

# 1 Ethics, Deaf-Friendly Research, and Good Practice When Studying Sign Languages

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## Chapter Overview

This chapter addresses a range of issues that become important during sign language research, where hearing and Deaf researchers work together. The aim of the chapter is to highlight ethical and practical factors that sometimes can get sidelined during the research process but are crucial for its sustainability. The three sections cover working with Deaf people, issues with fieldwork in other countries than your own, and working with organizations where Deaf people are participants.

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## Introduction

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The three authors are interested in how researchers can work best with Deaf people, Deaf schools, Deaf children and families, and other professionals who work in the area of deafness. In this chapter we weave these interests together to inform the future researcher of important considerations when embarking on studies that involve Deaf people and their sign languages. This is not just a philosophical question anymore; increasingly research funding agencies are expecting ethical compliance, good quality dissemination, and knowledge exchange, as well as evidence of how research is actually making an impact on the everyday lives of the participants and on wider society. We argue that sign language research that is *with* rather than *on* Deaf people will both be superior in scientific terms and will achieve more societal impact.

Historically, the study of Deaf<sup>1</sup> people has been influenced by the cultures of different disciplines (e.g. linguistics, medicine, or politics). Researchers thus bring to their investigations a set of practices that likely reflect discipline-specific goals such as the promotion of hearing and speech remediation, assistive technologies, Deaf education reform, the genetics of Deafness, sign language linguistics, psycholinguistics, and the study of Deaf cultures and communities. Regardless of their viewpoint, researchers who include Deaf participants in their research are nevertheless expected to conduct their investigations in an ethical manner, protecting the integrity of their research and the individual rights of the participants regardless of age, ethnicity, cultural and linguistic background and respecting and protecting the Deaf community by understanding the broader concerns of community-engaged research (CEnR) (Ross et al., 2010a, 2010b). CEnR is much more sustainable, as it enables researchers to build up long-term relations with the Deaf community on the basis of mutual respect and benefit, and these are relations where Deaf people are seen not only as informants but also as collaborators.

A number of scholars have raised important ethical issues in deafness-related research (Baker-Shenk and Kyle, 1990; Harris, Holmes, and Mertens, 2009; Pollard, 1992, 2002; Singleton, Jones, and Hanumantha, 2012, 2014). Of central importance is the risk that hearing researchers take on when conducting studies on a community to which they are considered “outsiders.” Harris et al. (2009) and Singleton et al. (2012, 2014) suggest that hearing researchers may be controlling the topics of study (thereby validating to the scientific community what issues are deemed important) and interpreting their findings from only their narrow disciplinary perspective (often to the exclusion of a theoretical framework that draws on sociocultural understandings of deafness: see Ladd, 2003; Padden and Humphries, 1988). Baker-Shenk and Kyle (1990) also express concern over whether hearing researchers are able to represent Deaf people’s views accurately if they work in isolation. Together, these authors argue that the scientific community will only attain some measure of ethical conduct if it adopts tenets held by the CEnR paradigm (Israel et al., 2008; Ross et al., 2010a; 2010b), namely by involving Deaf people in the research process and by encouraging hearing researchers to be more reflective about their role and to consider the possible detrimental perceptions or impact of their research findings on the Deaf community (Singleton et al., 2012; in press).

When hearing researchers work closely with Deaf researchers, the resulting collaboration can bring positive rewards; but it does not come without preparation and

conscientious effort (Benedict and Sass-Lehrer, 2007; Jones and Pullen, 1992). In the following three sections we outline some areas for reflection concerning the ethics of this collaborative research, with special attention to (1) Deaf-friendly research methods; (2) international work with Deaf communities in developing countries; and (3) the notion of agreements for good practice. We hope that serious reflection on these issues before embarking on a research study into deafness or sign language will mean that researchers (both Deaf and hearing ones) are able to ensure that their research is both scientifically valid and in harmony with the cultural and practical experiences of the people who are involved as participants or facilitators.

## Deaf-Friendly Research Methods

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The question of how Deaf people are involved in the research process is very important; some scholars argue that the authority for the construction of “admissible evidence” rests only with sign language community members themselves (Harris et al. 2009, p. 115; Ladd, 2003, p. 176). Harris et al. (2009) maintain that the Deaf community should be considered as *hosts* or *gatekeepers* and the researchers as *visitors*, and that the former should be collaboratively involved in the design, decision making, and monitoring of research projects from beginning to end. The CEnR framework provides helpful guidance for working with “host communities.” The action research paradigm, common in education research studies, also provides guidance for research oriented toward obtaining organizational change(s) in a community of practice (see Napier, Leigh, and Nann, 2007).

A number of papers have suggested practical ways to address methodological procedures in Deaf community-based research that would be more inclusive and culturally appropriate – in other words, more Deaf-friendly (Harris et al., 2009; National Institute on Deafness and other Communication Disorders (NIDCD), 1999; Pollard, 1992). For example, Singleton et al. (2012; in press) discuss the importance of offering informed consent documents translated into the Deaf individual’s native signed language – such as American Sign Language (ASL) or British Sign Language (BSL) – in order to ensure comprehension for Deaf participants with limited spoken language proficiency. These authors also address confidentiality concerns with respect to using video-recorded data to collect Deaf participants’ responses in sign language.

There are very few empirical data on the actual experiences of Deaf individuals as they engage in the research process, or on how best to make research more Deaf-friendly. To this end, Singleton et al. (2012, 2014) carried out a focus group study that directly engaged various people involved in the research enterprise. The focus groups were all conducted in ASL, which allowed interviewees to “own” the interview more (Balch and Mertens, 1999). The discussion reported in the focus groups covered experiences both as a research participant – “When you got to the research location, whom did you meet, what was it like being there, and was it what you expected?” – and as a researcher – “How should a researcher gain confidence that a Deaf research participant has truly given their informed consent?” The focus group participants’ responses were organized around three domains: the research process; the deaf researcher; and negotiating paradigms.

Singleton and her team discovered that a number of Deaf former research participants described rather troubling encounters with researchers. The participants expressed the feeling that they lacked the power to change uncomfortable situations with researchers (including communication inadequacy and cultural insensitivity). They further conveyed the impression of being unsure how to handle researcher conduct that could be construed as unethical (e.g., when the researcher asked Deaf participants to read and sign complex written consent documents without offering translation into signed language). Participants sometimes reported that they took part in research in order to be better informed; but, without adequate explanations of the purpose of the research, they also developed potentially incorrect ideas about how the data would be used (e.g., they shared fears that their blood sample might be used to find a “deaf gene” and lead to eradicating the deaf population). This example highlights the need for researchers to understand the implications of their research protocol from the Deaf community’s perspective and to be aware that they are ethically accountable for fully debriefing the Deaf participants and for sharing with the Deaf community the findings of their research.

The participants in the focus group study by Singleton et al. who were researchers themselves talked about the importance not only of having Deaf researchers in the research team, but that these people be appropriately trained to *lead* research activities. This is starting to happen in the USA and in the United Kingdom and is generally more expected these days than it was 20 years ago; but the availability of such people crucially depends on appropriate training and support for both Deaf and hearing researchers. Another topic emphasized was that most outlets for deafness-related research were in written academic English rather than in ASL (a notable counterexample is the *Deaf Studies Digital Journal*, which publishes online in ASL).

On the basis of prior literature and of the results of their focus group study, Singleton and colleagues offered several important recommendations for ethical practice in research involving Deaf individuals. Researchers coming to sign language research might from the outset consider the following points:

- 1 *Accessibility of informed consent* While funding agencies have developed some guidelines for scientists on obtaining informed consent from individuals who are deaf or hard of hearing (see NIDCD, 1999), this information does not appear to be widely disseminated in the research community, especially among professionals who review human subjects research and should be holding researchers accountable for providing evidence of their linguistic and cultural competence to work with the Deaf population and for creating consent procedures in the language most accessible to the Deaf participant. The NSF Science of Learning Center on Visual Language and Visual Learning (VL2) now provides on its web site (<http://vl2.gallaudet.edu>) some guidelines for ethical conduct in research involving Deaf participants, as well as informed consent sample videos in ASL.
- 2 *Awareness of “overtesting,” confidentiality risks, and avoiding a “sample of convenience” mindset* As the Deaf community in any country is likely to be small and close-knit, researchers run the risk of overtesting Deaf children and adults (which possibly affects their reliability, if the same child is being retested on the same instrument). With such a low incidence, researchers must also be very careful about revealing background characteristics of individual subjects in their presentations and publications, as the individual may be identifiable to a reader or audience

member on the basis of this information. Morgan, Simpson, and Swanwick (2008) have proposed some guidelines on “good practice” in working with schools and professionals. These will be summarized later in this chapter.

- 3 *Give back to the Deaf community, disseminate research findings in ASL* It is also good practice for researchers to make the results of their study available to any participant who expresses an interest; brief research reports could be created in a sign language of the community and shared through video clips offered on websites that are considered Deaf-friendly. For example, Singleton and her team have published their research findings in two languages: English (2014) and ASL (2012). Because this kind of work centers on a topic of such great interest to the Deaf community, it is essential to ensure that its findings are disseminated in a manner accessible to this audience. On the basis of their focus group findings as well as from the extant research literature, Singleton and colleagues argue that it is critical for researchers to *give back* to the Deaf community by disseminating the findings through newsletters, research debriefing, websites, and conference presentations (both research and community-based ones). Other teams, such as Quadros, Lillo-Martin, Koulidobrova, and Chen Pichler (2012), have developed a bilingual approach, where research is simultaneously delivered in ASL and English. Before such outreach activities are carried out, researchers should consult with the target audience as to their areas of interest and appropriate level and mode of delivery. There may be little value in delivering a theoretical linguistics talk to teachers of Deaf children or to sign language instructors. However, with preparation, most sign language or Deaf studies research can be adapted to the needs of its target audience. Again, the benefits of this community-based knowledge transfer are mutual. Researchers gain the sustained support of the research facilitators, and these same professionals are able to incorporate relevant and useful research findings into their practice.
- 4 *Research team dynamics: The role of interpreters and communication accessibility* When a research team consists of signing Deaf people and hearing people who are either new signers or not fluent in a sign language, efforts are usually made to bring in an interpreter to mediate between the two languages. However, the communication dynamic of the team’s research meeting often creates a situation where the science – with debate and argument – is conducted in the prevailing spoken language, whereas the Deaf researchers must follow the sign language interpreter in order to gain access to it. This dynamic significantly disadvantages the Deaf team members, as the sign language interpreter is likely less familiar with research terms and with the research project itself. Also, the time lag between spoken information and the signed translation prevents Deaf team members’ equal participation in the debate (Harris et al., 2009). Depending on the interpreter’s bidirectional ability to voice and convey the academic–professional discourse, Deaf researchers often struggle to establish and maintain their professional identity when relying on interpreters for adequate information sharing. It is important to discuss *ground rules* for research team meetings, so that every participant, Deaf or hearing, signing or non-signing, may feel to be an equal and productive member of the enterprise. It is often the case that a hearing lead researcher who can deliver information (or can chair a research or a lab meeting) in fluent sign language will engage the Deaf collaborators more than if this information were conveyed by an interpreter. A hearing principal investigator

who uses fluent sign in science meetings can greatly increase Deaf researchers' feeling that they "own" the research. Of course, this demands a significant time investment in learning to sign; but researchers starting in the field of sign language studies will benefit greatly from insights into the community as well as from the trust of their Deaf colleagues when they become able to discuss sign language research in sign language. Many Deaf scholars lose confidence when sign language researchers convey their scientific findings at a level of sign language proficiency that ranks far below that of their spoken language.

In 2014 leaders in the international sign language research community have adopted an ethics statement endorsed by the Sign Language Linguistics Society. Bringing these issues to a global stage encourages us to consider some of the very important issues that sign language researchers face when conducting their investigations in developing countries – especially in those where both hearing and Deaf members of society hold views about Deaf people and their signed language that are strikingly different from what these researchers have likely experienced in their own sign language and Deaf community.

## Ethical Considerations for Research in Developing Countries

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In the past decade there has been a growth of sign language research projects studying emerging sign languages and village sign languages around the world (e.g., Senghas and Coppola, 2001; Nonaka, 2011). The nature of this work often involves undertaking fieldwork to conduct the research, and this in turn requires researchers to travel outside of their laboratories and home institutions, and very often outside their home countries. Many of these research programs take place in developing countries whose cultural, ethnic, economic, and political contexts differ greatly from those of the researchers' home countries and institutions. The community of researchers involved in this kind of work is quite small by comparison to research communities in other areas of sign language and Deaf studies, although numbers are growing. Moreover, the nature of the fieldwork itself raises unique ethical considerations, which are rarely addressed in standard research ethics training and in courses on the protection of human subjects. Hence there is a dearth of resources and guidance tailored to these particular research contexts. The present section is not intended as a comprehensive overview of the ethical issues involved here, but only as a starting point in considering some of the unique ethical aspects of this kind of fieldwork (for a fuller picture, see also Cassell and Wax, 1980 and Pettifor and Ferraro, 2012).

The basic guiding ethical principles – such as *respect for persons* (to respect and uphold a person's right to autonomously make decisions about research participation) and *beneficence* (the researcher's obligation to maximize benefits and minimize harms to research participants) (United States National Commission, 1979; American Psychological Association, 2010) – do not change in the case of fieldwork in a foreign country. Deciding how to appropriately apply ethical principles in fieldwork, however, is a dynamic process that should be sensitive to an array of specific conditions, both

within the academic area of the researcher (e.g., choosing research topics of current scientific value) and on the ground, in the host country (e.g., considering the social context of Deaf participants, or that the goals of the community may change over time). As with all research, we must carefully assess how to ensure participants' rights in the research process. But many of the day-to-day applications of these principles differ from the processes we use at home. In this section we focus on four ethical considerations that are unique to research fieldwork carried out in developing countries: informed consent regarding the nature of the research; appropriate compensation; maintaining personal and professional relationships; and preparing the research team for fieldwork.

### *Informed consent and the nature of the research*

*Informed consent* is the cornerstone of the application of the principle of respect for persons (United States National Commission, 1979). It stipulates that the information needed to make an informed decision about research participation should be rendered understandable and accessible. We discuss elsewhere in this chapter the necessity of providing information and obtaining consent in the preferred language of the participant; but let us say here that the same practice applies when working in the field. However, in some communities additional considerations are warranted in order to ensure that participants receive all of the information they need to make a voluntary and informed decision.

The nature and purpose of the research may not be intuitive to people outside the research team. Researchers must be clear about what functions the work does and does not serve. Participants or their parents may believe, or hope, that the work is rehabilitative, or that it provides a service for themselves or for a Deaf family member. The research team must be clear that participation in the research will not likely benefit the participant or their family directly. Rather the participant and anyone designated to make decisions on his/her behalf should understand that they are the ones with the expertise in the language and community under study and that the researcher is learning from them. If it is the case that the findings of the research would benefit the community immediately or in the future, the participant should be aware of this. However, potential benefits should not be overstated. In many cases we do not know how or when the results of the work will be applied. In basic research it is often not before several years after the data are collected that any application is possible. Thus, when working in the field with a population that is not familiar with the research process, it is the responsibility of the researcher to anticipate potential sources of misunderstanding about the nature of the research and to resolve them.

### *Appropriate compensation for research participation*

How does the researcher decide what is an appropriate compensation for research participants? Compensation must balance our respect for our participants' time without introducing undue influence or coercion (Grant and Sugarman, 2004). Many institutions have specific guidelines for compensating participants in the

laboratory. The form and amount of participant compensation depends on various factors, including the length of time needed for participation, the intensity of the task, and the amount of potential risk. But, for participants who live in developing countries, researchers need to consider additional factors, such as potential loss of regular daily wages, the difficulty or expense involved in travel, and meals. Similarly, if we use “western guidelines” for compensation, participants could receive the equivalent to a week’s salary, which most institutional review boards would consider to be coercive: research participants should participate on a voluntary basis, with reasonable compensation, and not be unduly enticed by large sums of money.

If participants stand to lose working wages on account of participating, then, even if the session lasts only part of the day, researchers should consider compensating them fully for time lost; otherwise they should take care to schedule participation on non-working days, if possible. In some cultures it may be inappropriate for participants to accept cash remuneration for work that could benefit the community as a whole; in such cases alternative ways to compensate can be arranged. Determining appropriate compensation requires a dialogue with participants and their community before the research starts.

In addition to compensating individual participants and in accordance with the principles of CEnR (Ross et al., 2010a; 2010b), researchers should actively seek ways to *give back* to the larger *host* communities; and there are multiple ways to do this. As in our work in our home communities, one of the most important ways is to disseminate research findings back to the local community. Publications, posters, or summaries of the work can be translated into the local written and sign language, or findings can be more formally introduced to members of the community in a conference-style presentation. Researchers can also give back by making a monetary donation to the local Deaf association or Deaf organizations. Dialogue with the community will reveal other meaningful ways to give back.

### ***Maintaining professional relationships between researchers and informants***

The very nature of most fieldwork and the conditions that make these studies scientifically valuable are the very same factors that pose some potentially difficult ethical problems concerning the relationships between the researcher and the community. There is considerable theoretical value in studying sign languages that emerge within communities of varying sizes – from just a few speakers to a few dozen, or to much larger language communities. Fieldwork often requires the research team to work in a small or close-knit community for a prolonged time and to be in closer contact with participants than would happen in a typical laboratory setting. For these reasons, field researchers face the unusual task of striking a delicate balance between creating a personal rapport with participants and maintaining a professional distance, as observers in a community that is not their own. The dynamics of these relationships may vary depending on the researcher’s age and gender, on whether the researcher is Deaf or hearing, and on values held within the host community. Establishing a rapport with participants shows respect for them individually and ensures that they are comfortable and answer questions truthfully. But scientific and professional good practice stipulates that researchers be as unobtrusive as possible. Determining

how to maintain this balance requires thoughtful consideration of the particular circumstances of both the researcher's work and the community.

Researchers who frequently return to the same community must also consider how to maintain contact with it between visits. E-mail and social media are convenient ways to maintain contact; but, because of their very personal nature, they also pose risks to the maintenance of professional boundaries with participants. Social media are widespread, and many participants are likely to use various platforms frequently and casually. A laboratory might consider establishing a lab e-mail account or a social media profile as a means of staying connected. A further challenge is how to stay in touch with remote communities on the other side of the digital divide. One possibility is to establish a relationship with a nearby non-governmental organization (NGO) or with a voluntary citizens' support group that could facilitate regular messages or contacts with informants or with Deaf community members in-between research visits.

Lastly, field researchers must be aware of how their position as researchers impacts their relationship with, or their influence in, the host community. Community members may regard a researcher as an authority in areas outside of his/her academic expertise and may seek out his/her opinions. Researchers must be considerate in addressing requests for advice or recommendations. This does not mean researchers cannot provide insight when asked, but they must carefully evaluate their potential influence. One important aspect of the principles of CEnR is the notion of a "social advocacy" role and of when such a role is appropriate. A sign language researcher from a developed country may also hold strong convictions about supporting and partnering with host community members who seek to strengthen the status of their Deaf community. Two examples of researcher-initiated social advocacy are Manos Unidas – an organization established to support equal access to educational and vocational opportunities for Deaf individuals in Nicaragua (visit <http://www.manosunidas.org>) – and Nicaraguan Sign Language Projects (whose site can be found at [http://nicaraguansignlanguageprojects.org/Home\\_Page.php](http://nicaraguansignlanguageprojects.org/Home_Page.php)). The projects of both these organizations include offering sign language classes in rural communities that lack Deaf education and offering Deaf children scholarships to attend signing educational programs.

### *Preparing the research team for work in the field*

Principal investigators should choose and train their research team carefully. At a minimum, research team members should have basic fluency in a world sign language and knowledge of core issues in Deaf cultures and communities (while acknowledging that not all Deaf communities share the same values). Prior experience in traveling abroad is helpful. Team members should have knowledge of the current local political context and be familiar with local cultures and customs (their attire, for instance, should be acceptable in the local community).

Preparing the research team to collect data with Deaf participants also requires establishing a Deaf-friendly research protocol. The entire protocol should be designed to be accessible to Deaf participants and researchers. For instance, if stimulus item numbers will be declared to a recording camera in order for coders to identify them, they should be declared visually, so as to be codable by Deaf researchers, but also in order for the Deaf participant to be able to see the process. The participant can list

or number the items, or a visual cue can be signed to the camera by the researcher or presented on a small white board while the camera records. Hearing researchers should avoid speaking to the camera without a visual aid that is accessible to the Deaf participant. Throughout the research session researchers should converse with one another as much as possible, and in the language of the participant. Even simple instructions intended only for other research team members – such as when to begin or end a recording, or when to advance to a new stimulus item – can be signed in the participant's preferred language. Information that should not be revealed to the participant, such as which condition of an experimental task will be presented, should be discussed among the researchers before the participant's arrival. Minor adaptations to a research protocol may be all that is required to make the session fully accessible to a Deaf participant and to Deaf research team members.

## Establishing Good Practices in Field Research

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There are many ways to apply standard ethical principles in fieldwork on the ground, and researchers must adapt these applications to the communities in which they work. While the basic ethical tenets do not change from community to community, the ways they are applied in the field should be flexible and open to change – both in the circumstances of the research community and in those of the communities of our informants. We must remain receptive to changes from all sides: in the research community, in the informants' community, and in the interactions between them.

### *Good practice agreements*

This section outlines the development of formalized agreements between researchers and schools where Deaf children are educated in the United Kingdom (Morgan et al., 2008). The process described here focuses on schools, but it could be applied to other organizations from which researchers might want to gain access in order to collect sign language data. The motivation behind setting up an agreement framework was to ensure that research was carried out in a positive and mutually beneficial way. In constructing this agreement, the developers focused their attention on the gap that sometimes exists between research teams and the people who facilitate the research, namely the parents and the teachers of Deaf children. The description of the development process might be illuminating for researchers who are embarking on other areas of sign language studies. The agreement is similar to other research-practitioner partnerships – for instance in research on hearing people with mental health problems, or in research on hearing people with acquired language impairments. The good practice agreement (GPA) and the agreement form itself are described in detail on the web site of the British Association of Teachers of the Deaf (BATOD; visit especially <http://www.batod.org.uk/index.php?id=/articles/research/good-practice.htm>).

The GPA came out of interventions from practitioners who asked how research and education can link up and support each other more. Deaf children are the most

assessed (some would say overassessed) pediatric group in clinical and language sciences. This is especially true for children who use sign language. There is a range of research topics carried out with this group that vary in how quickly the results could be applied to the real-world lives of the participants. Some researchers test Deaf children with the aim of assessing how signing affects cognition, for example working memory, while other researchers aim to establish how Deaf children learn to read. Both these questions are valid, but they differ in their closeness to practical application. When embarking on research with Deaf people only, the researchers might want to ask themselves: How will my research benefit the population I am studying? The answers might not be obvious, but the challenge is to work with those organizations where the researchers recruit participants for the purpose of coming up with mutually beneficial results. A research question that is more distant from application could still lead to interesting interactions between researchers and research facilitators: researchers could do some work with facilitators on how to set up a systematic database and do simple statistics. Even so, this exchange of skills needs to come out of dialogue rather than just from the researcher side. While researchers might not be able to answer directly all the questions posed by facilitators, being aware of what is a priority in the work of facilitators can be beneficial for both groups. As research facilitators may be less aware of motivations for research, taking the time to explain the research objectives in a way that is accessible to this group is mutually beneficial for building sustainable relationships. A community-engaged approach, and one with clear practical linkages, need not compromise the scientific merit of the research. In fact, in the current research-funding climate, research proposals with clearly articulated and achievable impact plans (that is, links with the users of the funded research) have greater chance of success.

The GPA happened because schools felt that they were faced with an increasing demand from researchers, which needed to be balanced against the schools' capacity to deliver the project and manage the interruption to their pupils' education. For example, getting parents to sign informed consent documents takes a great deal of the school personnel's time and attention. Schools conveyed some negative experiences of researchers who set up their research without considering the practical demands they were making on the schools they visited. The GPA document now includes sets of responsibilities for both sides to endorse before any research starts. On the side of facilitators, this would involve working on recruitment, providing space for testing, and helping with informed consent. On the researchers' side, it would include arranging the tests at the best time for the school's timetable, explaining fully the research objectives, and exploring the possibility of including extra studies or workshops, warranted more by the needs of the school than by those of the researcher. The agreement also allows for clear planning of researcher follow-up and for dissemination strategies that are appropriate for both the participants and the schools.

The process of co-signing an agreement can guide schools and researchers on how to lead effective and relevant research projects and can provide schools with information toward improving children's progress and future learning objectives and toward supporting curriculum-planning efforts. It also gives criteria against which schools can assess the relevance of a particular research project for their own priorities. Moreover, it ensures that researchers work with the schools on the basis of mutually agreed feedback mechanisms, so that the goals and outcomes are shared with staff in an accessible way and thus can be more easily implemented by the schools.

## Conclusion

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We are very much aware that researchers undertake research primarily for theoretical reasons. However, when carrying out sign language work in the Deaf community, we should always bear in mind that the social impact of doing so is great. One conclusion is that doing Deaf-friendly CEnR will lead not only to better science, but also more sustainable research programs. It sometimes happens that new researchers into sign language would say: The Deaf community is a difficult population to work with. As is clear from what we write in this chapter, Deaf people are for the most part very motivated to take part in research, when this research is presented in a way that promotes a two-way process. Care in planning how the Deaf community is to be involved in the research will lead to much more satisfactory outcomes for all stakeholders.

### Note

- 1 We adopt the common convention in this literature of capitalizing the term *Deaf* to refer to the community of individuals who identify with Deaf culture and consider themselves a part of a linguistic and cultural minority group.

### Keywords

community-engaged research; deaf children; ethics; field-based studies; good practice; knowledge exchange; partnerships

### See Also

Chapter 3; Chapter 7; Chapter 11

### Suggested Readings

- Czaykowska-Higgins, E. (2009). Research models, community engagement, and linguistic fieldwork: Reflections on working within Canadian indigenous communities. *Language Documentation and Conservation* 3, 15–50.
- Frankham, J. (2009). Partnership research: A review of approaches and challenges in conducting research in partnership with service users. ESRC, National Centre for Research Methods. Accessed September 2, 2014. <http://eprints.ncrm.ac.uk/778>
- National Science Foundation (1999). Social science and the common rule. In *Frequently asked questions and vignettes: Interpreting the common rule for the protection of human subjects for behavioral and social science research*. Accessed February 16, 2014. <http://www.nsf.gov/bfa/dias/policy/hsfaqs.jsp>
- Watkins, M. (n.d.). Ethical guidelines for community/ecological fieldwork and research. Accessed February 20, 2014. <http://www.pacifica.edu/gems/EthicalGuidelinesCommunity.pdf>

### References

- American Psychological Association (2010). *American Psychological Association: Ethical principles and code of conduct*. Accessed November 7, 2013. <http://www.apa.org/ethics/code/index.aspx>.

- Baker-Shenk, C., and Kyle, J. G. (1990). Research with Deaf people: Issues and conflicts. *Disability, Handicap & Society* 5(1), 65–75.
- Balch, G., and Mertens, D. (1999). Focus group design and group dynamics: Lessons from Deaf and hard of hearing participants. *American Journal of Evaluation* 20(2), 265–278.
- Benedict, B., and Sass-Lehrer, M. (2007). Deaf and hearing partnerships: Ethical and communication considerations. *American Annals of the Deaf* 152(3), 275–282.
- Cassell, J., and Wax, M. L. (1980). Ethical problems of fieldwork. *Social Problems* 27, 259–378.
- Grant, R., and Sugarman, J. (2004). Ethics in human subjects research: Do incentives matter? *Journal of Medicine and Philosophy* 29(6), 717–738.
- Harris, R., Holmes, H., and Mertens, D. (2009). Research ethics in sign language communities. *Sign Language Studies* 9(2), 104–131.
- Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., Allen, A. J., and Guzman, J. R. (2008). Critical issues in developing and following community based participatory research principles. In M. Minkler and N. Wallerstein (Eds.), *Community-based participatory research for health: From process to outcomes*. San Francisco, CA: Jossey-Bass, pp. 53–76.
- Jones, L., and Pullen, G. (1992). Cultural differences: Deaf and hearing researchers working together. *Disability, Handicap & Society* 7(2), 189–196.
- Ladd, P. (2003). *Understanding Deaf culture: In Search of deafhood*. Tonawanda, NY: Multilingual Matters.
- Morgan, G., Simpson, K., and Swanwick, R. (2008). Deaf children and research: Developing a model of good practice and participation. Accessed February 16, 2014. [http://www.staff.city.ac.uk/g.morgan/BATOD\\_article\\_on\\_GPA\\_081008.pdf](http://www.staff.city.ac.uk/g.morgan/BATOD_article_on_GPA_081008.pdf)
- Napier, J., Leigh, G., and Nann, S. (2007). Teaching sign language to hearing parents of deaf children: An action research process. *Deafness Education International* 9, 83–100.
- National Institute on Deafness and other Communication Disorders (NIDCD) (1999). Working group on communicating informed consent to the deaf or hard of hearing. Accessed February 16, 2014. <http://www.nidcd.nih.gov/news/releases/99/inform/pages/toc.aspx>
- Nonaka, A. (2011). Interrogatives in Ban Khor Sign Language: A preliminary description. In G. Mathur and D. J. Napoli (Eds.), *Deaf around the world: the impact of sign language*. New York: Oxford University Press, pp. 194–220.
- Padden, C., and Humphries, T. (1988). *Deaf in America: Voices from a culture*. Cambridge, MA: Harvard University Press.
- Pettifor, J., and Ferraro, A. (2012). Ethical dilemmas, cultural differences, and the globalization of psychology. In M. Leach, M. Stevens, G. Lindsay, A. Ferraro, and Y. Korkut (Eds.), *The Oxford handbook of international psychological ethics*. New York: Oxford University Press, pp. 28–41.
- Pollard, R. Q. (1992). Cross-cultural ethics in the conduct of deafness research. *Rehabilitation Psychology* 37(2), 87–101.
- Pollard, R. Q. (2002, July). Ethical conduct in research involving Deaf people. In V. Gutman (Ed.), *Ethics in mental health and deafness*. Washington, DC: Gallaudet University Press, pp. 162–178.
- Quadros, R., Lillo-Martin, D., Koulidobrova, H., and Chen Pichler, D. (2012). Noun phrases in Koda bimodal bilingual acquisition. Paper presented at the conference *Theoretical issues in sign language research*, London, UK.
- Ross, L. F., Loup, A., Nelson, R. M., Botkin, J. R., Kost, R., Smith, G. R., and Gehlert, S. (2010a). Nine key functions for a human subjects protection program for community-engaged research: Points to consider. *Journal of Empirical Research on Human Research Ethics* 5(1), 33–47.
- Ross, L. F., Loup, A., Nelson, R. M., Botkin, J. R., Kost, R., Smith, G. R., and Gehlert, S. (2010b). The challenges of collaboration for academic and community partners in a research partnership: Points to consider. *Journal of Empirical Research on Human Research Ethics* 5(1), 19–31.

- Senghas, A., and Coppola, M. (2001). Creating language: How Nicaraguan sign language acquired a spatial grammar. *Psychological Science* 12(4), 323–328.
- Singleton, J. L., Jones, G., and Hanumantha, S. (2012). Deaf friendly research? Toward ethical practice in research involving deaf participants. *Deaf Studies Digital Journal* 3. Accessed September 7, 2014. [http://dsdj.gallaudet.edu/index.php?issue=4&section\\_id=2&entry\\_id=123](http://dsdj.gallaudet.edu/index.php?issue=4&section_id=2&entry_id=123)
- Singleton, J. L., Jones, G., and Hanumantha, S. (2014). Toward ethical research practice with Deaf participants. *Journal of Empirical Research on Human Research Ethics* 9, 59–66. doi: 10.1177/1556264614540589.
- United States National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. Washington, DC: US Department of Health, Education, and Welfare. Accessed February 19, 2014. <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>

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