



Conducting Research with the Deaf Community

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When doing research with the deaf community,* it is important to consider culturally appropriate data collection methods out of respect for participants and to obtain better data. In this brief, we describe the methods we used to evaluate Barrier Free Living's (BFL's) Deaf Services (DS) program,¹ which aims to improve direct services for domestic violence survivors who are deaf and increase local stakeholders' awareness of deaf survivors' needs in New York City. To make our evaluation culturally appropriate, it was key to (1) build trust with the deaf community we engaged in the study; (2) ensure one of the researchers was fluent in American Sign Language (ASL), which enabled direct communication with deaf staff and consumers;² (3) use interpreters and technologies to support communication with deaf participants; and (4) modify data collection tools and procedures to ensure they were accessible. These strategies helped us secure support from stakeholder partners and center the perspectives of deaf staff and survivors. We present considerations and lessons learned from our evaluation to encourage other researchers to pursue culturally appropriate research in the deaf community.³

* Lowercase deaf is typically used to refer to the physical condition of having limited or no hearing, whereas uppercase Deaf refers to deaf people who identify as belonging to the linguistic/cultural community that uses American Sign Language as its primary language. Except when referring specifically to Deaf culture, for purposes of inclusivity and simplicity, we use deaf in this brief to refer to people who are Deaf, deaf, hard of hearing, late-deafened, or Deaf-Blind.

ASL Fluency and Cultural Knowledge

When pursuing research with the deaf community, it is important to consider the qualifications of the researchers involved. These key qualifications include fluency in participants' signed language, knowledge of Deaf culture, familiarity with local signing nuances, and consideration for how differences in people's backgrounds shape their experiences and communication. In the United States, the primary signed language of the deaf community is ASL, but simply having ASL fluency is not enough in evaluation studies involving deaf people: a researcher in direct contact with deaf staff of service providers, deaf clients, and/or deaf community members must have a range of **communication fluency and cultural knowledge of and humility around the deaf community and Deaf culture**.

Deaf people who use ASL as their primary mode of communication are a subgroup of a larger group of people who have hearing losses (Crowe 2020). Cultural knowledge involves recognizing signing nuances and understanding social mores and norms of the deaf community. Someone knowledgeable about the deaf community will understand that health and mental health literacy is often low because of limited access to language during key developmental periods (Anderson, Craig, and Ziedonis 2017; Crowe 2020). Qualified researchers will also know that deaf people understand and engage in communication differently, that many deaf people experience social and linguistic barriers to accessibility, and that repeatedly encountering these barriers may make them reluctant to participate in research or access services.

Co-principal investigator for this evaluation Teresa Crowe, a faculty member at Gallaudet University, is fluent in ASL. Her fluency was measured using the American Sign Language Proficiency Interview, a holistic language evaluation used to determine ASL proficiency.⁴ The interview is a 20-to-25-minute video-recorded interactive dialogue between the examinee and the interviewer that is rated by a team of evaluators on a 0–5 scale, with 0 representing a new signer with very limited proficiency and 5 indicating native-like ASL fluency. Crowe scored a 4, signifying an ability to demonstrate “spontaneous elaboration on all familiar and most unfamiliar topics. [She is] able to use an array of rhetoric (narration, description, argument, and hypothesis) with complex topics in paragraph-length discourse related to employment, current events, and matters of public and community interest.” For its own faculty, Gallaudet University recommends a proficiency interview score of at least 3. Further demonstrating her knowledge of Deaf culture and familiarity with the deaf community, Crowe is a practicing social worker and researcher with 33 years of professional experience in the deaf community.

In addition, it is critical to **understand the variations in language and experience of people who receive deaf services**. There are approximately 300 distinct sign languages around the world.⁵ As such, deaf people born outside the United States may not use ASL as their primary language or be familiar with it. The experiences of those who have arrived in the United States as refugees or immigrants are also likely to differ substantially from those of deaf people born here (Moers 2017). Furthermore, deaf people, especially those with additional disabilities and deaf people of color, experience other challenges, including double oppression, lack of culturally appropriate services, isolation, shame, lack of trust for service providers, multiple cultural identities, multiple languages, communication barriers, and

societal prejudice (Crowe 2020; Lightfoot and Williams 2009). Lastly, people of different racial and ethnic backgrounds, including those who are deaf, have different experiences with domestic violence (Lightfoot and Williams 2009).

As many consumers in our evaluation of the DS program are from other countries, recognizing the languages they sign was important. In one on-site interview, the interpreter happened to be fluent in a particular Arabic sign language and was able to assist the interviewer with communication. Interpreters present during in-person site visits were also familiar with local sign language nuances (e.g., sign names, locations) and helped the researchers understand the cultural context. This was very helpful, especially when data collection strategies changed from in-person to videophone because of the COVID-19 pandemic. Though the interpreters were not used in videophone interviews, the researcher had previously learned of local signs, nuances, and the social service systems in the area. Differences in participants' understandings of interpersonal violence also became apparent through our interviews with BFL consumers.

Crowe's understanding and skills in these areas, and the efforts of the entire research team throughout the study, **built trust and rapport among staff and consumers**. For instance, the entire research team participated in a formal training on Deaf culture and communication during our first site visit to BFL. We then met at least quarterly throughout the project with DS staff to discuss the study and address staff concerns about privacy, confidentiality, and the researchers' impartiality. In the spirit of transparency and partnership, the research team also presented a final briefing for BFL staff to share our findings and recommendations and solicit feedback.

Data Collection and Communication Accessibility

Recruitment, sampling, and data collection procedures for the general public often exclude deaf participants. For example, random-digit-dial surveys are inaccessible for deaf people who sign, and English surveys may be beyond the language mastery of many deaf participants (Anderson, Craig, and Ziedonis 2017). In research with the deaf community, researchers must **consider particular components for the research to be culturally appropriate and maximize accessibility for deaf participants**, including different levels of comprehension in various languages, preferences for communication (e.g., written, signed directly, interpreters), and access to technology and other resources. To ensure it is accessible and representative, **it is important that research be vetted by experts in research ethics and the study population**.

As with any research design, this study was reviewed by the Urban Institute's institutional review board. Gallaudet University's institutional review board, which specializes in research with deaf populations, also reviewed and approved the research protocols. Crowe, a recognized expert in research with the deaf community who focuses on domestic violence, also reviewed all the research elements, including the methods, protocols, and materials, for accessibility.

The research team took care to ensure written products and communications for the study were accessible. For example, written text was kept to a minimum in outreach emails and flyers, the

informed-consent form, and the online survey; any text used was written using clear, concise wording. Staff at BFL reviewed our interview and survey questions to ensure they were accessible to their Deaf, deaf, and hard-of-hearing clients and that staff would feel comfortable recruiting clients to be involved in the research. As needed, we adapted the tools and recruiting strategies based on feedback from BFL. We also **used creative efforts to further increase accessibility and response rates**, including by embedding ASL videos in an online survey to ensure deaf respondents could see the consent form, survey questions, and responses options signed; by having Crowe (our ASL-fluent researcher) record a signed video introducing herself and the study in a survey outreach email; and by creating a simple flyer with a QR code to the survey that BFL staff could hand out to people during meetings or hang in common spaces. For interviews, Crowe provided informed consent, explained the research procedures, and interviewed deaf participants directly in their primary language to maximize comfort and accessibility.

We also used **a range of communication assistance strategies and technologies to further enable and encourage participation**. Initially, we collected interview data using Communication Access Realtime Translation (CART), a professional computer-aided transcription service that can be delivered on location or remotely.⁶ The CART system can use interpreters to translate ASL into spoken words through a microphone. A stenotype machine, notebook computer, and software can then create a typewritten text of interviews. The system can also project the typewritten words on a screen, but for this data collection, we intended for CART to create an immediate transcript. We ended up only using CART for one day, however, as the cost (of two paid interpreters and a CART operator) was prohibitive. We also felt it required too many people in the room to be a trauma-informed experience for participants. Subsequently (until the pandemic began), to collect interview data, we used interpreters who voiced the interviews into an audio recorder.

Our data collection procedures changed after the onset of the pandemic in March 2020 prohibited safe on-site visits and in-person interviews. As a result, the ASL-fluent researcher interviewed deaf staff and consumers using a videophone. Technologies that support visual communication, such as video remote interpreting, video relay services, and videophones, are often used for communication between deaf and hearing individuals and among deaf individuals conversing with other deaf individuals when live interpreting is not available (Bai and Bruno 2021).⁷ Videoconferencing equipment, such as videophones, can be used for direct communication similar to how people who are hearing use telephones. The videophone enabled the researcher and interviewee to converse directly in ASL; verbatim transcripts, however, were not available as they were with in-person interpreters. Using video relay interpreters for the purpose of audio recording would have proven invasive and disruptive to the interview process once on-site visits were not possible. Instead, the interviewer took detailed notes throughout and after the interviews for each question.

Recommendations for Studies with Deaf Participants

Based on our evaluation of BFL's DS program, lessons learned, and existing best practices, our team has identified recommendations for conducting research with the deaf community.

- Ensure researchers collecting data from deaf people have relevant sociocultural and linguistic expertise.
- Take time to build trust between the research team and the community participating in the study.
- Ensure deaf participants reflect the diversity of the communities they represent (including racially, ethnically, linguistically, and culturally). This also means including deaf individuals with additional disabilities (e.g., people who are deaf-blind, deaf people with mobility challenges).
- Ensure methodologies are appropriate for the deaf community and that the research design is reviewed and approved by experts familiar in this area.
- Think creatively about developing suitable research protocols and tools, such as using QR codes and embedded ASL videos for participant outreach, informed consent, and survey questions.
- Provide different accessible modes of communication (e.g., interpreters, CART, videophones).

We hope these recommendations help other researchers include deaf participants in their studies and begin to close the significant research gaps on deaf survivors' victimization experiences, the effectiveness of existing services for deaf people, and the policy barriers to meeting the needs of deaf survivors. Building knowledge in these areas in a responsible and culturally appropriate manner would help improve the availability and accessibility of programs and policy for the deaf community.

Notes

- ¹ From 2019 to 2022, the District Attorney of New York (DANY) funded the Urban Institute, in collaboration with Gallaudet University and NORC at the University of Chicago, to conduct a rigorous process evaluation of Barrier Free Living's Deaf Services. See our August 2022 report, *Strengthening Domestic Violence Services for Deaf Survivors: An Evaluation of Barrier Free Living's Deaf Services Program*, available at <https://www.urban.org/research/publication/strengthening-domestic-violence-services-deaf-survivors-evaluation-barrier>.
- ² Barrier Free Living refers to people who receive services or otherwise interact with its program as "consumers."
- ³ See our November 2021 *Urban Wire* blog post on strategies for including deaf and hard-of-hearing people in research, available at <https://www.urban.org/urban-wire/strategies-including-deaf-and-hard-hearing-participants-research>.
- ⁴ "American Sign Language Proficiency Interview (ASLPI)," Gallaudet University, accessed July 14, 2022, <https://www.gallaudet.edu/the-american-sign-language-proficiency-interview/aslpi/>.
- ⁵ "The legal recognition of national sign languages," World Federation of the Deaf, accessed July 14, 2022, <https://wfdeaf.org/news/the-legal-recognition-of-national-sign-languages/>.
- ⁶ "Communication Access Realtime Translation," National Association of the Deaf, accessed July 14, 2022, <https://www.nad.org/resources/technology/captioning-for-access/communication-access-realtime-translation/>.
- ⁷ "Video Relay Services," National Association of the Deaf, accessed July 14, 2022, <https://www.nad.org/resources/technology/telephone-and-relay-services/video-relay-services/>.

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