

October 2019

## Issues in Serving Deaf-Blind Persons

Marie Egbert Rendon

*University of California Center on Deafness*

Follow this and additional works at: <https://repository.wcsu.edu/jadara>

---

### Recommended Citation

Rendon, M. E. (2019). Issues in Serving Deaf-Blind Persons. *JADARA*, 25(1). Retrieved from <https://repository.wcsu.edu/jadara/vol25/iss1/7>

## ISSUES IN SERVING DEAF-BLIND PERSONS

---

**MARIE EGBERT RENDON, Ph.D.**

University of California Center on Deafness  
San Francisco, California

### Abstract

A panel discussion about deaf-blind issues brought together four experts in the field: Dr. Lea Hyvarinen, M.D., addressed the problem from the medical viewpoint; Charlotte Whiteacre, a deaf-blind professional, provided a view from a consumer as well as a professional; Carol Day-Drummer gave insight into clinical aspects; and Lindsay Gimble provided discernment into working with the deaf-blind population from the interpreting stance. This article is based upon these four "testimonies" and provides the reader with an all-around look at providing services to persons who are deaf-blind. In addition to the presentations, the question and answer session brought into action some topics which were not addressed during the panel discussion. The reader is provided with a four-way look at the field of deaf-blindness.

Dr. Lea Hyvarinen, MD, the first panel member, is the Chief Medical Officer in Ophthalmology at the Institute of Occupational Health in Helsinki, Finland. Dr. Hyvarinen will address the concerns of working with the deaf and blind from the medical field. Our second panel member is Charlotte Whiteacre, a deaf-blind professional working in the field of deaf-blindness; Ms. Whiteacre comes from generational deafness. Carol Day-Drummer is a licensed clinical social worker from the University of California Center on Deafness. In addition to her work with hearing-impaired persons, she has counseled deaf-blind individuals both in San Francisco and San Diego. Lindsay Gimble is a certified sign language interpreter, whose specialty is working with the deaf-blind population.

**Dr. Lea Hyvarinen, M.D.**

---

### Introduction

The following article is based on "UCCD Presents the Fremont Seminars: Issues in Serving Deaf Blind Persons" panel discussion. This specific seminar brought together the expertise of four professionals who have experiences, expertise, and information to share with regard to their work with the deaf-blind population. A brief introduction to each one of them and a synopsis of the panel discussion will be depicted in this article.

To be a deaf-blind person is difficult. For some, it is emotionally difficult to talk about their increasing visual loss. However, I have found that many deaf-blind patients are happy, calm and content. One of my profoundly deaf and blind patients, who always appears happy said:

"I've heard that those who hear and see quite often say nasty things to one another, but if a person comes with tactile signing, they don't do that. My life is easier that way. I have problems. It is inconvenient to be deaf and blind, but it is not that bad."

## ISSUES IN SERVICING DEAF-BLIND PERSONS

---

For people who are both deaf and blind, communication is doubly complicated. Communication requires motivation on the part of the client and the physician or therapist or anyone who hopes to engage in successful communication with the deaf-blind person. People have certain images of deaf-blind people, physicians included. Anyone working with an individual who is deaf-blind needs to know how the person became deaf and blind, the time of onset of each, the cause of the onset, etc. This information is important because knowing the time of onset of each will help the person understand the client's communication background. The time of onset affects how the person learned language or languages.

Physicians do not know much about deaf-blindness. In fact, many physicians know precious little about blindness, deafness, and hearing impairment, even in older people. They may overlook one or the other sensory loss or they may not see the person has having a dual sensory loss. The ENT may notice the decreased hearing, but not the decreased vision. The ophthalmologist may notice the decreased vision, but not the hearing loss. This further fragments the care a deaf-blind person might receive. This must change since hearing impairment is increasing.

The features that are important to know about the vision of a deaf-blind person include:

- (1) Their field of vision. With Usher's Syndrome, tunnel vision is a common feature.
- (2) Loss beginning in the mid to peripheral region of vision. The person will first have small patches of loss within their central field of vision. Then this loss enlarges to form "ring scotoma," which is when they have vision in the center, vision in the periphery, but little or no

vision in between these two regions.

- (3) Some will have central scotoma. The symptoms include trouble reading small text, trouble seeing faces, and decreased visual acuity.

Because of the variations of visual abilities and difficulties, it is important to be sure there is enough light for the person and that the light is not in the client's eyes.

Now let's look at some of the problems associated with assessing hearing. To many physicians a simple test is adequate; however there are ramifications of hearing loss that can not be determined by a simple hearing test. If one is to adequately assess the hearing of a client or patient, there are several prerequisites for making the assessment of the extent of a person's hearing losses:

- (1) Having a sufficient amount of time.
- (2) Paying close attention to the quality of one's communication with the client.
- (3) Having a readiness and willingness to rephrase statements in the event of miscommunication.
- (4) Having a sensitivity to the impact of one's nonverbal communication.

Most physicians find communicating with a deaf-blind patient difficult. Physicians are not trained to do so. Physicians may not be able to convey information about the person's sensory loss in a positive manner because of limited knowledge about people who are blind. They may want to only give medication or perform surgery, with the patient needing only to comply. If a patient has a permanent loss, ophthalmologists are lost. They cannot help the patient medically. The role of the physician, when working with such a patient, may need to change. The patient needs to learn how to cope with his/her situation, but physicians are often clueless as to what services the patient needs

## ISSUES IN SERVICING DEAF-BLIND PERSONS

---

and what services are available.

Physicians should be careful of what they say to the patient about the sensory loss. Physicians can needlessly take away the patient's hope. The M.D.s should encourage the patient to enter rehabilitation and to accept the loss as an inconvenience. Physicians should realize that the attitude they convey to the patient is very important. If the physicians have a negative attitude, this will negatively affect the patient's desire to learn.

Many physicians do not know about Usher's Syndrome. With Usher's Syndrome, the person is first deaf, then loses the eyesight. Among the group of persons who have Ushers Syndrome are persons who know American Sign Language and whose command of English is very good. There are those with low functioning skills and those with high functioning skills. One problem with Usher's Syndrome is that it is usually diagnosed when the person is between 12 and 20 years of age. This is late. Physicians who notice that a patient who is deaf and is also having decreased visual ability should have an ERG (electroretinography). This tells about retinal function. If there is no retinal function present, then Usher's should be suspected.

I have covered only a few of the pertinent topics around medical issues of deaf-blindness. Along with what I have addressed come concerns about acceptance into the deaf community, the deaf-blind community, support groups, and the blind community. All of these are as important as is the medial treatment.

**Charlotte Whiteacre**

I am a deaf-blind woman. I come from a deaf family; my parents and grandparents were deaf. Some of my uncles and cousins on the east coast

are also deaf. On my mother's side there is also optic atrophy. This is a disorder that allows one to see the periphery but not see very far. People with optic atrophy have night vision, but cannot read very easily. The visual symptoms are opposite that of Usher's Syndrome.

For a long time, many people did not know of my visual problems. When I applied for admission into Gallaudet, I was not able to read fast enough, so I decided to move to California and work. I worked at Hills Brothers for 14 or 15 years as a key-punch operator. The only problem I had was that I was a slow reader due to my visual problems. My boss sent me to a doctor, who told me I would go blind and that I should stop reading and working, and go on disability. I was given early retirement.

It was then that I decided to make the most of what I had. One day, I saw a television show broadcast from San Francisco about deaf-blindness; after seeing the program, I went to San Francisco and began working with a deaf-blind group as a volunteer. I recall working with one man who was deaf-blind. He was very angry, with me and with life in general. He told me that I could never understand him because I was not blind. At this point, I was still in denial about my blindness and had not told anyone. Finally, I told this man that I, too, was blind. This was the beginning of my acceptance of my blindness.

I recognized that one of my job limitations was that I did not have a college degree. I then enrolled in computer classes at Ohlone College. I realized then that the more I read, the more I used my eyes, the more steady my vision became. This was contrary to what I had been told by my doctors, who had cautioned me against using my declining vision.

While earning my A.A. degree at Ohlone and being frustrated at the lack of sufficient services for

## ISSUES IN SERVICING DEAF-BLIND PERSONS

---

deaf blind people, I decided to file a complaint with the state. The state responded and through this, I was able to get a job at the Bay Area's Deaf Counseling, Advocacy and Referral Agency (DCARA) helping coordinate transportation and other services for deaf-blind and mentally retarded. I learned that language deprivation is related to behavioral problems.

When a deaf blind person is deaf first, they have: (1) a history of ASL, and (2) background within the deaf culture. When they later become blind, they are different than the person who is blind-deaf. The disabilities are the same, but the cultures are quite different. A person who is blind and then becomes deaf is often not accepted by the deaf community. Moreover, the extent of the person's ability to communicate will depend partly on background, education, the extent of their loss and the time of onset for each loss. Deaf-blind people need to use tactile communication. A blind person who becomes deaf will often use finger spelling.

### The History of the Deaf-Blind Community

Today, more than ever, deaf-blind people are visible and working to gain more rights and independence. Historically, there were few services for deaf-blind people. Now this dearth is beginning to be filled. Parents of deaf-blind children have tended to be over-protective. Then, when the parents died, the people were unable to take care of themselves because they were not encouraged to explore outside the home. The need for deaf-blind people to learn to explore and negotiate within the outside world as much as possible is now recognized.

Many deaf-blind people have not had opportunities to make their own decisions. For example, in the midwest the state put up housing for deaf-blind people, but the deaf-blind persons for whom this was intended did not want to move to the area where the housing was. Instead, they felt the need for workshops, seminars, and services. The deaf-blind community has the need to be part of the decision making process from the onset. This paternalism has been partly buttressed by the deaf-blind community itself. In Seattle, deaf blind people 15 years ago did not know what they wanted in terms of political powers. Now they know and actively share that knowledge with others. The community has become much stronger as a result.

When a deaf person becomes blind, they are often placed in rehabilitation with people who are only blind. There they have trouble communicating. Fortunately, there are now more rehabilitation programs specifically for deaf-blind people across the United States. In Little Rock, Arkansas, they have researched rehabilitation for deaf-blind persons and published a directory of services. At the Lighthouse for the Blind, in San Francisco, they have a variety of activities for deaf-blind people. At Ohlone College, in Fremont, California, there are classes in the interpreter training program to help teachers who work with deaf-blind people. In Los Angeles, there is a housing complex for deaf-blind elderly.

Nationally, there is the American Association of the Deaf-Blind. This organization holds annual conferences and helps people share frustrations and triumphs, overcome obstacles, learn to lobby and change legislation, and become familiar with new devices and technology.

## ISSUES IN SERVICING DEAF-BLIND PERSONS

---

### Technology

There have not been many technological devices specifically designed for deaf-blind people. The blind have theirs; the deaf have theirs. The telebraille is one that has opened up communication for deaf-blind persons. Because it allows the deaf-blind person access to the telephone, it has eliminated the need for a third person to participate in phone conversations, thereby giving the users more privacy. Teletouch is also good for the blind; it is very portable and therefore makes communication easier. Visualtech is a machine that helps people who have some vision to read the small print. It can enlarge print up to 60 times and uses a monitor. The Sonic Pager lets deaf-blind people know when the telephone or telebraille rings. It is also good for letting a deaf-blind person know about the doorbell, fire, etc. It fits on the wrist and works via vibrations. Each one can be programmed to transmit about four different vibrations, which enables the person to distinguish between the telephone, the door, or a fire. Some people wear more than one.

Recognition of the deaf-blind population as "people", advances in technology, the movement towards independence, and the increase in services for the deaf-blind population have all helped to bring "deaf-blind people out of the closet."

### Carol Day-Drummer

I want to address deaf-blind mental health issues. It is impossible to generalize about deaf-blind people because they are each different, with different histories, concerns, and abilities. However, while I focus on people with Ushers' Syndrome, I will venture to make some generalizations about the psychodynamic

development and experiences due to the sequence of sensory losses.

With Ushers' Syndrome, the person is congenitally deaf and has adventitious blindness. The visual loss is usually diagnosed when the person is between 13 to 20 years of age. The visual loss is degenerative and its extent is hard to predict. Adolescence is generally a time when many children rebel, try to become more independent, and develop their own identity. A teen with Usher's Syndrome may have similar problems and concerns but may feel rejected by their deaf peers and feel they have no one to talk with about their fears of their new blindness. For these teens, it will be hard to develop their identity and sense of community. Their decreased ability to communicate will affect their socialization, which in turn, will affect their self-esteem. They may also be angry about their decreased independence and may direct this anger at themselves or at others. They may then become more isolated, more socially withdrawn, more depressed and increasingly passive.

Because working with the deaf-blind requires some special skills, and perhaps a different emotional impact than when working with hearing or deaf individuals, therapists should evaluate their own feelings about working with deaf-blind clients. They should resolve their own counter-transference issues. The therapist needs to avoid paternalism. They need to determine how comfortable they are with tactile communication. They need to evaluate their own attitudes about independence and dependence, being careful not to promote excessive amounts of either one. They should not have negative feelings or pity for the deaf-blind client. They must see beyond the person's deafness and blindness, seeing those qualities only as a part of who the person is. Deaf-blind people have the same goals, desires, needs and feelings as

## ISSUES IN SERVICING DEAF-BLIND PERSONS

---

do those of us who are sighted and can hear.

My clients come in, not because they are deaf-blind, but because they have the usual problems that bring people into therapy. Issues around their deaf-blindness are addressed as deemed appropriate. One observation that may or may not be termed a generalization is that all of my deaf-blind clients are very committed to coming to therapy, often more so than my other clients.

Working with deaf-blind clients can be very rewarding. One must be prepared, just as one must be prepared to work with any special population. There are issues to be addressed before therapy; issues for the therapist and his/her level of commitment and involvement. There are frustrating times as well. All of these concerns, cares, and issues are to be addressed just as they are in work with any persons who choose to bring their problems in to be discussed.

### Lindsay Gimble

It was once said that there are few activities humans value more, understand less, and perform worse than person-to-person communication. Person-to-person communication takes many forms, dependent upon the requirements and choices of those who are communicating.

I want to address the role of the interpreter in facilitating communication for the deaf-blind person. Working as an interpreter for a deaf-blind person is unique experience. It is valuable for the interpreter and deaf-blind person to spend 15-30 minutes together before the actual interpreting situation in order to help the interpreter learn about the person's language level, levels of comfort, etc. During this time the interpreter should measure the communication and visual field of the person. It is important that the interpreter sign only within the person's visual field. Signs for

people with tunnel vision should be narrow. The interpreter, therefore, should be aware of how the message of a particular sign might be changed by narrowing the field. The interpreter needs to be aware that signing closer to the body and face is more tiring and, therefore, more breaks for the interpreter may be necessary. The interpreter should also be aware of the physical distance and of how distance impacts the emotional tone, especially in a mental health setting. The interpreter and the other hearing person need to realize that communication may be slower and therefore extra time should be scheduled.

For someone who has central scotoma, the central field of vision is decreased or blurred. The interpreter needs to sit closer to the person. This positioning will naturally create an increased feeling of intimacy than when working with people who have tunnel vision. However, it may be harder for the deaf-blind person to read the signs because of the proximity, and this needs to be taken into account during the interpreting situation. Important information may be lost from the facial expressions, so the interpreter may need to modify and expand the signs.

Any interpreter working with deaf-blind people should dress in dark clothing and avoid jewelry that may be distracting. The interpreter should ensure that the lighting is appropriate as well. The interpreter should remember to interpret visual as well as auditory information for the person.

Tactile communication impacts the professional relationship, especially the therapeutic one, since hand-to-hand interpreting is much more intimate. The interpreter should check the person's and his/her own comfort levels with tactile communication.

Some deaf-blind people may have only a few people who understand them, a kind of "relay

## ISSUES IN SERVICING DEAF-BLIND PERSONS

---

interpreter", often a relative. If this is the case, the interpreter is still important to the situation to ensure that good, clear, and complete communication occurs.

For those who choose to interpret for the deaf-blind population, the rewards can be extensive. So can the responsibilities. Interpreting is the one-to-one communication which the deaf-blind person has the need for and the right to.

### Question and Answer Session

Q. Deaf people use vision to entertain themselves. A blind person uses auditory means. How do deaf-blind person entertain themselves? In other words, what does a deaf-blind person do in their private time?

A. (From the audience). I am totally blind and in the past five months have become totally deaf. I have used part of my time to figure out how to get on with my life and I don't mind admitting it is a lot of hard work. I have focused on learning American Sign Language (ASL), which for me fills the gap of not being able to hear or see. I love people and like to have them around and to interact with them. I have a guide dog, do a lot of walking, and because I was blind prior to losing my hearing, I read in braille, I sew, cook and clean in order to stay busy. Sometimes, I get scared and see my world as very dark and quiet. It is a strange sensation. Sometimes I cry or read a book, in order to get out of those moods. although I have housemates who help me, I had realize that it is my responsibilities not to get overwhelmed and overly isolated.

Q. What is the relationship between retinitis

pigmentosa and Usher's Syndrome? Can a person experience subtle changes in vision? How does a counselor work through this often gradual loss with someone in therapy?

A. (Carol Day-Drummer) It is hard to know how much vision will be ultimately lost with Usher's Syndrome. The counselor's role is to help the client do what he/she needs to do in order to function best.

A. (Dr. Hyvarinen) With Type I Usher's Syndrome, the person is born with a profound hearing loss and may also have a balance problem relating to their vestibular apparatus. These are diagnostic for Usher's. The person's vision may be normal for years. There is another type of Usher's, however. The person's hearing does not decrease much while they are between 0 and 35 years of age. Their vision keeps changing, just when the person is getting used to a certain level of functioning.

Q. How common is Usher's Syndrome within families?

A. (Dr. Hyvarinen) Usher's is an autosomal recessive, which means that both parents must be carriers. Usually what happens is that a family with it may have one child who is deaf. They may have two. Finally, the physician realize it might be hereditary. Statistically, the chance of two parents who are both carriers having a child with Usher's is one in four.

Q. Are there genetic tests for detecting Usher's?

## ISSUES IN SERVICING DEAF-BLIND PERSONS

---

A. (Dr. Hyvarinen) There is not yet a test. There is a new one for retinitis pigmentosa, but Usher's testing is somewhere in the future.

Q. What services are there for deaf-blind people in the Bay Area, what ones are needed, how does one find out about them, and how does one find other deaf-blind people in the area?

A. (From the audience) I am Katherine Dubois, Coordinator of Services for the Blind, Community Resources for Independence of Santa Rosa. What I would suggest is to look in the newspaper, ask around because sometimes word of mouth brings information rapidly, find a local newsletter for deaf-blind people in the local public library, attend workshops for deaf-blind about caring for self, decision-making and independence, ask at interpreter service agencies, meet hearing people who have a friend or who have a relative who is deaf-blind. In the telephone directory are listings of several agencies. One of them can provide you with information about some of the other questions you might have or give you a direction to go to seek answers.

Q. Compare services in the United States with those in Scandinavia.

A. (Dr. Hyvarinen) Scandinavia is a rich country; it also has socialized medicine and therefore care is cheaper for people. There is, however, a lot of redtape involved in getting those services. In the US, services come from so many sources, making it difficult for people to know where to go. I propose the idea system would be one in which services are provided at the site where the diagnosis is made. That way, people will be motivated to immediately begin to get the help they will need; they will be more likely to follow-up, especially during that vulnerable time when they are just learning of their hearing or visual loss.

This completes the seminar on "Issues of Serving Deaf-Blind Persons." We thank our four panel members: Dr. Hyvarinen, Ms. Whiteacre, Ms. Day-Drummer, and Ms. Gimble, for being with us and sharing their experiences. There are always more questions than we have time and answers for. We encourage you to talk to our panel members, read the newest available information, and write articles on issues of deaf-blind persons which we have not addressed today and which do not currently have answers in the literature.