desirable for the child to have a variety of microphones on hand to provide for environmental differences. If only one microphone is to be purchased, the uni-directional type is preferred.

Variations in Settings and Speakers

If the child is in an environment where more than one person is speaking (e.g., group discussions), several microphone arrangements are possible. One option is to pass the transmitter microphone and/or cabled receiver microphone around to each person as he or she speaks. Such an arrangement requires anticipation on the part of the group, instructor, and consumer. A speaker may have to wait for the microphone before offering comments. Another option is for a main speaker to paraphrase what other group members say. In a large group, it may be beneficial for the main speaker to retain the transmitter while an assistant paraphrases the comments into the microphone of the child’s receiver. A third option, especially helpful when there are two main instructors or speakers, involves the simultaneous use of two FM systems which can provide input into one receiving unit.

Children who have Hearing Loss and Other Disabilities

There are some simple, inexpensive ways to modify FM systems for better access by users who have visual impairments. For children who use braille, braille labels identifying components should be affixed to the system. Large print labels can be used for students with low vision. A rubber band or other tactile cue can be used to help the student distinguish the receiver from the transmitter. Materials such as Hi Marks™, which can be squeezed out of a tube to form a raised line when it hardens, is an excellent labeling tool for indicating volume setting. The use of a “loop” or sound field system may be less cumbersome than personal receivers for individuals with mobility impairments. But one drawback of the loop option is that the telecoil switch on the child’s hearing aid must be turned on and off to access or eliminate the FM signal. It should also be kept in mind that sound field systems do not bring the sound as close to the ear as personal receivers do. A receiver or transmitter can also be strapped to the arm rest of a wheelchair for easy access to sounds. In addition, wheelchairs can now be outfitted with speakers for FM systems on either side of the headrest.

Additional Information

Contact Dr. Barbara Franklin for additional or more specific information about FM systems for children who are deaf-blind. She can be reached at San Francisco State University, Department of Special Edu-
cation, 1600 Holloway Avenue, San Francisco, CA, 94132, e-mail: barbf@sfsu.edu, phone: 415-338-1161. A good general information book on FM usage with children is Flexer, C. (1994). Facilitating Hearing and Listening in Young Children, Singular Publishing Group, San Diego, CA.

NOTE: The project “FM Systems with Children who are Deaf-Blind” is supported by Grant Number H025400005 from the Office of Special Education Programs, United States Department of Education. The contents of this article do not necessarily reflect the opinions or policies of the Department of Education, and no official endorsement should be inferred. Barbara Franklin and Megan Jones provided the written information for this article which was edited by Harvey Mar as part of DB-LINK’s Research-to-Practice Initiative.

The Universality of the Usher Experience
Ilene Miner, CSW

During the past five years I have had an opportunity to travel and meet people with Usher Syndrome throughout the United States and in many different countries. I believe these experiences have much to offer those of us who do not have Usher Syndrome. If we attend to what is being said, we will learn about the lives, feelings, and thoughts of some extraordinary people. We will also learn ways in which service providers might meet their needs.

Many people have said they clearly remember the first time they met someone else with Usher Syndrome. First of all, they were grateful to learn they were no longer alone. Second, they discovered they have much in common no matter what part of the world they come from. One reason for this is that the “natural history” of either Usher 1 or Usher 2 is similar for people regardless of where they grow up. People with Usher 1 are born profoundly deaf and generally use sign language as their primary mode of communication. People with Usher 2 are born hard-of-hearing and generally use spoken language. In both groups, however, sometime during childhood or adolescence, vision problems become apparent, and the diagnosis of Usher Syndrome is made.

All children grow up internalizing a view of what they will become from those around them. Many times, those with Usher Syndrome grow up without ever meeting another person with Usher. As a result, they may have no idea of what the future holds for them. Sometimes this isolation is by design. Parents may fear that meeting a person with Usher whose vision has started to deteriorate will create despair in their child. They may have received this message from professionals. In some cases, professional advice to place children in inclusive education set-

tings has resulted in the child being removed from the only place in which he or she might have met other children with Usher, such as a deaf day or residential school, or a deaf class in a mainstream school.

The underlying message of never telling a child about Usher or keeping him or her away from other people with Usher is, “What is happening to you is so awful that we, your caretakers, your family, can’t even bear to mention it or expose you to it.” There is a further message which is strongly disabling, “People who are just like you have nothing to offer you,” and by extension, “People like you have nothing to offer.”

Many people with Usher Syndrome have told me they have felt “different” for most of their lives. They almost never had the chance to be with someone just like themselves to hash out issues, to share experiences and war stories, to worry, to wonder, to laugh. The following vignettes illustrate the importance of connections between people who have Usher Syndrome. All are situations in which I was personally involved. Names, ages, and gender are changed.

Bob, Lana, and Roberta are teens with Usher. Two of their parents told me not to mention the word “blind” when talking with their children. I agreed because I knew I wouldn’t have to, the teens would be discussing the subject themselves. Their discussion follows:

**Bob:** So, how is your vision?

**Lana:** Not so good.

**Roberta to Bob:** How’s yours?

**Bob:** OK so far. I am hoping to make it through college before I go blind. What about you?

**Roberta:** I am losing mine pretty quickly, so I don’t know if I will get through college first.

**Lana:** How are your parents taking it?

**Roberta:** Whew, not so good. They get upset so easily that I find I can’t discuss it with them.

Gail, a woman of 24 with Usher 1, recounted meeting Fran who also has Usher 1, at a party when they were 18 years old. Neither had ever met anyone else with Usher. Their boyfriends knew each other and introduced them. Soon they were trading “war” stories.

**Gail:** I was at a party, tripped and spilled a drink all over the hostess.

**Fran:** I was going into the movies and fell flat on my face.

**Gail:** I once knocked my drink into my friend’s TTY.”

When Gail described this, she told me that they laughed so hard that tears were rolling down their faces. Gail described both boyfriends standing and watching in a state of utter disbelief. She said it was the first time she felt safe enough to reveal her feel-
ings of embarrassment and laugh with someone who could really laugh with her and not at her.

These connections can also benefit parents. At a meeting of families of children with Usher, Sara, a mother of two teens with Usher from Europe approached Bill, who grew up in the USA, and has Usher 1 and an advanced university degree. She told him, “You have given me hope. You have given my life back to me.” Sara had never met an adult with Usher Syndrome and had thought her children could never work or be independent.

Jane and Lei have Usher Syndrome, Type 1. Jane grew up in the USA and Lei grew up in Asia. They initially met through the Internet and later had an opportunity to meet in person. They found they had much in common. Both were blind by their late 30s. Each has siblings with Usher, but because their parents never learned sign language, both Jane and Lei lost the ability to communicate directly with their parents when they lost their vision. Both of them use their country’s sign language for communication and read and write fluently.

Tom, who grew up in Europe, and Deb, who grew up in the United States, have Usher Type 2. They are 20 years apart in age. Both are hard-of-hearing, and learned sign language in graduate school. Both were mainstreamed and have advanced university degrees. It happens that they also share a profession. Deb has been working for 20 years, and Tom is just starting out.

**Tom:** When I look at you, I can finally see my future. I didn’t know what would happen to me. Could I continue to work? Can I have children? I have never met another person with Usher before.

**Deb:** When I look at you, I see myself as a younger person, but at the same time you are far ahead of where I was at your age.

**Tom:** I get strength from talking to you and seeing how your life has gone.

Kristin who has Usher 1 and is totally blind and I were in Europe where we met Jan, a man in his 60s also with Usher 1 and totally blind. Jan was thrilled to finally meet someone who really understood. Although Jan and Kristin did not share a common sign language, they communicated with ease using pidgin sign.

**Jan:** I am so depressed since I lost my vision 6 years ago. I think of suicide every day.

**Kristin:** Ah, I went through this too, a serious depression and suicide attempt, but that is over now. It can get better for you.

Kristin and Jan continued to talk and soon they were comparing life stories. Jan left our meeting with a kernel of hope. Many people I have worked with have attempted suicide or thought of suicide. The issue of depression in people with Usher who are isolated needs to be examined.

I met Mara in Europe at a school for the Deaf which has a deaf-blind high school incorporated within it. There were six girls who lived and went to school together. Watching them interact in their dorm, I was struck by their closeness although they had been together only six weeks when I met them. Mara also told me with great animation about the school trip to a deaf-blind youth conference in another country and the thrill of meeting dozens of teens just like themselves. People with Usher of all ages upon arrival for their first time at any large gathering of deaf-blind people have told me, “I feel I have come home.” When people meet, what is expressed is the comfort and joy of being among “family.” To use Theresa Smith’s word, being in a group of people with Usher affords time to be “unmarked.” It affords time and a place to just be a person, and not just a person with Usher. People with Usher also learn from and teach each other.

At the European Usher Study Group meeting in Madrid last July, I met with people who have Usher Syndrome from five or six different countries. Despite different backgrounds, different signed languages, and different spoken languages, there was communication every moment. There was excitement and closeness. They discussed issues that included having, caring for, and raising children; needing to change jobs; embarrassment at having to learn mobility skills; delight in socializing with others with Usher; communication issues and role changes at home; difficulty communicating with parents and siblings; episodes of sadness; and concerns about old age.

The need to be validated and to know that one is not alone in the world is universal.

### What Can We Professionals Do?

**Create More Opportunities for People With Usher To Connect With One Another**

Many people with Usher have said they feel isolated and lonely and wish they could get together easily on a regular basis. Some have said they would be happier at work if they could share time with others who also have Usher Syndrome. Students who do not have an opportunity to interact with other students who have Usher often experience isolation. Enclave schools and work sites are solutions to these problems. As the vignettes above demonstrate, being around others with Usher is extremely impor-
tant and positive. We should stop using the label “normalization” as a way to keep people with Usher away from each other in the classroom, and during social and work time. We need to “normalize” having Usher.

It is important to help young people with Usher Syndrome connect with other people who have Usher Syndrome as soon as they are diagnosed. Adults with Usher Syndrome should be the first source of support and information to newly diagnosed families. Teens enjoy asking questions of adults, and adults enjoy sharing their experiences and wisdom. Young people can find role models and heroes; older people can become mentors. These precious moments should be available to all. More opportunities for peer counseling, mentoring programs and large group events should be created. Early and consistent involvement with people of all ages will provide young people and their families with a sense of the future.

Other ways to decrease the isolation and information deprivation experienced by people with Usher Syndrome are to increase the availability of interpreters and support service providers, and to make computers available to all people who are deaf-blind. Through computer networks, information and people from around the world can get in touch with each other.

Become Involved in the Community and Culture of Deaf-Blind People

Professionals should spend more time outside the office setting, interacting with people who have Usher Syndrome. More professionals need to attend national or international conferences planned by and with people who are deaf-blind. It is also important to become fluent in sign language or at least to use an interpreter. People with Usher have told me it makes them angry when professionals don’t sign or use an interpreter, don’t wear clothing with solid background that contrasts to skin color, and don’t convey an attitude of respect.

When working with young people, professionals need to communicate directly with the young person, not just to the parents. Too often young adults have told me that, when they were being interviewed with their parents, no one directed any comments or questions to them. Teens and adults with Usher can tell their own stories. They have the right to be accorded respect and validation that comes with being responsible for their own life stories.

Professionals Don’t Have All the Answers

If professionals are to maintain credibility, we must admit we don’t have all the answers.

People with Usher Syndrome are the real experts. We must listen to them to find out what they need. The community of people with Usher Syndrome in Seattle is a good example of this. Members of the deaf-blind community in Seattle have been actively involved in developing improved transportation services, setting priorities for the community, consulting to service agencies, teaching in interpreter training programs, and working at the annual deaf-blind camp.

Additionally, there is a need for more people with Usher Syndrome to become professionals themselves. Too few of us speak from experience that is both professional and personal. People with Usher Syndrome would thus play more of a leadership role in the development of the information and services that affect their lives.

Summary

We find great consistency in the stories told by people who have Usher Syndrome. Over and over, we hear the need to be together, to learn from each other, to feel validated and less alone, and to share experiences. People with Usher need what everyone needs—friendship, respect, community, work, support, control of their own lives, and the power to make decisions. If we listen to what people with Usher tell us, the answers will be clear.

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For Further Reading


**E-mail Discussion Groups**

The following listservs provide forums for people who are deaf-blind, their families and friends, and professionals so they may share information via e-mail.

**Deaf-Blind Mailing List**

To subscribe, send the following command in the body of an e-mail message:

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SUBSCRIBE DEAFBLND firstname lastname
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Note that “deafblnd” is the correct spelling. Send the e-mail to listserv@tr.wou.edu. All messages are archived at [http://www.tr.wou.edu/archives](http://www.tr.wou.edu/archives).

If you have difficulty subscribing contact Randy Klumph at owner-request@tr.wou.edu.

**Usher-List**

To subscribe to this electronic discussion group, send an e-mail message to majordomo@farside.cc.misu.nodak.edu Subject category should be left blank for DOS users and filled in as “subscribe” for Windows users. The body of your message should read as follows: subscribe usher-list your-name@your.service.com If you have difficulty subscribing contact Lynne Krumn at aud2@minot.nodak.net

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**My Continuing Journey with Usher Syndrome**

Winnie Tunison

M y name is Winnie Tunison, and I have Usher Syndrome Type I. I was born deaf and became blind ten years ago when I was forty. This was a big disappointment because I had hoped that I would be much older when I lost my sight. My parents learned that I had retinitis pigmentosa when I was eight, but I was never told and didn’t find out until I was twenty-nine. I want to write about the feelings I experienced as I went through the stages of vision loss. I hope that my story will help others who read about it.

I have always felt different from other people—as a child, teenager, young adult, and as a deaf-blind woman now. I knew I was a little different from other students in the school for the deaf I attended for 15 years, however, I could not understand why. My peers could do a lot more than I could in sports and in poorly lit places, and they could sign to each other from a long distance. Even though I was well liked by everyone, I was not part of a group of close friends. When I was a teenager, I was not allowed to participate in sports, but I was never told why and I was too scared to ask. I had never heard of Usher Syndrome, so I assumed that I was nearsighted.

I married at twenty instead of going to Gallaudet University. I think this was partly because I felt it would be easier to be a married woman than a student. If I went to college, my “differentness” would stand out again, and I didn’t want to be different.

During the early years of my marriage, I participated in a Deaf Women’s Club once every month. During this time, my feeling of being different from my friends became stronger. It was hard to follow the many conversations going on between my friends, so I only watched one person at a time, and missed out on other conversations. I tried to ignore the fact that I was missing so much, but it became more difficult. I was beginning to feel badly about not being able to keep up. My friends tried to help by taking turns telling me what the others were discussing. Although this was thoughtful, it embarrassed me.

As my vision continued to deteriorate, I found peace at home with my family. I also enjoyed having friends over to visit, but only one or two at one time. Having fewer people meant I could control the flow of the discussion more easily and I could control the lighting, so I could see more clearly.
Early on, when my vision was deteriorating, I attended a convention of the American Association of the Deaf-Blind. At first, I was uneasy among so many deaf-blind people because seeing and being with them reminded me that I would be like them someday. I was also uncomfortable socializing with hearing people because I could no longer communicate freely with them, and with deaf people because they signed too fast for me to read. These issues made me feel very different from each of the groups. I belonged nowhere.

Seeing fewer and fewer people led me to become isolated and lonely. I knew I could not depend on my husband and daughters for entertainment. The isolation and depression I felt caused insomnia. This led me to attempt suicide by taking an overdose of medication. I was jealous of everyone and their independence and freedom. I felt unloved, unworthy, and unneeded. Of course I knew that my family and close friends loved and cared about me, but it was not enough. I needed to be more sociable, and meeting people and doing things, but I couldn’t.

After extensive counseling and therapy, I regained positive feelings about myself. Instead of bottling-up my feelings, I disclosed how I felt about becoming blind, and how I felt about life before and after blindness. I found that revealing myself was a great way to educate people about deaf-blindness. I started to make many friends, hearing, deaf, and deaf-blind.

Now that I am blind and after ten years of socializing with deaf-blind folks, I am much closer to them. Deaf-blind people have a very strong bond because of their dual disabilities. Although we are few in number and often live far apart, when we meet each other, whether old friends or strangers, we are very happy. I am also now happy among the deaf again. In spite of my blindness, I do not feel much difference between us. Calling with hearing people is still a challenge, but I feel wholly normal talking with hearing people with the help of an interpreter and I talk with my hearing relatives by using my Telebraille. It is a wonderful feeling to be able to talk with everyone once again.

I have spent a long time sorting out my feelings about my blindness and my life. I went through times of despair and depression. My feeling of being so different from other people kept me isolated. I remember all these feelings and know they are a part of me. But I am in a better place now. I have come to feel better about myself and my life and I have formed strong connections with many other people. I hope other deaf-blind people see and hear my story and know that they are not alone.

Winnie Tunison is a junior at Gallaudet University. She can be reached via e-mail at 11wtunison@gallua.gallaudet.edu

Notes From AADB
Sharing My Perspectives

Harry C. Anderson

As a deaf-blind consumer and president of the American Association of the Deaf-Blind (AADB), I wish to share with you my fervor, determination, modesty and enthusiasm. As I have traveled as a keynote speaker in workshops on deaf-blindness and as the spokesperson for AADB, I have witnessed professionals and parents become inspired and interested in the needs of deaf-blind children. I have seen children learn and gain self-esteem. And I have seen communities gain insight into the needs of the deaf-blind community and have found that they are eager to provide services.

My dream is to see children, youth and young adults who are deaf-blind blossom and become more visible and recognized by people in all walks of life. I also aim to increase awareness of AADB and our staunch advocacy for accessible services, independence, employment and above all acceptable attitudes and the respect that we deserve.

I believe in miracles, but I cannot do the miracle alone, spreading great words about the deaf-blind community to the huge mass of Americans in our country. Deaf blind consumers, parents of deaf-blind children, advocates, interpreters, and special service providers (SSPs) for deaf-blind people need to reach out and touch the hearts and minds of neighbors, civic organizations, community leaders and state legislators, as well as Congress. It is essential that we promote a positive panoramic view of the deaf-blind community, not only during Helen Keller Awareness Week, but all year round. It is a challenge for all of us. Making a change is a challenge, not a fear. We must all work for the common good. I urge you to become assertive and educate the public.

We all share something in common in our daily lives. It is important for us to tear down the barriers we encounter in society and face the issues that interfere with our children’s education, independence, and employment. We must strive to improve quality of life by working on the social complexities within our society.
I agree with this quote from the book, Getting the Best Out of Yourself and Others:

“We live in a time of paradox, contradiction, opportunity, and above all, change. To the fearful, change is threatening because they worry that things may get worse. To the hopeful, change is encouraging because they feel things may get better. For those who have confidence in themselves, change is a stimulus because they believe one person can make a difference and influence what goes on around them. These people are the doers and motivators.”

How do we make a difference? Be hopeful and confident doers and motivators! Where there is a beacon of hope and optimism, there is time and space for the spirit of making a difference. Where there is a beacon of hope and optimism, there is a will to push for the changes necessary to make parents, professionals, and deaf-blind consumers more active and stronger in the 21st century. We need to make a commitment to the growth of better services to meet the needs of deaf-blind people and to changes necessary for quality of life. We need to make a difference in society.

This article was originally published in the January - March 1998 issue of The Deaf-Blind American. It has been adapted by the author and reprinted with his permission.

For Your Library

Collaborative Teams for Students with Severe Disabilities: Integrating Therapy and Educational Services.

For parents of children with severe disabilities and professionals who provide services to these students, this book addresses issues that team members encounter as they work to collaborate with one another. Outlines principles, practices, and procedures for providing related services as integral components of special education programs for students with severe disabilities. Offers guidance on assessment, curriculum development, and instruction. Suggests processes for identifying team members, scheduling, developing IEP’s, co-teaching, conducting team meetings, assuming multiple roles, addressing issues as a group, making group decisions, resolving professional differences, and communicating with parents. Paul H. Brookes Publishing Co., (800) 638-3775. Price $35.00

XII Deafblind International (DBI) World Conference

Lisbon, Portugal
July 20-25 1999

The conference theme is “Developing Through Relationships: Celebrating Achievement.” There will be four subthemes:

- Relationships between congenitally deafblind children and young deafblind adults and sighted hearing people;
- Relationships between/among deafblind people;
- Relationships between families and professionals;
- Relationships across borders.

Call for Papers

All participants willing to present a paper at the Conference are invited to send an abstract of about ten to fifteen lines by September 30, 1998 to:

XII World Conference of DBI Planning Committee
Casa Pia de Lisboa / CAACF
Av. do Restelo, 1 1400 Lisboa
Portugal
Tel. 351..1. 362 00 06 Fax: 363 34 48
E-mail: np28ze@mail.telepac.pt

The committee will give priority to presentations directly related to the main themes of the conference, but will also consider papers addressing other issues concerned with the education and welfare of deafblind children and adults.

Foundations of Orientation and Mobility, (2nd ed).

This new edition offers contributions from more than 30 subject experts and includes an international perspective, as well as expanded contents on state-of-the-art research in low vision, aging, multiple disabilities, accessibility, program design, and adaptive technology. Chapters are divided into
four areas: human systems, mobility systems, the learner, and the profession. One chapter is devoted to orientation and mobility for people who are deaf-blind. AFB Press, (800) 232-3044. Price $68.95.

Including Deafblind Students: Report from a National Task Force
Goetz, Lori, Ph.D. San Francisco: California Research Institute, 1997.

This manual is based on the work of a federally funded, model demonstration project, “Full Inclusion Project for Students who are Deafblind.” The project developed a national task force that included parents, educators, technical assistance providers, and researchers, to address the concerns, challenges, and successes of including deaf-blind students full-time in general education classrooms. The manual can be ordered from California Research Institute, 612 Font Blvd., San Francisco, CA 94132, for $15.00, postage included. Checks should be made payable to San Francisco State University Foundation, Inc.

Instructional Strategies for Braille Literacy


Negotiating the Special Education Maze: A Guide for Parents and Teachers

Explains provisions of the Individuals with Disabilities Education Act (IDEA) in easy-to-understand language. New chapters have been added to the previous edition about early intervention and nondiscrimination protection (alternative strategies for using the ADA and Section 504 of the Rehabilitation Act to obtain services for children who don’t qualify for special education under IDEA). Also included are numerous charts and checklists, as well as listings of parent groups, state agencies, and disability organizations and hotlines. Woodbine House, (800) 843-7323. Price $16.95.

Self-Determination Across the Life Span: Independence and Choice for People with Disabilities

A collection of articles exploring the theoretical, developmental and practical aspects of decision making. It is written by adults with disabilities, parents of children with disabilities, and professionals working in the field. Offers suggestions on how to encourage the growth of self-esteem, incorporate self-determination skills into educational programs, begin skill training in the home, promote self-determination throughout the life span, and evaluate the progress of skill acquisition. Paul H. Brookes Publishing Co., (800) 638-3775. Price $35.00.

Teaching Self-Determination to Students with Disabilities: Basic Skills for Successful Transition

Provides instructional methods for teaching basic self-determination skills to students with disabilities. Designed to assist teachers in meeting IDEA requirements and planning transition programs according to student preferences. Field tested, hands-on activities provide a variety of ways to promote autonomous behavior and help students learn specific skills including decision making, problem solving, self-advocacy, self-management, self-awareness, goal setting, and assertiveness. Paul H. Brookes Publishing Co., (800) 638-3775. Price $34.95.


Contains more than 60 papers from the conference workshops. To order, contact Vhristine Toney, Hilton/Perkins Program, Perkins School for the Blind, 175 N. Beacon St, Watertown, MA 02712, (617) 972-7228. Price $23.00.

You and Me - Social Connections: Volume Four (includes Parts 4 & 5).


The fourth and final video of the four volume, five part video series that describes the education of a child who is deaf-blind. The series portrays Riley Ford, who is totally blind and has a profound hearing loss. Volume four contains Parts 4 & 5 and describes the importance of movement and mobility in building social connections for a child who is deaf-blind. This video and all other videos in the series may be ordered from Teaching Research, Western Oregon University, 345 N. Monmouth Ave., Monmouth, OR 97361, (503) 838-8792; TTY (503) 838-8821; Fax (503) 838-8150. Price $15. Video with open captioning are available upon request.
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