Is There a Hard-of-Hearing Identity?

Les personnes malentendantes ont-elles une identité de groupe?

Charles Laszlo, PhD
Institute for Hearing Accessibility Research
Department of Electrical Engineering and Graduate Studies, University of British Columbia

Abstract

Those who hear well are generally unaware or understand poorly the issues and problems that face hard-of-hearing people. The self-awareness of hard-of-hearing individuals is also inadequate. Awareness of the commonality of the obstacles faced by most hard-of-hearing people motivates organized efforts to define these obstacles and to find appropriate solutions. Awareness and self-awareness are more easily achieved by a group with a well-defined identity. Hard-of-hearing identity is clearly distinct from the Deaf identity that is rooted in signed languages and the Deaf culture. For hard-of-hearing people, the social dynamics and motivation to develop an identifiable and distinct cultural identity are very different from those of Deaf people, because of the wide variations in hearing problems and the fact that their social interactions remain mostly verbal. The lack of a common identity strongly influences the effort to change societal perceptions of the nature and consequences of hearing loss.

Abrégé

Ceux qui ont une audition normale comprennent mal les problèmes que rencontrent les personnes malentendantes. La perception qu'elles ont d'elles-même est également inadéquate. Ce n'est que lorsqu'on constate à quel point les obstacles rencontrés par les personnes malentendantes sont répandus qu'on tente de les mieux comprendre pour y trouver des solutions. Les résultats sont supérieurs si l'identité du groupe qui en est responsable est mieux définie. L'identité des personnes malentendantes est bien distincte de celle des personnes sourdes, celle-ci ayant ses racines dans la langue signée et sa culture. Pour les personnes malentendantes, la dynamique sociale et la motivation pour développer une identité culturelle identifiable et distincte sont très différentes, à cause de la grande diversité des problèmes d'audition et du fait que leurs interactions sociales sont surtout verbales, d'où la difficulté de cerner une identité commune. Ce manque d'identité a des répercussions importantes sur les efforts faits pour modifer la façon dont la société perçoit la nature et les conséquences d'une perte d'audition.

The exploration of the question of whether or not there is a hard-of-hearing identity must begin with first establishing some clear definitions and terminology. This is necessary because there are many misconceptions and misunderstandings arising from incorrect labelling of the different groups of people who have hearing loss.

Specifically, the *hard-of-hearing* person is an individual who has a hearing loss and whose primary mode of communication is the spoken word. It is important to note that, in this definition, the degree of hearing loss is not pertinent, and the hearing loss of hard-of-hearing people may range from mild to profound. However, all hard-of-hearing people attempt to make use of whatever residual hearing they have. They may also use additional communication strategies and technical aids to complement their understanding of normal speech. Thus, we distinguish hard-of-hearing people from *deaf* people who communicate primarily by sign language. This distinction is of major importance and, as we will see later, has a profound impact on almost every aspect of the lives of the people belonging to either of these two groups.

For the sake of completeness, and to avoid confusion, we also need to mention two additional groups of people with hearing loss. One group consists of *late-deafened* adults, who once had normal hearing but lost it, sometimes suddenly, due to trauma, medication or some other reason. People in this group have little or no hearing, and many rely on speechreading and written transmission of language. Some have learned sign language and are able to use it (to varying degrees) to communicate. There are also the *oral deaf*, who have profound hearing loss from birth, and have learned to speak. People in this group tend to be excellent speechreaders. Some later learn to complement speechreading with sign language communication. Moreover, those who capitalize the word *deaf* as *Deaf* do so to indicate that they view themselves as members of a cultural minority which is organized around sign language, specifically American Sign Language (ASL). This designation also serves to differentiate them from the hard of hearing, late-deafened and oral deaf. These groups use these terms to identify themselves; in many cases, the terms have also been adopted by people providing services to these groups.

It is not generally appreciated that the number of people with some form of hearing loss is large. About 70 people per 1000 are hard of hearing, six are late deafened, and one is deaf (either Deaf or oral deaf) (Schein, 1982). It is an interesting social phenomenon that although the number of hard-of-hearing people is obviously very large, there is relatively little visibility and general social awareness or understanding of this group. The awareness of the members of the "hearing world" of hard-of-hearing people and the awareness of hard-of-hearing people of themselves both have a direct bearing on their successful coping and social integration. For this reason, we need to examine the question of awareness first.

Awareness on the Part of the Hearing World

About 10 years ago, a magazine advertisement displayed a bust of Beethoven wearing hi-fi earphones. One cannot help but wonder how many people who saw this ad were aware that Beethoven was hard of hearing for most of his creative life, and that although he became deafened, he continued to compose. It is sadly true, in general, that the public has an incomplete or erroneous awareness of hard-of-hearing people, the nature of their disability, the way they cope with their handicap, their problems, and the technical, social, and educational solutions that are required by them.

How many people are aware that hard-of-hearing people can be found in all age groups, in all walks of life, in varied occupations, professions, arts, and sciences? How many people are aware of the differences between the hard of hearing and the deaf? It seems that only a very few are aware of the differences. In particular, most people do not understand that, while deaf people use sign language as their primary mode of communication, hard-of-hearing people communicate by speech. This lack of awareness hurts hard-of-hearing people everywhere. Not surprisingly, therefore, most hearing people are not aware that in many areas (for example, communication devices and aids, access to services, safety considerations, and access to employment), the needs of the hard of hearing differ from those of the deaf. Unfortunately, because of lack of awareness of this fact even sensitive people often ignore the special needs of the hard of hearing, the way the hard of hearing relate to the world, and the social consequences of their condition.

How many people are aware of the psychological and social problems of being hard of hearing? As a rule, hard-of-hearing people attempt to cope with the hearing world on its own terms. Work, education, family life, and the whole range of human interaction rely heavily on the spoken word, and more generally on the acoustical world. Thus hard-of-hearing people must make a tremendous effort to adapt to ever changing acoustical, technical, and communication circumstances; they must also overcome the barriers and

obstacles that result from incomplete comprehension of the spoken word and incomplete contact with the acoustical world (for example, difficulty hearing warning signals). The physical and psychological effort required to succeed can demand great energy and take a great toll on hard-of-hearing individuals and the people around them. Again, the social consequences are enormous yet they are poorly researched and understood.

Family members who hear well are under particular stress. First of all, parents, spouses, and children must live with everyday manifestations of communication difficulties. In addition, to be able to cope with the cumulative emotional effects of such difficulties, they must also develop a high level of awareness and understanding of the plight of their hard-of-hearing relative. Any failure to succeed in negotiating any one of these barriers may result in increased breakdown of relationships and in isolation.

The plight of the hard-of-hearing elderly is especially severe, since for them the downward spiral of less and less mobility and communication often leads to rapid deterioration of physical and mental well-being.

The problems that hard-of-hearing children face at the elementary and high school levels are now increasingly recognized because of the efforts of many parents and teachers. Yet awareness of the special needs of these children still exists only in a limited way, therefore the children must make an exceptional effort to develop to their full potential. Furthermore, the difficulties experienced by young adults in post-secondary education are neither fully understood nor appreciated. At technical institutes, colleges, and universities, lectures, seminars, laboratories, tape/slide shows, and videotapes are important parts of the communication process. The problems of hard-of-hearing students are caused by professors talking towards the blackboard with their backs to the class, improperly arranged seminar situations where talkers don't see each other, language laboratories, and noisy classrooms and laboratory facilities. Many of these problems are solvable at no or low cost, provided that teaching staff and hearing students become aware of and are prepared to make adjustments to their own behaviour in order to accommodate the needs of their hard-of-hearing colleagues.

The hearing world also lacks appreciation of the difficulty of the hard of hearing in a society rich with communication facilities. For example, depending on the length of the wire from the telephone company's facility to the telephone, some telephone sets may be too quiet for a person with a mild hearing loss. In addition, telephones without provision for hearing-aid compatibility will render the telephone system inaccessible for those who wear hearing aids. Public address systems are another problem, since their distorted sound is often unintelligible. In general, all widely-available communication systems suffer from distortion and

noise, making intelligibility a serious and often insurmountable problem for hard-of-hearing people. This has significant social consequences.

Awareness on the Part of Hard-of-Hearing People

In the foregoing, it was argued that the awareness of the hearing world is a crucially important factor in the successful integration of hard-of-hearing individuals in the social environment. It will now be argued that the self-awareness of hard-of-hearing individuals is equally important.

The hard-of-hearing person must first realize that his or her condition is not unique; many others share the same experience. It is a curious fact that, while people can admit to themselves that they have visual or mobility impairments, many are very reluctant to accept the idea that they suffer from partial hearing loss. Research has not yet explained this fully, but we know from experience that hard-of-hearing people tend to think that no one they know has a similar problem. This attitude is not related to factual knowledge; some of the best-educated become the most isolated. People who develop some hearing loss over the years are often very reluctant to fully accept and share their difficulties. They place themselves at a great disadvantage by isolating themselves and failing to learn from the experience of others. Frequently, these individuals rely on medical help, but since medicine's ability to offer a cure is limited, they conclude that nothing can be done to rehabilitate themselves. Self-pity and alienation from family and friends often follow.

Accepting that one is hard of hearing is the first step towards becoming aware that it is possible to overcome handicaps as well as to build and maintain a fulfilling life by taking responsibility for oneself. The assumption of such responsibility has many requirements. First, one must understand the process of hearing, the nature of the physiological changes that result in hearing loss, and the effectiveness and limits of medical intervention. In other words, one must know what is wrong and what can or cannot be done about it. Knowledge helps one eliminate false hopes of a "cure" and take a realistic approach to rehabilitation.

The second requirement in assuming responsibility for oneself is active participation in rehabilitation (Jones, Kyle, & Wood, 1987). The scientific literature shows that motivation and willpower are major contributors to success in overcoming handicaps (Miller, 1992). In addition, since individuals often have unique needs, lifestyles and environments, even aural-rehabilitation professionals may be able to offer only limited help and guidance. In all cases, the hard-of-hearing person must participate and provide leadership in the rehabilitation process.

The third requirement in assuming responsibility for oneself is to take responsibility for one's own health. *Health* is defined as both physical and mental well-being; one must be responsible for both (United Nations, 1984). Evidence shows that lifestyles (for example, smoking and alcohol consumption, dietary and exercise habits, and ability to cope with stress) have much to do with whether people stay well or become ill (Green & Kreuter, 1991). When under the stress of coping with deteriorating hearing, many people assume poor health habits. This leads to a vicious cycle in which deteriorating health and the difficulties of coping reinforce each other.

Since technological aids are important for hard-of-hearing people, familiarity with them is an important aspect of self-awareness and self-responsibility. Yet hard-of-hearing people often use their hearing aids and assistive listening devices in inappropriate conditions, and then blame these devices for not performing well. Hard-of-hearing people must know how and when to use the devices available to them, and they must also learn when such devices are useless. The understanding and use of technical aids can be especially difficult for some elderly people, who must be helped by individuals more familiar with the devices and the problems that arise from the use of such devices. Thus, hard-of-hearing people can be called upon to extend the concept of self-responsibility to include responsibility towards other hard-of-hearing people who cannot help themselves.

The Identity of Hard-of-Hearing People

Increased self-awareness, the acceptance of hearing loss, the recognition that many others are hard of hearing, the shared experience, and the camaraderie of the struggle to overcome hearing-related obstacles inevitably lead to the question: is there a hard-of-hearing identity?

Some hard-of-hearing people feel that the definition of such an identity would have practical value, because it would raise awareness among hard-of-hearing people and thus be an important factor in learning coping strategies. Such a definition would also clarify the differences between the hard of hearing and the Deaf, whose identity is recognizable and well-established.

The Deaf community is well aware of the importance of such clarification. Their viewpoint is very clear:

> Though some may disagree, the deaf prefer to be known as "deaf," and the hard of hearing "hard of hearing." This leads us to the crux of the matter: identity. There has been a tendency on the part of the hearing to lump the deaf and the hard of hearing together into an unnatural and unwieldy conglomerate, labelling it with a bland and nebulous term: "hearing impaired." The result has been confusion and loss of identity. How can a very deaf person be "hearing impaired?"...
> No matter how strenuous the efforts are to "normalize"

a deaf person or how long he may have been isolated from the other deaf in the hearing world, he invariably gravitates towards the deaf community like a moth to a light bulb, a phenomenon that the hearing like to think does not exist. Again, here, identity is the basic determinant....

Being deaf is not only having a severe hearing loss; it is also being part of a culture. (The Deaf Canadian Magazine, 1981)

Thus we can conclude that a Deaf identity exists because a culturally defined Deaf community exists.

Recently, some forceful arguments have been put forward stating that hard-of-hearing people form a similar, culturally distinct community. Ford (1992) argues that a hard-of-hearing community exists; its members are bound together by hearing loss and the way they choose to deal with this loss. He also argues that people who belong to this community have accepted its identity. He attempts to define this identity by exploring the notion of a hard-of-hearing culture in terms of language, values, traditions, group identity, group norms and social customs. In each of these areas Ford sees typical hard-of-hearing characteristics and behaviour. For example, while hard-of-hearing people use the spoken language of the dominant culture, they use it in particular ways that depend on supplementary speech-reading, body language, and written material. He also argues that self-help as a practice among hard-of-hearing people today will become the tradition of tomorrow. Similarly, he presents as evidence of a hard-of-hearing group identity the observation that more and more people are seeking help from established hard-of-hearing organizations. Once people become involved in hard-of-hearing organizations, they find the support that is provided reinforces continued participation in the organization. Furthermore, Ford claims to have identified 20 practices and customs that are common and culturally appropriate for hard-of-hearing people. Ford states, for example, that hard-of-hearing people tend to eat fast so they can participate in conversation at the table. A statement made by Ford difficult to interpret is that, as far as values are concerned, hard-of-hearing people are between the hearing and the Deaf. This statement is based on the perceived relative emphasis that these groups put on the auditory and visual aspects of communication.

A more personal but similar argument is presented by Kortright (1992). According to her, the many behaviours and coping strategies employed by hard-of-hearing people make such people identifiable. She also argues that through self-acceptance and public self-identification, hard-of-hearing people can influence the negative attitudes our society has concerning hearing loss. It is her view that through such self-identification comes empowerment, which will lead in turn to the emergence of a cultural model for the hard of hearing.

Israelite (1992) focuses on examining the membership of the hard-of-hearing community. According to Higgins (1980), a community is defined by its members, shared experiences, identification, and involvement. In the small group she investigated, Israelite could identify important shared experiences, including alienation caused by the hearing loss, involvement with other hard-of-hearing people, and efforts to cope with the consequences of hearing loss. Thus Israelite concludes that there is a basis for the notion that a hard-of-hearing community exists.

Who belongs to such a community? The members of the group studied by Israelite clearly feel that they do, but are they representative of the majority of hard-of-hearing people? The degree of difficulty and personal success an individual experiences in coping with hearing loss seems to greatly influence that person's feeling of "community." Thus, those who have been hard of hearing from birth and who have had to overcome major obstacles in education, employment, and family life strongly believe that they belong in a community formed by those who have had similar experiences. Indeed, it is very significant that this feeling of community leads such people to perform collective actions that benefit all hard-of-hearing individuals. Local groups, for example, have worked to provide hearing accessibility in public places.

It should be noted, however, that there are wide variations in the nature of the handicap experienced by hard-of-hearing people. Some individuals are able to function successfully with or without electronic aids in most situations. Such people develop and maintain personal interests, careers, friendships, and lifestyles which are not limited significantly by their hearing loss. It is doubtful that such people would identify themselves as part of the hard-of-hearing community.

Many other individuals experience increasing difficulty over time because of hearing loss. Such people must acquire the skills to cope with hearing loss and might benefit from participation in an established and supportive hard-of-hearing community. Yet, there is little evidence that the vast majority of people who might benefit in this way recognize and feel affinity with a hard-of-hearing community. For example, while approximately one million Canadians have impaired hearing which affects daily activities (Schein, 1992), only about 2000 belong to the Canadian Hard of Hearing Association. The psychosocial underpinnings of this phenomenon have yet to be explored.

If one believes that the hard of hearing form a distinct community, one must then define the culture of this community. Perhaps such a culture can be defined in terms of the various habits and strategies that hard-of-hearing people employ to cope with the effects of hearing loss. Since the degree of hearing loss is highly variable, the hard of hearing

possess a wide range of individual habits and coping strategies. This means that a culture defined by such behaviours can only be loosely defined, if it can be defined at all.

There is certainly no convincing evidence that hard-of-hearing people prefer the hard-of-hearing community in any cultural sense. Hard-of-hearing people interact with their natural social environment primarily through speech and hearing; this allows them to have some level of participation in the dominant language and culture. It is well known that hard-of-hearing individuals maintain a long, arduous, and sometimes frustrating struggle to ensure themselves continuing access to the (hearing) culture in which they live. Thus, we must conclude that a large proportion of hard-of-hearing people completely identify with the larger linguistic and cultural community surrounding them, and find no motivation to establish a cultural identity specifically associated with the hard of hearing.

It appears that efforts to define a hard-of-hearing identity run into the problem that the hard of hearing do not form a homogeneous community either culturally or in any other socioeconomic sense. It is equally apparent, however, that the hard of hearing do form a recognizable group in terms of hearing disability, the hearing handicap which is greatly influenced by the acoustical environment in which they live, and the desire to use whatever means are necessary to be able to communicate using speech. In this sense, the hard-of-hearing identity certainly exists. We must recognize, however, that the hard of hearing form a diverse group of individuals with some common interests, needs, and limitations, but they are not defined by their hearing loss.

The development of a vigorous and growing hard-of-hearing community depends on the recognition of not only their common condition, but also on the acceptance of the obligation that hard-of-hearing people have to each other to help overcome the obstacles they face. Those who seek the hard-of-hearing identity and hope to gain strength through it should derive strength from the diversity of hard-of-hearing people. The diversity in the talents, ages, cultural backgrounds, occupations, and interests of hard-of-hearing people will eventually give rise to a variety of ideas and actions, which will change societal attitudes towards hearing loss and assure hearing accessibility on a par with hearing people. Individual actions and community actions will bring hard-of-hearing people closer to the ultimate aim of ensuring that there is a fair opportunity for everyone to create and maintain a satisfactory and independent life.

Please address all correspondence to: Charles Laszlo, Institute of Hearing Accessibility Research, 2356 Main Mall, Vancouver, BC V6T 1Z4. E-mail: laszlo@ee.ubc.ca

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