

Comparison of American Community Survey and Washington Group Disability Questions

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Executive Summary

The purpose of this study is to inform the decision concerning whether to change the disability questions currently on the American Community Survey (ACS) by adopting the Washington Group Short Set on Functioning (WG). Both sets contain six questions with overlapping content in five of the questions. The primary difference between the two sets is the structure of response options: the ACS uses a yes/no response, while the WG uses a four-category graded response. For inclusion on the ACS, the WG requires adaptation for use on a self-administered survey. Specifically, wording within the questions would be changed from ‘you,’ ‘your child,’ or ‘[name]’ to ‘this person.’ The objective of this study is to compare the performance of the five overlapping questions from both sets of disability questions (i.e. the adapted WG and the current ACS questions) within the context of the ACS form. Of interest is whether the two question sets obtain information on the same constructs and how the two different response options perform.

There are three main findings:

- 1) There was little difference between the ACS and WG in terms of the phenomena considered by respondents; respondents had nearly identical interpretations of each pair of questions, thus capturing the same construct.
- 2) The source of the information on which respondents based their answers differed depending on whether they were answering for themselves or serving as a proxy on behalf of another member of their household. This was true for both sets of questions. When answering for themselves, respondents considered their own, self-perceived experiences or understandings. In contrast, as is often the case when reporting for others, respondents based their answers on observations of that household member—perceptions that were often mediated by their relationship with that person. In some cases, respondents did not feel sufficiently knowledgeable, so therefore relied on reports of others, such as teachers and doctors.
- 3) The WG, with four as opposed to two response categories, was better able to depict the range of functioning with more consistency. Specifically, when asked the WG, respondents answered ‘no difficulty’ when there was no experience of limitation, ‘some difficulty’ with difficulty in particular activities or in particular contexts, ‘a lot of difficulty’ with frequent difficulty in numerous contexts, and finally, ‘cannot do at all’ with the entire inability to perform the activity. In contrast, despite the specification of ‘serious difficulty,’ those answering ‘yes’ to the ACS set described a range of limitation, with some reporting lesser problems in certain situations and others reporting a great deal of constant limitation. Similarly, respondents answering ‘no’ to the ACS questions also reported a range of functioning, with some having no difficulty and others having lesser degrees of difficulty. Thus, for those experiencing less serious difficulty, there was a degree of inconsistency among ACS

respondents: some respondents answered ‘no’ while others with similar difficulty levels chose to answer ‘yes.’

Introduction

Models defining disability, and the methods for collecting data on disability, have varied over time reflecting the complexity of the subject and changing societal understanding of the concept of disability (1). Work to improve data collection on disability has occurred at both federal and international levels resulting in two commonly used sets of questions to capture information on disability status: the American Community Survey (ACS) disability set and the Washington Group Short Set on Functioning (WG) (2).

Both the ACS and the WG are comprised of six questions asking about difficulty in core domains of functioning and both use the World Health Organization’s International Classification of Functioning and Disability as a conceptual model (3). The ACS set questions ask about serious difficulty in seeing, hearing, walking, cognition, self-care and difficulty with independent living using a dichotomous yes/no response set. The WG questions ask about difficulty seeing, hearing, walking, cognition, self-care and communication using a four-category response set of no difficulty, some difficulty, a lot of difficulty and unable or cannot do at all. Five domains of functioning are common to both the ACS and WG, both sets are structured similarly and both are designed to obtain information on the same constructs. The main difference between the two sets is that the WG uses an ordinal response set to obtain information on a continuum of difficulty thus providing information in functional ability on a more granular level compared to the dichotomous ACS question set.

The current ACS disability questions, developed by a Federal interagency committee, were first administered on the ACS in 2008 (4). They have also been included on other federal surveys such as the Current Population Survey, the National Crime Victimization Survey, and the Survey on Income and Program Participation. The WG was developed by the Washington Group on Disability Statistics, chartered by the United Nations Statistical Commission, for use in censuses and surveys and are designed to enhance international comparability of disability statistics (5-6). The question set was endorsed by the WG in 2006. The WG has been recommended by both the United Nations (UN) Statistical Division and the United Nations Economic Commission for Europe’s Conference of European Statisticians as the preferred method for collecting information on disability in the current 2020 round of censuses. It has also been endorsed as the international standard for disaggregating the 2030 Agenda for Sustainable Development Goals by disability status, and added to over 90 censuses, surveys and data collections world-wide, including NCHS’ National Health and Nutrition Examination Survey and the National Health Interview Survey.

In light of the goals to collect disability data that are cross-culturally and internationally comparable, address UN recommendations for the collection of disability data in censuses worldwide, and collect additional information on disability severity, consideration is being given to replacing the ACS question set with the WG in the 2025 ACS data collection.

The objective of this study is to compare the performance of the five overlapping questions for both sets of disability questions (i.e. the adapted WG and the current ACS questions) within the context of the ACS form. Of interest is whether the two question sets obtain information on the same constructs and to compare how the different response options perform.

Methodology

Interviews took place in the NCHS Question Design Research Laboratory (QDRL) from August 2019 to February 2020. The methodology used in this study is detailed in Miller et al. (2014) and pertains to data collection, method of analysis and report preparation (7). In total, 43 interviews were conducted. To compare both sets of disability questions, approximately half of the respondents (n=23) received the ACS questions set, and the remainder (n= 20) received the WG. In addition to answering the set of disability questions for themselves, respondents answered for others living in their house. Household members could include respondents' spouse, children, grandchild, parent, sibling or other, non-related residents. In total, ACS respondents answered on behalf of 66 household members, and WG respondents answered on behalf of 64 household members.

Sample Selection and Respondent Characteristics

The CCQDER research team recruited respondents through newspaper advertisements, e-mail list contacts and flyers. All respondents were 18 years or older. Sampling was purposive, with selection based on respondents' and their household members' disability status. To examine the performance of questions for non-adults, parents of children ages 2-17 with difficulties in at least one of the disability domains were also prioritized. Finally, although demographic diversity was a recruitment goal, the ability to achieve this was limited by the characteristics of those who met the first criteria and were willing to participate in the study. Table 1 presents the demographic information of respondents answering ACS and WG questions.

Table 1: Respondent demographics for ACS and WG instruments.

	ACS	WG
Total	23	20
Race		
Black	22	16
White	1	4
Age (in years)		
18-29	2	2
30-49	9	7
50-64	10	10
65+	2	1
Gender		
Male	10	3
Female	13	17

Data Collection

Interviews were conducted in the QDRL by CCQDER staff. All interviews followed a set protocol to ensure comparability. First, respondents were handed an instrument formatted to appear like the ACS paper survey form and asked to fill out the questionnaire. Half of the forms contained the current ACS disability questions; the other half contained the proposed WG questions. Except for the disability questions, the two instruments were identical. Respondents answered questions for both themselves and household members.

After completing the questionnaire, respondents were asked to discuss the reasoning for their answers to each of the disability questions. Specifically, respondents were asked to describe the activities they considered as well as why they chose the particular response category (yes/no for the ACS set, and no difficulty, some difficulty, a lot of difficulty and cannot do for the WG). Typical follow-up questions included, “How so?” and “Why do you say that?” If a respondent’s answer seemed vague or unclear, the interviewer asked: “Can you give an example to describe what you are talking about?” Importantly, overly-focused and yes/no follow-up questions were avoided so as to not bias or circumscribe respondent explanations. That is, particular attention was given to ensure that respondents themselves determined what was relevant to the explanation of how they formulated their answer.

Once interviewers had a clear understanding of the respondent’s question-response process, respondents were asked to consider the alternative WG or ACS response-options (depending on the version they were originally asked). Respondents were then asked to explain their reasoning and make sense of any contradictions or inconsistencies. The culminating text from the interview relates how respondents understood or interpreted each question and also outlines the types of experiences and behaviors respondents considered in providing an answer.

Interviewers took notes and all interviews were video recorded. Using notes and video-recordings, interviewers entered data into Q-Notes, the QDRL software application for data storage and analysis of cognitive interviews (wwwn.cdc.gov/qnotes). Interviews were approximately 60 minutes. Respondents were compensated \$40.

Data Analysis

Data were analyzed qualitatively using the grounded theory approach—a process involving data reduction and theory building. First, original interview text from each interview was summarized into detailed interview notes. Summary notes specified the way in which individual respondents answered each survey question, including respondents’ interpretation of questions, activities and experiences considered by respondents, and any response difficulties and errors. Next, comparisons were made across all interviews, identifying interpretive patterns (including patterns of response error) across interviews. Findings from this second level of analysis depict the phenomena captured by each question as well as within each response category. Finally, thematic patterns were compared across the two versions of each question, thus indicating whether the WG and the ACS questions captured the same phenomena, thereby indicating whether the two questions measured the same construct. Additionally, patterns within each response category were assessed across the two versions to examine the comparability between the two types of rating systems (i.e. the ACS’ yes/no and the WG’s Likert-type response categories).

Summary of Findings

Three main findings emerged from the analysis. First, there was little difference between the ACS and WG questions in terms of the phenomena considered by respondents; respondents had nearly identical interpretations of each pair of questions, thus capturing the same construct. For example, for both the ACS and WG seeing questions, respondents considered vision quality (e.g. blurry) as well as the ability to perform certain activities (e.g. reading) and in particular contexts (e.g. at night). With the exception of the cognition question (the ACS version includes an element of ‘decision making’ whereas the WG version does not), the two versions captured the same construct for all other domains.

Second, while the same phenomenon was found for both versions of the question, the source of the information on which respondents' based their answers differed depending on whether they were answering for themselves or serving as a proxy on behalf of another member of their household. Specifically, when answering for themselves, respondents considered their own, more self-perceived experiences such as feeling pain. When reporting for others, respondents were limited to observations of the other household members such as seeing a family member struggling. This became particularly relevant for respondents reporting about children who did not necessarily display outward difficulties, for example, with seeing and hearing. In these cases, respondents were more likely to draw upon the assessments of teachers and pediatricians.

Third, while respondents experienced a wide range of limitations, the WG questions—with four as opposed to two response categories—were better able to depict the range of functioning across the options and did so with more consistency. Specifically, when asked the WG, respondents answered 'no difficulty' when there was no experience of limitation, 'some difficulty' with difficulty in particular activities or in particular contexts, 'a lot of difficulty' with frequent difficulty in numerous contexts, and finally, 'cannot do at all' with the entire inability to perform the activity. In contrast, despite the specification of 'serious difficulty,' those answering 'yes' to the ACS set described a range in limitation, with some reporting lesser problems in certain situations and others reporting a great deal of constant limitation. Similarly, respondents answering 'no' also reported a range, with some having no difficulty and others having lesser degrees of difficulty. Thus, for those experiencing less serious difficulty, there was a degree of inconsistency among ACS respondents: Some respondents answered 'no' while others with similar difficulty levels chose to answer 'yes.'

The following report details these findings within the various disability domains. For each domain, the two versions of the question are discussed in terms of constructs captured as well as process for selecting a response option.

Findings by Domain

SEEING

*ACS: Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?
Yes, No*

*WG: Does this person have difficulty seeing, even if wearing glasses?
No difficulty, Some difficulty, A lot of difficulty, Cannot do at all*

Summary

One of the main objectives of this study was to determine if the ACS and WG questions captured the same concepts, and this was shown to be the case. When answering either the ACS or WG question, respondents considered the same types of phenomena. Almost all respondents considered quality of vision, both for themselves and others, when wearing glasses. While self-response was based on self-perceived vision quality (e.g., blurry) and ability to perform certain activities (e.g., reading) and in

particular contexts (e.g., at night), respondents answering for others based their answers on observations of the others' ability to perform those same activities or on input from professionals.

Another objective was to compare the use of response options for each version of the questions. In both versions, the selection of a response category was based on the extent of the limitation in terms of the level of difficulty as well as contexts for performing various activities. However, the range in limitations is more fully depicted and with more discrimination across each of the four WG categories as opposed to the two ACS categories.

In particular, those answering 'no difficulty' to the WG question described having no limitations whereas some respondents answering 'no' to the ACS question did describe having some problems, although primarily minor or in certain situations. When offered the WG response categories, these respondents answered 'some difficulty.' Selection of the WG categories 'some' or 'a lot' reflects respondents' increasing levels of difficulty. No respondents answered 'cannot do.' A range of difficulty, including some with minor problems in certain situations, was also found for 'yes' responses to the ACS question even though the question specifies 'serious difficulty.' When offered the WG response options all of those who answered 'yes' to the ACS question either chose WG categories of 'some difficulty' or 'a lot of difficulty.'

Constructs Captured

Respondents considered the same types of phenomena regardless of the version they answered. When answering for themselves, respondents considered their self-perceived vision quality (e.g., blurry, foggy) as well as their ability to perform certain activities (e.g., reading, using a computer, driving) and in particular contexts (e.g., at night, in the dark). When answering the ACS question, for example, one respondent explained her answer of 'yes:' "Sometimes you get blurred vision. And then it clears up." Similarly, when answering 'some difficulty' to the WG question, a 64-year old explained:

I basically don't drive at night unless I know where I'm going. I don't have a problem driving during the day, it's just my eyes fatigue more... at night it's just harder to see the contrast.

When reporting for others, respondents tended to base their answers on observations of the others' ability to perform those same activities. In multiple cases, proxy-respondents, primarily answering for their children, based their answer on the results of eye exams and pediatrician's recommendation for glasses. One mother who answered 'yes' to the ACS question for her son, for example, described thinking about teachers' observations as well as medical assessments:

He wears glasses. Sometimes even when he has his glasses on, he can't see. So, in school, even though he wears glasses, they have him face to face in front of the board. So, he can see. So, even though he wears glasses, sometimes he writes down the total opposite of what's on the board. Even though he has his glasses. His doctor is going to try to put stronger medicine inside his glasses to help him to see proper.

Similarly, a woman answering 'some difficulty' to the WG question described her daughter's difficulties: "I feel like when we go to the eye doctor, her prescription gets a little bit stronger. Sometimes she'll say to me, 'Mom, I can't see that,' and I know it's time for a new prescription."

Except for two respondents answering the WG question and one answering the ACS question, all respondents considered quality of vision, both for themselves and others, when wearing glasses. That is, (aside from those three cases) no one whose vision is entirely corrected with glasses reported difficulties seeing.

Outside of these patterns, there were a few cases of unintended interpretations and/or question-response difficulties. When answering the ACS question, one woman struggled to answer because she first thought the question asked if she was blind. She initially understood the question to be asking if she was “blind *and* [had] serious difficulties” instead of “blind *or* [had] serious difficulties.” Since she is not blind, she first marked ‘no’ on the questionnaire. In another case, when answering the ACS question, a woman considered her ability to find objects when looking for them. She answered ‘yes’ and said, “I guess your mind is not focusing on what you’re looking for... I guess it has something to do with your brain or something getting twisted.” The interviewer asked if she understood the question to be asking about the cognitive process of concentrating as opposed to eyesight, and she confirmed.

Finally, when answering the WG question, a respondent experienced difficulty when answering for her aunt, who recently had a stroke. She has noticed that her aunt no longer reads or watches TV, but is not certain if this is because of difficulties with her vision or her ability to concentrate. The respondent, who ultimately answered ‘some difficulty,’ based her answer on the observation of her aunt’s inability to perform activities that require vision, specifically driving and reading: “She could see, because she could drive. Now with the stroke, she really can’t see. She can’t see anything; she can’t read anything.”

Formulating a Response

For both questions, in selecting a response category, respondents considered the extent of their limitation in terms of the level of difficulty as well as contexts for performing various activities due to vision problems. In this way, both questions accommodate a range in experiences of limitation across respondents. However, because the WG question contains four—as opposed to the ACS’s two—response options, the range in limitations is more fully depicted and with more discrimination across each WG category. Specifically, those answering ‘no difficulty’ literally experienced no limitations in activities (e.g., “I don’t have problems seeing at night or anything while wearing glasses”). Those answering ‘some difficulty,’ like the respondent above with problems driving at night, described having some limitations in certain circumstances, but were still able to perform the activity. Similarly, another woman with perhaps even more vision problems, answered ‘some difficulty’ and reasoned that, despite constant cloudiness in her right eye, she is still able to perform necessary activities: “I can still do things...like that paper over there [on interviewer's side of table], I can just pull it closer.” The one respondent who answered ‘a lot of difficulty,’ on the other hand, described being prevented from participating in certain activities altogether because of vision problems, specifically, she failed her driver’s license test.

Despite the ACS question specifying ‘serious difficulty,’ respondents answering ‘yes’ also described a range of limitations, with some reporting minor difficulties in certain situations and others reporting a great deal of persistent limitations. For example, one respondent with little impairment who answered ‘yes’ described several situations in which she experiences blurriness, “Like the other night [my vision] was cloudy. I took [my glasses] off, like to clean them, but that wasn't it. I think I need a new prescription.” Other respondents described having greater levels of difficulty, such as more frequent blurriness and inability to focus on objects. One such respondent, who had difficulties with her “depth perception, looking directly down is a bad thing for me,” said that there were situations in which she

couldn't focus on any object, including those right in front of her. In the most severe cases, respondents described experiencing pain in their eyes and difficulties seeing in most situations.

The range of experiences included in the ACS 'yes' category was also demonstrated through respondents' choices of alternative WG categories. During probing, after they had answered the ACS question, respondents were asked which of the four WG categories (i.e. 'cannot do at all,' 'a lot of difficulty,' 'some difficulty,' and 'no difficulty') best fit their experiences. All of those who answered 'yes' to the ACS question either chose WG categories of 'some difficulty' or 'a lot of difficulty.' Those who selected 'some difficulty' expressed having difficulties in certain contexts, such as a respondent who commented, "because some days my vision is better, other days it isn't. And I could not even explain why." The few respondents who chose 'a lot of difficulty' described experiencing blurriness and other difficulties with most activities.

Like the WG 'no difficulty' response, the ACS 'no' response captured those respondents with no vision problems, explaining that they (or the person they were reporting for) "don't [doesn't] wear glasses," or that they have "20/20...or close to that." Most noteworthy, however, *unlike* the WG 'no difficulties' category, some ACS respondents answered 'no' despite having some difficulties, though to lesser degree, in certain situations. For example, one respondent who answered 'no' explained, "I still have a little difficulty [when wearing glasses].... A little difficulty is, I've noticed when you get the reading glasses and they have the different levels of them, I have to increase the magnification." Similarly, another respondent answering 'no' described her vision by saying, "I can't see far away. I wear them for distance. If I'm up close, I'm fine.... Again, it's distance. I have to squint to see far [when wearing glasses]." As such, there was a degree of inconsistency among ACS respondents with less severe limitations: some respondents answered 'no' while others with similar problems chose to answer 'yes.'

HEARING

ACS: *Is this person deaf or does he/she have serious difficulty hearing?*
Yes, No

WG: *Does this person have difficulty hearing, even if using a hearing aid?*
No difficulty, Some difficulty, A lot of difficulty, Cannot do at all

Summary

As was the case for seeing, responses to the ACS and WG questions captured the same concepts. Respondents considered their self-perceived ability to hear when doing various activities (e.g., watching television) in specific contexts (e.g., in noisy restaurants) but also referred to the results of hearing tests. When reporting for others, respondents also considered input from doctors along with their own experiences with their household member, such as needing to repeat themselves or having to speak louder.

Also reflecting the results from the seeing domain, the selection of a response category was based on the extent of the limitation in terms of the level of difficulty as well as contexts for performing various activities in both versions. Even though no respondent reported a lot of difficulty or being unable to hear at all, the range in limitations was more fully depicted with more discrimination across the WG categories as opposed to the ACS categories.

Those answering 'no difficulty' reported no limitations in activities whereas those answering 'no' to the ACS question experienced a range of limitations. Reasons for selecting the 'some' category reflected an increasing level of difficulty reflected in the label selected. A range of difficulty (some minor difficulties not causing problems) was also found for 'yes' responses to the ACS question even though the question specifies 'serious difficulty.' When offered the WG response categories, nearly all these respondents chose 'some difficulty' from the WG categories. These respondents explained that they preferred the category 'some difficulty' because they observed only minor difficulties hearing or difficulties in specific situations. A portion of those who responded 'no' to the ACS question responded 'some difficulty' when offered the WG response categories.

Constructs Captured

Similar to the domain of seeing, respondents considered the same types of phenomena when answering the ACS and WG hearing questions and, to some extent, used different information to arrive at their responses when answering for themselves as opposed to answering on the behalf of others in their household.

When answering for themselves, respondents often considered their self-perceived ability to hear when doing various activities (e.g., watching television and having a conversation) in specific contexts (e.g., in noisy restaurants). One respondent answering 'no' to the ACS question, for example, claimed, "I can hear pretty good...because I can eavesdrop. I've got noisy neighbors and sometimes I'm like, what are you saying?" Similarly, one man answering 'some difficulty' to the WG question explained, "Say I'm in a room and somebody's giving directions, and it's loud, I might have a hard time hearing them."

In comparison to difficulty seeing, however, respondents were less clear about whether they actually have difficulty since inability to hear is less obvious; one does not always recognize when sounds are not heard. As one respondent explained, "To me it seems normal, but sometimes I have to have the TV kind of louder." Like this respondent, many respondents assessed difficulty hearing by considering their need to make accommodations, for example, increasing the volume or turning their head to their better ear. However, unlike the seeing domain, when answering for themselves, many respondents drew upon the results of hearing tests (e.g., "No, my hearing is perfect... I've been tested by an audiologist").

When reporting for others, respondents also considered input from doctors along with their own experiences with their household member, such as needing to repeat themselves or having to speak louder. For example, one respondent explained that his grandmother complained of constant popping sounds in one ear and that he could only speak to her in the other ear. Similarly, another respondent explained that her son did not have difficulty hearing because, "he comes when asked and interacts just fine with people when asked questions. Also, the doctor has never said anything negative about his hearing."

Outside of these patterns, for both the ACS and WG questions, a few respondents understood the question to be asking about the activity of 'listening' or 'paying attention.' For example, one woman answering the ACS question described her difficulty:

Your mind may be somewhere else, and you may not be focusing on what the person is saying to you. Or you probably just don't hear. Or thinking that... you know you ask me a question and I'm looking over this way, and you're not saying my name, I'm not going to respond to you.

While also occurring for adults, this pattern was most common among parents reporting for their children. For example, one respondent answering ‘yes’ to the ACS question for her child explained, “because I could be in the next room, and I’m calling [his name]! And there is no way in the world! I know you hear me. I know well!” Similarly, another mother, answering ‘some difficulty’ to the WG question, explained:

It may be selective, because you know when they get eleven they want to act like they don’t hear what you’re saying...she was sitting here talking to me, she would hear me. But if she went into another room, I’m trying to talk to her and [shaking head].

These few respondents who conceptualized the question to be about ‘listening’ as opposed to ‘hearing’ answered either ‘yes’ to the ACS question or ‘some difficulties’ to the WG question (depending on which question they were asked), noting that their children expressed difficulties in specific situations, such as with household chores or doing homework.

Formulating a Response

For both questions, in selecting a response category, respondents typically considered the extent of their limitations (or those of the person they were answering for) in terms of level of difficulty and context for performing various activities, for example; the amount of difficulty having a conversation in a noisy restaurant. Additionally, some respondents based their answer on the amount or degree of hearing loss they have—as told to them by a physician when having their hearing tested. No one in the sample, however, described having serious or constant hearing problems. Thus, there were no ‘a lot of difficulty’ or ‘cannot do’ responses to the WG question. Additionally, no one in the study who was asked the ACS question reported having difficulty for themselves; all ‘yes’ answers pertained to household members.

Again, like the seeing domain, those answering ‘no difficulty’ to the WG hearing question experienced no limitations or problems with their hearing (e.g., “I hear everything,” “my hearing test was perfect”). All of those answering ‘some difficulty’ described having some limitations in certain circumstances, or explaining that the hearing problem is “only partial hearing loss.” For example, one respondent described having difficulties hearing in one ear: “I have, this ear [points at right ear] is a little [hard] of hearing because of water damage. I can hear out of it, but I hear out of this one [points to left ear] better.” Similarly, a mother responding for her child explained: “Because I have [taken] her to the doctor for her hearing, and they said her hearing was like not really ‘high-high’ but it was medium at that time.”

Despite the ACS question specifying ‘serious difficulty,’ most respondents answering ‘yes’ described hearing difficulty that they themselves did not necessarily see as a problem; no one in the sample described having deafness or severe difficulties hearing. For example, a respondent answering ‘yes’ about her grandmother’s hearing explained:

She has suffered some degree of hearing loss because she’s 86 years young. That’s very common. Overall, for her age, her hearing is quite good.... It’s just every now-and-then that I have to repeat something that she doesn’t hear.

When offered the WG response categories, nearly all respondents who selected ‘yes’ to the ACS version chose ‘some difficulty’ from the WG categories. These respondents explained that they preferred the category ‘some difficulty’ because they observed only minor difficulties hearing or difficulties in specific situations. For example, one mother of a child with hearing loss in his left ear selected ‘some

difficulty' and said, "because if [he] is close, he can hear and if you are facing the other ear he can hear. He functions just fine." Likewise, another respondent answering 'yes' to the ACS version said that his grandmother had 'some difficulty' because he didn't always need to repeat things to her: "because it's not a lot or most of the time. It's just occasionally." Only one respondent who answered 'yes' to the ACS question opted for 'a lot of difficulty' when reporting for her 10-year-old granddaughter. In explaining her answer, she described the high television volume that she insists upon ("Well, I say, 'turn the tv down' and she'll say, 'what?' and then turn the tv up. She'll just say, 'grandma, I can't hear.'"), and chose 'a lot of difficulty' because this insistence was affecting others in the household.

Those responding 'no' to the ACS version also described a range of hearing experiences, from no difficulty to some difficulty in specific situations. For example, one respondent answering 'no' to the ACS also described some difficulty hearing: "Sometimes I just can't hear things. Like when my son speaks, he's right in front of me, and I have to say, 'what did you say?' And he's right there." When asked to further explain why he answered 'no,' he said, "because I can hear...it's just sometimes I have a hard time." Similarly, another respondent who answered "no" for his 81-year-old mother further explained that the more accurate answer should be 'a little': "And the reason why I would say a little is her TV...I can hear her TV over my TV [on a different floor]."

Respondents' choices of the alternative WG answer categories further demonstrate the range captured in the ACS 'no' category. While many answered 'no difficulty,' several others opted for 'some difficulty.' For example, one explained "what [the doctor] says is it's not bad, but it could be better." Likewise, another respondent said that his mother had difficulties hearing "across the room," but when "face to face talking she is fine."

Similar to the vision domain, therefore, there was a degree of inconsistency among ACS respondents with less severe limitations: some respondents answered 'no' while others with similar problems chose to answer 'yes.' All WG 'no difficulty' responses consisted of respondents reporting no limitations whatsoever; those with lesser limitations in certain situations chose 'some difficulty.'

WALKING OR CLIMBING STAIRS

*ACS: Does this person have serious difficulty walking or climbing stairs?
Yes, No*

*WG: Does this person have difficulty walking or climbing stairs?
No difficulty, Some difficulty, A lot of difficulty, Cannot do at all*

Summary

Responses to the ACS and WG questions captured the same concepts in this domain. When answering for themselves, respondents considered difficulty walking or climbing stairs due to pain, fatigue or a musculoskeletal condition as well as need for some type of accommodation. When answering for household members, respondents considered others' medical conditions and their own observations and experiences with that person's ability, need for accommodation, and fatigue or pain (as is it is relayed to them).

Like the other domains, the selection of a response category was based on the extent and impact of the limitation with the range in limitations more fully depicted with more discrimination across the WG categories as opposed to the ACS categories.

Those answering 'no difficulty' reported no limitations in activities whereas those answering 'no' to the ACS question experienced a range of limitations. Reasons for selecting the 'some', 'a lot' or 'unable to do' categories reflect increasing levels of difficulty are reflect the label selected. A range of difficulty with some reporting lesser problems in certain situations and others reporting a great deal of constant limitation was also found for 'yes' responses to the ACS question even though the question specifies 'serious difficulty.' All those who answered 'yes' on the ACS chose either 'some difficulty' or 'a lot of difficulty.' A few respondents answering 'no' to the ACS version described having a lower level of limitation similar to some of those respondents who answered 'yes.'

Constructs Captured

Regardless of the version asked, respondents considered the same phenomena. Specifically, when answering for themselves, respondents considered difficulty walking or climbing stairs due to pain, fatigue or a musculoskeletal condition as well as need for some type of accommodation. For example, when considering the ACS question, one respondent explained, "Because of my feet. I guess it's the Achilles. That feels like it's pulling. Sometimes in the middle of my foot. And then I got my toes.... I think it's just from working." Likewise, another respondent answering the WG question, explained "because steps, I don't like to do them. But I do, if I have to. And I try to hold onto the rail because I don't want to fall. And that's why I say 'some difficulty.'" Additionally, some respondents based their answer almost exclusively in terms of fatigue or cardiovascular fitness. For example, when answering 'yes' to the ACS question, one woman explained:

I'm a bit overweight because I had back-to-back children. I notice the difference.... Especially walking a distance, I'll get out of breath... and the steep steps we have at our house.

Likewise, other respondents, in justifying their answer of 'no' or 'no difficulty,' explained that they regularly exercise (e.g. "I'm very fit," "I play a lot of tennis," "I go to the gym at least two times a week").

When answering for household members, respondents considered others' medical conditions as well as their own observations and experiences with that person's ability, need for accommodation, and fatigue or pain (as is it is relayed to them). For example, one respondent answering the ACS version on behalf of his grandmother described her difficulty climbing stairs on account of pain from her arthritis: "She can do it, but it has to be slowly. She also has some arthritis, so this pain plays a role too in slowing her down." When answering the WG version, another respondent answered 'a lot of difficulty,' explaining that his mother requires his help when she uses the stairs: "She still can do the stairs a little bit, but I assist her with the stairs. She takes her time. It takes her a long, long time. We live on the second floor." Another respondent reporting 'no' to the ACS version for her son, based her answer on personal observation: "He plays football and basketball and is very physically active." Likewise, another respondent answered 'no' for his wife because she "is able to do activities such as shopping and keeping appointments without assistance."

There were two cases where respondents answered outside of the interpretive patterns described above. First, when answering the ACS question, a mother considered her son's clumsiness, answering 'yes' because he is "very careless." She explained:

He'll walk down the street, and all of sudden he'll just trip. Boom. Falls out the bed at night when he's sleeping. Who falls out the bed at night at 10 years old when they're sleeping? You know? Crazy stuff, it drives me nuts [laughing].

Second, when answering 'a lot of difficulty' to the WG question on behalf of his mother, a respondent explained that she takes high dosages of prescription opioid painkillers and is unable to walk alone outside:

She's very doped-up [on painkillers]. Let's put it that way. She can walk. She moves around. But for her to go outside, she won't go unless she needs to."

Formulating a Response

For both questions, in selecting a category, respondents considered the extent and impact of the limitation. As in the other domains, both questions accommodate a range of experiences across respondents. However, with the WG question's four response options, the range in limitations is depicted more discretely across each category.

Specifically, when asked the WG version, respondents answered 'no difficulty' when they did not experience or observe limits of any kind. Those who answered 'some difficulty' explained that they experienced (or observed) difficulties with certain, particular activities. For example, one respondent said her stepfather had 'some difficulty' because he needed to use handrails when going upstairs. Another respondent, answering 'some difficulty' for her daughter, based her answer on her daughter's cardiovascular fitness and ability to climb steps: "Sometimes she just comes up the stairs and says, 'oh my legs. Oh, those steps.' I think it's mostly she's tired, cause it's usually at the end of the day of school." Respondents who answered 'a lot of difficulty' described frequent problems, with some describing even constant difficulties—though none were incapable of walking. For example, one respondent answering 'a lot of difficulty,' described having persistent pain and, therefore, avoids walking: "I've got arthritis. I've got bad knees. I've got a slipped disc in my spine and arthritis in my spine. And, arthritis in my knees. I stay in the house, sit right there on my couch." The response category 'cannot do at all' was reserved for those who were entirely unable to walk or climb stairs. For example, one respondent's mother had been completely incapacitated since having a stroke. He said, "She's bed ridden, so she won't be climbing any steps. She's not doing anything.... She doesn't get around, period. She's in the bed. She has a catheter, you know."

Despite the specification of 'serious difficulty,' respondents answering 'yes' to the ACS version described a range of limitations, with some reporting lesser problems in certain situations and others reporting a great deal of constant limitation. For example, one woman answering 'yes' explained: "I have arthritis in my hips. I still climb steps—I don't shy away from climbing steps—but you have to think about it. 'Let me think about everything I need upstairs, so I don't need to go again.'" In contrast, a mother answered 'yes' for her son because he relies on crutches for all mobility since having polio. She explained, "He can move around with crutches, but to climb stairs is very difficult for him." The range of experiences for those who answered 'yes' was likewise demonstrated in their choices of alternative WG categories. All those who answered 'yes' on the ACS chose either 'some difficulty'

(e.g., the woman with pain in her hip when climbing stairs) or ‘a lot of difficulty’ (e.g., the mother of the boy who relies on crutches for mobility).

Most respondents answering ‘no’ to the ACS version described having no problems with mobility and typically described being able to do activities, including exercising, without pain or other limitations. For example, one respondent claimed that he goes “to the gym at least once a week and could climb the empire state building!” There were, however, a few ‘no’ respondents who described having the lesser types of limitation on par with those respondents answering ‘yes.’ For example, the man with the torn Achilles tendon answered ‘no’ despite having pain when doing physically demanding tasks required at his work. In another example, a woman described experiencing cardiovascular fatigue when climbing stairs to her apartment. Thus, similar to the previous domains, there was a degree of inconsistency among ACS respondents with less severe limitations: some respondents answered ‘no’ while others with similar problems chose to answer ‘yes.’

COGNITION

ACS: *Because of a physical, mental or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?*
Yes, No

WG: *Does this person have difficulty remembering or concentrating?*
No difficulty, Some difficulty, A lot of difficulty, Cannot do at all

Summary

Unlike other domains, constructs captured by the two cognition questions were not entirely identical. Both questions captured similar constructs for memory (from day-to-day memory lapses to more consequential lapses), concentration (focusing on tasks) as well as the ability to learn or “be educated.” However, because of the inclusion of ‘making decisions’ in the ACS version, a few ACS respondents considered the ability to make “good” decisions, a likely out-of-scope interpretation of the question. Respondents reporting on behalf of household members based their answers on their observations or experiences with that person.

When formulating their answer, respondents reflected on a range of factors, including intensity, frequency, and impact of the particular construct they were considering, that is, 1) day-to-day memory lapses, 2) significant memory lapses, 3) concentration problems, 4) learning difficulties, or 5) the ability to make good decisions (ACS only). This variety created a complex range of experiences that, more than any other domain, lacked consistency across respondents. Like the other domains, however, responses were somewhat more consistent in the WG version because of the four options.

For the WG version, those reporting ‘no difficulty’ described having no limitations pertaining to the concept in mind whereas some of those responding ‘no’ to the ACS question reported experiencing difficulties in specific or limited contexts. Reasons for selecting the ‘some’ or ‘a lot’ categories indicate the increasing levels of difficulty reflected in the label selected. For those receiving the ACS version, respondents who answered ‘yes’ reported a range of difficulties in terms of frequency, severity and impact. All those who answered ‘yes’ on the ACS chose either ‘some difficulty’ or ‘a lot of difficulty’

when offered the WG response categories. A few respondents answering ‘no’ to the ACS version described having lower levels of limitation (similar to some of those respondents who answered ‘yes’) and answered ‘some difficulty’ when offered the WG categories.

Constructs Captured

Unlike other domains, constructs captured by the two cognition questions were mostly, but not entirely, identical. While both questions captured memory and concentration problems as well as some learning difficulties, a few ACS respondents (due to the inclusion of the phrase ‘making decisions’) considered the ability to make “good” decisions.

For both questions, most respondents understood the questions to be asking about memory problems, with some focusing on day-to-day memory lapses (i.e., forgetting keys and wallets) and others on more consequential lapses such as forgetting names, appointments, and bills. One respondent, for example, in thinking of less serious problems explained:

Yes, I have some difficulties remembering and concentrating on things. Forgetting where I place things sometimes, or forgetting about what I come in this room for. Like confusion a little bit... not regularly, just sometimes when I'm under a lot of stress.

On the other hand, another respondent, thinking of more serious problems, answered ‘a lot of difficulty’ and noted that she often forgets things immediately in conversation: “I can’t even remember what you [the interviewer] said at first. I don’t know why I’m like that, I really don’t.”

Respondents reporting on behalf of household members based their answers on their observations or experiences with that person. For example, one woman answered ‘yes’ to the ACS question for her son because she “frequently” had to remind him to do things such as make appointments and pay bills. In a similar example, a woman answered ‘some difficulty’ for her elderly mother because “she will tell me ‘I need milk,’ and then moments later say, ‘Oh, did I tell you I need milk?’” The respondent said that incidents like these started when her mother was in her 50’s and have become more frequent.

Other than memory, some respondents viewed the question to be asking about one’s ability to concentrate or to focus on tasks. For example, one woman answering the ACS version noted that “remembering is not a problem” but explained how easily she gets mentally side-tracked:

Why “Yes?” I'm a thinker, and over-thinker. So, if I gotta worry about something, it's a total distraction. When that happens, I try not to get sucked into that whole one thing. So, I have a tendency to start 100 small things so I'm not dwelling on that. So, I'll make my bed, I'll wash a bucket of dishes...because if I sit down, that one thing that's actually bothering me will consume me.

Similarly, a woman answered ‘some difficulty’ to the WG question because she has difficulties multitasking:

If the phone rings and they're trying to say ‘do this that and the other,’ and then I'm trying to do the grocery list at the same time then I get finished talking to that person and go and grab something out of the fridge, and then I'm like ‘so what was I supposed to get from the grocery store?’

Particularly when answering for others, respondents who interpreted the question as asking about concentration, focused on symptoms associated with Attention Deficit Hyperactivity Disorder (ADHD). For example, one father answering ‘some difficulty’ for his son explained:

[He] gets distracted at school and will be playing around... We thought it was ADHD, but it turns out he just, it's not that. He just has problems concentrating.... It is something we've been working on as well as his teachers, so it's definitely getting better.

Similarly, another respondent answering ‘a lot of difficulty,’ described the way she struggles to sit and concentrate which impacts what she is able to accomplish. As it turns out, this respondent was diagnosed with ADHD at eight years old.

Even more so for some respondents, the term ‘concentrating’ was a synonym for ‘learning’ and ‘ability to be educated’ and heard the question as asking about an actual learning disability. In doing so, they appeared to implicitly link learning difficulties (diagnosed or not) with difficulties concentrating. Again, this was true for both versions of the questions. For example, one respondent answering ‘no’ to the ACS question explained that she was not “...slower than other people” and went on to explain that she was thinking about whether or not she could learn concepts and react as quickly as other people. Those who interpreted the question in these terms tended to compare themselves and others to people they identified as cognitively “slow,” “disabled,” or “mentally challenged.” For example, one man also answering ‘no’ to the ACS version explained that those who should answer ‘yes’ would be “if you were—you know—slower than other people.”

Finally, a few respondents explicitly interpreted the ACS question in terms of one’s capacity for making “good” decisions (as defined by the respondent), a likely out-of-scope interpretation of the question. For example, one respondent answered ‘yes’ on behalf of his aunt because she makes “food and diet decisions that are bad for her health.” He explained that even after being told by a doctor to improve her diet, she continued to eat unhealthy foods and that these poor decisions led to gastrointestinal problems and, ultimately, hospitalization.

Formulating a Response

When formulating their answer, respondents reflected on a range of factors, including intensity, frequency, and impact of the particular construct they were considering, that is, 1) day-to-day memory lapses, 2) significant memory lapses, 3) concentration problems, 4) learning difficulties, or 5) the ability to make good decisions (ACS only). This variety created a complex range of experiences that, more than any other domain, lacked consistency across respondents. Like the other domains, however, responses were somewhat more consistent in the WG version because of the four options.

For the WG version, those reporting ‘no difficulty’ described having no limitations pertaining to the concept in mind. For example, one father—who interpreted the question as asking only about major memory lapses—explained his ‘no difficulty’ answer for his daughter by saying, “She doesn’t have any more trouble remembering than a normal person.” Those answering ‘some difficulty’ included those who did experience difficulties, however, not constant or in a way that dramatically impacts daily life. For example, one woman with some long-term memory loss as a result of a car accident, answered ‘some difficulty’ because the loss does not force her to change her lifestyle. Similarly, another respondent answering ‘some difficulty’ explained that, on some occasions, he cannot remember the details of television programs he just watched or articles he just read—though this problem has been increasing with age. Of note, those respondents who understood the question as asking about normal

bouts of memory lapse (e.g., misplacing keys) or distraction (e.g., difficulty multi-tasking) also answered the question ‘some difficulty.’

Finally, only those respondents answering ‘a lot of difficulty’ reported serious instances of memory loss or concentration problems dramatically impacting their day-to-day life. For example, one respondent answered ‘a lot of difficulty’ on behalf of her mother who suffered a stroke a year ago, making it difficult for her to both process and communicate information. When asked why she did not answer ‘cannot do at all,’ she noted that her mother still had some ability, just in a drastically different way and speed than before her stroke.

No respondents in the cognitive interviewing sample reported ‘cannot do at all’ for this item.

For those receiving the ACS version, respondents who answered ‘yes’ reported a range of difficulties in terms of frequency, severity and impact. On the more serious end, for example, one woman explained, “I think I may have early dementia. It's been going on for about 6 months, because my daughter has told me to get it checked. I just lose focus, that's it.” When asked about the impact of her difficulty, she said, "I can't focus at all. Can't do what I got to do." Less impactful, there were some respondents who answered ‘yes’ and described problems that can be seen as normal, for example, occasionally losing keys, forgetting birthdays and names of acquaintances.

Most respondents answering ‘no’ to the ACS described having no problems or difficulties with the construct in mind. (e.g., “I focus on the task at hand,” “I can read for a considerable amount of time.”) However, there were also respondents who experienced difficulties in specific or limited contexts. For example, one respondent answering ‘no’ for her husband, explained:

I would say not anything out of the ordinary, but sometimes remembering – just short-term memory – just having to repeat myself over and over again with certain things. But not an excessive amount where someone is losing their memory.

A few respondents answering ‘no’ to the ACS version described having lower levels of limitation (similar to some of those respondents who answered ‘yes’) and answered ‘some difficulty’ when offered the WG categories. Thus, as in all other domains, there was a degree of inconsistency across ACS respondents experiencing less consequential limitations; while some respondents chose to report those experiences, others did not.

SELF-CARE

ACS: *Does this person have difficulty dressing or bathing?*
Yes, No

WG: *Does this person have difficulty dressing or bathing?*
No difficulty, Some difficulty, A lot of difficulty, Cannot do at all

Summary

For both versions of the question, respondents considered either the physical ability or the cognitive ability to dress or bathe oneself. Respondents’ physical capacities related to the relative levels of pain and other physical discomfort. When answering on behalf of household members, some respondents

described themselves as being the actual assistance providers. In a few cases when the respondent had not directly observed their household member performing self-care activities, the respondent surmised the level of difficulty based on observations of other activities. Like the other domains, the selection of a response category was based on the extent and impact of the limitation with the range in limitations more fully depicted with more discrimination across the WG categories as opposed to the ACS categories.

Respondents formed their answers to both the ACS and WG questions by assessing perceived levels of physical and/or cognitive limitations when dressing or washing. All of those who answered 'no difficulty' to the WG question described having no limitation. This was the case for most ACS respondents, though some who answered 'no' to the ACS version described some limitation in specific contexts. Reasons for selecting the 'some', 'a lot' or 'unable to do' categories in the WG question reflect increasing levels of difficulty. The ACS 'yes' category captured difficulties that ranged from severe to minor even though the question specifies 'serious difficulty.' All those who answered 'yes' to the ACS chose either 'some difficulty' or 'a lot of difficulty' when offered the WG response categories. A few respondents answering 'no' to the ACS version described having lower levels of limitation (similar to some of those respondents who answered 'yes') and answered 'some difficulty' when offered the WG categories.

Constructs Captured

For both versions of the question, respondents considered either the physical ability or the cognitive ability to dress or bathe oneself. For the most part, respondents' physical capacities related to the relative levels of pain and other physical discomfort they experienced. For example, one respondent answering 'no' to the ACS question, considered the potential pain that would limit his ability to dress and shower: "Normally, no. I exercise several days a week. And so often, when you exercise, it's very common to over-strain your muscles and pull a muscle." Similarly, another respondent with arthritis answered 'some difficulty' and explained, "Sometimes I can't. It depends if I took my medicine for my aches and pains. Because when I go to wash my legs or feet, it's hard for me to get down there." Likewise, another respondent answered 'yes' to the ACS question because she often needs help dressing and bathing on account of pain:

Well sometimes, my leg hurts. So, I got a chair, so I'm sitting up there when I take a shower. But the only thing is that my daughter has to rub [wash] my leg...I do a lot by myself, but when the pain comes on, [my children] are there to help.

When answering on behalf of household members, some respondents described themselves as being the actual assistance providers. For example, a man answered 'a lot of difficulty' to the WG question for his mother who has liver cancer and requires full-time care: "I have to help her because her legs swell up as well. And, she has... what do they call it... edema, swelling of the legs, fluid. So, I have to help her with her pants, off and on, stuff like that." Likewise, a woman answered 'yes' for her daughter because her daughter recently broke her leg and couldn't dress herself without help.

On the other hand, in a few cases, the respondent had not directly observed their household member performing self-care activities, which are often done in privacy. In these instances, the respondent surmised the level of difficulty based on observations of other activities. For example, a woman answered 'some difficulty' for her stepfather because he experiences pain and discomfort when walking and standing: "I said 'some' because standing in the shower. I'm just assuming he probably does have some difficulties taking a shower. I don't know I'm just assuming that part."

Finally, some respondents understood the question as asking about cognitive awareness. In most cases, this involved parents evaluating their child's maturity and knowledge of how to dress and wash themselves independently and reliably. In these situations, it is not always clear within the context of the cognitive interview whether these respondents are reporting a cognitive disability observed through the activity of self-care, or if the interpretation is a case of normal childhood behavior and, therefore, out-of-scope. For example, a grandmother answered 'yes' to the ACS question for her 10-year-old granddaughter because she takes too long when getting dressed in the morning. She commented, "she moves slow...you know, kids be silly and take their time." Likewise, another mother reporting on behalf of her young child answered, 'some difficulty' to the WG question because, "it's a fight to get him to do it." She continued to explain that "it's just a kid thing." The mention of "kids being silly" suggests that this may not be a case of cognitive difficulties and, therefore, would be out of scope.

Only one respondent answered outside of these two interpretations: A woman who recently gained weight with pregnancy considered her ability to fit into her clothes when answering the WG version. She selected 'some difficulty,' commenting, "somewhat, I'll say somewhat. Cause there [are] things that I just [can't] wear anymore."

Formulating a Response

Respondents formed their answers to both the ACS and WG questions by assessing perceived levels of physical and/or cognitive limitations when dressing or washing. All of those who answered 'no difficulty' to the WG question explained that they experienced no limitation. Respondents answered 'some difficulty' when assistance was required in particular contexts. For example, one respondent answered 'some difficulty' in regards to her housemate who suffers from fibromyalgia because she "sometimes need[s] to help her get out of the bathtub." Others selected 'some difficulty' when the activity could be done independently, but required more time. For example, one respondent answered 'some difficulty' for her son because it took him a while to dress himself but, as noted above, this response might not reflect difficulties dressing. Respondents who answered 'a lot of difficulty' described limitations that required help with most activities. One man, for example, answered 'a lot of difficulty' on behalf of his mother because he almost always needed to help her dress. Respondents answered 'cannot do at all' when dressing or bathing activities could not be performed at all. The respondent with the bedridden mother, for example, answered 'cannot do' because she requires a nurse to bathe and dress.

The ACS 'yes' category captured difficulties that ranged from severe to minor, including cases in which those being evaluated only needed help in specific contexts. For example, one woman answered 'yes' because there are times when she needs assistance with washing because it is too painful for her to stand in the shower. She explained, "Well sometimes, my leg hurts. So, I got a chair, so I'm sitting up there when I take a shower. But the only thing is that my daughter has to rub [wash] my leg." Likewise, a man answered 'yes' for his aunt because she "needed assistance with these things 50-75% of the time." Another mother answering 'yes' on behalf of her young son explained that her son always "has to be helped" because, if he dressed himself, then "it would be sloppy and take too much time." As noted above this could reflect difficulty dressing or could be out of scope.

In most cases, those answering 'no' to the ACS question reported experiencing no type of limitation, with respondents quickly commenting that they "had no problems dressing or bathing." Some respondents, however, did answer 'no' to the ACS question though describing some limitation in specific contexts, and answering 'some difficulty' when offered the WG questions. For example, a man

answered 'no' for his 86-year-old mother and then explained that because of her age, she moves more slowly than others with self-care activities: "It's not difficult, she just has to do it a bit more slowly... it usually takes a bit longer than someone who is younger." Thus, as in all other domains, there was a degree of inconsistency across ACS respondents experiencing less severe limitation; while some respondents chose to report those experiences, others did not.

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