

Working PAPER

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Conducting Surveys with Proxies: Evaluating a Standardized Measure to Determine Need

July 2012

ABSTRACT

People with chronic health conditions sometimes require the use of proxy respondents to complete surveys. The determination for proxy need is often subjective and can result in people either being excluded from participation when they actually could respond or participating and not providing accurate information. This can lead to variability, both in the assessment of cognitive ability and the quality of the data collected. Standardized tools that objectively and reliably assess cognitive ability for participating in an interview while maximizing self-response are needed. This paper describes the use of a three-question telephone screener within the context of the National Beneficiary Survey designed to standardize interviewers' assessments of whether sample members had the capacity to complete the survey or if a proxy was needed. Our results show that interviewer training on how to use the cognitive screener dramatically improved the accuracy of determining the need for a proxy.

I. INTRODUCTION

The use of proxy respondents for sample members who are unable to respond is common in research on people with chronic health conditions (Elliott et al. 2008). Research comparing the quality of self and proxy reports is mixed, however. Although proxies can accurately report factual information (Wright et al. 2007), there is greater variability on subjective items. For example, Andresen et al. (2000) examined disability questions from the 2000 Census and found that proxies reported greater levels of impairment for people with disabilities than what was self-reported. Although it is preferable to interview the person with the disability whenever possible, using proxies when the sampled person cannot respond reduces the potential for nonresponse bias that can result from the exclusion of people with severe physical or cognitive impairments and maximizes the representation of those unable to respond.

Historically, the decision to use a proxy has been left to interviewer judgment or gatekeeper reports. For example, a gatekeeper might inform the interviewer that the sample member is unable to participate, or the interviewer will infer this based on talking to the sample member. In both instances, the determination for proxy need is subjective and could result in people either being excluded from participation when they actually could respond or participating and not providing accurate information. This can lead to variability, both in how cognitive ability is assessed and the quality of the data collected. Despite this concern, research on alternative proxy selection methods is scarce. Currently available standard assessments, such as the Telephone Interview for Cognitive Status (TICS) screener, are measures of cognitive function. Screeners for cognitive impairment and dementia (Espeland et al. 2011), on the other hand, are clinical tools designed to assess cognitive functioning and the severity of cognitive impairment in specific groups of people, such as identifying dementia in elderly patients, and are not designed to assess the ability to complete a telephone interview. There is a need for a standardized tool that objectively and reliably assesses cognitive ability for participating in an interview while maximizing self-response.

The purpose of this analysis is to examine the use of a three-question cognitive telephone screener designed to standardize interviewers' assessments of whether sample members had the capacity to complete the survey or a proxy was needed. In this paper, we describe the use of this screener within the context of the National Beneficiary Survey (NBS). We provide an overview of the screening process and the screener's validity. We then present information on the number of respondents who failed the screener and the timing of that failure and examine characteristics of those who passed compared with those who failed. We also will suggest methodological improvements for proxy determination.

II. METHODOLOGY

A. Description of National Beneficiary Survey

The NBS, conducted by Mathematica Policy Research and sponsored by the Social Security Administration (SSA), is a multi-round, nationally representative survey of SSA disability beneficiaries and recent Ticket to Work (TTW) participants. The NBS is one of several components of an evaluation to assess the impact of TTW relative to the current system—the SSA Vocational Rehabilitation Reimbursement Program, which has been in place since 1981. A voluntary employment program for people with disabilities, TTW was authorized by the Ticket to Work and Work Incentives Improvement Act of 1999. Under the program, SSA provides beneficiaries with a “Ticket” or coupon that they can use to obtain employment-support services, including vocational rehabilitation, from an approved provider of their choice (called Employment Networks).

The 45-minute, dual-mode survey (presented as a computer-assisted telephone interview or a computer-assisted personal interview [CATI/CAPI]) gathers information on health, insurance, employment, income, and demographic characteristics. Interviewers first attempt telephone contact and then conduct face-to-face interviews with people whose telephone numbers cannot be located, request or require an in-person interview, evade telephone attempts, or refuse to participate by telephone. The survey instrument is identical in both modes. Approximately 64 percent of all respondents report having a physical disability or other impairment as their main limiting condition, 32 percent report a psychiatric or cognitive impairment, and 4 percent report a sensory impairment.

Sample members for the NBS are randomly selected from administrative records provided by SSA. The NBS uses a multistage sampling design with a supplemental single-stage sample for some TTW participant populations. To ensure a sufficient number of people seeking work for key analyses, the beneficiary sample is classified into sampling strata based on age, with those in the younger age categories selected at higher rates than those in the oldest age category. The target population for both the national sample of SSA beneficiaries and the TTW participant sample consists of Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries ages 18 to 64.

In 2010, the fourth round of the survey was fielded with a sample of 8,017 SSA beneficiaries. A total of 5,078 cases were completed, for a weighted response rate of 73 percent. Overall, 3,936 interviews were completed by CATI and 1,142 by CAPI.

B. Overview of Proxy Procedures and Cognitive Screener

To increase opportunities for self-response in all rounds, sample members could respond via text telephone (TTY), instant messaging, Relay, and in person. We also permitted “assisted” interviews. In these cases, beneficiaries answered most questions themselves but received help with specific items they could not answer on their own. As a last resort, we relied on proxy respondents to complete the survey on behalf of sample members who could not do so themselves (even with assistance), either by telephone or in person. This included sample members with severe communication impairments, severe physical disabilities, and cognitive or emotional impairments that precluded participation in any mode. Our preference was always to interview sample members themselves, as research has shown that they generally provide more complete and accurate information than do proxy respondents (Elliott et al. 2008). However, in cases in which the sample

members were unable to respond, we used proxies to minimize the risk of nonresponse bias that could have resulted from the exclusion of people with the most severe disabilities.

To identify the need for proxy respondents, we administered an innovative mini-cognitive screener designed expressly for the NBS under a separate contract with SSA.¹ The screener provided a systematic and standardized tool for determining when to seek a proxy, rather than leaving the decision to the discretion of the interviewer or a gatekeeper. This three-item screener was administered at the beginning of the interview. It tested the sample member's memory and comprehension and focused on the sample member's understanding of basic tenets of informed consent. First, we gave a general description of the survey topics to be covered (sample member's health, daily activities, and any jobs he or she might have) and asked them to restate the topics in their own words. Second, we described the voluntary nature of the survey and asked sample members to state, in their own words, what that description meant to them. Third, we described the confidential nature of the sample member's answers and asked them to state what that description meant. Each respondent was given two chances to answer each question. If an appropriate answer was given on the first or second attempt, the sample member was then asked the next screener question. A sample member had to answer all three screener questions appropriately to continue with the survey. If a sample member was unable to restate any description accurately after two attempts, we asked if someone else could answer questions on his or her behalf. The interviewer then asked the proxy the same three-question screener. Exact wording of the questions is shown in Table 1.

Table 1. Cognitive Screener Questions

Question #1: The survey asks about your health, daily activities, and any jobs you might have. Please tell me in your own words what the survey is about.

Question #2: Taking part in the survey is completely voluntary. Completely voluntary means you can choose whether or not to take part. If you decide to take part, you can refuse to answer any questions you do not like and you can stop the interview at any time you choose. Whether you choose to take part or not, your disability benefits will not be affected in any way. When I say your participation is completely voluntary, what does that mean to you?

Question #3: All your answers will be kept confidential and used only for the research purposes of the study. When I say that your answers will be kept confidential, what does that mean to you?

In some cases, a knowledgeable informant indicated that a proxy would be necessary before the cognitive screener could be administered to the sample member. Interviewers were trained to overcome gatekeepers' objections and start the interview with the sample member, informing the gatekeeper that questions within the survey helped to determine if participation was possible. If it was not possible, or if the sample member failed the screener, the interviewer was prompted to request an interview with the person most knowledgeable about the sample member's health, daily activity, and jobs. The interviewer then asked that person to serve as the proxy.

¹ Westat created the test as part of the design of the TTW evaluation; Mathematica modified it after pretesting.

C. Cognitive Screener Training and Administration Assessment

1. Training Interviewers to Administer the Cognitive Screener

On the first day of three-day training, following a brief lecture on the rationale for and administration of the cognitive screener, trainees listened to nine recorded mock screener administrations. Interviewers were asked to code the correct response to each screener item as to whether a proxy was needed. Interviewers' responses were compared with an expert assessment and scored as correct or incorrect. On the final day of training, after discussing the screening process in greater detail and participating in role playing, we replayed the same mock interviews and asked interviewers to code the outcome to assess whether scores changed. The number of interviewers with one or fewer errors improved from 56 percent on the first day to 80 percent at the end of training (Table 2). Those who scored three or more screening items incorrectly on the third day of training received additional one-on-one coaching on administration of the screener.

Table 2. Accuracy in Scoring, Day 1 Versus Day 3 of Interview Training

Day 1 Training				Day 3 Training			
Number of Items Missed	Number of Telephone Interviewers	Percentage Correct	Cumulative Percentage	Number of Items Missed	Number of Telephone Interviewers	Percentage Correct	Cumulative Percentage
0	16	24	24	0	32	48	48
1	21	32	56	1	21	32	80
2	23	35	91	2	11	17	97
3	4	6	97	3	1	2	99
4	1	2	99	4	0	0	99
5	1	2	100	5	1	2	100
Total	66	100		Total	66	100	

Note: Percentages may not sum to 100 due to rounding.

2. Assessing Accuracy in Implementing the Cognitive Screener During Data Collection

All Round 4 telephone interviews were digitally recorded, enabling us to perform an additional validation check approximately four weeks into data collection. For this, we randomly selected 5 cases in which a sample member had passed the cognitive screener and 5 in which the sample member had failed. From these 10 cases, we extracted a total of 25 cognitive screener items. An expert then reviewed the conclusions made by the interviewer to determine if the responses were coded correctly. More than half of the interviewers correctly coded at least 23 of the 25 items; 95 percent coded at least 20 of the 25 items correctly. For those interviewers showing a high degree of error, incorrect responses were reviewed and discussed as an additional learning opportunity. The results are shown in Table 3. From these 25 items, examples of some of the acceptable and unacceptable responses, as determined by an expert reviewer, are shown in Table 4.

Table 3. Accuracy in Scoring After Approximately Four Weeks of Data Collection

Percentage of Items Coded Correctly	Number of Telephone Interviewers	Cumulative Number of Telephone Interviewers	Percentage of Interviewers	Cumulative Percentage of Interviewers Coding Correctly
100	2	2	5.0	5.0
96	6	8	15.0	20.0
92	10	18	25.0	45.0
88	5	23	12.5	57.5
84	8	31	20.0	77.5
80	7	38	17.5	95.0
76	1	39	2.5	97.5
72	1	40	2.5	100.0

Table 4. Examples of Cognitive Screener Responses by Sample Members

	Acceptable Response	Unacceptable Response
Question #1: The survey asks about your health, daily activities, and any jobs you might have. Please tell me in your own words what the survey is about.	"What I do every day and my health."	"I don't have a job. I ain't able to do nothing ... total disability."
Question #2: Taking part in the survey is completely voluntary. Completely voluntary means you can choose whether or not to take part. If you decide to take part, you can refuse to answer any questions you do not like and you can stop the interview at any time you choose. Whether you choose to take part or not, your disability benefits will not be affected in any way. When I say your participation is completely voluntary, what does that mean to you?	"Like I don't have to go on with the interview or something." "Not mandatory, and I don't have to participate if I don't want to."	"Really means nothing to me."
Question #3: All your answers will be kept confidential and used only for the research purposes of the study. When I say that your answers will be kept confidential, what does that mean to you?	"You are going to abide by HIPAA rules." [INT: What does that mean to you?] You won't contract my information out. That this is a confidential survey for Social Security and nothing else."	"I don't know."

INT = interviewer; HIPAA = Health Insurance Portability and Accountability Act of 1996.

D. The Cognitive Screener in Practice

1. Characteristics of Sample Members Based on Screener Outcome

Sample members who failed the screener were quite different from those who passed. Those who failed were more likely to experience childhood onset of disability, have a cognitive impairment, require help to get around outside the home, live in a group setting, and receive SSI benefits. Those who passed the screener were much more likely to be college educated and more likely to be living alone. Results are shown in Table 5.

Table 5. Comparison of Screened-Out Versus Screened-In Sample Members on Selected Characteristics (percentages)

	Failed Screener (n = 222)	Passed Screener (4,080)
Sex*		
Female	37.4	51.9
Male	62.6	48.1
Onset of Disability*		
Adult	20.7	74.5
Child	79.3	25.5
Disability*		
Psychological impairment	32.2	32.1
Cognitive impairment	24.6	3.6
Musculoskeletal	2.5	18.2
Sensory	2.5	4.0
Other	38.2	42.1
Help to Get Around Outside the Home*		
Yes	85.7	61.1
No	14.3	38.9
Living Situation*		
Alone	6.3	29.3
With relatives or friends	84.7	65.7
Group setting	8.6	4.4
Other	< 1.0	< 1.0
Benefit Type*		
SSI	52.3	27.2
SSDI	21.2	49.5
SSI / SSDI	26.6	23.3
Highest Level of Education*		
High school or less	92.3	62.9
Some college or higher	4.5	36.9
Other**	3.2	< 1.0

Note: Percentages may not sum to 100 due to rounding.

* p -value < .001.

**Other includes never attended school and special education with no certificate of completion.

2. Timing of Screener Failure

Among sample members who failed the screener, most did so at the first item. Results are shown in Table 6.

Table 6. Timing of Screener Failure (percentages unless otherwise indicated)

	First Time	Second Time
Respondent Lists at Least Two Survey Topics	N = 222	N = 179
Yes	19.3	21.2
No	80.7	78.8
Respondent Understands Survey Is Voluntary	N = 78	N = 73
Accurate answer	6.4	5.5
Inaccurate answer	93.6	94.5
Respondent Understands Survey Is Confidential	N = 9	N = 9
Accurate answer	0.0	0.0
Inaccurate answer	100.0	100.0

3. Characteristics of Sample Members Requiring Proxies

Large differences were found between the group of sample members who did not require a proxy to complete the interview and those who did. Those who needed a proxy were more likely to have a disability with onset in childhood than adulthood, have cognitive impairments, and need help getting around outside the home than were sample members who did not need a proxy to complete the interview. They were also more likely to be living in a group setting or with others, as opposed to living alone. In addition, sample members who required a proxy were more likely to have lower levels of educational attainment than those who did not require a proxy to complete the interview. Table 7 illustrates these findings.

Table 7. Characteristics of Sample Persons Completing the Interview, by Proxy Status (percentage distribution unless otherwise indicated)

	No Proxy	Proxy
Total Number	4,080	998
Sex		
Female	51.9	36.1
Male	48.1	63.9
Onset of Disability		
Adult	74.5	24.5
Child	25.5	75.6
Disability		
Psychological impairments	32.1	31.3
Cognitive impairments	3.6	26.3
Musculoskeletal	18.2	2.8
Sensory	4.0	4.7
Other	42.1	34.9
Help to Get Around Outside the Home		
Yes	61.1	89.8
No	38.9	10.2
Living Situation		
Alone	29.3	8.0
With relatives or friends	65.7	75.0
Group setting	4.4	16.2
Other	< 1.0	< 1.0

	No Proxy	Proxy
Benefit Type		
SSI	27.2	49.2
SSDI	49.5	24.6
SSI/SSDI	23.3	26.3
Highest Level of Education		
High school or less	62.8	84.3
Some college or higher	36.9	7.6
Other*	< 1.0	8.1

Note: Percentages may not sum to 100 due to rounding.

*Other includes never attended school and special education with no certificate of completion.

4. Proxy and Interview Completion Status

In Round 4 of the NBS, 1,150 sample members—about 23 percent of all cases—needed a proxy. Most interviews with a proxy were completed, but some were not.

Proxy Interviews. In Round 4, we completed proxy interviews for 998 sample members (19.6 percent of all completes). Nearly three-fourths of the time (74.4 percent) ($n = 744$), the interviewer determined the need for a proxy before administering the cognitive screener, based on discussions with a knowledgeable informant. In 22.3 percent of cases, a proxy was sought because the sample member failed the cognitive screener ($n = 222$). In a small number of cases, the interviewer switched to a proxy after the sample member successfully completed the cognitive screener and had started the interview, when it became apparent that the sample member could not answer the survey questions ($n = 32$). These results are outlined in Table 8.

Noncompleted Interviews. In 152 cases, the interview was not completed because the sample member was unable to participate and the interviewer could not identify a viable proxy. Interestingly, in 20 percent of these cases, the interview was not completed because the identified proxy also failed the screener. In the other cases, reasons for noncompletion included refusal and difficulty in reestablishing contact with the proxy after a break in the interview. In contrast to the completed interviews, about 60 percent of the uncompleted interviews needed a proxy because the sample member was unable to complete the cognitive screener successfully. About 35 percent of the uncompleted interviews needed a proxy based on a gatekeeper report of a limitation. These results are outlined in Table 8.

Table 8. Final Status of Cases Identified for Proxy Interviews and Timing of Proxy Determination

Proxy and Interview Completion Status	Number of Cases	Percentage
Total Cases Identified for Proxy	1,150	100.0
Interview Completed with Proxy Respondent	998	86.8
Sample Member Failed Screener	222	22.3
Cognitive barrier	222	100.0
Physical barrier	0	0.0
Proxy Need Determined Before Screener	744	74.4
Cognitive barrier	576	77.4
Physical barrier	124	16.5
Other barrier	32	4.4
Missing	12	1.6

Proxy and Interview Completion Status	Number of Cases	Percentage
Proxy Substituted for Respondent After Initially Passing the Screener	32	3.2
Cognitive barrier	25	78.1
Physical barrier	3	9.4
Other barrier	1	3.1
Missing	3	9.4
Interview Required Use of Proxy but Was Not Completed	152	13.2
Sample Member Failed Screener	94	61.8
Cognitive barrier	94	100.0
Physical barrier	0	0.0
Proxy Need Determined Before Screener	54	35.5
Cognitive barrier	28	51.8
Physical barrier	26	48.1
Proxy Substituted for Respondent After Initially Passing the Screener	4	2.6
Cognitive barrier	2	50.0
Physical barrier	2	50.0

Note: Percentages may not sum to 100 due to rounding.

Note: We determined the reasons for use of a proxy after reviewing interviewer responses to question M14 of the survey ("Why was a proxy needed?"), interviewer notes, and status codes. If more than one reason was given, we reviewed the individual cases to determine the primary reason. Cognitive barriers included poor memory or confusion, not knowing how to answer, and other mental conditions. Physical barriers included hearing, speech, and other physical illnesses or disabilities. Other barriers included hospitalized, institutionalized, language problems, and other reasons unrelated to health. Missing included "don't know" responses from partially completed interviews.

5. Characteristics of Sample Members Based on Timing of Proxy

Sample members who required a proxy before the screener had similar characteristics to those whose need for a proxy was identified during the screener. The single largest difference can be found in the living situation: those whose need for a proxy was determined before the screener were more likely to live in a group setting and less likely to live with relatives and friends than were respondents whose proxy determination was a result of having the screener administered to them. Results are shown in Table 9.

Table 9. Sample Member Characteristics and Timing of Proxy (percentages)

	Before Screener	During Screener
Sex		
Female	35.4	37.4
Male	64.6	62.6
Onset of Disability		
Adult	24.5	20.7
Child	75.5	79.3
Disability		
Psychological impairment	30.6	32.2
Cognitive impairment	27.2	24.6
Musculoskeletal	2.7	2.5
Sensory	5.1	2.5

	Before Screener	During Screener
Other	34.5	38.2
Help to Get Around Outside the Home		
Yes	90.7	85.7
No	9.3	14.3
Living Situation*		
Alone	8.5	6.3
With relatives or friends	72.6	84.7
Group setting	18.0	8.6
Other	< 1.0	< 1.0
Benefit Type		
SSI	48.8	52.3
SSDI	25.0	21.2
SSI/SSDI	26.2	26.6
Highest Level of Education**		
High school or less	82.0	92.3
Some college or higher	8.2	4.5
Other***	9.8	3.2

Note: Percentages may not sum to 100 due to rounding.

* p -value < .01.

** p -value < .001.

***Other includes never attended school and special education with no certificate of completion.

III. DISCUSSION

In this analysis, we describe the implementation of a three-question cognitive screener to determine the need for a proxy respondent. We approached the analysis two different ways—by analyzing how well interviewers could administer the screener items (that is, whether they coded them the same way an expert did) and by examining how well the screener worked. For the latter, because we did not have the benefit of having asked people who failed the screener to continue to try to answer items in the survey—which would have given us a sense of whether they should have failed based on the screener—we examined the number of respondents failing, the timing of their failures, and the characteristics of those who passed the screener compared with those who failed.

Our results show that interviewer training on how to use the cognitive screener dramatically improved the accuracy of determining the need for a proxy. Additionally, we found that CATI interviewers were able to maintain this high level of accuracy after four weeks of data collection. We recommend performing additional validation checks throughout the field period as an enhancement to data quality monitoring.

It should be noted that our training and validity checks pertain to CATI interviewers only. We performed the training exercise at our CAPI training, but because our CAPI protocol does not allow interviews to be recorded, we could not perform the validity check for consistency. As at the CATI training, CAPI interviewers showed similar improvements at the end of training. We recommend expanding the validation checks to CAPI data collection to check for any mode-related differences.

Respondents who needed a proxy to complete their interviews were more likely to have childhood onset of their disabilities, need help getting around outside of the home, live in group homes, and have lower education levels than respondents who did not require a proxy. This profile might not be surprising as it is likely that these sample members had gatekeepers who precluding sample member participation. This is consistent with the fact that most of our proxies were identified before administration of the cognitive screener and therefore the sample member had a qualified proxy respondent nearby. However, cases that went to a proxy before the screener were much like their counterparts who went to a proxy during the screener. This might suggest a need for additional interviewer training on persuading gatekeepers to allow the sample member to continue with the interview to reach the three-question screener. Additionally, we recommend increased monitoring on this portion of the interview or employing production reports to more precisely illustrate when the proxy judgment is made.

The vast majority of interviews that needed a proxy resulted in a completed interview. Most of these completed interviews identified the need for a proxy before the sample member was asked the screening questions. In contrast, proxy interviews that were not completed most often identified the need for a proxy after the sample member failed the screener. More research will have to be done on the reasons for the difference, but it might reflect characteristics of the proxy respondents themselves. Among incomplete proxy interviews, the failure might have resulted from the sample members and/or gatekeepers not being able to identify a suitable proxy respondent, no other household member could be contacted, or all identified proxies failed the screener themselves. To increase the response rate for such people, our results point to a need for a way to accommodate them. We suggest closer monitoring of these cases during data collection and an examination of the number of proxy attempts made.

Given the very small number of cases for which a proxy was sought after the sample member successfully completed the cognitive screener and the fact that those who failed the screener were far more likely to have cognitive impairments than those who passed, we believe that the screener is a reasonably effective tool for identifying people not cognitively capable of answering the survey questions. Additionally, the fact that sample members with greater impairment were more likely to require a proxy provides face validity to our cognitive screener. However, although our three-question method could be easily adapted for other surveys and has undergone some validation and testing in its development phase, it has not been directly compared with another method of assessing proxy need. Such research should focus on advancements in the development of a standardized tool to objectively and reliably assess a person's cognitive ability to participate in an interview while maximizing self-response. Also, because most of our cases went to proxy before the screener, preventing us from meeting our goal of engaging the sample member directly in the cognitive screener, we suggest testing the screener with a different population—one not as likely to have gatekeepers. We also recommend creating and testing screener items that address other dimensions of cognition.

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