

November 2019

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Recommended Citation

Thomas, L. J. (2019). Deaf-Blind: The Role of the Deaf Community. *JADARA*, 12(4). Retrieved from <https://repository.wcsu.edu/jadara/vol12/iss4/21>

DEAF-BLIND: THE ROLE OF THE DEAF COMMUNITY

Laura J. Thomas

As a Rehabilitation Counselor at the Helen Keller National Center for Deaf-Blind Youths and Adults, I have come into contact with individuals with Usher's Syndrome and other individuals who are deaf-blind from other causes who are referred for rehabilitation training at our facility. Very often during counseling sessions, I hear the statement, "I have no friends."

"I have no friends" is not an uncommon statement made by persons with Usher's Syndrome. If you understand what Usher's Syndrome is and the implications of this dual handicap, the statement will become relevant. Briefly, Usher's Syndrome is congenital deafness and Retinitis Pigmentosa. Retinitis Pigmentosa is a degenerative eye disease, which gradually leads to total blindness. A congenital and hereditary disease, it generally appears at the age of 11-12. The first symptoms are difficulty seeing at night and adapting to changes of light.

Unfortunately, a majority of our trainees who have Usher's Syndrome, have no real or close friends of whom they can speak fondly of back home. The individuals have had normal social circles of deaf friends until the time visual difficulties began and then they have become deserted and isolated by their deaf friends. Now, the question is "why has this happened?" What has caused this to happen? What can we do to help these individuals with Usher's Syndrome and looking on the other side, what can contributing members of the

deaf community do to help?

In regards to the interchange of communication between deaf people with normal vision who normally have close contact, either side by side or in front of each other, visual communication is easily established. Even though it is close contact, a certain distance is maintained between the communicators. Whereas in the situation with an individual with Usher's Syndrome, communication cannot be easily established in the same manner because of the nature of his visual difficulties and the restricted fields of vision due to Retinitis Pigmentosa. Thus, any person, deaf or hearing, signing to the individual with Usher's Syndrome, would necessarily have to back up several feet or get up closer and sign smaller within the fields of vision in order to achieve any communication interchange. When a person has severely restricted fields of vision or has lost most of his vision due to a rapid progressive loss, tactual communication is necessary. (The person with Usher's Syndrome cups his hand over the signer's hands.) For most of these individuals, communication is on a one-to-one basis: the information reaches him from a single individual. The deaf person may feel strange, uncomfortable and awkward in adapting to the uniqueness of this method. It is mainly due to a lack of awareness about Usher's Syndrome and what small changes must be made.

Most persons with Usher's Syndrome find or think their deaf friends are rejecting them

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because of their eventual blindness. This presents a phobia among the deaf community which thus makes them withdraw from the person with Usher's Syndrome almost as if this was a contagious disease. The fear of becoming blind, in addition to deafness, scares them away and by staying with their own deaf friends, they will feel that they cannot contact the disease. People with Usher's Syndrome have been rejected by hearing people since their early childhood years because of their deafness and now it has happened again at the time when they need friends the most. Blind people despite their efforts are of little help because they use speech and do not know sign language. Where does this leave the person with Usher's Syndrome? The person is left with no friends.

Even for persons with Usher's Syndrome who do have deaf friends, communication has its own problems and obstacles when the person with Usher's Syndrome sometimes discovers he is missing out on parts of the conversation; this is frustrating because he must constantly ask for repetition of what was said. For instance, in a dimly lit place, or in a group sitting or standing closely to each other, access to communication is not easily achieved. A person sitting or standing directly in front of the Usher's Syndrome person is preferred.

During the course of conversation of just plain greetings, the person with Usher's Syndrome is subject to ridicule because he is misunderstood which can be emotionally damaging. Very often, the person with Usher's Syndrome may not see someone at his side or outside of his restricted fields of vision and the deaf person may greet him and discover that he did not respond. Then the deaf person would insult him for being snobbish, or having "tunnel vision".

The person with Usher's Syndrome after having these frustrating and humiliating experiences, will withdraw and feel it's better not to mingle with his deaf "friends". He would most likely not accept invitations because of these feelings, and the deaf community will be inclined to think that he's antisocial and doesn't want to be part of them.

In addition to the problems of communica-

tion, the person with Usher's Syndrome has other limitations. They are no longer able to drive and must rely on local transportation or someone to drive them, in which case they will need assistance. At night if he is untrained, he will need help to walk (with R. P., vision during the day is better than at night). Most are not able to use the phone or a TTY (very few have braille adapters and knowledge and proficiency of receptive braille skills is necessary. They are hard to contact and a light signal is less effective because of the person's restricted fields of vision.

In my experiences with the local deaf community, not very many were willing to make social contact with the person with Usher's Syndrome. As one deaf person said, "I would become very tired after signing tactually." Needless to say, more effort has to be put in for communication to be achieved. It is not the handicapped person's fault; he already has the effects of the dual handicap and doesn't need any more rejection than what he already has. A popular, but logical saying is: "The deaf cannot get their ears back, therefore the hearing must learn sign language." This is very true for the person with Usher's Syndrome who cannot get their ears and eyes back, therefore, it is hoped that the deaf and hearing will have the same attitude toward persons who are deaf-blind that the deaf want society to have toward them.

This indicates the need on the deaf community's part to be aware and sensitive to the problems encountered by individuals with Usher's Syndrome. Then in turn, the community can be sensitive, patient, supportive and be receptive to their needs. One way of achieving this, is by individuals who are coping with their future with Usher's Syndrome, educating the deaf community about their actual experiences in living and facing the daily problems of this disease. Schools for the deaf, colleges with programs for the deaf, current films on deaf-blindness, deaf clubs and publications are a few of the many where information about Usher's Syndrome can be disseminated and obtained.

The continuity of friendship is of crucial concern to the person with Usher's Syndrome

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and workers of the deaf-blind. When a deaf person is diagnosed as having Usher's Syndrome, one of his fears is the loss of his deaf friends. Unfortunately, most persons have lost their friends and this may remain true for the rest of their lives.

We are asking workers for the deaf to consider this and to make efforts to bring persons who are deaf-blind back into the deaf community. You are in contact with the deaf community and can be helpful. Join us in being ad-

vocates for people who are deaf-blind. I hope I have been able to inspire in some of you, as workers of the deaf who have contact with the deaf community, a desire to help in this important work. It is hoped that someday in the very near future, our deaf-blind trainees can return to their home communities, a more knowledgeable deaf community, and will be accepted and given the kind of help which they obviously need and deserve.