

**Report of Cognitive Research on Proposed
American Community Survey Disability Questions**

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Report of Cognitive Research on Proposed American Community Survey Disability Questions

**Evaluation conducted by
The National Center for Health Statistics
U.S. Bureau of the Census**

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This report summarizes the cognitive test findings of questions proposed by The American Community Survey Disability Working Group. In the interest of improving disability measures for the American Community Survey (ACS), the work group was established to consider possible modifications to the existing set of questions. After reviewing legislative requirements, the group identified ACS questions to be reworded or replaced and developed a proposed set of alternative questions. Cognitive testing of the proposed questions was conducted jointly by the cognitive laboratory staff at the National Center for Health Statistics (NCHS) and the U.S. Census Bureau's Center for Survey Methods Research in the Statistical Research Division. Specific goals of cognitive testing were to:

1. identify respondent interpretations and determine whether interpretations are consistent with the committee's intent;
2. identify potential response errors, particularly, false negative responses;
3. improve test questions (should errors become evident during interviewing) and retest revised versions; and
4. investigate question performance within the context of differing administration modes, specifically, face-to-face interviewer-administered, telephone interviewer-administered, and self-administered.

After a brief discussion summarizing the workgroup's deliberations, this report will first describe the cognitive test methods at NCHS and the Census Bureau and will, then, present results of test findings along with recommendations.

ACS Subcommittee Issues for Cognitive Testing

Consistent with the definition established by the Americans for Disabilities Act (ADA), the ACS subcommittee determined that, in order to measure prevalence, the concept of disability would be operationalized as functional limitations that would put the individual at a greater risk of participation restrictions. Additionally, the subcommittee concluded that a short battery of questions organized by functional domains would adequately generate a population estimate that could fulfill analytic requirements, specifically, to evaluate equalization of opportunity for those

with disabilities (e.g., housing and employment opportunity). The functional domains include: sensory (i.e., vision and hearing), motor function (i.e., lower body mobility), cognition, activities of daily living, instrumental activities of daily living, and work. The following questions, signifying each domain, represent the original questions proposed by the subcommittee and were the initial questions tested in the cognitive evaluation:

1. Do you/Does (insert name) have serious trouble hearing or are you/they deaf?
2. Do you/Does (insert name) have serious trouble seeing or are you/they blind?
3. Because of a physical, mental or emotional condition, do you/does (insert name) usually have difficulty concentrating, remembering or making decisions?
4. Do you/Does (insert name) usually have difficulty walking or climbing stairs?
5. Do you/Does (insert name) usually have difficulty dressing or bathing?
6. Because of a physical, mental or emotional condition, do you/does (insert name) usually have difficulty going outside the home alone to visit a doctor's office or to shop?
7. Are you/is (insert name) unable to work at all or are you/is s/he limited in the type of work you/s/he can do or number of hours you/he/she work(s)?

Methodology

The objective of cognitive testing is to provide an in-depth exploration of particular concepts, processes and patterns of interpretation within the survey question-response process. Analysis of cognitive interviews: 1) illustrates themes or patterns as well as inconsistencies in participants' interpretations of questions; 2) characterizes response problems or difficulties; and 3) indicates potential sources of response error.

Data collection procedures for cognitive interviewing differ significantly from those of survey interviewing. While survey interviews adhere to scripted questionnaires, cognitive interviews are less standardized and inquire into the ways in which respondents construct answers to survey questions, providing insight into accuracy as well as into the presence and type of response error. Emergent, non-scripted probes help to make sense of gaps or contradictions in respondents' explanations and elicit contextual information needed to precisely define question problems. Additionally, cognitive testing employs an inductive, qualitative methodology and, consequently, draws upon a relatively small non-representative sample.

Respondents' answers to survey questions are necessarily based on personal experience and perceptions of that experience. Therefore, it is impossible to altogether avoid respondent subjectivity and obtain an entirely objective picture of disability status. In their response, respondents may incorporate a variety of differing factors including their age, health status, sense of independence, whether or not they perceive themselves as having a problem, whether others have told them that they have a problem, and whether they need help or use an assistive device. Additionally, when respondents are asked to report for other members of their household (i.e., reporting as a proxy-respondent), an additional layer of context and meaning is added. Not only does the response represent their own perception of the household member's condition, but it also reflects their relationship with that household member.

In this regard, it is unfeasible to develop questions that yield a perfect measure of disability; disability statuses, as they are derived from survey questions, are subjective statuses that are grounded in respondents' perceptions and interpretations. The method of cognitive testing, however, provides insight into the types of potential response errors so that egregious errors can be fixed and so that decisions can be made to determine what, if any, errors will be tolerated to generate the best statistics. Additionally, the method provides a better understanding of both the strengths and weaknesses of the data.

Method for Testing the ACS Workgroup Disability Questions

Between NCHS and the Census Bureau, five rounds of interviews were conducted, comprising 69 total interviews. Interviews were conducted in rounds so that, if questions were revised, they could then be retested. Additionally, because rounds alternated between the Census Bureau and NCHS, findings between the two agencies could be compared.

Cognitive interview respondents had a range of health conditions and physical limitations including hearing and vision problems, mental health conditions (e.g. schizophrenia and depression), physical conditions (e.g. arthritis), learning disabilities and temporary injuries. Additionally, a few respondents had no conditions or physical limitations. Respondents were recruited either through a newspaper advertisement or were pulled from a database of eligible respondents. After the interview, all respondents were paid \$50.

Because the ACS uses a mixed-mode design, incorporating mail, telephone, and personal visits, all three modes were tested via cognitive interviews. NCHS conducted face-to-face and telephone interviews, while the Census Bureau conducted interviews using a self-administered questionnaire. Chart 1 summarizes the 5 different rounds, outlining which agency conducted the testing for each round, the interview mode, as well as the number and characteristics of respondents.

Chart 1: Cognitive Interview Rounds for the ACS Disability Questions

						Limitations reported by respondent in telephone screener			
	Total Respondents	Race	Education	Gender	Age	Hearing	Vision	Physical	Mental/emotional
Round 1 NCHS Face-to-face	17	White=14 Black=2 Hispanic=0 American Indian=1 Other=0	Some HS=0 HS degree=3 Some college=9 BA degree=2 Post-grad=3	F=9 M=8	18-30= 0 31-50= 9 51-70= 4 71+=4	5	3	9	7
Round 2 Census Bureau	18	White=11 Black=6 Hispanic=0 American	No HS= 1 Some HS= 1 HS degree= 2 Some	F=12 M=6	18-30= 3 31-50= 10 51-70= 4	(Telephone screener data not collected for Census Bureau interviews)			

Self-administered		Indian=1 Other=0	college= 6 BA degree= 3 Post-grad= 5		71+= 1				
Round 3 NCHS Telephone	9	White=9 Black=0 Hispanic=0 American Indian=0 Other=0	Some HS=0 HS degree=3 Some college=1 BA degree=3 Post-grad=2	F=5 M=4	18-30= 0 31-50= 2 51-70= 1 71+=6	5	3	5	2
Round 4 NCHS Face-to-face	15	White=13 Black=2 Hispanic=0 American Indian=0 Other=0	Some HS=0 HS degree=1 Some college=1 BA degree=4 Post-grad=9	F=8 M=7	18-30= 0 31-50= 3 51-70= 6 71+=6	6	2	5	7
Round 5 Census Bureau Self-administered	10	White= 3 Black= 7 Hispanic=0 American Indian= 0 Other= 0	Some HS=0 HS degree=6 Some college= 1 BA degree=0 Post-grad= 3	F= 8 M= 2	18-30= 0 31-50= 9 51-70= 1 71+= 0	(Telephone screener data not collected for Census Bureau interviews)			

Interviewing Protocol

The average interview was an hour in length, though interviews varied depending on the size of respondents' household as well as the type and number of limitations that a respondent experienced. The face-to-face and telephone interviews were structured by retrospective probing. That is, the interviewer first asked the participant each question for every member of their household (including themselves) and then returned to each question for a more in-depth examination of the question-response process. Because so few questions were evaluated, participants were able to retain and then speak to their perceptions of the question in a follow-up discussion. This approach, as opposed to concurrent probing, was deemed particularly useful by investigators because it ensured that participants' conceptualizations and orientation toward each question was unaffected by discussion of the preceding question. Additionally, a retrospective approach allowed the interviewer to re-ask each question, checking the consistency of the responses. In the follow-up discussion of each question, interviewers asked in-depth, emergent probe questions to fully understand how the respondent interpreted the question and constructed a response. In the cases where respondents were unable to or had difficulty providing an answer, the interviewer would ask questions specifically toward understanding the nature of the difficulty.

The self-administered interviews were conducted using a think-aloud method with probing. Using a paper questionnaire, respondents were instructed to read out loud as they completed the form and think out loud as they answered the questions. This allowed the interviewer to observe the respondents' misreading of questions, skipping over parts of the questions or instructions,

hand or facial gestures that indicate problems, as well as their initial thoughts as they encountered each question. In addition, interviewers asked emergent probe questions during the interview about how respondents came up with their answers, how they defined terms contained in the questions, and whether they thought specific issues would affect answers to the questions. Care was taken to administer these probing questions at places during the interview where the respondents' answers would have least impact on their answers to subsequent questions. At the end of the interview, debriefing questions were asked to clarify situations that surfaced during the interview but were inappropriate to probe at that time. Probes to identify difficult and sensitive questions were also asked during the debriefing.

Analysis of Interviews

Analysis was conducted from interviewer notes, audio taped interviews, and video recordings of interviews. For the NCHS interviews, interview notes and video clips were collated by question so that comparisons could be made systematically across all participants. For the Census Bureau interviews, audio-taped interviews were listened to and summarized by the interviewer, and then the summaries were analyzed across questions for all respondents. Two levels of analysis were then performed. First, distinct occurrences in which respondents specifically expressed difficulty or confusion while answering were noted. Second, respondents' interpretations of each question were examined. To analyze the interpretive aspects of question response, the constant comparative method, a standard method for analyzing qualitative data was employed. By comparing across all cases, individual responses were categorized according to a respondent's particular interpretation of a question. From these categories, interpretive aspects (e.g., the consistency and degree of variation among respondents) of each question were examined.

Summary of Findings

While each question generated specific findings from the cognitive interviews and are presented in the following section, several common themes emerged across the domains that also warrant discussion.

Determining level of functioning

The primary difficulty that respondents experienced when answering the set of questions was in determining whether or not their particular functional limitation was severe enough to warrant a positive response. To determine whether to report a limitation, respondents had to consider and weigh out various components of their condition as well as to compare and rate their level of limitation with others or with a more abstract standard. Although this process occurred throughout each functional domain, the various domains required respondents to consider different dimensions or characteristics inherent to that particular limitation. For example, in the domain of hearing, respondents considered the impact that their functioning actually had on their day-to-day life, whether they were able to adapt, the various contexts in which their hearing

trouble occurred (e.g. in a crowded room, on the telephone or watching television) and the number of times that they were in those contexts. On the other hand, for the lower mobility question, respondents considered their level of endurance, specifically, how far and how quickly they could walk as well as whether these activities required the use of a cane or a walker. In the cognition question, respondents considered the types of memories that they might forget—whether trivial (e.g. a name) or serious (e.g. taking essential medicine), and the frequency that the loss occurs. Additionally, for the cognitive functioning question, some respondents attempted to exclude episodes of aging-related problems which were seen as a part of a “normal” and “inevitable” process.

Although clear patterns or themes of consideration can be identified across respondents and within each domain, each domain question is a subjective measure based on respondents’ calculations and ultimate determination of what constitutes a report-able functional limitation. Especially for those respondents with undiagnosed conditions or in the beginning or middle stages of a progressive condition, this was the most burdensome aspect of the question response process. That is, the question structure required respondents to discern a clear line of yes or no in a reality that, for them, was essentially grey and multi-dimensional.

The role of assistive devices

Related to the issue presented above, for most of the domain questions, activities could be associated with corrective devices that, when used, would decrease limitations. Therefore, interviews investigated how the use of assistive devices might affect the question response process. For example, numerous respondents had vision problems that were entirely corrected with glasses. Many older respondents, who were unable to walk long distances were able to do so with a walker. Additionally, a few respondents, when reporting for their child diagnosed with ADD explained that, for the cognitive functioning question, when their child is taking medication, he or she has no problems concentrating. Respondents, however, did not consistently account for assistive devices (some accounted for the aid, and others did not), and whether or not respondents considered the use of the device would alter their response.

The initial version of all questions tested excluded reference to the corrective devices, and interview findings indicate that, for some domains (particularly vision), reference to the assistive device would dramatically improve consistency across reports. This pattern, however, was not consistent across the different domains. While the addition of a phrase, *even if wearing glasses*, was beneficial to the vision domain, an assistive device clause for the hearing domain had the opposite effect. When the phrase, *even if wearing a hearing aid* was added, respondents’ parameters for defining a hearing problem became much stricter, causing a decrease in the reporting of hearing problems. Additionally, some respondents misheard the question and interpreted the question to be asking whether or not they wore a hearing aid. Similarly, a phrase was added to the self-care question but, like the hearing domain, the clause appeared to restrict the scope of limitations that respondents reported.

The general conclusion in regard to inclusion of an assistive device reference is that no blanket

rule can be applied for all domains. It may be optimal to ask additional questions, first about the use of aids followed by a functional limitation question. This option, however was not possible for the space-limited ACS, and recommendations for the use of the clause are based on consideration of the need for consistency balanced with the need to reduce over-restriction of reported limitations.

Modal variation

As indicated in the methods section, the set of questions were tested in three administrative modes: self-administered, face-to-face interviewer-administered, and telephone interviewer-administered. Test results suggest that the differing modes of administration had little impact on the ways in which respondents interpreted or responded to questions. The only impact of administration mode on the question response process pertained to the use of the word “or” in the vision and hearing questions. Specifically, in NCHS interviews that were administered by an interviewer, many respondents heard the question, not as a yes/no question, but as a question inquiring into which particular type of hearing trouble they had, that is, were they deaf or did they have serious trouble hearing? Instead of answering *yes* or *no*, then, these respondents answered “neither” or “I have serious trouble hearing.” In these situations, the interviewer needed to restate the question, asking for a yes or no response. This problem did not occur in self-administered interviews where respondents could see for themselves that the question was yes/no and that they were to check either the box marked yes or the box marked no.

Question by Question Review

The following section of this report provides the cognitive test findings for each proposed question as well as the revised versions tested in subsequent rounds. For each domain, discussion will describe the ways in which the various questions were interpreted by respondents as well as response errors identified in the cognitive interviews. Recommendations are also included.

Hearing

Tested Versions of the Proposed Hearing Question

- Round 1: **Do you/Does (insert name) have serious trouble hearing or are you/they deaf?**
 Are you/Is (insert name) deaf or do you/they have serious trouble hearing?
- Round 2: **Is this person deaf or do they have serious trouble hearing?**
- Round 3: **Are you/Is [insert name] deaf or do you/they have difficulty hearing even when wearing a hearing aid?**

Round 4: **Are you/Is [NAME] deaf or do [you/they] have serious difficulty hearing?**

Are you/Is [NAME] deaf or do [you/they] have serious difficulty hearing without the use of a hearing aid?

Round 5: **Is this person deaf or do they have serious difficulty hearing?**

Question Interpretation

For versions of the question tested in Rounds 1 and 2, most respondents included hearing loss conditions that were doctor-diagnosed regardless of whether or not a hearing aid was used. Still, when describing their conceptualizations of *having hearing trouble*, the vast majority of respondents mentioned the need (or lack there) of a hearing aid. Most respondents in both NCHS and Census Bureau interviews indicated that the use of a hearing aid necessarily indicated serious trouble hearing, though a few respondents also noted that because hearing aid technology was substandard, not using a hearing aid should not imply that a person's hearing was satisfactory. Additionally, respondents typically defined *serious trouble hearing* within the context or circumstances of their daily life. For example, one Census Bureau respondent explained that serious trouble hearing was "when someone is hollering across a table at you." Another Census Bureau respondent who is a construction worker defined the condition as it pertained to safety in his job: "if you cannot hear someone who comes up behind you or you cannot hear loud noises."

The ways in which respondents conceptualized *serious trouble hearing* ranged across degrees of severity—from a severe disabling condition to one of inconvenience. This range was found in both Census Bureau and NCHS interviews. While the majority of respondents' interpretations were not extreme in either direction, some respondents did hold particularly conservative or particularly liberal conceptualizations. Respondents holding particularly conservative conceptualizations included only conditions that affect important daily activities or that demand the use of a hearing aid. For example, one NCHS respondent diagnosed with moderate hearing loss explained that, though he uses close-captioned television and does miss words in conversations, this was not a critical problem, and he is able to get by without a hearing aid. Another NCHS respondent who was diagnosed as having 30% hearing loss and requires hearing aids in both ears, held an exceedingly conservative interpretation of *serious trouble hearing*: "not being able to hear a fire engine going past you" or "you can't hear at all." Because her hearing condition was not at this extreme level, she experienced particular difficulty providing (what she deemed to be) an accurate answer. Instead of answering yes or no, she responded, "I'm hearing impaired," and when asked again, she responded, "I'm not deaf, but I wear hearing aids in both ears." When pressed by the interviewer, she ultimately responded "yes" and qualified her answer, explaining that she is unable to hear in only some situations, specifically, when there is a lot of background noise or when someone is speaking softly.

Some respondents, on the other hand, held particularly liberal interpretations of the question. These respondents possessed a much lower threshold for *serious trouble hearing* and considered hearing conditions which required others “to sometimes speak up” or “to repeat themselves” or that “needed the television volume up” above what was perceived as a normal level. These more liberal interpretations tended to occur for proxy responses, that is, when respondents were asked to answer for other members of their household. For example, one Census Bureau respondent, when providing a proxy report for her tenant, stated that although her tenant has neither a hearing aid nor cognitive problems, she surmised that the tenant must have serious trouble hearing: “Many times when I try to talk to her...she cannot hear what we are saying and gives off-the-wall answers.” Similarly, one NCHS respondent at first reported his girlfriend as having a serious hearing problem because she would often ask him to repeat himself. In later discussion of the question, however, he changed his response saying that her condition did not require a hearing aid and was “not really a *serious* problem.”

Impact of Word Order on Interpretation

In comparing the two question variations tested in Round 1, no differences were identified in response patterns. That is, patterns of interpretation as well as types of difficulties did not vary depending on the order of wording, suggesting that placement of the phrase *serious trouble hearing* before or after the word *deaf* did not impact respondents’ interpretations. In both questions, liberal and strict interpretations were identified across respondents. Other than wording order, respondents’ interpretations of the question are more likely based upon pre-existing knowledge and personal experience with hearing difficulty. For example, many respondents who throughout the course of their lives have had a hearing limitation were less likely to view the loss as serious because over time they have adapted. From their perspective, the loss does not dramatically affect their daily activities and, therefore, could not be serious. Conversely, those respondents who found themselves speaking up or repeating for family members, and who were also personally inconvenienced or worried that the inconvenience was symptomatic of a larger hearing problem were more likely to consider these more benign conditions as serious. It is the pre-existing circumstances, not word order in the question, that frames respondents’ interpretation, impacting how they will respond.

Inclusion of Hearing Aid Clause

With the addition of the hearing aid clause in Round 3, respondents’ interpretations of the question appeared more conservative than in versions tested in Rounds 1 and 2. Respondents tended to interpret the question as asking, “Is your hearing problem so severe that hearing aids cannot improve your hearing?” or “Are you deaf or are you essentially deaf?” Consequently, only respondents who routinely wore hearing aids even considered answering yes; those who did not (for whatever reason—lack of need, financial barriers, or cumbersomeness) tended to opt out. For example, one woman reporting as a proxy for her husband stated that she simply could not provide an answer. He has difficulty hearing, she explained, but he refuses to wear his hearing aids so is unable to know if they correct his problem.

For those respondents who did regularly wear hearing aids, considering what to answer involved determining whether or not their devices actually *corrected* their hearing, that is, corrected it enough to consider that they no longer had difficulty. However, because hearing aids typically do not entirely correct hearing problems in all situations, these respondents experienced difficulty determining whether their condition should be considered serious. Of the seven respondents in Round 3 with hearing conditions (either for self or as proxy), three respondents with situational problems ultimately chose to answer *yes* and one chose to answer *no*. However, three respondents stated that they simply could not answer and explained that the more accurate answer was *sometimes*.

After half of the interviews in Round 3 were completed, interviewers asked the identical question but without the clause (*Are you deaf or do you have difficulty hearing?*) just prior to the question with the clause (*Are you deaf or do you have difficulty hearing even when wearing a hearing aid*). Interestingly, none of the remaining respondents saw the two questions as repetitive; the questions were seen as asking about two different phenomena: the first about significant hearing loss, the second about the usefulness of hearing aids. Additionally, while 3 of the remaining 4 respondents with diagnosed hearing loss experienced difficulty responding to the version with the clause (i.e., hesitating or answering “sometimes”), none had difficulty responding to the question without the clause.

In round 4, the opposite version of the assistive device clause (i.e., *without the use of a hearing aid*) was tested. With the inclusion of this clause, several serious problems emerged. First, numerous respondents erroneously interpreted the question as pertaining only to respondents who used hearing aids. Consequently, those respondents with hearing problems but who do not wear hearing aids quickly answered no, thinking that the question did not apply to them and that they were “off the hook.” In another case, one woman responded no as a proxy report for her son, not because his hearing problem is not serious, but because his problem is so serious that hearing aids do not help and, consequently, he does not wear them.

Additionally, with the inclusion of the clause *without the use of a hearing aid*, numerous respondents mistakenly heard the assistive device clause in the vision question that follows. Instead of hearing *even when wearing glasses*, respondents intuited that the clauses in the two questions would be consistent and so, consequently, heard *without the use of glasses* (as opposed to *even when wearing glasses*). This change dramatically altered the meaning of the vision question (see discussion of Vision Question) and generated numerous false positive responses for the vision question.

Question Response Problems

The vast majority of response difficulties associated with this question occurred when respondents deemed their hearing condition (either their own or another household member’s) as situational or “on the brink” of being a serious problem. Those respondents who had difficulty hearing in specific circumstances struggled to determine if “on average” the problem was serious. Additionally, because respondents’ answers necessarily hinge upon the circumstances of their hearing trouble, some respondents had many factors to consider before answering. In order

to respond accurately, respondents considered factors such as the types of sound (i.e., high vs. low pitches), the number of people in a room, the amount of background noise, the frequency in which they find themselves in hard-to-hear situations, and the impact that the limitation has on their life.

Additionally, in NCHS interviews that were administered by an interviewer, many respondents heard the question, not as a yes/no question, but as a question inquiring into which particular type of hearing trouble they had, that is, were they deaf or did they have serious trouble hearing? Instead of answering *yes* or *no*, then, these respondents answered “neither” or “I have serious trouble hearing.” In these situations, the interviewer needed to restate the question, asking for a yes or no response. This type of response problem did not occur in Census Bureau interviews that were self-administered. In these interviews, respondents could see for themselves that the question was yes/no and that they were to check either the box marked yes or the box marked no.

Finally, a few NCHS respondents noted that the hearing question is sensitive and indicated that either they or their household members do not like to readily admit that they have a problem with their hearing. For example, one respondent explained that because hearing loss is associated with aging, he feels somewhat embarrassed by the question. Additionally, one Census Bureau respondent stated that the term *deaf* was offensive and said the American Psychological Association (APA) guidelines suggest using the term *person with hearing disability*. (Although the respondent seemed very knowledgeable about this topic, review of the APA website did not reveal this information.) Another Census Bureau respondent, a mother of an 18-year old with Downs Syndrome, felt that the question made her want to advocate for her son who technically does not have hearing difficulty but has auditory processing problems. While the respondent saw a difference between his problems and those confronted by the deaf, she felt obliged to answer yes to the question, stating that this problem will affect his ability to hold a job once he is on his own.

Version Recommended for the ACS: Are you deaf or do you have serious difficulty hearing?

This version of the hearing question is recommended because it was interpreted most consistently across cognitive interview respondents. Variations of the question which included the hearing aid clause received a broad range of interpretations among respondents and, in some cases, dramatically altered the intent of the question. Additionally, response error was generated in the following vision question when the clause *without the use of a hearing aid* was used.

The limitation domain of hearing, especially when compared to that of vision, was more complex in terms of design and potential response error problems. For example, hearing problems are not as correctable as vision problems and so respondents with hearing aids were faced with the additional burden of discerning if “on average” their problem was serious. Additionally, because of the stigma associated with hearing difficulty, some respondents were less inclined to readily identify themselves as having such a problem. Most significantly,

because hearing ability is particularly dependent on circumstances and context, many hearing-impaired respondents were compelled to weigh numerous factors before responding. Therefore, regardless of question wording, reports of hearing ability are based on respondents' personal understanding and experience with hearing difficulty.

Vision

Tested Versions of the Proposed Vision Question

- Round 1: **Do you/Does (insert name) have serious trouble seeing or are you/they blind?**

 Are you/Is (insert name) blind or do you/they have serious trouble seeing even when wearing glasses?
- Round 2: **Is this person blind or do they have serious difficulty seeing even when wearing glasses?**
- Round 3: **Are you/Is [insert name] blind or do you/they have difficulty seeing even when wearing glasses?**
- Round 4: **Are you/Is [insert name] blind or do you/they have serious difficulty seeing even when wearing glasses?**
- Round 5: **Is this person blind or do they have serious difficulty seeing even when wearing glasses?**

Question Interpretation

Unlike the relatively consistent interpretations in the previous hearing question, interpretations for the Round 1 vision question, specifically of the phrase *serious trouble seeing* (without the wearing glasses clause), varied immensely across respondents. Variation was primarily based on the fact that respondents differed in whether or not they considered the use of corrective lenses. That is, while some respondents did not consider the use of glasses as having a serious condition, other respondents did. This dramatic difference generated responses that were not comparable across respondents. For example, while one respondent answered no when reporting for her mother specifically because she is able to use corrective lenses for all of her daily activities, another respondent, when also reporting for her mother, answered yes specifically because her mother must wear glasses for every daily activity. Similarly, one respondent answered no for herself because she only uses glasses for reading, but yes for her nephew because he requires glasses for all activities.

Additionally, while some respondents considered *serious trouble seeing* as requiring the constant use of glasses in order to function, a few others also included vision problems that required corrective lenses for simply a few activities such as reading or driving. For example, one respondent answered yes for himself because he needs prescription bifocals to read. However, when answering as a proxy for his girlfriend, he answered no because, as he explained, she uses

non-prescription magnifying glasses to read.

Others who held more conservative interpretations, excluded every eye condition but those which are not correctable with glasses. A few others with particularly conservative interpretations viewed the question as asking about conditions that rendered individuals essentially blind or with extremely impaired vision. One woman, for example, explained “it’s when you open your eyes and all you see is black.” Consequently, it did not even occur to her to consider her own vision problem which requires her to use glasses throughout the day. Similarly, another respondent explained, “it’s when people bump into things and need to use their hands to help guide them,” so responded no for his grandmother whose vision is corrected with glasses.

Inclusion of Glasses Clause

Because of the extreme inconsistency of interpretations across respondents, the phrase *even when wearing glasses* was inserted into the question and tested in the remaining six interviews of Round 1 as well as the interviews in Rounds 2 through 5. With the inclusion of the clause, the scope of interpretations narrowed dramatically, and respondents were guided toward more conservative conditions: “like being legally blind,” “if a person’s corrected vision was not normal,” “if a person could not pass the driving vision test with glasses,” “if you still squint with glasses on,” “not being able to read the newspaper or things that come in the mail,” and “cataracts.” Additionally, one Census Bureau respondent defined the phrase in terms of the associated stigma including decreased opportunities for work or employability.

With the addition of the clause, then, reports of *serious trouble seeing* corresponded to more severe conditions than previously reported. For example, one respondent explained that he has macular degeneration and cannot read street signs in bright daylight. Another woman stated that her nearsightedness is not completely adjusted with glasses and, consequently, she tires quickly when reading. In fact, with the addition of the clause, two respondents’ conservative interpretations may have actually lead to false negative reports. One man, who is legally blind, answered no for his wife but then described her vision as being very bad—even with glasses, she must put reading material two inches from her face. Another respondent reported no for herself though she is blind in one eye and cannot see in three dimensions. She noted that it was difficult deciding how to answer, but in the end responded no because she can see “very well with glasses out of her good eye.”

Except for one respondent, no one in the remaining rounds of interviews included vision problems that were correctable with glasses. Despite having eye surgery and not seeing well out of one eye because of a perceptual deficit, for example, one Census Bureau respondent still answered no to the question because her vision is corrected to almost 20/20. Another Census Bureau respondent stated that her son has weakness in one eye and had to wear glasses, but did not respond affirmatively to the question because she did not view the problem as serious. The one exception of a false positive report involved a Census Bureau respondent’s 60-year-old mother, who cannot read well without her reading glasses. Though not particularly serious, the

respondent answered yes because “if she depends on them, then they really help her.”

Although it does not pertain to the specific design of this question, it should be noted that when the preceding hearing question contained the clause *without the use of a hearing aid*, many respondents mistakenly heard the vision clause as stating *without the use of glasses* (as opposed to *even when wearing glasses*). Consequently, as in the initial version of the vision question, many of these respondents reported conditions that were fully correctable with glasses. When the hearing question was revised, this particular context effect disappeared.

Question Response Problems

As in the previous hearing question, ambiguity over the phrase *serious trouble seeing* was the primary source of response difficulty for respondents. This was especially evident when the question did not include the glasses clause. Because many use glasses, numerous respondents struggled to determine whether or not to include vision problems that were fully correctable. For example, one NCHS respondent went back and forth in her mind for several minutes as she tried to determine whether needing glasses to drive or to see a movie would be considered serious trouble seeing.

Although reducing the problem substantially, the clause *even when wearing glasses* did not entirely eliminate the need for respondents to negotiate what they deemed to be an accurate interpretation of *serious trouble seeing*. A few respondents whose vision problems were not entirely corrected continued to struggle in determining whether their problem (even when wearing glasses) was serious. For example, one respondent explained that, even with glasses, his “up close” vision had been worsening over time and that each year he required increased correction. Ultimately, he answered no, determining that (at least for now) his glasses are able to correct his vision to the extent that he can see “good enough.”

Version Recommended for the ACS: Are you blind or do you have serious difficulty seeing even when wearing glasses?

Like the hearing question, addition of an assistive device clause affected interpretations so that they became much more conservative. Unlike the hearing question, however, it appears that the assistive device clause is necessary for the vision question. Without the clause, interpretations of the question included a dramatic range of conditions (i.e., from “needing glasses to read” to “total blackness”) to the extent that comparability between reports was essentially nonexistent. While the assistive device in the hearing question generated interpretations that were far too conservative (thereby producing numerous false negative reports), the assistive device clause in the vision question generates interpretations that are more consistent with the question’s intent. Additionally, without the clause, numerous respondents struggled to determine whether fully correctable conditions should be included.

Though respondent burden is greatly reduced with the addition of the clause, those respondents with vision problems that are not entirely corrected remain in the position of having to determine whether their condition should be counted as serious. Because the question is self-report, respondents are left to themselves to decide; how they report will be determined by their own perceptions of their problem and what they consider to be serious. Their responses may (or may not) be consistent with the original intent of the question. To this end, reports are subjective and, consequently, may not be comparable. For example, of the three respondents with blindness in one eye and not limited in the types of activities that they can perform, two answered yes and another answered no. In another situation, a respondent stated that his positive response was due to “almost a night blindness” in one eye that resulted from the respondent’s years as a military sniper, which weakened one eye.

Notes

The response problem regarding the word *or* did not occur in the vision question to the degree that it did in the previous hearing question. In responding to the hearing question, respondents became clued in to the fact that the entire set of disability questions appeared in a yes/no format.

As with the previous question, one respondent, a disabled person but not due to vision loss, felt that the term *blind* was offensive and said the APA guidelines suggest using the term “person with visual disability.”

Cognitive Functioning

Tested Versions of the Proposed Vision Question

Round 1: **Because of a physical, mental, or emotional condition, do you /does (insert name) usually have difficulty concentrating remembering, or making decisions?**

Because of a physical, mental, or emotional condition, do you /does (insert name) usually have difficulty concentrating, learning, or remembering?

Round 2: **Because of a physical, mental, or emotional condition, does this person usually have difficulty concentrating, remembering, or making decisions?**

Because of a physical, mental, or emotional condition, does this person usually have difficulty concentrating, learning, or remembering?

Round 3: **Because of a physical, mental, or emotional condition do you/does [insert name] usually have difficulty concentrating or remembering?**

Round 4: **Because of a physical, mental or emotional problem, do you have serious difficulty concentrating, remembering or making decisions?**

Because of a physical, mental or emotional problem, do you have serious difficulty learning a new task?

Round 5: **Because of a physical, mental, or emotional problem, does this person have serious difficulty concentrating, remembering or making decisions?**

Because of a physical, mental, or emotional problem, does this person have serious difficulty learning a new task?

Question Interpretation

For versions of the question incorporating the activities of *concentrating*, *remembering* and *making decisions* (tested in all rounds but Round 3), respondents' interpretations were based primarily upon age and the types of activities they do in their daily life. For example, when answering the question, one woman in her mid-40s considered her ability to "hold on to details" and described her ability to remember shopping lists and getting herself and children to appointments. When answering for herself, she described the question as being a mental health question, specifically, about depression—a condition that would prevent her from performing her daily errands. When answering for her son, however, she interpreted the question as

pertaining to a learning disability and considered his ability to sit long enough to focus on a book or a math equation. Though one older respondent reported having a learning disability, most middle-aged respondents answering yes reported having mental illnesses such as being bipolar, having schizophrenia, or depression. Additionally, one Census Bureau respondent who answered positively to the question explained that he was suffering from “suppressed memories of a childhood trauma.” Elderly respondents, on the other hand, tended to consider aspects of memory that were related to the onset of Alzheimer’s disease, specifically, remembering directions or names of friends and relatives. In this regard, the question (specifically the question containing the terms *concentrating*, *remembering* and *making decisions*) appeared to capture a wide range of conditions, including mental health problems, learning disabilities and serious age-related problems.

For questions containing multiple activities (i.e., those tested in all rounds but Round 3), respondents generally approached the question in one of two ways: 1) by individually assessing each activity (i.e. *concentrating*, *remembering* and *making decisions*); or 2) by conceptualizing the individual types of activities as one broad, general category. One woman using the latter approach, for example, stated that she saw the question as asking “do you think clearly at all times?” Another man perceived the question as asking, “in a very general way, do you have any mental issues like depression?” As stated previously, many older respondents saw the question as asking about the presence of Alzheimer’s disease. For those participants considering the activities separately, most focused almost exclusively on the two activities of *concentrating* and *remembering*, omitting the last activity of making decisions. The activity of *concentrating* involved respondents’ abilities to focus on reading or paying bills, while definitions of *remembering* ranged from knowing people’s names and not losing keys to forgetting major life events. When considered, *making decisions* was not typically discussed in terms of whether or not decisions could be made, but rather the quality of decisions. One woman, for example, focused on her autistic daughter’s ability to make safe or sound decisions, such as running a bath without letting the water get too hot. Another respondent focused on the fact that she does not always make “smart decisions,” for example, spending too much money.

In Round 3, the question was changed to include only the activities of *concentrating* and *remembering*. In this new version, however, respondents’ interpretations were less restrictive than in the previous version, and respondents were much more likely to count relatively trivial memory problems such as forgetting names or misplacing keys. More so with this version, respondents tended to view the question as an aging question. For example, one respondent summarized the question: “Are you beginning to notice that you are getting older?” Numerous respondents laughed out loud when asked this question and commented that they have indeed experienced “senior moments.” Additionally, unlike the previous version, a number of respondents grappled for an appropriate answer and struggled to determine whether their age-related memory problem was “serious enough” to provide a yes answer. Though in the previous version many respondents did not account for the activity of *making decisions*, it appears that the mere inclusion of the term in the string of activities impacted respondents’ overall interpretation of the question. That is, *concentrating* and *remembering* take on a more critical connotation when linked with *making decisions*.

Asking about the activity of *learning*

In Rounds 1 and 2, an alternate question replacing *making decisions* with the word *learning* was tested in 5 NCHS interviews and 9 Census Bureau interviews. In this version, the word *learning* was interpreted in two distinct ways: 1) having the cognitive ability to perform day-to-day living skills; and 2) gaining academic knowledge. One respondent taking the first approach, for example, described her ability to cook from a recipe. Contrastingly, another respondent taking the second approach considered school participation in his conceptualization of *learning* and explained that this portion of the question did not pertain because “his son is no longer in school.”

Although difficult to conclude with the few number of interviews, it appears that more often in the version containing the word *learning*, respondents tended to approach each activity individually (as opposed to combining activities) when arriving at an answer—perhaps because it is more difficult to conceptualize one general, underlying theme from the activities of *concentrating*, *learning* and *remembering*. This is certainly true for respondents who conceptualized *learning* as purely an academic accomplishment; the 3 activities together did not entirely make sense and, as several respondents explained, “should be split into separate questions.”

To provide additional insight into the reporting of learning disabilities in children, the following question was tested in Rounds 4 and 5: *Because of a physical, mental or emotional problem, do you have serious difficulty learning a new task?* Interpretations of this new question, however, were broad and varied immensely across respondents. When considering their answers, for example, one respondent thought of learning how to use a computer, another thought of starting a new career, while another thought of learning about how tsunamis formed. Additionally, several respondents indicated that the question was about “being open to new ideas” and “not being stubborn.” One woman, answering for herself, considered her own “ability to have a profession in academia,” but considered the use of “fine motor skills” and of “expressive language” when answering for her autistic son. Because of the numerous interpretations and the fact that it did not perform any better for children than the previous question, it was recommended that this item be dropped altogether.

Interpretations of the word *usually*

In the original version of the question, the committee incorporated the word *usually* to eliminate the need for longer, more complicated phrases traditionally used in disability questions to denote long-term conditions (e.g., “a health condition lasting six months or more”). In testing, no respondent included a problem associated with a temporary condition; related conditions included mental illnesses, age-related problems and learning disabilities. Instead of the inclusion of temporary conditions, possible response errors associated with the question pertained to the degree of severity associated with memory or concentration problems. That is, some respondents included conditions that were relatively trivial and typical, such as forgetting names

or losing car keys. Additionally, all positive responses to the question were based on currently occurring conditions. One Census Bureau respondent, for example, who had a liver transplant 7 years ago and will need another transplant soon, explained that the most accurate answer is “not yet.” He answered no, however, because he does not currently have the difficulty, though he anticipates having the difficulty in the near future.

Although the question as a whole functioned as intended (i.e., respondents included current, long-term conditions), when asked specifically “what does the word *usually* mean to you?,” no one stated outright that it implied a long-lasting condition. Instead, respondents reported a range of inconsistent, sometimes curious, explanations. For example, one woman who had no difficulty correctly answering the question stated (when probed) that she believed the word *usually* meant “ever” and restated the question: “Do you ever have a problem with concentrating, learning or remembering?” Another respondent stated that the word was confusing; she interpreted *usually* as meaning “often” but was not sure how often: “Do you mean often or very often?” These odd interpretations more likely indicate that the word *usually* did not contribute additional meaning to the question. Indeed, for the vast majority of cases, respondents were not confused by the word until they were specifically asked to provide a definition of the term. If respondents struggled with the question, it was more about the degree of seriousness, not the degree of time or frequency of the problem. Consequently, in a subsequent version, the word *usually* was replaced with the word *serious* and tested in Rounds 4 and 5.

Question Response Problems

Response difficulty for respondents primarily centered around assessing whether their particular limitation was serious enough to report. One woman who was diagnosed with ADD, for example, stated that it was somewhat difficult for her to decide whether or not her condition (which, she reported, impacted her life very little) warranted reporting. She noted that this question, unlike the previous two questions, did not specifically mention the word *serious*, so she ultimately decided that “anything goes” and responded *yes*. A few other respondents were unclear about whether or not they should include age-related memory problems. One man, for example, stated that he would have answered *yes* if the question asked *do you usually have difficulty concentrating, remembering or making decisions because of age?* Because aging is a natural phenomena and not a health condition, he answered *no*. In answering for her elderly mother, another respondent stated that the question was particularly difficult because her mother was only beginning to lose cognitive function. Because she was still able to live independently, the respondent ultimately answered *no*.

Another difficulty pertained to the use of medication for treating mental illness or learning disabilities. Several respondents, for example, were unsure of whether or not they should assess their problem when using medication. One respondent who reported stress problems explained that since he needs the medication, he should answer *yes* to the question. Conversely, another respondent who suffers from depression provided a *no*-answer specifically because his medication allows him to concentrate better.

Version Recommended for the ACS: Because of a physical, mental or emotional problem, do you have serious difficulty concentrating, remembering or making decisions?

In order to cue respondents to include only critical, activity-hindering problems, the word *serious* was replaced with the word *usually*. Additionally, the activity of *making decisions* was included with the activities of *concentrating* and *remembering*, not because it added a different dimension of cognitive functioning that needed to be measured, but because the term added to the implication of severity.

Lower Mobility

Tested Versions of the Proposed Lower Mobility Question

- Round 1: **Do you /Does (insert name) usually have difficulty walking or climbing stairs?**
- Round 2: **Due to a physical, mental, or emotional condition, does this person usually have difficulty walking or climbing stairs?**
- Round 3: **Do you have difficulty walking or climbing stairs without equipment such as a cane, walker or wheelchair?**
- Round 4: **Do you have serious difficulty walking or climbing stairs?**
Do you have difficulty walking or climbing stairs without equipment such as a cane, walker or wheelchair?
- Round 5: **Does this person have serious difficulty walking or climbing stairs?**

Question Interpretation

For Rounds 1 and 2, respondents primarily considered physical limitation factors such as the amount of pain or the degree of fatigue they experienced when walking or climbing stairs. Though the initial question tested did not mention assistive devices, in forming their answer some respondents considered whether they used a cane, wheelchair, walker or a handrail when climbing stairs. As in the other domain questions, the degree of difficulty considered to be serious varied across respondents, ranging from those who could not walk at all to those who could walk but with a significant degree of pain. Those reporting serious difficulty had a variety of physical conditions including fibromyalgia, difficulties resulting from an accident, old age, knee and ankle problems, rheumatoid arthritis, and being overweight.

When answering for other household members, a few respondents answered outside a physical interpretation of the question. For example, one NCHS respondent who answered yes for herself because of her arthritis, also responded yes for her mother, but explained that her mother has “mood swings” and “does not like to be out and around crowds.” Another respondent explained that while his girlfriend is not limited in doing any activities, she is “just physically out of shape.” Finally, another NCHS respondent explained that while her daughter can easily run up and down stairs, she is worried that she may fall and hurt herself or her younger brother because she does not have good judgment skills. In these cases, respondents’ answers were not so much an assessment of a household member’s physical limitations, but about other kinds of concerns.

Long Term vs. Temporary Conditions

As in the cognitive functioning question, the word *usually* was included to prompt respondents to include only long term physical conditions; mobility problems due to temporary injuries or short-term illnesses should not be counted. Unlike the cognitive question, essentially all respondents understood the term as intended (though one Census Bureau respondent who suffers fibromyalgic flares suggested that she was somewhat confused by the term). Difficulty walking and climbing stairs, as opposed to difficulty with cognitive functioning, is more likely to be affected by a temporal condition. Consequently, the term *usually* makes better sense within the context of a mobility question. Neither of the two NCHS respondents who reported household members as having temporary conditions responded affirmatively, suggesting that the word *usually* served its function in these cases. One NCHS respondent whose husband slipped and fell at work did respond positively because, as she explained, his injury occurred over a year ago and though he has had several surgeries (and was scheduled for another the next week), it appeared that his condition was not going to improve in the near future.

It should be noted, however, that one Census Bureau respondent with a torn meniscus responded affirmatively even though, after surgery, he anticipates a full recovery. Although he initially answered no, when the question was repeated, his focus shifted from the word *usually* to the introductory phrase (*due to a physical, mental, or emotional condition.*) Because his torn meniscus was a physical condition, he changed his answer to yes. This error, however, is likely an artifact of the cognitive interview because the question was repeated and the respondent was asked to scrutinize the wording of the question. Another Census Bureau respondent recovering from foot surgery, on the other hand, responded no to the question specifically because she interpreted the question as emphasizing the word *usually*. Though she did not initially focus on the introductory phrase, she stated that she did not need to reconsider her answer because the word *usually* outweighed the reference to a physical condition.

Inclusion of Assistive Device Clause

More than the potential problem of including temporary conditions, the question did not always capture limitations because respondents did not consider their mobility problem serious enough to report. For example, several respondents with clear difficulty walking (to the extent that they used walkers or canes) reported no difficulty because, they explained, the assistive devices grant them mobility. Similarly, one Census Bureau respondent who suffered from a fractured back and, as a result, requires a crutch, cannot bend, and is limited in the amount she can walk, answered no because she “can get by...it’s not really a difficulty...because it hasn’t stopped me from doing anything.”

With the aim of reducing these types of false negative reports, an assistive device clause was added in Round 4: *Do you have difficulty walking or climbing stairs without equipment such as a cane, walker or wheelchair?* As in the hearing question, however, the assistive device clause performed counter to its intention. In a third of the Round 4 interviews, respondents misheard the clause. Many interpreted the question as *Do you use a cane, walker or wheelchair?*

Consequently, those respondents who did not use an assistive device responded no without even considering their mobility status. Because of the negative in the clause (i.e., without equipment), a few others interpreted the question as *Can you walk without the use of a cane, walker or wheelchair?* This interpretation—opposite of the intended question—led to outright response error. For example, when asked the question, one older man answered no and explained that he was forced to retire because he was unable to walk without the use of a cane.

Question Response Problems

The greatest difficulty for respondents was determining whether their difficulty was serious enough to report. For example, in attempting to respond, one older respondent asked “to what degree?” He explained that he can easily walk about 50 yards, but then he gets tired. He also stated that, when he uses his walker, he can go “an unlimited distance” and so was not sure how to answer (though, he ultimately answered no). One Census Bureau respondent also interpreted the question as asking about short distances and was thinking about her ability to walk “inside the house.” Only if she had been completely unable to walk, she would have easily answered the question as yes-difficulty.

Additionally, a few respondents stated that the question was more difficult when reporting for their elderly parents. Unlike the previous cognitive question, no respondent was unsure as to whether they should account for age in their answer. However, the difficulty was in assessing in the degree of severity and the fact that when people age their abilities gradually decline.

Version Recommended for the ACS: Do you have difficulty walking of climbing stairs?

Because of the amount of response error associated with the inclusion of an assistive device clause, it is not recommended. It should be noted, however, that some respondents may provide a response of *no*, not because they do not have difficulty, but because they believe their assistive device grants them full mobility. Additionally, because respondents are less likely to respond positively unless their mobility is severely hindered, the word *serious* is not recommended. Many respondents, especially elderly respondents, are likely to not report a serious problem if they feel that they can get around with a cane or walker. The word *usually* was omitted because it did not add to the question. Especially by this question in the series, respondents understood that this was related to serious long-term conditions.

Upper Mobility

Tested Versions of the Proposed Vision Question

Round 1: **Do you /Does (insert name) usually have difficulty dressing or bathing?**

Do you /Does (insert name) usually have difficulty dressing or bathing without the help of another person or assistive device?

Round 2: **Does this person usually have difficulty dressing or bathing?**

Does this person usually have difficulty dressing or bathing without the help of another person or assistive device?

Round 3: **Do you /Does (insert name) have difficulty dressing or bathing?**

Round 4: **Do you /Does (insert name) have difficulty dressing or bathing?**

Round 5: **Does this person have difficulty dressing or bathing?**

Question Interpretation

In forming a response, many respondents considered the physical aspects involved in bathing and dressing, including the ability to close a zipper or to get in and out of a bathtub. For the most part, the question was interpreted as asking about relatively serious limitations. For example, a few respondents explained that this question pertained to “those people who were bed-ridden” or “needed to be in a wheel chair.” A couple of respondents noted that only very sick people would answer yes to the question.

In approximately one-third of the interviews that examined the question *Do you usually have difficulty dressing or bathing*, respondents considered aspects of mental health. For example, one NCHS respondent who answered yes explained that she is afraid of water because she almost drowned several times as a child. Another respondent explained that her nephew has difficulty picking out which clothes to wear and will often choose inappropriate clothes for the season. One Census Bureau respondent reported a yes-answer for her 18-year-old son with Downs Syndrome because he cannot wash his hair adequately to present himself at school or work. Another Census Bureau respondent, who suffers from depression and obsessive compulsive disorder, answered yes because she does “not bathe like normal people when it needs to be done,” and explained that she will not take a shower unless she has to go to school or work.

Use of accommodation and assistive devices

A few respondents were not certain if they should account for assistive devices used to facilitate bathing and dressing. For example, one man who had recently installed a seat in the shower and removed the edge of the tub allowing his wife to bathe alone did not know if he should account for the renovation of the bathroom. Ultimately, he included the accommodation into the answer, responding no difficulty. He also explained, however, that if he were asked the question prior to the renovation, the accurate answer would have been yes.

The question was tested with and without the phrase *without the help of another person or assistive device* in approximately half of the Round 1 and 2 interviews. Although it is difficult to make an assessment with so few interviews, no problems were identified because of the additional phrase. However, it does appear that, by comparison, the version with the phrase caused much stricter interpretations and limited reports to only physical limitations. That is, respondents receiving the question which included the accommodation clause were more likely to interpret the question within the dimension of physical disabilities and less likely to include mental or emotional problems.

Question Response Problems

Response difficulty primarily centered on respondents' abilities to assess the level of limitation and to decide whether the problem warranted reporting. One woman, for example, who sometimes needed help with a zipper in the back because of arthritis, changed her mind several times. And, in the follow-up discussion, she had forgotten her answer, suggesting that she never was able to settle on a definitive response. Another respondent stated that it was difficult to answer for his wife because, while she is able to bathe and dress by herself, it takes a longer time.

Additionally, some respondents had accommodated so that they did not have a problem. One respondent, for example, explained that since she fell in the shower because of a balance problem, she now only takes baths. Similarly, she changed the kind of clothing that she wears (e.g., not using zippers) so that she does not have any problems dressing.

Version Recommended for the ACS: Do you have difficulty dressing or bathing?

Like in the previous mobility question, inclusion of an assistive device clause is not recommended. The clause directs respondents to consider only physical dimensions of dressing and bathing, omitting any mental or emotional problems that may interfere with self-care. It should be noted, however, that some respondents may provide a response of *no*, not because they do not have difficulty, but because they believe some type of accommodation grants them full ability. Additionally, like the previous question, because respondents are less likely to respond positively unless their self-care ability is severely hindered, the word *serious* is not

recommended. Many respondents, especially elderly respondents, are likely to not report a problem if they feel that they can do the activity, regardless of the amount of time needed. The word *usually* was omitted because it did not add to the question; respondents understood that this was related to serious long-term conditions.

Daily Activities

Tested Versions of the Proposed Daily Activities Question

- Round 1: **Do you /Does (insert name) usually have difficulty going outside the home alone to visit a doctor's office or shop?**
- Round 2: **Does this person usually have difficulty going outside the home alone to visit a doctor's office or to shop?**
- Round 3: **Do you have difficulty doing errands alone such as shopping or visiting a doctor's office?**
- Round 4: **Do you have difficulty doing errands alone such as shopping or visiting a doctor's office?**
- Round 5: **Does this person have difficulty doing errands alone such as shopping or visiting a doctor's office?**

Question Interpretation

Responses were based on interpretations of the question that divided, almost equally, across respondents. They include:

- 1) a question about *emotional restrictions*, such as having agoraphobia or panic around crowds, being afraid of doctors, or being afraid of crime in the neighborhood;
- 2) a question about *cognitive functioning*, involving the ability to remember directions and safely cross the street;
- 3) a question about *physical limitations* which prevent individuals from going out of the home without any assistance, for example, being able to open doors or drive a car on one's own; and
- 4) a question about *access to resources*, for example, not owning a car or having access to public transportation or, as in one case, needing a better electric wheelchair.

Depending on the intent of the question, the possibility of multiple interpretations could be a problem. Importantly, responses may vary, not because individuals' circumstances (including physical limitations) vary, but because the responses are based on different interpretations of the question. For example, the question did not capture all instances of emotional problems that caused difficulties. One respondent with AIDS and depression who also described not being able to go to the doctor because of his mental health problem, answered no because he is still physically able to go to the doctor's office.

Additionally, respondents tended to focus on the first phrase of the question, *going outside the*

home alone, rather than the examples of shopping or visiting a doctor's office. Consequently, some respondents incorrectly interpreted the question to include lack of access to transportation resources. A second version of the question, therefore, replaced the phrase *going outside the home alone* with *doing errands alone*.

This new version performed well; there were no identified cases of misinterpretation regarding the question's intent. One Census Bureau respondent, for example, without probing, stated outright that the question pertained to mobility and to mind capacity. Another Census Bureau respondent stated that she was unfamiliar with the word *errand*, though still correctly understood the question because of the provided examples. In comparison to the previous version, respondents were more likely to consider the actual errands that they typically do (as opposed to the listed activities of shopping or going to the doctor's office). For example, interviewed men, whose wives typically do their shopping, described going to Home Depot and the bank as well as getting gas at a gas station.

Question Response Problems

Like the majority of previous questions, primary response difficulty centered on respondents determining whether or not their difficulty occurred often enough to report a positive answer. A couple respondents, for example, stated that they only had a problem "some of the time" or "occasionally" and were not certain whether they should answer yes. Additionally, a couple respondents stated that although they could do the activities, they were unsure if they should report a yes-answer because it required them to move very slowly and took them much more time.

Version Recommended for the ACS: Do you have difficulty doing errands alone such as shopping or visiting a doctor's office?

Work

Tested Versions of the Proposed Work Question

Round 1: **Are you/Is (insert name) unable to work at all or are you/is s/he limited in the type of work you/s/he can do or number of hours you/he/she work(s)?**

Because of a physical, mental or emotional condition, are you/is [name] limited in the amount or type of work you/s/he can do?

Round 2: **Because of a physical, mental, or emotional condition, is this person limited in the amount or type of work they can do?**

Because of a physical, mental, or emotional condition, does this person have difficulty performing the kind or amount of work they do at a job or business?

Round 3: **Because of a physical, mental, or emotional condition are you/is [insert name] limited in the amount or type of work you/s/he can do?**

Question Interpretation

The concept of work limitations was interpreted extremely broadly by respondents. Although the question asks about limitations due to physical, mental or emotional conditions, respondents also included limitations due to age (high school students are too young to work, senior citizens are too old to work), the health of other family members (a child who needs constant care), access to employment (someone who cannot drive or take public transportation), natural pace of activity (someone who works slowly), and job qualifications (someone who cannot play the violin cannot be in an orchestra). Some of these interpretations may be associated with health conditions, but respondents considered other factors besides health condition in making the assessment about work limitations.

A couple respondents answering for retired household members answered yes, not because of the individuals' limitations but because it was time to retire and "she shouldn't have to work."

Another respondent answered yes when reporting for a teenager "because she is in high school."

Additionally, two respondents initially answered yes because their child's condition (i.e., their age) limited their ability to work. One respondent changed her answer when the question was repeated with an emphasis on the phrase *because of a physical, mental or emotional condition*.

The other respondent, however, did not change her answer, explaining that her daughter's age does, indeed, prevent her from working. Other examples of respondents giving positive responses for reasons that do not involve physical, mental or emotional conditions included issues related to being able to travel to a job and considering jobs for which the respondent was

not skilled.

Another problem derived from interpretation of the term *usually*. This question was affected by respondents' temporary injuries, which restrict the ability of a person to conduct their work-related assignments in their injured state. One injured respondent, with a torn meniscus, responded yes to this question initially because he could not perform his job in his injured state while another injured respondent, recovering from foot surgery, responded yes because she recognized this injured state as temporary.

Because of the question length and numerous clauses, many respondents asked to have the question repeated. Additionally, because of the use of the word *or* in the question, one respondents believed that the question format had shifted from a *yes/no* format in previous questions to the format of *select one*. This shift in format in addition to the length of the question, confused the respondent. She ultimately reported no, when the correct response would have been yes.

Finally, because the question does not delineate what is meant by *work*, it is not clear if respondents should consider the type of work that they do (if indeed they do have a particular trade) or all types of work. Responses will vary if respondents are considering manual labor, such as bricklaying, as opposed to office work, where someone may need to sit all day, as opposed to waitressing or cashiering, which requires standing.

To compensate for the problems identified above, an alternative version was tested in 5 interviews of Round 1. Overall, there were dramatic improvements, specifically, no one needed the question repeated. However, different interpretations of work arose: some respondents (primarily those who are retired) answered in terms of general work around the house, for example, repairs, gardening, and housekeeping, while others thought only of their occupations and still others considered both scenarios.

Question Response Problems

Many false-positive reports were made because of question misinterpretation. These were in a variety of areas: people who naturally had a slow pace of working, people with temporary injuries, and people who considered jobs for which they were not qualified. In addition, there was an inconsistency between respondents' reports of work limitation and their official disability status. In some cases, respondents were not working because they were classified as disabled and receiving disability payments, even though they said they were not limited. In others, working respondents applied for disability status to allow them to survive after their physical condition deteriorated to the point when they could no longer work.

Version Recommended for the ACS: Due to the excessive extent of misinterpretation and misreporting in this question, it is recommended that the question be deleted from the field test.