

Ethical Considerations in Deaf-Centered Research

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ABOVE THE STUDY

Ethical considerations in deaf-centered research demand more than standard compliance with institutional review boards; they require a shift in how knowledge is produced, who participates, and whose perspectives are prioritized. In my view, the central ethical issue is not simply protecting deaf participants from harm, but ensuring that research respects deaf people as linguistic and cultural agents rather than treating them as subjects defined by deficit.

A persistent concern is the legacy of the medical model, which has historically framed deafness as a condition to be corrected. This framing can shape research questions, methodologies, and interpretations in ways that overlook the lived realities and values of deaf communities. Studies that focus narrowly on “fixing” hearing loss without considering cultural identity, language, or community risk reinforcing harmful assumptions. Ethical research should broaden its lens to include social, educational, and cultural dimensions, recognizing that deafness is not inherently a problem but a different way of experiencing the world.

Informed consent is another area where ethical practice must be re-examined. Traditional consent processes often rely on written or spoken language that may not be fully accessible to all deaf participants, particularly those whose primary language is a sign language. Providing consent materials in sign language through video formats or live interpretation is essential for genuine understanding. Moreover, consent should be seen as an ongoing process, not a one-time formality. Participants should have continuous opportunities to ask questions, clarify expectations, and withdraw without consequence.

Representation and inclusion in research design are equally critical. Too often, deaf individuals are included only as participants, not as collaborators or decision-makers. This creates a power imbalance where hearing researchers define the agenda and interpret the findings. Ethical deaf-centered research should adopt participatory approaches, involving deaf researchers, community members, and stakeholders at every stage from framing questions to disseminating results. This not

only improves the relevance and accuracy of the research but also aligns with principles of respect and equity.

Data collection methods raise additional ethical challenges. For example, video recording is frequently used in studies involving sign language, but it introduces privacy concerns that go beyond those associated with audio data. Facial expressions, body language, and signing styles can make individuals easily identifiable, even if names are removed. Researchers must take extra care in securing data, obtaining explicit consent for recording and sharing, and clearly explaining how visual data will be used, stored, and potentially published. Anonymity in such contexts is complex and must be addressed transparently.

Another important consideration is the interpretation of findings. Misrepresentation can occur when researchers lack fluency in sign language or familiarity with deaf culture. Subtle linguistic or cultural nuances may be lost, leading to inaccurate conclusions. This is particularly problematic when findings influence policy or public perception. Engaging qualified interpreters, consulting with deaf experts, and validating interpretations with participants can help mitigate these risks.

The issue of benefit sharing also deserves attention. Research often extracts knowledge from communities without providing tangible returns. Ethical practice should ensure that findings are shared in accessible formats such as sign language videos or community presentations and that they contribute to positive change. Whether through improved services, policy recommendations, or educational resources, research should offer clear value to the communities involved.

Finally, there is a broader ethical responsibility to challenge systemic inequities. Deaf-centered research should not be neutral in the face of barriers such as limited access to education, healthcare, or employment. While maintaining scientific rigor, researchers can advocate for inclusive policies and practices informed by their findings. This does not compromise objectivity; rather, it acknowledges that research exists within social contexts and has real-world implications.

In conclusion, ethical considerations in deaf-centered research extend beyond procedural safeguards to encompass respect,

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inclusion, and accountability. By prioritizing accessibility, participatory methods, cultural competence, and community benefit, researchers can move toward a more just and meaningful approach. The goal should not only be to study deaf

individuals, but to work alongside them in generating knowledge that reflects their experiences and supports their aspirations.