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The Role of the Worker for the Deaf

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THE ROLE OF THE WORKER FOR THE DEAF

Louis J. Bettica, ACSW

"These people are people too," is the title of a paper this writer presented to the American Association of Workers For the Blind, back in 1966.

At that time, I was the Coordinator of the Anne Sullivan Macy Service, a regional rehabilitation approach at serving individuals who were deaf and blind, and for whom, virtually, no opportunities were available in their local community or state. The paper was presented to elicit more cooperation from the workers serving the blind with the hope that they would recognize their professional responsibility to this group. I concluded that paper by saying, "The worker's responsibility is a serious one as often he alone is the bridge or link between the deaf-blind person and his family, community and society at large, and often he can help the community fulfill its obligation to these people for — THESE PEOPLE ARE PEOPLE TOO."

Throughout the years, preceding and following that conference, we not only have been strong advocates for deaf-blind people, but we have provided training for professionals interested in initiating or developing service to deaf-blind people. It is in this role as an advocate and a worker for the deaf-blind that I speak to you today.

As most of you know, the Helen Keller National Center for Deaf-Blind Youths and Adults, operated by The Industrial Home For The Blind, was established in 1969. Since its inception, we have been bringing our message to workers for the deaf because we have always felt that you have an important role in the

social and vocational rehabilitation of this group.

We are hoping that with the increased number of workers serving the deaf, we will be able to find common grounds upon which we could unite our efforts, share our information and search for specific areas of cooperation and service. I am very pleased to report that we are beginning to see areas of sunshine where once there was only darkness.

There has been help from some workers and, in a few instances, this help has been quite extensive and we are pleased that this cooperation is on the increase. In our beginning stages, we may not have been specific enough to outline to you what type of help is needed. This time, I am taking this opportunity to be specific. The remarks made below are only a brief outline of thoughts that have developed after years of experiences with several hundred deaf-blind people who have been transferred from services for the deaf, to services for the blind. Some of us have been associated with deaf-blind people for many years prior to the formation of the Helen Keller National Center. Our work, for the most part, has been on a very intensive level which has given us the opportunity to learn of their feelings relative to the type of life they had led, prior to coming to us for service. In order to be specific, I am making the following suggestions with the hope that you will accept them in the spirit in which they are given:

1. Do not let deaf-blind people be caught in the middle of the conflict or confusion as to who will serve them. No deaf-blind

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person should sit at home waiting for a bureaucratic decision to change the regulations developed to serve this group.

2. As a result of our aggressive efforts at encouraging complete eye examinations of deaf children and adults, regulations have been developed for these eye examinations by many agencies serving the deaf. In those areas of the country where no such regulations exist, you can be helpful by encouraging your agency to have every deaf person's eyes examined as part of the information necessary in planning his program. Unless the individual is extremely skilled in communication, I am also suggesting that you arrange to have someone accompany him during this examination.
3. If the individual does have an eye diagnosis of Retinitis Pigmentosa (Usher's Syndrome), or other serious eye problems, use your counseling skill to work this out with him; or, refer to someone else who can provide him with an adequate explanation and the necessary counseling. All too often, deaf people learn too late about their eye pathology. For example, recently, as a result of a physical examination necessary for employment, a 34 year old deaf man, who is a chemist, learned that he had a diagnosis of Retinitis Pigmentosa. You may have some questions about the wisdom of having the individual learn about his eye condition. Therefore, let me quote from several people who have been closely associated with Usher's Syndrome, or in the field of eye care:

Harry C. Anderson (An Usher's Syndrome Individual)

"It is best to explain to the youngster as soon as test results done by an ophthalmologist show positive diagnosis of Retinitis Pigmentosa." "The attitude of wanting to delay telling the son or daughter why his/her eyes were being examined, or keeping him in complete ignorance of his eye condition, does more harm than good."

Dr. Richard E. Hoover (Assistant Professor at John Hopkins School of Medicine)

"Specialists should give information about condition and prognosis as early as possible. The importance of early timing must be emphasized. Hope for recovery or a miraculous cure when it is not justified is usually detrimental. Guilt feelings may cause the specialist to withhold a diagnosis of irreversibility and arouse dangerous false hopes in the patient."

Joseph Wiedenmayer (An Usher's Syndrome Individual)

"It should be incumbent upon every ophthalmologist to tell the patient specifically about eye diseases he may have."

"Every school for the deaf should have all students examined for tunnel vision because loss of peripheral vision restricts one's ability to read manual language or lipread effectively. A student with this double handicap needs special recognition by the teachers."

Dr. Walter Nance (Professor and Chairman of the Department of Human Genetics — Medical College of Virginia)

"Real value of counseling lies in the psychological benefits that the family can derive from a clear understanding of the cause and prognosis of the disease and the medical and educational benefits the patient may obtain because of early diagnosis."

Linda Annals (An Usher's Syndrome Individual)

"These victims are at an age where something like eventual sight loss might not seem such a threat, but when they get older they are bound to look back and wonder why they were not told about it or given training in a field where they could continue even after their vision begins to fail."

"I am also concerned about people having Usher's Syndrome who hold successful jobs, but cannot maintain them because of their deteriorating vision."

4. If the individual's vision is so poor as to place him with the classification of "blind," he may have to be referred to an agency serving the blind. I am suggesting that you counsel with him on this point and prepare him for the move from you, to a worker serving the blind.
5. Although an increasing number of workers serving the blind are becoming more efficient at communication, I would like to think that you can offer your cooperation to this worker. This could be a valuable asset toward a smooth transfer of the client. I can appreciate the fact that you all have heavy caseloads, but isn't it also true of the workers serving the blind?
6. There has been a good deal of emotion and anxiety spent on the Usher's Syndrome individual who is classified as

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“blind.” I say to you, that if proper eye examinations are given to the people on your caseload and to those who you know are employed, you will have plenty to contend with, since I am sure you will locate numbers of deaf people with Usher’s Syndrome who have more vision than those classified as “blind.” This is another group that has been overlooked. You may be able to reach them at a time when their future plans can be developed in such a way as to avoid much of the tragedy that has affected many in the past . . . those who suddenly find themselves bewildered and incapable of adequately functioning as a result of a lack of the type of information that persons with Usher’s Syndrome state they have a right to know.

7. Communicate directly with the deaf-blind person. Provide him with the dignity of your personal attention rather than going through a third person. I had outlined tips on communicating with this group in my paper presented at the last conference entitled, “Counseling the Usher’s Syndrome Individual,” in 1976.
8. You can be helpful to the agency for the blind and the Usher’s Syndrome in-

dividual by jointly working toward returning him back to the community. You can do this by bringing to the agency for the blind your knowledge of the various services for the deaf.

9. Help us in our efforts at making it mandatory for deaf children and adults to have periodic eye examinations.
10. Encourage universities with programs for rehabilitation counselors serving the deaf to develop courses on vision and eye pathology.

In conclusion, we in work for the deaf-blind, have always felt that this group deserves the type of help that can only be gained by the use of professionals from the various disciplines, and no one group should feel that they can or must do this work alone. For this reason we once again appeal to you for your cooperation, understanding and appreciation of our efforts on behalf of the group you have been serving. Only in this way can we develop a better future for those who are deaf-blind, and it is our intention to see to it that people who are deaf-blind will have a better future which they so richly deserve.