

# Linguistic expertise key to improving Deaf health research

August 1 2018, by Gillian Kiley

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Anderson, Riker and their research team created a 40-minute training video that aims to help health researchers conduct informed consent with Deaf research participants. Credit: Tim Riker

For the past two years, Tim Riker, a lecturer of American Sign Language at Brown University's Center for Language Studies, has worked with a group of University of Massachusetts Medical School researchers to

tackle a significant problem: low levels of health literacy within the Deaf community, due in part to the disconnect between biomedical researchers and the Deaf population.

The collaboration, led by Melissa L. Anderson, assistant professor of psychiatry at the UMass Medical School, integrates Riker's cultural and linguistic expertise with the expertise of clinicians and researchers. A group of Deaf community advisors—laypersons from the Deaf community who advise on how best to meet the needs of their peers—rounds out the research team.

"The objective is to understand the social, political and historical experience of Deaf people and to transform [health research](#) in order to improve population [health](#)," Riker said.

The team conducted focus groups and community forums with Deaf individuals to collect information on how hearing researchers can do a better job of including Deaf people in biomedical research, Anderson said. From there, they developed and tested a new research methodology, which they outlined in a recent commentary in the journal *Qualitative Health Research*.

Cracking the code on effective qualitative research within the Deaf community could help address a range of health issues, Riker and Anderson said.

"Mental illnesses, addiction and trauma within the Deaf community are higher than among the general population," Riker said. "Rates of obesity, diabetes, suicide, domestic violence and sexual or intimate partner violence are also higher, along with other types of health disparities."

While reduced health literacy and its negative health outcomes arise in part from reduced incidental learning—for example, through

overhearing and understanding conversations or spoken health information disseminated by radio or televised public service announcements—Deaf [sign language users](#) also often miss the chance to engage with health providers and health researchers, Riker said.



Credit: Tim Riker

Some methods used in data collection, like telephone surveys, are inaccessible to some sign language users, and health researchers often do not include the interpreters and video technology needed to interview Deaf subjects as they plan their research, Riker said.

Written materials can also be problematic, according to Riker and his

colleagues. Median English reading level among the Deaf population falls at approximately the fourth grade level. This is due, Riker said, to lack of resources and systemic failures related to early language acquisition and literacy. And ASL "is fully distinct from English—that is, it is not 'English on the hands,'" the researchers wrote, but has its own structure and syntax. To move between ASL and English, ASL must be translated, rather than transcribed. When such translations are conducted by hearing researchers, they can be inaccurate or biased, the authors noted.

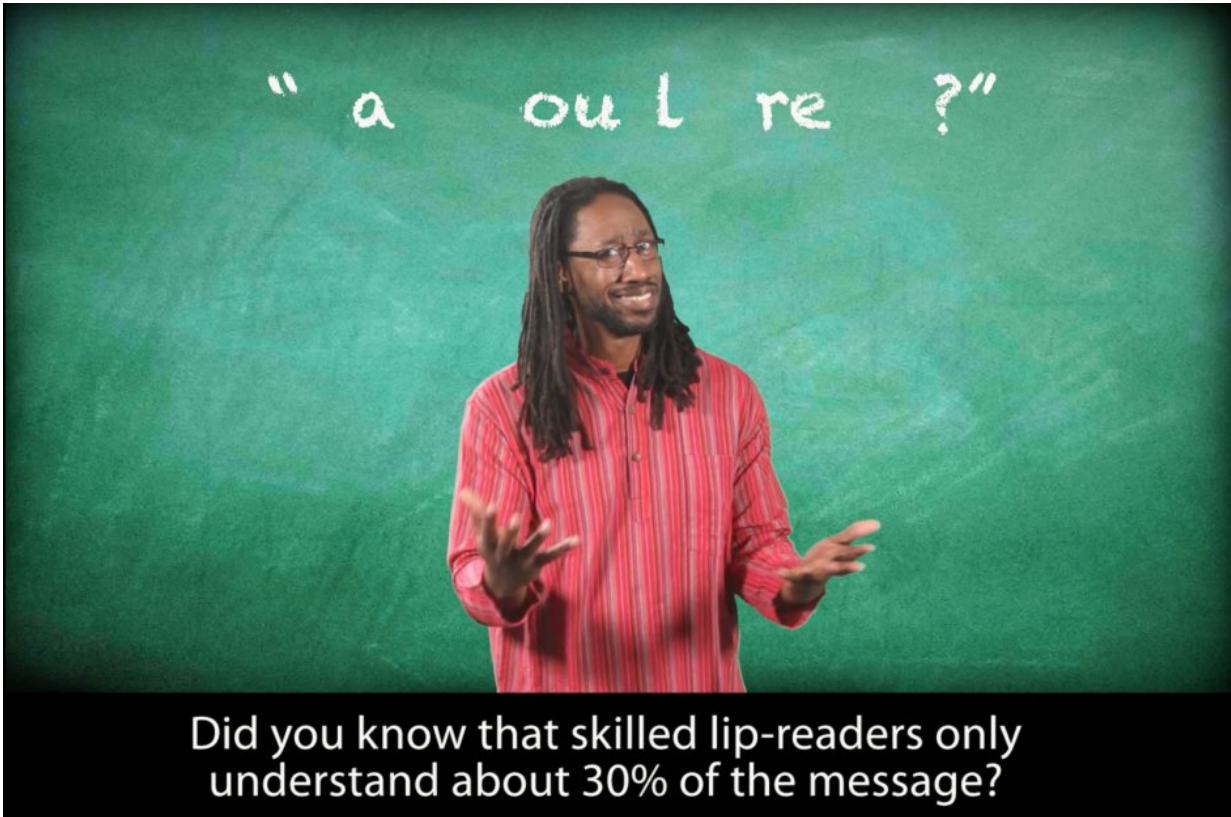
"As a hearing researcher within the Deaf community, I have to be aware of my limitations," Anderson said. "It's always important to be partnering with people who truly understand Deaf experience to avoid pursuing research questions that are not important, not appropriate, or even offensive to Deaf people."

To engage the Deaf community, which has had negative experiences with biomedical researchers, according to Riker, the group used the truth and reconciliation model—a form of fact-finding perhaps best known for its use in post-Apartheid South Africa.

"We use the model to help to heal, to come together collaboratively and to make suggestions and recommendations," Riker said. "The Deaf community was part of the research from the beginning. In the past, non-[deaf people](#) would lead research without the Deaf community being involved. This is a more integrative type of research and an even exchange."

Jeroan Allison, a professor quantitative health sciences at the UMass Medical School, has used the truth and reconciliation model to engage underserved black and Latinx communities in biomedical research with good results, Anderson said: "We applied that same process of listening to the transgressions of the majority world, apologizing and trying to

move forward together."



Credit: Tim Riker

### **A new methodology**

In developing and testing the new research methodology, Riker, Anderson and their colleagues considered everything from the composition of the research team to specific technological concerns. They recommend reforming research practice in the following ways:

- Cultivate a Deaf-majority research team to provide cultural and linguistic expertise as well as input on study design, interpretation

- and strategies for disseminating findings to the Deaf community.
- Collect data directly in the primary language of the participants (ASL) using a sign-only environment.
  - Use multiple video streams to fully capture what is being expressed, including facial expressions, which can impact the meaning of an utterance.
  - Upload video data into a qualitative analysis software package for coding without first transcribing it. This allows the researchers to code both linguistic and nonlinguistic data that a text translation would miss.
  - Analyze data collaboratively to interpret the meaning of Deaf participants' statements without personal or cultural biases.
  - Disseminate findings back to key Deaf stakeholders and the lay community through open-access products and ASL research briefs.
  - In disseminating findings to the scientific community, translate only salient direct quotes, rather than the entire dataset, into English, with the guidance of community advisors who serve as linguistic experts and cultural brokers. This preserves data in its original form, rather than as a body of translated material.

The research team created a 40-minute training video that demonstrates how to interact with Deaf research participants, specifically during the informed-consent process. The researchers are developing a larger grant proposal for an expanded five-year project that will test the efficacy of the training intervention.

Riker said that this work paves the way for creating practicum and internship opportunities for Brown students. Brown began offering ASL as an elective in 1995, and since 2005 has offered ASL as a course of study on par with other languages, Riker said. He added that while language study and health are not often integrated, the effect of such integration can be transformative.

"Some researchers have done community-based participatory research with the Deaf community, while others have published articles talking about the socio-politically respectful way to do it, or maintained the traditional approach of translating to English and analyzing the data is effective," Riker said. "We moved from theory to application. We built a team and went from start to finish with Deaf community engagement as the driving principle. Through our findings, we encourage health research to improve population health by leveraging technology rather than marginalize or exclude linguistic minority groups."

While the focus of the team's work was research in the Deaf community, the methodology can also apply to [research](#) in the 3,233 living language languages that do not have a standardized writing system, including over 138 documented sign languages, the authors noted.

Provided by Brown University

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