

Self-Perceived Needs of Adults with Hearing Impairments

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A workshop to assess the needs of hearing-impaired adults was held at the New York League for the Hard of Hearing (League) on December 17, 1979, as part of a project sponsored by the Academy of Rehabilitative Audiology and Psi Iota Xi. Representatives from each of the clinical areas at the New York League for the Hard of Hearing were participants in the workshop along with sixteen hearing-impaired persons and one relative of a hearing-impaired person.

The consumers were chosen by surveying all patients who received hearing aids during the last third of 1978. This list was then reviewed to determine which patients had been seen for services in at least three departments of the New York League for the Hard of Hearing, and the final group was selected from this list. Invitations were mailed to participants with instructions for them to respond by mail. The participants were asked to indicate whether a manual language interpreter would be required; however, none were requested. All patients communicated orally. The group consisted of seven males and nine females. They ranged in age from 27 to 84 years with a mean age of 58. Two members had mild hearing losses, five had moderate hearing losses, six had severe hearing losses, and three had profound losses. Five were prelingually hearing impaired and eleven were postlingually impaired.

ORGANIZATION OF THE WORKSHOP

The workshop participants consisted of sixteen hearing-impaired consumers and five professionals in the area of hearing rehabilitation. The size of the group provided for relative ease in communication. Participants were encouraged to notify the leader when they had any difficulty communicating, and a staff member would repeat the material that was not understood. The system worked well, and the consumers reported limited difficulty with communication. Some consumers had difficulty hearing because the room was large and the acoustics were not as advantageous as they might be. Communication was assisted by having a staff member summarize comments from

workshop participants on a large flip chart strategically placed to be easily visible to all participants.

The workshop began by having each member of the group introduce him/herself. The workshop leader then explained the purpose of the workshop. The stated purpose was to ascertain what difficulties hearing-impaired consumers had in obtaining services both within the New York League for the Hard of Hearing and outside of the agency and to ascertain whether any changes were indicated to facilitate delivery of services to the hearing-impaired consumer. It was made clear to the consumers that this was *their* meeting and that the leader wished to hear from them. The staff participants were available to answer questions if the need was indicated, but consumer perceptions and concerns were of primary interest.

A list of the five basic areas about which complaints had previously been received from consumers was listed on the blackboard. These areas were: money, transportation difficulties, availability of resources, community awareness of hearing loss, and communication problems. It was made clear to the workshop participants that this was only a beginning to give them some ideas but that they were to feel free to comment in anyway that they wished. The staff participants were most impressed by the ability of the workshop participants to speak very freely. They had no difficulty in utilizing the more than two hours that were allotted for listing topics. The group sat in a circle to facilitate speechreading, and persons who wished to comment simply raised their hands and were called on by the leader. Some participants spoke more than others, but everybody spoke at least twice during the morning. A summary of the comments is shown in the Appendix. These covered difficulties and problems in communication (including the fact that the room in which the meeting was held had poor acoustics since it had a high ceiling and hard walls), with physicians, in school, with hearing aid dealers, with hearing aids in general, with the telephone, and with public understanding of hearing loss. The topic that arose repeatedly related to difficulties resulting from lack of public awareness about hearing loss and the needs of hearing-impaired persons.

GROUP DISCUSSION

Four afternoon workshops were scheduled. Workshop topics were financial concerns, quality of services, difficulties of obtaining services, and vocational concerns. Two workshops were held simultaneously, and participants attended a total of two workshops of their choice. Each workshop had one staff member who acted as coordinator and recorder. The number of hearing-impaired members who attended each group varied from six to ten. The participants were encouraged to state their concerns and to suggest possible solutions. Each workshop group compiled a list of concerns and recommendations which were then brought to the full group for discussion at the end of

the day.

In the workshop on financial concerns, a number of issues were discussed. The lack of Medicare coverage for hearing health care was the major topic. Health care bills that are presently being considered by Congress were discussed, and some members of the group reported that Congressman Dellums' bill seems to offer the most inclusive health care for hearing-impaired persons. Some of the group members encouraged other members of the group to talk to neighbors and friends and to get people to write letters encouraging coverage of hearing aids by Medicare and other health care groups.

Price of batteries was a concern. The group believed that batteries and repairs of hearing aids should be included in health care coverage.

It was suggested that a coalition of groups concerned about hearing-impaired people be formed to obtain grass-roots support. Groups such as the New York League for the Hard of Hearing, ASHA, otolaryngology groups, groups of hearing aid dealers, the Office of the Aging, AARP, and the Grey Panthers were considered for membership. It was suggested the New York League be used as a clearing house for such a consumer group.

The cost of obtaining necessary legislation was discussed as was the need for a fund-raising program to deal with the prohibitive costs of securing the necessary legislation. The need to contact legislators in an attempt to get some support was also discussed.

Another major area of concern was the lack of insurance coverage for hearing loss and hearing aids. Suggested solutions included contacting the New York State Insurance Department, the Office of the Aging, the Mayor's Office on the Handicapped, and the New York City Consumer Affairs Department. Difficulties in regulating prices of hearing aids were discussed.

The final area of concern was consideration of a tax deduction for hearing-impaired persons. Since visually-impaired persons receive a tax deduction, the group believed that hearing-impaired persons should receive such a deduction. Some discussion concerned an attempt to get the Internal Revenue Service to change the deduction laws to include the hearing impaired. The group recognized that this would require Congressional action.

The second workshop dealt with vocational concerns. In the area of vocational problems, a major concern was the Office of Vocational Rehabilitation (OVR). The group reported that they were of the opinion that OVR counselors had low expectations for hearing-impaired clients which made it difficult for clients to reach their potential and personally expected goals.

The group discussed whether prospective employers should be informed about their hearing loss. The pros and cons of informing them were discussed. Suggestions about the kinds of jobs to seek and the employment settings where individuals might respond less negatively to the hearing impaired were made by various members of the group. Recommendations included trying smaller companies and using self-addressed, stamped envelopes to assist in

getting responses to applicants since the use of the telephone presented difficulties to a number of the members in the group.

The need to educate employers was reiterated frequently. The difficulties that employers have in understanding what a person with a hearing aid can and cannot hear were discussed. The members believed that people expect the hearing aid to function similar to eyeglasses and that it restores hearing to normal as eyeglasses restore vision to normal in many cases. Therefore, normal-hearing people do not understand why hearing-impaired people do not understand everything and are often unsympathetic.

The third workshop concerned difficulties in obtaining services. Difficulties in hearing aid distribution were discussed. A number of people in the group suggested the possibility of eliminating intermediaries and distributing hearing aids directly from the manufacturer to the hearing aid user. The manufacture of hearing aids at no profit was suggested. The necessity of trial periods for hearing aid users and difficulties with hearing aid dealers were also discussed.

Referrals from the medical community were another topic of discussion. Most of the group indicated that many of their physicians did not know where to refer them when they requested services for hearing loss, and inappropriate referrals were often made. The patients also discussed the difficulty in obtaining general medical care because they believed that physicians do not have the time or inclination to make the extra effort to communicate with a hearing-impaired person.

Difficulties with the telephone company in obtaining services were also indicated. The participants reported not being able to find pay telephones compatible with hearing aids, problems in hearing the phone from another room, and problems in obtaining services from the telephone company. The participants were given information on devices to assist in everyday living.

Waiting for appointments at the New York League did not appear to be a problem for the members of the group.

The fourth workshop covered the quality of services. Several areas were discussed. Since most of the members of this group had only obtained services at the League, it was difficult to obtain input about services elsewhere.

The participants believed that speechreading programs should routinely involve family members.

Members reported that not enough services were available and that more complete services should be offered at a larger number of centers around the city.

A prepaid health plan for hearing aid services was also discussed. The group believed that a monthly fee could be charged which would cover all services related to the hearing loss.

Hearing aid dealers and the difficulties with hearing aid dealers were brought up.

A better follow-up system using a social worker as case manager at the League was requested. A number of the patients were not aware of all available League services. Although patients are given information about the varying services at the initial appointment, it appears not to be comprehended at that time. A method of notifying patients of all of the possible services at varying times during their rehabilitation program needs to be developed. The need for better licensing and consumer protection was discussed. Something similar to the Nader group was suggested. Expanding services so that they can be provided more quickly and in more areas was also recommended.

A bureau for peer counseling was recommended. The group members believed that their initial contact with the agency should include the phone number of other hearing-impaired people who could be called for support.

A number of patients suggested that they did not wish to be evaluated by interns or clinical fellows. They believed that services to patients who are seen initially for an evaluation should be rendered by a fully licensed audiologist, and interns should be used only for patients who are coming for reevaluations. If interns are to be used, the clients should be advised and offered a choice.

SUMMARY

The entire group reconvened at the end of the day, and each group leader reported the suggestions of each workshop. A group was organized by the consumers to attempt to get action on some of the major concerns. Twelve members expressed interest in being involved in the consumer group, and a meeting was scheduled three weeks after the workshop. No New York League staff members are involved in the initial organization of the consumer group.

The group was most enthusiastic about the value of the discussion. Many participants believed that they learned a great deal and were hopeful that their input would result in some changes in the areas of concern. The League staff believed that the sessions were valuable in providing reinforcement for continuing work in certain areas and considering changes in the way programs are offered in other areas. Several staff meetings were held to review suggestions made at the workshop, and procedures have been modified to incorporate many of the suggestions into agency policy.

APPENDIX

Concerns Expressed by Workshop Participants

1. Medicare should provide coverage for hearing aids.
2. Insurance companies need to be educated about hearing loss and the costs involved with it.
3. Hearing aids and battery prices are too high.
4. Hearing-impaired people should see an audiologist and a physician before buying a hearing aid and not go directly to a hearing aid dealer.

5. Physicians do not understand hearing-impaired people. They do not take the time to communicate. Their evaluations of hearing loss are not always thorough, and they do not always follow up.
6. The public needs to be made more aware about hearing loss and the communication needs of hearing-impaired people.
7. Teachers and fellow students need to be educated about hearing loss.
8. More volume-controlled telephones and phones compatible with the tel-coil of a hearing aid should be available.
9. Amplification systems and oral and manual interpreters should be more readily available for hearing-impaired people.
10. Professionals need to prepare newly hearing-impaired people for what to expect in regard to their hearing loss.
11. Employers, Office of Vocational Rehabilitation, vocational counselors, and educators often have unreasonably low expectations for hearing-impaired workers which prevent them from reaching their potential.
12. Rehabilitation services, such as speechreading and hearing aid orientation, should be available in more places.
13. Information or devices to assist in daily living should be available.
14. Hearing-impaired people must take some responsibility for educating people about hearing loss and integrating hearing-impaired persons into the mainstream.