# Introduction to the Special Issue on the Psycho-social Impact of Hearing Loss in Everyday Life

# Introduction au numéro spécial sur l'impact psycho-social de la perte auditive dans la vie quotidienne

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#### Abstract

The goal of the symposium was to explore how an anthropological framework might facilitate a more coherent view of the handicapping effects of hearing loss. The symposium assembled a range of information and opinions about the everyday experiences of hard-of-hearing persons. The presenters included hard-of-hearing individuals and researchers from a variety of disciplines (sociology, linguistics, psychology, audiology, nursing, and engineering) who have a converging interest in understanding the psycho-social ramifications of hearing loss. We attempted to arrive at a new framework through juxtaposition and discussion of ideas. There were two sessions: the first explored factors that modulate handicap in the hard of hearing, including personal, institutional, and environmental factors; the second presented the experiences of specific groups of hard-of-hearing persons.

#### Abrégé

Le but de ce symposium était d'examiner dans quelle mesure une perspective anthropologique pourrait mener à une vue plus cohérente des conséquences néfastes d'une perte d'audition. Le symposium a réuni une gamme de renseignements et d'opinions sur les expériences quotidiennes des personnes malentendantes. Parmi les conférenciers, on retrouvait des personnes malentendantes et des chercheurs de disciplines aussi diverses que la sociologie, la linguistique, la psychologie, l'audiologie, les soins aux malades et l'ingénierie dont les intérêts convergent vers une compréhension des ramifications psychosociales de la perte de l'audition. Nous avons tenté d'arriver à une nouvelle perspective par la juxtaposition et la discussion des idées. Ce symposium comprenait deux sessions : la première explorait les facteurs qui influent sur le handicap des personnes malentendantes, que ce soient des facteurs personnels, institutionnels, ou environnementaux; la seconde présentait les expériences de groupes spécifiques de personnes malentendantes.

In early 1994, William McKellin, a professor in the Department of Anthropology and Sociology at the University of

British Columbia (UBC) and a co-organizer for the XXI Annual Conference of the Canadian Anthropology Society (CASCA), asked the members of our recently-formed Institute for Hearing Accessibility Research (IHEAR) to organize a symposium about the meaning of hearing loss or the handicap experienced by hard-of-hearing people in their everyday lives. As an audiologist, I was at first surprised to think of this as a topic of interest to anthropologists. I agreed to chair the symposium, with Dr. McKellin's assurance that our topic could be cast within the context of the meeting, the theme of which was "The Production and Reproduction of Culture and Society." The exercise of attempting to describe our research and present our points of view to anthropologists turned out to be one which greatly enriched our own appreciation of how our diverse inter-disciplinary interests in hard-of-hearing people did indeed converge. The symposium gave us a new forum for the discussion of issues that we recognize to be increasingly important in our society as the roles of consumers, clinicians, researchers, and policymakers evolve in a new era of health care and, indeed, as a new concept of health emerges. The purpose of this special issue of the Journal of Speech-Language Pathology and Audiology is to share the proceedings of the CASCA symposium with speech-language pathologists and audiologists so that they may reflect on our views and enter into the discussion with us.

The goal of the symposium was to explore how an anthropological framework might facilitate a more coherent view of the handicapping effects of hearing loss. The symposium assembled a range of information and opinions about the everyday experiences of hard-of-hearing persons. The presenters included hard-of-hearing individuals, clinicians, and researchers from a variety of disciplines (sociology, linguistics, psychology, audiology, nursing and engineering) who have a converging interest in understanding the psycho-

social ramifications of hearing loss. We attempted to arrive at a new framework through the discussion and the juxtaposition of ideas.

There were two sessions in the symposium: the first explored factors that seem likely to modulate handicap, including personal, institutional, and environmental factors; the second session consisted of presentations about the experiences of specific groups of hard-of-hearing persons. Specifically, Session 1 included presentations on how acoustic (Hødgson), cognitive (Pichora-Fuller), linguistic (Johnson and Pichora-Fuller), and technological (Unger) factors may modulate handicap. Session II began with the question of whether or not there is a "hard-of-hearing" identity" (Laszlo), followed by presentations about the experiences of various sub-groups of hard-of-hearing people: Canadian youth (Warick), members of a university community (McCormick, Pichora-Fuller, Paccioretti, and Lamb), industrial workers (Getty and Hétu), inmates of penitentiaries (Dahl), and residents of a home for the aged (Pichora-Fuller and Robertson).

In the introduction to the symposium, working definitions for some key terms were set forth. Following the definitions of the World Health Organization (WHO, 1993; for reviews see Giolas, 1990; Hétu & Stephens, 1991; Hyde & Riko, 1994; Schow & Gatehouse, 1990), impairment was defined as a physical, physiological, or anatomical loss or abnormality of function (for example, an impairment in the ability of a listener to detect sound), disability was defined as the loss or reduction of normal ability resulting from impairment (for example, a disability related to difficulty perceiving speech), and handicap was defined as the detrimental effect that the disability has on an individual's life, especially on the activities and roles he or she normally performs. Another set of working definitions concerned the labels that are applied to people with hearing loss. Specifically, the term hearing impaired was designated to describe any person who cannot detect tones presented at sound levels sufficient to be heard by a person with clinically "normal" hearing; the term hard of hearing was designated to describe a hearing impaired person whose primary mode of communication is oral/aural; the term Deaf was designated to describe a hearing impaired person whose primary mode of communication is sign language. An additional category oral deaf was designated to describe people who as adults lost all or almost all ability to hear, but whose primary mode of communication remains oral/aural. It was noted that the criteria for applying these labels were predominantly linguistic or cultural, as opposed to strictly auditory. Finally, the concept of hearing accessibility was defined by stating that an activity or place is accessible if hard-of-hearing people can participate in it as effectively as can normal-hearing people (Health and Welfare Canada,

1989). The fact that even normal-hearing people find it difficult to hear in some situations prompted a refinement to the definition so that it would also include the idea that activities or places are hearing accessible if difficulty hearing does not interfere with the participation of any person, regardless of hearing status.

Given the working definitions for the symposium, potential implications for practice were drawn (see Table 1). Over the last decade, there has been an increasing awareness

Table 1. Implications of Conceptual Shift for Practice

Concept	Clinical paradigm	
Impairment	Diagnostic/medical	
Disability	Rehabilitation	
Handicap	Accessibility	

that the clinical orientation of audiologists is shifting from a diagnostic medical model focusing on impairment to a more rehabilitative model focusing on disability (for example, see Erdman, 1993). Although some audiologists would like to shift further towards a model that focuses on handicap, this shift seems to have been inhibited by the fact that most audiologists continue to work in clinics where it is difficult, if not impossible, for them to develop insights into how their clients face the challenges of listening in the real world (Noble & Hétu, 1994; Pichora-Fuller, 1992). To complete the shift in clinical paradigm, I propose that we need to adopt an accessibility model that would be more anthropological in nature. Such a shift would parallel other shifts that have begun in other domains (for example, the shift to "neuro-anthropology" recently popularized by Sacks, 1995). The very organization of the symposium reveals an important way in which a new anthropological view of handicap would differ from the more traditional way in which clinicians have attempted to define and measure handicap. As measurers of impairment and, perhaps to a lesser extent, as measurers of disability, audiologists have traditionally sought to quantify characteristics of individuals who are being assessed in the clinic. In contrast, the organization of the symposium was inspired by the belief that handicap is not a characteristic of an individual and that it cannot be measured out of context. We need to understand how the handicap experienced by individuals and by groups is modulated by context: physical context, psychological context, institutional context, and social context. Ultimately, we need to discover ways to manipulate these contexts to reduce the handicap experienced by individuals and groups. This goal would supplement or perhaps even replace the more typical goal of clinicians to reduce the handicap experienced by individuals by treating the individual in isolation.

To accomplish such a shift, audiologists would need new clinical and research partners. The realization that the team needs to be reconfigured was a motivating factor for the formation of IHEAR at UBC in 1994. In keeping with this view, IHEAR promotes participation by and collaboration amongst consumers, audiologists, speech-language pathologists, otolaryngologists, educators, acoustical engineers, electrical engineers, architects, psychologists, physiologists, linguists, health promotion experts, anthropologists, sociologists, and any others who wish to promote the health and well-being of hard-of-hearing people.

To facilitate the discovery of the nature of a new paradigm during the symposium, the following questions were put forth:

- 1. How do the data and reflections of researchers, clinicians, and consumers about the handicap experienced by hard-of-hearing people compare and contrast?
- 2. Do we have any common experience or understanding of the concept of handicap in hard-of-hearing people?
- 3. Can an anthropological framework help us reconceptualize handicap so that the meaning of hearing loss to hard-of-hearing persons becomes more consistently and better understood by professionals from diverse disciplines and by hard-of-hearing people themselves?

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# Editor's note

Readers will no doubt have noticed that the current issue of *JSLPA* is arriving late. The lateness is due to unavoidable delays in processing the manuscripts for this special issue. We regret this inconvenience, and apologies are given to all readers for the delay. Both the guest editor, Kathleen Pichora-Fuller, and I hope that readers will accept our apologies.

I would like readers to join me in thanking Kathy for the tremendous amount of work she has done to pull this special issue together. Readers are encouraged to respond with commentaries to either Kathy or myself, care of the JSLPA office.

Susan Haske Editor

## Note de la rédaction

Vous aurez sans aucun doute constaté le retard qu'accuse cette livraison de décembre 1994 de la ROA dû, en grande partie, à des délais inévitables de traitement des manuscrits présentés dans ce numéro spécial. Kathleen-Pichora-Fuller et moi-même nous excusons auprès de chacun de nos lecteurs pour les inconvénients que ce retard aura pu leur causer.

Je souhaite aussi que vous vous joigniez à moi pour remercier Kathy pour la somme de travail incroyable qu'elle a investie dans ce numéro spécial. Nous vous encourageons à nous faire parvenir vos commentaires, à mon attention ou celle de Kathy, aux soins de la ROA.

Susan Haske Rédactrice en chef