

Results of Cognitive Interview Testing of Adult Participation Questions for the National Health Interview Survey (NHIS)

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I. Introduction

This report summarizes the findings of a cognitive interviewing study designed to evaluate questions on adult participation that are included in the National Health Interview Survey (NHIS.) These questions were tested as part of a larger project that also tested questions on child disability for UNICEF/the Washington Group. The participation questions were initially developed as part of the Washington Group Extended Set of Questions on Functioning (ES-F.) The questions were designed as follow-up probe questions that were added to the field test instrument in order to capture some indication of the impact of the functional difficulty in a particular domain on ‘life activities.’ Subsequently, the questions were added to the 2010 NHIS to test their properties and attributes on a large, representative random sampled population. The current cognitive testing was conducted to in order to ascertain how the questions perform in this broader context. See Appendix A for a copy of the questionnaire.

This evaluation is based on 25 cognitive interviews that were conducted by the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS). Cognitive interviewing is a qualitative question evaluation method used to evaluate the validity of survey questions (Willis 2005; Miller 2011). The main goals of the project were to: 1) ascertain respondents’ interpretations of the survey questions and 2) identify any potential question response problems that could lead to response error in the survey data.

The following report is organized into four sections. Following this initial introduction, section two discusses the methods used in this question evaluation study, including the sample selection, sample characteristics, and interviewing procedure. Section two also summarizes the cognitive interviewing methodology and describes how data analysis was conducted. Section three provides a summary overview of the findings. Section four presents a detailed question-by-question review of the findings.

II. Methodology

Sample

A team of researchers conducted interviews with 25 individuals who met at least one of the recruitment categories. A purposive sample of respondents was recruited using newspaper advertisements, flyers, word-of-mouth, or by contacting participants from past QDRL projects. Respondents were recruited based on inclusion criteria for the testing of the child disability questions that were tested at the same time as the participation questions. The project recruited parents or guardians of children ages 2 to 17 who may have difficulties in the following areas: seeing, hearing, walking, learning, and/or behavior. Respondent demographics for the full sample are shown in Table 1. The sample was mostly female, non-Hispanic black, and had completed some schooling beyond high school.

Table 1: Demographic Profile

	N=25	Total (%)
Gender		
Female	18	72%
Male	7	28%
Age		
18-29	1	4%
30-39	6	24%
40-49	11	44%
50-59	7	28%
Hispanic/Non-Hispanic		
Hispanic	2	8%
Non-Hispanic	23	92%
Race/Ethnicity		
Black	15	60%
White	10	40%
Other	0	0%
Education		
Less than high school	0	0%
High school diploma/GED	6	24%
Some college	3	12%
Associate's Degree	3	12%
Bachelor's Degree	5	20%
Master's Degree	4	16%

Questions were evaluated using cognitive interviewing methodology. This is a qualitative method of question evaluation that can be used both to uncover potential response errors and as a means of assessing construct validity (Willis 2005; Tourangeau, Rips, and Rasinski 2000; (Miller, Willson, Chepp, and Padilla, *forthcoming*.) During the interviews, retrospective, intensive verbal probing was used to collect response process data. Given that two different sets of questions were tested in this project, respondents were retrospectively probed after each set of questions were administered. For each set of questions, retrospective probes included such things as: Why did you answer the way that you did? How did you arrive at your response? Can you tell me more about that? Can you clarify what you mean? Of the 25 interviews, 15 were conducted in the QDRL at NCHS, and ten were conducted off-site at locations convenient for the respondents. The 15 interviews conducted in the QDRL were video recorded and the ten interviews conducted off-site were audio recorded. Video and audio recordings and interview summaries were used to conduct data analysis. All interviews were conducted face-to-face. Interviews typically lasted 60 minutes and respondents were remunerated \$40 for their time.

Data Analysis

Data from this evaluation were analyzed using the constant comparative method of analysis, in which analysts continually compared data findings to original data (Lincoln and Guba 1985; Strauss and Corbin 1990; Creswell 1998). This involved a process of data synthesis and reduction (Strauss and Corbin 1990; Suter 2012). Synthesis and reduction were carried out in five incremental yet iterative steps: analysts conducted interviews, produced summaries, compared across respondents, compared across groups, and reached conclusions (Miller, Willson, Chepp, and Padilla, *forthcoming*). Specifically, once interviews were conducted, analysts synthesized interview data into summaries, detailing how and why each respondent interpreted the question and formulated their answers. Next, analysts compared summaries across respondents, identifying common themes. Once themes were identified, analysts compared themes across subgroups, identifying ways in which different groups of respondents processed questions differently depending on their differing experiences and socio-cultural backgrounds. Finally, analysts made conclusions, determining and explaining how a question performed as it functioned within the context of respondents' various experiences and socio-cultural locations. With each analytic step in this process, data was reduced and systematically extracted in order to produce a theoretical summary detailing a question's performance. As such, these different analytic steps represent both data reduction and a movement toward larger conceptual themes. Analysts used Q-Notes, an analysis software tool developed by NCHS, to facilitate data organization and analysis.

III. Overall Findings

This section summarizes overall findings that were derived from the analysis of the full set of participation questions. Two significant overall patterns were related to context and reference period.

Context

Context is crucial to the performance of this set of participation questions. The intent of these questions is to capture whether respondents' life activities are limited by their health conditions. Therefore, in order for the questions to perform as intended, it is essential that respondents frame the questions in terms of their health. Respondents are prompted to attend to this context by the preamble statement,

“The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.” However, it is clear that most respondents did not consider health problems when formulating their responses. Most respondents focused on external limitations such as caregiving, time or money when formulating their answers. There are several reasons why this may be the case.

Sample: Rather than focusing on their own health and functioning, many respondents answered from the point of view of their role as caregivers. The respondents in this 25 person sample were purposively selected for the purposes of testing the set of child disability questions that were asked along with the participation questions. The sample was comprised of parents or guardians of children ages 2-17 who may have difficulties in certain domains (e.g. seeing, hearing, mobility, and learning.) As such, many of the respondents were considerably burdened by the care and attention required by their disabled children. Additionally, respondents were aware of the selection criteria, and this awareness may have activated their focus on their identity as “parents” or “caregivers.”

However, the fact that some respondents also focused on other external factors (eg. time, money) indicates that even when not focusing on their caregiving burdens, respondents did not necessarily think about the questions in terms of their own health. Despite the preamble directing them to consider the questions in terms of health, respondents generally thought about the questions in terms of the limiting factors in their life in general which, in this sample in particular, often meant a focus on caregiving burden.

Framing: The participation questions were tested as part of a larger project that also tested questions on child disability. The first seven respondents were asked the child disability questions first and then asked the participation questions. This initial group of respondents overwhelmingly focused on their role as caregivers when responding to the participation questions. Two strategies were used in an attempt to reframe the participation questions. First, the remaining respondents were asked the participation questions before the child disability questions. Second, before being asked the participation questions, respondents were first asked a series of six functioning questions (the Washington Group’s short set of disability questions, see Appendix B.) The purpose of asking the functioning questions first was to orient respondents to think about their own functional status before answering the participation questions. This reframing effort was only marginally successful. When framed in this way, some respondents considered their own functioning but many still focused on caregiving and other external limitations.

Response categories: The response categories for all but the first question in this set are “do the activity,” “don’t do the activity” and “unable to do the activity.” The first response category, “do the activity,” was straightforward, and respondents almost always supported their choice of this response with examples of their participation in each activity. The next two response categories, however, were somewhat ambiguous. Respondents who answered “don’t do” and “unable to do” often described similar circumstances. For example, some respondents who care for disabled children answered “don’t do” because they have to care for their children while other respondents answered “unable to do” for the same reason. In some instances, the choice of answer came down to the respondents’ own feelings of agency. That is, respondents who felt that they had chosen to spend their time caring for their children, tended to answer “don’t do” while those who felt that they had no choice in the matter tended to answer

“unable to do.” The same pattern was seen in respondents who answered based on other external limitations (e.g. time, money).

In fact, even when considered within the context of the respondents’ own functioning and health, there is no precise distinction between the response options “don’t do” and “unable to do.” Clearly, when respondents choose “do the activity” this indicates that they are also *able* to do the activity. However, respondents may answer “don’t do the activity” when they are *able* to do the activity but choose not to or when they are *unable* to do the activity but also feel that they have some agency in their lack of participation. This is an important analytical point as the category “don’t do the activity” cannot be clearly distinguished from “unable to do the activity” for analytical purposes.

Reference Period

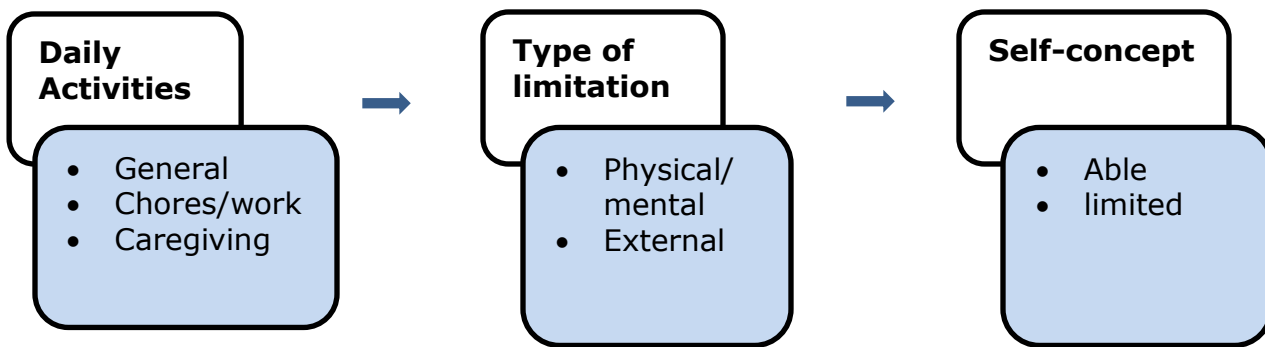
In general, respondents considered their current situation when selecting their responses. However, for some activities, working and going to school in particular, respondents also considered their hypothetical ability to participate. Thus, some respondents answered “do the activity” because they *could* do the activity or they *intended* to do the activity even though they were not currently doing the activity. Other questions had the potential to function as identity questions, so that respondents might answer based on their identification with the activity rather than on their current practice of doing the activity. For example, in answering the question about participation in religious activities, some respondents answered based on their identification as “religious” rather than on their current participation in religious activities.

IV. Question by Question Review

This section provides a detailed examination of the performance of each of the participation questions. This set of questions was introduced by the preamble, “The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.”

1. Are you limited in your ability to carry out daily activities?

Respondents had three decision points to consider when answering question 1: 1) definition of daily activities, 2) Type of limitation and 3) self-concept.



Definition of Daily Activities: The first decision point that respondents considered was their interpretation of “daily activities.” The majority of respondents understood the question to refer to the tasks of everyday life such as work, chores, errands and personal care. For instance, one respondent enumerated his daily activities:

I wake up, walk dogs, get kids up, make them breakfast, make their lunches, get kids to school, work, pick kids up, do laundry, make dinner, take kids to sports, do dishes, more laundry and go to bed. That’s every single day.

Other respondents interpreted the question as a question about general functioning without thinking about specific activities. For example, one respondent explained her answer of “not at all” saying, “Physically I’m able to go places I want to go, and mentally I’m motivated to do things.” Another respondent also explained her answer in terms of general functioning, “I can’t walk; I can talk; I can read; I can write.”

While the previous respondents considered both physical and mental dimensions of functioning, two other respondents considered only physical functioning; both referenced their daily exercise regime. One of these respondents answered “a little” because being on dialysis limits his ability to take long walks.

The third pattern involved respondents who interpreted the question in light of their caregiving burden. This pattern was most prevalent in, although not limited to, respondents who were first asked the set of questions related to child disability. When the participation questions were asked first and framed by the short set of functioning questions, respondents were more likely to answer based on their own functioning and health. However, regardless of which order the questions were asked, respondents with severely disabled children tended to answer the question based on their role as caregivers, and thus, they focused on the activities of caregiving such as carrying children and taking children out to activities as well as general caregiving duties.

Type of limitation: Next, respondents considered factors which might impose limitations on their activities. The introduction to the questions asks respondents to think about their own health, and most respondents understood the question in regard to their own ability to function. The majority of respondents’ narratives made reference to physical limitations and abilities. For example, one respondent answered “not at all” explaining how, despite his age, he has a complete exercise and weight training regime. A few respondents also mentioned mental/cognitive factors such as motivation and ability to think clearly.

As noted above, respondents with severely disabled children often answered based on the limitations imposed on them by their caregiving burden. For example, one respondent with a severely disabled daughter answered “a little.” When asked about her limitations, this respondent said:

[I’m limited by] her weight. It’s harder to move her around now that she’s heavier. We can’t do everything we used to do.”

Similarly, another respondent with a disabled child answered “a lot” saying:

[I’m limited] because of outside factors. I would say because of my daughter, yeah, I’m limited.

A third respondent answered based on the difficulty of caring for a newborn. This respondent explained her answer:

“Now I have a newborn. Now I feel...I don’t go out more because I have to carry everyone downstairs. I don’t take them to activities like I should.

When probed, all three of the above respondents indicated that their limitations were solely a function of caregiving and that on their own, they have no limitations.

However, not all respondents with a significant caregiving burden answered the question interpreted the question in this way. Some answered based on their own functioning. For example, a respondent whose wife has stage IV breast cancer indicated that he is responsible for everything in his household including the care of his wife and three children. This respondent noted that his wife’s condition limits his ability to do things, but he answered “not at all” because he is not limited in his functioning.

Apart from caregiving, respondents considered external burdens such as time and money when answering this question. For example, one respondent who answered “a little” said, “What hinders what I can or can’t do is time.” Similarly, another respondent said, “It’s not a physical barrier, it’s just that I don’t have the time right now.”

Self-concept: Self-concept played a role in shaping respondents answers to Question 1. Some respondents provided extensive narrative evidence of their limitations but answered “not at all” because they see themselves as people who “get things done.” For example, one respondent described how much time it takes to care for her disabled daughter but then explained that she answered “not at all” because:

If it’s something I need to do, I’ll figure out how to do it.

Similarly, another respondent explained her answer of “not at all” saying:

I’m exhausted, but I can do it. I have to do these things. I get it done. I was thinking you were asking “Can you get it done?” and I do...to the best of my ability.

Other respondents, such as the respondent who is on dialysis, did not hesitate to identify with their limitations:

“I’m a dialysis patient.. it limits certain things I can do....I just... I can do everything, but I have to do it at a slower pace.”

This respondent's identity as a dialysis patient enabled him to answer "a little" even though he can still do things.

The rest of the participation questions are introduced in this way:

For each of the following activities, please tell me if you do the activity, don't do the activity, or are unable to do the activity.

2. Working outside the home to earn an income?

Scope: Respondents interpreted "work" in two distinct patterns. For most respondents employment status was the determiner. Not surprisingly, respondents felt that both full-time and part-time jobs qualified as *work*. This pattern held true for one retired respondent and one unemployed respondent who both answered "don't do" the activity because they are not currently employed.

The second pattern occurred in only two respondents one of whom is retired and the other of whom is unemployed. In contrast to the retired and unemployed respondents mentioned above, these respondents answered "do the activity" because they *could* work. These respondents focused on their current ability to work rather than on their employment status.

Two respondents expressed uncertainty about the phrase "outside the home." For example, one respondent who runs a business from his home but who travels to New York City at least once a month answered "do the activity" but indicated that he would have answered "don't do" if he did not travel because in that case his work would be based entirely within his home. Another respondent also stumbled on this phrase:

Outside?

[Interviewer: ...outside the home to earn an income...]

Outside the home, right? I do the activity.

[Interviewer: tell me about that.]

Normally I don't work at home because I go out to work. My work is not in my home.

While no response error was evidenced in these cases, there is the potential for response error if respondents focus on the phrase "outside the home" and answer based on the location of their work (inside vs. outside the home).

Self-determination: For most respondents who are not currently employed, their choice of either "don't do" or "unable to do" was influenced by their feeling of self-determination. Many respondents in this sample do not hold jobs because they care for their children but some feel that this is a choice while

others feel that it is not. For example, one respondent described her decision to stay home with the children as a choice:

My husband and I decided that that's what we wanted to do.

Another respondent described her situation differently:

They [her disabled children] require care. I have to stay home with them. I can't work.

Generally, despite similar circumstances, respondents who felt they had a choice in their decision to stay home with children rather than to have a job answered "don't do" while respondents who answered "unable to do" expressed a lack of choice in the matter.

3. Going to school or achieving your education goals?

Scope: Similar to the previous question, respondents answered Question 3 either on the basis of their engagement in certain activities or on the basis of their ability to do those activities. Most respondents considered enrollment in a degree program when answering Question 3. For example, one respondent said:

I equate that literally with being enrolled in some formal degree program like working on a Master's Degree. I attend professional development activities but that's through work so I consider that work education.

A few respondents had a broader understanding of "school or educational goals" which included classes and training that were not necessarily part of a formal degree program. One respondent initially answered "don't do" because she was thinking of formal degree programs, but changed her answer to "do the activity" when she remembered that she has to take classes for her job:

I have to take continuing education courses for my career. I do take classes for career development- to keep my license.

Another respondent was thinking of similar educational activities:

I was thinking about additional certifications or trainings that I would do for my job.

All respondents agreed that "school or educational goals" would only include formal, "substantive" educational experiences. One respondent who answered "don't do" explained her answer:

Sure I've taken community college stuff and cooking classes and hobbies, but I don't consider that. It has to be substantive...

As noted, a few respondents considered only their ability to do educational activities. For example, one respondent answered “do the activity” because:

I have support for my family so I could do it.

[Interviewer: You’re not currently taking any classes?]

No. I’m not, but that’s something I could adjust to my life.

Reference Period: In addition to deciding what type of educational experiences to consider, respondents also had to decide what time period to use as the basis for their answer. The response categories are in the present tense, implying that the time frame is limited to current activities and some respondents answered based on their current situation. For example, a respondent who answered “don’t do” explained, “I’m not doing that now.” In fact, all of the respondents who answered “don’t do” and “unable to do” used the present timeframe.

However, only one of those who answered “do the activity” was currently enrolled in school. Other respondents who answered “do the activity” either focused on their current ability to attend school (as described above) or they used timeframes other than the present. For example, one respondent answered based on the recent past, saying, “I just finished taking two computer courses.” Additionally, some respondents answered “do the activity” based on their future plans. For example, one respondent said, “I’m not currently enrolled in school, but I was at Georgetown and I’m planning to finish.”

Finally, there was no clear distinction between respondents who answered “don’t do” and those who answered “unable to do.” The two respondents who indicated they were “unable to do” the activity had both put their educational goals on hold in order to care for their disabled children. However, other respondents in similar circumstances chose “don’t do” instead.

4. Participating in leisure or social activities?

Scope: In answering Question 4, almost all respondents considered a variety of both leisure and social activities such as reading, watching TV, playing sports, going out with friends, visiting family or shopping. Two respondents understood the question to refer only to social activities. One of these answered “don’t do” because she prefers to be alone. The other answered “unable to do because her child doesn’t behave when she takes him to people’s houses. She explained:

He be bad, so that person house where we be may say he tearing it up, so I can’t do too many social activities

In contrast, other respondents with children described how they “do the activity” despite the limitations imposed by their burden of care. One respondent said:

My leisure time is with my kids. I do it because my leisure activities are with my kids.

And another explained:

I do it but not as much as I'd like. Because of [child], I can't go out very often.

5. Getting out with friends or family?

Scope: Question 5 demonstrated considerable conceptual overlap with Question 4 since most respondents had already included “getting out with family and friends” as part of their leisure and social activities. Respondents mentioned activities they do with friends such as exercising, playing games or going to ‘happy hours’ after work. Respondents also mentioned visiting extended family as well as activities they do with their immediate families.

Two respondents focused on family in particular, both indicating that they “don’t do” this activity. One said that she doesn’t have family and the other explained that he doesn’t want to spend time with his family because they drink too much.

Many respondents framed their answers in terms of their perceived limitations, but most felt they were able to “do the activity” despite lack of time or the need to provide care for family members. For example, one respondent answered in terms of the limitations she feels due to her child’s special needs:

I still do it because that’s a big part of my life with my son. I want to keep doing everything I would normally do. Just because he has special needs I don’t want to sit in the house and do nothing.

However, one respondent answered “unable to do” because his wife’s illness keeps them from being able to make plans with others.

6. Doing household chores such as cooking and cleaning?

Scope: In addition to cooking and cleaning, which were given as examples in the question, respondents also mentioned yard work, laundry, dusting and general household upkeep.

All respondents indicated that they do this activity, and all seemed to feel that these were activities that must be done despite any external limitations. One respondent said, “I do this every day. Nothing can stop me from this.” Another noted, “I have to do that. For the kids’ sake, I have to do that.”

Even when respondents noted that they aren’t able to do as many household chores as they used to or that they can’t do as much around the house as they want to, respondents focused on the things that they are able to do. Therefore, even when severely limited in their ability to do household chores, respondents answered “do the activity” because they view their participation in this activity as essential.

7. Using transportation to get to places you want to go?

Scope: In answering Question 7, respondents considered a variety of modes of transportation such as car, metro, walking, and airplane. Some respondents considered only public transportation while others considered only private transportation. A few were not sure which to consider and asked for clarification. For example, one respondent asked, “When you say transportation what do you mean: public or personal?” Almost all respondents reported that they could use transportation to get wherever they wanted to go. One respondent said, “I don’t have any problem getting anywhere I need to get.”

Response error was seen in one respondent who answered “don’t do” the activity. Even though he uses his car every day, this respondent answered “don’t do” because he was thinking only about public transportation. However, he also reported that he uses public transportation at least once a month when he goes to New York City on business.

8. Participating in religious activities?

Scope: Respondents interpreted Question 8 in one of three ways. Either they thought about attendance at religious services, their religious self-identification or their ability to participate in religious events. First, respondents mentioned attendance at a variety of activities such as religious services, bible study, book club and religiously-affiliated social events such as a barbeque or carnival. For example, one respondent who considers herself a “non-practicing Jew,” answered “do the activity.” This respondent described her thought process:

My son goes to the preschool [at the temple] and so by default we end up doing things... I was thinking I don’t do any religious things but then I remembered I just went to a Purim carnival, so I said ‘yes.’

Even though this respondent doesn’t consider herself to be a part of this religious community, she answered in the affirmative because she had been to an event.

However, some respondents prioritized religious identity over attendance. Generally, even those who felt only loosely affiliated with their religious community answered “do the activity.” For example, one respondent answered “do the activity” because he went to church in the past and intends to go in the future. He still felt connected to his religious community even though he doesn’t currently attend events. Self-identity was also important for those who answered “don’t do” as most respondents who answered in this way explained their answer by describing themselves as “not religious.”

For one respondent, the ability to participate fully was the most salient factor. This respondent explained that her child’s limitations prevent her from participating in the ways she would like to.

If they have seminars going on or Bible night, he doesn’t sit still. I don’t think he wants to listen or understand.

[Interviewer: What did you have in mind when you said ‘unable’?]

Most time our church has activities like outings. He so busy and he don't listen. I can't do what I want to do with the outings. Then we have things like little parties...he listens but he still don't listen that much.

Therefore, this respondent answered "unable to do" even though she regularly attends church activities.

9. Participating in community gatherings?

Scope: Respondents' interpretations of what was meant by "community gathering" varied widely. Some respondents had a very broad interpretation of "community gathering" that included public outings such as grocery shopping or social activities. Others thought this term referred to more specialized events such as parades or carnivals. Two respondents had a very narrow notion of "community gathering" and thought it only referred to events in their own immediate neighborhoods. For example, one respondent answered "don't do" thinking about activities in his immediate neighborhood:

I don't like my family around large groups of people where there may be gang violence. I don't want to be anywhere where there are people pointing guns in any directions

[What types of events were you thinking of?]

I was thinking of [City] day and what they called 'block parties' and stuff like that.

[Interviewer: You're thinking of your immediate neighborhood?]

Yes!

[Interviewer: How about going to the Smithsonian where they have fireworks displays?]

Yeah! I've done that! We've been down to the Smithsonian all the time to see free plays and activities.

Therefore, even though this respondent does go to some community events he answered "don't do" because he does not attend events in his immediate community.

Finally, because the term was open to such broad interpretation one respondent was not sure how to answer. She said:

I don't know what that means. Do we go out in the community? Yes. We go swimming, to parks, to the Folk Life Festival, but are these "community gatherings"? I don't know.

While this respondent clearly had some notion of *community gathering*, she felt that the term was too vague and could not answer the question.

Appendix A

1. Are you limited in your ability to carry out daily activities? Would you say:

1. Not at all
2. A little
3. A lot
4. Completely limited

2-9. For each of the following activities, please tell me if you do the activity, don't do the activity, or are unable to do the activity.

2. Working outside the home to earn an income?

3. Going to school or achieving your education goals?

4. Participating in leisure or social activities?

5. Getting out with friends or family?

6. Doing household chores such as cooking and cleaning?

7. Using transportation to get to places you want to go?

8. Participating in religious activities?

9. Participating in community gatherings?

Appendix B: the Washington Group's short set of disability questions

1. Do you have difficulty seeing, even if wearing glasses? Would you say:
 1. No difficulty
 2. Some difficulty
 3. A lot of difficulty
3. Cannot do at all / Unable to do
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual language, do you have difficulty communicating, (for example understanding or being understood by others)?

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