

# Cross-Cultural Ethics in the Conduct of Deafness Research

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**ABSTRACT:** This paper argues for and illustrates the application of contemporary cross-cultural ethical principles and practices in deafness research. The relevance of framing some deafness research as cross-cultural is first explained. A gradient is defined where cultural bearing varies from low to high, depending on a study's topic and design. It is concluded that scientists should employ contemporary cross-cultural ethical practices when their studies have cultural bearing. The evolution and nature of these special ethical practices are then detailed. They extend research protections beyond the individual participant to the host community as a collective entity. They address: relations with the heterogeneous host community, the research agenda and design, the participation of host community scientists, publication foci and channels, and more. Specific applications of these principles and practices to deafness research are described.

In the literature on research ethics, consensus opinions have emerged regarding how to appropriately conceptualize, plan, and conduct cross-cultural studies (Casas, Ponterotto, & Gutierrez, 1986; Manson, 1989; Sartorius, 1988; Tapp, Kelman, Triandis, Wrightsman, & Coelho, 1974; Trimble, 1988; Warwick, 1980). Although the cross-cultural perspective has traditionally been associated with research conducted in foreign countries, the concept of the "host" community is now frequently applied to research involving minority communities within a given country. In America, this is impacting research with Native American, Native Alaskan, Hispanic, African-American, and other minority populations. This thesis examines the need for, and application of, contemporary cross-cultural ethical practices in research concerning the American Deaf<sup>1</sup> community.

## RESEARCH IN DEAFNESS AS CROSS-CULTURAL RESEARCH

The distinct sociocultural characteristics of the American Deaf community have been well documented (Baker & Cokely, 1980; Cagle & Pollard, 1987;

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Gannon, 1980; Higgins, 1980; Padden & Humphries, 1988; Wilcox, 1989). If one acknowledges the existence of the Deaf community and culture, and further recognizes that this community is, at times, the focus of research, then it is possible to frame at least some deafness research as cross-cultural. If a given deafness study is cross-cultural, then it can be argued that contemporary cross-cultural ethical practices should be employed.

However, studies in deafness do not always appear to have cultural bearing and persons (or research participants) who are deaf are not always members of the sociocultural Deaf community. While these complications may preclude a simple, direct comparison between deafness research and traditional cross-cultural research, the fundamental analogy and its ethical implications remain cogent when deafness studies can be shown to have cultural bearing. Furthermore, heterogeneity and community-specific complications are present in every population (e.g., Native Americans and tribal sovereignty). While each community's specific characteristics may necessitate modifications in how cross-cultural ethical standards are operationalized, they do not vitiate those standards.

In deafness studies, the validity of the cross-cultural perspective is most apparent when research focuses on characteristics of the Deaf community and/or exclusively employs members of the Deaf community in the participant pool. An investigation of the prevalence of alcoholism in the Deaf community would certainly constitute cross-cultural research; so would a study of how Deaf parents teach their children American Sign Language (ASL). Both these studies focus on the Deaf community and employ its members as research participants.

The relevance of the cross-cultural perspective appears much less significant, however, in studies that only remotely relate to deafness and simultaneously do not include members of the Deaf community as participants. Research on the mechanisms of hearing is an example. It is unlikely that an investigator studying the cochlear anatomy of animals or mapping neural pathways of audition can be reasonably construed as conducting cross-cultural research in deafness.

In contrast to these extremes, the degree of cultural bearing is more debatable when studies bear identifiable but indirect implications for the Deaf community. For example, research on the prevention or treatment of deafness can lead to interventions that alter the number and characteristics of persons who have hearing impairments. Changes in this population can be associated with changes in the membership of the Deaf community. Depending on one's perspective, this may or may not be a sufficient reason to view such medical research as cross-cultural (Cagle & Pollard, 1987; Glickman, 1986). The development and use of cochlear prostheses ("implants") has sparked such cross-cultural debate that the National Association of the Deaf (NAD) issued two position papers on the topic (NAD, 1986, 1991). Another area of investigation that engenders significant cultural discussion is research on the education of children with hearing impairments. Studies that focus on communication methods (especially ASL), compare deaf to hearing teachers, or focus on educational settings traditionally associated with Deaf culture (e.g. state residential schools) bear more cross-cultural relevance than other types of education research.

Reflecting on the variety of research situations noted above, the presence of cultural bearing in a given deafness study is sometimes quite clear, sometimes virtually absent, and at other times open to interpretation. A gradient of cultural bearing can thus be envisioned, where research on hearing and audition falls at the least culturally relevant end of the spectrum and research on ASL or characteristics of the Deaf community falls at the most culturally relevant end of the spectrum. In between lie other types of deafness research, where the degree of cultural bearing is debatable. This gradient models the strength with which a compelling argument can be made that a given deafness study is cross-cultural.

The further implication of this gradient is that the presence of cultural bearing denotes a corresponding responsibility to conduct deafness research in accordance with contemporary cross-cultural principles and practices. Like all ethical frameworks, cross-cultural research ethics are a continually evolving set of objectives or attitudes that are designed to guide the specifics of cross-cultural research activity. When they apply, they apply unabridged, although the manner in which they are operationalized will differ from situation to situation.

### CONTEMPORARY ETHICAL PRINCIPLES AND PRACTICES IN CROSS-CULTURAL RESEARCH

Ethical concepts and practices in cross-cultural research have evolved over time, just as they have in other fields. Initially, persons from other cultures were equated with "vulnerable populations" and, on that basis, viewed as needing special safeguards in the research setting (American Psychological Association [APA], 1982). However, the vulnerable population analogy is based on the premise that prospective research participants have cognitive or at least volitional limitations that undermine their ability to participate knowledgeably and freely in research. These characteristics are not necessarily present just because someone is from another culture. The vulnerable population analogy obscures the assumptions of individual capability and the host community's right to self-determination that are central to contemporary opinions of cross-cultural research ethics.

Over the past three decades, a number of national and international cross-cultural research efforts have drawn strong criticisms (Casas et al., 1986; Howard, 1991; Kaufman, 1983; Manson, 1989; Pedersen & Marsella, 1982; Trimble & Bolek, 1989; Warwick, 1980). It has become increasingly clear that the impact of cross-cultural studies can reach beyond the individual and affect the entire host community, sometimes quite negatively. Host communities in Alaska, India, and Australia have banned or severely curtailed outside research activity after an investigation's agenda, data collection methods, or published results proved detrimental to them (Manson, 1989; Warwick, 1980).

The consensus opinion of contemporary ethicists is that guidelines meant to protect individual research participant's rights are insufficient for cross-cultural research because they fail to recognize and protect the rights of the host

community as a collective entity. The host community is thus viewed as a "participant," in the same sense that individuals are, and as holding the same rights to information, consent, freedom from harm, etc., that individuals hold.

In their efforts to recognize and protect these host community rights, a number of authors have elaborated formal ethical principles and/or recommended general or specific cross-cultural research practices (Casas et al., 1986; Ibrahim & Arredondo, 1986; Manson, 1989; Sartorius, 1988; Tapp et al.; 1974, Trimble, 1988; Warwick, 1980). There is much unanimity in these writings, which can be summarized as follows:

1. There must be formal channels of communication between the visiting researchers and the host community's political and scientific bodies.
2. Through these communication channels, the perspectives of the researchers and the host community are shared as they relate to all aspects of the research endeavor. Particular attention is focused on: (a) the researchers' interests and the concordance of the research agenda with the host community's interests and needs, (b) the purpose and methodology of specific research projects and their appropriateness in the cross-cultural setting, (c) the risks and benefits of the proposed studies (for the community as well as for individual participants), (d) the implementation of informed consent and other safeguards, and (e) the manner in which the research results will be communicated to the professional and lay public.
3. The research agenda, design, activity, and reports cannot be harmful or inappropriate from the perspective of the host community or the researchers. In fact, the research must benefit the host community in ways that are recognized and valued by that community, not just by the researchers.
4. The research collaboration must foster the skills and self-sufficiency of host community scientists. To the greatest degree possible, it should be conducted by them, on an equal-status basis with the visiting researchers.

Ethical propriety is not the only reason these principles and practices are endorsed. Without them there is a risk that research designs will be inappropriate for the culture, that the data obtained will be incomplete or lack relevance, or that the conclusions drawn will be erroneous or detrimental to the host community. Far from constraining research activity, these ethical procedures have the effect of enhancing its quality and value. "Attending to cultural issues in research is not only ethical behavior, but constitutes good scientific inquiry" (Ibrahim & Arredondo, 1986, p. 350).

These concepts and practices have become so influential that many funding bodies now require that they be evidenced in the cross-cultural research they sponsor. Trimble (1990) stated that relevant grant applications submitted to the National Institutes of Health (NIH) are stringently evaluated to determine adherence to contemporary cross-cultural ethical principles. The National Institute on Disability and Rehabilitation Research (NIDRR) now requires its grantees to demonstrate close collaboration with the disabled community (Graves, W., NIDRR Director, personal communication, March 18, 1991).

## APPLICATION OF CROSS-CULTURAL ETHICAL PRACTICES TO THE DEAFNESS FIELD

### Collaboration with Communities of Hearing-Impaired Persons

Scientific and ethical propriety in cross-cultural research depends, in large part, on the quality of the collaborative relationship between researchers and the host community. Yet, even in traditional cross-cultural settings, it is recognized that no single person or group can fully represent the needs and interests of a heterogeneous population. The effective consideration of the many scientific, community, cultural, and ethical issues that a cross-cultural study raises requires input from a variety of sources.

In the deafness field, establishing effective, long-term relationships with Deaf community leaders is of obvious importance. Their viewpoints assist researchers in guarding against assumptions that a particular topic or procedure is not culturally relevant.<sup>2</sup> Their information, feedback, and opinions are of particular value to researchers who do not otherwise have close associations with the Deaf community. Community leaders also act as an important communication conduit between researchers and the wider Deaf community.

Consultation with Deaf community leaders is not, however, a sufficient mechanism for fulfilling the responsibility of collaboration with the host community. The opinions of Deaf community leaders do not necessarily represent the opinions of the majority of the Deaf community. Furthermore, if several viewpoints are prominent in the community, one individual can rarely represent them equally well. Deaf community leaders are also not formally empowered to represent the Deaf community. Finally, some deafness studies deal more directly with other segments of the heterogeneous deaf population.

Researchers should therefore insure that their collaborative relationships include other individuals or groups from within the Deaf community as well as relevant individuals or groups from outside the sociocultural Deaf community.<sup>3</sup> Additional input may come from parents or educators of deaf children, professionals in the deafness field, fellow researchers, research funding bodies, and grant application review committees. Knowledge regarding cross-cultural research in deafness will also evolve over time, as further research and debate lends clarity to this topic. Various combinations of: conversations with colleagues and Deaf community leaders, readings in Deaf culture and cross-cultural research ethics, and temporary or regular consultation and feedback meetings with constituencies of deaf or hard-of-hearing persons may be needed to fulfill this ethical responsibility.

Given the various perspectives among the many sources listed above, differing or even directly conflicting opinions will sometimes be expressed on a given topic. Again, this does not vitiate the collaborative process. The researchers' objective is not to negotiate an agreement among these parties nor to seek their formal approval (and then not maintain the relationship) as if these

parties constituted an ethics committee. The objective is for the researchers and the host community to maintain a relationship, where a sufficient amount and diversity of cultural and scientific information flows between them. Through this ongoing relationship, the researchers are able to knowledgeable and thoughtfully consider the social, cultural, technical, and ethical implications of their work and adapt their research agendas, designs, and implementation and dissemination methodologies to meet the broader responsibilities expected of cross-cultural research. Members of the host community in turn increase their access to and knowledge of the research enterprise and, over time, take an increasingly active role within it.

### Scientific Collaboration in Deafness Research

The maximal participation of host community scientists is a central ethical concept in cross-cultural research. Sartorius (1988) and Tapp et al. (1974) provide particular detail on this responsibility. An obvious problem in the deafness field is that the number of scientists who are deaf is quite small. This complication is not unique to deafness; it is present in many other cross-cultural settings where economic, educational, or political barriers limit research training opportunities. The contemporary opinion is that cross-cultural researchers bear a responsibility to contribute directly to the solution of this "chicken and egg" dilemma.

First, researchers should promote the establishment of formal research training opportunities for individuals who are deaf or hard of hearing. In most cases, deaf persons are not considered eligible for existing research training programs targeting ethnic minority students (NIH staff, personal communication, Spring, 1991), despite their commonalities in terms of discrimination, limited access and support services in education, and linguistic and cultural variation from the majority community. Funding bodies that support deafness research should be particularly conscientious about establishing research training grants and programs (e.g., the Department of Education and its branches—the NIDRR and the Rehabilitation Services Administration—the newly established National Institute on Deafness and other Communication Disorders [NIDCD], and the Deafness Research Foundation).

Second, scientists should prioritize the inclusion of deaf and hard of hearing persons on their own research staffs, recognizing that these persons may have lesser levels of training and experience than would otherwise be desired. Expending extra effort to recruit, train, and mentor hearing-impaired individuals, not just for one study but throughout their careers, is part of the ethical responsibility of promoting host community scientific self-sufficiency. Early involvement and mentoring fosters interest in pursuing research careers. Therefore, participation and training opportunities should be provided on a number of levels, especially those that do not require a great deal of previous research experience. Conducting cooperative studies with established deaf and hard of hearing scientists also helps fulfill this responsibility.

Baker-Shenk and Kyle (1990) note that ASL research is one of the few areas where Deaf individuals are commonly involved on research teams. However, they stress that communication and attitudinal barriers still exist, even in these research settings, which hinder a deaf person's full participation. In addition to these problems, they describe a dilemma that confronts junior research team members who are Deaf when principal investigators fail to establish the type of collaborative relationship with the Deaf community that was described earlier. In such circumstances, the Deaf colleague may be put in the unavoidable position of representing the research teams' agenda, methods, etc. in the natural course of their interactions with the Deaf community. The individual may be further pressured to bring community concerns back to the research team and advocate them. This intermediary-by-default role is not appropriate for any junior member of the research team, hearing or deaf. The principal investigators must take the lead in this area and not depend on the host-community bonds of research colleagues to fulfill their cross-cultural responsibilities.

### **Deafness and the Research Agenda**

The current ethical view on establishing cross-cultural research agendas emphasizes the need to identify issues and questions that are important to the host community and incorporate them in the research plan. This applies to funding bodies as well. Funding bodies set broad research agendas, prioritize projects in certain areas, choose grant proposal review committees, and set educational, methodological, and other criteria for their grantees. The authority and funding prerogatives exercised by these agencies are quite influential and should be used to improve the ethical as well as the scientific state of cross-cultural research (Trimble, 1990; Warwick, 1980).

Differences of opinion can arise between funding bodies, individual researchers, and the host community regarding the relative value of a given research program. Research agendas that promise little or no direct benefit to the host community are of questionable ethical merit by contemporary standards. Unrepresentative research agendas are difficult to carry out anyway; even the best design and methodology cannot overcome a lack of support by a host community who feels that the work is not in its best interests (Manson, 1989). Cross-cultural research activity should seek knowledge that will assist the host community in meeting its own goals. When the research agenda is perceived as ill-matched with community priorities, such criticisms should be addressed through the collaborative process by providing explanations that satisfactorily resolve those criticisms and/or by making alterations in the research program. Some have suggested the compromise of balancing the focus of studies in a research program, addressing some to high priority host community concerns and others to high priority researcher concerns (Tapp et al., 1974; Warwick, 1980).

An example of differing priorities in deafness research is the valuation of studies designed to prevent or ameliorate deafness. When the NIDCD was

formed, many deaf and hard-of-hearing persons, as well as researchers in the field, criticized the Institute's apparent prioritization of medical research over studies that address the many nonaudiological problems and issues of concern to people who are deaf or hard of hearing.

Some deafness research agendas are clearly inappropriate by contemporary ethical standards, particularly those which further perceptions that people with hearing impairments are inferior to the general population. Heller (1987) notes that such studies comprised an entire phase in the evolution of research in the deafness and mental health field. Oppressive and scientifically unsound research reports still appear. Not long ago, an investigator identified an increased rate of hearing loss in a sample of prison inmates and concluded that persons who are deaf are more likely to commit crimes than persons who are hearing. Research agendas that challenge the Deaf community's binding facets also raise ethical questions, for example, studies that devalue ASL. Recent articles in the *American Annals of the Deaf* provide insights into the scientific and cultural debates that surround communication research in deaf education (Caccamise, 1991; Moores, 1990).

Respect for the host community's priorities also implies an honest recognition that a successful research career brings personal rewards that may confound one's motivations for working in the cross-cultural setting. While striving for professional success is understandable, career advancement should not be realized at the expense of the host community. Researchers, especially those who are not themselves members of the host community, should remain vigilant against the improper or disproportionate influence of personal career motivations in their cross-cultural work.

### Research Methodology and Deafness

The specific methods employed in cross-cultural studies should be appropriate for the community, the culture, and the scientific questions that are being explored. Planning appropriate methodologies requires a thorough knowledge of the host community's language, politics, values, social customs, and other characteristics. Fortunately, this issue is widely recognized. Special methodological procedures for cross-cultural research have been developed (Cronbach, 1982; Triandis & Lambert, 1980; Warwick & Osherson, 1973), including some specific to the deafness field (Brauer, 1989; Cohen & Jones, 1990).

One of the methodological questions often raised in cross-cultural research (and in research with vulnerable populations) is how to insure that truly informed consent has been obtained from the participants. "Research with...participants who have impairments that would limit understanding *and/or communication* requires special safeguarding procedures" [italics added] (APA, 1982, p. 32). Informed consent is not a trait that participants possess nor is it necessarily evidenced by a signature on a consent form. Informed consent is something that is established, not obtained, through what Stanley, Sieber, and Melton (1987) describe as an effective researcher-participant relationship.

Obviously, oral/aural methods will not be satisfactory for communicating with most deaf and many hard-of-hearing research participants. Written communication will also be unsatisfactory when it requires English proficiency beyond the participant's ability. For the average American Deaf adult, this would preclude material written at a sixth grade level or beyond. (A given Deaf participant may, of course, demonstrate English proficiency above or below this average level.) The potential hazards of using the typical written research consent forms are underscored by observations that hearing, majority culture research participants frequently fail to understand them (Stanley et al., 1987).

The effectiveness of sign language communication depends on many factors. The proficiency of the examiner or sign language interpreter is one. In addition, sign language preferences and proficiencies differ widely in the deaf population. Some deaf individuals never had the opportunity to acquire ASL or other sign language skills. Some learned specific manual communication methods (e.g., Signed Exact English or Cued Speech) that may not be known by the examiner or interpreter. When very limited sign language abilities coexist with very limited reading, writing, and oral/aural communication skills, there may be no effective way to communicate with the individual at a level satisfactory to establish informed consent.

Deafness researchers must insure that communication options are diverse and flexible, in keeping with the variability of communication skills and preferences in the participant group. The decision to proceed with the conduct of research must be scrutinized when the quality of the communicative relationship with a given participant is in question. Research participants who are hearing-impaired should have continual communication access to the investigator in the event that questions or problems arise during the course of the study or afterward. This may require the presence of a sign language interpreter and a telecommunication device for the deaf (TDD) in the research office.

Tapp et al. (1974) note the additional complication that "informed and free consent must be determined in each cultural context" (p. 238). What is perceived as harmful may vary across cultures. Physical injury is not the only type of harm to be avoided. Dishonor and embarrassment constitute harm as well, and can be experienced differently in different cultures. This is a relevant concern for deafness research; differences in the ways that Deaf and hearing persons define and experience privacy and attribute personal meaning to sign language and vocal abilities have been described (Cagle & Pollard, 1987; Padden & Humphries, 1988; Wilcox, 1989; Woodward, 1979, 1980). When deafness researchers are unaware of these issues and differences, there is increased risk that the research activity may be detrimental to individual participants or the Deaf community as a whole.

The reliability and validity of survey, interview, and assessment techniques must also be evaluated in cross-cultural research. In addition to the validity of any language translation methods used, there may be social, cultural, or other factors that could affect participants' comprehension, comfort, and accuracy in disclosing information. Techniques for assessing and enhancing the validity and cultural applicability of surveys, tests, and interviews have been developed (Cronbach, 1982; Jones, 1987; Shuman, 1973), some of which specifically

pertain to persons who are deaf and/or who communicate in ASL (Brauer, 1989; Freeman, 1989; Pollard, 1986, in press; Zieziula, 1982).

Another methodological objective, particularly relevant to social science research, is to insure that psychosocial characteristics of individuals from one community are not inappropriately contrasted to standards or characteristics from a culturally different community. "Category fallacy" results when constructs of pathology (e.g., diagnostic nosologies or criteria, or Minnesota Multiphasic Personality Inventory code types) developed in one culture are applied to persons from another culture for whom they are not valid. This does not imply that diagnostic methods, test norms, or models of human functioning can never be validly applied across cultures, only that ethics and good scientific and clinical practice dictate that the question of cross-cultural validity be explored. Long-standing debates in the assessment field imply that, in some situations, it may not be necessary or wise to develop separate evaluation methods, norms, or constructs for different populations; doing so may actually undermine the validity of one's conclusions. This opinion has been expressed by some deafness researchers as well (Braden, 1985; Pollard, in press). These complex issues will only be clarified through further study. To this end, cross-cultural research reports should describe whether the procedures and models used were developed and/or validated for use with the population studied, and if so, why they were utilized, and if not, why the alternative assumption of cross-cultural validity was indicated.

Casas et al. (1986) point out that social science research sometimes searches for simplistic causal relationships to explain cross-cultural findings and fails to recognize host community heterogeneity and the presence of extrapersonal psychological variables, such as discrimination, that are often relevant to understanding host (especially minority) community participants' affect and behavior. There may also be culturally divergent views of what constitutes psychopathology (Marsella, 1982). These issues, too, are relevant to social science research in the deafness field (Heller, 1987; Pollard, 1989; Sussman, 1991).

Cohen and Jones (1990) have suggested that research methodologies that compare deaf persons to hearing persons are inherently inappropriate because they "evolve out of a medical pathology view of deafness" rather than from an "anthropological view of the cultural dimensions of the Deaf community" (p. 45). While comparative research questions should stimulate ethical and methodological review, to dismiss the comparative approach as routinely inappropriate is unnecessarily extreme. There may well be times when comparative methodologies are the best means to answer an important question. Furthermore, comparative studies can be conceived, conducted, and their results disseminated in full accord with contemporary ethical principles for cross-cultural research. Though a given study may indeed compare deaf and hearing people, this does not require that any differences found be oppressive, pathologizing, or pejorative for either group. Research on different patterns of language organization or studies documenting the lack of accessibility to business, education, or other social institutions are good examples.

### Dissemination of Deafness Research

While most scientists readily concur with the need to modify research methodologies for use in another culture, it is less common to modify research reporting methods as well. In preparing the write-up, one should be cognizant of how various presentations may impact the host community. The mere release of data that are likely to bring shame to the host community is ethically questionable, regardless of the way in which it is communicated (Manson, 1989; Tapp et al., 1974). In addition, some characteristics of the community or its culture may be considered private and not appropriate for sharing with audiences outside the community itself (Tapp et al., 1974). This has been cited as an important concern in the deafness field, particularly in regard to private aspects of ASL (Cagle & Pollard, 1987; Glickman, 1983; Woodward, 1979, 1980).

Multiple avenues of research dissemination are usually preferred for cross-cultural research, since diverse audiences must be addressed. Not only will publications in scientific journals be considered but also dissemination through media sources that are most relevant to the host community (Tapp et al., 1974; Warwick, 1980). In fitting with the intent and audience of each type of publication, there may be different languages used, different authors, different emphases, or different writing styles employed. The technical, objective writing style that is common to professional research publications may be less appropriate in some circumstances. Depending on the nature of the study and the intended audience of the report, a narrative, persuasive, or other writing style may be preferred.

Some contemporary authors stress the importance of cross-cultural research reports describing the collaborative process and any special methodological procedures and observations that took place during the conduct of the study (Adair, Dushenko, & Lindsay, 1985; Warwick, 1980). This information allows others to better evaluate the quality and replicability of the research. Moreover, when the cross-cultural arrangements were comprehensive, the detailing of such information provides a model for other researchers to follow and furthers the proliferation of a standard paradigm for conducting cross-cultural research.

Like many who have observed host communities' lack of access to research publications concerning them, Baker-Shenk and Kyle (1990) note that deafness research has largely bypassed Deaf people. They attribute this to Deaf community apathy engendered by years of exclusion from the decision-making processes that affects it. A more reasonable explanation is that research reports are disseminated primarily in higher education settings to which Deaf persons have historically had limited access. Furthermore, such reports typically require high levels of English reading proficiency. Both these barriers can be reduced.

Scientists should make deafness research information available to Deaf and hard-of-hearing people in physically, culturally, and linguistically accessible ways. Research reports could be disseminated in the *NAD Broadcaster*, *Silent News*, *DeafLife*, or other relevant publications, including those distributed by the constituency groups footnoted earlier. Reports could also be disseminated

through public lectures or meetings accessible to persons who communicate in sign language and/or who use assistive listening devices. Local cable television channels sometimes have shows geared to the Deaf community; these can be another valuable avenue of research dissemination. When information is videotaped, it should be open-captioned and ASL, Signed English, and Cued Speech versions made available. The additional costs for such accommodations should be anticipated and added to research and conference budgets.

In closing, let me note that it is quite possible to conduct cross-cultural research in the deafness field that is of high ethical and scientific quality, that responds to host community priorities and perspectives, that results in new and valid knowledge, and that yields meaningful benefits for researchers and community members alike. These outcomes, however, require careful thought and, most importantly, an effective collaborative relationship between researchers and the heterogeneous community of persons with hearing impairments. Guidelines and principles like those presented here will never be exhaustive nor specific enough to prescribe every aspect of a particular research endeavor. It is by remaining abreast of ethical and cultural opinions and developments, demonstrating real concern for the issues raised, and employing research practices that are in accordance with one's best informed and reasoned judgments that ethical responsibility is fulfilled.

## NOTES

<sup>1</sup>In keeping with preferences in the deafness field, the upper-case "D" will be used when referring to this specific sociocultural group and the lowercase "d" when a more general reference to hearing loss is intended. While acknowledging the Deaf community's heterogeneity, the term is generally understood as referring to persons who have hearing loss in the severe to profound range, communicate in American Sign Language, and otherwise demonstrate an association with the American Deaf community.

<sup>2</sup>One such perspective, a controversial one that asserts cultural bearing in studies where it is initially less obvious, is that the Deaf community has a direct interest in circumstances and decisions that affect individuals who are audiological but not culturally deaf (e.g., deaf children of hearing parents). This perspective arises because ASL and Deaf culture are almost always passed "horizontally," between nonrelated persons, rather than vertically from parent to child (Cagle & Pollard, 1987). Thus, every person who is hearing impaired can be viewed as a potential member of the Deaf community. In turn, the viability of the Deaf community, culture, and ASL can be viewed as largely dependent on this *horizontal enculturation* process.

<sup>3</sup>There are many national organizations that represent the diverse interests of persons with hearing loss. They include: the National Association of the Deaf, Self-Help for Hard of Hearing People, the Association of Late-Deafened Adults, the Alexander Graham Bell Association, the National Fraternal Society of the

Deaf, Gallaudet University Alumni Association, and the American Society for Deaf Children. There are also many state and local deafness organizations that represent various interests and constituencies.

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