6th Meeting of the Washington Group on Disability Statistics Kampala, Uganda October 10-13, 2006

Summary of results of pre-tests of the WG short set of questions

Introductory phrase:

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

Question on vision

Do you have difficulty seeing, even if wearing glasses?

- a. No no difficulty
- b. Yes some difficulty
- c. Yes a lot of difficulty
- d. Cannot do at all

Summary of pre-test results:

In the cognitive tests, 191 of the cases (out of 1014) fell into the "problematic" group of response patterns for the vision questions. Responses were more consistent when the difficulty and effort questions were taken into account; only 117 out of 1014 remained in the "problematic" group of response patterns after considering responses to these additional questions. For example, there were instances where respondents answered the WG question affirmatively, but answered "no" to the near/far vision questions. This was considered a problematic response pattern because responses did not agree. However, if respondents expressed that it was difficult or required effort to see well on the difficulty/effort questions, then the difference in responses to the WG question and the near/far vision questions was no longer considered problematic since it appeared that the WG question was detecting a different aspect of vision than the more detailed near/far vision questions. Thus, it was suggested that the near and far vision questions² may not be capturing all the relevant cases. In addition, difficulties with understanding the glasses clause and it's location within the question appeared to explain only part of the discrepancies between the WG question and the near/far vision questions. Seven countries had response patterns suggesting that respondents were missing or misinterpreting the glasses clause (Argentina, Brazil, Egypt, Kenya, Mexico, Paraguay and Vietnam). However, the clause was understood by respondents in 4 countries (Argentina, Brazil, Mexico and Paraguay). There were very few cases where respondents replied "no difficulty" to the WG question but reported "a lot of difficulty"/ "a lot of effort"/ "[difficulties] very often" to the extended vision questions^{1,2,3} (n=5 of 1014). There were only 15 instances where respondents reported "a lot of difficulty" or "unable" to the WG question but "no difficulty" / "no effort"/ "[difficulties] never" to the extended vision questions. It was suggested that the near and far vision questions may be

¹ Difficulty and effort questions: Without/With your glasses, (i) how often do you have difficulty seeing well? (ii) how much effort do you have to put into seeing?

² Near and far vision questions: Without/With your glasses, do you have difficulty, (i) seeing the print in a map, newspaper or book? (ii) seeing/recognizing a person you know from 7 meters away?

³ Additional extended question: Do you wear glasses all of the time, only for certain activities, or none of the time?

missing aspects of visual problems (such as cataracts, problems with one eye only) that are being reported using the WG question.

Vietnam expressed concern about the discrepancy in responses of "unable" on the WG question compared to the near/far vision questions. Their field test data indicated that while 3.3% (of 3409 persons) reported "unable" to the near/far vision questions, only 0.7% reported "unable" to the WG question. Subsequent discussion suggested that this supported the premise that the near and far vision questions detect specific aspects of visual problems whereas the WG question was more comprehensive (it appeared that respondents that were unable to see near/far reported only some difficulty seeing on the WG question because they were not unable to see at all...that is, a person unable to see closely may be able to see in the distance; this requires further analysis). WHO/ESCAP analyses indicated moderate correlation between the WG question and the extended questions and low sensitivity of the WG question compared to the extended questions. However, three issues confound the comparison of responses: the extended questions refer to a health problem lasting 30 days while the WG question has no reference to duration; the WG question asks about the quantity of the problem while the extended questions ask about severity; and finally, the extended questions have a 5 points response scale versus a 4 point scale for the WG questions. It was noted that the results of sensitivity and specificity analyses need to be interpreted with caution since there is no gold standard and to reset the cut point and reanalyze the data from the WHO/ESCAP test.

Overall, the WG question on vision was interpreted consistently across countries. Consideration will be given as to how to best address the glasses clause. It was suggested that better concept translation is needed rather than direct language translation since "even if" is not easily interpretable in some languages.

Question on hearing

Do you have difficulty hearing, even if using a hearing aid?

- a. No- no difficulty
- b. Yes some difficulty
- c. Yes a lot of difficulty
- d. Cannot do at all

Summary of pre-test results:

In the cognitive tests, only 37 of the cases (out of 877) fell into the "problematic" group of response patterns for the hearing question. When the difficulty and effort questions⁴ were taken into account (see related comment on vision question), only 21 out of 877 remained in the "problematic" group of response patterns. Fourteen respondents did not report difficulty on the WG question, but reported difficulty on the extended questions⁵ or reported they missed words⁶. Most of these respondents reported only minimal difficulty on the extended questions suggesting that they may not consider their impairment to be serious enough to report in the general WG

⁴ Difficulty and effort questions: Without / With your hearing aid, (i) how often do you have difficulty hearing well? (ii) how much effort do you have to put into hearing?

⁵ Extended questions: (i) Do you wear a hearing aid all of the time, only for certain activities, or none of the time? With / Without your hearing aid, (ii) do you have difficulty hearing what is said in a conversation with one other person in a crowded room? (iii) do you have difficulty hearing what is said in a conversation with one other person in a quiet room?

⁶ Missed words: (i) *How often do you miss words in conversation or on the radio or television because you have difficulty hearing?* (ii) *Do household or family members often tell you that you have a hearing problem?*

core question. Five of these respondents reported use of a hearing aid which may have improved hearing overall so that no difficulty was reported for the WG questions, but specific problems as captured by the extended set may persist. Two respondents reported difficulty on the WG question but did not report problems on the extended questions or missed words. Most of these respondents reported "some difficulty" hearing.

WHO/ESCAP results indicated low sensitivity of the WG question compared to the extended questions. Again, the three issues confounding the comparison of responses were raised: the extended questions refer to a health problem lasting 30 days while the WG question has no reference to duration; the WG question asks about the quantity of the problem while the extended questions ask about severity; and finally, the extended questions have a 5 point response scale versus a 4 point scale for the WG questions. It was reiterated that the results of sensitivity and specificity analyses need to be interpreted with caution since there is no gold standard and to reset the cut point and re-analyze the data from the WHO/ESCAP test.

Similar to the question on vision, the WG question on hearing was interpreted consistently across countries. Since the proportion of problematic responses was quite low, there were no suggestions for revision of this question.

Question on mobility

Do you have difficulty walking or climbing steps?

- a. No- no difficulty
- b. Yes some difficulty
- c. Yes a lot of difficulty
- d. Cannot do at all

<u>Summary of pre-test results</u>:

In the cognitive tests, only 81 of the cases (out of 852) fell into the "problematic" group of response patterns for the mobility question. The majority of cases fell into pattern "I" (48 of the 81 problematic responses) where respondents answered "no" to the WG question but "yes" to one or more of the extended questions ⁷. Most of these respondents reported only some difficulty on the extended questions suggesting that they may not consider their impairment to be serious enough to report in the general WG question. Alternatively, the extended questions may be detecting aspects of mobility that differ from walking (such as problems with sitting, stooping or standing) or that are more specific than the WG question (such as difficulty walking long distances).

Data from the field test indicated more reports of difficulty moving inside the home (extended question) compared to the WG question also suggesting that the extended questions may be detecting different aspects of mobility than the WG question. In field tests, there was better correspondence between the WG question and extended questions that were more closely related to walking (such as the question about walking a long distance). Data from Vietnam (the largest field test) showed good (but not very good) correspondence between the degree of difficulty reported on the WG question compared to the extended questions. Responses usually

⁷ Extended questions: (i) Do you use any kind of equipment, such as a wheelchair, walker or cane, to help you get around? Do you have difficulty (ii) going outside of your home? (iii) walking a long distance such as a kilometer (or a mile)? By yourself and not using aids, do you have any difficulty (iv) walking for a quarter of a mile (about 2 or 3 blocks)? (v) walking up ten steps without resting? (vi) standing or being on your feet for about 2 hours? (vii) sitting for about 2 hours? (viii) stooping, crouching or kneeling?

differed by only one level (for instance "a lot of difficulty" on the detailed question and "some difficulty" on the WG question).

Because of these discrepancies, there was discussion about whether to make the WG question more specific (i.e. add a clear reference to distance). Concern was raised that this would make the question less comprehensive and would introduce error because of the additional complexity. This generated a more general discussion about the necessary level of generality / specificity for all 6 WG questions. After much discussion, it was agreed that some error is acceptable and to be expected. Based on the pre-test results, the overall level of error with the WG questions was small and bias in responses because of contextual differences across countries did not appear to be a problem. It was agreed that increasing the specificity of the questions would not be beneficial, particularly in a Census format and given cultural and contextual differences across countries.

Overall, the question on mobility was well understood by respondents. Since there was a relatively small number of problematic cases, and correspondence between the WG question and the extended questions was relatively good on the field tests, the results were considered positive and there were no recommendations for revision of this question.

Question on cognition

Do you have difficulty remembering or concentrating?

- a. No no difficulty
- b. Yes some difficulty
- c. Yes a lot of difficulty
- d. Cannot do at all

<u>Summary of pre-test results</u>:

Cognitive test results were reviewed and the issue was raised that memory and concentration represent only a small part of mental functioning, but within these specified aspects of mental functioning, the WG question was well understood by respondents. Reported difficulties were usually in reference to those experienced at work or school. Since respondents may report a little difficulty in concentrating or remembering because of being overly busy or stressed, it was suggested that a meaningful distinction in functioning is between those reporting no difficulty or some difficulty versus those reporting a lot of difficulty or inability to remember or concentrate. This operationalization was used as an outcome variable in multiple logistic regression analyses. In adjusted analyses, key concepts that were independently related to the degree of difficulty reported on the WG question included the degree of effort required to remember/concentrate, how worried respondents were about their memory/concentration, difficulty remembering names, and difficulty problem solving. The need to evaluate the results of the proxy data were emphasized since respondents with severe cognitive problems may have had a proxy respondent reporting for them.

Field test results indicated that the WG question identified almost as many respondents as the 3 extended questions⁸ identified in combination. There was poor correspondence between

4 1/17/07

_

⁸ Three extended questions: Do you have difficulty (i) concentrating on doing something for 10 minutes? (ii) learning a new task, for example, learning how to get to a new place? (iii) finding solutions to problems in day to day life?

the WG question and extended questions^{8,9} that capture different aspects of mental functioning such as learning a new task and finding solutions to problems in everyday life. However, correspondence was very good between the WG question and extended questions that capture similar aspects of mental functioning (i.e. remembering and concentrating). This was interpreted as a limitation in the aspects of mental functioning captured by the WG question, but not a problem with the question itself. It was emphasized that we have to be really clear about the issue of who we are missing with the WG questions. It was suggested that at some point in the future, we may need to add another question to identify children with cognitive problems (such as learning problems) and those with intellectual functioning problems (mental retardation).

Overall for the cognitive tests, only 82 of the cases (out of 920) fell into the "problematic" group of response patterns for the cognitive question. The WG question on cognition was well understood by respondents, captured the intended aspects of mental functioning (i.e. remembering and concentrating), and the WG question correlated well with questions on related concepts. There were no recommendations for revision of this question.

Question on self-care

Do you have difficulty (with self-care such as) washing all over or dressing?

- a. No no difficulty
- b. Yes some difficulty
- c. Yes a lot of difficulty
- d. Cannot do at all

Summary of pre-test results:

In the cognitive tests, only 96 of the cases (out of 1197) fell into the "problematic" group of response patterns for the self-care question. There were only two problematic response patterns: pattern "d" where respondents reported difficulty on the WG question but not on the extended questions 10 and pattern "h" where respondents reported no difficulty on the WG question but reported difficulty on three or more of the extended questions. Potential explanations include misinterpretation of the question by respondents; for example, in Vietnam, respondents were not clear whether the question was asking if the respondent actually cared for themselves or if they had the ability to do so. Since the WG question only asks about washing and dressing, some respondents may have answered "no" because they do not have difficulty with these tasks although they may have difficulty with other self-care tasks. One problem that makes interpretation difficult is that the extended questions were dichotomous while the WG questions had scaled responses. Thus, some of borderline patterns might have disappeared if there were scaled responses on the extended questions. Also, some of the extended questions may be less relevant in certain cultures / countries (for instance tying shoelaces or putting on socks or stockings). Thus, inconsistencies in responses to the WG question versus the extended questions may have to do with extent to which extended questions are relevant to the culture and context.

⁹ Additional extended questions: Do you have difficulty (iv) remembering the names of people or places? (v) remembering appointments? (vi) remembering how to get to familiar places? (vii) remembering important tasks, like taking medications or paying bills?

¹⁰ Extended questions: By yourself and not using aids, do you have any difficulty (i) reaching up over your head? (ii) reaching out as if to shake someone's hand? (iii) using your fingers to button a shirt or dress? (iv) putting on socks or stockings? (v) tying your shoelaces? (vi) combing your hair? (vii) feeding yourself?

Data from the field tests demonstrated a similar pattern for the WG question compared to the extended questions, although respondents tended to express more difficulty on the extended questions than the WG question. Field test data from Vietnam revealed a potentially important difference between "unable" on the WG question versus the extended questions. There was a recommended to evaluate these data in more detail to understand the discrepancy.

Overall, the self care question performed well. The question was generally understood by respondents and there were very few problems with the question. Although problems were anticipated with this question because it was oriented toward more complex activity compared to the other WG questions (and therefore potentially more culturally influenced) this did not seem to pose a problem when comparing data across countries. Some of the discrepancies that did exist could have been due to the difference in the number of response categories in extended questions compared to the WG question. The results were felt to be good; the question was interpreted as intended. There were no recommendations for revision of this question.

Question on communicating

Because of a physical, mental or emotional health condition, do you have difficulty communicating, (for example understanding others or others understanding you)?

- a. No no difficulty
- b. Yes some difficulty
- c. Yes a lot of difficulty
- d. Cannot do at all

Summary of pre-test results:

In the cognitive tests, only 85 of the cases (out of 1165) fell into the "problematic" group of response patterns for the communication question. The majority (n=58) of problematic responses were in pattern "n" where respondents answered "yes" to the WG question and "no" to all of the extended questions¹¹. This was interpreted as a problem due to respondent's focus on the introductory phrase of the WG question ("Because of a physical, mental, or emotional health condition...). Examination of responses to cognitive probes revealed that respondents understood the WG question and that for problematic responses, respondents either focused on the introductory phrase, found the question ambiguous, or had a second language problem (i.e. had communication problems because primary language in country was not their native language). At least one of the extended questions captures a concept that is somewhat different than the ability to communicate (it asks whether respondents feel shy in a group or social situations). This extended question was interpreted in a number of different ways by respondents and some of the discordance in responses between the WG question and the extended question was due to this conceptual difference. It was noted that it is important consider the respondent's hearing along with communication because some people reported no communication problem but had hearing problems.

WHO/ESCAP results indicated low sensitivity and high specificity of the WG question compared to the extended questions. The rates of endorsement for the extended questions were higher than that of the WG question. It was reiterated that the results of sensitivity and specificity analyses need to be interpreted with caution since there is no gold standard. Since the extended questions have a 5 point response scale and the WG questions have a 4 point scale, the

6 1/17/07

_

¹¹ Extended questions: (i) *Do you feel shy in a group or social situations? Do you have difficulty* (ii) *in making new friends?* (iii) *in stating and maintaining a conversation?* (iv) *in generally understanding what people say?*

cut-point was reset and preliminary analyses were repeated for this question at the time of the annual meeting. The agreement was better when the cut-points were reset so that more comparable comparisons could be made. The WG question was moderately correlated with the two extended questions that were closely related conceptually to the WG question (difficulty understanding what people say and difficulty starting and maintaining a conversation). It was felt that the complicated phrasing (introductory phrase) of the WG question caused some problems for the respondents which may have contributed to lower correspondence between the WG question and the extended questions.

Generally, the WG question was well understood, however the introductory phrase was found to be misleading. The question was long and interviewers had to repeat the question to respondents. There were few (but some) instances where respondents answered affirmatively because of a second language problem. Concern was expressed that if the introductory phrase is removed, we might create more false positive responses because of second language problems. Therefore, it was recommended to omit the introductory phrase and to move it to the beginning of the entire question set. It was also recommended to add a reference to communicating in one's normal language to avoid false positive responses due to second language problems.