

November 2019

## Counseling the Usher's Syndrome Deaf-Blind Individual

Louis J. Bettica

*Assistant Director of the Helen Keller National Center*

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

---

### Recommended Citation

Bettica, L. J. (2019). Counseling the Usher's Syndrome Deaf-Blind Individual. *JADARA*, 12(4). Retrieved from <https://repository.wcsu.edu/jadara/vol12/iss4/20>

## COUNSELING THE USHER'S SYNDROME DEAF-BLIND INDIVIDUAL

---

Louis J. Bettica, ACSW

Counseling as a process has many more similarities than different characteristics when applying it to people whose handicaps may vary from the most severe to individuals with minor physical problems. The differences, however, may be so difficult for a worker to overcome or to cope with that the counseling sessions are sometimes aborted and counseling services terminated.

Once counseling sessions are underway with a deaf-blind person, the theoretical concepts applied to others less handicapped would also apply here. However, we have found that theoretical concepts are often overlooked and even forgotten when a counselor meets his first deaf-blind client. Although we can readily understand that the need to utilize another method of communication other than voice has inhibited many workers from attempting to counsel the deaf-blind, we have also found that workers skilled in communicating with the deaf, and indeed deaf people themselves, have not offered deaf-blind people their services or help.

This is not meant to criticize these groups, but merely to point out the fact that the ability of an individual to skillfully use the sign language is not assurance that the deaf-blind person will receive meaningful assistance.

Factors involved go beyond the counselor's skill in communication, since a fruitful meeting can only be accomplished when both parties are communicating and communication by both parties can only be obtained when a true working relationship is established, even if the level of language is many years below the

chronological age of the client. This paper is written with the hope that those of you about to work with deaf-blind people can avoid the pitfalls that I have seen others experience and to urge you to keep them in mind when meeting your first deaf-blind client.

In keeping with the program chairman's request, the material presented today will focus upon practical suggestions and general information relative to blindness and Usher's Syndrome.

Those of you who are familiar with deaf-blindness know that knowledge of the onset of the handicap is of major importance and that deaf-blind people fall into a number of categories. Some of the categories are:

- a) Those who are born deaf and blind;
- b) Those who become deaf and blind at a later age;
- c) Those who are born blind and become deaf after the acquisition of speech;
- d) Those who are born deaf and become blind at a later age.

Those of you in work for the deaf are not likely to see clients from categories a, b, and c, but you most certainly will meet up with the client in category d. Within this category is a very large percentage of individuals who have the eye condition known as Retinitis Pigmentosa. These people are now referred to as having Usher's Syndrome. Because this type of individual is the one least understood, and the one you are most likely to find in your caseload, the remainder of this paper is devoted to this group.

We owe a vote of thanks to McCay Vernon

---

Mr. Bettica is the Assistant Director of the Helen Keller National Center.

## COUNSELING THE USHER'S SYNDROME DEAF-BLIND INDIVIDUAL

---

for bringing this condition to the attention of workers for the deaf. Generally, I also believe that workers for the deaf should have a sense of gratitude to the workers for the blind for their efforts in the rendering of services to those deaf-blind people who are brought to their attention.

The definitions of deafness and blindness for this paper on Usher's Syndrome and the ones used as a criteria for the entrance of trainees into the Helen Keller National Center for Deaf-Blind Youths and Adults are as follows:

Deafness — The inability to understand connected discourse.

Blindness — Briefly described, is having no better than 20/200 in the better eye, or no better than 20° field of vision if the visual acuity is better than 20/200.

The counselor serving the deaf, like others, prepares himself for the first meeting by reviewing the information available to him. A very important part of this case record is the medical information. This provides the counselor with objective information about the client's general physical condition. It should also provide the counselor with an objective appraisal of the individual's eye situation. Unfortunately, this is not always the case. All too often the M.D. giving the general physical examination merely gives the applicant a vision screening test. Therefore, he cannot recognize the fact that the applicant's field of vision is not normal and is, in fact, deteriorating to such a degree that the possibility of total blindness can be 10 or 15 years away.

The Helen Keller National Center for Deaf-Blind Youths and Adults has always recommended that schools for the deaf and state agencies sponsoring education or training for the deaf provide each deaf person with an ophthalmological examination as part of their routine examination.

Taking a close look at the report, you learn that your client has had a special eye examination revealing that he has Retinitis Pigmentosa with a visual acuity of 20/30 and restricted fields less than 20°. Being curious and interested in your client, you will want to learn

what this means. Upon investigation, you will learn that Retinitis Pigmentosa is an eye disease which gradually leads to total blindness. Although some people who have hearing loss may continue to have vision until very late in life, others may become totally blind at much earlier ages.

After many years of experience in working with several hundred people with Usher's Syndrome, we have observed that among those who are deaf, it appears that the more severe the loss of hearing at birth, the earlier is the onset of visual loss and ultimate total blindness. It is congenital and hereditary and the person with Usher's Syndrome (total deafness from birth and Retinitis Pigmentosa) will generally start to be affected about the age of 11 or 12. The first symptom is that the individual begins to have difficulty at night and some difficulty in adapting to the changes of light. Although a decrease in the field of vision may occur as early as 11 or 12 years, this may go undetected since the customary routine screening merely tests an individual's visual acuity.

Having this information and learning that your client has some remaining vision, every effort on your part should be made to utilize this remaining vision and you should closely, but unobtrusively, observe how he functions visually in your presence. The first few minutes of your contact set a tone for understanding and a mutual working atmosphere. This may be the first professional meeting your client has had with someone who recognizes his eye condition. I might add here that failure at this meeting may see the client's efforts at receiving help diminish, if not disappear completely.

Some practical suggestions are as follows: go out to meet the client rather than have him sent to your office; upon meeting him, offer a handshake, a nod of welcome and ask him to follow you to the office; walk in front of him if this is possible; if you walk side by side, don't be alarmed if he tends to head toward you; once in the office, place an ash tray near him if he smokes, don't let him search for it; if you have a window behind you, watch his reaction to the light; most likely cutting down the light by adjusting the blinds would be helpful and

## COUNSELING THE USHER'S SYNDROME DEAF-BLIND INDIVIDUAL

---

more comfortable for him; and it would let him know that you are acquainted with his eye condition and have some concern for his comfort.

This is a point where some counselors with communication skills have failed at communicating effectively with other individuals with Usher's Syndrome. Right at this point you must remember the fact that he only has central vision (as mentioned earlier). You must remember that with his narrow field, the closer you sit, the narrower his field of vision will appear. It becomes necessary then to restrict your signs to a smaller area rather than waving your arms and, of course, in close proximity to your face, in order to take advantage of any lip-reading skill he may have. Any movement of your hands from this position may be only a meaningless gesture to him and an important idea may have been overlooked. You must make sure that he understands. Sometimes the client is embarrassed or inwardly becomes annoyed at the inept communication and takes the easiest way out and nods yes, yes, yes, and secretly wishes he could leave. If the client's sight is so poor as to make it impossible for him to visually read the sign language, efforts should be made to help him to tactually communicate with you. The One Hand Manual Alphabet lends itself very well to tactual perception by having the client cup one or both hands over your hand while spelling out every word. It is also possible to receive the sign language tactually by having the client feel both your hands while you use sign language with him.

I don't think I need to mention to you the language and vocabulary gaps that are found among many deaf people. The one with Usher's Syndrome is no exception. However, in addition to this language gap, he may have other serious gaps because of the type of sedentary life he has been forced to lead due to his eye condition and without benefit of any successful counseling. This client throughout his teen years may have had little, if any, social intercourse because of his inability to see well at night, making travel at night impossible. He may also have had very limited opportunities for conversation other than at school and he

may never have had any constructive discussion relative to his eye condition or future plans.

Now the counselor is faced with an individual who is totally deaf, and has this eye condition which will lead to total blindness. He may deny or not fully understand his problem, and is looking for work.

You are at the point now where good communication has been established; the client recognizes your interest and desire to be helpful and discussion is to start relative to employment. It is here, regardless of your feelings, that it becomes important for the counselor to learn from the client himself what he knows about his eye condition. Honesty at this time is important and ethics forbid any counselor to lie to his client, although our experience indicates that the truth has often been kept from this individual.

The counselor need not feel that he is taking the place of an eye doctor, but with empathy and care, tries to help or counsel the individual toward understanding his situation so that appropriate help can be obtained for him which conceivably could lead to successful and satisfying employment. Since your client by this time is aware that you have some knowledge of his poor vision, it may be the appropriate time to start a discussion relative to this condition.

Perhaps the questioning should follow by asking the client to tell you what he knows about his eye condition. If the client is vague or if he is unfamiliar with his eye condition, it would be wise to have him try to explain to you the difficulties he has with his vision and continue to assure him that the questioning is really for his benefit. It is important, at this time, to try to have him review his functioning over a period of several years, and this may help him recognize the fact that his vision has become worse within the past few years. Here, he may start showing concern about the future. At this point, if not earlier, the counselor should ask him what he has learned about his eye condition from his eye doctor. In some instances, the client will report that the eye doctor has informed him that his vision is uncorrectable with glasses and most likely will worsen in

## COUNSELING THE USHER'S SYNDROME DEAF-BLIND INDIVIDUAL

---

time. If he provides this information, the counselor can become involved with planning since planning has to take into consideration his worsening vision.

All too often eye doctors who have had no experience in examining deaf people with such an eye condition, and who may also be overwhelmed by the communication problem, or assume that the eye examination is routine, seldom discuss the pathology with the client. This lack of information can easily feed into the client's need to deny the problem or his need to hope that his vision can and will improve. There have been instances when a doctor sees a young man with this condition and is really so sympathetically overwhelmed that he leaves the client with the belief that his vision will remain stable or will actually improve. To add to this, some counselors have also mistakenly thought that the avoidance of the subject matter was prudent. We have seen many individuals who have suffered a good deal as a result of this misinformation and poor counseling. As a result of this poor counseling, clients have wasted years waiting for the improvement that will never materialize.

If the relationship at this point is a solid one, the client may ask or even appeal for information. Since the counselor is not an eye doctor, he can discuss this in terms of what he knows about the eye condition, utilizing every lead the client has given him up to this point.

If, however, the client is reluctant to discuss his condition or refuses to accept the information given to him by the counselor, it is suggested that he be sent to an eye doctor for another examination, including a field test, and a specific request to inform the client of his situation. A friend, an interpreter, or even the counselor should accompany the client during this visit to assist the doctor with the examination and to make sure the client is given the information and has an opportunity to ask questions. It does not take much imagination to realize that this information can be traumatic, but we have found that people do have more strength than is usually attributed to them. Some clients need time to go through a mourning period. Others might have been through a period of mourning and this exami-

nation confirms what they already knew and now may actually be ready for a constructive discussion relative to rehabilitation and employment. The Helen Keller National Center for Deaf-Blind Youths and Adults is prepared to be helpful by providing its training facilities at Sands Point, New York, and consultation services through its eight Regional Representatives. Other agencies, some affiliated with the Helen Keller National Center, are also prepared to be helpful. It may be advisable to initially contact the state agency offering services to the blind in order to seek their cooperation in a joint effort.

This is merely a brief description of practical suggestions which I hope will encourage counselors to get started and ultimately to gain skill and experience.

In summary, deaf-blind people can benefit from counseling services when the counselor is capable of demonstrating to the client that he understands the severity of the handicap, but despite this, he also conveys to the client that regardless of the difficulties that are ahead, the client and he will plan the future together and no longer will the client have to face the future alone.

### QUESTIONS AND ANSWERS

*Q: What types of jobs are being performed by deaf-blind people?*

*A:* This is a question often asked by workers in both adult and children's programs. The Helen Keller National Center has been hesitant about publishing such a list, but in view of the number of queries received, we are planning to do this in the issue of *NAT-CENT NEWS*.

In presenting this list, workers must be cautioned to think of it as information relative to the types of work that some deaf-blind persons are employed in at the present time. There is always the danger that this list may be used as a stereotyped guideline, and that some workers may plan to train a deaf-blind person to operate a drill press just because others are doing it, rather than completely exploring the individual's abilities that can be developed to perform a variety of operations.

## COUNSELING THE USHER'S SYNDROME DEAF-BLIND INDIVIDUAL

---

Teachers of deaf-blind children often ask the above question in the interest of preparing their students for a specific job. It is more logical to develop those attributes of good work habits which will be important to the individual's potentials and work skills. There are more jobs lost because of poor work habits and attitudes than because of poor production performance.

A list is just a list; but imagination, perseverance, and faith in the people we serve are paramount characteristics professional workers must have to insure the best opportunities for each person served.

### **JOB'S FOR DEAF-BLIND PEOPLE**

by Robert J. Prause, Placement Specialist

In the last issue of *NAT-CENT NEWS*, Mr. Louis J. Bettica, Assistant Director, discussed the question: "What types of jobs are being performed by deaf-blind individuals?" In reply, he mentioned that a list would be published in this issue. However, it will not be a complete list, but rather a compilation of jobs known to us that are being performed by deaf-blind persons throughout the United States.

The various occupations of deaf-blind people range from the professional to workers in sheltered workshops. These individuals have demonstrated abilities and skills necessary for performing required tasks. Their skills were learned through an academic program and/or vocational rehabilitation training program, whereby the individual learned transferrable abilities and skills.

Mr. Bettica warned that listing jobs could be harmful and misleading if an individual's skills and abilities are not matched to the requirements of the job he wishes to enter. For example, a drill-press job is one which could easily be stereotyped as an occupation for the deaf-blind. This is a job currently being performed by a deaf-blind worker who operates both a single-spindle and multiple-spindle drill press. It should be noted that the kinds of coordination and perception required in performing on this job are the same as those required in performing a number of similar jobs. The worker must have good bimanual coordi-

nation, good finger dexterity and finger control, good spatial perception, and the ability to work with moving parts, oil and grease. He must be able to tolerate dust and metal chips.

However, when examining the job title of the "drill-press operator," one finds two basic differences. When operating the single-spindle drill press, the pressure is less on the operator's arm as compared to the greater pressure when operating a multiple-spindle drill press. The other difference is that the single-spindle drill requires this operator to sit, whereas the multiple-spindle drill requires the operator to stand. Before placing an individual at any job, one must look at the individual's transferrable abilities and skills, as well as the general medical, ophthalmological, audiological, and other diagnostic reports which may impose work restrictions and limitations.

It is also necessary, before selecting a job for an individual, to do a thorough job analysis to determine all the movements and other demands required to perform work tasks. Evaluation must be made of the individual's ability to stand, bend, lift, reach, stretch, stoop; his tolerance to heat or dampness — and his ability to work with others.

Job titles alone do not tell us the different requirements in order to perform the tasks essential to complete specific operations. Therefore, in compiling titles of jobs that deaf-blind people are performing throughout this country, we must bear in mind the necessity of matching an individual's skills and abilities to job requirements.

It is important not to train an individual for a job just because the job is being successfully performed by other deaf-blind persons. Rather, it is important for a deaf-blind individual to gain maximum skill from an academic and/or vocational training program so that he may have a choice of several jobs. It is this opportunity that the deaf-blind person will appreciate most, as he will be able to choose the job, taking into consideration all alternatives, with the knowledge that he has taken an active role in making his own selection.

Keeping all this in mind, we will list in categories jobs presently being performed by deaf-blind persons.

## COUNSELING THE USHER'S SYNDROME DEAF-BLIND INDIVIDUAL

---

### *Competitive Employment:*

Machine operations: drill press operator, tapping, boring; counter-sink operator; maudrel operator; flat-iron feeder and receiver; washing machine and dryer operator; dish-washing machine operator; lathe operator; power-press operator; kick-press operator; arbor hand-press operator.

### *Service Industry:*

Shaker, sorter, and folder in hospital laundry; manual dish and pot washer in hospitals/motels; assistant to vending stand operator.

### *Assemblies:*

Electrical assembly - including assembling electrical circuits and calibration work; power-pack assembly - assembly on a production line, using both power and hand tools, and small, medium and large parts; mass-production assembly - assembling bicycle components on a mass-production line; combination machine and hand assembly - fitting parts into machines using both pneumatic and hand tools.

### *Clerical:*

Messenger; library worker; (It should be noted that the blindness of a number of deaf-

blind individuals takes the form of a severely constricted visual field, in which a fairly high degree of usable vision remains); collator and packager in large mailing division.

### *Paraprofessional:*

Instructor's aide; child-care worker.

### *Professional:*

President of an educational institution; teacher/counselor with a state agency; systems analyst; computer programmer; public speakers; community education director.

### *Sheltered Workshops:*

Sewing machine operator; bench and line assembler; broom maker; steel band mop assembler; trimmer; packager; collator and packager in sub-contract shops.

### *Homebound Industry:*

Weaver; chair caner; broom maker.

As the rehabilitation program at Helen Keller National Center grows, we hope to have the above list expand into new areas of employment offering greater opportunities for qualified deaf-blind persons. It should be noted that a high level of communication and language is not always a prerequisite for employment.