Part I Collecting Data WITH the Deaf Community

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

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[1] 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 is 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; 2014).

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

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 comunity-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; 2014) 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

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., Nonaka, 2011; Senghas and Coppola, 2001). 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) (Belmont Report, 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 (Belmont Report, 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

Orfanidou, Eleni, et al. Research Methods in Sign Language Studies : A Practical Guide, Wiley, 2014. ProQuest Ebook Central, http://ebookcentral.proquest.com/lib/cuni/detail.action?docID=1895428.

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). 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

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

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

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2 The Deaf Community as a "Special Linguistic Demographic": Diversity Rather Than Disability as a Framework for Conducting Research with Individuals Who Are Deaf

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Chapter Overview

This chapter points to the fact that the much of the published research on individuals who are deaf[1] derives from population models that embrace medical, rehabilitation, and normative educational descriptions of the population subgroups of interest. Nowhere is this more evident than in the literature specifically oriented toward demographic analyses of the population of individuals who are deaf and hard of hearing. As a result, our current understanding of the population

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is based on models in which deviation from normality guides the design of research and the interpretation of results. This chapter argues that an alternative strategy for enumeration, one based on linguistic diversity, will lead to a valuable (and very different) knowledge base, which may contribute to the improvement of society and of the lives of deaf individuals. Focusing on "difference" rather than "disability" may help us design studies that honor and document differences among individuals in the rich tapestry of human experience.

Introduction

Researchers intending to do population-level studies, as well as other researchers who intend to include background questions for their participants in order better understand the characteristics of their samples, should be aware that there are complex issues surrounding how questions are phrased and how response categories are defined. For over 100 years in the United States, population studies of individuals who are deaf and hard of hearing have sought to characterize deaf people according to medical, rehabilitation, or normative-based educational (M/R/NE) models. These models, in turn, have driven research design efforts and have contributed heavily to determining relevant categories for enumeration in demographic studies and for understanding the background characteristics of deaf participants in experimental studies. During this time, a considerable amount has been amassed of data that contribute to our understanding of the "demographics of deafness." From one perspective, this has been a good thing: both the demonstration and the documentation of prevalence and incidence rates using categories of interest based on M/R/NE modes have certainly contributed to policies that have directed considerable resources to M/R/NE improvements. For example, when "degree of hearing loss" has equated to "degree of deviation from wellness," access to federal health dollars has been in direct proportion to the magnitude of the deviation. Equally, the "achievement lag" in literacy for deaf children (documented through studies of academic achievement that rely on normative comparisons between deaf and hearing test takers), has contributed to the direction of resources (at federal and state levels) toward attempting to remediate this lag.

From another perspective, the focus on M/R/NE categories for enumeration has created a frame of mind for determining progress that derives from the same normative conceptions of wellness and achievement that have driven the research agendas – a focus on reducing the gaps and on bringing deaf individuals "closer" to hearing individuals on indicators of societal attainment. This is a narrow view of attainment, and also one that is very difficult to achieve.

Of course, there are many situations in which we do wish to improve the lives of persons who are deaf by increasing their levels of academic attainment, by reducing the incidence of mental health problems, by improving their prospects for successful employment, and so on. In pursuing these societal ends, comparisons to individuals who are hearing are unavoidable as indicators of success. Yet an a priori presumption that what constitutes normalcy for hearing individuals is the sole lens through which we should judge the attainments of deaf individuals can lead society down errant pathways.

It can also prompt researchers to ask inappropriate questions, develop hypotheses that derive from inappropriate assumptions and theories about language development, and employ measures that have very limited validity for this unique population.

Consider the acquisition of reading skills, for example. We certainly want to reduce gaps in reading skills between deaf and hearing individuals; but, if we believe that deaf children have difficulty reading *because they cannot hear the words they are reading and therefore have no auditory phonological basis for reading the letters on the page*, we will be tempted to focus our research – and the guiding schema that determines how we see the population – on categories of hearing loss and speech perception rather than on visual language experience and the visual nature of print literacy.

An alternative framework for working with deaf participants – whether the researchers are population scientists, neuroscientists, or linguists – is to adopt a linguistic or sociocultural model for defining the population under study, formulating research questions, and developing appropriate empirical measures. This approach derives from an interest in understanding human differences (as opposed to understanding their disabilities) and recognizes that considerable variation exists within the range of "normal" language behavior and that attainment in society is a diverse concept. In this way it furthers not only the articulation of the myriad of outcomes that contribute to a complex human world, but also the idea that individual outcomes (reading English, for example), may be achieved through developmental pathways that M/R/NE approaches fail to notice.

This chapter makes a case for this alternative strategy and will, throughout, suggest specific examples of how questions should be asked under this model. Our primary focus will be on population studies. Such studies are critical to all research with deaf participants, as these provide a demographic and social context from which generalizations can be made from individual studies to the broader population of deaf people. Given the importance of these studies, the nature of the data collected and reported from them must be reviewed, in order for us to ensure that the manner in which categories of enumeration are defined, the procedures by which individuals are selected for inclusion, and the analytical strategies used to summarize population characteristics will accurately reflect the population for which emerging research studies have relevance. In many ways, the decisions demographers make about how to categorize people set the stage for all the research that is carried out on individuals within a society, as they prescribe how society is defined. To date, there has been a mismatch between the voluminous amount of demographic data on the "deaf and hard of hearing" population and the growing interest that researchers have in understanding the social and linguistic characteristics of deaf people.

We will discuss the predominant medical frameworks that have determined the course of demographic studies to date, describe their shortcomings and limitations, summarize some of the issues that are pervasive in existing demographic analyses of this population (as well as some of the challenges for conducting any kind of population study of this population), and make some specific suggestions about how questions might be posed to participants.

Embracing this diversity perspective is important not only for demographers, but for all researchers interested in conducting sign language studies. Understanding the extant literature requires sensitivity to how deaf individuals have been viewed and portrayed in society, expressed by researchers and authors throughout history. Thus, when quoting population statistics, one must take care to contextualize individual studies when generalizing specific results. Going forward, researchers must always be aware of their own biases in formulating their research questions and hypotheses, in designing their studies, in conducting their statistical analyses, and in interpreting their results.

How might the methods selected by researchers interested in studying language use in the classroom, for example, differ between those who espouse a medical/normative model of social context and those who are more embracing of a diversity perspective? In the case of the former, there will be an emphasis on the language of the majority (a spoken language), and little attention will be given to understanding sign language. The focus of studies will be on teaching deaf children to master this language, and assessments will focus on measures of English (or other spoken languages). The ultimate goal will be that all children in the classroom achieve equality in the acquisition of the majority language.

Researchers who view classrooms as places where diversity should flourish will have a different set of questions and will employ a different array of methods. They will be interested in understanding the structure of a visual language and in identifying its variations; they will be interested in evaluating the strategies for maximizing the cognitive benefits of bilingual instruction; they will be interested in looking at social interactions among deaf and hearing children; they will be interested in understanding the early language experiences of children in classrooms, in the impacts that these early experiences have on cognitive development, and in how teachers can facilitate this development by employing the child's existing language skills; they will be interested in how higher order literacy skills are developed through a visual language – for example, how narrative abilities can be developed through the use of sign language and gesture. And the list goes on. In sum, embracing the diversity perspective opens the realm of questions that are of critical importance to directing research toward discoveries that honor and account for individual differences evident among individuals in society. Statistical methods will focus on characterizing smaller segments of the population, with known social, cultural, and linguistic backgrounds.

Suggestion for Researchers

Ask questions of your participants that probe their history of sign language use, especially during their early childhood. For example:

To the best of your memory, or from what your parents have told you, which of the following best describes your use of sign language in your home during your early childhood?

☐ We only signed and used no spoken language.
☐ We mostly signed, but we used some spoken language as well.
☐ We signed and spoke in roughly equal amounts.
☐ We mostly spoke, but used some sign language too.
☐ We only spoke and used no sign language.
☐ We rarely spoke or signed, but relied on gestures to communicate.

This question (or one similar to it) does not attach a higher value to spoken or signed languages and will give you a sense of the modalities of communication (spoken and signed) that contributed to your participants' language development.

Predominant Medical/Rehabilitation/Normative–Educational Frameworks in the Demographic Studies of Individuals Who Are Deaf and Hard of Hearing

While the US Census Bureau began asking national samples of citizens about the prevalence of hearing loss in its first National Health Interview Survey in 1957 (National Center for Health Statistics, 1963), the real impetus for the scientific study of the demography of deafness in the United States, especially with a focus on education, originated in 1964, with the appointment of an Advisory Committee on the Education of the Deaf by then US Secretary of Health, Education, and Welfare Anthony Celebrezze. The report of this committee, now famously called "The Babbidge Report," after the chair of the committee (US Department of Health, Education, and Welfare, 1964), was published a year later and lamented the poor state of education for deaf children as well as the lack of federal data pertinent to understanding the nature of the population of deaf children in schools and their needs. The decade following the publication of the Babbidge Report witnessed a burgeoning of interest, federal support, and general activity in response to this lack of information, which was needed so desperately to inform educational policy. The Bureau of Education of the Handicapped (BEH) awarded a grant to Gallaudet College to establish the Annual Survey of Hearing Impaired Children and Youth in 1968 (Rawlings and Gentile, 1970). The National Association of the Deaf was awarded a grant from the Social and Rehabilitation Services Administration to conduct a National Census of the Deaf Population (NCDP) in 1971 (Schein and Delk, 1974). Other initiatives, such as the National Health and Nutrition Examination Survey, conducted by the National Center for Health Statistics, and the Survey of Income and Program Participation, conducted by the US Bureau of Labor Statistics, have also included questions about hearing loss, which were designed to inform medical and employment policy respectively.

Researchers who are carrying out studies of the deaf community as a linguistic demographic group should realize that we are aiming at a scientific approach to population studies that is radically different from those that grew out of the work of demographers in the 1960s and 1970s. Mitchell frames the issue clearly:

> In the process of identification and enumeration of deaf persons, or any other particular group within the population, at least four constraints are encountered: *the context of the inquiry* [emphasis added], the indicators used to establish group membership, the methods employed to collect indicator data, and the resources available to execute the project. (Mitchell, 2005, p. 113)

Critically, any enumeration or study of a population must articulate the context of the inquiry, and those studies that are based on medical or normative–educational contexts will yield quite different information from those based on a linguistic context. The indicators to establish group membership will be radically different, as will the methods used to collect indicator data. Researchers should put this contextual information clearly up front in the research process.

A research project about American Sign Language (ASL) use that employs survey questions, whether administered only to deaf participants or to a broader population, has to take several factors into consideration. Consider the initiatives described previously. The National Health Interview Survey and the National Health and Nutrition Examination Survey are designed to report on the health status of Americans. The context of these surveys is medical, and the indicators used to establish a respondent's membership as a deaf person derive from answers to a survey question that asks: "Do you have no trouble hearing, a little trouble hearing, a lot of trouble hearing, or are you deaf?" (Ironically, the self-report of being "deaf" may be an effective indicator of membership in the deaf community, although clearly this was not the intent of the survey writers, who simply view "deaf" as the most severe level of pathology.) The critical words in these questions are: "trouble hearing," clearly identifying deafness as a medical burden to be overcome. In the NCDP, Schein and Delk (1974) define their population as "those persons *who could not hear and understand speech and who had lost (or never had) that ability prior to 19 years of age*" (p. 2). This definition is more oriented to a perceived requisite for success in schools, namely the ability to hear and understand speech. In the Annual Survey, data records are gathered from schools across the United States for those "deaf and hard of hearing children and youth who have been identified as requiring an individualized education program (IEP) or an individualized family service plan (IFSP)" (Mitchell, 2004, p. 337). As Spencer and Marschark (2010) point out, "this is a bit of a circular definition, but it is a practical solution" (p. 10). Interestingly, the definition focuses more on the practices of individual schools and on the manner in which they categorize and serve a group of students than on the characteristics of the students themselves. Thus it is important to point out that a given child attending a school in one location may be counted as a "deaf or hard of hearing child," while she might not be so counted if she attended a different school, with different IEP criteria.

Suggestions for Researchers

Avoid using the term "deafness." It implies a unidimensional condition in which more deafness is bad and less deafness is good. It also confounds cultural definitions with medical or audiological definitions pertaining to the level of hearing. Use phrases such as "individuals who are deaf," or, preferably, "individuals who are deaf and come from families where sign language was regularly used." The more the definitions are oriented toward language use, the greater their ability to shed light on the characteristics of linguistic and culturally defined subgroups.

Schein and Delk, in their introduction to the report on the NCDP, state:

> Impairment of hearing is the single most prevalent chronic disability in the United States. More persons suffer a hearing defect than have visual impairments, heart disease, or other chronic disabilities … Because deaf people constitute such a small minority within the general population, they must accommodate to the larger group, rather than vice versa. The extent of the accommodation can be seen in the communication patterns adopted by deaf people. Most use speech, expressively, and lipreading, receptively, at least some of the time in their daily intercourse. But they also use fingerspelling, signing, and writing in their interpersonal contacts. (Schein and Delk, 1974, p. 8)

This quotation set the stage for the contexts that have guided demographic studies of individuals who are deaf over the past 40 years. Words like "suffer," "defect," and "disability" clearly place population studies into a medical context. The notion of "single most prevalent" is highly misleading, in that it refers to all degrees of hearing loss, in individuals of all ages. If cited incorrectly, this phrase might lead one to grossly overestimate the prevalence of signing deaf individuals in the United States. The implication in a population statistic that individuals with different language and cultural backgrounds (ASL and English, for example) can be grouped together is that these backgrounds hold little relevance for enumeration studies. Unfortunately these studies are used in order to determine policy in areas such as education, which should be paying closer attention to the language and cultural backgrounds of students with particular needs.

Mitchell, Young, Bachleda, and Karchmer (2006) have thoroughly discussed issues associated with trying to estimate the number of people who use ASL by relying on highly divergent estimates of prevalence of deafness. (Their paper will be discussed in a little more detail in the following sections.) Holt, Hotto, and Cole (1994) report that 8.6 percent responded to the National Health Interview Survey that they had some "trouble hearing." However, when prevalence rates are reported by age, the numbers range from 1.8 percent for children between the ages of 3 and 17, to 29.1 percent for individuals aged 65 and older. Clearly individuals who lose their hearing later in life (the overwhelming majority) are native speakers of English (or of other spoken languages) and would not be considered among the population of ASL users. Further, when the definition shifts to "deaf in both ears," the national rate (for individuals of all ages) is only 0.18 percent (which represents fewer than two people in a thousand). While Holt et al. (1994) do not report the rates for children aged 3–17 in the "deaf in both ears" category, they do report prevalence rates for this age group in a broader category, defined as "at best can hear words shouted in their better ear"; and this is 0.1 percent (one person in a thousand). Thus the overwhelming majority of individuals typically referenced in national statistics are older hard-of-hearing Americans who are English speakers, and the overgeneralization of this fact to the full population is patently incorrect.

Suggestions for Researchers

Do not overgeneralize your results to individuals who do not share relevant background characteristics. Define what constitutes meaningful subgroups within the population and relevant to your research questions, for instance older individuals who lose their hearing late in life; individuals of all ages who are hard of hearing versus those who are deaf; or deaf individuals using specific language systems in their homes, at school, and at work (including sign languages). This last suggestion is very important; the recognition of sign language as a language and the reporting of demographic data about the prevalence of its use would greatly enhance our understanding of the use and importance of sign language in society.

One can easily see how this disability normative framework has influenced population studies of deaf individuals over the years. In turn, these studies have propagated the idea that deaf persons are "impaired." But many have questioned the ethics of a strict adherence to norm-referenced notions of "wellness." For example, Kawa and Giordano (2012) point to controversies surrounding the medicalization of cognition, emotion, and behavior (and we might emphasize the inclusion of language as a medical issue in the case of deaf individuals), which in turn fosters presuppositions about what constitutes "normal" or "abnormal" in the context of society and culture. The application of this medical view, in the context of "oppression," to persons who are deaf has been well discussed in the literature (see Friedner, 2010; Ladd, 2003; Lane, 1993). Population studies must embrace (and indeed celebrate) behavioral diversity and sociocultural differences, with a view toward providing research findings that shed light on population patterns of language diversity and on their implications for the improvement of a multilingual and multicultural society.

A Linguistic Basis for Demographic Studies

Research with deaf participants or research on sign language use in the general population could consider an alternative approach to categorizing participants. In 1960, three years after the National Health Interview Survey began to pose questions to American survey respondents about the status of their hearing, William Stokoe published a monograph in which he began outlining a taxonomy for the phonological (which he called "cherological" to differentiate it from the sound-based sublexical units of spoken languages) and morphological analysis of ASL. In his introduction he states:

> The primary purpose of this paper is to bring within the purview of linguistics a virtually unknown language, the sign language of the American deaf. Rigorous linguistic methodology applied to this language system of visual symbols has led to conclusions about its structure, which add to the sum of linguistic knowledge. (Stokoe, 1960, p. 1)

There is, perhaps, some historical irony in the fact that these two events occurred so close in time. Just as the National Center for Health Statistics began charting a path that would be followed for the next fifty years by documenting the hearing status of a population for medical reasons and needs, the linguistics community began taking note of, and describing, the natural language of those who are deaf. These trajectories derive from different, if not opposing scientific worldviews. In one view, the focus is on disability; in the other, the focus is on the development and use of a natural, visual language. To understand ASL users as a linguistic minority, we must, as Mitchell (2005) suggests, re-specify the *context* in which population enumeration takes place so as to focus on the diversity of languages and on the implications of this diversity for social and educational programming.

Issues and Challenges

In conducting or evaluating research on ASL usage among individuals we would want to consider as members of a particular linguistic subgroup – in this case, the "Deaf community" – there are a number of critical issues that need to be examined by researchers in the future. These include considerations of the role of parental hearing status and parents' use of ASL in the home in establishing the social context for language use, confusions about language and modality, controversies over the benefits and risks of bilingualism, and misunderstandings about how prevalence rates are determined and interpreted.

Taking one of these examples (parental hearing status and use of ASL in the home), it should be evident how a medical perspective that relies on hearing norms to define what it means to be "healthy" would differ dramatically from a linguistic or cultural perspective. A medically oriented researcher would point both to the deafness of the parent as a pathology and to the use of ASL early in life as potentially damaging to a deaf individual's subsequent ability to learn speech; this researcher might use the argument that ASL activates or "recruits" areas of the auditory cortex normally recruited by spoken language in hearing individuals. The common claim of those who adopt this perspective is that "the brain is naturally wired for learning language through hearing … Auditory–Verbal professionals agree that sign language and lip reading at an early age inhibit the child's dependence on LISTENING to acquire language" (Auditory–Verbal Communication Center, 2013). This perspective would have a huge impact on the types of research that may be undertaken, leading to an emphasis on speech perception and the listening abilities of the participants.

However, other researchers (for example, Petitto, 2000), looking *at the same data about the brain* and noting that regions of the auditory cortex are activated by ASL in deaf native signers but not in hearing non-signers, draw very different conclusions: these researchers claim that this area of the brain is responding to the phonologically structured and segmented language input regardless of its modality – spoken or signed. They interpret these data as providing evidence that there is a visually based phonology of sign language, which performs the same role in language processing by deaf individuals as the sound-based phonology of spoken language performs for hearing individuals. To be sure, research studies that emanate from this perspective focus on such topics as models of bilingual ASL–English learning, the importance of early exposure and access to a visual language, and the cognitive benefits of having an early visual language experience.

In the following sections we elaborate on a few of the more prominent issues that have emerged from previous studies, in hope that what we say here will inform future researchers. Importantly, almost all of these issues derive from definitions and perspectives that are imprecise and proceed from erroneous assumptions. For example, there is no legal definition of "deaf," nor is there a universal definition of ASL. Therefore, as research develops, attempts must be made to improve the level of precision in the definitions used and to clearly specify the assumptions that underlie the interpretation of findings. The collection of issues we present here is by no means exhaustive, and the short treatment given to each one comes nowhere near to a complete treatment.

Prevalence of deaf individuals and prevalence of ASL usage

This issue combines three important questions: (1) How many deaf people are there? (2) How many ASL users are there? (3) What is the relationship between 1 and 2? We have already presented the problem related to question 1, noting that national prevalence rates typically do not acknowledge either the huge differences in the rates of deafness of individuals with different levels of hearing or the relationships of these differences to the individuals' age. Questions 2 and 3 are largely unanswered. In spite of the growing recognition of ASL as a full language (e.g., Armstrong, Karchmer, and Van Cleve, 2002; Chamberlain, Morford, and Mayberry, 2000; Emmorey and Lane, 2000; Liddell, 2003; Stokoe, 1960; Valli and Lucas, 2001), there are no national census questions pertaining to its use. The recent paper by Mitchell et al. (2006) presents this issue in great detail. They tackle the common belief that "ASL is the fourth most prevalent language in the United States"; they disentangle concepts of native languages versus languages used in the home; and they describe the imprecisions of definitions and the repeated use of secondary and tertiary sources as primary ones. Interestingly, in their review, Mitchell and colleagues trace citations regarding the prevalence of ASL usage back to a single source: the National Census of Deaf Persons in the United States (Schein and Delk, 1974). That census, as we have noted, viewed deafness as a medical "condition." Its queries into sign usage avoid the term ASL, focusing on a more generic "sign," which, as we have noted, Schein and Delk view as only useful for deaf people in informal communication.

Regarding the question of whether the prevalence of deaf people yields information about the prevalence of ASL, Mitchell et al. (2006, p. 312 observe: "American Sign Language is a social and linguistic phenomenon, for which deafness is a necessary human condition motivating its sustained use (Johnston, 2004), but an individual's deafness is neither a necessary nor a sufficient condition for becoming an ASL signer." Even if prevalence rates for deaf individuals were precise and known, we would still not be able to infer the prevalence rates for ASL usage.

Language and modality

Demographic studies of deaf individuals have often failed to separate the very different constructs of language and modality. For example, the 2007–2008 Annual Survey (Gallaudet Research Institute, 2008) asked schools to report on the communication mode used in the classroom for each of the 36,710 children and youth reported to the survey in that school year. The response categories (and the resulting percentages from the survey) were: speech only (52 percent); sign with speech (35 percent); sign only (11 percent); cued speech (0.2 percent); and other (1.5 percent). Clearly this question is oriented toward language modality and not toward language per se, and therefore the language implications are quite ambiguous. First, the majority of children are reported to fall in the "speech only" category; however, inspection of the hearing levels of the sample reveals that only 41 percent of the children had hearing losses in the severe to profound categories. Clearly these percentages have to be interpreted very carefully. Educational policy often flows from demographic data, and there is a danger that, when demographic findings are overgeneralized, policies can be easily misdirected. Using the above figures, only 11 percent use "sign only" in the classroom, but this does not mean that 11 percent of the children with severe to profound levels of deafness use sign only in the classroom. Further, the "sign and speech" category is totally ambiguous with respect to whether classroom communication is bilingual (children receive some instruction in English and other instruction in ASL) or whether teachers are using a communication method that incorporates the simultaneous use of signs and speech. Finally, can we infer that children in the "sign only" category are receiving instruction in ASL? Probably not. There are different sign systems that bear different approximations to English and ASL (Stedt and Moores, 1990; Woodward and Allen, 1986).

Suggestions for Researchers

Differentiate language questions from modality questions and allow for multiple responses for each question, as in the following example from a recent survey at http://signupvl2.gallaudet.edu:

What languages and/or language systems do you use on a regular basis? (Check all that apply.)

Languages:
☐ English
☐ ASL
☐ A sign language other than ASL, such as BSL or LSQ
☐ Spanish
☐ French
☐ Chinese
☐ Japanese
☐ German
☐ Other

Language Systems:
☐ Spoken English
☐ Signed English
☐ Cued language/Cued speech
☐ Fingerspelling
☐ Gestures
☐ Other

These questions permit participants to respond separately for language and modality (here broadened to incorporate different systems of language use), and also allow for the use of multiple languages and multiple modalities for each participant. This strategy will more accurately reflect the diversity in your samples and will help specify the populations to which you wish to generalize.

Another confusion arises over the imprecise definition of ASL and the possibility that participants in a study will employ quite different understandings of what is meant by "ASL." Woodward, Allen, and Schildroth (1985, p. 481) amusingly quote a teacher's verbatim response to a survey question about the communication policy of her school district:

> Our policy follows the view that sign language is speech or specifically manual speech and American Sign Language is English. We use only ASL signs and put them in straight English Syntax. Some words are only fingerspelled in Sign Language. We use the formal ASL usage and not the colloquial form used in everyday life of the deaf. The students will develop that naturally when they start to sign fast.

While this quotation is taken from a study that is 25 years old – and it is (hopefully) unlikely that such a quotation would be found today if a similar study were undertaken – it is no doubt true that the term "ASL," from the vantage point of classroom teachers, still covers a wide range of language usage, with varying approximations to English grammar. Effective population studies that include a category for ASL usage (whether in classrooms or in the general public) will need to make clear what is meant.

Suggestions for Researchers

Devise linguistically based behavioral questions that will differentiate ASL use from other manually coded language systems. Woodward and Allen (1986) employed a scaling technique that assumed a continuum between ASL and English. They posed a small number of behavioral questions that asked participants to look at two short English sentences, such as "I am looking for him" and "She is looking at me." Respondents were then asked to report whether they would sign "looking" the same or differently in the two sentences; whether they would sign "I" and "me" the same or differently in the two sentences; and so on. For each choice, there was one option that represented use of ASL and one that represented use of signing in English. Using this simple scaling strategy rather than asking participants to self-classify as to whether they were using ASL gives a behavioral indication of the kind of signing being used and avoids possible ambiguities associated with the term "ASL."

Bilingual and bimodal

Bilingualism has been a very controversial topic in research and in social policy. Research debates have centered on the impact of bilingualism on the developing brain and on the acquisition of language and literacy. Traditional views posited that being presented with two languages would have a harmful impact on children's development. However, current research has challenged this view, pointing to the benefits of bilingualism on a range of developmental characteristics – such as reading and cognitive control. These are discussed more fully in Chapter 14. Social debate centers on the potential harm that bilingualism might have by preventing the

Suggestions for Researchers

In the research literature on deaf individuals the terms "bilingual" and "bimodal" are frequently used, though not always consistently. Bilingual refers to having knowledge of two languages (ASL and English), and, most often (though, confusingly, not always), "bimodal" refers to speaking and signing. The importance of these constructs cannot be overemphasized, and the recognition that most deaf users of ASL are bilingual is central to what distinguishes population studies that derive from the M/R/NE models described above from those that derive from the perspective of language diversity.

"assimilation" of bilinguals into a monolingual society. This view is thankfully fading away, as society becomes increasingly tolerant and embracing of different languages and cultures.

Turning to modality, ASL is a language that is almost universally rendered in the visual–gestural modality. On the other hand, English (and other spoken languages) are rendered primarily in the auditory–spoken modality. However, in the case of written languages, spoken words are given visual form through a writing system. Some writing systems employ an alphabet to convey the sound-based phonological information encoded in the written words (as in the case of English), while others are logographic (for instance, Chinese characters) – that is, they convey the semantics or the ideas of the words through their symbols. There are ongoing efforts to develop writing systems for conveying ASL; this is a seemingly logical progression in the evolution of a language, especially given the visual nature of the sign and the possibility for logographic representation of is phonology, morphology, and syntax on the written page (see Arnold, 2012 and Sutton, 2002 for examples).

Confusions arise in understanding and describing the nature of ASL/English bilingualism, particularly with respect to issues surrounding modality. What is the written word? To be sure, written words are encountered in the visual modality, yet their close association with the sound-based phonology of the spoken words they represent has led many to believe that successful reading requires knowledge of these sound–grapheme associations.

Not all researchers believe this to be true. Citing a wealth of correlational research that demonstrates a strong relationship between ASL skill and reading ability, many have postulated that a sound-based phonological knowledge is neither necessary nor sufficient for the development of the reading skill (e.g., Allen et al., 2009; Morere and Allen, 2012; Prinz and Strong, 1998). Additionally, Mayberry, del Guidice, and Lieberman (2011) conducted a meta-analysis of over 60 studies on the relationship of sound-based phonology to reading skill among samples of deaf individuals and found a remarkably low effect size for phonological knowledge on the prediction of reading skill. Given these findings, a considerable amount of research and thinking has been directed toward understanding why and how ASL fluency can lead to reading ability in the absence of sound-based phonological knowledge.

One subgroup of individuals is truly bilingual *and* bimodal: children who are learning both ASL and speech. While most research on this mixed bilingual and bimodal group is carried on hearing children born to deaf parents, deaf children who come from signing families and receive cochlear implants make up an important subpopulation for study. This group is increasing in prevalence, as more and more signing families are electing to implant young deaf children (and, conversely, more and more children with cochlear implants are coming from families who sign). Allen and Anderson (2010) report 11 percent of the 8,325 students with profound deafness reported to the 2008 Annual Survey as *both having a cochlear implant and coming from a signing family*. In a recent research brief that summarizes the research evidence on the advantages of a bilingual and bimodal approach, Mitchiner, Nussbaum, and Scott (2012) conclude that educational programs that foster the development of both speech and ASL for children with cochlear implants have the potential for providing considerable bilingual advantages for the children enrolled in these programs. Future enumeration studies examining ASL as a linguistic subgroup should devote some attention to this "subgroup of the subgroup" and should consider the broad range of implications of being both bilingual and bimodal for language development in children.

Age at onset of deafness, age at identification, and age of exposure to a visual language

The ages at which deaf individuals become deaf, are identified as being deaf, and are exposed to a visual language are extremely critical characteristics and they need attention in any attempt at population enumeration within a language diversity model, as both perceptual and language experiences in childhood will greatly influence these individuals' later language choices and abilities. A baby who is born deaf, is known to be deaf at birth, and has access to a visual language from birth will, as an individual, develop quite differently from one who is born hearing and becomes deaf later, is born deaf but not identified as being deaf until later, or is not exposed to a visual language until later, in spite of being born deaf and identified early. Clearly the timing of these events is critical in determining the language development of young deaf children. There is near-universal agreement that early identification is important, and there is common support for universal newborn hearing screening (see, e.g., Yoshinaga-Itano, Sedey, Coulter, and Mehl, 1998). However, the support for early visual language is not universal: promoters of approaches such as auditory–verbal therapy actively discourage the use of any visual language (or really any visual support up to and including lip-reading), believing that developing listening skills, even among deaf children with profound hearing loss who use assistive technologies, is the only way to optimize chances for developing speech and language skills (A. G. Bell Academy for Listening and Spoken Language, 2012). This prescription is highly controversial, and there is little published research to support the claim on which it is based. In fact there is mounting evidence to support the idea that early visual language exposure ensures the development of areas of the brain responsible for language processing and ultimately benefits the development of both spoken and signed language skills, as well as the development of literacy (Mayberry, Chen, Witcher, and Klein, 2011; Petitto, 2000; Yoshinaga-Itano, 2006).

Suggestions for Researchers

Given the importance of these three questions (age when a participant became deaf, age when a participant was identified as being deaf, and age of exposure to visual and spoken languages) to a full understanding of any deaf individual's use of language at any age, you should consider asking your participants to report on these factors. As noted above, language experiences during a child's first few years of life will have a profound impact on their language usage throughout their lives.

Parental hearing status and language use in the home

Another critical characteristic of deaf individuals is whether they were born to deaf parents and, as a related issue, what language (or languages) are used in the home. From a cultural perspective, being born into a deaf family clearly has implications for the course one's life will take (Padden and Humphries, 1988; 2006). Not only does having a deaf parent usually imply an early access to visual language; it also appears to be true that deaf parents are more adept at managing the visual gaze of their children during critical activities like book sharing (Lieberman, Hatrak, and Mayberry, 2011; Singleton and Crume, 2010) and during critical periods in language and cognitive development. While one might be tempted to focus studies of the demographics of deaf ASL users as a linguistic subgroup solely on the group of deaf individuals from deaf families, it should be noted that this focus might lead to some erroneous oversimplifications. The prevalence of deaf children with deaf parents is very low (Mitchell and Karchmer, 2004). One often hears "one in ten" as representing the percentage of deaf children born to deaf parents; however, a close scrutiny of the research fails to validate this contention. Early studies in the 1970s (both in the Annual Survey and in the NCDP) are plagued with missing and unknown responses to questions about the hearing or deaf status of parents, especially the father. Mitchell and Karchmer (2004) performed an analysis of 1999–2000 data from the Annual Survey. They take note of the pattern of missing and unknown data, the differential response rates for mother's and father's hearing status, and conclude that previously reported rates of 10 percent are significantly overstated (the true rates are most likely in the 5–6 percent range). Thus, limiting study of linguistic diversity to deaf individuals from deaf families will result in the study of a very small number of individuals indeed. While it is critically important to study this population to fully understand the nature of being culturally deaf and born into a social environment where the language in the home is a fully accessible visual language, a field of inquiry that seeks to describe and understand ASL use in a broader context will lead to a greater understanding of how ASL is used throughout society. Important questions about ASL use extend beyond comparisons of native and non-native users. For example, how do teachers use ASL in classrooms for deaf individuals? What are the most effective means of teaching ASL? Given that hearing parents will often be learning ASL at the same time their children are, what constitutes "enough" ASL to effectively prepare deaf children for school? What variations in sign are in evidence among different societal subgroups?

Sociocultural studies of sign use and linguistic diversity among deaf signers is a fascinating area of study that contributes to our understanding of cultural diversity in our society.

The lives of deaf children in hearing families are not well studied or understood (other than from the M/R/NE perspectives). Allen and Anderson (2010) analyzed data from 8,325 students with a profound level of hearing loss (90dB average hearing threshold in their better ear). In 88 percent of the 7,358 students for whom parental hearing status was reported, *both* parents were hearing (see the previous cautions about missing data and its potentially biasing influence on prevalence rates), and 53 percent of these 7,358 students came from homes where signing was regularly used. Thus it is clear that signing is regularly used in many homes of deaf children whose parents are both hearing.

We do not know the nature or the quality of the sign communication that is going on in the homes of deaf children with hearing parents, even when they report that they are signing with their children. Young (1997), in an interesting qualitative study that employed semi-structured interviews of hearing parents, their deaf child's hearing teachers in a bilingual early intervention program, and deaf home visitors (consultants) who served as role models and provided some sign instruction in the homes, queried the informants about how they conceptualized parents' early sign language use. She found quite different frameworks employed by her three types of informants. Teachers were likely to focus on the parents' lack of ability to employ formal aspects of British Sign Language (BSL) grammar and vocabulary. For teachers, parents were not using BSL at all, and parents' communication was different from the language that was used in the classroom. Quite differently, the Deaf consultants saw little relevance in whether parents were signing in formal BSL or not. They were concerned with the more practical and functional relevance of the parents' signing, and they expressed more concern over visual quality and the child's appropriate use of individual signs in specific situations. Finally, parents were split between those who were striving to master formal BSL and those who were focused on achieving effective communication with their children. This research points to the pursuit of linguistic rigor versus effective pragmatic communication as a useful distinction that will inform studies on ASL use.

Conclusion

In all research with human participants, researchers must define a population of interest on a clearly defined set of research questions, develop a means for sampling from this population, create indicators for determining membership in subgroups of the population that have relevance for the stated research questions, and employ strategies for collecting data that will provide information on how answers to the research questions are informed by a knowledge of the characteristics of the sample. It is evident that there is considerable diversity *within* the overall population of sign language users. Thus any piece of research must identify its place within the broader population and be clear about the extent and limitations of its generalizations. Hopefully, future demographic studies will provide a means for better positioning individual research projects within the population at large and will provide a framework that takes language use and family experiences into consideration in defining the nature of the inquiry.

In the case of studies based on the M/R/NE models described earlier, establishing the categories of interest is straightforward. Nonetheless, as we have seen, in spite of the fact that the categories of interest may be easily defined (an audiogram, a grade equivalent, an income), the means for collecting and interpreting data are by no means simple, and we have seen how methodological issues (missing data on one or both parents' hearing status, for example) can cause misleading and incorrect conclusions.

Moving from an M/R/NE model to one that has language diversity as the underlying framework certainly makes the research endeavor more complex, as we do not have a clear, unambiguous understanding of ASL. We have noted earlier how simple questions to participants about whether or not they use ASL may result in identical responses that represent quite different actual communication practices. This compounds the lack of a legal or accepted definition of who is either audiologically deaf or culturally deaf (often spelled "Deaf"). If the latter is a matter of individual choice, we would still be at a loss as to how best to calculate or enumerate any reliable prevalence rates. Who can be defined as Deaf? Only people with abnormal audiograms? Hearing individuals who are fluent users of ASL, given that children of deaf adults often identify with the Deaf community? Much of the critical work in ASL also pertains to its role in the learning experiences of young deaf children (including infants). Certainly young children do not themselves choose to identify with a particular culture. In the situation of deaf children *born* into Deaf signing families, we might make assumptions that allow us to accurately describe a Deaf, ASL-using subgroup. Indeed this would be an excellent approach for studying the linguistics of ASL. However, many questions about deaf people and their use of ASL are much broader, extending into domains of cognitive psychology, child development, sociology, education, and neuroscience. Answering these questions requires a more inclusive view of the population of interest. Throughout this chapter we have argued that it is precisely this inclusive point of view that will embed the findings of our research in a cultural, social, and linguistic context that will enhance the relevance of our work as researchers.

As we have seen, this work is complex, but sorting out this complexity is worth the effort for all researchers working in sign language research, as well as for population scientists who seek more appropriate ways to describe a unique population of individuals. Returning to Mitchell's four constraints for population enumeration (context, indicators for group membership, methods of data collection, and resources available), the first constraint (specifying the context) drives the others. Cultural contexts in which our goal is to understand the interactions among Deaf individuals within the Deaf community may indeed benefit from a narrowly defined population. But often our interests are broader, especially given the higher prevalence of deaf children born to hearing parents and the profound impact that early language experience has on the wellbeing of deaf individuals as they grow. Critical studies of this population, more broadly defined to include hearing families who may be emerging as bilingual, will contribute to a deeper understanding of the role of linguistic diversity in society and education and of the benefits that accrue with a greater understanding and appreciation of human differences.

Note

1 Throughout this chapter we will use a lowercase *d* when referring to deaf individuals. While the uppercase *D* is often used to refer to members of the Deaf community, our point here is to encourage the adoption of a diversity perspective when evaluating language use in a population, across a wide span of linguistic and cultural contexts, which include individuals who may or may not identify with the Deaf community but may use sign language regularly in their lives.

Keywords

ASL prevalence; deaf culture; demographics of deafness; linguistic diversity

See Also

Chapter 12; Chapter 14; Chapter 15; Chapter 17

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3 Dissemination and Transfer of Knowledge to the Deaf Community

Robert Adam

Chapter Overview

There is currently a great emphasis on knowledge transfer during the research process. While in the past this has been an additional element for researchers to consider, presently it is a central component of any successful research team's work. In the context of carrying out research into sign language, this transfer involves disseminating the findings of the research in a timely, accessible, and appropriate way to the Deaf[1] community. The ultimate aim of knowledge transfer is to appropriately inform and in the long term empower the Deaf community. This chapter discusses the origins of linguistic and cultural research into the Deaf community as a research population (over the years, this has been the subject of research undertaken by hearing and Deaf researchers who have

Research Methods in Sign Language Studies: A Practical Guide, First Edition.
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examined the history, culture, anthropology, linguistics, sociolinguistics, and neuroscience of being Deaf). Then it focuses on the examination of the public engagement process as undertaken in British universities, with specific reference to the Deafness Cognition and Language Research Centre (DCAL). Finally this work will be used to make some recommendations concerning information dissemination and the transfer of knowledge to the Deaf community.

Introduction: The Sign Language Community as a Research Population

The genesis of modern sign language research can be traced back to the early investigations in the Netherlands during the 1950s by Bernard Tervoort at the University of Amsterdam, who was looking at how Deaf school children had their own esoteric communication system (Tervoort, 1953). Tervoort concluded with this advice for teachers: "if you want deaf children to learn your language, you first have to learn theirs" (quoted in Knoors, 2007, p. 242). While he tantalizingly refers to "their" language, he was not the first to describe this communication system as sign language; the first to do this was William Stokoe, then a professor of English at Gallaudet College, a liberal arts college for Deaf people in Washington, DC. Stokoe, who is considered a pioneer of sign language research, suggested that Deaf people did not use a poor form of English in their signing; in his view signing was in fact a proper language (Stokoe, 1960). Stokoe's pioneering study was followed by a dictionary compiled by him and colleagues (Stokoe, Casterline, and Croneberg, 1965), which included a form of sociolinguistic description of the Deaf community of the United States. This was the impetus for early research into American Sign Language (ASL), which thus led to the early neuroscientific analyses of sign language by Klima and Bellugi (1979) and the first sociolinguistic discussions of the sign languages of Deaf people in the USA by James Woodward (1973).

Sign language research commenced in the United Kingdom in the early 1970s, and the name "British Sign Language" (BSL) made its first appearance during this period (Brennan, 1975); it was followed by early publications by researchers at the University of Bristol (Woll, Kyle, and Deuchar, 1981) and by the first book on BSL (Deuchar, 1984). The first sociolinguistic discussion of the Deaf community in the UK appeared in 1981 (Woll et al., 1981). The first dictionary of BSL was published in 1992 (Brien, 1992), although this research was not replicated all around the world.

It is important to recognize that research on Deaf people as a cultural minority only began in earnest once it was established that they were actually a language community. In terms of knowledge transfer, most of these early insights were useful for the academic community; but the questions raised by this research, while being scientific, inevitably had social implications for the lives of Deaf people. For example, once it was established that ASL was a real language, it became important that interpreters for Deaf people be appropriately trained – just like any other language interpreters. Lou Fant, a well-known American actor and interpreter, did not realize that ASL was a true language until he first met two American academics, Edward Klima and Ursula Bellugi, who referred to Stokoe's early work and assured him that ASL was a full-blown language (Fant, 2000). However, this was some time before research findings on sign language were translated into sign language, for the Deaf community to use them in their own political and professional lives.

While research on aspects of Deaf culture has appeared in various articles, book chapters, and dictionary introductions, the first book devoted to Deaf culture in the USA was published by Carol Padden and Tom Humphries (1988) and in the UK by Paddy Ladd (2003), all of whom are Deaf people. These books have been followed by knowledge transfer activities at community, college, and university level through courses and workshops in Deaf culture. Further investigation of Deaf culture has not been highly prioritized over the years, and research into the linguistics of sign language has always been better resourced than the research into cultural aspects of being a member of this language community. Hence research methodology relating to Deaf people has tended to focus on sign language data, as opposed to social and cultural data. Yet cultural research yields an important part of our understanding of sign language and of the people who use this form of communication.

It can be said that this body of research into the language and culture of Deaf people has led to a better understanding of them as a linguistic minority, and this in turn has caused an improvement in the quality of their life. The recognition of BSL by the British government in 2003, for example, stimulated increased funding for specific sign language initiatives, although full legal recognition has not yet been achieved and there is more work still to be done in this area. In Australia, the publication of the first Auslan dictionary (Johnston, 1987) was followed by the mentioning of Auslan in the National Policy on Languages (Dawkins, 1991). Other organizations, such as the World Federation of the Deaf, have over the years relied on this academic body of research to substantiate their policies and position papers (visit its web site at www.wfdeaf.org).

It is important to recognize that research on Deaf culture and sign language would not have been possible without the participation of Deaf people as a linguistic group. This is why knowledge transfer activities as part of the research process become very important. Sign language research depends on collaboration with Deaf people and Deaf organizations around the world. If researchers want the Deaf community to engage positively with their research, Deaf people need to understand what the research is about and what its benefits for their community are. Yet public engagement and research dissemination are not always factored into research projects, and this is so for a number of reasons. In the past, sign language researchers have often been hearing people who are for most part from outside the Deaf community. Consequently data have been collected by various means, conclusions drawn by hearing and Deaf researchers, and findings published in books and journals or presented at academic conferences. These published books, book chapters, and journal articles are all in a written language and the presentations and lectures are mostly in a spoken language – and not in the first language of Deaf people.

The situation relating to the accessibility of academic publications for Deaf people is changing. One of the earlier books on the linguistics of BSL included a CD-ROM with a BSL version of the book signed by Deaf people (Sutton-Spence and Woll, 1999), and a more recently published dissertation by a Deaf PhD student on the citizenship of Deaf people included a translation on a DVD (Emery, 2011). These are more the exception than the rule. Other canonical publications on sign language and Deaf culture still do not have an equivalent translation or a version in sign language, either in print or on the Internet. Sign language researchers, both Deaf and hearing, have from time to time been invited to local, national, and international conferences of Deaf people to present their research, and this has been a form of public engagement; however these invitations have usually been the initiative of the conference organizers as opposed to being an objective of the research project. Consequently, as a research population, Deaf people have largely not had access to research and research findings in their own language.

Another important consideration is that Deaf people do not know as much about their sign language as hearing people know about their spoken language: sign language is not studied as a language in schools, and there are very few places in the UK where it can be studied as part of a university degree. Deaf people do not always understand the nature of their language and how being Deaf can influence their experience. They do not have equal access to society, because not everyone can sign and interpreters are not readily available. To repeat: in the past, research on Deaf people and sign language has often not been made accessible for Deaf people. Here is where knowledge transfer comes in.

The Public Engagement Process

Public engagement has become more relevant in recent years as research funders became more aware and more concerned about how researchers and the public interact with each other. Brown (2011) quotes Alan Leshner, the chief executive officer (CEO) of the American Association for the Advancement of Science, as saying:

> simply trying to educate the public about specific science-based issues is not working. We need to move beyond what too often has been seen as a paternalistic stance. We need to engage the public in a more open and honest bidirectional dialogue about science and technology.

Hence, in the UK and USA, there have been moves to enhance the public engagement process between research and science on the one hand and the wider community on the other.

The Research Councils UK (2011) defines public engagement as "any activity that engages the public with research, from science communication in science festivals, to consultation, to public dialogue." Rowe and Frewer (2005) discuss some of the terminology used in the "public participation" process by listing three key concepts which can be seen in Figure 3.1: public communication, public consultation, and public participation; these are distinguished by differences in how information flows between the "exercise sponsors" and the "participants." Rowe and Frewer's typology

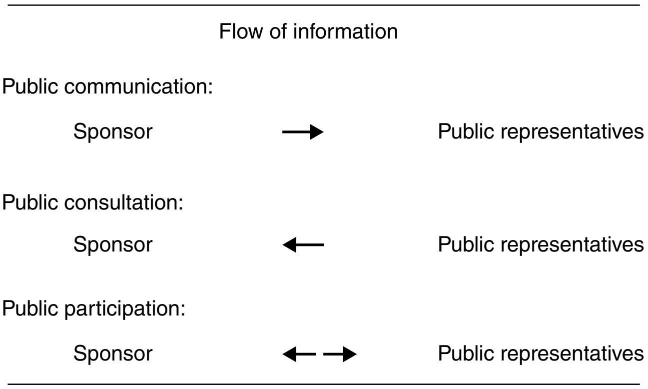

Figure 3.1 The three types of public engagement. Source: Rowe and Frewer, 2005, p. 255.

has four communication, six consultation, and four participation mechanism classes. The authors discuss the great vagueness in defining the terminology related to public involvement and public engagement, as well as the mechanisms of this participation process. Because of differences in how information flows between the "sponsors" of the process and the "public representatives," public participation is generally defined as having three concepts of "engagement."

"Public communication" is characterized by an information flow from the sponsors to the public; "public consultation" is characterized by a flow from public representatives to the sponsor; and in "public participation" information is exchanged as part of a dialogue, usually in groups of participants.

Public engagement, on the other hand, can take a variety of forms – Rowe and Frewer refer to almost a hundred different forms (including question-and-answer sessions, task forces, workshops, and action planning) and discuss the possible vagueness of and overlaps between the different terms used. Within the typology, the different forms of communication engagement include cable TV, drop-in centers, hotlines, information broadcasts, the Internet, public hearings, and public meetings with question-and-answer sessions. Consultation engagement includes citizens' panels, consultation documents, electronic consultation, focus groups, open spaces, opinion polls, referenda, study circles, surveys, and telepolling. Participation engagement includes action-planning workshops, citizens' juries, consensus conferences, deliberative opinion polls, negotiated rulemaking, planning cells, task forces, and town meetings with voting.

Each of these mechanisms differs from the others in terms of whether the selection of participants is controlled or uncontrolled, whether facilitation includes elicitation of responses, whether responses are open or closed, whether the information input is set or flexible, whether the process is face to face or not, and whether the whole process is structured or unstructured. Rowe and Frewer conclude that public engagement takes different forms and is enacted through different mechanisms and that this proposed typology should enable further development and elaboration and more extensive discussion.

Researchers working with the Deaf community could therefore engage with their research population – Deaf people – by using various means; and there are many opportunities for them to do this.

Public Engagement at the Deafness Cognition and Language Research Centre

A number of research institutions around the world undertake research into various aspects of Deaf people's lives. Such are the Visual Language and Visual Learning (VL2)—a science of learning center (SLC) on visual language and visual learning funded by the National Science Foundation and hosted by Gallaudet University—and the International Institute for Sign Languages and Deaf Studies (iSLanDS) based at the University of Central Lancashire, UK. Other universities – such as the University of Hamburg, the Chinese University of Hong Kong, the Centre for Deaf Studies at Bristol, and the University of the Witwatersrand in South Africa – have centers that undertake academic teaching and research in this field. Here I will use the Deafness Cognition and Language Research Centre (DCAL) as a model of good practice for knowledge transfer: this is a multidisciplinary research centre based at University College, London and is funded by the Economic and Social Research Council, the British government's research funding organization (Adam, 2009). DCAL opened in 2006 with a first tranche of funding for five years and was awarded its second five-year funding in 2011; this will take it to the end of 2015. According to its web site, DCAL brings together researchers from different areas, including sign linguistics, psychology, and neuroscience (visit www.ucl.ac.uk/dcal). This is the largest research centre of its type in Europe, and its researchers are both hearing and Deaf.

The DCAL web site explains what distinguishes its work: the vast majority of research studies on language and thought are based on languages that are spoken and heard, whereas DCAL's research provides a unique perspective on language and thought on the basis of Deaf people's communication; hence also its great need to engage with the Deaf community. DCAL places sign languages and Deaf people at the center of the general understanding of how language and communication work within linguistics, psychology, and child development. Deafness offers an important model for exploring questions in linguistics, cognitive sciences, and neuroscience. This is now much more widely recognized, thanks in large part to DCAL's research efforts over the past five years.

Three years of research and publication were followed by the decision to initiate a public engagement program and to disseminate information to the Deaf community. After publishing research updates in the *British Deaf News* (Adam, Orfanidou, McQueen, and Morgan, 2007; Stone, Adam, and Carty, 2008) and in the *World Federation of the Deaf News* (Adam, 2009), DCAL decided to host workshops to be attended by members of the Deaf community and other interested people. A Deaf Open Day was thus held at UCL on March 20, 2010, with presentations in BSL from Deaf and hearing researchers and with hands-on interactive sessions and posters in the foyer outside the lecture theater. Researchers reported back to members of the Deaf community on research undertaken at DCAL; and this was done for the first time in BSL, the language of the Deaf community. The Deaf Open Day was also supported by Beacons for Public Engagement program, an initiative funded by the UK funding councils, Research Councils UK, the Wellcome Trust, and the Economic and Social Research Council (ESRC) Festival of Social Sciences.

The presentations, the hands-on interactive sessions, and the posters illustrated a range of disciplines at DCAL, particularly neuroscience, psycholinguistics, sociolinguistics, and sign language interpreting. The presentations were well received, and the hands-on activities were a great success; people queued up for an opportunity to have a try. The posters were modified so as to be accessible to the general Deaf audience. The interactive activities included a fingerspelling game where Deaf people were challenged to a high-speed set of fingerspelled words – which was most popular.

Presentations highlighted a number findings that, until then, had not been formally disseminated to the Deaf community in BSL:

- In a study of the Deaf brain, it was found that the same classical language processing regions in the brain were activated in sign language as in spoken language, particularly the Broca's and Wernicke's regions. This is neuroscientific evidence that sign languages are processed in a similar way to spoken languages (MacSweeney, Waters, Brammer, Woll, and Goswami, 2008).
- Deaf people are unique in that the visual processing areas of the brain are also activated when watching sign language and the mouthing of words that occurs with sign language (MacSweeney, Capek, Campbell, and Woll, 2008).
- The same area of the brain that is used for reading is also used when watching fingerspelling. This has significant implications for teaching Deaf children reading through fingerspelling (Waters et al., 2007).
- In Deaf people the auditory cortex is still activated when sign language is used (Capek et al., 2008).
- A study of how Deaf people segment signs while watching a constant stream that contains both real signs and nonsense signs found that they made, in their sign language, phonological errors similar to those made by hearing people when listening to real words and nonsense words (Orfanidou, Adam, McQueen, and Morgan, 2009).
- Another study found that Deaf children do have a specific language impairment; this is a significant finding in that it highlights the need for parents and teachers to understand the needs of these children. This impairment may manifest itself in sign production (the ability to produce sign language) or in sign comprehension (Mason et al., 2010).
- Deaf people act as translators or language brokers within the community (Adam, Carty, and Stone, 2011).
- An update on the British Sign Language Corpus project, a three-year corpus project funded by the ESRC (www.bslcorpusproject.org), included information about dialect change in the British deaf community (Stamp et al., 2014).

The Deaf Open Day ended with a cultural event where two Deaf poets performed and three short films made by emerging Deaf directors were screened: a relaxed ending to a very detailed and informative workshop. With such events, researchers could ensure that public engagement activities are not only informative in terms of the research being disseminated but also educationally fun and culturally appropriate.

There was also a video booth where it was possible to give evaluations in BSL. The feedback was overwhelmingly positive, with minor comments relating to the lack of afternoon tea. Many participants also asked when it would be possible to have another such day. A total of 175 individual enquiries were logged, although just over

100 people attended; it can be said that, through this activity, the DCAL was able to reach a wider cross-section of the community for the first time. This public engagement activity can be said to have been conducted face to face, in a structured form, although it had open participation (as opposed to controlled participation), with a question-and-answer session at the end. However, this public engagement process was not restricted to one single research project; it was conducted separately from the funding objectives of the various projects that featured in the DCAL Deaf Day.

After the Open Day in London, it was decided to take this event out of the capital, to Deaf people in other areas of the UK. Funds were then obtained from the UCL Beacons for Public Engagement to organize a roadshow and visit six other cities in Britain and to add pages to the DCAL web site where Deaf people would be able to find out more, in BSL, about research at DCAL. The following cities were visited as a part of this initiative: Birmingham (March 19, 2011), Glasgow (April 9, 2011), Newcastle (May 7, 2011), Manchester (May 28, 2011) and Belfast (September 3, 2011). A deliberate decision was made to hold each of these events in the local Deaf club, to encourage as many Deaf people to attend as possible. People are less likely to attend a workshop in an unfamiliar location. The fact that these events were held outside London is in itself an acknowledgement that Deaf communities exist in both metropolitan and regional cities and that public engagement should not be confined to major cities.

At each roadshow, three to four DCAL researchers presented their work on topics such as language acquisition, the Deaf brain (MacSweeney, Capek, et al., 2008), Deaf interpreters (Adam et al., 2011), Deaf people and autism, Deaf people and dementia, the sign segmentation project (Orfanidou, Adam, Morgan, and McQueen, 2010), and the BSL Corpus project (Stamp et al., 2014). Deaf people have been very interested to come and learn about our research at DCAL.

Feedback was, again, positive. Participants were given feedback forms to complete that had the following questions:

1. What did you find the most useful about the day?
2. What did you find the least useful about the day?
3. Is there anything we could have done better?
4. Was the use of academic language easy to understand?
5. How did you hear about the DCAL Deaf Roadshow?
6. How would you like to hear about our research in future (newsletter, another open day, etc.)?

Quotations from the feedback include:

> *Having access to the research that is being carried out at DCAL firsthand!* (Belfast)
> *All the presentations were useful and interesting.* (Bristol)
> *Keep up the fantastic work!* (Glasgow)
> *Yes, very (much) looking forward to the next one!* (Glasgow)
> *The statistics and proof are very important, and it was very interesting.* (Birmingham)

The 10th-year anniversary of the recognition of BSL was seen as another opportunity for DCAL to pass on research findings to the Deaf community for political lobbying outcomes, with the aim of further enhancing the standard of life for Deaf people in general. Organized in partnership with the British Deaf Association, this event was called “BSL Recognition: The Way Ahead” (British Deaf Association, 2013). Speakers included Robert Adam, a doctoral researcher into bilingualism, Paddy Ladd, an anthropologist who proposed the Deafhood framework, Maartje De Meulder, a PhD student from the University of Jyväskylä, Finland, and two representatives of the British Deaf Association – David Buxton, the chief executive and Terry Riley, the chair. This event was attended by 99 people and was streamed live over the Internet and continually watched by 187 people (with 1,333 hits over the duration of the event).

The DCAL presentation by Robert Adam covered a range of research aimed at empowering Deaf people, which covered historical, linguistic, neuroscientific, psycholinguistic, and genetic aspects of being Deaf. Maartje De Meulder spoke on language policy and legislation in the UK and Europe, and Paddy Ladd spoke on the Deafhood concept and how it related to minority linguistic rights and cultural rights (as opposed to rights under national and international disability legislation). David Buxton and Terry Riley spoke at length about how the British Deaf Association planned to represent the linguistic human rights of Deaf people.

This public engagement session was unique in that it was not originally proposed or written into a research funding proposal but sought to collate currently available research relating to Deaf people and their linguistic and cultural rights and to present this information in BSL; so it could perhaps be said that this exercise was based on previous public engagement efforts and was aimed at engaging Deaf people not on a research project, but on a very specific aspect of their everyday lives: their linguistic human rights. It can also be said that this activity prepared this group of Deaf people by equipping them with current knowledge and making them ready for any future public engagement activity specifically related to a research project. As a consequence, the British Deaf Association established a Legal Status of British Sign Language working group, which will report back to another public engagement seminar to be held on March 18, 2014 – one year on from the 10th-year anniversary event. This illustrates the importance of the relationship between research and community lobbying; the seminar in 2013 led to the formation of this working group. Similarly, the publication of the *Dictionary of British Sign Language* (Brien, 1992) led to an enhanced status of BSL and its recognition by the British government in 2003. Without such research evidence to show that BSL exists as a full language, it would not have been possible to lobby for this recognition.

Another possible area of empowering Deaf people is work with Deaf children in schools. There is no reason why this information should not be available to school-age children, especially as other hearing children have access to new developments in their own language. This has a very positive, long-term empowering potential.

In summary, there are a number of ways in which a researcher (whether Deaf or hearing) can engage with the Deaf community. The engagement can be either formal or informal, but it is essential for researchers to become involved with the Deaf community at a social level, to get involved in its events, and to familiarize themselves with the local community. One can even start by subscribing to the local or national Deaf community newsletter. The researcher should also learn the language of this community. Public engagement can take many different forms, as long as it is a two-way process and is factored into research programmes. Only then will it be possible for researchers to engage effectively and ethically with the Deaf community and undertake research that will be of scientific interest and will at the same time benefit a disadvantaged group in society.

Conclusion

Research-funding councils are increasingly interested in the impact factor of research undertaken by sign language researchers and in funding research projects that outline public engagement with the research population. Not only should conference presentations be factored into funding applications; public engagement and information dissemination should be included as a matter of course into every project dedicated to the development of a research question, planning a research project, outlining data collection from Deaf people, and reporting back to the Deaf community. To not consider doing this is often seen by Deaf people as opportunistic and deeply unethical, and such practices should be discontinued where they existed in the past. This is also a challenge, as many sign language researchers who are hearing cannot sign and are not able to engage with Deaf people. Parallels can be drawn with cases of feminist research (Sanger, 2003) where the researcher benefits personally from undertaking research into a disadvantaged group whose members do not necessarily find their situation improved. It is hoped that, with an increased awareness of the need for scientists and researchers to take part in public engagement processes, the Deaf community and the general public will have, in the long term, greater involvement with scientific research. Given the bidirectional process of the public engagement process, the Deaf community will be able to have a greater stake in research, and researchers, Deaf or hearing ones alike, will have a greater awareness of what is high on the agenda for Deaf people, be that a social, cultural, political, or linguistic agenda.

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Note

1 When capitalized, the word *Deaf* refers to the social and cultural aspects of membership of a language community. Simple *deaf* refers to the medical and pathological aspects of deafness.

Keywords

Deaf community; knowledge transfer; public engagement; public communication; public consultation; sign language

See Also

Chapter 1; Chapter 2

Suggested Readings

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