



Volume 9
Number 2
Winter 2009

Sign Language Studies

ISSN 0302-1475

Gallaudet University Press
Washington, D.C.

Research Ethics in Sign Language Communities

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PEOPLE WHO ARE DEAF reflect the full range of diversity found in the general population, with added layers of complexity related to levels and type of hearing loss, parental hearing status, access and ability to benefit from auditory-enhancing technologies, language usage based on signs and/or voice, and use of visually accessible sign languages. Such complexity generates uniquely difficult challenges for the ethical conduct of research because of issues of power that surround the cultural and linguistic legacy in the Deaf community. Ladd (2003, in press) proposes the use of postcolonial theory and a cultural linguistic model as means to understanding and addressing this complicated aspect of the D/deaf community in ethically responsible research.¹ Furthermore, he posits that the ethical model for research in the Deaf community is centered in the Sign Language community because it represents a “collectivist culture in which participants are bound to

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one another through common cultural traditions, beliefs, actions and responsibilities—both personal and communal.”²² The purpose of this article is to explore the meaning of ethical research under the cultural umbrella of Sign Language communities through a critical examination of scholarship related to social transformation, justice, and indigenous peoples’ terms of reference for research in their communities.

The importance of research ethics is supported by both legal and moral imperatives. Ethical considerations are an integral part of research planning, implementation, and use. In the United States, ethical guidelines for research are based on the principles of the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research (1978), which are embodied in the review process of the Institutional Review Boards and further codified in the Buckley Amendment (also known as the Family Educational Rights and Privacy Act of 1974), the Hatch Act, and the National Research Act (Mertens 2005).

In the United States, research ethics that involve human participants are based on three principles that serve as justifications for the many ethical prescriptions and evaluations of human actions: respect, beneficence, and justice. The Belmont Report (1979) provides the following definitions of these concepts: Respect refers to treating people as autonomous agents and providing protection for those with diminished autonomy (Kitchener and Kitchener, 2009). Beneficence includes securing the participants’ well-being by doing them no harm, maximizing possible benefits, and minimizing possible harm. Justice focuses not on the individual relationship between the researcher and the participants but on the distribution of goods and services in the research setting. In other words, one group should not be singled out for excessive participation in research, nor should another group be excluded from this opportunity. Extensive discussion in the social research community has yielded arguments to broaden the meaning of these terms (Mertens and Ginsberg, 2009), as is reflected in the codes of ethics discussed in the next section.

Most professional associations such as the American Psychological Association (APA) and the Council for Exceptional Children (CEC) have codes of ethics that address cultural issues in broad terms but do not address the specific cultural issues of research in Sign Language

communities. Given that codes are designed to have broad applicability, a tension is created when they are applied within specific cultural contexts. For example, the CEC's code of ethics states that special education professionals are required to protect the rights and welfare of participants, interpret and publish research results with accuracy and a high level of scholarship, support a cessation of the use of any research procedure that may result in undesirable consequences for the participants, and exercise all possible precautions to prevent misapplication or misuse of research efforts (Mertens and McLaughlin, 2004). However, the CEC's code of ethics is silent regarding the need to frame research ethics from a cultural standpoint, an issue of particular salience for Sign Language communities.

In addition, these general principles, guidelines, and codes do not clearly address the need for the researchers to establish trust with the participants in the community and to ensure that the participants view the research as collaborative and culturally valued. Historically, a lack of awareness of various cultural aspects of the Deaf community led to research that today can be considered ethically abusive. For instance, *The Psychology of Deafness* (Myklebust 1964) claimed that, when compared with hearing people, D/deaf people were more immature; had increased emotional problems; were defective, more naïve, and more primitive; had inferior physical coordination; exhibited marked retardation in language; were able to complete only concrete tasks; and were schizophrenic, maladjusted, belligerent, in need of admiration, subhuman, deviated, isolated, paranoid, neurotic, suspicious, psychotic, dependent, autistic, and depressed. He also claimed that deaf males were effeminate and deaf females were masculine (ibid.). Myklebust's textbook, which was used as the standard training text for teachers of deaf students from the mid-1960s until the 1980s (Maher 1996), was written mainly for students in audiology, language pathology, and psychology; it also served as a reference text for people "concerned with the various ramifications of sensory deprivation" (Review of Publications 1965). Deaf researchers Humphries and Padden (in Maher 1996) commented, "Myklebust's authority was enough to establish the tone of official thought. For the next generation of those influential in deciding how D/deaf children in America would be taught, Helmer Myklebust's *Psychology of Deafness* set the standard" (23). This is an example of how

powerful and dangerous hegemonic discourse in academic fields can be for those who are traditionally unrepresented.

Scholars writing from the perspective of feminists, indigenous peoples, and human rights advocates have commonly expressed dissatisfaction with discipline-based codes of ethics because of the lack of “voice,”³ that is, lack of representation or agency, in the conversation on research ethics (Cram, Ormond, and Carter 2004; Chilisa 2005; Osborne and McPhee 2000). An emerging body of literature is providing food for thought on how to address this aspect of social injustice. Members of the Sign Language communities and their advocates can learn from others who share in this struggle, as well as contribute much to this topic.

Pollard (1992, 1994, 1996, 2002) has addressed many ethical issues related to the intricacies of research in Sign Language communities. His work raises questions about how research can represent these communities in terms of their interests, values, and priorities. In general, the field of research ethics has not yet reached the point of clearly defining differences and similarities between, as well as implications of, different methodological approaches, a variety of populations, emerging social trends, and new developments in the various disciplines (Ginsberg and Mertens, 2009). Pollard (2002) claims that Sign Language communities have not established any organizations to oversee research specifically about themselves. Furthermore, the need to develop ethical guidelines for social science research in the Sign Language communities is supported by the current changes in the broader social science communities.

To achieve our purpose of exploring an ethical framework for researchers in Sign Language communities, we present a philosophical context for considering what such a code of ethics would look like, examine parallels with other transformative movements, and propose a process and a number of principles to guide Sign Language communities in the development of their own set of research guidelines.

Philosophical Framework

A paradigm provides a tool to identify the specific philosophical assumptions that describe one’s worldview. Guba and Lincoln’s (2005)

taxonomy of elements for research paradigms was modified by Mertens (2005; 2009) to derive basic beliefs commensurate with research that is conducted with a goal of social transformation. Guba and Lincoln describe four basic belief systems that define a paradigmatic stance: ontological assumptions that deal with the nature of reality; epistemological assumptions about the nature of knowledge and the relationship between the knower and what-would-be-known; methodological assumptions that provide a foundation for choices of methodologies; and axiological assumptions that are characterized by beliefs about what is ethical.

The transformative paradigm with its accompanying philosophical assumptions provides a way of examining the underlying beliefs that elucidate the role of the researcher as one who works in partnership with others for social change and thereby challenges the status quo. The transformative paradigm (Mertens 2005, 2007, 2009; Mertens, Harris, and Holmes, 2009) is a framework of belief systems that directly engages members of culturally diverse groups while focusing on increased social justice. Because they are firmly rooted in a human rights agenda, ethical implications for research are derived from the conscious inclusion of a broad range of people who are generally excluded from mainstream society. It strives to extend the meaning of traditional ethical concepts so that they reflect more directly ethical considerations in culturally complex communities. In this article we also examine power issues in determining research focus, planning, implementation, and use from a transformative stance based both on axiological assumptions related to respect for communities that are pushed to the margins and on recognition of the community members' resilience.

As table 1 shows, four basic beliefs make up the philosophical assumptions that characterize the transformative paradigm. The axiological assumption asks the question, what is considered ethical or moral behavior? As the introduction to this article indicates, three basic principles underlie regulatory ethics in research: respect, beneficence, and justice. The transformative axiological assumption challenges traditional definitions of these concepts on the basis that they fail to be responsive to ethical issues that arise in cultural contexts with differential power structures. Transformative scholars reframe these principles in

TABLE 1. Basic Beliefs of the Transformative Paradigm

axiology: assumptions about ethics	Ethical considerations include respect for cultural norms of interaction; beneficence involves the promotion of human rights and increased social justice.
ontology: assumptions about the nature of reality	Ontological considerations reject cultural relativism and recognize the influence of privilege in sensing what is real and the consequences of accepting perceived versions of reality. They recognize multiple realities shaped by social, political, cultural, economic, ethnic, gender, and disability values.
epistemology: assumptions about the nature of knowledge and the consequent relationship between the researcher and the participants, who hold the knowledge	Epistemological considerations constitute an interactive link between researcher and participants; knowledge is socially and historically situated; power and privilege are explicitly addressed; development of a trusting relationship is critical.
methodology: assumptions about appropriate methods of systematic inquiry	Methodological considerations recognize that the inclusion of qualitative (dialogic) validity is critical; quantitative and mixed methods can be used; contextual and historic factors are acknowledged, especially as they relate to oppression.

Source: Mertens 2005 and 2009

several ways in an effort to be responsive to those who were not party to the formulation of the definitions at the time the Belmont Report was published. For example, within the context of a specific application in research with D/deaf people, respect is defined in terms of the cultural norms of interaction within the Sign Language community and throughout the hearing and D/deaf worlds. Beneficence is defined in terms of the promotion of human rights and increased social justice. An explicit connection is made between the process and outcomes of research and furtherance of a social justice agenda.

The concept of validity in social research implies that one can make supported claims in a research study and hence enters the axiological arena as a critical dimension in the pursuit of ethical research practice. To establish the validity of social science research through a cultural lens, researchers need to address the cultural diversity by developing an

accurate understanding of the community by means of meaningful and respectful interaction with its members. Researchers' embedded biases toward culturally diverse groups threaten validity, which cultural awareness, on the other hand, enhances (Kirkhart 2005). An important dimension of validity in research involves researchers' appreciation and understanding of culture. In 1995, Kirkhart (*ibid.*) introduced the term *multicultural validity* to refer to "the authenticity of understandings across multiple, intersecting cultural contexts" (22).

The ontological assumption asks the question, what is the nature of reality? In a research context, researchers identify certain variables and measure aspects of them in an attempt to look for truth or what is perceived to be real within some level of defined probability. A transformative lens changes the focus from cultural relativism and acknowledges that perceptions of what is real are influenced by the societal power structure that privileges certain versions of reality over others. When hearing researchers who are unfamiliar with Deaf culture have the power to define reality for D/deaf people, some common forms of "reality" that arise include the following:

- tests developed for the general population can be used with D/deaf people
- research results based on a sample of D/deaf people apply to the Deaf community as a whole
- interpreters who are used in research team meetings or data collection are equally skilled in mediating culture and language
- hearing researchers' advanced degrees and years of research experience are sufficient to conduct valid research in Sign Language communities

When D/deaf people are in a position to express reality as they perceive it, these false assumptions and beliefs are challenged.

The epistemology of the transformative research paradigm describes the nature of knowledge and leads to questions about the relationship between the researcher and the participants whose experiences the researcher is studying. Transformative epistemology is characterized by a close collaboration between researchers and community members, whether the latter are participants or coresearchers.⁴ The research pur-

pose, design, implementation, and utilization are developed and implemented with appropriate cultural sensitivity and awareness. Researchers require collaboration with the hosts of the community (not necessarily its leaders, but average people). This relationship is interactive and empowering. Inclusion of members of Sign Language communities leads to changes that are specifically grounded in issues of importance to them. For example, research on court access for D/deaf and hard-of-hearing individuals was generated by a request from D/deaf attorneys who served D/deaf clients that had experienced discrimination in the court system (Mertens 2000). The W. K. Kellogg Foundation funded a study that involved an advisory board of D/deaf attorneys and judges, as well as hearing court interpreters and judicial educators. As a result, D/deaf people were invited to share their experiences in court via focus groups and participation in the training of judges in all fifty states, as well as in planning teams for improving access to court systems.

Methodological assumptions refer to the philosophical basis for deciding which methods are appropriate for systematic inquiry. Research in the transformative paradigm is a site of multiple interpretive practices. It has no specific set of methods or practices of its own. This type of research draws on several theories, approaches, methods, and techniques. Quantitative, qualitative, or mixed methods can be used; however, the inclusion of a qualitative dimension in methodology is critical in order to establish a dialogue between the researchers and the community members. Mixed-methods designs can be considered in order to address the community's information needs. However, the methodological decisions are made with a conscious awareness of contextual and historical factors, especially as they relate to discrimination and oppression. Thus, the formation of partnerships with researchers and the Sign Language communities is an important step in addressing methodological questions in research.

The methodological assumption of the transformative paradigm provides guidance in the choice of research approaches. Methodologies that are commensurate with the transformative paradigm's assumptions are exemplified by the advances in participatory action research (PAR) (Brydon-Miller 1997; Reason and Bradbury 2001), as well as by the changes at the National Institutes of Health (2007) and the Centers for Disease Control and Prevention (2006) that promote

community-based participatory research (CBPR). Cross-cultural researchers such as Trimble (as cited in Pollard 1992) and Matsumoto (1996)⁵ predated these changes in methodology and thus provided valuable contributions to the growing awareness of the need to consciously consider culture and community involvement in research methods.

Culturally Appropriate Research Guidelines

Scholars in the broader social science community have begun exploring ethical practices that are commensurate with the transformative paradigm. The emerging “culturally sensitive” research approaches “both recognize ethnicity and position culture as central to the research process” (Tillman 2002, 1123). Many arguments for culturally sensitive research ethics for specific communities have already been made, for example, for Māori (Cram, Ormond, and Carter 2004), the African Botswana community (Chilisa 2005), Canadian natives (Mi’kmaq College Institute 2006), Australasians (Australasian Evaluation Society, Inc. 2006), indigenous communities (Osborne and McPhee 2000), and Navajo people (Brugge and Missaghian 2003). These emerging voices provide both a parallel justification and a model for researchers in Sign Language communities to join in a reexamination of ethical principles and practices in research.

If researchers in Sign Language communities borrow from that discussion, many questions such as the following arise: What are the most culturally appropriate research guidelines for these groups? What do we include in the guidelines to indicate respect and show sensitivity toward their culture? How would we address the importance of culturally appropriate research guidelines within these populations? How may researchers who are conducting studies in culturally complex communities incorporate the voices of their members when facing ethical and methodological issues?

Mertens (2005) notes that cultural competency is an integral concept for those working within the philosophical assumptions of the transformative paradigm. Cultural competency is a critical disposition that is related to the researcher’s ability to accurately represent reality in culturally complex communities. Symonette (2004) makes explicit the implication that culturally competent researchers must understand

themselves in relation to the community in question. Cultural competence is not a static state. Rather, it is a journey in which the researcher develops increased understanding of differential access to power and privilege through self-reflection and interaction with members of the community (ibid.; Sue and Sue 2003). *Cultural competence* in research can be broadly defined as a systematic, responsive mode of inquiry that is actively cognizant, understanding, and appreciative of the cultural context in which the research takes place; it frames and articulates the epistemology of the research endeavor, employs culturally and contextually appropriate methodology, and uses community-generated, interpretive means to arrive at the results and further use of the findings (SenGupta, Hopson, and Thompson-Robinson 2004). The benefits of cultural competency and culturally responsive research approaches include (but are not limited to) the ability to transform interventions so that the community perceives them as legitimate (Guzman 2003). The American Psychological Association (2002) recommends that the researcher serve as an agent of prosocial change to combat racism, prejudice, bias, and oppression in all their forms. To this end, culturally competent researchers endeavor to build rapport despite differences, gain the trust of community members, and reflect on and recognize their own biases (Edno, Joh, and Yu 2003).

The transformative paradigm provides a useful framework for addressing the role that researchers play when dealing with issues related to oppression, discrimination, and power differences. The transformative paradigm places central importance on the dynamics of power inequalities that have been the legacy of many members of Sign Language communities with regard to whose version of reality is privileged. The transformative epistemological assumption raises questions about the nature of relationships among researchers in terms of who controls the investigation, especially when it is conducted by a team of members and nonmembers of Sign Language communities. Transformative methodological assumptions encourage researchers who are interested in investigating a topic within a Sign Language community to follow research guidelines developed by the community itself. The transformative axiological assumption puts issues of social justice and human rights at the forefront of decision making with regard to research in Sign Language communities.

Terms of reference are defined as principles and procedures that need to be considered when researchers decide to study Sign Language communities. The following terms of reference are proposed for use with these groups. They are in no way exhaustive and represent only the beginning of a code of research ethics for such communities. We welcome your ideas and suggestions for changes.

Creation of Sign Language Communities' Terms of Reference for Academic Research and Publications

What do investigators need to know to make decisions in specific situations? We base this guide on indigenous terms of reference (ITR) (Osborne and McPhee 2000). The ITR make explicit the fact that the concept of community and culture is dynamic and acknowledge the changes that may occur within a culture over time. The application of the ITR to a nonindigenous domain (e.g., a Sign Language community) is encouraged (ibid.).

Sign language communities' terms of reference (SLCTR) must be inclusive of the community's perspectives. These guidelines should also include a protocol for handling issues as they emerge. This inclusive process empowers the community members to take a stand on how researchers may investigate them. The first question to ask when developing the sign language perspective for the SLCTR is, Why are we trying to get Sign Language community members' viewpoints on research that involves them? We have adapted a set of core values and principles that indigenous people have developed and discuss them here. It is critical that researchers attempt to determine the ways in which Sign Language community members feel and think about the world and give these the recognition they deserve. People who use sign language are a diverse population, and one or two D/deaf or hearing researchers cannot effectively represent a sign language viewpoint for these groups; thus, the importance of having a set of core values and principles that the community endorses.

The SLCTR core values (adapted from the ITR) include the following: the worth and validity of contemporary deaf cultures; the right of expression of Sign Language community realities; self-determination and self-management; the right of sign language groups to work and

TABLE 2. Sign Language Communities' Terms of Reference Principles
(Adapted from ITR)

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1. The authority for the construction of meanings and knowledge within the Sign Language community rests with the community's members.
 2. Investigators should acknowledge that Sign Language community members have the right to have those things that they value to be fully considered in all interactions.
 3. Investigators should take into account the worldviews of the Sign Language community in all negotiations or dealings that impact on the community's members.
 4. In the application of Sign Language communities' terms of reference, investigators should recognize the diverse experiences, understandings, and way of life (in sign language societies) that reflect their contemporary cultures.
 5. Investigators should ensure that the views and perceptions of the critical reference group (the sign language group) is reflected in any process of validating and evaluating the extent to which Sign Language communities' terms of reference have been taken into account.
 6. Investigators should negotiate within and among sign language groups to establish appropriate processes to consider and determine the criteria for deciding how to meet cultural imperatives, social needs, and priorities.
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make decisions within their own cultural terms; Sign Language community control; the recognition and acceptance of Sign Language community diversity; reconciliation of competing interests among people who use sign language; and the worth of the group (see table 2). We next discuss each of these principles and provide clarifying examples.

Principle 1. The authority for the construction of sign language meanings and knowledge rests with Sign Language community members.

The ontological assumption of the transformative paradigm explicitly places the authority for the construction of meaning and knowledge within Sign Language communities in the hands of community members. Ladd's (2003) commentary provides insights into the relationship between discourse systems and knowledge creation. He writes that a discourse system contains the following:

its own unspoken rules as to what can or cannot be said and how, when and where. Each, therefore, constructs canons of "truth" around whatever its participants decide is "admissible evidence," a process that in the

case of certain prestigious discourses, such as those found in universities, medical establishments and communication medias, can be seen as particularly dangerous when unexamined, for these then come to determine what counts as knowledge itself. (76)

The presence of unexamined discourse systems indicates the importance of recognizing the Sign Language community's authority to determine meanings and knowledge within the population. Dialogic validity is also an effective way to decenterize "hearingness" in research on Deaf people. The concept of "decenterizing" comes from Cram, Ormond, and Carter (2004) in their writing about research by and with Māori. People who are pushed to the margins, like the Māori and Deaf people, in other words, are "decenterized." The Māori have lost their land and family structures, their relationships were disrupted, and their languages were repressed, thus pushing the Māori people away from the center. Cram, Ormond, and Carter (*ibid.*, 167) argue that "Māori researchers are essentially seeking to decentre 'whiteness as ownership of the world forever and ever'" (as discussed by black activist DuBois [1920], cited in Myers 2004, 8). Research with the Deaf community requires decenterizing "hearingness," so that American Sign Language and Deaf culture are given back to Deaf people. Ensuring that research accurately represents the people it undertakes to study increases its validity; therefore, research in the Deaf community should be by Deaf, for Deaf, and with Deaf people, just as Cram, Ormond, and Carter (*ibid.*) argue that research involving the Māori must be done "by Māori, for Māori, with Māori." "By Deaf, for Deaf, and with Deaf" does not necessarily exclude hearing researchers, nor does it rule out the collaborative model; in fact, the last part of the phrase, "with Deaf," emphasizes the joint role of both hearing and Deaf researchers while keeping in mind the primacy of the latter and their essential roles in research projects involving Deaf people.

Principle 2. Investigators should acknowledge that Sign Language community members have the right to have those things that they value to be fully considered in all interactions.

The transformative paradigm emphasizes the critical examination of power relations. In academic research, the extent to which ASL is

used is one indicator of the incorporation of Sign Language community values in research ethics. Historically, ASL has been suppressed by people who advocate that speech replace sign language (Lane, Hoffmeister, and Bahan 1996; Lane 1999). Ladd (2003) claims that in the twentieth century the prevailing research discourse was both pro-oralism and anti-sign language. For their samples, researchers often selected children who had become deaf after acquiring spoken English or partially deaf children who were oral successes (*ibid.*). Studies were conducted according to the prevailing educational policy (Lane 1999). Ladd (2003) points out that there is an “*almost total absence of any academic research into Deaf collective life on its own terms*” (171; emphasis in original). The purpose of SLCTR is to examine power relations, deconstruct hegemonic research, and rebuild research in which Deaf collective life is represented.

Scholars from outside the Sign Language communities have noted that journals have begun to accept more “experimental, ‘messy’ layered poetic and performance texts” (Lincoln and Denzin 2005, 1121). More researchers are now “increasingly preparing research papers and dissertations that are, at a minimum, bilingual—writings that address the needs of multiple rather than singular audiences. It is no longer unheard of, or even strange, for students to produce doctoral dissertations that include portions that some of the members of their dissertation committees may not be able to translate” (*ibid.*). This shift toward the inclusion of the values of Sign Language communities is discussed in chapter 5 of Bienvenu’s dissertation, which she published entirely in ASL; moreover, some of the members of her dissertation committee did not know ASL (Bienvenu 2003).

On the other hand, Gilmore and Smith (2005) state that “research not conforming to the prevailing academic genres still risks being either patronized or denigrated as ‘not real scholarship’” (78). However, by taking the risk, researchers indicate community solidarity by blending academic genre with the conventions of the target culture. Those who take such chances in research that departs from the conforming standards imposed by those who hold academic power in fact teach the latter a thing or two (Lincoln and Denzin 2005). In fact, researchers have much to learn from the target culture. A good deal of work lies ahead, for we must “*re-write and reright* existing and often

damaging academic research” (Gilmore and Smith 2005, 71; emphasis in original). Thus, the role that SLCTR and the transformative paradigm play here is to support and encourage researchers within the Sign Language communities to take risks, thereby freeing them from conforming to hegemonic practices and creating liberating research.

Principle 3. Investigators should take into account the world views of the Sign Language community in all negotiations or dealings that impact on Sign Language community members.

Partnerships in research situations also require a critical examination of power relations. Scholars in D/deaf research have discussed the issues of power in D/deaf and hearing research teams and raised questions of respect and privilege (Stinson 1994; Foster 1994). More recently, scholars have raised issues of discrimination that sometimes appear in such partnerships. Bauman (2004) provides an example of institutional audism in communication dynamics in both hearing and Deaf professional interactions. Decisions about data collection and language use among the research team represent a typical conundrum in research on Sign Language communities. When research teams consist of signing Deaf people and hearing people who are new signers, an interpreter is usually requested to mediate between the two languages. With an interpreter, the research members are automatically at a disadvantage because the information is filtered by an interpreter (who is for the most part not familiar with research terms and the research project itself), and the time lag between spoken and signed information and translation impedes the equal participation of the team members. The use of interpreters negatively impacts the project, which only emphasizes the need for urgency in mastering the signed language in use.

Instead of having a hierarchical research team with a primary investigator at the top, assistants in the middle, and participants at the bottom, the research project should be a horizontal dialogue between research teams and participants. The former should include both members and nonmembers of the target culture. The dialogue between the participants and those on the research team helps to expand

and further refine everyone's understanding of what is happening. What they discover is always partial and ongoing; for this reason, research in itself should be a dialogue among all those involved (Cummins 2000).

More and more researchers now realize the importance of participant voice throughout the research project. The National Center for Deaf Health Research (NCDHR) employs the "community-participatory research" approach by having a Deaf Health Community Committee (DHCC), 51 percent of whose members are deaf, give feedback on the research design and data-collection process (National Center for Deaf Health Research 2006).

Silka (2005) and colleagues have developed a research cycle model that is commensurate with transformative approaches to research in complex immigrant communities as a way to guide strong, culturally competent research partnerships. When a project is begun, new sets of applications emerge from earlier studies. The new project is thus not just a one-shot study but a cycle of multiple studies based on a research partnership with the target community. The model indicates areas where the research partnership might encounter difficulties during the cycle (e.g., in the beginning, the middle, or the end). It also illustrates ways in which research partners can focus their efforts, find new ways to move from one study to the next, and develop better practices.

The Signs of Literacy research model provides an example of a cyclical approach that equalizes the contributions of hearing and D/deaf team members, as well as researchers and participants. Erting (2003) laments that "collaborative interdisciplinary research involving Deaf and hearing teachers and researchers is rare" (456); however, she documents the experience of the Signs of Literacy research team and ways in which they address issues of language, D/deaf-hearing collaboration, and researcher-participant collaboration. Everyone involved in the project is expected to "learn to see the world through Deaf eyes" (460) by trying to make sense of cultural scenes they did not understand and asking questions. This project has generated numerous publications by Deaf and hearing researchers, such as the chapter on bilingualism in a Deaf family by Erting, Thumann-Prezioso, and Benedict (2000).

Principle 4. Investigators should recognize the diverse experiences, understandings, and way of life (in sign language societies) that reflect contemporary sign language cultures in the application of Sign Language communities' terms of reference.

Respect for and acknowledgement of diversity is a key principle for transformative research. In Sign Language communities, this means a recognition of the community's close-knit nature and implications for confidentiality or anonymity in research. Pollard (2002) argues that anonymity is one of the top three issues for research with Sign Language communities. Additional precautions are necessary to preserve the anonymity of D/deaf research participants, who are at heightened risk for confidentiality breaches, as would be the case for any small community. For instance, all of the participants should be informed of the names of all of the researchers, research assistants, and interpreters who may have access to the data. Video documentation of sign language participants creates still greater risks because these people's faces are captured on film. Pollard points out that "Even techniques for disguising facial features will not hide characteristic signing styles that may lead to inadvertent identification of participants" (165). He further explains that ASL conveys linguistic information on the face that is necessary for correct understanding of the message. Privacy issues such as these are addressed in informed consent forms that clearly delineate how research data, including video footage, may be disseminated and who might have access to the videos. It is up to the researcher or the research team to clearly convey these plans to the participant, who then decides whether to allow such access to this information. Institutional review boards (IRBs) and in particular the Gallaudet University IRB are vigilant about video data, especially in the Sign Language community.

Principle 5. Investigators should ensure that the views and perceptions of the critical reference group (the sign language group you work with) is reflected in every process of validating and evaluating the extent to which Sign Language communities' terms of reference have been taken into account.

The axiological assumption of the transformative paradigm raises the question of who has the authority to determine whether ethical

guidelines were followed during the research project. Pollard (2002) points out that unintended deceptions commonly arise in research with sign language populations in the form of lack of equal access to information, communication, and knowledge. For instance, if the research information is less accessible to D/deaf participants than it is to hearing participants, this imbalance constitutes a form of deception by the researchers. If the researchers' communication methods with D/deaf and hard of hearing participants are inadequate, this is another form of deception. Hearing and D/deaf people have different funds of knowledge due to differences in access to information, and researchers who do not consider this when collecting data are participating in yet another form of deception (*ibid.*).

The Signs of Literacy research team mentioned earlier made it explicit from the beginning of the research project that everyday, face-to-face discourse and team meetings were always conducted exclusively in ASL and that written English was the language of e-mails, documents, journals, data analysis, and academic reading and writing. Hearing researchers and teachers struggled to express complex ideas in ASL, while Deaf researchers and teachers tried hard to understand their nonnative signing; however, this steadfast commitment to using ASL helped keep the "Deaf experience at the center of the inquiry" (Erting 2003, 464). The experience of all of the participants in this project was both profound and enriching compared to that of past research projects, indicating the importance of language access for everyone involved.

Even in collaborative research between D/deaf and hearing researchers, the latter are usually called "team leaders," "lead researchers," or "research coordinators." When comparing the positions held by first- and third-world researchers, Chilisa (2005) found that the former usually hold positions of prestige in research studies. Smith (1999) points out that, in a document known as the Tropical Forests Charter, the indigenous tribal peoples of the Philippines have proclaimed that "all investigations in our territories . . . [will be] carried out with our consent and under joint control and guidance" (cited in Lincoln and Denzin 2005, 1120). Moreover, the First Nations people of Nova Scotia have established the Mi'kmaq Ethics Committee, which screens research projects to ensure that the integrity and cultural knowledge of the Mi'kmaq people are protected, along with a "guarantee that the

right of ownership rests with the various Mi'kmaq communities” (Mi'kmaq College Institute 2006).

Historically, D/deaf people generally had no control over research projects due to language-accessibility differences between the researchers and the Sign Language communities under study. Lincoln and Denzin (2005) assert that researchers nowadays cannot simply insert themselves in the target culture whenever they want to. Rather, they “must negotiate for that knowledge and respect the forms in which the owners may wish to have it presented or re-presented” (ibid., 1120). Duchesneau and McCullough, both Deaf mental health professionals said, “Without a doubt, one of the most sensitive issues in the Deaf community today is the role of hearing professionals who work closely with Deaf people” (2006). The roles of a hearing and a Deaf researcher working in collaboration would be more equalized through a partnership in which the hearing researcher shared specialized knowledge of the field with the Deaf researcher; conversely, the Deaf researcher would contribute specific linguistic and cultural knowledge about Deaf people with the hearing researcher (ibid.). These responsibilities for hearing and Deaf researchers are relatively common because Deaf researchers might not be able to access specialized knowledge due to limited access to training in specialized fields. Likewise, Deaf professionals “might not as easily specialize in such an area simply because there are not as many job opportunities available in that narrow field” (ibid, 1). However, the hearing researcher would be unable to do research effectively with Sign Language communities without the Deaf researcher’s expertise. McCullough (2007) states, “In order to ensure that research on Deaf people is conducted in the best possible manner, hearing researchers should make a conscientious practice of collaborating equally with Deaf researchers in all phases of their studies, with credit given equally to the Deaf and hearing researchers” (1).

The idea that ethnographic researchers possess the “knowledge” and that the “knowledge” belongs to them leads people to believe that the researchers—not the participants in the project—have ownership of the intellectual property. This issue is not new for social science researchers, and it concerns all of those who plan to publish the results of their studies (Greenwood 2006). Indigenous peoples are starting to

reclaim ownership of research done in their communities. They are also controlling the way in which the information is shared. Hegemonic research discourse typically includes contract stipulations such as “Any and all intellectual property including copyright in the final and other reports arising from the work under this agreement will be the property of the University of X” (Chilisa 2005, 676). Indigenous peoples and D/deaf communities need to challenge the hegemony of this interpretation of ownership of research data. The target culture should not first be exploited for data, and researchers must not then claim ownership of the information they have obtained. Ethically, ownership should remain in the hands of the target culture (ibid.). Coauthorship with community partners is seriously considered not for the knowledge itself but for its dissemination.

There are several options for coauthoring publication of the research, such as listing the names of all of the participants as coauthors whether or not they helped write the manuscript; others opt for calling themselves a collaborative writing team (Greenwood 2006). The method employed to accomplish this goal may vary from university to university, or it may mean moving the research out of academe and into community arenas. Making the research accessible to those who participated in its creation is a basic principle associated with the transformative paradigm and one that needs to be addressed in guidelines for research with Sign Language communities. Rethinking ownership of the research from the perspective of those who originally “owned” the knowledge is essential.

Principle 6. Investigators should negotiate within and between sign language groups with the aim of establishing appropriate processes and determining the criteria for meeting cultural imperatives, social needs, and priorities.

There have been groundbreaking debates on who will conduct research within various cultural groups. What would be the impact on research if researchers of the target culture directed the research process? Working within the disability community, Oliver and Barnes (1997) and Shakespeare (1996) recognize that “without disabled people leading and doing the research, it is argued that some studies have little relevance to

the lives of disabled people” (Young and Ackerman 2001, 179). Their work has applicability for D/deaf researchers who lead research projects within Sign Language communities as a cultural group since they possess the necessary cultural understanding and knowledge of the community members. If D/deaf researchers conducted studies within their own cultural community, their work would have a profound impact on the members’ lives.⁶ Sign Language communities stand to benefit by building on the work of members of indigenous communities because of their shared concerns related to language, culture, and historically differential positions in the societal hierarchy. Thus, processes recommended by indigenous peoples could be adapted for the SLCTR development (Osborne and McPhee 2000).

Once community members and/or researchers identify issues for which a sign language user’s viewpoints are needed, then specific representatives of the Sign Language community need to be named and involved. The appropriate individuals can be determined by asking, Who is affected by this issue? Who are the stakeholders? How does this affect other groups? Who should be involved in this process? The research team can bring members of the Sign Language communities together to explain the reasons for their involvement and to decide together how to proceed. The Sign Language community members must be in control of defining the issues and processes. With the advent of technological innovations, blogs, vlogs,⁷ videophones, and text pages can be used to contact many D/deaf people in the United States and around the world.

These various communication methods can be used to outline the context of the issues in terms of their impact on the community or on important sociopolitical factors. Information can be gathered on the following dimensions:

- cultural elements: Both the impact of the investigation on the culture and, conversely, that of the culture on the investigation must be considered.
- experiences: Identify the community’s past and present experiences with the issue under study. This historical background is critical to understanding how the community has been shaped.

- understandings: The community's opinions, knowledge, and understanding of the issue should be included.
- aspirations: The community's goals and desired outcomes for the issue being discussed and analyzed should be made explicit. "It allows the community to clearly identify their visions of '*what they want*' in the future for the issue" (Osborne and McPhee 2000, 10–11). [Emphasis in the original]

Differences of opinions are bound to surface, and these must be negotiated to reach agreement on interpretations that reflect the majority; alternatively, different viewpoints in the final version of the investigative report must be represented. Researchers who are working with Sign Language community members can construct a consolidated picture of all of the information to represent the D/deaf view of the issue under discussion. At this stage it is critical to again consult with the community to ensure the accuracy of the expressed conclusions.

The goal of this discussion is to determine which courses of action are suggested by the research results and whether they will help the group achieve its goals.

Conclusions

We contend that the ITR core values, principles, framework, and processes are adaptable and consistent with those of the Sign Language community. However, as the ITR points out, a few D/deaf people cannot speak for the entire Sign Language community. By presenting this concept here, we hope to receive feedback from a broader constituency. At our web site, readers may share ideas and comments on the SLCTR: www.slcthics.org.

We invite your thoughts regarding changes or additions to the adapted version of the ITR for D/deaf people and other issues related to research ethics in Sign Language communities. Your opinions are important as this is a concerted effort by members of these groups.

Discussions can be conducted about the nature of researchers' obligations to follow the ethical guidelines of the community in which they conduct their research and the extent to which they must be in-

formed about ethical issues by the community itself; in other words, researchers must not assume that all ethical guidelines can be automatically applied to every individual of the community. These are not simple matters, however, and they are worthy of continued debate.

When should a community have its own ethical guidelines, and who establishes them for a particular group? How do researchers protect the community when conducting research? These questions raised by Wallwork (2002) address ways in which researchers can remain unbiased and professional, yet treat the community members with respect while interpreting the ethical principles. Wallwork concludes that “the partnership ideal usefully suggests that our research ethic itself needs to be jointly negotiated and constructed among mutually respectful participants, willing to be changed through dialogue about how to cooperate in joint undertakings” (21). The researchers and community members work together through collaboration and dialogue to make the research study ethical.

Notes

1. The *American Heritage Dictionary of the English Language*, 3d ed. (1992), defines “Deaf” as “relating to the Deaf or their culture” and “deaf” as the “lack of hearing sense.” Ladd (2003) elaborates on the lowercase deaf terminology, which refers to people who wish to retain their membership and primary experience with the cultural majority. The authors try their best to keep the distinction clear throughout the paper.

2. Sign Language communities refer to people whose primary experience and allegiance are with Sign Language, as well as the community and culture of Deaf people. However, all researchers who are interested in studying Sign Language communities should always be conscious of the complexity of deaf people and the Sign Language community. The capitalization of the term *Sign Language* signifies a cultural group similar to African Americans and the Jewish community.

3. The irony of using the term *voices* in an article on research with the Deaf community is not lost on the authors, nor do we expect that it would go unnoticed by the readers. Readers familiar with feminist, indigenous, disability, or minority rights will recognize this metaphor and not see any irony in using the term, “voice.” However, due to a lack of a better term at this time and the common usage of the term *voices* in the scholarly literature, we will use the “voices” to represent the perspectives, values, and experiences of the Deaf and Sign Language communities.

4. Researchers may or may not be members of the community. In the transformative paradigm, members of the Sign Language community hold the power to make decisions about the conduct of the research. If a researcher is hearing, then a relationship needs to be developed in which the D/deaf and hearing members of a research team collaborate in a meaningful way.

5. Matsumoto published the first edition of *Culture and Psychology* in 1996. He and L. Juang have now written a fourth edition (2008).

6. While some people view deaf people as having a disability, many members of the Deaf and Sign Language communities reject the “disabled” label and prefer to be considered culturally different.

7. Originally termed “video blogs,” vlogs are blogs with videotaped footage. Sign Language communities have embraced this technology because members can videotape themselves signing in their own language.

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