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CREATING COMMON GROUND TO PARTICIPATE IN SURVEYS

Sharon L. Durant¹

ABSTRACT

In 2002, the Bureau of Transportation Statistics (BTS) conducted a transportation survey to obtain interviews from about 5,000 people, half of whom had disabilities. Creating common ground among survey respondents provided the best opportunity for participation by this difficult-to-reach population group. Using a strategy of “Nothing about us, without us” which is a popular slogan within the disability community, at each stage of the survey’s life-cycle, BTS sought involvement by people with disabilities. These methods resulted in broadened perspectives, more relevant topics, improved questionnaire design, increased respondent understanding, greater interviewer sensitivity, reduced non-response bias, and improved data quality.

KEYWORDS: People with Disabilities; Survey Life-Cycle; Transportation Survey.

1. INTRODUCTION

People with disabilities represent one of the most difficult-to-reach populations for survey work. Although survey designers are becoming increasingly sensitive to the need for diverse representation during each phase of a survey, very often they are unenlightened about the need to consider disability status when determining relevant “representation variables” in sample design, and uninformed about how best to reach/include sampled people with disabilities in survey data collection. This paper describes how to create common ground for people with disabilities in a survey’s life-cycle, and the benefits of such participation.

National demographic surveys draw their respondent samples from the national population. These samples are designed to represent the national population, even though only a small fraction of that population is actually interviewed. Great care is taken to ensure that common demographic variables are adequately reflected in the sample. For example, that each race, age group, or income category has sufficient representation. Because at the end of the day, when the survey data are tallied up, the answers submitted by individuals are “weighted up” to a national level, and so ensuring “representation variables” matters.

Most (if not all) demographic surveys do not go to any great lengths to include disability status as a “representation variable,” primarily because there is no standard definition of disability, and so determining who is disabled and who is not is a “moving target.” Although the author acknowledges the difficulties inherent in designing samples to ensure adequate representation by people with disabilities, the focus of this paper is on a methodology for their participation in surveys, once they are identified as disabled.

Even setting aside the issue of sampling, people with disabilities are known to be a very hard-to-enumerate population group. For one thing, the mode of data collection may inadvertently exclude people with disabilities. For example, deaf people may not have telephones at all in the household, so they never have a chance at selection in a telephone sample survey. For another, even if the mode allows for response by people with disabilities, the questions may be so irrelevant to people with disabilities that they opt-out of participation.

¹ US Department of Transportation, Bureau of Transportation Statistics; 400 Seventh Street SW; Washington, DC, USA 20590

2. AN INCLUSION MODEL TO CREATE COMMON GROUND

How do you spell inclusion of people with disabilities in the life-cycle of a survey?

A-W-A-R-E-N-E-S-S

There are three important awareness considerations for today's survey designers. The first, as already addressed, is to assure that the sample design represents the entire national population, taking into account not only the "usual" characteristics such as race, geography, and income, but also disability status as a "representation variable."

The second and third considerations are the primary focus of this paper: to make certain that the survey planning process includes diverse representation by design, so that the survey topics and questionnaire wording will result in collected data that truly represent the population, and to ensure that the actual implementation, that is, the data collection phase, allows for response by each person selected for the survey.

In 2002, the Bureau of Transportation Statistics (BTS) developed and conducted a transportation survey targeted to people with disabilities. Three important conclusions emerged from this project:

- Whether it is a transportation survey, a health survey, an income survey or any other kind of demographic survey, the subject matter itself will be improved based on the involvement of people with disabilities from the start. So if they are not included from the get-go, then survey designers miss the opportunity for such improvement.
- Offering alternative data collection formats (for example, if it is a telephone survey, to offer paper, teletype/teledata, or Internet access as well) will result in more people with disabilities having access to the interview, resulting in higher response rates.
- The costs of involving people with disabilities from the start, and of offering alternative data collection formats, are not prohibitive.

The BTS methods are fully transportable to other demographic surveys, and should be considered by the survey industry as a model for how to include people with disabilities in survey development and implementation.

3. CONCEPTUAL FRAMEWORK

Gerry Hendershot, a consultant and recognized expert on disability and health statistics, writes, "The survey paradigm continues to hinder the full participation of persons with disabilities at all stages of the survey process, including (1) choosing topics, objectives, and variables; (2) choosing methods of data collection; (3) designing the sample; (4) designing the questionnaire; (5) collecting the data; and (6) analyzing and reporting the data."²

The BTS transportation survey was designed so that about half of the interviews would be with people with disabilities. BTS' strategy in the design and implementation of the survey was, "Nothing about us, without us," which is a popular slogan within the disability community. In other words, at every stage of the process, BTS sought guidance and advice from people with disabilities.

4. METHODS AND COSTS FOR SURVEY PLANNING, IMPLEMENTATION

4.1 Contractor Selection

The BTS invited bids from private data collection companies to conduct the survey, and our interest in the topic of disability started even at the contractor selection stage. When we interviewed company representatives, we asked questions about their records in hiring people with disabilities, and their experience in contacting people with

² Source: *Survey Research*, Volume 34, Number 2, 2003.

disabilities for survey interviews. We asked whether their offices and telephone centers had disability access, observed whether contractors brought people with disabilities to the presentations, and inquired about the roles such people would have if that company were to receive the contract. The purpose in asking for such information from the bidding companies was not only to measure their levels of sensitivity toward people with disabilities, but also their levels of success in interviewing people with disabilities. There were no costs for this phase of the project.

4.2 Questionnaire Content

We convened a meeting among transportation and disability decision-makers at the US Department of Transportation (DOT) to determine the relevant topics for the survey. This group, which defined the survey purpose and objectives, became a key constituency and resource throughout the survey's life-cycle. The information this group provided established the topic basis for the first draft of the questionnaire. There was no cost for this phase of the project.

We took that first draft questionnaire to a focus group comprised entirely of people with disabilities employed by the DOT. The director of the DOT Disability Resource Center facilitated the meeting. We obtained feedback about whether the questionnaire content was appropriate to the group's actual transportation experiences, or what modifications were needed. Information collected through this focus group was instrumental in refining the draft questionnaire that we then delivered to the contractor. Because we convened the group during work hours, and the participants had their supervisors' permission to attend, there were no direct costs to the project.

The contractor reviewed the draft questionnaire, and provided it to a panel of transportation and disability experts outside their company who volunteered to review it. The contractor also tested the questionnaire with a core group of people with disabilities employed by that company – again, there were no direct costs. The contractor suggested extensive questionnaire changes based on the feedback from the “experts” and the employees, and further refined the draft questionnaire.

Once this further-refined draft questionnaire was approved by the BTS, the contractor convened several cognitive sessions with paid volunteers (not company employees) to ensure that the questionnaire content and flow “worked,” that the questionnaire would elicit the kind of responses we were looking for, and to assure that the response categories were mutually exclusive and exhaustive. The contractor paid each volunteer a small stipend, but incurred no facility rental costs because it had its own cognitive lab on-site. The questionnaire went through repeated rounds of revision based on the cognitive testing results, and by the end of this stage we considered the questionnaire near-final.

The near-final questionnaire was iteratively field-tested through “hot house” in-person interviews and telephone interviews to ready it for production. Respondents with disabilities, as well as those without, participated in this phase. The costs for this phase were the same as would be incurred through any other survey pre-test, and were driven by the number of interviews completed. At the conclusion of the “hot house” pre-test, the questionnaire was finalized.

4.3 Data Collection Materials

Once we had the final questionnaire, we took steps to ensure that it could be administered to every person selected for the survey, regardless of disability status. Therefore, although the survey predominantly was to be a random-digit dialing (RDD) telephone survey, the contractor developed alternative formats – Internet and mail questionnaires – so that respondents with hearing or speech impairments could have full access to the interview. During the data collection phase, these options were offered to anyone who could not (or would not) participate via telephone. Because the RDD answer categories were quite lengthy, it was not possible to simply mimic the RDD questionnaire to a web-based or paper version, so these were designed as a sub-set of the RDD questionnaire. As such, the RDD program code was transportable to the alternative format versions. The cost for putting the questionnaire on-line was modest. Printing the questionnaire, and bearing the postage expense to mail out, was more costly but certainly not prohibitive. And having the paper questionnaires available provided the opportunity to mail out to every non-interview household near the end of the project, in hopes that we would obtain a few more interviews.

The project called for written materials to be sent to the house prior to the initial interview contact. We used large-font type for all brochures, letters, and envelope labels to assist household recipients with low vision to read them. We relied on the head of our DOT Disability Resource Center for direction on the font size, since he himself has low vision. He also advised us not to translate the materials into Braille but, in hindsight, we believe it would have been more productive for us to have had the Braille materials available on request.

4.4 Interviewer Training

The data collection contractor trained its 84 interviewers specifically on the potential challenges of phone interviews of people with disabilities, such as the possibility of unusual voice diction or slower response time; emphasized that the respondent must set the pace; and that patience would be required to get the interview. They completed a number of role-play exercises as part of their training, and altogether received 6 hours of training specific to interviewing people with disabilities. They were well sensitized to the unique aspects of interviewing this population group. Moreover, during routine monitoring by supervisors, every interviewer was “listened in on” throughout the project period to ensure that the data were collected appropriately.

4.5 Sample

The BTS survey was designed to obtain interviews from a national, non-institutionalized, random sample of 5,000 people, about half of whom had disabilities. By far, the most difficult part of the entire project was to determine disability status. What does it mean to be disabled? The reality is what is considered by Person A to be a disability may be considered by Person B to not be a disability. Since there is no universal definition of disability, in order to determine disability status, we used a household screening approach, administering an “additive” set of disability questions. First, we asked two questions using Americans with Disability Act (ADA) language:

A focus of this survey is on transportation needs of persons with disabilities. The Americans with Disabilities Act defines a disability as a physical or mental impairment, and these next few questions use that specific language.

4a. (B2a) Does anyone in your household have a physical or mental impairment that causes him or her to be unable to perform a major life activity? Examples of major life activities include seeing, hearing, speaking, caring for one's self, performing manual tasks, walking, breathing, learning or working.

Yes 1
No..... 2

4b. (B2b) Other than anyone who is unable to perform these activities, does anyone else in your household have a physical or mental impairment that significantly restricts the conditions, manner, or duration under which he or she can perform a particular major life activity?

Yes 1
No..... 2

Then, we asked the Census 2000 series of questions, augmented by one clarification question (question C5b):

4c. (B2c) More specifically, does anyone in your household have any of the following long lasting conditions:

	Yes	No
a) Blindness, deafness, or a severe vision or hearing impairment?	1	2
a1) (C5b) If anyone has a vision or hearing impairment, please indicate if this affects vision, hearing, or both. <div style="margin-left: 40px;"> Vision 1 Hearing 2 Both 3 </div>		
b) A <u>condition</u> that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?	1	2

4d. (B2d) Because of a physical, mental or emotional condition lasting six months or more, does anyone in your household have any difficulty in doing any of the following activities:

	Yes	No
a) Learning, remembering or concentrating?	1	2
b) Dressing, bathing, or getting around inside the home?	1	2
c) Does anyone <u>16 or older</u> have difficulty going outside the home alone to shop or visit a doctor's office?	1	2
d) Does anyone <u>16 or older</u> have difficulty working at a job or business?	1	2

We used an “additive” approach, meaning that if the household responded positively to any of the questions (whether the ADA or the Census questions), we included them in the disabled sample. Then, within each household that included one or more persons with a disability, at least one such person was selected for the extended (person-level) interview. Sub-sampling was used in households where more than one person with a disability resided. Sub-sampling was also used among the non-disabled households to select persons for the extended interview, so that the data collection effort would yield interviews with approximately half the sample comprised of people with disabilities and half without. The sampling methodology used for this project was quite complex and the contractor needed 40,000 randomly-drawn phone numbers in order to reach the target number of disabled people. A full discussion of the sample design and methodology is available in the public use files, as part of the on-line survey documentation under “National Transportation Availability and Use Survey 2002.”³ The data files and

³Go to the BTS.GOV website home page and type “disability” in the search box. Then click on “National Transportation Availability and Use Survey 2002” to access the survey documentation and public use files.

documentation include many different disability measures, allowing analysts to construct their own definition of disability using the multiple items in the survey.

One important departure in sampling from that used for other random-digit-dialing (RDD) surveys was the inclusion of teletype/teledata (TTY/TDD) machines. Other surveys routinely purge such numbers at the same time they purge fax/modem numbers, which are discernable from “regular” voice line numbers by their unique tones. The BTS survey captured all TTY/TDD, fax, and modem numbers. Although they did not need the fax and modem numbers, they DID need the TTY/TDD numbers so as not to exclude an important group of people with disabilities...those with hearing impairments. Of the 40,000 numbers called for the disability transportation survey, 2,160 were identified as possible fax/modem/TTY/TDD lines. Using TTY/TDD telephones, trained staff called every phone number flagged as fax/modem to identify which ones were actually TTY/TDD lines and which ones were households, versus businesses or organizations. Staff then arranged for surveying these households through alternative methods (Internet or mail).

5. RESPONSE RATES

Altogether, we obtained 5,019 interviews: 2,321 for people with disabilities and 2,698 for non-disabled people. The response rate calculation for the survey used standards defined by the Council of American Survey Research Organizations (CASRO), and achieved a person-level response rate of 87.21 percent.

6. SURVEY RESULTS

Although the purpose of this paper is not to provide specific data results from the BTS transportation survey, the reader can find the public use data files and some initial analyses at the BTS website address shown as footnote 3. A few survey results follow:

- ~4% of people with disabilities (PWDs) never leave home, compared with ~1% of non-PWDs
- ~12% of PWDs have difficulty getting needed transportation, compared with ~3% of non-PWDs...but due to similar reasons (public transportation limited, POV unavailable, cost)
- Bus is most frequent mode for local travel by 3.7% of PWDs and 3.3% of non-PWDs. There is a high level of satisfaction with various aspects of bus travel, such as proximity to home, comfort, safety, reliability, and affordability, but...
 - Top bus stop problems include schedule not kept, inadequate shelter at stop, and...
 - Top problems while on the bus include crowding and insensitivity (by passengers, drivers)
- About ¼ of both PWDs and non-PWDs report living within 5 miles of a local train station, and...
 - Top problems at the station include personal safety concerns and limited audible, visual, or tactile information
 - Top problems with trains include lack of on-time performance; others include crowding, insensitivity, and security concerns
- About 1/3 of the PWDs who use paratransit said they encounter problems such as long wait times, insensitivities, and poor mechanical condition of vehicles
- PWDs are significantly less likely than non-PWDs to travel long distance (100+ miles one way) (60% vs 76.3%)

7. CONCLUSIONS

The implications of including people with disabilities in a survey’s life-cycle include: broadened survey design perspectives, more relevant topics, improved questionnaire design, increased respondent understanding, greater interviewer sensitivity and expertise, reduced coverage error, reduced non-response error, and improved data quality.

This paper describes steps the BTS took to ensure the involvement of people with disabilities in the survey planning process of the BTS transportation survey, and to assure that at the actual implementation stage, every person selected for the survey could access some version of the questionnaire – whether by telephone, TTY, TDD, internet, or mail.

We believe these steps resulted in a questionnaire that was more relevant to people with disabilities, and resulted in survey data that were more reflective of this group than otherwise would have been possible. This paper also provides a link to the BTS methodology describing the sample design used to obtain data from the targeted number of people with disabilities, and the data collection alternatives that were designed to provide a means to achieve the greatest possible participation rates for the survey.

It took A-W-A-R-E-N-E-S-S by the survey designers to make certain that people with disabilities were included in the survey's life-cycle. Quite honestly, if this had not been a disability transportation survey, it is likely that such awareness would not have been raised. But now that it has been, we feel confident that future surveys designed by the BTS will include this important "representation variable" in all aspects of design and implementation. Our experience taught us well that, regardless of the survey goal and objectives, its subject matter and resultant data will be changed and improved based on the involvement of people with disabilities at each stage of the project.