Why Researchers Working with the Deaf Community Should Learn ASL

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Abstract

Accessibility research is often performed by people without disabilities. Though there are not always easy ways to increase the number of researchers with disabilities in our field, there are simple ways that we can help non-disabled, accessibility researchers in the field better understand the populations they serve. In this paper, the authors, one hearing and one Deaf, explore the ways that becoming acquainted with the Deaf community via taking Deaf culture or American Sign Language (ASL) classes can be mutually beneficial to both the research and Deaf communities.

Author Keywords

Deaf community; Deaf culture; American Sign Language; accessibility research.

Introduction

The Deaf community includes people who are Deaf¹, people who are hard of hearing, children of Deaf adults (CO-DAs), and more. What links these people is their shared language and culture, common experiences and values, and a common way of interacting with each other and with hearing people [6]. Unfortunately, their history with hearing individuals is fraught with paternalism and discrimination [7, 8], and in order to make sure history does not repeat itself,

¹The capital 'D' refers to Deaf culture as opposed to the audiological status of having a certain level of hearing loss (deaf).

researchers must engage with the deaf community while doing research for this population [10]. Members of this Deaf community tend to view deafness as a special human experience rather than a disability or disease. Most members take pride in their Deaf identity, though this is often not understood by hearing individuals.

Much of the research that focuses on the Deaf community is not performed by members of the Deaf community. While there are not always straightforward ways to increase the number of researchers with disabilities in our field, there are simple ways that we can make hearing, accessibility researchers doing Deaf and Deaf-related² research better at understanding the populations they serve: learning about the community through classes and reading literature.

The authors of this paper are two researchers with different levels of exposure to the Deaf community: one author is learning sign language and has been involved in the community for over a year; the other self-identifies as a Deaf member of the Deaf community. American Sign Language is her primary mode of communication. We pull upon our experiences and knowledge of the community and use concrete examples from literature and research papers to discuss how an increased understanding of the Deaf community — through Deaf culture/ASL classes or Deaf studies literature — can be mutually beneficial to both the researcher and the Deaf community.

How Ignorance of Deaf Culture Can Affect Deaf and Research and Communities

Understanding Deaf culture is a necessity when doing research with the Deaf community. By understanding the culture, the researcher understands the values the people have, biases and discrimination that the group faces, and the language that the people use (often American Sign Language—ASL). Because of the strength of Deaf culture, ensuring research takes these values into account is extremely important.

Risk of perpetuating audism through research and discussion. When a researcher fails to understand the needs of the target population, they increase the risk of creating technology that is unwanted. How they then talk about the research further impacts the community. As an example, we discuss a project built for the deaf people which had no interaction with the Deaf community during its construction: SignAloud [9]. This project was created in 2016 by undergraduate university students who did not have the resources to conduct a full needs assessment in the Deaf community and likely did not know that they needed to. We do not criticize them for failing to do so; the technology they created (gloves which recognized hand gestures and mapped them to English words) was impressive and with further work could be built into a useful solution for the Deaf community.

However, this project was then advertised by two top tier universities as a "sign language translation system", and a prestigious organization gave the students a \$10,000 award for solving the same issue. The issue with this media coverage is that these gloves did not provide sign language translation. ASL is a complex language that relies on things like facial expressions (which were not recorded by these gloves), and the signs recognized by the gloves could not be understood by native signers, as a university linguistics

²Note, in this paper we choose not to use "Deaf and hard of hearing (DHH)", a common term used in accessibility research. However, this term implies there are only two parts to the Deaf community (one can only be Deaf or hard of hearing), when there are many more identities of people belonging to the community (late deafened, Deaf, deaf, hard of hearing, etc).

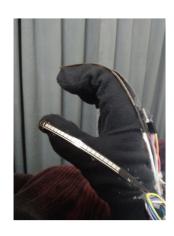


Figure 1: The glove technology created by [11].

department explained in an ensuing note [3]. Therefore, this news-proclaimed "solution" was unusable by the community for which it was meant to serve. There were several points in this competition pipeline where this misinformation which promoted both audism³ and cultural appropriation could have been stopped: the group giving the prize could have consulted with at least one Deaf person when reading the application and the two university communications offices could have validated their claims about the system with sources in the Deaf community before stating that students created a sign language translation system.

It is important to note that SignAloud was not a unique occurrence. For instance, a project called "Talking Gloves" advertised itself the same way: a translation of sign language to speech in 2018, see Figure 1 [11]. The system only used gloves for the "translation" (ignoring facial expressions), the paper did not report on consulting with any deaf or Deaf individuals, and the people who tested the gloves were people who did not have "muscular disorders" (likely hearing) and only signed letters and numbers for the experiment.

How to combat: discuss cultural/ethical debates in research It is important that, as researchers, we take the time to engage with the communities we serve, state the proper scope and limitations of our project, and hold other groups like news organizations accountable for doing the same. Many solutions in accessibility research are intermediate steps to the generation of a whole, working solution. For example, SignAloud could be used to inform the development of a more complete solution. In these intermediary steps, besides ensuring that researchers communicate clearly about the limitations of one's work (e.g., this does

hand gesture recognition only, or this only handles one direction of communication), they can also share in their work discussions, reactions, and concerns from any communities involved in the project. One paper that exemplifies this idea is Al-khazraji et al.'s paper about timing of computergenerated ASL [1]. The authors have almost one page of content dedicated to explaining concerns from the Deaf community about appropriate use of the technology and other ethical implications. We suggest more researches share the opinions of the Deaf community and Deaf organizations about the research at hand in a similar manner.

Deaf and Disability Identity

An important fact to note about the Deaf community is that many members *do not* consider themselves to be disabled. Indeed, if you ever attend a Deaf event where Deaf people are the majority, hearing people are the minority, and you are the only person who does not know ASL, you will feel "disabled" in that setting. Similarly, Deaf people often consider themselves to be non-disabled since they are by no means limited when they are surrounded by people who know their preferred method of communication, norms, and culture. A classic piece of Deaf literature which explains this via case study is "Everyone Here Spoke Sign Language" [4].

At the same time, identity is not unanimous among people who are deaf, and a person's identity can change overtime. This paper has focused on members of the Deaf community, or in other words, people who identify with Deaf culture. These people identify as capital 'D' Deaf. There are people who are deaf (meaning they have a certain level of hearing loss) but do not identify with the culture (and therefore are not Deaf). Both people who are deaf or Deaf can choose whether or not to identify as disabled.

³"[Audism] appears in the form of people who continually judge deaf people's intelligence and success on the basis of their ability in the language of the hearing culture."[5]



Figure 2: Ann Silver's *A Century of Difference*. Photo from: https://deaf-art.org/profiles/ann-silver/.

Risk of offending participants

Without understanding the identity and history of participants, researchers can more easily offend them by using non-preferred terminology. Over the years, Deaf people have been called many things including "hearing impaired", "deaf mute", and more, as one Deaf artist famously portrayed with licence plates⁴. The Deaf community chose their own label to be "Deaf", as many of the older terms have negative connotations associated with them. Using these older terms often offends people in the community [2]. "Disabled" can be a similarly unpleasant label for Deaf people who do not choose to identify as having a disability. Yet, many research papers to this day use the term "hearing impaired" (or older terms) to describe users and do not ask for disability identity when working with Deaf populations.

How to combat: ask about participant identities
Knowing that this population has a diverse range of identities, it is crucial that researchers inquire about both Deaf and disability identity and present the research in a way that respects all of these identities, especially without casting a lens of disability on those who don't identify as such. Similarly, preferred terminology can be discussed at the start of a study and used consistently throughout the study to ensure comfort of the user.

A Call to Researchers

We urge you to consider the following in your research with the Deaf community:

 Understand the community and your users by taking a Deaf culture class, taking an ASL class, engaging in the Deaf community, or at the least, reading Deaf studies literature. Understand not only the language, but the culture of this community. In user studies, take the time to ask about the identities and preferences of your users (both cultural and disability identity).

- Come in with a goal of supporting rather than influencing. In line with suggestion one, in a community with such a rich culture, our solutions for this group should do their best to support and protect the culture, not change it.
- Involve members of the Deaf community in the research. We suggest using co-design or participatory design with Deaf users. By not including them deeply in the design process, we are removing the decision making process one step further from the people who understand the community's needs the best: Deaf community members. Once research has been created, state its limitations clearly, and share opinions from the Deaf community about the research itself (see [1]).

In return for approaching research with the Deaf community with these principles in mind, we suspect that research will better serve the Deaf community, and therefore prove to be better quality research as a whole. Additionally, we may be able to strengthen the bonds between the Deaf and research communities that have been worn or, unfortunately, broken over years of researchers not understanding Deaf culture.

So from two researchers to others, we ask of you, if you are doing research with the Deaf community, please, read critical Deaf studies literature about Deaf people and Deaf culture, and maybe even take a Deaf culture or ASL class. You will do better research that is respectful of the Deaf community. What's more, you may end up making lifelong connections for research, and even friends, in the process.

⁴See Ann Silver's A Century of Difference

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