

APPENDIX B

Advance Letter to Key Informants and Interview Schedule

Advance Letter to Key Informants

July 8, 1999
Dr. Key Informant
XYZ Organization
1234 Street Road
Wherever, OH 40404

Dear Key Informant:

The Survey Research Laboratory at the University of Illinois at Chicago is working on a set of recommendations regarding the ways in which survey research methods can be improved to better accommodate people with disabilities.

We are trying to gather the insights of those with relevant experience in the area of disability, disability statistics, and survey methods. We hope to develop a set of strong recommendations that will contribute to greater accessibility of surveys to people with disabilities. Because of your experience with the topics that we are exploring, we would like to invite you to participate in an interview.

In the near future, you will be contacted by Sara Baum to set up an appointment for a brief interview (about 30 minutes to one hour). We encourage you to participate or to indicate another time that is more convenient for you.

The interview will include questions regarding your experience or knowledge of surveys with people with disabilities. We hope to briefly explore topics such as adaptive technology, proxy response, interviewer training, questionnaire design, cultural factors, and the inclusion of people with disabilities in the survey design and implementation process.

The results will help in the design of important recommendations and will identify areas for further research in this area. We are willing to send you a draft copy of our final report for suggestions or comments. And, we expect to present our final results in a format and medium accessible to people with disabilities.

If you have any questions, please call me at 312-996-5310. We appreciate the time that you will take out of your schedule to speak with us. We see this project as an important contribution to the field of disability research and to the inclusion of those with disabilities in the survey process.

Sincerely,

Timothy Johnson, Ph.D.
Director

Key Informant Interview Schedule

1. What is your area of research/expertise/interest in the field of surveys and/or disability?
2. What experience do you have with surveys of people with disabilities (not necessarily on disability issues)? Were these experiences generally positive? What complications arose?

If you are a person with a disability, what experience do you have with being surveyed? Were these experiences generally positive? What complications arose?
3. What type of adaptive or technological resources could you suggest that might make it easier to accommodate people with disabilities in survey research? Which adaptive technologies might create problems during the survey process? Why?
4. Are there any general suggestions that you would offer to those responsible for developing and implementing training for interviewers who may not have a great deal of experience working with people with disabilities? For example, if you were leading a training session for interviewers, what would you communicate to them? What vocabulary, if any, are interviewers trained to use to talk about disability?
5. Do you have any suggestions regarding how an interviewer should determine whether to use a proxy (someone who speaks on behalf of respondent) is necessary, and, if so, how to ensure that the respondent still has a voice in the response?

How do you think that the relationship between the respondent and the proxy might affect the survey responses?
6. Are there any ethical issues that you perceive in including people with disabilities in survey research? Are there any ethical issues that might relate particularly to people who have disabilities?
7. Are there any sampling issues that you perceive as important to consider for including people with disabilities in survey research? For example, who in the disability community might be left out if researchers are unaware of how to properly sample respondents with disabilities for a survey?
8. Do you think that there any factors related to disability that may have an effect on whether or not a person with a disability chooses to cooperate in a survey? If so, do you have suggestions for how this might be addressed?
9. What do you see as the implications of the intersection of cultural/ethnic background with disability in terms of reaction to concepts, vocabulary, and the interview process?
10. What modifications to the physical environment (for example, in a focus group or face-to-face interview) might be necessary to ensure that people with disabilities can fully participate in surveys?

11. What modifications to the survey instrument (questionnaire) itself might be necessary to accommodate people with different disabilities? For example, spacing, font, and format?
 - Did you use the word disability in letters about the survey or in the survey itself?
 - Do you recall any particular questions that were problematic?
12. What role do you see people with disabilities playing in the process of developing the guidelines and surveys that we have been discussing?
 - Have you used or recruited interviewers with a disability?
 - In pretests of people with disabilities, did any issues come up?
13. Do you know of other researchers or publications that deal with the issue of including people with disabilities in surveys or who have had to adapt their methods to accommodate people with disabilities?
14. Do you have any concerns or experiences regarding this topic that I haven't addressed during our conversation?