

**RESULTS OF THE WHO MODEL DISABILITY QUESTIONNAIRE
COGNITIVE INTERVIEWING STUDY: 2013 ASSISTIVE DEVICE AND
FUNCTIONING SECTIONS**

**Question Design Research Laboratory, the National Center for Health Statistics
Institute for Survey Research, University of Michigan**

Paul Scanlon, Ph.D.

Kristen Miller, Ph.D.

This is the first in a series of three National Center for Health Statistics reports evaluating the WHO's Model Disability Survey (MDS). This cognitive interviewing project did not evaluate the entire MDS questionnaire as a whole, but rather focuses solely on the Assistive Devices and Functioning sections due to the great length of the entire MDS.

This report documents results of the cognitive interviewing study to examine the performance of a select set of questions from the proposed WHO Model Disability Survey (MDS). The survey uses the definition of and conceptual framework for disability based on the WHO International Classification of Functioning Disability and Health (ICF). The goal of the survey is to provide data that social, health and other sectors require, and which can respond to monitoring requirements of the UN Convention on the Rights of Persons with Disabilities. The questions tested during this evaluation can be found in Appendix A.

The analytic intent of the survey is to gather information that depicts how the health state of an individual limits functioning including how features of the environment facilitate or create barriers to functioning. Functional limitations are described as creating problems for the individual. For example, a person who has arthritis in their knees might report that they have a problem walking but that walking does not present a problem for them because they use a cane and do not live in an area with many hills or steps. Hence, questionnaire items are intended to capture not only the combined aspects of physical limitation and environment, but the respondent's personal assessment of whether or not this poses a problem for them in their everyday life.

Given these necessary analytic requirements of each questionnaire item, the primary focus of the cognitive interviewing study was to examine the constructs captured by the set of questions. Questions that capture a personal assessment of the degree of problem are deemed in-scope because they capture the intended construct; those that do not indicate specification error because the question captures a construct outside of the required intent.

The majority of this report will present a question-by-question analysis. Given that each cognitive interview was limited to 1 hour, the entire set of functioning questions was not examined. Rather, a subset from each domain was chosen. The reported findings of each question include descriptions of respondents' interpretations and the types of experiences that respondents considered in their answer. Most importantly, findings include whether items produce specification error. Additionally, difficulties experienced by respondents when attempting to answer a question are described.

The next section presents an overview of findings, which is then followed by a methods section describing cognitive interviewing methodology. The methods section also includes recruitment and interviewing procedures for this study, as well as the process for analyzing the cognitive interview data. The final section of the report presents findings for each question.

SUMMARY OF CONCLUSIONS

This section provides an overview of significant findings and is organized into three sub-sections: 1) constructs captured by functioning questions including indication of specification error, 2) performance of response categories, and 3) performance of aid questions. The question-by-question overview following the methods section provides more detailed discussion of each question's performance.

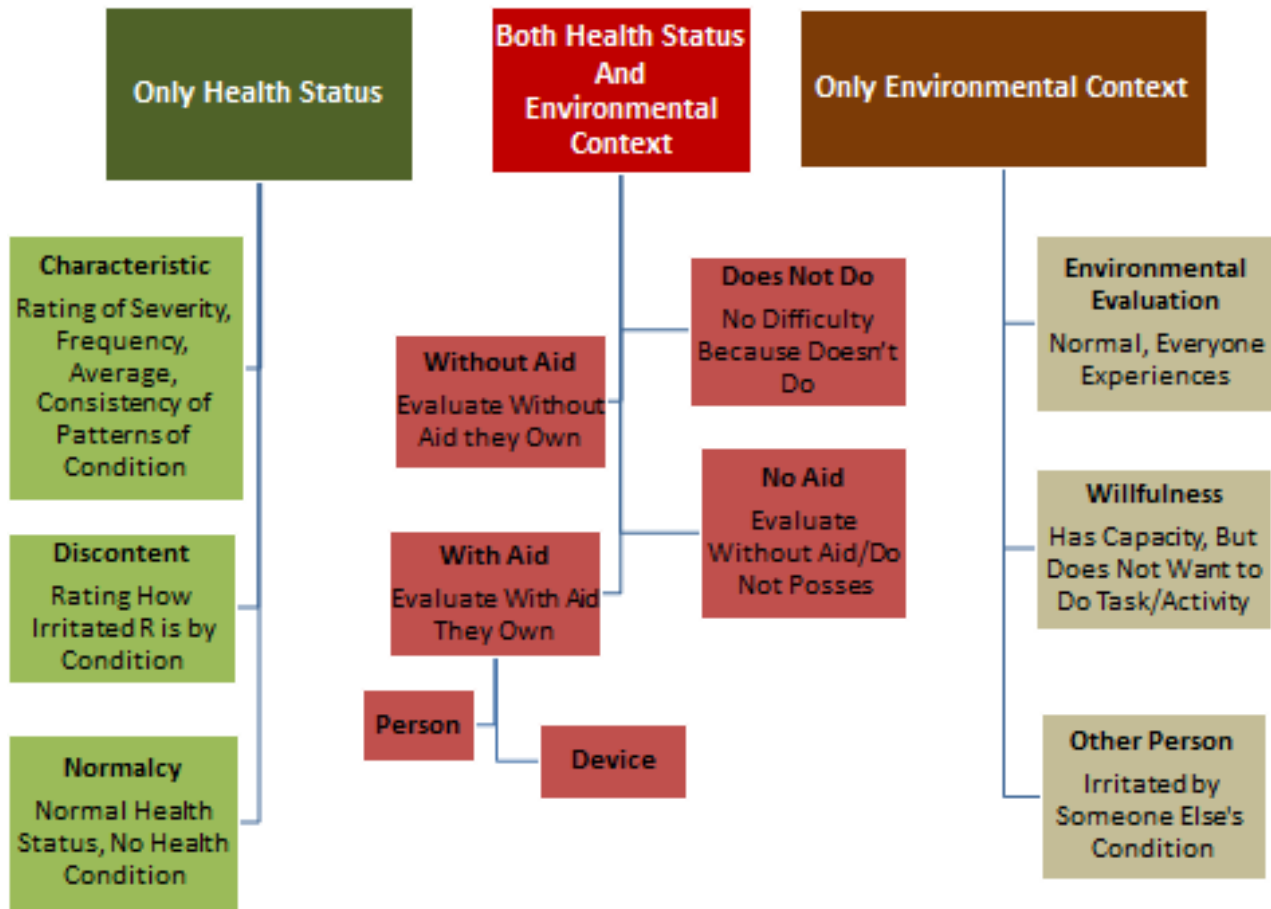
Functioning Question Constructs

As articulated above, in order for a question to successfully capture the intended construct, questions must capture not only the combined aspects of physical limitation and environment, but the respondent's personal assessment of whether or not this poses a problem for them in their everyday life. This section presents study findings in regard to the constructs captured. The first part of the section attends only to the dimensions (i.e. health status and environmental context) in which respondents based their answers; the second part attends to whether or not their answers are based on their personal assessment of a posed problem.

Dimensions Considered by Respondents

A primary focus of this study was to determine whether each functioning item captured respondents' assessment of the problem that the interaction of the two dimensions (i.e. health state as well as the environmental context) may pose for them. In considering only whether or not the two dimensions were included by respondents, analysis of cognitive interviews reveals that, for each of the functioning questions, both dimensions were relevant. However, not all respondents considered both dimensions for all of the items. Respondents based their answer on one of three patterns: 1) health status only, 2) a combination of health status and environmental context or 3) environmental context only. (Please note that the terms "health state" and "health status" are used interchangeably throughout this report.) As determined by the intent of the questions, items that do not capture respondents' combined assessment of health status and environmental context generate specification error. Figure 1 below illustrates these patterns. When a respondent basis their answer along either the green path or the brown path, specification error is produced. The red path is the only path that does not necessarily produce error (supposing that the respondent also basis their assessment on the degree of problem posed for them).

Figure 1. Three Conceptualizations for Basis of Respondents' Answers



The three paths represent the different phenomena on which respondents based their answers. The three upper boxes signify the concept captured, and the lower boxes in the paths are sub-themes (or patterns of interpretation) that more fully discriminate the phenomena captured. The three paths are described below:

1. Only Health Status. The green path of the diagram represents those answers based solely on respondents' evaluation of their health status. That is, respondents provided information only about their health state and did not include consideration of their environment or how it impacts their ability to perform the specified function. In providing an answer, respondents with health conditions rated a particular characteristic of their condition (e.g. severity, frequency or consistency) or their level of irritation with that condition. In short, their evaluation was based on the condition itself, not the amount of problems it posed in their everyday life. For example, when answering the question about pain, respondents who had a health condition that generated pain, such as arthritis, answered in terms of the frequency or intensity of their pain, not how much the pain impacted their functionality. Those without a health condition also considered their

health outside of environment and ability to perform tasks, for example, evaluating the level of pain that they experienced because of too much exercise. Because respondents considered only health status in the formulation of their answer, the intended construct is not captured and specification error is produced.

2. Both Health Status and Environmental Context. The red path represents answers capturing both respondents' health status as well as environmental context and is the only path capturing the intended construct. Specifically, respondents evaluated their ability to perform the specified function with consideration of their health status and within their environment. For example, when answering the question about getting outside of the home, many respondents considered their physical ability to stand up and walk out of their home while also considering their own home environment (e.g. thinking of the stairs or elevators needed to exit). Whether or not a respondent used an assistive device such as a cane or a hearing aid was a significant part of the question response process. Aids were conceptualized as both personal aides and assistive devices. Whether respondents considered their aids when formulating their answer, however, varied; some respondents included the use of their aid, while others did not. Noteworthy, in several cases, some respondents answered 'not at all,' not because they had no difficulty, but because their health state prevented them from doing the task. For example, one woman who requires 24-hour assistance answered 'not at all' to the question about household tasks because her aide preforms those duties.
3. Only Environmental Context. Finally, the brown path represents answers based solely on respondents' evaluations of the environment without regard to health status. For example, in answering transportation questions, some respondents evaluated the effectiveness of Metro, Washington, DC's subway system. For the question pertaining to job applications, some respondents reported having a problem because of few job openings. Another respondent reported difficulty because he was African American, implying that his difficulty was due to discrimination. For questions that asked about performing specific activities, some respondents reported having problems because they personally do not like to do the activity. For example, one woman answered 'yes, to an extreme extent' to the household task question because she refuses to do housework. Finally, in a few instances, respondents based their answer, not on their own limitations, but on irritation they felt because of someone else's limitation. For example, one respondent stated that he has a 'problem with remembering' because his girlfriend often forgets her keys and medication and this interrupts their plans. Because respondents considered only their environmental context, this pattern produces specification error.

For *every* functioning question, at least two of the three patterns were identified as the basis for respondents' answers, evidencing that all items were error prone. Therefore, no functioning item fully captures its analytic intent. However, some questions were more likely to capture a particular construct more often than others. For instance, questions that respondents interpreted as pertaining to a specific ailment were more likely to capture health status only. These questions included pain and depression. On the other hand, questions that pertained to activities were more likely to include the environmental dimension. Among activity questions, however, the types of activities that can, on their own merit, be problematic for individuals even without a

health condition (e.g. applying for a job, having access to good public transportation, managing money) were often conceptualized without consideration of health status, often leading to false positive responses as a result of out-of-scope constructs. This type of false positive response occurred for both respondents without a health condition and those with a health condition. (Those with a health condition did not consider it when answering the question). It is interesting to note that while depression tended to be viewed as a health condition (and therefore tended to capture health status only), anxiety was more often viewed as a situational problem caused by work pressure or unemployment and, therefore, more likely to capture only environmental context.

Assessment of Problem Posed

In addition to consideration of combined health status and environmental context, questions must capture whether or not (and the degree to which) respondents view a limitation as posing a problem in their daily activities. Respondents, however, did not always base their response on the problem posed. Those respondents who considered only their health status based their answers only upon their assessment of their condition—not the degree to which that condition posed a problem for them in carrying out their daily activities.

On the other hand, those who based their answers solely on the environment almost always reported the amount of problem that was posed. For example, those who considered the inadequacies of the city’s public transportation evaluated the degree of problem that these inadequacies created in their ability to carry out their activities.

Those who based their answer on a combination of health status and environmental context reported on how their health status and any modifications either caused or alleviated problems in their environment. Often, these respondents thought about the “problem” in the same way as those who only considered the environment, in that they reported on its *magnitude*.

Response Category Performance

For the functioning questions, response options included 5 categories: 1) Not at all, 2) Yes, a little, 3) Yes, to some extent, 4) yes, to a moderate extent, and 5) yes, to an extreme extent. While it appeared that respondents made sense of the ‘not at all’ and ‘extreme’ categories, most were not able to articulate clear differences between the middle categories. The category labels, in and of themselves, do not meaningfully define the middle points, and many respondents stated that the categories were not distinguishable and overlapped. Regularly, respondents either did not remember their answer or changed it as they explained their answering process. In this regard, it appeared that respondents who were inclined to answer in the middle range were not able to place their experience discretely in one of those categories.

Aid Question Performance

The set of questions regarding assistive devices proved to be the most complex and challenging in the questionnaire. Often respondents were not certain what questions were asking or what types of aids (i.e. devices, medications or persons) should be included. Many respondents asked for

questions to be repeated (for instance, a full one-quarter of respondents asked the interviewer to repeat the question about accessibility of public toilets). Respondents also asked for clarification to determine what types of devices that they should include. For a few of the questions, particularly those about work and education aids, respondents did not necessarily interpret the questions through a disability lens. Instead they considered various devices that anyone could use to facilitate their work, for example, the spell checker in a Word document. As a result, the aids that respondents actually counted varied substantially across respondents. Noteworthy, for the aid questions that began with the phrase ‘Are there any modifications that make it easier for you to...,’ one respondent interpreted the word ‘you’ in a generalized sense. Therefore, he interpreted the questions to mean ‘do these types of devices exist?’; his answer to all of these questions were “I’m sure there are.”

METHODS

This section details the methodology of this study. First, an overview of cognitive interviewing methodology will be presented. Then, the specific methods used for this project will be described.

Cognitive Interviewing

The aim of a cognitive interviewing study is to investigate how well survey questions perform when asked of respondents, that is, if respondents understand the questions according to their intended design and if they can provide accurate answers based on that intent. As a qualitative method, the primary benefit of cognitive interviewing is that it provides rich, contextual insight into the ways in which respondents 1) interpret a question, 2) consider and weigh out relevant aspects of their lives and, finally, 3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it ultimately serves the scientific goal. Findings of a cognitive interviewing project typically lead to recommendations for improving a survey question, or results can be used in post-survey analysis to assist in data interpretation.

Traditionally, cognitive testing is performed by conducting in-depth, semi-structured interviews with a small sample of approximately twenty to forty respondents. The typical interview structure consists of respondents first answering the evaluated question and then answering a series of follow-up probe questions that reveal what respondents were thinking and their rationale for that specific response. In this regard, cognitive interviews unfold within a narrative format. Through this semi-structured design, various types of question-response problems, such as interpretive errors or recall accuracy, are uncovered—problems that often go unnoticed in traditional survey interviews. By asking respondents to provide textual verification and the process by which they formulated their answer, elusive errors are revealed.

As a qualitative method, the sample selection for a cognitive interviewing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute that is relevant to the type of

questions being examined. When studying questions designed to identify persons with disabilities, for example, the sample would likely consist of respondents with a previously known disability and, to discover potential causes of false positive or false negative reporting, some respondents with no known disability. Because of the small sample size, not all social and demographic groups are represented. Analysis of cognitive interviews does not produce generalizable findings in a statistical sense, but rather, provides an explicit understanding of response processes including patterns of interpretation.

As is the case for analyses of qualitative data, the general process for analyzing cognitive interview data involves synthesis and reduction—beginning with a large amount of textual data and ending with conclusions that are meaningful and serve the ultimate purpose of the study. For example, Miles and Huberman (1994) describe qualitative analysis as an interactive process of “data reduction (extracting its essence), data display (organizing its meaning) and drawing conclusions (explaining the findings)” (cited in Suter, 2012). For analysis of cognitive interviews, reduction and synthesis can be conceptualized within five incremental steps—conducting interviews, producing summaries, comparing across respondents, comparing across subgroups of respondents, and reaching conclusions. With each incremental step, a data reduction product is created. A description of each of these steps and the resulting reduction product is presented below:

- 1) Conducting interviews to produce interview text: collecting narratives from respondents that reveal how each respondent made sense of and went about answering a survey question,
- 2) Synthesizing interview text into summaries to produce detailed summaries: detailing how and why each respondent interpreted the question as well as how they formulated their answers, including events or experiences considered as well as any difficulties answering the question,
- 3) Comparing summaries across respondents to produce thematic schema: identifying and mapping common themes that detail phenomena captured and the process of formulating a response,
- 4) Comparing identified themes across subgroups to produce an advanced schema: identifying ways in which different types of respondents may process questions differently depending on their differing experiences and socio-cultural backgrounds,
- 5) Making conclusions to produce final study conclusions: determining and explaining the performance of a question as it functions within the context of respondents’ various experiences and socio-cultural locations.

Although these steps are described separately and in a linear fashion, in practice they are iterative; varying levels of analysis typically occur throughout the qualitative research process.

As each step is completed, data are reduced such that meaningful content is systematically extracted to produce a summary that details a question’s performance. In detailing a question’s performance, it is possible to understand the ways in which a question is interpreted by various groups of respondents, the processes that respondents utilize to formulate a response as well as any difficulties that respondents might experience when attempting to answer the question. It is the ultimate goal of a cognitive interviewing study to produce this conceptual understanding, and it is through data reduction that this type of understanding is possible.

While the two processes of data reduction and knowledge production may be heuristically separated, in reality the processes occur simultaneously. In reducing the cognitive interview data the analyst produces a more comprehensive understanding of a question’s performance; as analysis is performed, understanding of the question response process becomes more complex and complete. In the beginning it is only possible to understand how each individual respondent makes sense of and answers the survey question. By the end, individual interpretations are understood as well as how those interpretations relate across groups and within the overall context of the question’s performance.

WHO Cognitive Interviewing Study

Twenty face-to-face cognitive interviews were conducted in the NCHS Questionnaire Design Research Laboratory (QDRL) from September 2 through September 12, 2013. Prior to the interview, respondents completed a demographic sheet as well as a consent for video-recording the interview. Once completed, the interviewer described the purpose of the study and how the interview would take place. Interviews lasted one hour, and \$40 in remuneration was provided to each respondent. Interviewers included staff from the QDRL as well those from the University of Michigan’s Institute for Survey Research.

During the interview, respondents were asked each survey item and were then asked to explain their answer. The types of follow-up questions asked by interviewers depended on respondents’ interpretation of the questions as well as their health status and physical abilities. However, typical follow-up questions included, “How so?” and “Why do you say that?”

Respondents. The demographic breakdown of respondents appears in Table 1 below. Respondents were recruited through newspaper advertisements, flyers and by contacting previous respondents who met the criteria of this study. A screening process was employed over the telephone to determine the caller’s eligibility for participation. Because questions focused primarily on respondents’ abilities and physical conditions, particular effort was made to recruit individuals with a variety of health conditions.

Table 1: Demographic summary of respondents

Race		Age	
Black	12	18 - 29	1
Multiple	1	30 - 49	6
White	6	50 - 64	7
Refused	1	65 and Over	6
Ethnicity		Education	
Hispanic	1	HS no degree	3
Non-Hispanic	18	HS diploma	5
Refused	1	Some college no degree	5
		Associate Degree	1
		College Degree	4
Gender		Professional/Doctorate	1
Female	6		

Race		Age	
Male	14	Dont Know	1

Method of analysis. Analysis of interviews was performed in the manner described in the above description of cognitive interviewing methodology. After an interview was conducted, summary notes were written for each question. Summary notes included the way in which a respondent interpreted and processed individual questions, what experiences or perceptions the respondent included as they formulated their answer, and any response difficulties experienced by the respondent. Video-recordings of interviews were utilized to ensure the accuracy of summaries.

After all interviews and summaries were completed, interviews were compared to identify common patterns of interpretation and response difficulties for each question. For this project, the interpretive patterns involving health status and environmental context were particularly salient. Once themes were identified for each question, themes were compared across questions to identify commonalities and to develop a larger conceptual understanding regarding the performance of the set as a whole. This final level of analysis provides a summary understanding of the functioning questions' performance, that is, whether together they capture the intended analytic intent of the survey.

A data entry and analysis software application (Q-Notes) was used to conduct analysis. Q-Notes, developed by the Question Design Research Laboratory, ensures systematic and transparent analysis across all cognitive interviews as well as provides an audit trail depicting the way in which findings are generated from the raw interview data.

QUESTION BY QUESTION REVIEW

This section presents detailed findings of individual questions. Findings primarily include the various phenomena captured by each question. However, when relevant, discussion also includes difficulties experienced by respondents as they attempted to answer the question as well as potential response error.

ASSISTIVE DEVICE QUESTIONS

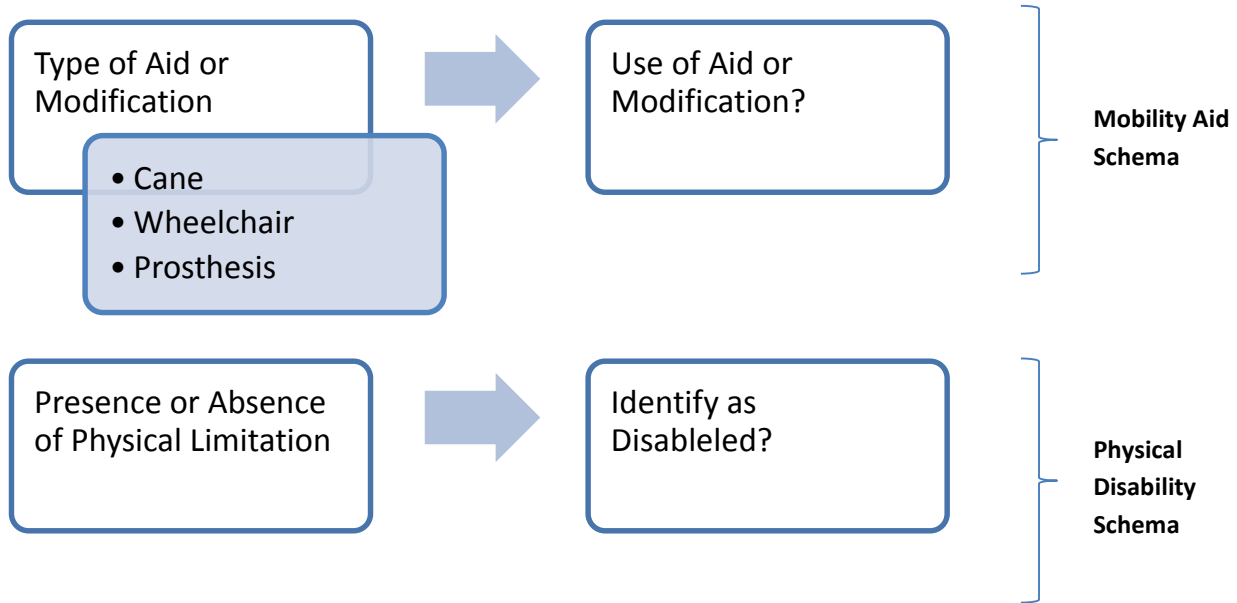
The first set of questions (Questions 1 through 9) was designed to capture respondents' uses of various aids and modifications across different realms and domains of social life. While the cognitive schemas that respondents used to interpret these questions are similar across this set, they are independent and presented separately for each question.

- 1. Do you use any mobility aids [e.g. cane, crutch, wheelchair, walking frame, prosthesis or orthopedic devices] or aids for self-care [e.g. hand, arm brace or grasping tool]?**

Construct Interpretations:

Respondents interpreted Question 1 in one of two ways. Either they thought about the use of mobility aids, or they considered their self-identification as a person with a physical disability. These two ways—or schemas—were considered independently, and very few respondents thought about both when considering the answer to Q1. These schemas are visualized in Figure 2.

Figure 2: Response Schemas for Question 1



Mobility Aid Schema: The mobility aid schema is the more straight-forward of the two, and was the most common across the sample. There were two decisions that the respondents had to make in the course of this schema, each represented by a set of boxes in the above figure. The respondents first had to determine what type or types of mobility aids they would be considering, and then secondly had to decide whether or not they actually used those aids. If they did use them, they would answer the question “yes,” and if they did not, they would answer “no.”

In the first box above, the types of aids that the respondents considered included walking aids such as canes, wheelchairs, and prostheses. These were all examples provided in the question text, indicating that the respondents’ thinking was strongly framed by these examples, and they did not consider the wider domain of “mobility aids.”

Once they had determined which types of aids they were considering in their response, the respondents then had to decide whether or not they actually used that aid (this is the second box on the top row in Figure 2 above).

For example, one respondent who answered “yes” to the question explained that she was thinking about her cane, which she uses when she leaves the house. Another respondent, who answered no, explained that he thought the question was asking about things like the use of

wheelchairs, and that he answered the way he did because he didn't use anything like that to get around town.

Physical Disability Schema: The second schema represents respondents who did not directly consider the use of a mobility aid. Instead, the respondents who approached their response by this pathway understood the question to ask, "Are you physically disabled?" Again, respondents had two decisions to make in this schema. First, they determined whether or not they were physically disabled. Those who said they were not stopped here and answered "no" to the question. However, those who determined that they did indeed have a physical disability of some sort then went on to decide whether or not they wanted to *label* themselves as "disabled." In other words, even if a person had a disability (and perhaps used an aid like a cane), he or she could still decide they did not want to identify "disabled," and answered "no" to the question—a false negative.

For example, one male respondent who answered "no" to the question explained what he was thinking about by saying:

[It is asking me] Am I disabled? Do I need this to help me get around? No, I don't

Thus, in the first box of this schema, this respondent decided that he did not have a disability. He therefore stopped and answered "no." Contrast this with another male respondent who answered "no" but admitted to occasionally using a cane. When asked why he answered negatively, he explained:

Probably the appearance of being disabled, physically. I have an image I like to maintain, so I would say no for that reason.

So even though he freely admitted that he had a disability that required him to use at least occasional assistance, when it came time to label himself as disabled, he would not.

Reference Period:

All in all, the respondents were all thinking about their present situations, and ignored past use of mobility aids or issues of disability. For example, one respondent noted that he used to use a cane, but answered "no" because he does not use it still. Along these lines, a number of respondents indicated that even occasional use of an aid counted, and that they would not have to use it constantly for them to respond in the affirmative.

2. Do you use any hearing or communication aids?

Construct Interpretations:

The respondents' interpretations of Question 2 varied only a little, and they considered only those aids pertaining to hearing difficulty, most often hearing aids, but also the use of sign language and telecommunication aids for the deaf. As in Q1, there were two paths by which respondents processed their answer: responding as though the question asked about the actual use of a device and whether they identified as having a physical limitation. Unlike the previous question, however, respondents were more inclined to consider the two paths simultaneously.

For example, one respondent explained his “no” answer to the question by saying that he did not wear hearing aids because he did not have a hearing problem. Likewise, another respondent explained that she was thinking about hearing aids and the use of American Sign Language, and went on to say:

No, I might need them. I’m having a hard time hearing, [but] so far I don’t [use aids].

Reference Period:

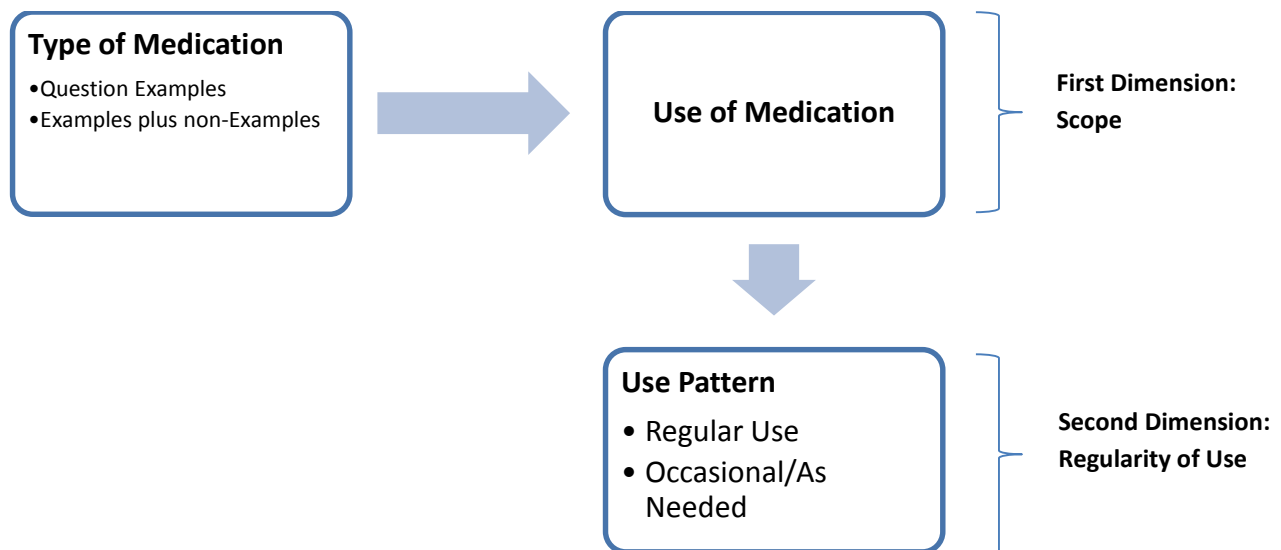
As in the previous question, respondents considered their current use of hearing aids or their current problems with hearing. Respondents who did not consistently use their aids still counted that use for the purposes of the question.

4. Do you take any medication on regular basis such as for pain, sleep disturbances or high blood pressure?

Construct Interpretations:

Two dimensions contributed to variation in respondents’ interpretations: 1) the scope, including the types of medicines under consideration and 2) the regularity of use. Figure 3 illustrates respondents’ thought processes and types of considerations as they formulated their answer:

Figure 3: Schema for Question 4



Scope: Respondents first had to determine which medication to consider for Question 4. Most respondents considered only the medicines listed as examples in the question—pain, sleep or high blood pressure medicine. Respondents considering only the examples appeared to consider each of medication separately and then respond “yes” if they used at least one of these three, and “no” if they did not take any. For example, one respondent explained her “yes” answer by saying “Yes, all of the above.”

Respondents often neglected to include medicine that they regularly took because those medicines did not appear in the question. For example, one respondent who answered “no” to this question revealed during probing that he takes both depression and anxiety medicine. However, he explained that he thought the question was only asking about those three specific types of medicine.

Yeah, I take medication, but it’s not for none of those...I take it for depression and anxiety—Lexapro...one a day. I take sleeping pills every now and then. I forget the name, you don’t need to know the names right?

[Interviewer: How often do you take those?]

Oh, about once a month, whenever I have sleeping problems.

Likewise, another respondent who answered “no” later mentioned that he took daily HIV and liver pills.

In addition to respondents who only considered the examples, some respondents considered the examples along with other types of medicines. For example, one respondent initially explained his “yes” answer by saying that he takes pills for his blood pressure, but then went on to talk about his HIV medication. Another respondent noted that he took blood pressure and sleep medication, as well as “depression medication” and various experimental drugs he gets from an NIH trial:

Yes I do, yes I do. Blood pressure and sleeping medicine. And some depression medicine too for depression...I’ve been on those for about three years now, every day...I was actually taking another medicine that wasn’t even approved by the FDA for my Hepatitis C. I just actually left the NIH today when they were drawing my blood. I’m on a trial thing for the drug up at the NIH.

After figuring out what medication to consider, respondents then had to decide whether or not they actually used those medicines.

Regularity of Use: In answering affirmatively to the previous decision point, respondents also had to consider whether their usage of the particular drug was frequent enough to count towards a “yes” answer to Q4. Most respondents only considered those medications that they took on a regular, scheduled basis. For instance, one respondent noted that she takes pain, depression, and blood pressure drugs every day, and therefore answered “yes”:

Yes, all three. On a daily basis. I’ve been taking them—I became disabled about ten years ago, and I’ve been taking the medications for ten years. Especially the blood pressure medicine and different types of pain medication. Because I don’t want to take anything narcotic, but right now I’m taking Percocet because I’ve just been diagnosed with palsy out of the blue. It’s the only thing that helps with the pain in my head.

Another respondent who answered “no” noted that occasionally takes pain medication if he has a sports injury. He explained that he did this so infrequently that he did not want to count it.

On the other hand, few respondents did consider occasion, non-regular usage for this question. One male respondent, for example, counted over-the-counter pain medication that he occasionally takes for knee pain.

Reference Period:

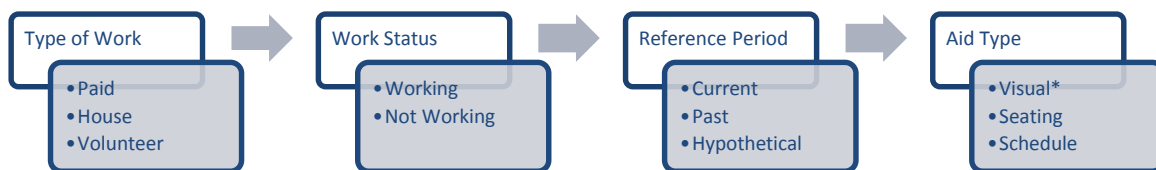
All respondents understood the reference period to be their current use of medication. What respondents considered as current, however, varied according to their decision in the Regularly of Use Dimension. Those respondents who only counted medicine that they took regularly appeared to consider the current day or week. The respondents who counted occasional use took a broader view, and considered a period of weeks or even months when answering the question.

5. Are there any aids or modifications that make it easier for you to work, such as a computer with large print or voice recognition, adjustable height desks or modified working hours?

Construct Interpretations:

Respondents had a total a four sequential decision points to consider when answering Question 5: 1) what constitutes work, 2) their work status—whether or not they work, 3) the reference period—whether they are answering based on their current work, past work, or hypothetical work, and 4) the type of aid or modification they are considering. Each of these four decision points generated multiple patterns of interpretation across respondents. Figure 4 provides a visualization of the cognitive schema of the decision points in Q5.

Figure 4: Response Schema for Question 5



Type of Work: The first decision point that respondents considered was their interpretation of the word “work.” The majority of respondents understood Q5 to be strictly asking about paid employment. For instance, one respondent explained that he was retired, so he answered “no”:

Because I don’t work. Cause you’re looking at employment I assume?...My reaction is that I interpreted the question about employment, and I’m retired, so that really didn’t apply [to me].

He went on to say that if he were to consider working outside of employment, such as doing work at his home computer, he would have said “yes” because he has special glasses that help

him see his computer. Another respondent explained that she would have liked a modified schedule at her last job. The examples in the question—computers, desks, and work hours—are clearly related to (but obviously not limited to) employed work, thereby framing the question as asking about on-the-job aids and modifications. In fact, some respondents noted that there was a bias towards office work. One respondent noted that he didn't need to use any of the example aids or modifications because he worked in construction and never held an office job. Another respondent made a similar point, saying:

No, I mean, even when I was working—which I'm not now—I mean I worked construction, so none of that would have applied.

Other respondents considered work around the house. For example, one respondent [3804] said:

The large print, I do it myself, like how you can just change the font. I do it on my laptop.

She explained that she was thinking about her home computer, as she does not hold a job at the moment.

The third pattern was to consider volunteer work, though this emerged from only one of the 20 respondents. This respondent answered "yes" and noted that she did not hold paid employment, but did have a volunteer job:

I have need an adjustable height chair...Because I have fibromyalgia, and I need to be able to move and adjust it to where—I need to be able to move around when I sit....I do volunteer work, I haven't been able to work a job since I had cancer.

Work Status and Reference Period:

As demonstrated above, respondents who were not working often answered 'no' to the question. However, some respondents, in formulating an answer considered a previous job or considered a hypothetical job. In the first instance, respondents typically considered the last job they held before their current period of unemployment. One respondent explained that he did not currently work because of foot problem, but answered "yes" to the question thinking about his last job:

A commuter with big print was better for me...I don't work currently because of my foot, so I don't know when I'm going back to work...I was working before my surgery.

Besides considering past work, a small number of respondents also considered hypothetical jobs when answering this question. They all seemed to do this with the idea that they would be going back to work eventually, and that whatever aid or modification they were thinking of would be helpful. For example, one respondent who was currently unemployed explained that she was considering what aids she would need were she actually employed:

Mostly the thing is, because if I was working, I would have to work with computers. And I don't really have bad vision or problems with

communication—whether it’s written or oral. It’s the hours that could be modified...if I could work and get home before dark that would be awesome. Or maybe not even work a full eight hours.

Aid or Modification Type: Similar to the previous questions, most respondents only considered the examples listed in the question; the large majority reported thinking of vision problems and visual aids. For example, one respondent explained that:

It would be easier for me to work if I had a large print screen. Cataracts, at least in one eye. I have them in one eye. I have a magnifying glass to read. Glasses of course...I use a computer, and I can enlarge the print on the screen.

As has been noted above, some respondents indicated that they needed visual assistance, but did not self-identify as disabled. A respondent who explained that he uses large font sizes on his computer and has glasses rejected the notion that he had a visual impairment, saying:

I just need them [glasses] to read. But for talking and walking, I don’t need any help.

Besides visual aids, some respondents also latched on to some of the other examples given in the question text. The most frequent was the modified working hours. For example, one respondent noted that he now worked only part time because of his disability. The respondent who was thinking about volunteerism also mentioned modified work hours:

I have insomnia, so I like to work on a modified schedule. Where they say come in and as long as you can work 10 hours a week, you can work whenever.

A few individuals did break away from the examples, most commonly by considering seating modifications. One respondent was thinking about his ergonomic chair:

You didn’t mention seating. If I can’t sit for two minutes, everything else is worthless!

However, the effects of the framing are even evident with this respondent as they felt it important to clearly say the question *should* have been asking about something other than the examples.

Reference Period:

The reference period for this question varied largely according to each respondent’s work history. If respondents were working now, they applied a “current” reference frame to the question, and answered about their employment at the time of the interview.

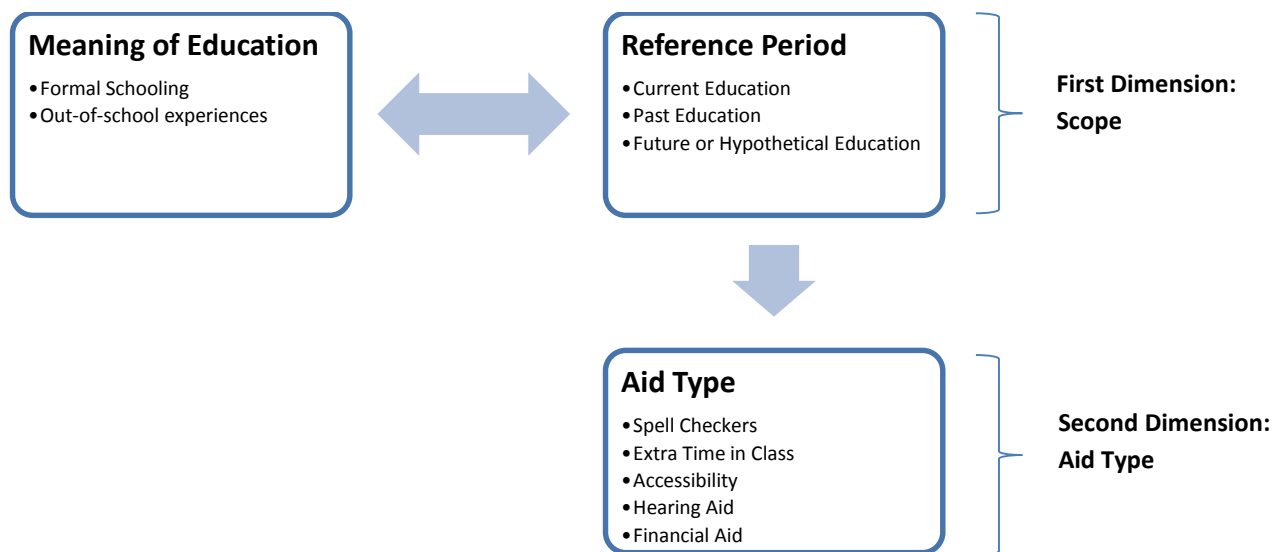
Those respondents who were not working at the moment either applied the current period frame, or they answered about the last time that they worked, based on their interpretation of the question.

6. Are there any aids or modifications that make it easier for you to get an education, such as portable spell checkers, extra time for exams or accessible classrooms?

Construct Interpretations:

Two major dimensions provided the framework for the respondents' interpretations of Question 6: Scope and Aid Type. While variations of both of these dimensions have already been seen in previous questions above, there are question-specific patterns to these dimensions that contribute to the large amount of variation noted across the interpretations of this question. The overall cognitive schema of Q6 is shown below in Figure 5.

Figure 5: Response Schema for Question 6



Scope: The first dimension that respondents considered was the scope of the question—which incorporates both their understanding of the construct “get an education,” as well as the reference period they use. In other words, respondents had to determine what an education was, and when they had or could receive this form of education.

Most respondents understood “get an education” to mean formal schooling, which was normally glossed as “school.” For example, one respondent explained:

I haven’t been to school in a long time. When I did go to school...

However, some respondents also spoke about online courses and continuing education classes. One respondent explained that he already had a PhD, but that he was currently taking some courses for fun:

You know. I have a PhD. So at first, I was thinking “does this question apply to me?” And I thought no. But then, I thought, I go out and take courses as a senior. And that’s learning.

Besides interpreting “education” as formal schooling, a few respondents understood the question to be asking about work around the house or in everyday life. For instance, a respondent noted that he uses the Microsoft Word spell checker in his everyday life:

I mean, a spell checker? Sure. On my computer. That’s standard. Windows Spell Checker. Yeah, I use that.

This non-education interpretation is probably due to a couple of framing effects. First, the question’s examples begin with “spell checker”, and a number of respondents thought about both portable spell checkers and the spelling functions on Microsoft Word that they either carry with them or use regularly. Second, this question’s explicit limitation to “education” is over-ridden by the framing effects of the previous questions, which focused more broadly on life and work.

The second aspect of the scope dimension is the reference period. As the respondents considered what they counted as education, they concurrently decided what period of education to use as the basis for their answer—current education, past education, or future and hypothetical education. Those respondents who considered their current education included all the respondents who were taking formal classes at the time of the cognitive interview, such as the respondent quoted above who was taking continuing education courses. However, some respondents who were not engaged in formal education at the time of the interview also applied this pattern, often to explain a “no” or “not applicable” answer. For instance, one respondent answered “not applicable” because he was not currently in school:

I’d say not applicable. I’m not in school. I have no desire to go back to school if I was going to be honest with you. Although I do enjoy a good spell checker, because you know. You need to get your words right!

Others considered past formal educational experiences. For example:

I said no, because I’m not gonna say we didn’t get help. It’s just whatever they give us, they give us. We had to make our own way.

All but one of these respondents did not participate in any current formal education, and in fact mentioned that before talking about their past experiences.

Finally, the third of interpretation of the reference period was to consider a hypothetical, future educational experience. As an example, one respondent explained her “yes” answer by saying that while she wasn’t in school now, she could think of things that would make her experience smoother:

There’s a lot of stuff already on online classrooms, and that’s very good. Along with it...you know, I want to go back to school, but I not sure how comfortable I am. I’m still adjusting to the life [living with her disability], and I came through a lot...So if went back to school, I would want to have that internet access and have the classroom online.

While none of these three patterns was dominant, very few respondents applied the first one (considering only their current state), with the majority considering either their past or hypothetical future education. This could be an artifact of the sample, however, which largely consisted of people aged 30 and above.

Type of Aid: The second dimension that the respondents had to interpret was which types of aids or modifications they should count towards this question. As seen throughout the previous questions, the examples provided in the question text (in this case, spell checkers, extra time for exams, and accessibility) were heavily cited by the respondents, indicating a framing effect. The most common type of aid or modification that the respondents mentioned when explaining their answer was a spell checker, which was the first example given in the question text. Most respondents noted that they were thinking about the spell check feature in most word processing programs, such as Microsoft Word and GoogleDocs. When asked to explain what she was thinking, one respondent explained:

No, um. Maybe so. When I'm on a computer, and I get the word wrong, it lets me know with the red line.

Interestingly, this respondent answered “no” to the question, as she did not consider the word she did on the computer to be “education.” On the other hand, the respondent already quoted above talking about the Windows Spell Checker did count his home use of a computer’s spell checker for this question.

Other respondents thought about both spell checking software and portable spell checkers:

Yes, on occasions, yes [he uses the computer spell checker]. But I used to carry one [a portable spell checker]. It's like a small organizer, a portable organizer. It's small, rectangular shaped. You've probably seen one at Radio Shack. It carries a limited dictionary...you put a word in there and it lets you know how it's pronounced and what it means.

In addition to spell checkers, some respondents cited the other two examples given in the question text. For instance, two respondents mentioned accessibility, though they conceptualized this in different ways. One respondent was thinking about accessible parking and classrooms at his continuing education location—physical accessibility. The other respondent was thinking about accessing online educational content:

I would want to have that internet access and have the classroom online. I would want to have that communication with the teacher who's teaching that class, so maybe something visual...For me, just speaking for myself, I know that moving around would help me get back to being myself. But I have a spinal cord injury, and there's no fixing that. So the symptoms that I have are the ones I'm going to live with and trying to adjust my life...And though I want the education bad, right now I'm not ready to be out walking around.

This latter pattern can also be tied to physical accessibility, but this respondent went on to talk about how online classes are better for her financially as well, indicating a broader interpretation of “accessibility.”

Finally, some few respondents mentioned types of aid that were not given as examples in the question text. The respondent who above had mentioned accessible parking also went on to talk about how his hearing aid allowed him to actually hear what the professor was saying. Another respondent (in addition to the lady cited above who talked about online learning) mentioned financial aid:

Help with the finances. Cause it [school] can be expensive. So that’s what I was thinking about that question.

In addition to these two dimensions, some respondents thought that the question was asking whether or not they had a learning disability—a similar interpretation to what was observed above with physical disabilities in Q1. In this case, respondents who approached the question through this lens appeared to believe that they were being asked if they were “educable.” For instance, one respondent explained that when he was in school, he didn’t need extra support because he could teach himself:

When I did go to school, I always did...I kinda teach myself. I’m kinda a speed reader...I was always, they would give me a test and I’d be the first to put all the answers...In subjects I liked I got A+s.

Reference Period:

As seen in previous questions, the assumed reference period in Question 6 varies greatly depending on the respondent’s interpretation of the question’s scope alongside their lived experience. This will be described in detail in the discussion above in the “Scope” dimension, but suffice to say if a respondent is current in school, they will answer about their present circumstances. However, if a respondent is not in school, he or she will consider past educational experiences, future or hypothetical educational experiences, or even current non-educational experiences.

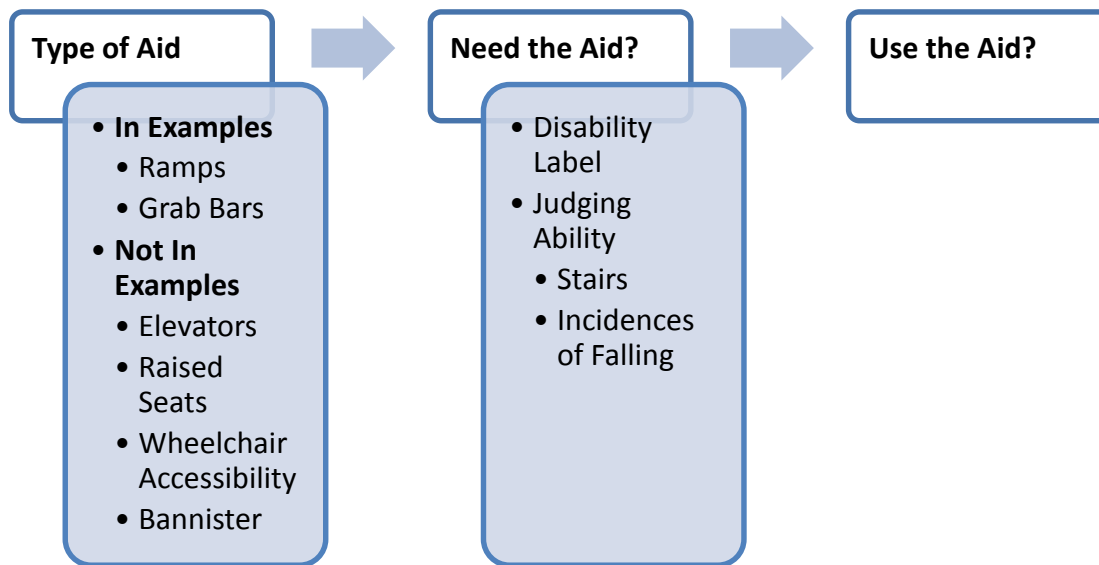
7. Are there any modifications that make it easier for you to be at home, such as ramps, grab bars, or any other accessibility features? [If No, go to I3012]

Construct Interpretations:

This question functioned similarly to the previous questions, with the examples provided in the question text (here: ramps and grab bars) providing some framing about which the respondents structure their interpretations. However, there was much more respondent “creativity” observed in this question, with a large number of respondents considering types of aid that were not mentioned in the question text.

In addition to the ranged of aids and modifications under consideration, more variation was due to a series of decision points that the respondents had to deal with—whether they needed the aid or modification and whether they used the aid or modification. The proposed cognitive schema for this question is shown in the figure below. Unlike the two previous schemata, note that the data suggests that respondents first consider what types of the aids or modifications count, and then move on to the decisions about need and use. This cognitive structure may explain the higher-than-usual number of false negatives for this question that were observed during the cognitive interviews.

Figure 6: Response Schema for Question 7



Type of Aid: Across the cognitive interviews, the respondents cited a number of different types of aids and modifications that they linked to the home environment, and it appears as though two major patterns of interpretation contributed to this depth of the cognitive domain. The first is, again, the reliance of the respondents on the examples given in the question text—in this case ramps and grab bars. Those examples framed the thinking of those respondents who employed this cognitive strategy. One respondent, for example, explained his “no” answer by focusing on whether or not he used a ramp:

I’m just able to walk up to the front door. I don’t need a ramp or anything like that.

Likewise, another respondent answered “yes,” stating that:

Uh, yeah. Right now I’m staying with someone who has ramps and grab bars and stuff like that. She’s deaf, and she has a lot of grab bars—the apartment complex she’s in has a lot of grab bars in the bathroom. In the tub area and by the commode...Mostly grab bars in the bathroom, not really in the hallways.

Some respondents used the frame provided by the question text to move beyond the examples and consider other potential aids. This second pattern of interpretation sometimes began with a respondent citing one of the examples, and then moving on to other modifications:

I have a limited supply of energy. I get tired easily and I get tired quickly. Um, steps make it worse for me. I prefer a ramp. Or an elevator. If I have to go above to the second or third flight...I live on the tenth floor.

Similarly, another respondent appeared to begin with the “grab bar” example and then move on from there:

Grab bars...Well I have grab bars in my apartment, cause as I said, I live in a senior citizen and disability apartment. And I have a very large bathroom. I have grab bars and I have a hand-held shower. I have a raised toilet. My door is wide enough for me to get in with my scooter. Those are the modifications that I really need.

Others did not cite the provided examples at all. For instance, one respondent talked exclusively about elevators:

I wish it was, but no...Well basically I get tired a lot. But we don't have elevators, so I have to walk the stairs. Sometimes I get a feeling in my legs—very painful.

Within this second pattern of interpretation, it seems as though the respondents used the examples to guide their thinking towards a particular sub-domain of accessibility aids. Those respondents who mentioned elevators and bannisters tended to start by mentioning ramps—so they were considering a “walking” or “climbing” sub-domain. Those who started with the grab bars tended to go on to mention modifications from a “bathing” sub-domain, such as raised toilet seats and seats in the shower.

Does the Respondent Need the Aid? Once the respondent decided what aids or modifications to consider for this question, he or she moved on to the other two decision points. The first of these was whether or not the respondent thought he or she *needed* to use the aid or modification. In a number of cases, this decision came down to the inquiry observed in previous questions—namely whether or not the respondent thought of him or herself as disabled. For instance, one respondent explained his “no” response labeling himself as explicitly normal or regular:

At home I just have a regular apartment, regular stairs to go up. Nothing fancy. No elevator, no ramps. I don't need it.

If the respondent followed this pattern of interpretation, and decided that he or she was not disabled, then they would simply answer “no,” and move on to the next question.

This pattern of interpretation can lead to false negatives if a respondent reacts to the perceived label of “disabled” and does not consider the aids or modifications that he or she actually needs

or uses. For instance, a respondent who upon further probing revealed that he uses the bannister to help him down the stairs in his apartment answered the question based on the fact that he did not feel “stuck” in his apartment because of the disability label:

[R answered no] cause I’m not going to stay in my apartment, I’m gonna stay moving...

Other respondents appeared to compare their abilities against some standard to decide whether or not they needed the aid. The most common standard was the ability to climb stairs. Returning to a previous example, we see a respondent explain that he does not need to use a ramp because he can easily climb up the stairs to his front door:

I’m just able to walk up to the front door. I don’t need a ramp or anything like that.

Since this respondent was able to make the climb up the stoop to his door, he decided that did not need any modifications and thus answered “no.” On the other hand, this respondent (who answered “yes”) explains that she doesn’t like using the stairs and has to take them one at a time:

I live in the apartment building and there’s an elevator... There are stairs and a ramp if you need it. But I just use the steps. I take it slow and go one at a time. Just one and the next and the next and the next...but the ramp is all the way around the side of the building..

At this point, respondents who have decided that they *need* an aid or modification then proceed to the second decision point (*use*). However, those respondents who determined that they have no need of an aid or modification in the sub-domain(s) that they were considering will answer “no” and move on to the next question.

Does the Respondent Use the Aid? Those respondents who did determine that they did in fact need the accessibility aid or modification that they were considering then questioned whether or not they actually *used* the aids. For instance, one respondent that we saw above noted that he had a hard time climbing the stairs, but that there was no elevator available:

I wish it was, but no... Well basically I get tired a lot. But we don’t have elevators, so I have to walk the stairs.

Contrast that to a different respondent who explained his “yes” answer by telling a story about falling down the stairs previously when carrying laundry, and noted that he now uses the bannister regularly:

I’m thinking about rails. I don’t have a ramp, I don’t need one yet... I have them, I have modified ones—railings—going down my stairs... they’re reinforced... I don’t have a tooth now because I fell backwards going down the stairs with a crutch and a basket of clothes. So instead of holding on to that railing I went down 13 stairs. And the last thing to hit me was that crutch, and it hit me in the

face and it knocked my teeth out. So that taught me: use the bannister. You're not superman. Use the bannister.

Another respondent [notes that she has slipped and fell in the shower before, and now she uses grab bars:

My mom has those grab bars in the bathroom, because she lives in the 55+ residences. And those things are helpful! Sometimes I feel like a bath instead of a shower because I've already been on my feet all day, and I be wanting to get in the tub. It's small but there are millions of grab bars to help me down...I fell in my sister's tub a few times when I was taking a shower, and I think I have fallen in my boyfriend's tub just once. And their tubs were huge and they didn't have anything like a grab bar.

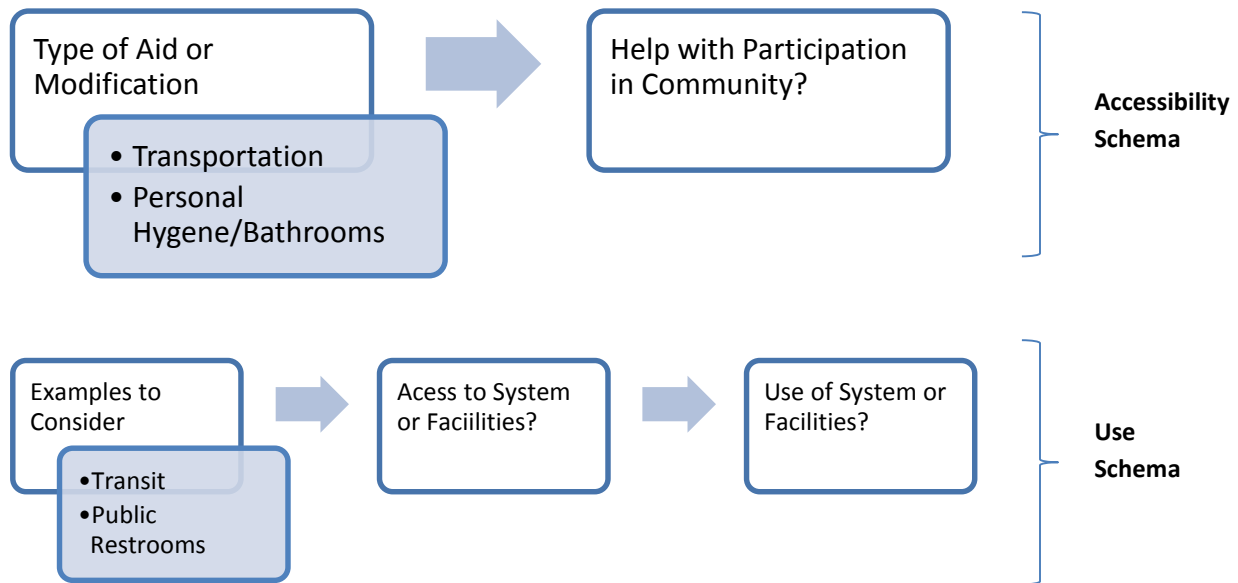
Reference Period: The respondents all answered this question thinking about their present circumstances and how they normally use or don't use accessibility aids and modifications. Practically, their "present circumstances" ranged from the day of the interview to a year or so in the past. While this may appear to be a variable reference period, in actuality there is not much *cognitive* variation as the respondents were thinking about how their lives are lived at the moment and considering the events within that stage or period of life. For instance: if a respondent had an injury that prevented her from working two years ago, and at the time of the interview she was still recovering and not working; then the respondent would consider her experiences throughout the last two years. If the injury happened four months before the interview, she would instead only consider those four months.

8. Are there any modifications that make it easier for you to participate in community such as accessible public transportation or accessible public toilets?

Construct Interpretations:

Overall, respondents either understood this question to be asking about the various accessibility options that allowed them to participate in family and community events (the "Accessibility Schema" below); or they understood the question to be asking about whether they are able to access public transportation and/or public toilets, and whether or not they use these two types of services (the "Use Schema" below). These two schemata are conceptually non-overlapping, and all the respondents answered using only one or the other. However, given these two separate interpretations, many respondents expressed confusion when first hearing the question and indicated they were unsure what it was asking about. The two schemata are visualized in the figure below:

Figure 7: Response Schemas for Question 8



Accessibility Schema: The first decision respondents make in this schema is to determine which modifications they will consider for the question. As seen throughout the previous questions, the examples provided very strong frames. Unlike previous questions however, the respondents *only* mentioned modifications related to either transportation or bathrooms, and did not break away from these cognitive sub-domains at all. For example, one respondent noted that he was considering modifications to the MetroBus system. Another respondent spoke about mobility in slightly more broader terms:

Is there any way they can make it easier for me to get around. To get to places I need to go.

While most people focused on the mobility and public transportation aspect, a few respondents used the public restroom example in this schema. One respondent was thinking about public, handicap-accessible toilets:

Are you talking about handicap accessible bathrooms? The ones with the wider doors? Yeah, I use that.

The second decision point in this pathway is to determine whether or not modification under consideration helps the respondent “participate in community.” This phrase produced confusion for respondents across both schemata, and will be addressed separately below. It suffices to say here, that because of this confusion some respondents appeared to simply answer whether or not they *benefit* from the modification(s) they were considering—without thinking about the larger issue of whether or not the modification helps them “participate in community.” For example, one respondent explained that various modifications on MetroBuses and Metrorail help him out:

You say accessible public transportation, right? So I'll say yeah. Cause I have an accessible card so I can get priority seating and priority fares. And that's important when you can't walk as well, and you can't stand as well...on the buses and on the rail.

Others touched on the issue of community without explicitly mentioning it. One respondent explained how the difficulty of getting access to accessible parking hindered his ability to go to New York City to see his daughter:

I'm thinking about accessible parking. That's a big one for me. Try going to NYC. You have to get two notes from doctors, so I gave up ...But in the state of Maryland, they let handicap people park in regular parking meters for double the regular time for free.

Note that even though he mentions that he cannot use this modification all of the time because of the hassle, he answered "yes" to the question because the modification aided him.

Use Schema: The second schema focused squarely on the presence and use of public transportation and public toilets—the examples given in the question text. The first decision in this pathway is when the respondent determines which of these examples to consider. Cognitively, this is a different decision than the "Type of Modification" one the respondents employing the Accessibility Schema make. While those respondents using the other schema are actually considering sub-domain of accessibility modifications (either mobility and transportation modifications or personal hygiene and toileting modifications), in this pathway the respondents are simply considering the examples at face value (public transportation—including Metrobus and Metrorail—and public restrooms).

The second decision point in this schema is to determine whether or not the respondent has access to whichever example he or she is considering. For example, one respondent explains that when he's in public, he can find a public restroom:

No, I don't do anything out of the ordinary. If you in public—if you're in a restaurant, you use a public restroom.

Some respondents noted the access-ability of public transportation by noting its convenience to where they live or work. For instance, one respondent explained her "yes" answer by noting that the bus line was near her house.

Once the respondent has determined whether or not they have access either to public transportation or to public toilets, the third and final decision point is requires them to determine whether or not they actually use these facilities. No respondents mentioned that they did not use public transportation—in fact some respondents took this question to be asking about their attitudes towards it. For example:

With public transportation: Metro is awesome. While I do have access to a car, I drive, when it comes to Washington, DC I prefer Metro.

Again, the sample was pulled from the Washington, DC metropolitan area. Respondents from other areas with less extensive transit systems might answer differently when following this schema and considering public transportation.

Respondent who were considering public toilets, on the other hand, did make observable decisions on their use of these facilities, and answered the question accordingly. For example, one respondent proclaimed that he would never use public restrooms, even though they are available:

I despise public restrooms. I like my privacy. And my private restroom is much cleaner, and I don't have to worry about germs.

Because the Use Schema does not focus on accessibility modifications at all, but rather on the presence or absence (and use) of common systems and facilities, this pathway has a high potential for false positive answers.

Participation in Community: As noted above, the phrase “participate in community” was not a clear signifier for the respondents. This is probably due to one of two syntactical issues. First, the phraseology “*participate in X*” is an awkward construction in the vernacular American English. Respondents are probably more used to the construction “*do X*.” Second, the word “*community*” is usually a modifier (i.e. “community service,” “community events,” and “community interest”), and is used only as a stand-alone noun in limited circumstances (viz. “Does she belong to a community?” “Was there agreement across the community?”). In employing both awkward phrasing and the uncommon, stand-alone construction, this phrase appeared to cause a noticeable amount of confusion among the respondents—producing a variety of interpretations.

Some few respondents did appear to consider the broader implications of the modification on their social and civic life. However, most respondents did not apply this meaning to “community.” Some respondents were clearly uncomfortable with the stand-alone construction explained above, and noted that they were thinking of “community” in terms of one of the common compound-phrases that uses the word. For instance, when asked to explain what he was thinking about vis-à-vis “community, one respondent said:

Community service; working with people in the public.

He went on to say that he could do things like “speaking out” against injustice to help with this cause. Other respondents seemed to simply equate the word “community” with the word “public.” One respondent said he did not participate in community because he is not “big on crowds.”

The most common way for respondents to approach the phrase “participate in community,” however, was simply to ignore it and either just think about their personal use of the system or

facility, or to use the word “community” to put a physical bound on where these systems or facilities are located.

Reference Period:

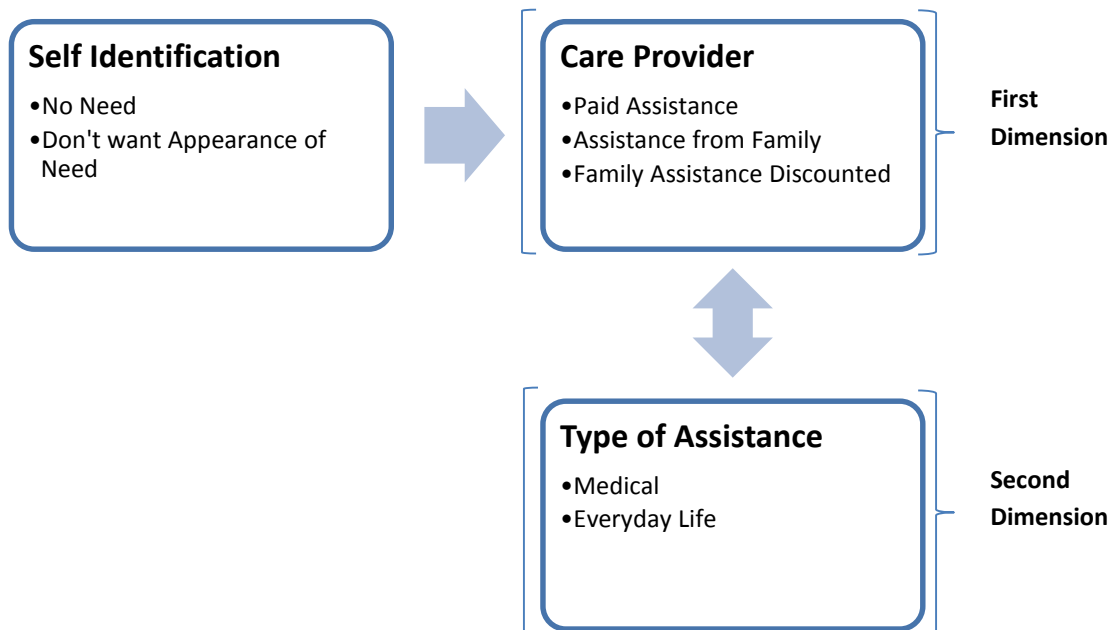
The respondents all carried the reference period from the last question to Q8, considering their experiences in their present circumstances. Again, this reference period includes *chronological* variation as the time period under consideration ranges between respondents, but not much *cognitive* variation as all the respondents appeared to be thinking about their normative actions in their current stages or periods of life.

9. Do you have someone to assist you with your day to day activities at home or outside? If No, go to I3012

Construct Interpretations:

Two cognitive dimensions framed the respondents’ interpretations of Question 9—Care Provider and Type of Assistance. These dimensions, which are visualized in the figure below, explain most of the variation in interpretation observed across the respondents’ answers to Q9. In addition to these two dimensions, the question of whether or not the respondent self-identifies as “in need” or disabled emerged strongly in Q9, and functioned as a sort of gateway in the schema seen below.

Figure 8: Response Schemas for Question 9



Self-Identification: As seen in previous questions, a number of respondents reported concern with being seen as in-need or disabled. This emerged strongly in Q9, and actually appears to be

the first decision point that a respondent comes to. If he or she decides that they are either 1) not disabled or in-need, or 2) that they don't want to appear to be disabled or in-need they will simply answer "no" to the question and move on to the next question.

For an example of the first case, one respondent notes that he once had a caretaker for a brief period of time, but now he is "independent." Likewise, another respondent indicated that he did not "need" anyone to help him out:

Is someone helping me with my laundry and my cooking? I do it myself.

Other respondents focused less on whether or not they *actually had* a disability or need, and instead spoke about the perception of others vis-à-vis disability and need. For instance, one respondent who initially answered "yes" to the question began to waver back and forth between that and "no," explaining:

I'm not to the point where I'm helpless. Some people might resent that question.
I'm disabled, not *unable*.

Another respondent mentioned that she did not want to be a burden on others and that she did not actually need anyone to help her.

This second pattern of interpretation has a high potential for false negative answers—a respondent could be answering "no" because of perception, and not because of the "reality" of his or her situation. This last respondent actually went on to say that she could sometimes use help walking, and liked it when she had someone to walk with—indicating that she did have someone to assist her at times.

Care Provider: After respondents cleared this question of self-identification, respondents proceeded to consider the two dimensions that frame this question, with the first being the type or kind of care provider under consideration. Three major patterns emerged around this dimension, with respondents thinking about paid caregivers, family members, or by discounting the aid of family members.

By and large, most respondents reported thinking about paid assistance in this question. This ranged from nurses to personal health aids (or PHAs) to maid services. For example, this respondent was thinking about a PHA who comes to her house every day:

I have a home health aide...every day, 8 hours a day.

A few respondents mentioned their family members—wives, husbands, or significant others—as people who assist them, such as one gentleman who explained that his wife functioned as his medical aid.

Other respondents seemed to ignore the help that their family members gave them. For example, one respondent who answered "no" went on to mention that her boyfriend took her to all of her doctors appointments. Likewise, another respondent explicitly ignored the assistance

his wife provides him, because it was not her “job.” These respondents tended to only think about assistance they receive from paid assistants and discounted the aid they received from people they lived with. As a result, this pattern of interpretation has a high potential for false negative answers.

Type of Assistance: Alongside the first dimension dealing with the type of care provider, the respondents also considered a second dimension centered upon the form of assistance they could or did receive. The respondents cited specific tasks ranging from help walking to medication assistant to help with chores and transportation around town. Generally, these specifics fit into two categories—medical assistance and assistance with everyday life.

The first pattern of interpretation deals with all types of medical assistance. Some respondents mentioned how they received assistance taking their medicine or with help walking. One respondent, who answered “no” to the question, explained his reasoning by saying:

Do I have a helper who assists me in taking my medication, or that sort of thing.

The second pattern of interpretation, by far the more common, was to consider non-medical assistance—the tasks of everyday life. This ranges from transportation assistance to household tasks, such as cleaning. One respondent, for instance, was thinking about someone coming to the house to do chores. Others took a broader view and considered social life. Another respondent explained his “no” answer saying:

Do I need someone to be with me to make sure my day goes good? Do I need someone to help me through my day?

This gentleman went on to talk about how people like company and the security of being around others, mentioning that some people just do not like going out alone.

Reference Period:

The reference period for this question was far more variable than the last few questions, with some people continuing to consider their present circumstances, and others focusing on major events in their past. These include surgeries, injuries, and illnesses. In these cases, some respondents explained that they had help after these incidents and answered “yes,” even if they did not use or rely on that assistance at the time of the interview.

FUNCTIONING QUESTIONS

The analytic intent of each functioning question is to capture two dimensions: 1) respondents’ health status, and 2) the environmental context that impacts functional abilities. The primary focus of this analysis, then, is to examine the constructs captured by this set of questions.

The response options for this set of questions is: 1) Not at all, 2) Yes, a little, 3) Yes, to some extent, 4) yes, to a moderate extent, and 5) yes, to an extreme extent. Throughout the analysis

below, the first of these options is referred to as the negative response or answer category, whereas the latter four are referred to as the positive or affirmative response or answer categories.

For each functioning question below, each pattern of interpretation in the Functioning Schema (Figure 1) that respondents used is delineated and explained. These patterns of interpretation are visualized as the boxes in Figure 1 above. As stated above in the Introduction, only those patterns of interpretation within the “Both Health Status and Environmental Context” pattern of interpretation can, but do not necessarily, produce in-scope responses. An interpretation in the other two pathways—where only health status or environmental context are considered alone—produces specification error and is out-of-scope.

14. Let us continue with the problems you experience. For all the questions I am now going to ask you, please think of people who help you, any assistive devices you use or any medication you take. Please think about the last 30 days taking both good and bad days into account. Is engaging in vigorous activities, such as exercise or sport a problem for you?

Construct Interpretations:

In conceptualizing the term ‘vigorous activity,’ most respondents considered some form of exercise or sport. The most common examples included walking and playing sports such as basketball or tennis. A couple respondents, however, included everyday life tasks, such as housecleaning, as vigorous activities. Another respondent noted that something was vigorous only if it physically pained him to do or accomplish the activity. Although explicitly stated in the question, most respondents did not speak about use of an assistive device as they explained how they formulated their answer. In answering this question, respondents based their answer on their environment (without consideration of their health) or their environment as well as their health status.

Both Status and Context – No Aid: Of the two patterns of interpretation within the Both Health Status and Environmental Context pathway, this was by far the most common. Respondents who used this pattern tended to explain how they have changed or adapted their schedules and activities to accommodate health state. One respondent explained that he has starting doing new types of exercises since he broke his leg:

I walk a lot. I play tennis on occasion. I used to run a lot, but I don’t do that anymore—when I broke the leg and I broke my ankle. They said it might not be a good idea to run marathons or anything like that anymore. Unfortunately, that was how I used to keep the weight off!

Another respondent noted that he is not in as good shape as he was in the past, though he could easily return if he tried:

If I was to play basketball or football or something like that. That would pretty much be the only physical activity. That wouldn’t be a problem...The only

problem would be that I haven't done it for a while, but I would just have to get adjusted to it.

In both of these two previous cases, the respondent answered "not at all" to the question. However, those respondents who answered using one of the various "yes" categories employed similar reasoning. For instance, one respondent explained his "yes to some extent" answer by saying:

It's a reality...because of my hip and my back. I had a double injury when I got hurt on the job 23 years ago...So there are things I can do safely. Swimming. I can walk. I can ride bikes. I haven't ridden a bike in a year or two, but I could do that safely. Run I don't do.

The respondent went on to say that since his injury he has to stop playing some sports like football, but that he can still do other things like shooting a basketball and bowling. He answered "yes to some extent" because he cannot do everything like he used to do.

Both Status and Context – With the Aid of a Device: Respondents who employed this pattern of interpretation tended to be thinking about exercise equipment, such as stationary bikes, that allow them to engage in vigorous activities. For example, one respondent first thought about playing tennis and using a stationary bike:

At first I was thinking of tennis. But now what I do, is I have a stationary bicycle in my bedroom. Plus I try to walk for half an hour every day. Usually at the mall or in the hallways.

Others were more explicit about how these types of aids allowed them to accommodate any disabilities or injuries. For instance, another respondent explained that he cannot walk for exercise anymore due to an injury, so he uses a bike:

Biking. Biking, that's about it. It's easier to get on the bike than to walk because of my foot...I bike almost every day. To my girlfriend's house and to my brother's house...some hills. I'm in the Adams Morgan area, so there's some hills like on 16th street.

He went on to explain how he adapted his riding style to his foot injury, placing more pressure on the heel and less on the balls of his feet, which is where he was hurt.

Environmental Context – Environmental Evaluation: Along with the previous pattern of interpretation, this was the most dominant way that respondents thought about their answers to Q14. In this particular case, respondents noted that they could do exercise and were only constrained by what they considered to be the "normal" limits to the activity. For example, one respondent who answered "not at all" explained that he gets out of breath after a hard run and figures that he would be tired after standing for a few hours. Likewise, another woman notes that she gets sore from her four-times-a-week exercise classes:

I just started water therapy and water aerobics, and I take both two days a week. So that's Tuesday and Thursday. So believe you me, by the end of Thursday, I'm sore.

These respondents were not thinking of their health status at all, but rather evaluated what physical consequences they would experience because of exercise.

Environmental Context – Willfulness: One respondent used this pattern of interpretation, noting that when it is hot outside, she just does not feel like leaving the house to go swim for exercise:

Because sometimes I can't make up my mind. I say I'm going to do it, but I don't...it's too hot outside. I swim. And getting there is a problem. I can catch a bus, but just going outside in the heat I don't like.

In this pattern, respondents are able to engage in vigorous activities, but choose not to sometimes due to personal preference.

Reference Period:

Most respondents were thinking not about the last 30 days, per se, but rather about their present circumstances as explained above in the Aid Questions section. Some respondents mentioned that they play sports, but upon probing note that it has been a year or two since they actually engaged in that activity. Like observed previously with the aid questions, many respondents appeared to consider their lives since some major event, illness, or injury.

15. Is getting where you want to go a problem for you?

Construct Interpretations:

Across the respondents and the varying patterns of interpretation within the Functioning Schema, there was overwhelming agreement that Question 15 asked about transportation. Likewise, there was very little variation in the modes of transportation that the respondents considered for this question—with most respondents thinking about transit services (such as Metrorail and the bus) and cars. This lack of variation could be unique to this sample, however, as it was drawn exclusively from a region (the Washington, DC Metropolitan Area) that has an extensive transit system. A few respondents did consider other modes of transportation, such as walking and bicycling.

Like with Q14, the respondents limited their patterns of interpretation to those found in the Both Health Status and Environmental Context and the Only Environmental Context pathways in the Functioning Schema, with the majority of respondents employing the out-of-scope Environmental Evaluation pattern of interpretation.

Both Status and Context – No Aid: As in Q14, respondents who followed this pattern of interpretation largely considered how they have modified their schedule due to some health status. One man explained how his arthritis prevented him from walking to the store every day, so he only went on days when his condition was not acting up. Another gentleman explained

that he simply had to sit down after an hour or so of walking, but that it didn't prevent him from getting where he needed to go:

If I'm going to get there, I'm going to get there...It's painful, but [shrug]. I can walk for an hour or so then sit down.

Both Status and Context – With the Aid of a Device: A number of respondents noted how various modifications helped them move around in spite of a condition. Because the respondents were thinking about Q15 as transportation—and often *transit*—question, the most commonly cited modifications were those provided by WMATA (Washington Metropolitan Area Transportation Authority, commonly referred to as “Metro”). For instance, one respondent noted the handicap modifications to Metrorail helped him:

Metro is always accessible, and because I'm disabled, I ride the bus for free.

This last point the respondent made—about the bus being free—was a common theme. Most respondents using this pattern considered financial aids when answering this question. This was not only applied to transit, but also to other facets of transportation. One woman explained that she was thinking about the type of transportation her health insurance will cover:

If it wasn't for friends and family. Getting to my doctors' appointments is the most important. But there are days where I have to go to social services to recertify for my Medicaid and things. My insurance provides transportation for “medical things,” but other than that you are on your own.

Environmental Context – Environmental Evaluation:

By far, the most dominant pattern of interpretation of Q15 was to think about it as a question of how good the transportation/transit systems are and how easily the respondents can access these systems to move around the city. In doing so, these respondents are not thinking about their health statuses at all, but rather are evaluating the quality of the transportation systems and their access to them. For example, one man explained how he could get anywhere he needed to using buses and cabs:

Cause it isn't a problem! Well, if I want to get here, I just went across the street, caught a bus, went to the metro, and got here. There's no problem...It's pretty good around the DC area...You just need to give yourself sufficient time is all. If you're doing public transportation then it will take you longer, but it's a little more convenient...[For places there is no Metro service] You can get a cab, or if you have a friend going out in the same direction...

He does note some issues, but they are structural and are not presented as relating to health or wellness. Another respondent notes that she normally uses the subways system, but can use a car if need be:

I drive, and but mostly use the metro. And I walk. Sometimes people pick me up, but I have no problem with it

Similarly, another woman explained her “yes to some extent” answer by explaining that the bus system did not always work for her:

The way the bus routes are routed. Sometimes you have to take three or four buses to get somewhere. And the city’s not even that big, really!

Reference Period:

The respondents all appeared to consider very recent activities when answering Q15. While all the examples given fell within the “last 30 days” instruction, it is unclear if this is because of that instruction or because transportation is such a salient social domain that all the respondents had recent examples to think about.

16. Is getting out of your home a problem for you?

Construct Interpretations:

A small amount of variation across the respondents’ interpretations of Question 16 was observed during the interviews. Again, all respondents used the Both Health Status and Environmental Context pathways, with the majority of respondents considering both their health and environmental situations together.

Both Status and Context – No Aid: A few respondents explained how health conditions, such as leg injuries, could affect how they or others physically get out of the house without mentioning aids or modifications such as ramps or elevators. These respondents tended to explain their answers by hypothesizing what could potentially keep people confined to their homes. For example, one man noted that he was thinking about people who:

Maybe somebody who has a physical disability—who couldn’t get up out of bed on their own or get to the door. Or didn’t want to go out—some people are reclusive, so I guess that’s a part of it.

While most respondents who interpreted Q16 this way were not thinking about themselves (and answered “none at all”), one respondent who was thinking about himself explained how he shifted his chore schedule to accommodate his leg issues:

I accommodate it like you said. I avoid going out...I have to take care of my wife’s cat litter box, but I put it off yesterday because of my leg. And I didn’t get the paper yesterday, just got both today.

Both Status and Context – With the Aid of a Device: When answering Q16, the majority of respondents considered some type of aid or modification that helps them, or hypothetically helps others, leave the home. Most respondents considered physical aids, such as ramps and elevators. Recall that these were also the most frequently cited examples in Q7—the aid question about home modifications.

While most respondents were thinking about the aids or modifications they have access to and use, a few respondents who answered “none at all” explained that they were comparing themselves to people who would have to use those aids to get out of the home. One man explained his answer by comparing himself to individuals who could not walk down the few stairs from his stoop to the street:

It’s not like I’m in a wheelchair. It would be a problem then...

Both Status and Context – With the Aid of a Person: While most respondents were clearly thinking about the assistance of an inanimate aid or modification, a couple of individuals mentioned the help they received from other people in getting out of the house. One lady mentioned how her doorman helps her up the stairs. Another respondent noted that he helps his neighbor who uses a wheelchair carry her groceries into her apartment.

Environmental Context – Environmental Evaluation: Some other respondents considered only whether or not they could leave the house without mentioning their health statuses. This pattern of interpretation emerged strongly when people were thinking about the social pressures to leave the home and participate in society. Most of these respondents were thinking about going to appointments or to events, and noted that they just went out when they felt like it. One respondent noted that he has a lot of cats, and that he bases his schedule around taking care of them.

Environmental Context – Willfulness: One respondent noted that he sometimes does not leave the house because of the weather or because Metro is sometimes frustrating. This respondent did not have a physical disability keeping him in, and notes that when it’s nice outside, he feels more motivated to leave the house.

Reference Period:

The respondents appeared to carry the reference period over from the last question into Q16, with most respondents thinking and speaking about recent events in the last week or so.

Response Difficulties:

There is one issue to note pertaining to response difficulties. Some few respondents believed that Q16 was explicitly asking about the presence of a physical disability. These respondents had a negative reaction to the question, and all answered “none at all.” For example, one respondent explained his answer by saying:

If I want to get out of the house, I’m going to get out of the house.

This respondent had previously mentioned that he did not want to be labeled as someone who has a disability. In this case, after further probing he went on to explain that getting out of bed was painful, and that it takes a while to loosen up so that he can walk out from his second-floor apartment. While such a negative reaction to the disability label or identity might not always lead to false negative answers, it does greatly increase their probability.

18. Does eating and drinking pose a problem for you?

Construct Interpretations:

There was a strong trend that respondents who used an affirmative answer category to respond to Question 18 considered both health status and environmental context, whereas those who replied using the negative answer category considered only their environmental context. In fact, the variation seen throughout this question came less from the patterns of interpretation, *per se*, and more from the wide diversity of concepts relating to *eating and drinking* that the respondents considered.

Both Status and Context – No Aid: Alongside the Environmental Evaluation pattern discussed below, this was the most common pattern of interpretation by respondents in Q18. These respondents generally concentrated on how some health condition impacted, or hypothetically could impact, their eating or drinking. The specific conditions and aspects of eating about which the respondents were thinking varied, however. For instance some respondents reported that they were considering the physical ability and dexterity needed to bring food to one's mouth, such as this male respondent who was thinking about people in a hospital or senior care facility:

A person in a hospital or something...or a senior citizen building.

Other respondents reported thinking about the physical ability to chew and swallow, such as this respondent:

Maybe they have, well I had a first cousin of mine who had cancer of the esophagus. And eating and drinking because a real problem for her. Obstructions or inflammations—that kind of thing. There are various problems that people can have. I had an uncle that throat cancer, and they had to cut out his voice box...and that probably affected what you can eat and how much you can eat.

Other respondents were thinking about diseases or conditions—such as sickle cell anemia, hiatal hernias, and acid reflux—that make it harder to digest food, make it painful to digest food, or make people choose to eat only certain foods.

Both Status and Context – With the Aid of a Device: Only one respondent across the sample considered the use of a device or modification—in this case, a spoon—for eating when considering this question.

Both Status and Context – With the Aid of a Person: Likewise, only one respondent thought about the assistance one person could give another when eating. This respondent was hypothetically thinking about how people with certain disabilities or who are paralyzed need other people to feed them.

Environmental Context – Environmental Evaluation: As noted above, this pattern usually produced the negative “none at all” response. Like seen above with the “No Aid” pattern of interpretation, there was a great deal of variation within this pattern due to the particular aspects

of eating and drinking each respondent considered. The most common aspect was *healthy eating*. For example, one female respondent explained her thinking by saying:

Is it a problem to eat the right thing? So it's no problem...Knowing what I should eat.

Thinking about a closely-related concept, other respondents reported thinking about dietary restrictions to which they or others hold, such as vegetarianism and dairy-free diets. Another group of respondents focused on the amount they ate and the “problem” of over-consumption. These respondents either listed the foods that they thought led to over-eating (such as chips and candy) or mentioned the bodily effects of over-eating (such as obesity). For example, one respondent noted that he did not eat too much because he wanted to maintain his figure:

Well I love to eat; if I have a chance to eat I'll eat it!
But I try to eat the right foods. You have to be conscious what you eat these days...I'm a partial vegetarian now. I know that a lot of meat isn't good for you...You are what you eat. And with obesity. I don't want to see myself like that. I don't want to see no bulges on the stomach!

Overall, respondents who were thinking about eating healthy food, eating health-based diets, or about over-consumption used these behaviors to explain why eating and drinking was not a problem. For this group, a “problem” was eating unhealthily.

Completely unrelated to these consumption-based aspects of eating and drinking, some respondents focused on the “drinking” part of the question and were considering their alcohol intake. One gentleman, for example, explained that he tended to have a case of beer every weekend:

I do drink, I drink almost every weekend a twelve-pack [of beer]. I don't know if that would be considered [a problem]. Cause it's only once a week, but when I do drink, I get drunk. I never get blackout drunk, cause it's only a twelve-pack.

In this case, the respondent answered “yes, a little bit,” as his drinking rarely got in the way of the rest of his life. This interpretation is not surprising, as the use of the un-modified word “drinking” in vernacular American English tends to refer to the consumption of alcohol.

Reference Period:

Again, it appears as though the respondents largely continued to carry over the reference period from the previous questions, and answered about their experiences in the last few weeks before the interview. A few respondents did search further into their past for specific events, such as for a past illness in the family.

Response Difficulties:

Some respondents needed Q18 to be repeated during the administration of the survey, and seemed confused about the question. This difficulty is probably due to salience, as the large

majority of respondents expressed that they had no problems with eating or drinking. One respondent, for example, stated that she didn't know what "pose a problem" meant in terms of eating and drinking. Since this concept might not be very salient in the general population, there is an increased risk of both false negative and false positive answers as respondents try to expand the construct to match their lived experiences.

19. Is looking after your health, eating well, exercising or taking your medicines a problem for you?

Construct Interpretations:

Most respondents interpreted Question 19 as asking about their eating habits and whether or not they had healthy diets. In doing so, respondents again stuck to the two pathways in the Functioning schema that consider environmental context.

Both Status and Context – No Aid: One respondent thought about how a disease has prevented her from eating and exercising. Following the pattern noted above in Q14 and Q15, this respondent noted that she has altered her eating and workout scheduled to accommodate her illness.

Both Status and Context – With the Aid of a Person: A couple of respondents reported thinking about how people can help others look after their health and eat well. One respondent was thinking about how his doctors and counselors have put him on the track towards better health:

Basically years ago, before I was seeing my counselors, it was a problem. But they've put me on the right track, so it's not a problem anymore.

Similarly, another respondent noted that her home health aide helps her shower and remember what pills to take and when. She commented that the biggest problem she has to deal with is not taking the pills, or eating well, or even being able to shower, but rather remembering to do everything. This type of assistance from another person, which both of these respondents considered, is mental or psychological at its core, and not necessarily physical.

Environmental Context – Environmental Evaluation: This pattern of interpretation was, by far, the dominant pattern across Q19. Generally speaking, respondents considered and reported on whether or not they believed they had healthy habits, and in most cases, healthy eating habits. This pattern usually resulted in respondents answering "none at all" to the question. In doing so, they tended to be thinking about what types of foods they consumed made them healthy, and about what amounts of food made them healthy. For example, one respondent focused on how he eats well:

Now we're talking about the health benefits of eating well, and it's no problem...I'm thinking that it's necessary for me to eat well, and I'm conscious of it. And I try to do it as well as I can. I still eat junk once in a while, but I do eat

well because I know it's important. And I have the means to get it, and some people don't have the means to eat healthy.

Other respondents focused their thinking on the issue of quantity, such as this respondent who notes that he tries not to eat too much junk food:

Cause I mean. I basically exercise every day and make sure I take care of myself. I don't eat too much fast food and I try to eat vegetables every day.

After thinking about these healthy habits, most respondents concluded that they had these habits,, were therefore in good health, and should answer in the negative. The opposite was also seen, however, with some respondents judging that they did not eat the best food, or consume the “correct” quantities. These respondents thus answered using one of the affirmative categories, as their behavior was not matching their standard.

As seen throughout the questionnaire, particularly in the Aid Questions (Q1-Q9) detailed above, the examples used in the questions have a strong framing effect. And while in this case, food was obviously the most salient example; the others (viz. exercising and taking medication) were present as well. Some respondents noted that they made sure to take the right medicines at the correct time each day; whereas others noted that remembering to do so was a little bit of a problem:

I have to remember. I take my pills at 9 o'clock...It's kind of a nuisance.

While these respondents are considering examples other than food (or not considering food exclusively), the same cognitive pattern applies: they establish in their minds what the “healthy” behavior is and then evaluate their fidelity to this behavior. In the previous example, the woman noted that taking her medications on time every day was a hassle and that she did not always do it correctly—therefore, she answered, “yes, a little” to the question.

Reference Period:

The respondents were all considering their present circumstances. Most respondents were evaluating their current behavior against a standard of “healthy.” Some respondents considered their past situations as a comparison against their present ones, but everyone answered about their current lives.

Response Difficulties:

As structured, this question can be seen as a “quadruple barreled” question—a single question which is actually composed of four separate questions. This was an issue when, during probing, some respondents wanted to provide different responses for each of the four question constructs (looking after your health, eating well, exercising, taking your medications). As explained above, most respondents focused on the “eating well” construct. However, it became apparent during probing that some respondents would provide different answers if they were instead thinking about one of the other three constructs or all four of them together in intersection.

20. Once again, please consider your health and people who help you, any assistive devices you use or any medication you take. Is hearing what is said in a conversation with another person in a quiet room a problem for you?

Construct Interpretations:

Unlike the previous Functioning Questions, the respondents' interpretations of Question 20 fall along all three pathways of the Functioning Schema, with most respondents either only considering health statuses, or only considering the environmental context, and very few considering both at once.

Only Health Status – Normalcy: These respondents understood this question to be asking “do you have a hearing problem?” and explained that they did not have one. For example, one respondent simply stated that he did not have a hearing problem:

No, no hearing issues...[The question means] basically, “Can you hear?”

Likewise, another respondent said that he did not “have a problem hearing anyone” in conversation.

These respondents simply understood this question to be about the presence or absence of a perceived hearing disability (even though the question was not asking about a disability at all), and all respondents who used this pattern of interpretation responded with the negative answer category “none at all.” As seen throughout the questionnaire when this type of interpretation emerged (such as in Q1), however, there is an increased risk of false negative answers when respondents only think about the question in terms of a perceived inability to hear. For example, one respondent said right off the bat that she has no problem hearing conversations. This respondent had already mentioned some form of hearing problems, however. When probed about this, the respondent said she was only thinking about conversations in a room, and ignored the fact that she keeps the television loud and has to keep her phone volume turned up high. So, in reality, this respondent has hearing issues and uses aids for hearing (even in a quiet home), but did not consider these in her answer.

Both Status and Context – No Aid: Respondents employing this pattern considered their health states and then compared their behavior against an ideal. In this question, the respondents' ideal or standard was clearly framed by the question text, which instructs them to think about a quiet room. While across the sample, the type of room varied—from a bedroom to the interview room itself—the overall cognitive pattern did not: If a respondent evaluated that his or her hearing in a quiet room was sufficient for a conversation, they answered the question in the negative.

Just like in the last question (Q19), most respondents who employed this pattern of interpretation answered in this negative way, there were a couple who judged that their behavior was not up to their mental standard and responded using one of the affirmative answer categories.

Both Status and Context – With the Aid of a Device: A couple of respondents considered their hearing aids, and noted that their ability to hear is much better with the aids than without them.

Only Environmental Context – Willfulness: A few respondents mentioned that the content of the conversation was the deciding factor about whether or not they would hear a conversation. However, in reality, it appears as though these respondents are answering the question “can you *listen* to a conversation in a quiet room?” These respondents mentioned a number of things that would turn them off to paying attention, but that sometimes they just decided to “zone out.” For instance, one gentleman noted that he has “selective hearing” around his wife (though he answered “none at all” to the question).

Only Environmental Context – Other Person: Related closely to the Willfulness pattern, the respondents who used this pattern of interpretation considered specific conversations with individuals or groups of people to be the deciding factor on how they would answer the question. For example, one woman noted that she chooses to ignore people on the bus or Metro who talk loudly or about things she finds irritating. Because she does not always hear them (or really, *listen to them*), she answered in the affirmative. Likewise, another respondent noted:

Because I usually communicate with people who speak with different dialects, and it’s difficult sometimes.

Again, this respondent answered affirmatively based on the fact that she cannot *comprehend* everyone because of their accents, not based on whether or not she can *hear* them. Because of the difference between the constructs of “hearing” and “listening,” both the Willfulness and Other Person patterns have a risk of response errors in either direction.

Reference Period:

The reference period for Q20 remained the same as the previous questions, with respondents answering about their current situations. Because hearing (or listening, as it may be) is a salient construct, it appears as though respondents did not have to think far back into time to find the examples they needed to answer the question.

21. Is hearing what is said in a conversation with another person in a noisy room a problem for you?

Construct Interpretations:

In the last question, where they were asked about a “quiet room,” respondents’ interpretations favored the “only” pathways in the Functioning Schema; in Question 21 this trend intensified. Overall, respondents interpreted this question in two ways: 1) Do you have a hearing condition? or 2) Is it difficult to listen to other people in a noisy room?

Across these two interpretations there was very little variation around base construct of a “noisy room.” Most respondents were thinking about rooms with large crowds or social settings that are crowded. A few specific examples were cited repeatedly, including concerts, restaurants, and parties.

Only Health Status – Normalcy: A few respondents, all of whom answered using the negative answer category “none at all” followed this pattern of interpretation. As seen above in Q20, these respondent focused on whether or not they had a hearing condition or disability. For example, one respondent noted:

No, no problem. I have no problem hearing...In a noisy room it wouldn't be a problem unless it's too noisy, like a concert.

In this pattern, the “problem” asked about in the question text is interpreted as being hard of hearing, and the respondent does not consider any environmental or social issues beyond that.

Both Status and Context – With the Aid of a Device: One respondent considered both a health condition and how this condition (and the aids that mitigate it) impacted life. In this case, a respondent noted that he has a hearing condition, uses a hearing aid, and that it helps (but does not totally eliminate) his ability to function in a noisy room.

Only Environmental Context – Environmental Evaluation: As has been the pattern in the previous questions, this pattern of interpretation was dominant in Q21. When using this pattern, the respondents did so in two distinct ways. The most common form was for respondents to focus just on the “noisy room” aspect of the question, and indicate that it was more or less a truism that it is difficult to hear in a noisy room. These respondents *defined* a noisy room as somewhere it was difficult to hear. For example, one respondent explained her affirmative answer by saying:

Yeah. Yes, because in a noisy room you can't hear. Because you have noise around you. So it's a little hard to concentrate.

While this form of the pattern tended to produce affirmative answers, in a few cases it lead to negative ones as well—potential false negatives. For example, one respondent who answered “none at all” reported:

I was thinking about background noise [at a restaurant]...it could present a problem.

However, the respondent was thinking about this as a hypothetical, and decided that he did not actually have a problem hearing people over the background noise somewhere like a restaurant.

The second form of this pattern was when people evaluated their ability not to hear, *per se*, in a crowded room, but rather their ability to concentrate and “listen.” In this case, the problem asked about in the question text is interpreted as the ability or inability to concentrate on something being said. One woman explained that while the TV was on, she could not concentrate on a conversation with another person:

I can't like—it's too much chaos, too much noise for me to try to hold a conversation. If the room is noisy, or if the TV is on, and someone is trying to talk to me, it drives me crazy. I have to put it on mute.

Other respondents mixed these two forms of the pattern together, for instance noting that noisy rooms make for poor places to both hear and understand a conversation.

Only Environmental Context – Other People: A couple of respondents did not focus on how a noisy room impacted their own ability to hear or listen, but rather on how other people's conversations did. These respondents noted that when lots of other people are talking at once and having their own loud conversations, they have a difficult time having their own because of the cross-talk.

Reference Period:

The reference period for Q21 was the same as for Q20, with respondents considering recent salient events while answering the question. All the events appeared to be within 30 days prior to the interview.

22. Is having pain a problem for you?

Construct Interpretations:

All respondents considered their health statuses, in one way or another, in Question 22. This was the first Functioning question the respondents received that they clearly interpreted to be about health—the presence or absence of pain. Overall, most respondents interpreted this question to be asking whether or not they were *in pain* or tended to *experience pain*, and not how pain impacted their lives. In doing this, they perceived the “problem” that the question was asking about to be the *pain itself*, and not the *effects of the pain*.

Only Health Status – Characteristic: This pattern of interpretation was the most common those respondents who answered using an affirmative answer category. These respondents were considering the frequency or the severity of the pain they experienced. Many respondents explained that they felt some pain after everyday events, such as long walks or participating in sports. For example, one man reported:

I don't get hurt too often, maybe once every two or three months. Because you fall sometimes. And I play like 3 times a week, I play a lot of basketball...But that [pain] just comes from working out, you know? You just get sore like here [points to shoulders] and stuff.

Other respondents were considering more chronic issues, including illnesses and injuries, which cause pain. One respondent noted that his teeth ache frequently:

No, I understand how to deal with pain. It only lasts for a little while. I have tooth aches, no headaches. Basically toothaches, but you know it's not going to last forever.

It did not matter from where these respondents' pains originated, in all of these cases they only considered the pain itself. Generally, they were quantifying their pain and then translating this value into one of the answer categories. A good example of this is a female respondent who appeared to put her pain on a numerical scale:

When I have pain, it depends on the degree. And I'm thinking about when it's bad...And sometimes I take medicine and it doesn't help it. If I stand too long, it will get extreme, and I will do anything...But I have those days too, when it's just a 2 or a 3, when I'm ok—it's a good day!

Only Health Status – Discontent: A couple of respondents simply noted that pain is a problem, because it is irritating or something that nobody enjoys having. For instance, one respondent noted:

I mean that I don't like pain period. And to have it from time to time is annoying. Likewise, another respondent simply noted that having pain is "irritating," and that he would like to be "rid of it forever!"

Again, it is apparent that these respondents are thinking not about how pain impacts their day-to-day functioning, but rather that pain is a problem in and of itself.

Only Health Status – Normalcy: This was the dominant pattern for those respondents answering in the negative to Q22. As seen above in the hearing and anxiety questions these respondents understood the question to be asking whether or not they were in pain, and that they were not. Most of these individuals noted that have experienced pain in the past, but were not in either chronic or acute pain at the moment.

Both Status and Context – No Aid: One respondent noted that his chronic pain led to mobility issues and limited the places he could go and the activities in which he could participate.

Both Status and Context – With the Aid of a Device: A couple of other respondents also considered how their pain affected their lives and the activities they could do, but also considered the effects medicine had on this pain. One lady, who answered the question in the affirmative, noted that she has chronic pain in her legs, and that normally she "just deal[s] with it." However, if it flares up, she needs a pain balm which brings some relief. Another respondent, who answered "none at all" noted that his pain is a problem when he doesn't take his pain medication. He also went on to note that the specific pain medication he was taking was hurting his liver, so he would have to eventually decided between liver health and pain, but that that decision was in the future.

Reference Period:

The reference period for Q22 was wider than seen in previous few questions, returning to the "present circumstance" scenario explained above in Q7. If respondents considered infrequent chronic pain, they only considered it for a condition they had presently. For example, one

respondent noted that he had really bad pain about once a month, and explained that this had been going on for a few years.

23. Does sleep pose a problem for you?

Construct Interpretations:

All respondents considered their health status in some way when answering Question 23. There was even less observed variation in Q23 than in Q22 however, with the patterns of interpretation closely aligning with the respondents' answer categories to the question itself.

Similar to the general interpretation of Q22, respondents overall understood this question to be asking whether or they could and did sleep, with only a few individuals also considering how their sleeping conditions affected the rest of their lives.

Only Health Status – Characteristic: This pattern of interpretation was dominant among those respondents answering Q23 in the affirmative. Overall, the “problem” that these respondents considered was poor sleep—ranging from not getting to sleep, not getting enough sleep, or not being able to stay asleep for the whole night. These respondents did not move beyond considering their sleep condition to how it might affect their lives. For example, one woman explained in detail how she wakes up a few nights a week with leg spasms, and then cannot get back to sleep. Another female respondent was more explicit, noting that she responded “yes, to an extreme extent” because her lack of regular sleep was something she thought about a lot and considered a problem:

Every night, when I go to bed, it's there. Not that it changes my world, but it's always there. I'm always thinking, should I take a shower, should I drink chocolate milk—would those work? It's always there.

This respondent noted that her sleeping issues do not always affect how she lives her day-to-day life, she just deals with being constantly tired and sticks to her everyday schedule.

The consistency of the respondents' sleep patterns emerged as the most common construct they considering when applying this form of interpretation. For example, one respondent explained how working the graveyard shift had disrupted his sleep schedule:

Sometimes I have trouble sleeping...since probably 2002 maybe. I used to work the graveyard shift—12 hour shifts for Siemens. I worked from 12 midnight to 12 in the afternoon. And that messed my sleep up, it's been years. It's taken a long time to get my biological clock back to normal...sometimes I can't fall asleep, sometimes I can't get back to sleep, sometimes I don't want to go to sleep.

This respondent does not go on to explain how this is a problem in detail, just implying that having an irregular sleep schedule in and of itself is a bad thing, but not considering whether and how that irregular schedule affected his day-to-day life.

Only Health Status – Discontent: One respondent noted that the problem she was focusing on when answering this question was how miserable her lack of consistent sleep made her:

Yes. I have periods where I just won't sleep. It's better than it used to be...I'm just miserable...It poses a problem, it's just so frustrating when you can't sleep. Your body's tired, but you just can't. It's gotten to the point where I just want to pull my hair out!

So while consistency of sleep is again the base construct in this pattern of interpretation, the respondent goes a bit further by fleshing out the problem as something that upsets her. Again, however, this respondent does not link her discontent over her lack of sleep to how she functions in her day-to-day life—she is discontented by the lack of sleep, not by the effects the lack of sleep have on her ability to function.

Only Health Status – Normalcy: This pattern of interpretation matches what has been noted for previous questions, and was again the most common pattern for those answering with the negative “none at all” category. These respondents considered whether or not they had an issue with sleeping and decided that they did not. For example:

I basically go right to sleep. I can sleep just fine!

When probed about what types of people would answer yes to this question, these respondents tended to contrast themselves to people with sleeping conditions, such as insomniacs.

Both Status and Context – No Aid: A few respondents applied this pattern, and in doing so considered both their sleep conditions and how their lives have been affected because of this issue. They indicated that their inability to get a full night's sleep sometimes made them sleepy during the day, and that they had to alter their schedules or activities to fit this. For instance, one older woman noted how she had to come home and take naps during the day because she could usually only muster a few hours of sleep a night, and that this impacted her social life.

Both Status and Context – With the Aid of a Device: One respondent who answered using the negative answer category “none at all” explained that the medication he took allowed him to get a full night's sleep, and then as a result he “feels fine” during the day.

Reference Period:

The respondents carried over the reference period from the previous question, and continued to answer about their present circumstances, even if those extended beyond the 30 day instruction.

24. How much of a problem do you have due to feeling sad, low or depressed?

Construct Interpretations:

Unlike the previous two questions, the respondents' interpretations of Question 24 spanned all three pathways of the Functioning Schema. This question, like the next one (Question 25) asks about the respondents' feelings and emotions. However, the respondents answered these two

questions in very different ways—with most considering their health states in Question 24, and only considering their environment situations in Question 25. Respondents generally understood Question 24 to be asking whether or not they were depressed, and how that depression affected their lives.

Only Health Status – Characteristic: A number of respondents considered whether they were depressed, or whether they suffered from similar mental illnesses. As has been noted for this pattern in previous questions, the “problem” that the respondents considered here is the mental illness itself. For example, one woman commented on her diagnosed bi-polar disorder:

Well I have bi-polar disorder and manic depression...[I have been diagnosed] since 1999.

While in previous questions this pattern of interpretation was almost exclusively used by respondents answering in the affirmative, in this case the pattern is split between affirmatives and negatives. Those respondents who answered using the negative “none at all” category appeared to consider the *severity* of their depression when responding and decided that it was not as bad as it had been once, or could possibly be. A good example of this is a gentleman who admitted that he was clinically depressed in the past, but has decided that he could not live his life that way anymore and refuses to consider himself to be sad or depressed and “changed his attitude.”

Only Health Status – Normalcy: The Normalcy pattern of interpretation appears in the same form it has throughout the Functioning Questions. Here respondents understood the question to be asking about whether or not they were depressed, and then reported that they were not. Almost all of the respondents who applied this pattern only considered clinical or diagnosed depression. For example, one male respondent noted that sometimes he was sad, but that it did not count for this question:

No, because I don't. I try to look at the good side of things. I joke a lot. No real reason to feel depressed. Sometimes things happen and you feel sad or stressed, but you just deal with, and they go away. But no, not depressed.

With the exception of one “Don't Know” answer (which, after probing, was revealed to be a “none at all”), all of the responses using this pattern were in the negative.

Both Status and Context – No Aid: A couple of respondents considered both their health statuses and how depression might or does affect their lives. In one case a respondent (who answered the question in the negative) compared himself to someone who could not break through their depression and get out of the house to do anything. He contrasted himself to this hypothetical, calling himself an “active senior” who did lots of activities. In the other case, the respondent answered in the affirmative, and explained that her depression has made it even harder on her to get out and do things, which in turn makes her more depressed.

The mark of this pattern of interpretation, present in both these cases, is that the respondents think about how their (or a hypothetical depressed or sad person's) environmental context would be affected due to their health status. Simply put: the health status leads to the problem.

Both Status and Context – With the Aid of a Device: Another pair of respondents thought about how the use of medication—specifically anti-depressants—helped them control their depression and live a less affected life. Though both of these respondents answered in the negative, it was apparent that their health statuses still affected their life. One of the respondents, for example, explained how he believes that his medicine prevented him from committing suicide, but that he feared it was not strong enough and needed to have his doctor prescribe him something stronger soon.

Only Environmental Context – Environmental Evaluation: This pattern was present only among respondents answering in the affirmative, and can be understood as the opposite of the No Aid pattern above. Whereas the respondents applying the No Aid pattern thought about how their lives were impacted by depression, these respondents believed that they were sad or depressed *because of things in their life*. In other words, the problem leads to the health condition.

A good example of this is a male respondent who could not work anymore due to an injury. He explained that he likes to work, and not doing so makes him sad. Similarly, a female respondent talked about the deaths in her life, and how thinking about them depressed her:

Well my brother just died recently, and I lost a son when he was 29 years old. And that's always with me, in the back of my head. And I have another son with some problems, so that's another thing. So it's a life thing...I can't say I'm happy, because it's life, but I'm ok.

This respondent went on to explain though that the depression itself—which was not diagnosed but instead just “sadness”—did not cycle back and further disrupt her life. Her definition of the construct of definition was similar to almost all of the respondents using this pattern—they were not considering diagnosed or clinical depression, but just general depression and sadness.

Reference Period:

The respondents used the same reference period in Q24 as they did in the last question, again thinking not about a set period of time, but rather of their present life circumstances.

25. How much of a problem do you have due to feeling worried, nervous or anxious?

Construct Interpretations:

Overall respondents were generally did not consider their health conditions at all, and instead focused on the environmental context in Question 25. As noted above in the last question, Q25 and Q24 both cover feelings and emotions (depression and anxiety, respectively). However, while in Q24 most respondents considered their health state (either alone or alongside their environment), a large majority of respondent in Q25 only considered anxiety as a health condition that potentially stems from one's environmental and social situation. Therefore, even

though “on paper” depression and anxiety are very similar concepts, respondents interpret them in almost opposite ways—the first as a condition that leads to problems, and the second as a condition that is a result of problems.

Only Health Status – Normalcy: A few respondents applied this pattern of interpretation to Q25 in the same way as in previous questions. These individuals understood anxiety to be a specific diagnosis, which they reported they did not have (and all answered in the negative). All of them interpreted the construct to more or less be a point on a personality scale, which they do not meet. For instance, one male respondent noted, “Not at all. I don’t get to that stage.”

Similarly, a female respondent reported that she did not have “that kind of personality.” As this respondent had just finished describing her clinical diagnosis of depression, it appears as though anxiety is understood as a completely distinct construct than depression.

Both Status and Context – No Aid: In this pattern of interpretation, respondents think about anxiety as a health status and consider how that may or may not impact their or someone else’s life. Take the example of this respondent, who is dealing with a range of issues such as his mother’s death and not having a job:

I’ve been worried a whole lot...worried about a lot of things in my life. Jobs. My mother...I just really few bad. It just seems so hard, it’s just so much. I feel like I’m boiling over. Sometimes it’s not bad, sometimes it’s worse. But I’m losing interest in some of the things that I liked doing.

Even though the original source of the anxiety may be environmental, this respondent is then considering the continued effects of the health condition. Therefore, the “problem” these respondents are considering is the impact on their environmental or social situation.

Only Environmental Context – Environmental Evaluation: The majority of respondents applied this pattern of interpretation to Q25. In a way, it’s similar to the example shown above for the No Aid pattern, but with one large difference. Whereas the respondent above explained how the anxiety that he feels due to his mother’s death has affected his life and created more problems, respondents in this pattern stop their consideration at the point of anxiety occurring and do not consider any further impacts. In other words, the “problem” they are considering for this question is not the impact on their environment or social situation, but *rather the anxiety itself*.

For example, one respondent who answered “none at all” explained that although he had some money issues, that the internet and gas could be potentially cut off; he was not overly worried about these things. Likewise, another respondent (who answered in the affirmative to the question) mentioned financial issues:

I’m pretty even keeled, not too much upsets or worries me. But there’s always just—general anxiety. I do live pretty close to the edge financially, so one big bill could. I don’t think about it too much, but it’s there. I don’t think about it a lot, but one big bill could really set me back.

Other respondent brought up family matters, and explained that they caused them to worry. One lady mentioned that she worried that her son was not trying hard enough to get a job, and although it “was on him” to find one, because she is his mother she is a little concerned for him.

Reference Period:

Again, the respondents carried forward the reference period from the last few questions, and considered their current lives without regard to the 30-day limit.

26. Please continue to consider your health and people who help you, any assistive devices you use or any medication you take. Is getting along with people who are close to you, including your family and friends, a problem for you?

Construct Interpretations:

There is a large amount of variation in the respondents’ interpretations of Question 26, with multiple respondents applying all three pathways of the Functioning Schema. In general terms, these patterns function much like what was seen in the above questions: responses from the Health Status pathways considering how their health conditions lead to social problems or affect their environmental situation, whereas responses from the Only Environmental Context pathway considered only the outcomes or how those outcomes lead to other problems.

The construct “people who are close to you” had a relatively tight interpretation, with all respondents sticking to the frame of “family and friends,” with a majority of respondents thinking about family.

Only Health Status – Normalcy: A number of respondents used the Normalcy pattern when interpreting the question, and did so in a way that should be familiar by now. These respondents understood the question to be asking about their ability to “get along” with, or “talk to” the people who are close with them. They then answered using the negative response category “none at all,” having determined that they had that ability to be social in a normal way.

Both Status and Context – No Aid: In the few cases where this pattern was employed, the respondents considered how their health conditions—framed by the conditions covered in the Aid Questions and the previous Functioning questions—could or did impact their ability to interact with their family and friends. This pattern again follows the general form of: a health condition leads to a problem or outcome.

For instance, one woman reported that sometimes the pain she’s in because of her disability makes her “cranky,” and she knows that it is difficult for her friends and family to deal with her at those times.

Only Environmental Context – Willfulness: A couple of individuals applied this pattern of interpretation to their response, and both cases were thinking about how they do not like to be around other people that much—including their friends and family—and therefore limit the amount of interaction they have. They are not considering a health status here—both respondents note that they could have more interaction, they just *choose* not to.

Only Environmental Context – Other Person: This form of interpretation was dominant among individuals respondent to the question in the affirmative. These individuals did not consider their health status at all, and simply think about their environment. Thus: a condition does not cause a problem, a problem causes a condition.

Here, the respondents were specifically thinking about their issues with family members or friends, and how those people's behaviors made them not want to, or even unable to, interact with them. One example comes from a man who was annoyed at the fact that his extended family rallied around another family member in prison, but do not seem to care that his son is the first member of the family to go to college:

I have a nephew who went to jail, and my family rallied around him. Now my son, when he graduated, is going to college. And it wasn't a big thing [to them]...So I basically came to the conclusion that it's a dysfunctional family. Why would they rally around someone who's going to jail, and my son is going to college and nobody help...and he's the first person to go to college, and nothing. So I don't even know how to deal with them, how to talk to them...first one in the family to go to college, and nobody rallied around him. So I've been avoiding them, avoiding my brother's calls.

Most respondents who used this pattern explained that they found the people they were thinking about to be "irritating," and that it was best to just avoid interacting with them.

Reference Period:

The respondents continued considering their current circumstances instead of a strict time period. One good example of this was from a respondent who noted that after his injury, he found it difficult to interact with his family and close friends. However, this respondent answered "none at all," and in explaining noted that:

It used to be, for some time after I got hurt. But I've learned. I've come to understand. I think it was more me than them. I pulled away, I didn't...I didn't want to go out, I didn't want to do. It was a mental thing more than anything...But that's fallen away, I'm fine. Whatever it was, I'm socializing now.

So his current circumstances of improved health are in a different era of his life than the injury a couple of years ago.

27. Does dealing with people you do not know pose a problem for you?

Construct Interpretations:

While Question 27 and Q26 share similar constructs (interaction with strangers and interaction with friends and family, respectively), there was a much wider interpretation of Q27 and therefore more variation was observed across the respondents.

It appears as though this diversity is due in large part to how the respondents conceptualized the core construct of “people you do not know” as compared to Q26’s “people you are close to.” This latter construct, tightly framed by the “friends and family” examples give in the question text, seemed to focus the respondents in on a small number of people who shared similar roles in a number of the respondents’ lives. “People you do not know,” on the other hand, is clearly a wider category. While most respondents defined this phrase as “new people” or “strangers,” those social contexts in which the interactions the question is asking about ranged from bus stops to work to parties.

Only Health Status – Normalcy: In somewhat of a shift from the previous questions, this pattern was used by only one respondent (but still by someone who answered the question in the negative). The basic conceptualization of the health status—the ability to get along with people—remained the same from Q26.

Both Status and Context – No Aid: A number of respondents applied this pathway, with most answering the question using the negative answer category “none of the above.” In this question, as compared to the previous one about “people you are close to,” more respondents went beyond the simple normalcy statement (as in the respondent mentioned directly above) and went on to consider outcomes and their environment as well. In fact, all but one of the respondents who employed this pattern of interpretation in Question 27 used the “Only Health Status—Normalcy” pattern in Question 26.

These respondents not only talked about their ability to be social, but also considered either the outcomes of that ability or the hypothetical outcomes for someone who does not have that ability. For instance, one respondent explained that she is a “people person,” and went on to explain how this allows her to be active in advocacy and how this gives her the opportunity to talk with lots of people.

Only Environmental Context – Environmental Evaluation: This pattern was actually the dominant one for those respondents who answered Q27 in the negative. Semantically, the best marker that differentiates this pattern from the above one is that in the No Aid (and the Normalcy) pattern, people stated that they were something, whereas in the Environmental Evaluation pattern they stated that they did something. So, while in the last example above, the lady noted that she *is* a people person; one male respondent employing this pattern noted that he “easily meets new people and engages in conversation.” Thus, these respondents are focused not on their status or attributes, but rather on what they can do.

Only Environmental Context – Willfulness: With the exception of one individual who applied the No Aid pattern, all the respondents who answered in the affirmative used this pattern of interpretation. Just as seen in the Q26, when contemplating this question, some respondents thought about how they did not like to interact with strangers, and therefore did not have a problem with them. Again, they have the *capacity* to interact with others, they just simply choose to not do so.

Reference Period:

There was a small amount variation in the reference period for Q27 that was not evident in the previous questions. While most respondents stuck to the standard interpretation, and carried the reference period from the last question forward, a few respondents thought about past experiences that they were no longer having (such as being at work) to answer this question. For example:

I mean, when I worked, I got along with everybody. I'm a pretty easy guy. You always find some co-worker you don't like, but I get along with most people.

As this respondent has not worked for a few years, this is clearly outside the respondent's "current circumstances." This small amount of variation is probably due to the fact that this type of interaction—"dealing with people you do not know"—is less salient to some respondents than interacting with friends and family.

29. Is having an intimate relationship a problem for you?

Construct Interpretations:

Most people considered only their environmental context and social situation in Question 29, and very few considered any health status whatsoever.

Likewise, there was not much variation in the interpretation of the core construct—"intimate relationship." While some few mentioned family and close friends, the vast majority of respondents were thinking about significant others (including spouses, boyfriends, and girlfriends) and sex.

Both Status and Context – No Aid: Two respondents considered both their health statuses, and how those statuses impacted their ability to have an intimate relationship. The respondent who answered the question with the category "none at all" explained her thinking by saying:

It's as natural as it ever was!

She thus determined that her health condition (age, as she was 80 at the time of the interview) did not cause a problem in her social situation (having sex).

Only Environmental Context – Environmental Evaluation: By far the dominant interpretation of this question, in the Environmental Evaluation pattern respondents focused only on the outcome they perceived "having an intimate relationship" was asking about. Some respondents understood this to be asking about whether or not they were in (or could be in) a relationship. For example:

The relationship might not last, you never know. But that's not a problem.

This respondent was thinking about whether or not he could get into a relationship, and went on to comment that he has never "had a problem with that" either.

Most respondents focused not on the presence or absence of an intimate relationship, but rather on its quality. For example, one respondent who answered in the affirmative to this question was thinking about a bad past relationship:

Yes, I had an abusive relationship 15 years ago, and my trust level is down about the opposite sex.

That bad relationship in the past has affected her trust. She used this past event to note that her current relationships are not of the same quality as before this happened. Another respondent who answered using the category “yes to some extent” mentioned that he was looking to break up with his girlfriend of seven years:

The relationship I’m in now, I’m not happy with. But we’ve been in this situation for a long time, and we’re used to it and comfortable with it. But I want to get out.

The “some” amount of problem he was having was not on his ability to have a relationship, but rather a rating of the quality of his current relationship.

Only Environmental Context – Willfulness: One respondent applied this pattern of interpretation to the question of intimate relationships. This pattern again emerged as one of choice, with the respondent deciding that he did not want to have an intimate relationship (which he understood to be a sexual relationship) at the moment, while insisting that he was capable of doing so.

Reference Period:

The variation observed in the last question in regards the reference period was not present in Q29, with all the respondents again considering their current circumstances.

30. Is handling stress, such as controlling the important things in your life a problem for you?

Construct Interpretations:

The respondents interpreted this question similar to the ways they did the anxiety question, Q25. Most of the respondents considered their environmental context in some way, with a majority not thinking about a health status in any way.

As seen in the other Functioning Questions with similar core constructs (Q24 with depression, Q25 with anxiety, and the next question, Q31 with coping), there were two basic ways the respondents perceived the “problem” in this question. Those respondents who considered their health statuses (the Only Health Status and the Both Health Status and Environmental Context pathways of the Functioning Schema) understood the problem that the question was asking about to be a result of health-related stress. On the other hand, those respondents who only focused on their environment understood the problem to be stress, which was a result of some environmental or social situation.

It should be noted that most of the health-related issues that respondents cited were ones that had already been asked about in either the Aid or the Functioning Questions.

Only Health Status – Characteristic: One respondent only thought about his health conditions, and did not consider how they impacted his social environment. This respondent noted he smokes, but when he has tried to quit, it makes him stressed and angry, so he gave up trying.

Both Status and Context – No Aid: A few respondents explained that they tried to deal with their stress before it impacted their life too dramatically. All of these respondents noted that they “just dealt with” the stress, to varying degrees of success.

One respondent noted that he sometimes experiences stress so bad that “it makes me want to cry,” but he still answered “none at all.” When asked why, he compared his current state to what he had been dealing with in the past, and noted that things were much better now.

Both Status and Context – With the Aid of a Device: A pair of respondents considered not only their health conditions, but also the medicines they take to control them when answering this question. In both cases, the respondents noted that their medicines allow them to control their illnesses, and therefore their stress, and go about their lives. As such, both of these respondents answered “none at all” to this question.

Only Environmental Context – Environmental Evaluation: This was the most common pattern of interpretation across both negative and affirmative responses to the question. Generally speaking, these respondents considered their *stressors* and evaluated how stressed they became because of these situations.

There was little agreement over what constituted a stressor, with some people considering family obligations and others considering their jobs or financial situations. Those respondents responding in the negative to Q30 tended to explain how they managed or did not let their stressors “get to them.” For example, one respondent who was thinking of the array of stressors he faces by raising his 4-year-old daughter by himself answered “none at all” and explained:

I always try to keep a level head, even in stressful situations. I can always find a solution...I got it together.

Those respondents who responded in the affirmative said similar things, but explained that they did not always succeed. One woman who answered “yes a little” explained that she likes “to be in control,” but because she could not always be, she was a little stressed.

Only Environmental Context – Other Person: In this case, this pattern is nearly the same as the Environmental Evaluation one, but the stressor in this case is the behavior of a specific person, or specific people. For instance, one respondent explained that avoids stress by staying away from people he knows will stress him out.

Reference Period:

The respondents all found salient examples by considering their current circumstances, and tended to think about things that had occurred in the last few months.

31. Is coping with all the things you have to do a problem for you?

Construct Interpretations:

The respondents tended to understand this question, about coping, to ask something very similar to the previous question (Q30), which was about stress. In fact, a number of respondents noted the similarity and gave nearly the same explanations for their answers across the two questions. One major difference between Question 31 and Q30, however, was the decrease in number of people considering their health status. No respondents used a pattern of interpretation from the Only Health Status pathway in the Functioning Schema, and only a handful used the Both Health Status and Environmental Context one. This is certainly due in part that it is harder to conceptualize the core construct of Q31—“coping with all the things you have to do”—as a health issue than it is to do the same for “stress.”

The respondents had a very wide interpretation of this construct of coping, however. Across the sample, the respondents reported thinking about:

- Doing dishes
- A friend getting shot
- Visiting friends
- Mowing the lawn
- Keeping up with their calendar
- Finding transportation
- Cooking
- Surgery
- Going to the doctor or hospital
- Maintaining their car
- Taking their medicine
- Making it to appointments on time
- Having a messy bedroom
- Their job

This is a very wide pattern of interpretation, containing items from a number of common cognitive domains. As such, it contributes to variation and could be responsible for false positive answers.

Both Status and Context – No Aid: Similar to the pattern of interpretation above in Q30, some respondents explained that they attempted to cope with things before they had a negative impact on their lives. Unlike the last question, however, the only people to use this pattern were individuals who responded to the question using the negative “none at all” answer category.

All of these respondents were thinking about adopting a mindset that allowed them to deal with and move past whatever was troubling them. For example, one respondent who suffered from sickle cell anemia explained that at some point, he simply decided that he would adopt the mantra “quality over quantity” in regards to his life, and stopped letting things bother him so much.

Both Status and Context – With the Aid of a Device: One respondent considered how his medication allowed him to cope with the various issues in his life. This respondent was thinking about an anti-depressant, which was the same medication he considered for the stress question.

Only Environmental Context – Environmental Evaluation: These respondents rated how their environmental context and social situation affected them. While in the last question these respondents considered and evaluated their *stressors*, in this case they considered and evaluated their *hassles or obstacles*. For example, one female respondent explained how she has to deal with, and plan her schedule around, the transit system:

Well just that scheduling and getting there...it's just something that it's an inconvenience that you have to deal with, it's frustrating sometimes. Like when the bus is late or it breaks down and doesn't come. So you're standing there at the bus stop for 45 minutes.

Respondents tended to focus on one or two major sources of hassle in their lives and evaluated whether or not it was something with which they had to “cope.”

Reference Period:

Just like with the last question, the construct “coping” was very salient in the respondents’ lives, and they all answered thinking about examples from their current circumstance.

32. Please remember to consider your health and people who help you, any assistive devices you use or any medication you take. Is forgetfulness a problem for you?

Construct Interpretations:

There was much more variation in how the respondents answered Question 32 than in the last few questions and all three pathways in the Functioning Schema are present. The core construct of “forgetfulness,” has two clear interpretations, which contributed to this overall variation. The first interpretation is that forgetfulness is a condition that leads to problematic outcomes; whereas the second is that forgetfulness was a problem in its own right. The first form of interpretation was used by the respondents who used the two “Health Status” pathways, while the second was used by the respondents who used the “Only Environmental Context” pathway.

Only Health Status – Normalcy: A couple respondents applied this pattern to their response, reporting that they were not forgetful, or that they did not forget things. Clearly they forget something sometimes, but recall that these respondents are interpreting “forgetfulness” as a health condition. By saying, as one respondent did, that he “doesn’t really forget things,” he means that he is not a *forgetful person*.

Both Status and Context – Without an Aid: One respondent, who answered the question in the negative, notes that he has a mental system down to stop him from forgetting things. This respondent noted that he did have a calendar, but that he chose not to use it because his system worked so well.

Both Status and Context – No Aid: The two respondents who employed the No Aid pattern for Q32 had an interesting interpretation of the health condition “forgetfulness.” Both of these

respondents talked about how they had difficulty learning—forgetting new concepts. For example, one gentleman reported that:

Forgetting someone’s name that I maybe met a week ago, or forgetting a coworker’s name. Or forgetting how to do a task, if it’s a new task. I have to keep iterating until I get it...I’m not the type that can read something once and pick it up.

Both of these cases resulted in affirmative answers, though the two men discussed different ways of dealing with this form of forgetting. While the gentleman above went on to explain that he would re-read things two or three times until they stuck in his memory, the other man said that he has simply given up trying to learn whole classes of new things, such as how to use computers.

Both Status and Context – With the Aid of a Device: The most common pattern of interpretation among the respondents who consider forgetfulness to be a health condition was to explain how they used some device to battle their forgetfulness. Most respondents explained that they would jot down notes or keep calendars to remind them of important things, such as appointments and shopping lists. Most of the respondents who answered this way responded to the question in the negative, but the one who responded in the affirmative simply noted that sometimes she missed writing something down. If she didn’t, things tended to go “in one ear and out the other!”

Besides writing notes and keeping a calendar, two respondents also mentioned that they were on medicine that helped them stay focused and remember more things.

Only Environmental Context – Environmental Evaluation: All but one of the respondents who used the second interpretation of forgetfulness—that it was a problem in and of itself, and not an inherent condition—used the Environmental Evaluation pattern. These respondents reported the various situations in which they forgot things and then judged whether or not that forgetfulness was a problem.

Only Environmental Context – Other Person: As seen in some of the previous questions, the Other Person pattern of interpretation is a specific modification of the above Environmental Evaluation one where the respondents consider how the actions of other people affect them. In this case, one respondent explained his affirmative response by talking about how his girlfriend forgot things—such as appointments and bills—that made his life more difficult.

Reference Period:

The respondents all carried the reference period forward from the last question and answered Q32 about recent events, usually in the weeks prior to the interview.

33. Does remembering to do the important things in your day to day life a problem for you?

Construct Interpretations:

This question was understood by nearly all the respondents to be asking the same thing as Q32, and in turn they carried over all of their interpretations from the previous question into Question 33.

Some respondent, upon probing, said that they understood there was a difference between the two questions and noted that Q33 was probably asking specifically about “appointments” or “medicine.” However, since there was no frame around Q32, most of the respondents had already considered seemingly important things—such as doctor’s appointments, taking medicine, and paying bills—before they ever reached Q33.

For specific analysis on the various patterns of interpretation and the reference period, please see Question 32.

34. Does getting your household tasks done pose a problem for you?

Construct Interpretations:

All the respondents considered their environmental context in some way when answering Question 34, while only a few considered their health status as well. The core construct of Question 34, “household tasks” was clearly understood by the respondents to be referring to actions such as cleaning, doing laundry, and cooking.

Both Status and Context – Does Not Do: In a very interesting case, one respondent answered the question using the negative response “none at all.” When asked to explain her answer, she said: [3804]

Cleaning, washing. But I have an aide. And she does the majority of that, so it’s not a problem for me.

The respondent interpreted this question to be asking about the *personal* effort or difficulty she had doing these tasks. Since she has a home health aide who does all her housework, the respondent experiences no difficulty whatsoever.

What makes this case stand out, is that another respondent also thought about how her home health aide helped her out with household tasks, saying that she “...cleans, washes dishes, and does the laundry”—all tasks that this respondent notes she cannot do by herself. However, this respondent answered the question with the affirmative, “yes to an extreme extent.”

So in the first case, the respondent reported experiencing no difficulty because she was considering her aide’s assistance; whereas in the second case the respondent reported experience extreme difficulty *in spite* of the assistance.

Both Status and Context – No Aid: This pattern follows the same form here as it does in the previous questions, with respondents thinking about how their health condition, or how a

hypothetical health condition, impacts their ability to do household chores. These respondents did not mention the use of any aids or modifications that could lessen this impact. Instead, they simply reported how conditions, such as arthritis, slows down their chores or how they have to be careful not to hurt themselves.

Only Environmental Context – Environmental Evaluation: The Environmental Evaluation pattern was dominant across respondents answering “none at all” to Q34. They considered a household task that they do, and then evaluated whether or not getting it done is difficult. In doing so, these respondents did not think about their health status, but rather judged their actions against some internal standard.

For example, one respondent evaluated the amount of time it takes him to do his chores, and explained that it was not a problem because he was a “house husband,” who stayed home during the days. Others considered the quantity of tasks they tend to have, or how well they get them done.

Only Environmental Context – Willfulness: A number of respondents who answered the question in the affirmative applied this pattern of interpretation, which as in previous questions emerged here as a judgment on *choice*. These respondents all noted that their choices they made increased the difficulty of getting their chores done.

This choice was usually reported as “laziness” or “not caring.” One respondent who lived alone, explained that since he had no housemate to check him, and because he did not feel like going to the basement laundry room, he would simply buy new undergarments every two weeks or so instead of doing the laundry. This was not a matter of ability, as the respondent noted that when he lived in another house with its own washing machine he did the laundry frequently.

Reference Period:

Since household tasks are very salient activities, the respondents all considered examples from their present circumstances when answering the question. Most respondents mentioned activities that occurred in the past week.

35. Is managing your money a problem for you?

Construct Interpretations:

There was remarkable agreement across the respondents’ interpretations of Question 35. Almost all the respondents understood this question as asking them to evaluate their financial situation. On the other hand, only two respondents thought about a health status or condition would affect their financial condition.

There was some variation, however, across how the respondents interpreted the core construct of “managing money.” Some people considered their entire financial situation—including debt, credit, and savings. Most respondents, though, only thought about their ability to pay bills. This last interpretation in particular has the potential to lead to false negative answers, when used with the Environmental Evaluation pattern, as explained below.

Both Status and Context – No Aid: A couple of respondents applied the normal form of this pattern, considering how their health condition (or a hypothetical one) could impact their ability to pay their bills. Of these respondents, one answered in the affirmative, and was thinking about how her ADD made it difficult for her to remember to pay bills. The other respondent answered in the negative and thought about how a cognitive impairment could make it difficult for people to manage their money, though he himself was not cognitively impaired.

Only Environmental Context – Environmental Evaluation: Besides the two respondents mentioned above who used the No Aid pattern, everyone else employed the Environmental Evaluation pattern when considering their answer to Q35. These respondent thought about the act of managing money and evaluate how successful they were at doing it.

As noted above, the interpretation of the core construct of money management varied a bit, which had a corresponding impact on the way the respondents thought through the question. For example, some respondents thought about money management holistically, taking everything from paying bills to staying out of debt to building credit and savings into account. One respondent who answered “none at all” revealed during probing that he was thinking about how he budgets and saves, and thinks he does a fine job. Another respondent answered “yes a little” and explained that while she does a good job budgeting, she did not think she did a good enough job saving.

Other respondents focused only on one aspect of money management, most often paying bills. One gentleman who answered in the affirmative explained that he had a really hard time prioritizing expenses:

I just can't manage money...Not having enough to do what I have to do, and I'm not working so my income isn't continuous. And then prioritizing, like if something important is coming down the road, but I just keep spending. And then when it comes up, I'm like: "I had this money!"

Likewise, another respondent noted that she can pay her bills, so she answered “none at all.” Interestingly however, this respondent went on to talk about how she did not have a lot of money, and was only scraping by. This was a common sentiment. For instance, another respondent who was on food stamps and received a public benefit that gave him cell phone calling minutes, also answered “none at all,” explaining that he has no trouble managing his benefits to stretch the entire month. In these, and other similar cases, the respondents reported a negative answer because they judged that their financial situations could be worse. In fact, it appears as though the standard that they were evaluating themselves against was bankruptcy or default. This pattern could easily lead to false negative responses.

Reference Period:

The respondents were all thinking about their normative actions in the current circumstances. Very few respondents cited individual examples of money management; rather they thought about how they generally were able to pay bills, save, and avoid debt at present.

36. Is doing things for relaxation or pleasure in the same way as anyone else can a problem for you?

Construct Interpretations:

One of the most important things to note about Question 36 is the lack of diversity in the *answers* to this question. Of all the respondents who received it, only one person answered in the affirmative, with the rest answering “none at all” or “don’t know.”

As one might expect given this lack of separation between the respondents in the survey answers, there was also very little variation in the interpretations behind these responses. Similar to the other two household questions (household tasks and money management), no respondent used the “Only Health Status” pathway, and only two respondents employed the Both Health Status and Environmental Context pathway and considered how a health condition might impact one’s ability to relax.

As to the core construct of “doing things for relaxation or pleasure,” most respondents understood this to mean “things you enjoy doing.” While the examples obviously varied across the sample—from eating ice cream to clipping coupons to watching sports—this variation was cosmetic and did not affect the overall interpretation of the question

Both Status and Context – No Aid: Again, a pair of respondents considered how a health condition might impact their ability to relax. In one of these cases, the respondent answered in the negative, and then went on to explain that his illness has stopped him from enjoying a lot of the things that he used to enjoy. When asked why he answered “none at all,” he replied that he could still *do* those activities, he just doesn’t want to anymore because of his illness—potentially a false negative response.

The other respondent interpreted the question in a similar way, saying that he enjoys dancing. However, his arthritis makes it hard from him to dance much anymore, so he responded to the question in the affirmative.

Only Environmental Context – Environmental Evaluation: This was again the dominant pattern of interpretation across the sample for Q36. In this case, respondents were evaluating whether or not they had the ability to do enjoyable activities.

In most cases, the respondents ignored or did not know what to do with the instruction in the question text, “the same way as anyone else can.” These respondents returned to the same mode of evaluation seen in the previous few questions—comparing themselves against a hypothetical standard in their mind. In most cases, this standard was constructed as a binary—“are you able to do something you enjoy” or “are you not able to do something you enjoy.” This black and white judgment might explain why there were so few affirmative answers to this question—as long as a respondent could do something they enjoyed, no matter the quality or frequency, they would evaluate themselves as not having a problem.

While most people ignored the instruction to compare themselves to others, a few respondents did, though there was no apparent standard across these cases. For example, one respondent compared her ability to go out and get coffee to the worse-case scenario—“people with psychological issues that force [them] to stay in their homes.”

On the other hand, another respondent compared himself to the best-case scenario. This respondent explained that he liked watching sports, and determined that the best sports-watcher could watch 4 or 5 games in a row. While he judged that he could “relax” to that level, he still answered “none at all” because he could watch some games.

Only Environmental Context – Willfulness: Just as how it emerged in previous questions, this pattern of interpretation dealt with the respondents’ *choices* to not relax. These respondents explained that they did not like being in crowds or hanging out with other people, and instead found other ways to relax and enjoy themselves on their own.

Reference Period:

Doing enjoyable things was a salient concept for the respondents, and they all carried the reference period from Q35 forward. They answered about normative events in the current, everyday life and did not cite many specific examples.

Response Difficulties:

There were a number of response difficulties observed during the administration of this question, most of which appeared to center upon the instruction in the question text to think about relaxation as compared to “the same way anyone else can.” This instruction led to requests for repeated readings, interpretation difficulties, and item drop-outs.

The interpretation issues surrounding this question are explained above in the Environmental Evaluation section, but they obviously have at least the potential to lead to false negative or false positive responses (depending on whether the respondent compares him or herself against the best-possible or worst-case scenarios).

What is perhaps more important than the potential for false responses is the potential for item drop-outs. Two respondents answered the un-read response “don’t know” to this question. When asked to explain, both expressed confusion and frustration over the comparison instruction, questioning how they were supposed to know what other people did to relax and how well they did it. For instance, one of the respondents said he could not answer the question because:

I don’t know how to interpret that: I can’t relate to how other people do it.
Everybody finds different ways to relax.

37. Please remember to consider your health and people who help you, any assistive devices you use or any medication you take. Does providing care or support for others pose a problem for you?

Construct Interpretations:

While there was more differentiation between the respondents' answers to Question 37, there was almost no variation in their interpretations behind these responses. Only one respondent considered their health status, with the rest thinking only about their environment and social situation.

There was also very little variation around the interpretation of the core construct of "providing care to others." Most respondents thought about their family or close friends, though a few individuals did mention pets or more casual acquaintances.

Both Status and Context – No Device: One respondent considered how she babysits for her grandchild, but has to also take her medicine at the same time. She reported that she had no trouble doing so, and simply ducks into the bathroom to take her pills. She was not thinking about the medicine as an aid that helps her provide care in this case.

Only Environmental Context – Environmental Evaluation: The rest of the respondents applied the Environmental Evaluation pattern to their responses, thinking about the types of care they provide and whether or not they had difficulty doing it.

One of the most common forms this pattern took in Q37 was for people to simply explain that they did not provide care to anyone, thus evaluating that they had no problem doing it. Some respondents explained that they lived alone and did not need to care for anyone besides themselves, while others thought about how their children had grown up and moved out of the house. For example:

Well I don't have any need to, it's not applicable. My days of taking care of my kids are long gone...I don't really do that.

Others did mention that they had people (or pets) to care for, and followed the normal Environmental Evaluation pattern to determine whether or not they had a problem by comparing their behavior to some hypothetical standard. For instance, one gentleman who answered the question in the affirmative explained that he did not always have the money to provide the amount of care he wanted, or felt like he needed, to give.

Reference Period:

The respondents continued to carry the reference period forward from the previous questions, and answered about their current circumstances.

38. Is applying for and getting a job in the same way as anyone else can a problem for you?

Construct Interpretations:

There was a slight bit more consideration of health status by the respondents in Question 38 as compared to Q37, but again the majority ignored it and focused only on whether and how they could "get a job."

There was variation around this core construct, however. While most respondents understood the question to be asking about applying for a job, the specific issues they considered when thinking about what would or would not prevent them from getting and holding a job diverged. Some respondents mentioned their age, while others mentioned their work history. Others focused on past problems, such as criminal convictions, that would hamper their ability to get hired now. Still others thought about their qualifications for specific careers, and how those qualifications would compare with others.

Both Status and Context – No Aid: Two respondents employed the No Aid pattern when considering their response to Q38, both of whom answered in the affirmative. These respondents reported that they had health conditions (and eye issue and bipolar disorder) that prevented them from either working, or from getting the jobs for which they believed they were qualified. In one case, the respondent noted that he could hold some jobs, but only ones that he clearly thought were below his abilities.

Only Environmental Context – Environmental Evaluation: With the exception of one other respondent, who used the Willfulness pattern, the rest of the respondents applied the Environmental Evaluation pattern of interpretation to their responses. The general form is the same as in previous questions—respondents attempted to evaluate how much of a problem they would have getting a job without taking any health status into consideration.

As noted above, however, there was not a tight interpretation of the core construct; consequently, there was some variation in how this pattern emerged here in Q38. A number of respondents thought about personal issues—work and life histories—that would or would not make it more difficult to find a job. For example, one male respondent thought about when an incorrect arrest (that was later expunged) made him un-hirable. Even though the police wrongly arrested him, it took a long time to remove it from his record and during that time, employers would not consider him for a job.

A number of other respondents thought about their qualifications for specific jobs or careers. One lady, who answered in the negative, explained that in the past when she was looking for work, she never had a problem:

I usually get a job if I apply for it.

She said she was not comparing herself to others, just thinking about her own abilities and qualifications. Other people who thought about qualifications were comparing themselves to other people. For example, one man who answered in the affirmative explained that if he was applying for a job and competing against people who were more qualified than him, then he would have a problem getting that specific job.

Only Environmental Context – Willfulness: One respondent explained his affirmative answer by saying that he sometimes lacked motivation to find work. He noted that in the past it had always been easy to find a job, but recently as the economy tightened and it became harder, he “backed off” and stopped trying so hard to find one.

Reference Period:

The reference period for Q38 varied greatly, with some respondents continuing to answer about their present circumstances (as with the above example of the un-motivated job seeker), and others thinking about the past. This latter way of thinking about the question was particularly noticeable among the older respondents—people who were in their 50s and above. Many of these respondents were retired or out of work due to a disability or injury, and therefore had no recent salient examples in their lives to consider.

39. Is getting things done as required at work a problem for you?

Construct Interpretations:

There was a more even balance of respondents who considered health status with those who only thought about their environment in Question 39, as compared to the previous question, which was also about employment.

Across the respondents, the core construct of “getting things done as required” was nearly universally understood to mean one’s job requirements. It is important to note that no skip instructions were used during the cognitive interview, and all of the respondents received all of the questions (time permitting). Thus, a number of individuals who reported in previous questions that they did not work still received this question—affecting the reference period and resulting in a number of false positive and false negative answers that would not occur if these respondents skipped Q39.

Both Status and Context – No Aid: A number of respondents considered their health statuses and how any condition they have might affect their ability to do what is required of them at work. These respondents, who answered both affirmatively and negatively to the question itself, tended to think about *how much* their condition affected their abilities.

For instance, one gentleman who answered “none at all” noted that he has mobility issues, but that they do not get in the way of his part time work. While they might bother him, he can work around them.

Others answered in the affirmative, and explained that their health condition limited what they could get accomplished. For instance, one woman noted that the pain she has due to her illness makes it difficult some times to grasp and pick up items around the office in which she works part time.

Only Environmental Context – Environmental Evaluation: Following the regular pattern, some respondents thought only about the core construct of “getting things done as required” and then evaluated whether or not they were able to carry out their responsibility or if doing so was a “problem.” Most of the respondents who used this pattern of interpretation answered the question in the negative. One gentleman judged his abilities in a straight forward manner:

I go, clock in...and then I’m done. I don’t have any problem.

The one respondent who answered in the affirmative seemed to misinterpret the core construct, apparently believing that the question was asking if she only got the things done that were required of her. In explaining her “yes a little” answer, she said that at her last job she was almost always able to get all of her own work done and then also helped out others with their jobs.

Reference Period:

As noted above, because there was no skip pattern, individuals who were not currently working at the time of the interview received this question alongside those who were currently working. While the latter group considered recent examples from the present jobs, those in the former group tended to think about the last job they held—regardless of how long ago that was.

40. Does using public or private transportation pose a problem for you?

Construct Interpretations:

No respondents considered their health status when answering Question 40, considering their environmental and social situation first and foremost. This is not to say that nobody mentioned a health condition, but rather that all the respondents *based their answers* on their perceptions of their environment and not on how their health status impacts their functioning.

The core construct in this question, “public or private transportation” is the same as seen in the Use Schema in Q8. The respondent thought about both their access to private vehicles such as cars, and to the transit system. As has been mentioned before, because the sample was pulled from the Washington, DC metropolitan area—home to an extensive transit system—this form of transportation was the most salient, and almost all the respondents considered the Metro or Metrobus system.

Only Environmental Context – Environmental Evaluation: With the exception of two cases discussed below, all of the respondents employed the Environmental Evaluation pattern of interpretation. In doing so, they understood Q40 to ask them, “How good or reliable is the transit system or your car?” These respondents mainly considered their use of the Metro system and then evaluated whether or not *Metro caused them problems*.

For example, one respondent explained his affirmative answer by talking about how he uses buses more than the subway. He believed that Metro puts more effort into the subways lines, and as a result the buses are frequently late, causing him some problems. Another respondent spoke about her access to both friends’ cars and to MetroAccess. She evaluated that she had no problem getting where she needed to go because she had so many different modes available to her, and answered the question “none at all.”

Other respondents, perhaps due to framing from the previous few questions that explicitly asked for a comparison, compared their ability to use transportation against others’ abilities. For instance, one respondent explained that she found the Metro system was very convenient and usable, whereas someone who was a “cripple” or “someone who couldn’t figure out where to get

off [the train]” would not. By evaluating her behavior to this “worse-case” scenario, the respondent judged that she had no problems, and answered the question in the negative. Still other respondents based their responses on a simple rating of a mode of transportation or evaluated how convenient that mode was. One man who answered “none at all” explained his answer saying:

It’s easier to use the metro than to walk!

Another respondent explained his negative answer by talking about how easy it was for him to get to the subway and how convenient the fare cards are.

Only Environmental Context – Other Person: A couple of respondents directly considered how the actions of other people made their transportation more problematic. Both of these respondents answered Q40 affirmatively, and were considering the MetroBus system. However, unlike the people above in the Environmental Evaluation pattern who evaluated the MetroBus system, these respondents were thinking about specific individuals or groups within that system.

For example, one of the respondents explained that she found it distasteful when people on the bus did not surrender their seats to the elderly or to people with physical disabilities. She thinks that these people are “so cold,” and their behavior upsets her. She answered the question “yes a little” because she doesn’t like being upset, but it does not stop her from taking the bus.

The other respondent also considered the accessibility aspects of the bus system, but again focused her response on the “rude bus drivers.” She believes they do not know or care about the proper procedures regarding disability, including issues of seating preference and when to lower the buses to make it easier to get on and off. As mentioned before, even though this respondent mentioned a health condition—physical disabilities—she based her response not on how that health condition made transportation more difficult, but rather on how specific people in the transportation environment made transportation more difficult.

Reference Period:

As transportation was a very salient aspect of the respondents’ lives (they all had to get to NCHS to participate in the interview), they based their responses on normative events in their present situations. While most spoke generally, when they did provide specific examples they tended to be from within the 30 days prior to the interview.



MODEL DISABILITY SURVEY



MODEL DISABILITY SURVEY

Questions selected for 1st round
cognitive testing

Section 3000: FUNCTIONING

In this section I want to understand the kinds of problems you experience in your life.
By problems I mean not getting things done or not getting things done in the way you want to.

These problems may arise because of your health or because of the environment in which you live.
These problems may also arise because of the attitudes or behaviours of people around you.

Let us start with people or things that may assist you and the environment in which you live.

1	Do you use any mobility aids [e.g. cane, crutch, wheelchair, walking frame, prosthesis or orthopaedic devices] or aids for self-care [e.g. hand, arm brace or grasping tool]?	1 Yes 5 No	
3	Do you use any hearing or communication aids?	1 Yes 5 No	
4	Do you take any medication on regular basis such as for pain, sleep disturbances or high blood pressure?	1 Yes 5 No	
5	Are there any aids or modifications that make it easier for you to work, such as a computer with large print or voice recognition, adjustable height desks or modified working hours?	1 Yes 5 No 9 <i>Not applicable</i>	
6	Are there any aids or modifications that make it easier for you to get an education, such as portable spell checkers, extra time for exams or accessible classrooms?	1 Yes 5 No 9 <i>Not applicable</i>	
7	Are there any modifications that make it easier for you to be at home, such as ramps, grab bars, or any other accessibility features?	1 Yes 5 No	
8	Are there any modifications that make it easier for you to participate in community such as accessible public transportation or accessible public toilets?	1 Yes 5 No	
9	Do you have someone to assist you with your day to day activities at home or outside?	1 Yes 5 No	→ if 5, go to I3012

Let us continue with the problems you experience in your life.

For all the questions I am now going to ask you, please think of people who help you, any assistive devices you use or any medication you take.
Please think about the last 30 days taking both good and bad days into account.

		1 NOT AT ALL	2 YES, A LITTLE	3 YES, TO SOME EXTENT	4 YES, TO A MODERATE EXTENT	5 YES, TO AN EXTREME EXTENT	8 Don't Know
MOBILITY							
14	Is engaging in vigorous activities, such as exercise or sport a problem for you?	1	2	3	4	5	8
15	Is getting where you want to go a problem for you?	1	2	3	4	5	8
16	Is getting out of your home a problem for you?	1	2	3	4	5	8
SELF-CARE							
18	Does eating and drinking pose a problem for you?	1	2	3	4	5	8
19	Is looking after your health, eating well, exercising or taking your medicines a problem for you?	1	2	3	4	5	8
Once again, please consider your health and people who help you, any assistive devices you use or any medication you take.							
HEARING							
20	Is hearing what is said in a conversation with another person in a quiet room a problem for you?	1	2	3	4	5	8
21	Is hearing what is said in a conversation with another person in a noisy room a problem for you?	1	2	3	4	5	8
PAIN							
22	Is having pain a problem for you?	1	2	3	4	5	8
ENERGY AND DRIVE							

		1 NOT AT ALL	2 YES, A LITTLE	3 YES, TO SOME EXTENT	4 YES, TO A MODERATE EXTENT	5 YES, TO AN EXTREME EXTENT	8 Don't Know
23	Does sleep pose a problem for you?	1	2	3	4	5	8
AFFECT (DEPRESSION AND ANXIETY)							
24	How much of a problem do you have due to feeling sad, low or depressed?	1	2	3	4	5	8
25	How much of a problem do you have due to feeling worried, nervous or anxious?	1	2	3	4	5	8
Please continue consider your health and people who help you, any assistive devices you use or any medication you take.							
INTERPERSONAL RELATIONSHIPS							
26	Is getting along with people who are close to you, including your family and friends, a problem for you?	1	2	3	4	5	8
27	Does dealing with people you do not know pose a problem for you?	1	2	3	4	5	8
29	Is having an intimate relationship a problem for you?	1	2	3	4	5	8
HANDLING STRESS							
30	Is handling stress, such as controlling the important things in your life a problem for you?	1	2	3	4	5	8
31	Is coping with all the things you have to do a problem for you?	1	2	3	4	5	8
Please remember consider your health and people who help you, any assistive devices you use or any medication you take.							
COGNITION							
32	Is forgetfulness a problem for you?	1	2	3	4	5	8
33	Does remembering to do the important things in your day to day life a problem for you?	1	2	3	4	5	8

		1 NOT AT ALL	2 YES, A LITTLE	3 YES, TO SOME EXTENT	4 YES, TO A MODERATE EXTENT	5 YES, TO AN EXTREME EXTENT	8 Don't Know
HOUSEHOLD TASKS							
34	Does getting your household tasks done pose a problem for you?	1	2	3	4	5	8
35	Is managing your money a problem for you?	1	2	3	4	5	8
COMMUNITY AND CITIZENSHIP PARTICIPATION							
36	Is doing things for relaxation or pleasure in the same way as anyone else can a problem for you?	1	2	3	4	5	8

Please remember to consider your health and people who help you, any assistive devices you use or any medication you take.								
		1 NOT AT ALL	2 YES, A LITTLE	3 YES, TO SOME EXTENT	4 YES, TO A MODERATE EXTENT	5 YES, TO AN EXTREME EXTENT	8 Don't Know	9 Not applicable
CARING FOR OTHERS								
37	Does providing care or support for others pose a problem for you?	1	2	3	4	5	8	9
WORK & SCHOOLING								
38	Is applying for and getting a job in the same way as anyone else can a problem for you?	1	2	3	4	5	8	9
39	Is getting things done as required at work a problem for you?	1	2	3	4	5	8	9
40	Does using public or private transportation pose a problem for you?	1	2	3	4	5	8	9

Health Insurance

Finally, I am going to ask you just a few questions about health insurance and healthcare coverage.

45	Do you have health insurance or health care coverage?	Yes	No	Don't Know
46	Is there a monthly premium for your health care coverage?	Yes	No	Don't Know
47	Was the cost of the premium subsidized based on [your/your family] income?	Yes	No	Don't Know