

**JOINT HARMONIZED MEASUREMENT OF
DISABILITY**

FINAL REPORT

COMBINED COGNITIVE AND FIELD TEST

JUNE 30, 2006

GENERAL DIRECTORATE OF STATISTICS, SURVEYS AND CENSUSES

PARAGUAY

INTRODUCTION

Paraguay's General Directorate of Statistics, Surveys and Censuses (*Dirección General de Estadística, Encuestas y Censos de Paraguay* or DGEEC) carried out a combined cognitive and field test of a series of questions proposed by the United Nations' Washington Group (WG) on Disability Statistics, for the improvement of measurement of disability. This test was also carried out by Argentina's and Brazil's national statistical agencies.

This survey elicits information on the health status of individuals, including aspects of both physical and mental health. Thus, the health status refers to the respondents' perception regarding a lack of physical, mental or emotional well-being. It includes illnesses and handicaps such as chronic conditions, loss of a limb or organ, or some other type of physical injury. It also includes vague disorders such as senility, depression, mental retardation, drug dependency, injuries due to accidents, etc.

From April to June 2006, the DGEEC carried out all the activities anticipated within the framework of the Combined Cognitive and Field Test for the measurement of disability according to the terms of reference proposed by the WG.

In the current document we discuss the objectives, terms of reference established, methodological aspects and the main conclusions about the implementation of the combined test for the case of Paraguay. Appendixes include the questionnaire administered, the timeline, tables prepared from the database, summaries of the interviews by age groups and domains, and the interviewer manual.

1. AIMS OF THE COMBINED COGNITIVE AND FIELD TEST

The general aims of this project are to determine how the questions work in terms of their wording and interpretation, in order to finally develop a set of questions that will be used as data collection instrument on disability in the next census.

Specifically, we aimed to:

- Determine if the questions were being understood as anticipated
- Determine if a single question per dimension is representative of such dimension
- Determine if the questions are being uniformly understood across different countries
- Determine if each question yields data that can be compared across countries
- Determine how comparable the proposed question set is to other questions used by each country
- Increase understanding about ways of measuring prevalence
- Identify problem questions and document respondent comprehension as it relates to the goals of each question
- Generate a guide for preparing disability questions for the next census

The aims of the question set are as follows:

- To obtain data comparable across nations
- To be usable in Censuses
- To reliably identify the highest possible number of individuals with disabilities

2. TERMS OF REFERENCE FOR DGEEC

Contract Agency: Paraguay's General Directorate of Statistics, Surveys and Censuses de Paraguay

Context

The Washington Group on Disability Statistics is testing disability questions to be used in the collection of statistics that can be compared internationally through national censuses. Paraguay's General Directorate of Statistics, Surveys and Censuses is one of the organizations in Latin America that agreed to carry out the cognitive and field test. Findings and the testing report are expected no later than June 2006.

Duties

Paraguay's General Directorate of Statistics, Surveys and Censuses will test the Washington Group's general disability questions (combined cognitive and field test).

Tasks

1. Develop the combined cognitive and field test plan
2. Deliver the testing plan for approval to the Washington Group's Secretariat
3. Carry out a training program for interviewers and field supervisors
4. Carry out the combined cognitive and field test. This will involve:
 - Identification of a minimum of 100 participants (some with and some without disabilities)
 - Test the short set of questions proposed by the Washington Group with the additional questions provided in the cognitive test protocol, through interviews
 - Key the data in the format provided and deliver them to the Washington Group's Secretariat.

Final Products

Paraguay's General Directorate of Statistics, Surveys and Censuses will deliver the following final products:

- Plans for the test of the Washington Group's short set of disability questions,
- Report on the activities to prepare for the combined cognitive and field test, indicating the number of persons interviewed,
- The data collected in the prescribed formats, and
- The report on the experiences of the combined cognitive and field test.

The final products will be delivered no later than June 30, 2006.

Duration of the consulting project: from June 1 through June 30, 2006

Payment Plan and Schedule:

The first payment of USD\$ 2,500.00 will be made upon contract signing, given the expenses of the advance stages:

- Fieldworkers' training;
- Questionnaire printing for the cognitive test;
- Office supplies;
- Hiring of field workers and transportation expenses.

The final payment of USD\$ 2,500.00 will be made after successful completion by the contractor of all tasks and delivery of the final products.

3. ACTIVITIES - METHODOLOGY

A. INTERVIEWERS

The selection of interviewers was done using the list of the technical-professional staff of Paraguay's General Directorate of Statistics, Surveys and Censuses, attached to the Census Department. Individuals were selected if they fulfilled the requirements determined by the WG, all being university-educated, specialized in the area of demography and with ample experience in data collection. The fieldwork team was integrated by 8 interviewers, 5 (five) of which are female and 3 (three) are male, all between the ages of 27 and 43. A general supervisor was assigned to the operation. All the interviewers speak both of the country's official languages (Spanish and Guaraní), a basic requirement for carrying out fieldwork.

B. RESPONDENTS

The combined cognitive and field test was administered among residents of Asunción's metropolitan area, given the cost and time that would have been incurred if coverage had been extended to other areas. Fieldwork was carried out between May 26 and June 13, 2006, meeting the planned timeline.

According to the WG's recommendation, individuals age 16 and over were selected, in two main groups: those aged 16-59 and those 60 and over, taking into account the fact that the prevalence of disabilities for the latter is higher than that for those aged 16-59, within each of these groups the incidence of disabilities in the areas covered by the Washington Group protocol was considered, according to data from the last national Census of Population and Housing 2002.

C. SAMPLE SELECTION

The sample was purposive and was elaborated following the distribution of disabilities according to the 2002 National Census of Population and Housing (see appendix).

Respondents were selected on the basis of specific personal characteristics according to the distribution of the sample, such as age, presence or absence of disability, and type of disability. The project had constant cooperation from different institutions that work on the topic of disabilities such as: the National Institute for the Protection of Exceptional Persons (INPRO), the Association for the Rehabilitation of the Physically Handicapped (ARIFA), the School of Job Training of the Ministry of Education and Culture, National Commission for the Protection of the Disabled (CONAPRODIS), and the collaboration of other volunteer individuals.

Initially, 100 surveys were planned, of which 70 would be done among individuals with disabilities and 30 among individuals without disabilities. Finally, a total of 111 interviews were conducted: 81 with people with disabilities and 30 with people without disabilities. It is worth highlighting that of the total number of interviews, 91 were done with their corresponding informants, 13 without informants, and finally 7 were done by proxy only, given the fact that these surveys were directed to people with advanced communication difficulties (deaf, mute, and severely mentally retarded) which made completely impossible their participation as respondents.

Completed interviews by type, 2006

	Total # respondents
With informants	91
Without informants	13
By proxy	7
Total	111

Completed interviews by condition and type of disability, 2006

Condition and type of disability	Total # respondents
With disability	81
Visual	10
Auditory	5
Motor	20
Speech	8
Cognitive-Mental	28
More than one disability	10
Without disability	30
Overall total	111

D. QUESTIONNAIRE

The starting point for designing the questionnaire was the English version sent by the WG and the questionnaire adapted by IBG in Portuguese, which were first translated, as well as the questionnaire used by Argentina's INDEC.

The final questionnaire consists of three ways of administration: one directed at the respondent (disabled), another directed at the informant (a household member), and finally one at the interviewer.

The original questionnaire sent by the WG was followed as closely as possible, only incorporating changes in the questions regarding the socio-demographic characteristics of the population so as to make them comparable to the way in which they were measured in Paraguay's last census of population and housing.

One change that was made was the operationalization of the variable for education level, grade, current and previous attendance, age, working status, occupational category, marital status, and monthly household income, since it was contemplated that each country would adapt these questions as appropriate.

The disability questions were literally translated. Even though problems had been identified in prior review and in the pilot test regarding skip instructions, missing or inadequate response categories, the decision was made to maintain the structure of the original questions and response categories of the WG, according to the guidelines.

1. QUESTIONS TO BE TESTED FOR CENSUSES (GENERAL MEASUREMENT OF DISABILITY). Appendix 2

Core Questions:

Do you have difficulty seeing, even if wearing glasses?

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

Do you have difficulty walking or climbing steps?

Do you have difficulty remembering or concentrating?

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

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

Control Questions:

The questionnaire presents a series of additional questions that should be used to verify the general validity of the core and secondary questions.

Response categories for the six questions (core and additional):

No – no difficulty

Yes – some difficulty

Yes – a lot of difficulty

I cannot do this activity

(For measurement of degrees of difficulty – The Washington Group's plan is to develop an index of severity by combining the answers received for the different dimensions)

E. TRANSLATION

Following the guidelines in the translation protocol for adapting the questions to the language of the country, a bilingual translator conducted the translation of the questionnaire preserving the original meaning of the questions and the methodological documents. We started with the English version of the questionnaire and simultaneously translated IBGE's Portuguese version into Spanish. To insure the correct interpretation of the meaning and spirit of the original draft, we also consulted methodological documentation on the measurement of disabilities.

The final process for translation of the questionnaire consisted in submitting a Spanish version to external review by an independent translator, who verified the sequence of the translation and recommended final fine tuning. With the aim of insuring the reliability of the translation, the Paraguayan translation was also compared with the version translated by Argentina, which allowed for clarification of some concepts which were not completely clear. The final version utilized is enclosed.

Most interviews were carried out in Spanish but in some cases it was necessary to use Guaraní to provide explanations for certain questions or response options.

In order to establish the sequence and nature of the activities to be carried out, as well as the conceptual framework for the measurement of disability, the methodological documents were translated, such as the guide for administration and specification of the interviews, instrument development, aim of the questions, translation protocol, among other materials.

No significant changes were made in the translated version of the original questionnaire for measuring disability. Only language adaptations were made to achieve better comprehension on the part of the respondent and the interviewer.

The translated questionnaire was adapted to the cultural and linguistic characteristics of Paraguay in workshops with the Technical Team on Disability (ETD) of the Census Department (use of local terminology, response choices adequate to the country's reality).

The interviewers conducted practice interviews with each other, with their relatives, as well as with staff from the National Institute for the Protection of Exceptional Persons (INPRO), in order to identify and prevent potential problems in the execution of tasks in the field and in order for the interviewers to become familiar with the use of the questionnaire. This experience allowed to verify the reliability of the translation and to make final adjustments.

F. DATA QUALITY

1. The set of core questions performed satisfactorily, without major comprehension issues among respondents, except for the term 'audífono'¹ (sometimes confused

¹ Translator's note: 'Audífono' means hearing aid.

with headphones) and for the need to clarify that mobility is measured without the use of assisting devices.

2. The data were recorded as per the respondent’s answers, even when the interviewer noted they were inconsistent with earlier answers provided.
3. Given the way in which core question #3 is worded – Do you have any difficulty remembering or concentrating? – it apparently only captures the disabled person’s ability to concentrate and not the ability to remember.
4. For every domain, questions X3, X4 y X5 are not applicable when the answer to the corresponding core question is Can not... see, hear, do – (code 3).
5. We recommend a change in the response categories for question 2.11 “How often do you miss words in conversation or on the radio or television because you have difficulty hearing?”

<u>Current</u>	<u>Recommended</u>
Never	Never
Once a week	Sometimes
Every day	Almost always
	Always

6. Questions 2.3, 2.3a, With and without hearing aid, how often do you have difficulty hearing well? 2.4 and 2.4a, With and without hearing aid, how much effort do you have to put into hearing well? are confusing to the interviewer, requiring a great degree of attention to distinguish when or when not to ask them.
In some cases the word ‘audífono’ was interpreted as ‘headphones’ by respondents who do not use hearing aids, and this required an additional explanation on the part of the interviewer.
7. In cases in which there are no informant or in which data from the disabled respondent is not available, the data should be coded as ‘9’, code corresponding to “**No answer/Don’t know**”.
8. For each of the dimensions being researched it would be useful to explicitly collect the name of the disability, that is, it would be useful to record the type of disability suffered.
9. Regarding the collection of income data: household income is currently collected, but it would also be advisable to collect data on the income of the person with disabilities, as this can indicate a great difference in the availability of resources to attend to the person’s needs.
10. In question X.1 Why did you answer that way? which is present for all domains, a) Sometimes the answers are too obvious and brief: “just because”, “because that’s the truth”, “because that’s how he was born”, “because I have no problems”. b) At other times, upon reading the first question Do you have any difficulty...?, one simultaneously elicited the explanation for the following question. In such cases, the interviewer chose not to ask this question and simply recorded the answer, or

asked the question while apologizing for asking something for which s/he already knew the answer.

Vision

11. Individuals with intraocular lenses: they should be treated the same way as those who use other types of lenses (eyeglasses or contacts).
12. Persons who are completely blind but who wear eyeglasses for aesthetic reasons were not considered as wearing glasses, since the purpose is to measure the person's ability to see with an assistive device.
13. Question 1.5 Are there any activities that you cannot do because of a problem with your vision?, should specify whether this is with or without eyeglasses.
14. Question 1.10 "Do you have difficulty...? The use of glasses for short distance and long distance (depending on which one the person has) leads people to indicate they have or do not have difficulty when it is actually a problem of which glasses they are using.

Hearing

15. Question 2.9 Without your hearing aid, do you have difficulty hearing what is said in a conversation with one other person...
 - a. ...in a crowded room?, some respondents asked what they should assume is the sound level in the room.

Cognitive

16. The problem for learning is not associated with mental retardation in the questionnaire, although the person whose mental development is lower than it should be for his/her biological age is not considered as being mentally retarded in question 7.3.
17. When a task is new for the person, there is always some initial difficulty to carry it out, independently of the disability the person may suffer.
18. The example in Question 3.10, Do you have difficulty learning a new task, ***such as learning to get to a new place?***, makes it harder to elicit a wide response given that the respondents associate their answer only to the example provided and not regarding their ability to learn to do other types of activities.
19. Question. 3.8: In option a) names of people or places, there are no problems when these are known places or people, except for occasional or low frequency instances. Option d) important tasks like taking medications or paying bills or taxes. Note: among people with disabilities, with the exception of heads of household, paying bills or taxes is not a very frequent task.
20. In Question 3.5, Do you believe that your memory or concentration difficulties are...?, informants in particular, but also in some cases the disabled individuals,

mention that they remember things selectively, depending on how much they are interested in the specific thing.

Mobility

21. To obtain better responses, an explicit clarification is lacking in the question regarding the fact that in this domain the point is to research the disability without the use of any type of assistance.
22. Question 4.11e: Most individuals with motor disabilities indicate they have difficulty kneeling, but not crouching or stooping.
23. This identifies the visually impaired who have difficulty moving about, not because of a physical impairment or disability, but rather because their blindness makes them dependent on others.
24. Persons with lateral physical impairment (hemiplegics) are not identified as persons with disabilities with this questionnaire, since with their able extremity they are capable of performing all the activities mentioned in the questionnaire.
25. In the translation, some respondents associated the word “aparato” with orthopedic equipment.²
26. In the questions asking about distances that people are able to walk, 4.10 y 4.11 a) and b) : it would be useful to sort the distances from shorter to longer, since if the person reports s/he can walk 10 blocks, s/he can obviously cover the other shorter distances mentioned, and this order sounds odd to the respondent.
27. In some cases, persons with disabilities (mobility and vision) reported that their problems getting around outside the home are due to the lack of accommodations in the physical and social environment, rather than to the disability itself. In cases of persons with mental problems, the difficulty in going outside of their homes is related to discrimination.

Self-care

28. Difficulty in self-care is tied to architectural barriers, such as narrow doors, steps, handles, and not to the person’s disability.
29. Dressing: Paraguayans associated this just with clothing; that is, the act of putting on shoes is not considered a part of getting dressed.
30. The degree of worry or concern about personal care is associated with the concern about cleanliness rather than the ability to take care of one’s self.

² Translator’s note: Although there is no question number, apparently ‘aparato’ is the word Paraguay used to translate ‘equipment’.

31. In question 5.4 “How concerned are you about your ability to care for yourself?”, in some cases – particularly those with mental problems – report indifference or loss of the ability to worry. The same is true with individuals with extreme visual or hearing impairment.
32. In question 5.8, Do you ever feel too tired or sad to dress or bathe?, a) there is a mixture of concepts that should be separate; tiredness is of a physical-psychical nature, while sadness is psychical-emotional. b) This question does not always elicit an absolute answer; it became necessary to force an answer. Respondents often answered “sometime” or “a little”. c) It would be useful to add to the possible Yes/No answers an in-between alternative such as “sometime” or “a little” or “once in a while”, all of which were frequent responses that presented difficulties for coding as one or the other available extreme response choices.
33. In question 5.6 “Do you always³ need someone to help you with everyday activities, such as eating, showering, dressing or toileting?”, in the set of activities for those persons who have lower mobility problems, respondents report they are able to carry out all of the activities listed (such as showering, dressing), except for toileting, since the infrastructure in their homes requires that they be transported and set up to use the facilities.

Communication

34. Difficulties to begin and maintain a conversation depend on two factors: the person’s ability to communicate and their level of language.
35. In question 6.8, “Do you feel shy in group or social situations?”, the answer to this question was not always an absolute Yes/No and required forcing the respondent to make a choice. With some frequency respondents answered “sometimes” or “a little”.

General Health

36. To obtain an answer in question 7.2 (“Were you thinking about the ... physical, mental, spiritual state of ?”) it was necessary to refer, in most cases, to question 7.⁴
37. Question 7.3: There is an overall ‘Don’t know/No answer’ response category for the set of alternatives, however, each response category is independent and in order to properly specify the answer and avoid omissions, there should be three alternatives in the questionnaire for each item: yes, no, don’t know/no answer.

³ Translator’s note: This item reflects an inaccurate translation from the original English item which read “Do you ever need...?”

⁴ The original English item was posed as a question to the interviewer, not as one for the respondent or informant (proxy) as this seems to indicate.

Data Entry

Here we discuss some considerations to be taken into account for managing the data base.

38. With regard to question 12 in the “Socio-demographic Characteristics” section, in the column for gender the same codes will be used as in question 1, that is, code “1” for female and “2” for male. In the same question, in the last column the letter “I” will be entered in cases where the survey was done with the informant and “D” when it was done with the household member with a disability.
39. Data entry for open-ended answers to the questions Are there any activities that you cannot do because of a problem... with your vision, with your hearing, with your memory or concentration, or with your legs?, will be done verbatim as provided by the respondent. The corresponding codes will be set up after data entry is completed.
40. Notes fields are added for all variables.
41. **Questionnaire ID number** is the key variable for the data base.

Recoding of Respondents’ Answers to Fit in the Questionnaire Response Options

Vision

Question 1.3 “[Without your glasses or contact lenses], how often do you have difficulty seeing well?

“Always” into Almost always

Question 1.4 “[Without your glasses or contact lenses], when you have difficulty, how much effort do you have to put into seeing?

“Always” into Almost always

Question 1.4a “With your glasses or contact lenses, when you have difficulty, how much effort do you have to put into seeing?

“Always” into Almost always

Question 1.5 “Are there any activities that you cannot do because of a problem with your vision?

“My blindness is total” into A lot of effort

“Not applicable” into A lot of effort

Hearing

Question 2.3 “[Without your hearing aid], how often do you have difficulty hearing well?

“Always” into Almost always

Question 2.11 “How often do you miss words in conversation or on the radio or television because you have difficulty hearing?”

“Sometimes, when they talk very softly” into Once a week
 “Sometimes” into Once a week

Cognitive

Question 3.3 “How often do you have difficulty remembering or concentrating well?”

“Always” into Almost always

Mobility

Question 4.4 “ [Without your equipment – REPLACE WITH NAME OF EQUIPMENT USED], how often do you have difficulty walking or climbing steps?”

“Sometimes I can’t stand up” into Almost always
 “I cannot walk without my wheelchair” into Almost always
 “Always” into Almost always

Question 4.4a “When using your [REPLACE WITH NAME OF EQUIPMENT USED], how often do you have difficulty walking or climbing steps?”

“Always” into Almost always

Question 4.5 “When you are having difficulty, without using your [REPLACE WITH NAME OF EQUIPMENT USED], how much effort do you have to put into walking or climbing steps?”

“I can’t do it” into A lot of effort

Question 4.5a “When using your [REPLACE WITH NAME OF EQUIPMENT USED], how much effort do you have to put into walking or climbing steps?”

“I cannot walk” into A lot of effort

Self-care

Question 5.8 “Do you always⁵ feel too tired or sad to dress or bathe?”

“Sometimes” into Yes

FINAL COMMENTS

A. Cards

The use of cards was feasible when the respondent was a person with the right level of education. However, in certain circumstances, it was unnecessary, and without the cards the interview progressed more fluidly.

Nevertheless, when the person interviewed has a very low level of education, the cards are entirely useless or unnecessary.

⁵ The English version of the questionnaire has ‘ever’ instead of ‘always’ in this item.

B. Informants

1. In cases where the person with disabilities lives alone or with elderly persons or household help it is difficult to find the right person to assist in the interview or answer as proxy.
2. Some informants do not know the disabled person well, even when they may be close relatives.
3. Persons with disabilities sometimes fail to report certain illnesses because their relatives have kept their conditions from them.
4. In some cases, clarification was requested for the secondary questions but not for the corresponding core questions, apparently due to the fact that the secondary questions are longer and, after the response choices are read, they ask to hear the question again.
5. In very few cases, the informant acknowledges that the respondent has some difficulty at the time of the core question. However, when asked the secondary question, the informant answers as though such difficulty is not present; in those cases, the answer is written in on the margin, by the response choices, and a field is added in the database where the corresponding note is recorded, proceeding in the same fashion in the other cases.

C. Recommendations

1. In the response choices there should be a category corresponding to absolute difficulty, although we understand that the word ‘any’ covers the categories of a little, a lot and complete difficulty, not all respondents understand it that way.
2. Provide response columns for question 7.3 ¿Do you have any of the following difficulties?⁶, since in the current format it is not possible to distinguish between cases in which the respondent has none of these difficulties and those in which the interviewer omitted the question.

	Yes	No	Doesn't know
Asthma/bronchitis			
Arthritis/rheumatism			

3. In the fourth question to the interviewer “The respondent had one of the following impairments making it difficult to respond”, add response category “none of the above” for control of non response or missing answers.

⁶ Translator’s note: the original English question reads: Do you have any of the following conditions?