Using Focus Groups to Improve Surveys for American Sign Language Users

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American Sign Language users as a survey audience

- To date, there is little to no research on how users of American Sign Language (ASL) respond to surveys
 - Especially to questions of language use
- Assistance and accessibility can be provided in various ways for ASL users:
 - TDD Telecommunication Device for the Deaf. This may be a teletypewriter (TTY), a textphone, or other similar device
 - Captioned videos
 - Live interpreter or live captionist



Counting ASL users

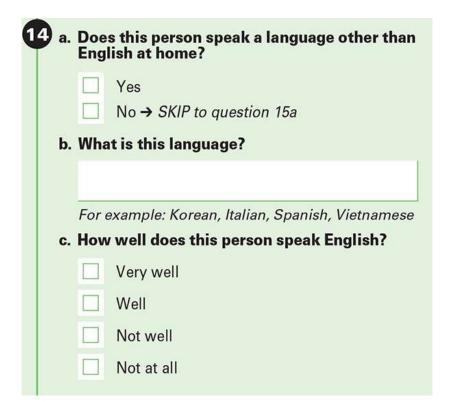
- It is important to distinguish ASL users (language) from the deaf population (health/ability)
 - Not everyone who is deaf uses ASL, and not everyone who uses ASL is deaf
- The latest national estimates available for the number of ASL users in the United States were estimated to be about 500,000 in 1974 (Schein and Delk 1974, Beale 1974)
 - These data are outdated
 - Later work has highlighted that these data are not representative of the number of ASL users in the U.S. (Mitchell et al. 2006)





Current language questions

- One widely used current example of language use is one the American Community Survey (ACS)
- We provided focus group participants with this example two days prior to the focus group for them to analyze the question to provide feedback





Goals of this project

- This project investigates the impact that the wording of language questions has on accurately counting the number of ASL users in the U.S.
- The project as a whole is split into two parts:
 - Small focus groups with experts whose work involves using ASL or working with users of ASL
 - Individual cognitive interviews with users of ASL, as well as monolingual speakers of English and Spanish, with focus on commonly used language questions
 - Total: 3 focus groups, 72 cognitive interviews
- This talk highlights preliminary findings from the focus group segment



Focus Group Methodology

- The participants for the focus group were selected based on their expertise in issues faced by users of ASL in the U.S.
 - n=4
- The focus group was conducted as a video call over Microsoft Teams
- Participants included hearing, hard of hearing, and deaf participants
- An ASL interpreter and live captioning were provided for accessibility during the focus group



Research Questions

- Primary research questions for focus groups:
 - What terminology should be used to be as inclusive as possible with regard to the deaf community and those who use ASL?
 - What technology currently exists that would allow a deaf respondent to get assistance remotely for a survey?
 - Is there a need for information on the number of ASL users in the U.S.? If so, what kind of data do experts wish were available?
 - Are oft-used survey questions about language use (such as that on the ACS), as they are currently worded, equipped to accurately collect data on numbers of ASL users in the U.S.?



Findings - Terminology

- Participants agreed that people "use" ASL, as opposed to people who "speak" other languages
 - "In layman's terms, many people say 'use' sign languages".
- The D/d deaf distinction is falling out of use
 - Previously, Deaf (capital D) indicated cultural identity associated with hearing loss, while deaf (lowercase d) indicated a physical condition of hearing loss
 - Participants indicated:
 - Researchers and community organizations are moving away from using this distinction
 - For some websites, "deaf" may include people who may identify as Deaf, late-deafened, deafdisabled, etc.



Findings – Technology available to deaf respondents for surveys

- TTY's (teletypewriters) are rarely used anymore, mostly by senior citizens living in rural areas
- The same options should be available to deaf respondents as to hearing respondents
 - This would include that all online materials offer sign language videos and FAQ's
- One participant suggested including small links or QR codes that could link to video FAQ's or to live assistance
- One participant made clear that accessibility should be provided without request; the onus should not be on deaf people to have to request accessibility

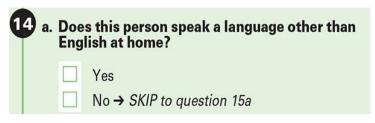


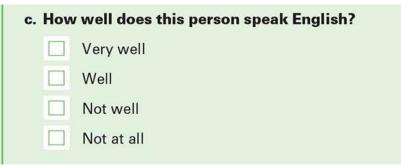
Findings – Importance of ASL numbers

- Data on the number of ASL users in the U.S. are needed and wanted
 - The National Association of the Deaf has been continuously advocating for change in how language data are collected
- Absence of these data was a significant limitation on the work that the participants do
 - One participant mentioned that this limits the way that she can use Census data for her work



Findings - Language questions





- Generally, participants suggested modifying these questions to ask about how respondents engage with language
 - One participant suggested editing the question to include all the ways someone might use English
 - Could include reading and writing
 - Another participant said she did not see speaking ability as relevant for Census purposes
 - Depends on the intent of the question and data requirements



Findings – Language questions



- One participant stated that, before the census, deaf people let each other know to answer this question with ASL
 - Note: This question does not appear on the decennial census
- Suggestion: Remove one of the current "For example:" languages, and replace it with ASL
- One participant pointed out that American Sign Language is not the only signed language used in the U.S.
- Participants did not know whether the question accepted multiple answers
 - Consensus that multiple answers should be allowed for multilingual respondents



Lessons learned

- Lessons learned from pilot focus group
 - Difficulty integrating live captioning and a sign language interpreter into some virtual programs
 - Difficulty "pinning" sign language interpreter in some virtual programs in a web browser
 - Idea of increased input from the deaf community on the project



Future plans for this project

- Two more focus groups with ASL experts
- 72 cognitive interviews
 - 24 interviews each with English, Spanish, and ASL monolinguals
- We hope to present next year on the full results of the project



Thank you!

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