Cognitive Evaluation of Proposed Disability Questions for the 1998 Dress Rehearsal

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The cognitive evaluation of the two proposed versions of the disability questions for the 1998 Dress Rehearsal questionnaire consisted of twenty cognitive interviews. This evaluation consisted of interviewing people with disabilities, people who could report for a disabled household member, and people without disabilities. We also included both the parents of children with and without disabilities. Our resultant "disabled" population consisted of a wide range of physical and mental disabilities. We had respondents or household members with diabetes, epilepsy, multiple sclerosis, back injuries, heart disease, blindness, severe hearing impairments, severe learning disabilities, attention deficit disorder, brain damage, mental retardation, and obsessive-compulsive disorder. We had reports for children with cerebral palsy and attention deficit disorder. Interviews were conducted between August 17 and September 13, 1997.

The following short report summarizes the highlights of our research. We will first outline some general findings across the two versions, then the main findings from each version of the disability questions, and finally our recommended revision. The disability questions used in the interviews are included as Attachments A and B.

A. General Findings:

1. Age Screeners:

The age screeners were presented in the following form:

When was this person born?

Born on or before (date)

Born after (date)

The OMB version contained two such screeners (one to screen for 5-year-olds and one for 15-year-olds). The Census version contained only the 5-year screener. The 5-year screener will not be included on the census in this format, but was included in the test form to identify the appropriate universe. The 15-year screener is planned for inclusion in this format on the census form.

It should be noted that respondents had great difficulty completing the age screeners. The format which requires someone to determine whether or not they are "born on or after" or "born on or before" a particular date is confusing. It would be better to ask people if they are a certain age as of a particular date. For example, "Is this person over/under 5 years of age as of DATE?"

2. Skip Instructions:

In general, skip instructions in self-administered questionnaires can be problematic for respondents. Often respondents do not follow the intended skip instructions and wind up answering questions which they were not intended for them. This was an issue with the disability questions. Both forms contained an instruction to "Answer if person is 16 YEARS OLD OR OVER--" for some questions. Often the skip instruction was missed and all of these questions were answered for very young children. Since these questions were not age appropriate for those persons (i.e., going out alone, working, driving), determining the appropriate response created some confusion. Unfortunately, this problem cannot be totally avoided so it will be necessary to have the appropriate edit specifications in effect so that the data can be cleaned.

3. Item 6a. "Mental Activities":

This item referring to "learning, remembering or concentrating" seems to produce poor quality data across both versions of the disability questions. The vast majority of respondents who would have been expected to note problems with these activities did not. Sometimes this appeared to be due to the fact that the respondent determined that there were no problems in this area. However, these problems seemed obvious to the interviewers. At other times it seemed that difficulties were detected but that the respondent simply did not want to report them or wanted to minimize them. Reports for people with ADD, mental retardation, obsessive-compulsive disorder, learning disabilities, and brain damage all did not identify any difficulties with these activities.

B. OMB Version:

1. Findings:

a. Question 6: Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty doing any of the activities listed below?

The wording of question 6 was clear to respondents. Their paraphrases of the question demonstrated that they understood that both physical and mental/emotional conditions were to be considered. The time frame was not emphasized in the paraphrases but seemed to be understood. Respondents noted that the question was asking about "disabilities, handicaps, limitations."

The use of the term "or" between the activities listed within one item (e.g., dress, bathe, or get around inside the home) was not problematic. Respondents were comfortable responding "yes" to an activity, even if they only had difficulty with one of the multiple activities listed.

b. Question 6. b. Talk, see (with glasses), or hear

Item b. was difficult and confusing for most of the respondents who wore glasses. The "with glasses" in parentheses had multiple interpretations. Respondents thought that it either meant that they had "difficulty seeing with their glasses on" or that they had "difficulty seeing and needed glasses." Thus, their answers varied depending on their interpretation of the phrase "see (with glasses)." Many respondents who wore glasses reported that they had difficulty with this activity (either some or great difficulty) because they wore glasses. Since this is not the intended interpretation or response for that item, it is problematic.

Also, two of our respondents did not indicate that they had difficulties talking, when these difficulties seemed quite apparent to the interviewers. One respondent was a woman with epilepsy and the other was a man with a brain injury from a fall. Another parent reported that her child had no difficulty, but later noted that he goes to a speech therapist because his speech is slurred. We are not sure if this failure to report was due to the term "talk" being unattended to or somehow it being somehow unclear. Follow-up probing was not sufficient to determine the reason for the lack of reported difficulty; however, the quality of this data is suspect.

c. Question 6. c. Walk 3 blocks or lift a bag of groceries

Item c was in general not problematic. However, upon probing it was clear that respondents often had differing ideas about what constituted a bag of groceries. Some respondents, who answered this question inappropriately for young children, noted that often the child may want to help and will carry a bag of groceries which consisted solely of a loaf of bread.

- d. Multiple respondents missed the "16 YEARS OLD OR OVER" age screener embedded within Question 6. It seems that this screener is not often attended to. Many respondents simply did not read it or follow it. Thus, reports for children under that age of 16 were common. This can create some confusion because the activities are not age-appropriate. However, the data can be corrected with appropriate edit specifications.
- e. Question 8. Special Accommodations Question: Does this person need special work arrangements for people with disabilities? (For example: special equipment, accessible bathrooms, changes in work schedule or assignment, personal attendant, wheelchair ramps.)

Although the question asks about work arrangements, it was not always interpreted that way. Some people thought it could refer to accommodations for school or getting around the home.

For this to be a good question, a "yes" response should indicate that a person needs special accommodation to work and a "no" response should indicate that a person does not need such accommodation. This is difficult to accomplish with this question because it is asked of the entire population, including people in a wide variety of circumstances. Age is one factor that affects how a person should answer the question. We had several elderly persons (65+), either self responses or proxies, in our "sample." Retired persons without disabilities were not sure how to answer the question since they did not work and, in some cases, hadn't for quite a while. They were generally unsure whether they should answer "no" or leave the question blank. However, one person of retirement age was reported as needing special accommodation because he uses a cane, wheelchair, and walker. While it is true that he might need accommodation because of his inability to get around, he is not likely to work if he had them due to his age.

Another factor is whether or not a disabled person is working. One disabled respondent, a younger man with multiple sclerosis who reported many physical disabilities reported that he does not need special accommodation because he is not currently working. He noted that he might be able to do some jobs, although not the job he was trained for. He does not need the physical accommodations listed in the question; but he did not mention change in work assignment, which may have allowed him to continue working. If there are other reasons, such as trying to qualify for disability, for a disabled person not to work at any job, this question may not accomplish its goal.

2. Recommended Revisions for OMB Version:

Item b. "Talk, see (with glasses) or hear" is extremely confusing and should be changed. There does not seem to be a "quick fix" solution. Our recommendation is to make the concept clearer by incorporating terminology that respondents are familiar with. The Census wording of these activities uses the terms blindness and deafness which are easily understood. In addition, it allows the data to be captured separately which seems useful.

The special accommodations question should not be included. We noted several cases of incorrect reporting, the question was troublesome for elderly persons, and there does not seem to be a simple way to make this question relevant to the entire population.

C. Census Version:

1. Findings:

a. Question 6. Mark the category that best describes this person's usual ability to perform the following activities: No difficulty, Some difficulty, Great difficulty or unable

One of the major problems with this version of the disability questions was caused by the response scale associated with Question 6. Since the stem of Question 6 is not in the

form of a question, it makes the interpretation of the response scale somewhat ambiguous. Some respondents understood the question to be asking them if they could do an activity. Thus, they were expecting a "yes/no" response option. However, those are not the options they encountered so they then had to translate their yes/no response into something that matched the scale. This proved difficult for many respondents and there were many examples of answers being changed because they could not readily map their response onto the "level of difficulty" response scale. Further, when probed about their interpretation of the meaning of these response categories, their responses did not indicate that they could clearly differentiate between them. There did not seem to be consistency in the meaning of each category across respondents. It seemed to be easier for respondents to just be able to report that they either had or did not have difficulty in performing the activity.

b. Question 7. Does this person have any of the following long-lasting conditions -- Yes/No

The formatting of the response categories across items 6 and 7 in this version was also problematic. Several respondents were observed checking the "yes" box while saying out loud "some difficulty." They were confused because the "yes" boxes (in item 6) and the "some difficulty" boxes (in item 7) are in perfect alignment. This is particularly problematic in 7.c., where respondents stated the words "some difficulty" and reported "yes." However, item c. asks specifically about substantial limitations, so a person with some difficulty should not necessarily answer yes.

Another problem was noted when respondents checked the "yes" box while noting that they had "no difficulties." Again, the "yes" box is the first response option in this question and the "no difficulty" option was the first response in the previous question. So the dimensions are actually reversed across the two questions. If the respondent reported not having difficulty in question 6 they used the left-most option "no difficulty." However, if they wanted to continue to indicate that they did not have any difficulty they had to use the right-most option in question 7 for "no." Thus, the formatting created errors for several different reasons.

c. The wording of question 7 was easily understood and respondents clearly interpreted all of the sub-items in this question. The vision and hearing questions did not bring about the range of uncertainty which was observed with the OMB "talk, see, hear" item. Also, the catch-all item c. (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying) was clear to respondents.

2. Recommended Revisions for Census Version:

Question 6 should be re-written to read as a question. The response scale needs to be changed so that it is consistent across questions 6 and 7. Additionally, items a and b should be shortened because while they were clearly comprehended in this version, they were also clear in their shorter OMB version counterparts.

Question 7 was easily understood and should not be changed.

C. CSMR Recommended Revised Version:

Based on the cognitive interviews across these two versions of the disability items we have revised the questions to accommodate the best aspects of both the OMB and Census versions to create a new combined version. This new version resolves the formatting and response scale problems of the Census version, while retaining the question-asking format and the more simplistic wording of the OMB version.

6. Does this person usually have any difficulty performing the following	lowing activities?	
	Yes	No
a. Learning, remembering, or concentrating?	[]	[]
b. Dress, bathe, or get around inside the home?	[]	[]
c. Go outside the home alone to shop or visit a doctor's office?	[]	[]
7. Does this person have any of the following long-lasting conditions?		
	Yes	No
a. Blindness or severe vision impairment?	[]	[]
b. Deafness or severe hearing impairment?	[]	[]
c. A condition that substantially limits one or more basic physical	Į.	
activities such as walking, climbing stairs, reaching, lifting or		
carrying?	[]	[]

This new version poses Question 6 as a question. Since in the Census version respondents did not have any difficulty in determining someone's "usual ability" a variant of this phrasing was retained for this revised version. Additionally, since with this wording respondents never assumed the question was referring to a condition that lasted less than 6 months, the need for the reference period to appear in the question is eliminated.

This new version uses the shorter OMB wording for the items about "mental activities" and "to dress/bathe." The item about "outside the home activities" (i.e., go outside, shop, visit a doctor's office) was retained and was also identical across the Census and OMB

versions. The problematic OMB Question 6.b., which combined "talk, see, and hear" is eliminated and the Census version of obtaining this information in Question 7 is retained. Respondents clearly understood the Census version terminology used to assess blindness, deafness, and severe impairments in either area.

The only items in the OMB version that are not directly assessed in the new version are items 6.d. (*work or keep house*) and 6.c. (*walk three blocks or lift a bag of groceries*). Item 6.d. is not in the new version. It is our understanding that this item was the preferred item to be dropped in the OMB version, if the special accommodations question was to be included. Thus, it seems to be of lower priority. On the other hand, Question 6.c., is technically subsumed in Census item 7c. (the catch-all item) which asks about any conditions that limit "walking" or "carrying." Therefore, those types of physical activities are assessed in the new version.

Person 1

Print name below. Start with a person living here who owns or rents this house or apartment.	4. What is this person's race? Mark 2 ONE box for the race that this person considers himself/herself to be.	
Last Name	White	
	Black, African Am., or Negro	
	☐ Indian (Amer.) → Print name of enrolled or principal tribe. ▼	
First Name MI		
	☐ Eskimo ☐ Vietnamese	
2. What is this person's sex? Mark 🔀 ONE box.	☐ Aleut . ☐ Japanese ~	
☐ Male	Chinese Asian Indian	
☐ Female	☐ Filipino ☐ Samoan	
	Hawaiian Guamanian	
	Korean Other Asian or Pacific Islander - Print race. 7	
IOTE: Please answer both Questions 3 and 4.		
3. Is this person Spanish/Hispanic/Latino? Mark 🔀 the 'No'		
box if not Spanish/Hispanic/Latino.	Some other race – Print race. 🛫	
No, not Spanish/Hispanic/Latino		
Yes, Mexican, Mexican Am., Chicano		
Yes, Puerto Rican		
Yes, Cuban	5. When was this person born?	
Yes, other Spanish/Hispanic/Latino – Print one group. 🔀	Born on or before August 10, 1992	
	☐ Born after August 10, 1992 → Skip to 9	
	6. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the activities listed below?	
	Yes No	
	a. Learn, remember, or concentrate	
	b. Taik, see (with glasses), or hear	
	C. Walk 3 blocks or lift a bag of groceries	
	Answer if person is 16 YEARS OLD OR OVER —	
	d. Work or keep house	
	e. Go outside the home alone to shop or visit a doctor's office	
	f. Dress, bathe, or get around inside the home	
. ·	7. When was this person born?	
<u>.</u>	Bom on or before August 10, 1982	
	Born after August 10, 1982 — Skip to 9	
	8. Does this person need special work arrangements for people with disabilities? (For example: special equipment, accessible bathrooms, changes in work schedule or assignment, personal attendant, wheelchair ramps.) Yes No	
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	9. NOTE: If only 1 person lives here, skip to the instructions for finishing the form on page 10. Otherwise, go to Person 2.	

Person 1

1. Print name below. Start with a person living here who	A vertical in white annual of a second of the second of th
owns or rents this house or apartment.	4. What is this person's race? Mark ONE box for the race that this person considers himself/herself to be.
Last Name	☐ White
	🔲 Black, African Am., or Negro
Sam Nama	Indian (Amer.) – Print name of enrolled or principal tribe. 🗾
First Name MI	
	_
·	☐ Eskimo ☐ Vietnamese
2. What is this person's sex? Mark 🔀 ONE box.	Aleut Japanese
☐ Male	☐ Chinese ☐ Asian Indian ☐ Filipino ☐ Samoan
Female :	Hawaiian Guamanian
•	Korean Cther Asian or Pacific Islander – Print race.
NOTE: Please answer both Questions 3 and 4.	
3. Is this person Spanish/Hispanic/Latino? Mark 🔀 the 'No'	
box if not Spanish/Hispanic/Latino-	Some other race - Print race. Z
No, not Spanish/Hispanic/Latino	
Yes, Mexican, Mexican Am., Chicano	
Yes, Puerto Rican Yes, Cuban	5. When was this person born?
Yes, other Spanish/Hispanic/Latino ~ Print one group.	Born on or before August 10, 1992
- Cardina spaniari ispania and a contra groups g	☐ Born after August 10, 1992 → Skip to 8
	6. Mark the category that best describes this person's usual
	ability to perform the following activities:
	Great No Some difficulty
	difficulty difficulty or unable
	a. Perform mental tasks such as learning, remembering, OR
	concentrating
	D. Dress, bathe, and get around inside the home without help
	C. Answer if person is 16 YEARS OLD
	OR OVER - Go outside the
	home alone to shop or visit a doctor's office
	7. Does this person have any of the following
·	long-lasting conditions —
-	Yes No a. Blindness or a severe vision
4	impairment?
	D. Deafness or a severe hearing impairment?
	C. A condition that substantially limits
	one or more basic physical activities such as walking, climbing stairs, reaching,
	lifting, or carrying?
	8. NOTE: If only 1 person lives here, skip to the instructions for
	finishing the form on page 10. Otherwise, go to Person 2.
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