

Report on the Cognitive Test and Field Test

Individuals with Disabilities

Brazil

April 2006

Introduction

This report is about the Cognitive Test and Field Test conducted in Brazil to test the questions on the topic of Individuals with Disabilities. The report includes an executive summary, a discussion of the methodology employed, the operational aspects and the analysis of the results obtained.

**Demographic Census
Committee**

Table of Contents

1. Executive summary
 - Introduction
 - Methodology
 - Interviewers
 - Respondents
 - Questionnaires
 - Translation
 - Data quality
 - Findings
2. Methodology and Operational Aspects
 - Fieldwork
 - Team
 - Training
 - Sample
3. Analysis
 - Structure and general aspects of the questionnaires
 - Question by question
 - Analysis comparing each basic question with a corresponding additional questions
 - Informant bias
 - False negatives
 - Analysis of open questions

1. Executive Summary

Introduction

The Cognitive Test on Individuals with Disabilities in Brazil was fielded in April 2006 in the southeast, northeast and southern regions in which specific areas were selected in the municipalities of Rio de Janeiro (Rio de Janeiro), Olinda (Pernambuco) and Curitiba (Paraná).

The Team of the Demographic Census Committee was involved in the conceptual design and questionnaire design, drafting of the instructions manual and other training materials, the analysis plan, and the selection of sectors.

The Team of the Demographic Census Committee administered the training for the technicians of the aforementioned State Units who were assigned as survey interviewers. In addition, it conducted observations and supervision of the data collection of the Cognitive Test on Individuals with Disabilities in the selected areas.

Methodology

a. Interviewers

Interviewers were selected among IBGE professionals, both permanent and contract employees, taking into account their previous experience with censuses and/or other household surveys. With the exception of an interviewer with just one year of experience in household surveys, all had over 10 years of experience in either household surveys or the census. None of the interviewers were students, but 30% have higher education, 47% middle level (over 10 years of education) and 23% basic education level. Of the total of 15 interviewers, 9 are females -- one in her 20s and the rest between the ages of 45 and 55. Among the men, one is in his 20s and the others between 45 and 54 years old. All interviewers speak Portuguese.

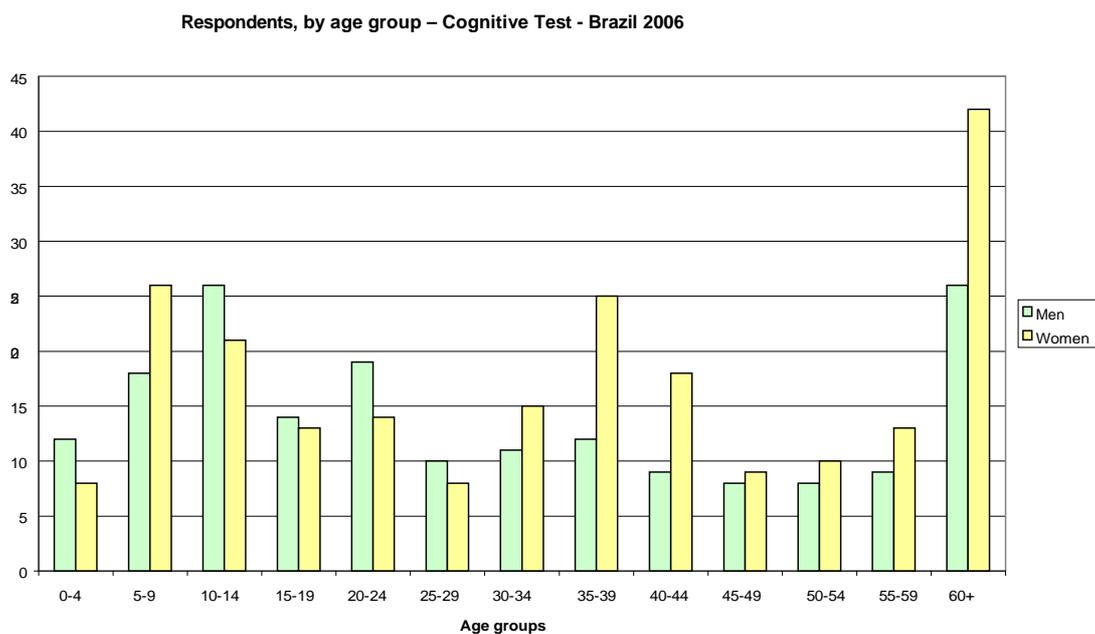
b. Respondents

A total of 406 people were interviewed. Among them, 227 indicated they have at least one of the difficulties being investigated. Since all the people with at least one of the difficulties being investigated answered all the questions in the Self-report Questionnaire, a total of 641 cases of disabilities were recorded, that is, each person with a disability, on the average, gave a positive answer in more than two modules. The socio-demographic profile of the respondents can be seen below.

First, a list of addresses was prepared, of individuals with the disabilities researched in Census 2000; it was developed on the basis of data from the Census. Due to sample loss mainly associated with change of address of people with disabilities, it was necessary to complement the list. This was done on the basis of

information obtained from the field, through indications of previously selected informants and visits to institutions serving people with disabilities.

The quota sample was stratified by type of disability researched in Census 2000, trying to include both genders and the following age groups: 0-14, 15-64, 65 and over.



Source: IBGE, Demographic Census Committee. Cognitive Test and Field Test on Individuals with Disabilities. 2006

Total number of respondents by gender and age groups, by years of education

Gender and age groups	Respondents						
	Years of Education						
	Total	Missing	Never Attended School	0 to 4	5 to 8	9 to 11	12 or more
Total	406	28	49	148	83	70	28
Age 0-14	111	10	28	52	20	1	0
Age 15-64	243	15	12	71	54	67	24
65 and over	50	1	9	25	9	2	4
Unknown	2	2	0	0	0	0	0

Source: IBGE, Demographic Census Committee. Cognitive Test and Field Test on Individuals with Disabilities. 2006

Total number of respondents, by gender and age group, by activity condition in the reference week and by earnings from all jobs.

Gender and age groups	Respondents											
	Work					Earnings from jobs (R\$)						
	Total	Missing	Paid Work	Working, Not for pay	Not Working	Total	Missing	Does Not have	300.00 And under	>300.00 and <= 1500.00	>1500.00 and <= 3000.00	>3000.00
Total	406	57	101	6	242	406	291	5	40	62	5	3
Age 0-14	111	30	0	0	81	111	109	2	0	0	0	0
Age 15-64	243	24	97	6	116	243	137	3	38	57	5	3
65 and over	50	1	4	0	45	50	43	0	2	5	0	0
Unknown	2	2	0	0	0	2	2	0	0	0	0	0

Source: IBGE, Demographic Census Committee. Cognitive Test and Field Test on Individuals with Disabilities. 2006

c. Questionnaires

Four questions were added that had been used in the 2000 Demographic Census. Also, a thematic module was augmented: Body Structures and Functions, since this topic was requested by the National Coordinating Body for the Integration of Individuals with Disabilities – CORDE. In addition the response categories of some probes and functional questions were modified, however the basic questions and their response categories were preserved.

d. Translation

All interviews were conducted in Portuguese. A translation of the questionnaire was carried out by technicians involved in the project, taking into consideration the cultural characteristics of the country, so that some terms were not translated literally.

The questionnaire was tested among IBGE staff, with relatives and friends of the technical staff involved in the project. There were no problems related to the translation, so it was not necessary to make modifications to the questionnaire due to translation difficulties.

e. Data Quality

Because of the length of the questionnaire, respondents' cooperation declined in the questions of the final modules. Therefore, there is some concern that these data are not of the same quality as those related to the questions in the initial sections of the questionnaire.

Interviewers reported problems related to the sample list: addresses not found and potential informants that moved away; excessive questionnaire length, and problems related to interview administration training such as the fact that reading all questions exactly as worded made the interviews tiresome.

Generally speaking, few inconsistencies were identified. There was only partial non-response, with no loss of information in the core questions. In some cases the respondent did not wish to continue with the interview, in others it was not possible to complete the interview because the respondent was not available during the field period.

f. Results

The six core questions recommended in the Washington Group protocol for the cognitive test: 1) Do you have difficulty seeing, even with glasses or contact lenses?; 2) Do you have difficulty hearing, even with a hearing aid?; 3) Do you have difficulty remembering something or concentrating?; 4) Do you have difficulty walking or climbing steps?; 5) Do you have difficulty caring for yourself, such as dressing or bathing?; 6) Because of a physical, visual, auditory, mental or emotional condition, do you have any difficulty communicating, for example understanding others or being understood by others?

In addition to those questions, an additional module of questions was added to research aspects related to body structure and functions, in which the basic question was: Do you have any of the following physical impairments: (record only the first response), the body functions and structures with response options that include different types of paralysis or a missing limb or body part.

Considering the wording of the questions, in most cases the questions recommended by the Washington Group were easily understood. Frequently respondents gave their answer before hearing all the response categories, given the clarity and simplicity of the questions, which made them easy to understand by people with different levels of education. In many cases, it was necessary to wait for the respondent to finish answering, to then read the categories and ask him/her to choose that which best described his/her situation. However, some problems were observed regarding strictly following the objectives of the questions.

Generally speaking, the questions about vision and hearing did not present comprehension problems. These questions were well understood during the interviews. On the other hand, the questions did not make clear that the objective is to investigate the difficulties that imply impairment or limitation of activities and therefore all types of difficulties were captured. Thus, the question overestimates the population with difficulties as it includes persons who are suffering from temporary limitations.

The question about cognitive limitations did not present problems in terms of formulation; however it presented many problems regarding the goal of capturing serious limitations. It is a very inclusive question and for that reason it captured all types of difficulties related to memory and concentration. On the other hand, the question did not capture some cases of mental deficiencies such as Down's syndrome, which were captured by the question used in the 2000 Demographic Census.

The question in the mobility module was also easily understood by respondents. Nevertheless, the question does not mention that the degree of difficulty needs to be evaluated without the use of equipment or assisting device. Therefore, individuals who normally use some type of aid to move around will remain in doubt as to whether or not to take such aid into consideration.

Generally speaking, the question about self-care was easily understood, although in some cases respondents found the example of bathing odd. Some people quickly answered that they have no difficulties to bathe and that no, they do not have difficulties caring for themselves, giving the impression that they wanted to show they had good hygiene habits. As in other questions, this one does not make it clear that the goal is to research permanent difficulties, and therefore it also included persons with temporary difficulties.

The question about communication did not present comprehension problems. Nevertheless it was hard to administer because of its length. As other questions, it does not make it clear that it is about communication difficulties that make it hard to carry out daily activities, and therefore it also captured all types of difficulties. Considering that it is administered together with the questions about vision, hearing and cognitive difficulties, this question duplicates the efforts to identify persons with difficulties, because it also included conditions previously investigated by the abovementioned questions.

2. Methodology and Operational Aspects

For the Cognitive Test and Fieldwork, 142 addresses were visited, in which 406 direct interviews were conducted in the period between April 10 and 20, 2006. Respondents had the following characteristics:

Gender and Age groups	Persons interviewed according to their characteristics					
	Years of education					
	Total	Missing	Never Attended School	0 to 4	5 to 8	9 or more
Total	406	28	49	148	83	98
0 to 14	111	10	28	52	20	1
15 to 64	243	15	12	71	54	91
65 and over	50	1	9	25	9	6
Unknown	2	2	0	0	0	0
Men	182	11	19	66	40	46
0 to 14	56	4	14	29	9	0
15 to 64	112	7	5	29	27	44
65 and over	14	0	0	8	4	2
Women	224	17	30	82	43	52
0 to 14	55	6	14	23	11	1
15 to 64	131	8	7	42	27	47
65 and over	36	1	9	17	5	4
Unknown	2	2	0	0	0	0

Gender and age groups	Characteristics of persons interviewed											
	Employment Status					Work earnings (R\$)						
	Total	Missing	Working for pay	Working – not for pay	Not working	Total	Missing	None	Under 300.00	>=300.00 & up to 1500.00	>1500.00 & up to 3000.00	Over 3000.00
Total	406	57	101	6	242	406	291	5	40	62	5	3
0 to 14	111	30	0	0	81	111	109	2	0	0	0	0
15 to 64	243	24	97	6	116	243	137	3	38	57	5	3
65 and over	50	1	4	0	45	50	43	0	2	5	0	0
Unknown	2	2	0	0	0	2	2	0	0	0	0	0
Men	182	25	52	3	102	182	122	2	17	35	4	2
0 to 14	56	16	0	0	40	56	54	2	0	0	0	0
15 to 64	112	9	50	3	50	112	57	0	17	32	4	2
65 and over	14	0	2	0	12	14	11	0	0	3	0	0
Women	224	32	49	3	140	224	169	3	23	27	1	1
0 to 14	55	14	0	0	41	55	55	0	0	0	0	0
15 to 64	131	15	47	3	66	131	80	3	21	25	1	1
65 and over	36	1	2	0	33	36	32	0	2	2	0	0
Unknown	2	2	0	0	0	2	2	0	0	0	0	0

Fieldwork

Given that this work is quite different from the other surveys done by IBGE, there was a need for interviewers to get used to the structure of the cognitive test, as well as familiarizing themselves with the questions,. In the first few days it was necessary to hold meetings to remember the goal of the study, the reasons why it is necessary to ask similar questions, the importance of having more than one questionnaire about the same person (Proxy and Self) and mainly the importance of this work for the next Census. To a certain extent, the interviewers are used to quantitative research and this cognitive test does not seem to them to be very practical. Because the interviews are lengthy, there is the feeling of lack of progress in the work, which caused them some distress.

Once the adaptation phase was over, the work was conducted as planned and, understanding the goals of the cognitive test, the interviewers were able to do their work independently.

There were two supervisors/observers per Unit of the Federation. Each of them accompanied different interviewers so that each interviewer was observed at some point during the field period.

On the first day of fieldwork it was observed that the mean interview time with each respondent was about 40 minutes. Therefore, in a household of four people and only one person with a disability, the total interview time would be over three hours.

The interview length was due to the following factors: first, the fact that according to the instructions, in each residential address selected, an Informant Questionnaire needed to be pre-filled with the information about each household resident and the Self Questionnaire with the information provided by the person with disability his/herself; but also due to the size of the questionnaire that, in eight modules, includes more than 100 questions. Moreover, the topic requires certain sensibility and disposition to listen to the respondents. In some cases the respondent wanted to think before responding, in other s/he wanted to tell his/ her family history and talk about the motives that led to the person's impairment. In other situations, they wanted to speak about their experiences living with the disability. There were also cases in which the respondent did not want to complete the interview because s/he got tired and bored with so many questions. Two interviews were not completed because the respondent did not want to continue providing information, asking the interviewer to return the following day.

The time taken was too long for the interviews to be completed on the same day, which made it necessary in several cases to return to an address. Once this was determined, and the estimated time for data collection, the decision was made to conduct the complete interview, in the Informant Questionnaire, only with some of the household residents including one person with a disability, and to pre-fill some characteristics such as gender, age, and others for all residents.

Reading all the questions with their corresponding response categories exactly as worded made the interviews tiresome, both for the interviewer and for the respondent. The requirement that the questionnaire be read to the respondent made the interview seem like a mechanical act, preventing good interaction between interviewer and respondent. Even in cases in which the respondent attempted to chat about the topic, rather than simply responding to the questions, the requirement to

read the questions made it difficult to create an environment where both, interviewer and respondent, could feel more relaxed, with the cordiality required of an interview.

The requirement to read the questions in sequence (see, for example, in questions 4.08 through 4.14, 5.11 through 5.15, among others) which were initially identically worded, with the exception of the question ending (type of difficulty about which the question is asking), took too long and bored the respondents. In some cases it was noted that the interviewer asked only the first question in the sequence, asking in the remaining items just the ending of the question, as for instance in: "Do you have difficulty remembering names of persons or places?"... "and remembering appointments?" ... "and taking medications?" ... Although it greatly facilitated the interview, the adoption of this procedure was an individual decision, since the general instruction given was that all questions had to be read.

In a majority of the cases, the respondents were patient and helped with the interviews. Only in two cases the respondents refused to continue the interview. One of them was too tired and, after almost 3 hours of interview requested that the interviewer return another day. Another one said he did not wish to answer questions any longer because they were personal and repetitive. Many respondents mentioned that the interview is very long and the questions are repetitive and boring. In some of the cases observed, the interviewer abbreviated the interview, asking general questions instead of reading the questions exactly as worded, when they perceived that they were taking too much of the respondent's time and that s/he was getting impatient.

The questionnaire is too long to be administered to one single person. Perhaps it would be more productive to only apply one or two modules to each person with a disability. This might be a strategy to spare the respondent and gain in interview quality. We observed, for instance, a person with a physical disability who had to answer the whole questionnaire before getting to the module that best captures his disability, got tired and abbreviated his answers regarding Body Structures and Functions.

The interview conducted with the person with disability him/herself seems to have worked well for most questions, although we observed two cases in which a person with mental impairment denied having such impairment. In both cases, the impairment was apparent and was confirmed by an informant.

Equipment

To conduct the cognitive and field test three work teams were organized, one for each unit of the federation. In Rio de Janeiro and in Olinda, each team was composed of two experts based in the Research Directorate and four interviewers based in the local agencies. In Curitiba the team was integrated by two experts based in the Research Directorate and seven interviewers based in the local agencies.

The experts, with experience in different stages of implementation of demographic censuses and other surveys were responsible for training the interviewers as well as escorting and supervising the interviews. The interviewers, all with prior experience in data collection in surveys or in the demographic census, were responsible for conducting the interviews.

The coordination was done by the Census Committee Coordinating Entity.

Training

Training was conducted over a two day period and covered concepts and definitions about persons with disabilities, methodology of the cognitive test, presentation of two different types of questions (core, probes, functional and additional) and different types of questionnaire (Proxy/Informant and Self), as well as the presentation of the questionnaire, question by question with the respective goals and formulation of each question.

Sample

In each of the Units of the Federation, a limited number of addresses was selected in which it was expected that persons would be found who would answer each module/question, of the Proxy and Self Questionnaires, thus reaching pre-established quotas of persons with disabilities and persons without any of the researched disabilities as specified below:

- 14 interviews with persons with visual disability (module 2/Vision – Self Questionnaire) prioritizing ‘great difficulty’ or ‘unable’ to see.
- 14 interviews with persons with auditory disability (module 3/Hearing – Self Questionnaire) prioritizing “much difficulty” or unable to hear.
- 14 interviews with persons with mental disability (question 4.15 in module 4/Cognitive – Self Questionnaire)
- 10 interviews with persons with difficulty walking/climbing steps (module 5/Movility – Self Questionnaire), prioritizing “much difficulty” or “unable” to walk/climb steps)
- 10 interviews with persons with difficulty to care for themselves (module 5/Self Care – Self Questionnaire)
- 10 interviews with persons with difficulty to communicate (module 6/Communication – Self Questionnaire)
- 14 interviews with people with physical disabilities (module 7/Body structures and functions – Self Questionnaire)
- 14 persons without any of the disabilities being investigated

In total, considering the quotas of each of the three Units of the Federation where the interviews would be carried out, it was expected that 100 interviews would be obtained in each Unit of the Federation, for a total of 300 interviews.

Taking into account that the database for the selection of the sample was Census 2000, it was expected that there would be some sample attrition due to respondents having moved in the intervening six years or even died. Yet the possibility was considered of having made some classification mistake in the Census, though minimal. Therefore, 276 addresses were selected in which it was expected to find 460 persons with a disability and 671 without. In interviewing persons with a disability it was expected that 711 cases of disability would be identified since some persons had more than one of the types of disabilities researched in Census 2000.

The difficulty in carrying out the fieldwork on the basis of the information from Census 2000, due to loss of addresses and consequently of respondents was larger than anticipated. Nearly 45% of the addresses could not be visited due to the fact that they could not be found (change of street numbers, demolitions, or incomplete addresses in the Census 2000 listings), due to being locked or vacant, or due to refusals. In about 60% of the addresses visited we were unable to find at least one of the persons with a disability sought, due to respondents having moved or died. In some cases it was

possible to interview a different person with a disability at the same address but in other cases there was not even one person with a disability. It is worth noting that in only one case there was a person identified as having a disability in the Census 2000 database who had had surgery since and therefore no longer had the disability reported on.

Given the difficulties to conduct the work on the basis of the previously built list, strategies were adopted for the construction of complementary lists. Such lists were built in the field and had as basis the information provided by the interviewers who, given their extensive knowledge of the area, were able to identify institutions or associations of persons with disabilities, through which it was possible to find individuals, and also on the basis of the information provided by the persons with disabilities themselves who provided referrals to find other persons.

At the conclusion of the fieldwork, 227 persons had been interviewed with at least one of the difficulties researched, therefore the effective sample were 406 interviews. As all the persons with at least one of the difficulties under research answered all the questions in the Self Questionnaire, in total 641 cases of disability were recorded, that is, each person with a disability had an average of 3 disabilities.

3. Analysis

The qualitative analysis was based on the observations in the cognitive and field test interviews. Therefore, the report presented in this section takes into consideration basically the perception of the interviewers and observers regarding the reactions of the respondents, as well as the additional comments and suggestions made by respondents during the interviews.

Structure and General Aspects of the Questionnaires

Skip Instructions

The skip instructions formulated as a headline were difficult to grasp for the interviewers. In some of the interviews that were observed, the interviewer needed to read the headline, even if to him or herself, so as not to ask questions inappropriately.

It was also observed that the interviewers' need to use critical thinking, and should have freedom to introduce skips according to specific situations. This is the case of prefilling of the module on mobility in the interview to persons with physical disabilities. Even if this module comes earlier than the module where the physical disability is detected, already in the core mobility question the respondents mentioned that the difficulties reported are the result of a physical disability. According to the instructions, the questions that inquire whether the person can walk short or long distances, for example, must be done for everyone. However, this question does not apply to a person who always uses a wheelchair to move around or even for the persons who do not have both legs (we did not run into any such case; thus, this is just an example). In some situations, the respondent provided the information in advance, already in the core question, telling a long story, covering what s/he is able and unable to do, which made the reading of some of the questions to cause distress.

Open-ended Question

In most of the cases observed the question was confusing for the respondent. It was observed that when choosing the response category of the core question, the respondent explained the reason for the choice, as for example: "I have much difficulty seeing because I have myopia and I don't wear glasses", or "I have much difficulty walking and climbing steps because I have arthritis". However, when we asked "why did you answer that way?" the majority of persons did not understand the question. At first, they did not understand that it was related to the core question and when we explained it, the person was surprised because s/he knew that s/he had already answered why when they provided an answer to the core question. Some persons were not able to grasp the goal of the question, not even after the interviewer's explanation and said that they had answered that way because "it's the right answer", "just because", "because I live with this person", or "because I see what goes on".

In specific situations, such as those found in module 7, Body structures and functions, it is very restrictive to ask this question. In the interview of persons with some physical disability, whether it is paralysis or a missing limb, it is very unpleasant to ask why did the person reported s/he is paralyzed or is missing a limb. There is a subtle difference between persons with a physical disability and the other types of difficulties. Generally speaking, when they are talking about vision, hearing, mobility or some other difficulty, the individuals spontaneously tell that something happened and therefore they have such difficulty, but when it is physical, it seems that the disability is obvious in general or the respondent tells what caused the disability and not because they answered that way.

To obtain information that in fact complement the answer provided to the core question, it was necessary to be at the given response.

Question by Question of the Topic Modules for Vision, Hearing, Cognitive, Mobility, Self-Care, Communication, and Body structures and functions

This section presents comments about the fulfillment of the goals of the core questions in each module, as well as about the adaptation and understanding of the other questions, in the context of the cognitive test. The questions not mentioned did not present comprehension problems and attended to the objectives of the cognitive test; therefore they were not included in this section.

Vision Module

Core Question

Taking into consideration the goal of the core question "**Do you have difficulty seeing, even if using glasses or contact lenses?**", that is, "to identify persons who have some visual impairment or some type of difficulty seeing, that contributes to make difficult his daily activities" in a majority of the cases observed, the question did not facilitate the total comprehension that it aimed to identify the cases in which the persons had difficulty to carry out daily tasks due to the loss or limitation of vision. In a general way, the question captured all types of difficulties with vision, including the cases in which the difficulty does not imply impairment or limitation of activities.

For this reason, the question overestimates the population with visual difficulties that impede the realization of daily activities.

Since the question does not make explicit the type of visual difficulty that is of interest to the investigation, that is, only those that imply limitation of activities, the response category “Yes, some difficulty”, frequently added false positives. Many persons with a little difficulty seeing that did not impede or make harder to carry out daily activities, chose this response option, which would not have happened if the question were more complete, as for example, **“Do you have any difficulty seeing, even using glasses or contact lenses, that impedes carrying out daily activities?”**

If on one hand the recommended wording prevents the overestimation of the group that in fact has limitations due to visual difficulty, on the other hand it still includes those persons with temporary difficulties which in fact prevent them from carrying out daily activities, such as those who have suffered accidents, had surgery or emotional shock at the time of the survey. In this case, a formulation even more complete could be utilized as, for instance, **“Do you have any permanent difficulty seeing, even using glasses or contact lenses, that prevents you from carrying out daily activities?”**. Despite its length, the question would be more clear and in agreement with its goal.

Considering only the wording, in most of the interviews the question recommended by the Washington Group was easily understood. Given the clarity and simplicity of the question, which made it easy to understand by people with different levels of education, respondents frequently answered before the response categories were read. In many cases it was necessary to first wait for the respondents to finish answering, to then read the categories and ask the respondent to choose the one that best described his/her situation.

Other Questions

The question **“Is there any activity that you are unable/incapable of doing because of your difficulty seeing?”** proved to be excellent to help distinguish between the difficulty due to injury or loss, and that one which affects the majority of persons, such as small difficulties with their vision, but which do not impede the carrying out of daily activities. In a majority of the cases observed, when the person reported having some difficulty due to injury or loss, s/he also reported that there is some activity s/he is unable to do because of this lesion or loss. Nevertheless, in some cases it was observed that even when people had a more serious injury which prevented them from doing some activity, they mentioned it because of the personal or social context in which they live. Some persons are not used to reading the newspaper, for example, and therefore they did not mention the difficulty reading due to the loss or reduction in their ability to see.

The question **“How do you rate your degree of concern with your vision?”** seemed difficult to understand. Even when the response categories were read right after the question, the respondent showed difficulty understanding the question. In the majority of the interviews observed it was necessary to ask a different way, formulating the question including the response categories, as for example “are you very concerned or a little concerned with your vision?” Generally speaking, to ask the respondent to “rate his degree of concern” does not seem like the best way to research the concern of the respondents regarding his vision, especially if we consider that it is a question to be formulated for persons with different levels of education and

of vocabulary capability. In any case, this question seems to reveal more the cultural context of the respondent than the situation of his vision per se, since many people without vision problems reported concern about their vision, while others, with serious vision problems, reported that they had no preoccupation at all, adding comments such as: “there’s nothing that can be done about it, so why worry.”

In the questions about **the “difficulty seeing an illustration in a map, newspaper or book”**, many respondents replied that it depends on the size of the figure. A respondent recommended changing this question to read: “are you able to read the Bible?” because it is printed in standard font size.

Regarding **recognizing an object at arm’s length**, some respondents had difficulty understanding if it was about the shape of a bottle, for instance, or the reading of the label. If we take into consideration the autonomy to pick out the right medication in a cabinet with several medication bottles, the ability to read the label may be crucial.

The additional question **“How do you rate your ability to see? [if you use glasses or contact lenses, please answer about when you are using them]”**, which has the same goal as the core question (WG), and which was also tested, it was not as well understood as the core question in this module. The expression “rate your ability” did not appear to be easily understood or comprehended by respondents. Nevertheless, the response categories appeared more appropriate once the term “permanent” was added, which prevented the inclusion in the group of persons with difficulty seeing of those with temporary difficulties and impairments due to surgery, accidents or emotional shocks.

Hearing Module

Core Question

Considering the goal of the core question **“Do you have difficulty hearing, even using a hearing aid?”**, that is “to identify persons who have some hearing limitation or some type of difficulty to hear that contributes to make difficult to carry out their daily activities, in the majority of cases observed, the question did not facilitate the total comprehension that it aimed to identify the cases in which people had difficulty doing daily activities due to the loss or limitation of hearing. Generally speaking, the question captured all types of difficulties with hearing, including the cases in which the difficulty does not imply an impairment or limitation of activities. Thus, the question overestimates the population with hearing difficulties that prevent them from doing daily activities.

Since the question does not specify the type of auditory difficulty that we intend to research, that is, only those which imply limitation of activities, the response category “Yes, some difficulty”, it frequently added false positives. Many persons with a little difficulty hearing which in no way prevents or makes harder to carry out daily activities, they chose this response option, which would not happen if the question were more complete as in, for example, **“Do you have any difficulty hearing, even using a hearing aid, that prevents you from doing daily activities?”**.

If on one hand the recommended wording prevents the overestimation of the group that in fact has limitations due to auditory difficulty, on the other hand it still

includes those persons with temporary difficulties which in fact prevent them from carrying out daily activities, such as those who have suffered accidents, had surgery or emotional shock at the time of the survey. In this case, a formulation even more complete could be utilized as, for instance, **“Do you have any permanent difficulty hearing, even using a hearing aid, that prevents you from carrying out daily activities?”**. Despite its length, the question would be more clear and in agreement with its goal.

Considering only the wording, in most of the interviews the question recommended by the Washington Group was easily understood. Given the clarity and simplicity of the question, which made it easy to understand by people with different levels of education, respondents frequently answered before the response categories were read. In many cases it was necessary to first wait for the respondents to finish answering, to then read the categories and ask the respondent to choose the one that best described his/her situation.

Other Questions

The question **“Is there any activity that you are unable/incapable of doing because of your difficulty hearing?”** proved to be excellent to help distinguish between the difficulty due to injury or loss, and that one which affects the majority of persons, such as small difficulties with their hearing, but which do not impede carrying out daily activities. In a majority of the cases observed, when the person reported having some difficulty due to injury or loss, s/he also reported that there is some activity s/he is unable to do because of this injury or loss. Nevertheless, in some cases it was observed that even when people had a more serious injury which prevented them from doing some activity, they mentioned it because of the personal or social context in which they live. Some persons who reported not having any tasks they cannot carry out because of their difficulty hearing, simply increase the volume of the TV or radio and live with people who have gotten used to speaking louder to be heard; thus, despite the reduction in their ability to hear they do not perceive that in a “normal” situation they would be unable to carry out some activities such as, for example, to communicate or to watch television.

The question **“How do you rate your degree of concern with your hearing?”** seemed difficult to understand. Even when the response categories were read right after the question, the respondent showed difficulty understanding the question. In the majority of the interviews observed it was necessary to ask a different way, formulating the question including the response categories, as for example “are you very concerned or a little concerned with your hearing?” Generally speaking, to ask the respondent to “rate his degree of concern” does not seem like the best way to research the concern of the respondents regarding his hearing, especially if we consider that it is a question to be formulated for persons with different levels of education and of vocabulary capability. In any case, this question seems to reveal more the cultural context of the respondent than the situation of his hearing per se, since many people without hearing problems reported concern about their hearing, while others, with serious problems, reported that they had no preoccupation at all, adding comments such as: “there’s nothing that can be done about it, so why worry.”

In the questions about **the “difficulty hearing someone speaking in a normal tone of voice,”** some respondents with limitations in their ability to hear had difficulties perceiving or admitting that they are unable to hear under those conditions. Some rated a normal volume of voice as ‘low.’ When the information provided by the

person itself was contrasted with the information provided by someone s/he lives with, it was clear that the difficulty is not felt due to the habit of increasing the volume of the television or radio and because the persons they live with speak louder than normal to be heard.

The additional question “**How do you rate your ability to hear? [if you use a hearing aid, please answer about when you are using it]**”, which has the same goal as the core question (WG), and which was also tested, was not as well understood as the core question in this module. The expression “rate your ability” did not appear to be easily understood or comprehended by respondents. Nevertheless, the response categories appeared more appropriate once the term “permanent” was added, which prevented the inclusion in the group of persons with difficulty hearing of those with temporary difficulties and impairments due to surgery, accidents or emotional shocks.

Cognitive Module

Core Question

Considering the goal of the core question “**Do you have difficulty remembering something or concentrating?**”, that is “to identify persons who have some limitation or some type of difficulty to remember or concentrate that contributes to make difficult to carry out their daily activities, in the majority of cases observed, the question did not facilitate the total comprehension that it aimed to identify the cases in which people had difficulty doing daily activities due to the serious limitation to remember something or concentrate. Generally speaking, the question captured all types of difficulties with remembering or concentrating, including the cases in which the difficulty does not imply an impairment or limitation of activities. Thus, the question overestimates the population with difficulties remembering or concentrating that prevent them from doing daily activities.

Since the question does not specify the type of difficulty with memory or concentration that we intend to research, that is, only those which imply limitation of activities, the response category “Yes, some difficulty” frequently added false positives. Many persons with a little difficulty remembering or concentrating which in no way prevents or makes harder to carry out daily activities, chose this response option, which would certainly not happen if the question were more complete as in, for example, “**Do you have any difficulty remembering something or concentrating that prevents you from doing daily activities?**”.

If on one hand the recommended wording prevents the overestimation of the group that in fact has limitations due to memory or concentration difficulty, on the other hand it still includes those persons with temporary difficulties which in fact prevent them from carrying out daily activities, such as those who have suffered accidents, had surgery or emotional shock at the time of the survey. In this case, a formulation even more complete could be utilized as, for instance, “**Do you have any permanent difficulty remembering things or concentrating, that prevents you from carrying out daily activities?**”. Despite its length, the question would be more clear and in agreement with its goal.

Considering only the wording, in most cases the question recommended by the Washington Group was easily understood. Given the clarity and simplicity of the question, which made it easy to understand by people with different levels of

education, respondents frequently answered before the response categories were read. In many cases it was necessary to first wait for the respondents to finish answering, to then read the categories and ask the respondent to choose the one that best described his/her situation.

Other Questions

The question **“Is there any activity that you are unable/incapable of doing because of your difficulty remembering or concentrating?”** proved to be excellent in helping to distinguish between serious difficulties and those which affect the majority of persons, such as difficulties remembering names or dates, or even to concentrate when the task is not interesting or the environment is noisy, but which do not impede carrying out daily activities even if they make them somewhat harder. In a majority of the cases observed, when the difficulty remembering or concentrating was serious, the respondent also reported that there is some activity s/he is unable to do because of this difficulty. Nevertheless, in some cases it was observed that even when people had a serious difficulty which prevented them from doing some activity, they did not mention it because of the personal or social context in which they live. Some of the respondents, for instance, did not mention that are neither studying nor working as a result of the difficulty in memory or concentration.

The question **“How do you rate your degree of concern with your ability to remember something or concentrate?”** seemed difficult to understand. Even when the response categories were read right after the question, the respondent showed difficulty understanding the question. In the majority of the interviews observed it was necessary to ask a different way, formulating the question including the response categories, as for example “are you very concerned or a little concerned with your memory or concentration?” Generally speaking, to ask the respondent to “rate his degree of concern” does not seem like the best way to research the concern of the respondent regarding his ability to remember or concentrate, especially if we consider that it is a question to be formulated for persons with different levels of education and vocabulary capability. In any case, this question seems to reveal more the cultural context of the respondent than the situation of his memory or concentration per se, since many people without memory or concentration problems reported being concerned, while others, with serious problems, reported that they had no preoccupation at all, adding comments such as: “there’s nothing that can be done about it, so why worry.”

In the questions about **the “difficulty remembering something”** like names of persons or places; appointments; how to get to known places; and important tasks, were perfectly understood. Nevertheless, they are also able to distinguish the cases in which the difficulty is serious and implies a negative impact to their quality of life from those which are common to the majority of people. Therefore, these questions identify all types of difficulties and not only those stemming from disabilities. Moreover, people with some difficulty remembering names or places after a first contact, are considered the same way than those who are incapable of doing it. In the majority of the interviews observed, the respondents mentioned occasional difficulties such as “sometimes I cannot remember something” or “sometimes I forget to do something”.

The question **“Do you have difficulty concentrating for 10 minutes on what you are doing?”** did not help the identification of the level of difficulty as well as the distinctions between chronic difficulty and occasional difficulty associated with the environment. Some persons with difficulty concentrating, for example, when they are

in a busy and noisy environment, use the category “yes, some difficulty” to express that sometimes they have concentration difficulties, instead of using it to identify the level of difficulty.

This question should be investigated in two stages. The first one about the frequency with which they have difficulty and the second one -- beginning with the expression “when you have difficulty...”-- about the level of difficulty, as exemplified in the initial questions in this same module.

The additional question “**Do you have any mental impairment that limits your usual activities (such as working, going to school, playing, etc.)?**” which, as well as in the core question, was being tested, it was very easily understood. Despite having a different objective than the core question in the module, because it aims to identify objectively the cases of mental impairment that imply a limitation of activities, it fulfilled an important role, since some cases with impairments that implied a limitation in activities were not captured by the other questions in the module, but only by this question.

Mobility Module

Core Question

Considering the goal of the core question “**Do you have difficulty walking or climbing steps?**” that is “*to identify persons who have some hearing limitation or some type of difficulty to move around on foot. Such difficulties **may or may not contribute to make it difficult to carry out their daily activities...**, to walk some distance without stopping to rest or even walk **without using any aids or equipment such as a cane, walker or crutch.** It may be entirely impossible to stay on one’s feet for one or two minutes, needing a wheelchair*”, in the majority of cases, the question did not facilitate the comprehension that it aimed to identify any locomotion difficulties without using auxiliary equipment.

Generally speaking, the question captured all types of difficulties for walking or climbing steps, including the cases in which the difficulty does not imply an impairment or limitation of activities, thus partially fulfilling its objective. Still, it is not clear in the sense that the evaluation should be done without the use of devices or equipment, as is the case in the questions in the modules on vision and hearing, therefore it did not capture those cases in which people are able to walk or climb steps although with the aid of or use of equipment. Thus, the question promotes the underestimation of the population with difficulties walking or climbing steps without the use of equipment. To promote a better identification of the population with locomotion problems, in the sense of the established objective, the question should be more complete, as in for example, “**Do you have any difficulty walking or climbing steps without the aid or use of equipment such as a cane, crutch or walker?**”

On the other hand, the question is also addressed to those persons with temporary difficulties, such as those who have suffered accidents, had surgery or emotional shock at the time of the survey. In this case, to prevent overestimation of the persons who in fact have a permanent limitation, a formulation even more complete could be utilized as, for instance, “**Do you have any permanent difficulty walking or climbing steps, without the aid or use of equipment such as a cane, crutch or walker?**” Despite its length, the question would be more clear and in agreement with its goal.

Other Questions

The question **“Do you use any type of equipment or assistive device, such as a prosthesis, wheelchair, walker or cane to move around?”** did not present any comprehension problem, although it generated internal discussion about the need to distinguish internal from external prosthesis. Since the population that uses prosthesis is rare, there was no case found in the sample that implied the need to distinguish, however, thinking that the question will be used in a census, it could be useful to discuss this question in advance.

The question **“Is there any activity that you are unable to do because of a problem in your legs?”** is restricted if we consider the objective of the core question to investigate the locomotion difficulties in a general way, since it associates the difficulty to problems in the legs. In that way, the question does not make it possible to record the difficulties due to problems in the feet or even in the spine, which depending on its degree can prevent locomotion. To probe the core question, these could be more useful if reformulated as in, for instance, **“Is there any activity that you are unable to do because of difficulties walking or climbing steps?”**

The question **“How do you rate your degree of concern with your ability to walk or climb stairs?”** seems difficult to understand. Even when the response categories were read right after the question, the respondent showed difficulty understanding the question. In the majority of the interviews observed it was necessary to ask a different way, formulating the question including the response categories, as for example **“are you very concerned or a little concerned with your ability to walk or climb steps?”** Generally speaking, to ask the respondent to **“rate his degree of concern”** does not seem like the best way to research the concern of the respondent regarding his locomotion abilities, especially if we consider that it is a question to be formulated for persons with different levels of education and of vocabulary use. In any case, this question seems to reveal more the cultural context of the respondent than to confirm the respondents' mobility. People without mobility problems reported being concerned, while others, with serious problems, reported that they had no preoccupation at all because they are paraplegic, for instance, and not have any possibilities for improvement or worsening of their ability to walk or climb steps.

The questions about the **“locomotion difficulties inside or outside the home”** did not present comprehension difficulties, but there is a need for a **“not applicable”** option and an instruction that the questions should not be read to, for example, people with total paralysis. In the same fashion, the questions about **“difficulties walking or being on your feet”** there is a **“not applicable”** option missing as well as the instruction that the questions should not be read to persons with, for instance, total paralysis, paraplegic or quadriplegic. Both question sets caused a certain distress, once the interviewers were instructed to read all the questions in the questionnaire.

The additional question **“How do you rate your ability to walk/climb stairs? [if you use a prosthesis, cane, or assistive device, please answer about when you are using them]”**, which has the same goal as the core question (WG), and which was also tested, was not as well understood in this module as it was in the core question. The expression **“rate your ability”** did not appear to be easily understood or

comprehended by respondents. Moreover, the expression to climb stairs is more restrictive than to climb steps, since, in the common sense, it does not include climbing onto the sidewalk, for instance. However, the question is more complete than the core question since it establishes the conditions (such as the use of equipment...) in which the evaluation should be done, without leaving any doubts regarding its objective. Moreover, the response categories seemed to be more appropriate, since the addition of the term “permanent” prevented the inclusion in the group of persons with locomotion difficulties of persons with temporary difficulties and impairments due to surgery, accidents, or emotional shocks.

Self-Care Module

Core Question

Considering the goal of the core question “**Do you have difficulty caring for yourself, such as bathing or dressing?**”, that is “to identify persons who have some limitation to take care of themselves”, in a majority of the interviews the question was easily understood. The wording made it easy to understand that it sought to identify persons with any difficulty with regard to personal care. Nevertheless, in some cases it was observed that the example “to bathe” caused surprise and that some people quickly answered that they had no difficulties to bathe, giving the impression that they did not think about the question because they were concerned to appear as persons with good hygiene habits.

On the other hand, the question included those persons with temporary difficulties, such as those who have suffered accidents, had surgery or emotional shock at the time of the survey. In this case, a formulation even more complete could be utilized as, for instance, “**Do you have any permanent difficulty caring for yourself, as, for instance bathing or dressing?**” The question would then be more clear and in agreement with its goal.

The question “**Do you use any type of equipment or assistive device, such as a prosthesis, wheelchair, walker, or cane to move around?**” did not present any comprehension problem, although it generated internal discussion about the need to distinguish internal from external prosthesis. Since the population that uses prosthesis is rare, there was no case found in the sample that implied the need to distinguish, however, thinking that the question will be used in a census, it could be useful to discuss this question in advance.

Within the context of the thematic module, the question “**How often do you wish you could take better care of yourself?**” was easily understood. Nevertheless it would be necessary to have one more response category to identify the cases in which the question was “always”. In any case, this question seems to reveal more about the cultural context than to actually confirm the autonomy of the respondent to take care of him/herself.

The questions about the “**difficulties reaching up over your head and reaching out to shake someone’s hand**” did not present comprehension problems; still it caused certain issues since it was not possible to establish a relationship between the questions and the objective of the self-care module. An attempt was made to associate the act of raising the arms with that of washing or combing the hair, but that question is asked later. In any case, it was not possible to establish any relationship between greeting another person and self-care, therefore such questions

would not belong in this module, but rather in the mobility module if the concept were not restricted to lower limb mobility.

The questions about **“difficulties buttoning clothing, putting on socks, tying shoelaces, combing hair and eating”** did not present any comprehension difficulties; on the contrary they are objective and clear. Furthermore, mainly because they began with “By yourself and without any aids...” they delimit better than the core question the universe under investigation.

Regarding the wording, the question **“Do you have difficulty staying by yourself for a few days?”** it was easy to understand. Still, in some cases the type of difficulty under research was confusing, and some persons who do not like to stay alone answered that they do have difficulty, eluding the objective of the question.

Communication Module

Core question

Considering the objective of the core question **“Because of a physical, visual, auditory, mental or emotional condition, do you have difficulty communicating, for example understanding or being understood by others?”**, that is, “to identify persons with difficulties speaking, hearing or understanding someone speaking, in such way that that contributes to make harder to do daily activities”, in the majority of cases the question did not help realize that it sought to identify the cases in which people had difficulty doing daily activities due to difficulties speaking, hearing or understanding someone speaking. Generally speaking, the question captured all types of difficulties with communication, including the cases in which the difficulty does not imply impairment or limitation of activities. Thus, the question overestimates the population with communication difficulties that make it harder to do daily activities.

Since the question does not specify the type of communication difficulties that are under investigation, that is, only those which imply a limitation of activities, the response category “Yes, some difficulty” often led to adding cases that could be considered false positives. Many people with a little difficulty hearing or expressing themselves which in no way prevents or makes harder carrying out daily activities, chose this response option, which would certainly not happen if the question were more complete as in, for example, **“Because of a physical, visual, auditory, mental or emotional condition, do you have any difficulty communicating, such as, for example understanding others or being understood by others, which makes it difficult to do your daily activities?”**

If on one hand the recommended wording prevents overestimating the group that in fact has limitations stemming from visual difficulty, on the other hand it still includes those persons with temporary difficulties which in fact prevent them from carrying out daily activities, such as those who have suffered accidents, had surgery or emotional shock at the time of the survey. In this case, a formulation even more complete could be utilized as, for instance, **“Because of a physical, visual, auditory, mental or emotional condition, do you have any permanent difficulty communicating, such as, for example understanding others or being understood by others, which makes it difficult to do your daily activities?”** This way the question would be more clear and in agreement with its goal.

Considering the original wording recommended by the Washington Group the question is very long, which made it difficult to fluidly read for the respondent. The introduction “Because of a physical, visual, auditory, mental or emotional condition” made it hard to understand the central issue of the question which is the communication difficulty. Since this introduction presents an exhaustive list of the reasons why people can report having difficulty communicating, it could be replaced by “Because of any reason...” or even be excluded, since not mentioning the reasons is generally understood as meaning “regardless of the reason”. Thus, taking into account the prior concerns with fulfilling the question objectives and given also the need to reduce the text, the question could, for example, read: **“Do you have any difficulty communicating, such as, for example understanding others or being understood by others, which makes it difficult to do your daily activities?”**

Other Questions

The question **“How do you rate your degree of concern with your ability to understand or be understood?”** seemed difficult to understand. Even when the response categories were read right after the question, the respondent showed difficulty understanding the question. In the majority of the interviews observed it was necessary to ask a different way, formulating the question including the response categories, as for example “are you very concerned or a little concerned with your ability to understand or be understood?” Generally speaking, to ask the respondent to “rate his degree of concern” does not seem like the best way to research the concern of the respondent regarding his/her ability to understand or be understood, especially if we consider that it is a question to be formulated for persons with different levels of education and of vocabulary use. In any case, this question seems to reveal more the cultural context of the respondent than the situation of his/her ability to understand or be understood, per se.

The questions **“Do you have difficulty making new friends?”** and **“Do you feel shy in group or social situations?”**, were easily understood; however, in a more strict context of limitation of activities, the questions would not contribute much to the analysis of communication abilities. On the other hand, difficulty to make friends and shyness are also associated to the cultural context and the type of education received in the family, therefore they are not always associated to the physical, mental or emotional conditions as mentioned in the question. Thus, some persons without any communication difficulty due to their physical, mental or emotional condition feel shy or have difficulty making friends.

Body structures and functions Module

Core Question

Taking into consideration the goal of the core question **“Do you have any of the following disabilities: (record only the first response)”**, that is, “to identify persons who have some physical deficiency,” the majority respondents easily understood the question, given its objectivity and clarity. Still, given the instruction to record only one disability, the question does not favor the identification of all the disability that the population under investigation has. Thus, for a person who does not have both arms and therefore cannot take care of himself without help, but also has paralysis of the legs, only the legs’ paralysis will be captured, which does not

necessarily imply a limitation for self-care or locomotion. Therefore, the universe of physical disabilities will not be complete. In this way, the question underestimates not the number of people with disabilities but the number of persons with the disabilities presented in the last positions in the order of presentation, especially those who are missing a leg, arm, hand, foot or thumb.

Considering that the question did not present any comprehension problem, and it won't restrict the universe of the disabilities under study, the instruction for assigning the type of disability should be reformulated. Thus, the question could read, for example: **“Do you have any of the following disabilities (assign more than one if applicable)”**.

Other Questions

The question “Is there any activity that you cannot do because of a physical problem?” turned out to be excellent to help evaluate the degree to which the physical disability affects the ability to do daily activities but, mainly, it provides some information to help identify other disabilities not enumerated in the core question.

The question **“Has any health professional told you that you have an injury or illness (such as paralysis) that affects your ability to use the your hands or feet?”** caused some doubts, because it does not make it clear if the term injury can also include physical disabilities such as loss of limbs or parts of them. The question also presents a conceptual problem, since “paralysis” is not an illness, but rather the consequence, and therefore should not be used as an example.

The quantitative analysis was done based on the questions and answers recorded on the questionnaires of the cognitive and field test interviews. Therefore, in the next section we will present the comparisons of the answers provided by the persons with disabilities themselves against those provided by an informant/proxy (informant bias), analysis of false positive and false negatives according to the answers to the core, additional and probe questions, analysis of the open-ended questions and...

Analysis Comparing the Core and Additional Questions

Vision

Of the total of 406 interviews, in 221 of them a response was elicited both for the core question “Do you have difficulty seeing, even using glasses or contact lenses?”, as well as for the additional question “How do you rate your ability to see? [If you use glasses or contact lenses, rate your ability while using them]”. In 165 cases, that is in about 75% of the cases for which both responses were elicited, the same degree of difficulty seeing was reported. In the remaining interviews, the great majority of the response categories obtained are contiguous and vary between “none” to “some” or “a lot” to “some” difficulty.

The responses obtained for each degree of severity appear in the following table.

Answers obtained for the question “Do you have difficulty seeing, even using glasses or contact lenses?”	Answers obtained for the question “How do you rate your ability to see? [if you use glasses or contact lenses, rate your ability to see while using them]”					
	Total	Missing	Unable	Much permanent difficulty	Some permanent difficulty	No difficulty
Total	406	183	8	27	61	127
Missing	47	47	-	-	-	-
No, no difficulty	245	125	-	2	12	106
Yes, some difficulty	61	6	-	5	34	16
Yes, much difficulty	43	2	3	20	14	4
Cannot see at all	8	3	5	-	-	-
Don't know/No answer	2	-	-	-	1	1

Hearing

Of the total of 406 interviews, in 187 of them a response was elicited both for the core question “Do you have difficulty hearing, even using a hearing aid?”, as well as for the additional question “How do you rate your ability to hear? [if you use hearing aids, rate your ability while using them]”. In 172 cases, that is in nearly 92% of the cases for which both responses were elicited, the same degree of difficulty hearing was reported. In the remaining interviews, the great majority of the response categories obtained are contiguous and vary between “none” to “some” or “some” to “much” difficulty.

The responses obtained for each degree of severity appear in the following table.

Answers obtained for the question “Do you have difficulty hearing, even using hearing aids?”	Answers obtained for the question “How do you rate your ability to hear? [if you use hearing aids, rate your ability to see while using them]”					
	Total	Missing	Unable	Much permanent difficulty	Some permanent difficulty	No difficulty
Total	406	217	6	18	34	131
Missing	49	48	-	-	-	-
No, no difficulty	295	159	2	1	4	129
Yes, some difficulty	36	3	-	5	28	-
Yes, much difficulty	20	5	1	12	2	-
Cannot see at all	5	2	3	-	-	-
Don't know/No answer	1	-	-	-	-	1

Cognitive

Of the total of 406 interviews, in 243 of them a response was elicited both for the core question “Do you have difficulty remembering something or concentrating?”, as well as for the additional question “Do you have any permanent mental deficiency that limits your usual activities (such as working, going to school, playing, etc.)?”. Taking into consideration the fact that, in contrast with the other questions compared, the universe for investigating the two questions that constitute this module is not the same, there is no inconsistency in the fact that 185 persons who reported to have some difficulty to remember something or to concentrate had also reported they did not have any mental disability. Still, analyzing the universe of persons with mental disability, some 60 interviews, 6 cases were found, that is 10% of the persons with mental disability who reported they did not have any difficulty remembering or concentrating. In two other interviews, the respondent knew to report that s/he had difficulty remembering or concentrating. Taking into account both situations, in 8 interviews the core question in the module did not capture the mental disability; which was captured only by the more direct (additional) question.

The responses obtained for each degree of severity appear in the following table.

Answers obtained for the question “Do you have difficulty remembering or concentrating?”	Answers obtained for the question “Do you have any permanent mental disability that limits your usual activities (such as working, going to school, playing, etc.)?”			
	Total	Missing	Yes	No
Total	406	160	60	186
Missing	53	52	-	1
No, no difficulty	209	97	6	106
Yes, some difficulty	73	1	12	60
Yes, much difficulty	38	1	21	16
Cannot remember or concentrate at all	22	-	19	3
Don't know/No answer	11	9	2	-

Motor

Of the total of 406 interviews, in 233 of them a response was elicited both for the core question “Do you have difficulty walking or climbing steps?”, as well as for the additional question “How do you rate your ability to walk/climb stairs? [if you use a prosthesis, cane or assisting device, rate your ability while using them]”. In 192 cases, that is in about 82% of the cases for which both responses were elicited, the same degree of difficulty walking or climbing steps was reported. In the remaining interviews, the great majority of the response categories obtained are contiguous and vary between “none” to “some” or “some” to “much” difficulty.

The responses obtained for each degree of severity appear in the following table.

Answers obtained for the question “Do you have difficulty walking or climbing steps?”	Answers obtained for the question “How do you rate your ability to walk/climb stairs? [if you use a prosthesis, cane or assisting device, rate your ability to while using them]”					
	Total	Missing	Unable	Much permanent difficulty	Some permanent difficulty	No difficulty
Total	406	173	35	43	31	124
Missing	52	52	-	-	-	-
No, no difficulty	232	101	1	3	8	119
Yes, some difficulty	32	5	-	7	17	3
Yes, much difficulty	52	4	9	31	6	2
Cannot see at all	37	10	25	2	-	-
Don't know/No answer	1	1	-	-	-	-

Respondent Bias

Of the total 406 interviews, 178 were conducted directly with the person who had at least one of the disabilities under study. In 20 cases, or about 11%, in addition to the interview with the person with a disability, an interview was also conducted with a family or household member who provided proxy information about the person, thus making it possible to evaluate if there is a difference between the information provided by the person him/herself and that provided by an informant.

In all cases in which the two interviews were conducted, a difference was found in at least one of the answers provided by the person and the information provided by the informant. Still, the number of disagreeing answers found was small. The great majority of the answers provided by the informant coincided with those from the person him/herself. In the following table the number of same and different answers found is shown, according to the thematic modules and the type of question, whether core or additional (Census 2000).

Thematic Module	Total # of Interviews	Core Question		Additional Question	
		Proxy response same as self	Proxy response different from self	Proxy response same as self	Proxy response different from self
Vision	20	18	2	13	7
Hearing	20	15	5	15	5
Cognitive	20	17	3	17	3
Mobility	20	17	3	15	5
Self-care	20	17	3		
Communication	20	18	2		
Body Structures and Functions	20	16	4		

Of the total of 140 answers provided by the person to the 7 **core** questions in the different thematic modules, in 22 (16%) the information provided by the proxy informant was different. In five interviews the difference was due to the fact that no answer was elicited from the self reporter to the core question in the Cognitive (1) and Body Structure and Functions (4). For the other 17 cases, in 10 of them the informant reported a more severe degree of difficulty than the person. In 7 cases the opposite was true, the more severe degree of difficulty was self reported. In a majority of the cases, the response categories chosen by the person and those chosen by the proxy informant were contiguous as, for example, when the person reported “no difficulty” and the informant reported “some”, or when the informant reported “some” difficulty and the person answered “much difficulty”. The answers elicited with the core questions in the interviews appear on the following table.

Thematic Module	Core Question Additional Question		
	Total # of Interviews	Response categories	
		Self	Proxy Informant
Total	22		
Vision	2		
	1	Much difficulty	Some difficulty
	1	Some difficulty	Much difficulty
Hearing	5		
	1	No difficulty	Some difficulty
	1		
	1		
	2		
Cognitive	3		
	1		
	1		
	1		
Mobility	3		
	1		
	1		
	1		
Self care	3		
	1		
	1		
	1		
Communication	2		
	1		
	1		

In 20 (25%) of the total of 80 responses provided by the person him/herself to the 4 **additional** questions of the different thematic modules, the information provided by the informant was different. In nine interviews, the difference was due to not having obtained an answer from the person him/herself to the additional question (6) or to the informant (3). Of the remaining 11 cases, in 7 the informant reported a more serious degree of difficulty than was self-reported. In 4 cases the opposite was true: the more severe difficulty was reported by the person him/herself. In the majority of the cases, the response categories chosen by the person reporting about self and those chosen by the informant are contiguous as, for example, when the person self-reported “no difficulty” and the informant reported “some”, or when the informant reported “some difficulty” and the person reporting about him/herself reported “much difficulty”. The answers to the additional questions collected in the interviews appear in the following table.

Thematic Module	Additional Question		
	Total # of responses	Response categories	
		Self	Proxy Informant
Total	20		
Vision	7		
	1	Some difficulty	No difficulty
	3	No difficulty	Some difficulty
	1	Unknown	Much difficulty
	2	Much difficulty	Some difficulty
Hearing	5		
	2	Much difficulty	Unknown
	1	Unknown	Some difficulty
	1	No difficulty	Much difficulty
	1	No difficulty	Some difficulty
Cognitive	3		
	1	Unknown	Yes
	2	Unknown	No
Mobility	5		
	1	Unknown	Much difficulty
	1	Some difficulty	Much difficulty
	1	Some difficulty	No difficulty
	1	No difficulty	Some difficulty
	1	No difficulty	Unknown

Of the total of 220 responses obtained to the 7 core and 4 additional questions, in 28 cases – nearly 13% – the answer provided by the informant was different from the self-report. If we consider that only the cases in which the response provided by the informant modify the person’s status, that is, when the person reports having a disability, independently of the degree of severity, and the informant reports there is no difficulty, or vice versa, this number decreases to 22 cases, that is, 10% of the cases.

False Negatives

The following analysis was done comparing the responses to the core questions in each of the first six thematic modules with those obtained in selected questions of the same module. Therefore, the responses to the core questions were compared to those obtained in some of the functional questions, probe questions and the additional questions in the modules.

In selecting for which questions to compare the answers to those to the core question, a potential contradiction between their answers was considered, for example if a respondent reported not to have any vision problem but later reported he could not see an illustration in print, this was considered a false negative.

The following tables show the questions considered potentially contradictory, as well as the response categories considered for testing for false negatives.

Questions in the Vision Module	Response Categories
<p>Do you have difficulty seeing, even using glasses or contact lenses?</p>	<p>No, no difficulty</p>
<p>Is there any activity that you cannot do because of difficulty seeing?</p>	<p>Yes</p>
<p>How do you rate your ability to see? [if you use glasses or contact lenses, rate your ability while using them]</p>	<p>Unable or with much permanent difficulty or some permanent difficulty</p>
<p>With your glasses or contact lenses, do you have difficulty seeing a printed figure in a map, newspaper or book?</p>	<p>Yes, unable or yes, much difficulty or yes, some difficulty</p>
<p>With your glasses or contact lenses, do you have difficulty seeing and recognizing someone on the other side of the street (approximately 7 meters away)?</p>	<p>Yes, unable or yes, much difficulty or yes, some difficulty</p>
<p>With your glasses or contact lenses, do you have difficulty seeing and recognizing an object at a distance of about one meter (a stretched arm)?</p>	<p>Yes, unable or yes, much difficulty or yes, some difficulty</p>

Hearing Module Questions	Response Categories
<p>Do you have difficulty hearing, even using a hearing aid?</p> <p>Is there any activity you cannot do because of difficulty hearing?</p> <p>How do you rate your ability to hear? [if you use a hearing aid, rate your ability while using it]</p> <p>When using your hearing aid, do you have difficulty hearing someone speaking in a normal voice on the other side of a room?</p> <p>When using your hearing aid, do you have difficulty hearing what is said when you are talking in a crowded room?</p> <p>When using your hearing aid, do you have difficulty hearing what is said in a conversation in a quiet room?</p>	<p>No, no difficulty</p> <p>Yes</p> <p>Unable or much permanent difficulty or some permanent difficulty</p> <p>Yes, unable or yes, much difficulty or yes, some difficulty</p> <p>Yes, unable or yes, much difficulty, or yes, some difficulty</p> <p>Yes, unable or yes, much difficulty or yes, some difficulty</p>

Cognitive Module Questions	Response Categories
<p>Do you have difficulty remembering something or concentrating?</p> <p>Is there any activity you cannot do because of difficulty remembering or concentrating?</p> <p>Do you have difficulty remembering names of persons or places?</p> <p>Do you have difficulty remembering appointments?</p> <p>Do you have difficulty remembering how to go to places you know?</p> <p>Do you have difficulty remembering important tasks, such as taking medicines or paying bills?</p> <p>Do you have difficulty concentrating on what you are doing for 10 minutes?</p> <p>Do you have difficulty learning a new task, for example, how to get to a new place?</p> <p>Do you have difficulty solving daily problems?</p> <p>Do you have any permanent mental disability that limits your usual activities (such as working, going to school, playing, etc.)?</p>	<p>No, no difficulty</p> <p>Yes</p> <p>Yes</p> <p>Yes</p> <p>Yes</p> <p>Yes</p> <p>Yes, unable or yes, much difficulty or yes, some difficulty</p> <p>Yes, unable or yes, much difficulty or yes, some difficulty</p> <p>Yes, unable or yes, much difficulty or yes, some difficulty</p> <p>Yes</p>

Mobility Module Questions	Response Categories
Do you have difficulty walking or climbing steps?	No, no difficulty
Is there any activity you cannot do because of a problem with your legs?	Yes
Do you have difficulty moving around inside your home?	Yes, unable or yes, much difficulty or yes, some difficulty
Do you have difficulty going outside of your home?	Yes, unable or yes, much difficulty or yes, some difficulty
Do you have difficulty walking a long distance such as 1 km?	Yes, unable or yes, much difficulty or yes, some difficulty
By yourself and not using equipment or assistive devices, do you have difficulty walking 2 or 3 blocks?	Yes
By yourself and not using equipment or assistive devices, do you have difficulty walking up ten steps without resting?	Yes
By yourself and not using equipment or assistive devices, do you have difficulty standing on your feet for about 2 (two) hours?	Yes
By yourself and not using equipment or assistive devices, do you have difficulty sitting for about 2 (two) hours?	Yes
By yourself and not using equipment or assistive devices, do you have difficulty stooping, crouching, or kneeling?	Yes

Self-Care Module Questions	Response Categories
Do you have difficulty caring for yourself, such as, for example, bathing or dressing?	No, no difficulty
How often do you wish you could take better care of yourself?	Frequently
By yourself and without any type of aid, do you have any difficulty reaching up over your head?	Yes
By yourself and without any type of aid, do you have any difficulty reaching out to greet someone?	Yes
By yourself and without any type of aid, do you have any difficulty using your fingers to button a shirt or dress?	Yes
By yourself and without any type of aid, do you have any difficulty putting on socks or stockings?	Yes
By yourself and without any type of aid, do you have any difficulty tying your shoelaces?	Yes
By yourself and without any type of aid, do you have any difficulty combing your hair?	Yes
By yourself and without any type of aid, do you have any difficulty feeding yourself?	Yes
Do you frequently need someone to help you with everyday activities such as eating, showering, dressing or toileting?	Yes
Do you have difficulty, using your hands and fingers, to pick up small objects or open or close containers?	Yes
Do you feel too tired or sad to dress or bathe?	Yes

Communication Module Questions	Response Categories
Because of some physical, visual, hearing, mental or emotional condition, do you have any difficulty communicating, such as understanding others or being understood by others?	No, no difficulty
Do you have difficulty in generally understanding what people say?	Yes, unable or yes, much difficulty or yes, some difficulty
Do you have difficulty in starting and maintaining a conversation?	Yes, unable or yes, much difficulty or yes, some difficulty
Do other people have difficulty understanding you?	Yes

The number of “false negative” cases was found in each thematic module was found using the criterion described above, that is, a negative response about difficulty in the core question and an affirmative response about difficulty in at least one of the selected questions in the same thematic module, as the following table shows.

Thematic Module	Number of interviews with negative response about the difficulty asked about			
	Total	Other Questions Answered (2)	False Negatives	% False negatives
Vision	245	138	17	12.3
Hearing	295	170	20	11.8
Cognitive	209	118	32	27.1
Mobility	232	134	27	20.1
Self care	281	173	47	27.2
Communication	267	164	15	9.1

(2) At least one of the questions selected to test for false negatives

The table shows that of the 245 persons who reported **No** difficulty seeing, 138 also answered at least one of the other questions in the module, selected to test for false negatives. Of that total, in 17 interviews at least one question was found for which the answer conflicts with the response to the core question. This represents about 12% of the total number of interviews in which a negative response to the core question was obtained and also an affirmative response was elicited in at least one of the selected questions. This same analysis could be done for the other thematic modules, referring to the corresponding table, although it is worth mentioning that the Communication thematic module was the module with the lowest proportion of false negatives – nearly 9% – as well as the modules with the highest proportion of false negatives which were

Cognitive and Self-Care, with approximately 27%.

For some of the questions selected to test for false negatives no answer was elicited that contradicted the response given to the core question, while for others there was a significant number of cases with inconsistent answers. The questions that contributed most to the number of false negatives in each thematic module can be seen in the following table.

Thematic Modules and Corresponding Questions for which Answers conflict with answers given to the core questions	Total # of false negatives	Total # of interviews
Vision	17	
2.12 – How do you rate your ability to see? (if you use glasses or contact lenses, rate your ability while using them)		14
Hearing	20	
3.12 – How do you rate your ability to hear? (if you use hearing aids, rate your ability while using them)		7
3.17 - ¿Does any family or household member frequently say that this person has difficulty hearing?		11
Cognitive	32	
4.08 – Do you have difficulty remembering names of persons or places?		12
4.11 – Do you have difficulty doing important tasks such as taking medicines or paying bills?		9
4.13 – Do you have difficulty learning a new task such as going to a new place?		10
Mobility	27	
5.10 – Do you have difficulty walking a long distance such as 1 km?		10
5.13 – By yourself and without any equipment or assisting device, do you have difficulty being on your feet for 2 hours?		14
5.14 – By yourself and without any equipment or assisting device, do you have difficulty sitting for 2 hours?		10
5.15 – By yourself and without any equipment or assisting device, do you have difficulty stooping, crouching, or kneeling?		9
Self-care	47	
6.09 - By yourself and without any aid, do you have difficulty tying your shoelaces?		18
6.15 – Do you have difficulty staying alone for a few days?		19
Communication	15	
7.06 – Do you have difficulty communicating and maintaining a conversation?		11

Analysis of the Open-Ended Question

Vision

In 49 of the total of 406 interviews, the respondent did not answer the core question, and therefore the open-ended question was not asked. In 230 of the 357 interviews with an answer to the core question, an answer was elicited for the open-ended question. Therefore, the following comments are based in those answers.

In the great majority of the interviews, that is in about 200, the answer provided to the open-ended question confirmed the information provided in the core question. In only 7 interviews, the answers provided were not specific, such as “just because” or “because that is the right answer”, “because I live with the person”, “because it’s how I

understood it”, among others. Instances of inconsistency between the answer to the core question and the open-ended question were also rare. In just two interviews there was a contradiction between the core question and the open-ended question. The respondents reported not having difficulties seeing, however, in the answer to the open-ended question, they indicated they have difficulty seeing even when wearing their glasses or have difficulty reading.

In 64 interviews the verb ‘to see’ was mentioned in the answer, whether to confirm the answer given to the core question – as in, for example, “because I see/don’t see well” or “because I see/don’t see well with my glasses on” – or explaining/complementing the answer given to the core question – as for example in “because I don’t have any problem seeing” or “because I don’t see well up close or at a distance”. On the other hand, in just 11 cases the respondent associated his/her visual abilities to the act of reading, manifesting s/he had or did not have visual problems because s/he could or could not read. This suggests that the prevailing understanding was that the question aimed to investigate visual difficulties in the widest sense, such as in seeing, is not restricted to the act of reading.

In 42 interviews the respondent consistently mentioned the use of glasses or contact lenses, whether explaining s/he can’t see because s/he needs to have a stronger prescription or that s/he does not have a problem when using glasses, making it evident that the respondent is clear about the fact that the question refers to difficulties even when using glasses or contact lenses.

In about 100 of the 134 interviews in which the respondent reported not having a vision problem and also answered the open-ended question, the answer provided to the open-ended question only confirmed the answer to the core question. Only one respondent said s/he did not know how to answer and another provided an inconsistent response saying that, “despite using glasses” he did not see well. In the other cases, the respondents added information to the answer as, for example, in “I see near and far”, “I see small and large letters”, “I don’t have any problems leaving the house or watching TV”.

Nineteen of the 56 respondents who reported having “some difficulty” in their vision and who answered the open-ended question, mentioned facts as basis for the response they had provided, such as “because I use glasses”, “because I had an accident”, “because I had a stroke”, “because I fell a lot”. Nevertheless, the great majority of respondents based their answers on the degree of difficulty they experience, using expressions such as: “sometimes I cannot see,” “I can’t see well,” “I have difficulty reading.”

In just 4 of the 34 interviews in which the respondent reported “great difficulty” and also answered the open-ended question, the respondent indicated having much, great or serious difficulty seeing. One respondent said s/he only has 10% visual capacity and another one said s/he cannot read magazines or newspapers. Most answers followed the pattern of the answers given in the cases in which the respondents reported having some difficulty seeing. However, although they confirmed the difficulty reported in the core question, they did not contribute much to the differentiation of the degree of difficulty, since many answers are similar to those observed among persons who have some difficulty seeing, as for instance in

“sometimes I can’t see well”.

Of the eight persons who cannot see at all, only two said they were blind. Two of them did not answer the open-ended question and the others mentioned that they cannot see or that they have a serious problem such as glaucoma.

Hearing

In 50 of the total of 406 interviews, the respondent did not answer the core question, and therefore the open-ended question was not asked. In 216 of the 356 interviews with an answer to the core question, an answer was elicited for the open-ended question. Therefore, the following comments are based in those answers.

In the great majority of the interviews, that is in about 210, the answer provided to the open-ended question confirmed the information provided in the core question. In only 3 interviews, the answers provided were not specific. In those interviews the respondent answered “because it is true”. There were no cases of inconsistency between the answer to the core question and the open-ended question. In just one interview the respondent mentioned he had found the question “strange because it mentions the use of equipment”, although not making any additional comments.

In 148 of the 164 interviews in which the respondent reported not having a hearing problem and also answered the open-ended question, the answer provided to the open-ended question only confirmed the answer to the core question, without adding additional information such as, for example, “because he can hear/listen well” or “because he does not have difficulty”.

Seven of the 336 respondents who reported having “some difficulty” in their hearing and who answered the open-ended question, mentioned that “sometimes I have difficulties” or that they suffer minor difficulties. Six respondents said that they have to “yell” or “speak loud”. The others gave different answers such as for instance, “because I went to the doctor”, “because he works in a noisy environment”, “because he does not hear him/her”. In just one case, the respondent indicated that the person “is always distracted”, revealing some sort of confusion about the aim of the question to capture a physical hearing problem.

In 17 interviews in which the respondent reported “much difficulty” and also answered the open-ended question, in just 4 of the responses to the core question there was a mention of the fact that the respondent “almost cannot hear”. In the remaining interviews the answer does not permit to evaluate the degree to which the hearing is compromised, but simply confirms that there is a problem.

Such responses would fall in a different degree of hearing loss since they barely mention that there is an auditory problem, that the person cannot hear, that they have to speak loud, among other responses, however not specifying how much difficulty the person feels they have.

Of the five persons that cannot see at all, only two answered the open-ended question. These people reported being deaf since birth.

Cognitive

In 64 of the 406 interviews, the respondent did not answer the core question, and therefore the open-ended question was not asked. In 225 of the 342 interviews with an answer to the core question, an answer was obtained for the open-ended question. Therefore, the following comments are based in those responses.

In the great majority of the interviews – 210 – the answer given to the open-ended question confirmed the information provided in the core question. In most cases, the answers to the open-ended question were very rich in examples and descriptive comments about the difficulty experienced. In just one interview there was a contradictory response. The respondent reported having difficulty but, in the open-ended question, he said he did not know how to evaluate it. In 4 other interviews, the respondent indicated that “I don’t have difficulty; it’s just because of my age”. This reveals that the respondent actually has some difficulty with his memory or concentration, but that nevertheless he considers it “normal”. In the other interviews the responses obtained were not specific, for instance, “just because”.

Among the 113 interviews in which the respondent reported not having difficulty to remember or concentrate and also answered the open-ended question, in just about 35 of them the answer given to the open-ended question simply confirmed the answer to the core question, as for example “because I don’t have any difficulty” or “because I remember things”, without however adding any additional information. In the great majority of cases, respondents mentioned they had no difficulties for specific reasons such as, for example, “because he knows all the relatives’ phone numbers”, “because he always finds the objects he hides”, “because he remembers things that happened when he was a child”. In three interviews the respondent referred to the age of the child he was proxy respondent for as the reason for the answer provided.

Of the 62 respondents who reported having “some difficulty” remembering or concentrating and who answered the open-ended question, 28 mentioned difficulties remembering something or easily forgetting, while only 3 reported difficulty concentrating. Several respondents justified the answer provided based on attitudes or external factors such as “is anxious and is always joking”, “has no patience to do things”, “gets easily distracted”, “is old”, “it’s a consequence of the stroke”, but in a more general way, the majority confirmed the answer given in the core question. There was only one case in which the respondent could not tell why he answered as he did.

In 3 interviews in which “much difficulty” remembering or concentrating was reported and the core question was also answered, the majority of respondents mentioned difficulties related to remembering names of persons, remembering to give messages or where they put something. In three cases, the respondent mentioned difficulty learning and, in two others, problems related to the use of drugs/alcohol. In four interviews there was a report of a mental disability.

Of the 22 persons who cannot remember things or concentrate at all, five did not answer the open-ended question. Among the answers provided, about half

mentioned reasons why they have difficulty such as, for example, “because I have cerebral palsy”, “because he is mentally disabled,” “because she suffered an accident.” The other half simply reinforced their answer to the core question, mentioning they had problems concentrating or remembering something.

Mobility

In 53 of the total of 406 interviews, the respondent did not answer the core question, and therefore the open-ended question was not asked. In 232 of the 353 interviews with an answer to the core question, an answer was elicited for the open-ended question. Therefore, the following comments are based in those answers.

In the great majority of the interviews, that is in about 221, the answer provided to the open-ended question confirmed the information provided in the core question. In only 6 interviews, the answers provided were not specific. In those interviews the respondent answered “because that’s the truth” and “that’s it”. In 3 interviews there were cases of inconsistency between the answer to the core question and the open-ended question.

In 126 of the 131 interviews in which the respondent reported not having difficulty walking or climbing steps and also answered the open-ended question, the answer provided to the open-ended question only confirmed the answer to the core question, without adding additional information such as, for example, “because I have no difficulty”. In 3 interviews the following responses were obtained: “because of obesity”, “holding a hand” and “suffered an accident”, which suggests inconsistency between both answers.

One of the 27 respondents who reported having “some difficulty” walking or climbing steps and who answered the open-ended question mentioned that “does not run, because he’s epileptic, but he has no difficulty walking”. One respondent said he has “some difficulty” but when answering the open-ended question he said that “he walks aimlessly and in a semiconscious state because of drugs”, showing confusion about the aim of the question to capture difficulties regarding locomotion.

In only 1 of the 46 interviews in which respondents reported “much difficulty” walking or climbing steps and also answered the open-ended question, the respondent mentioned that s/he “is somewhat sick”, which does not help figure out if the difficulty is permanent or temporary. In the remaining interviews the response to the open-ended question only confirmed the answer provided to the core question.

Of the 36 respondents who reported they cannot walk or climb steps at all, 13 are quadriplegic, 3 are unable cannot walk or climb steps since birth because of cerebral palsy and 5 are paraplegic. Only 1 reported missing lower limbs. Eight respondents did not answer the open-ended question.

Self-Care

In 53 of the total of 406 interviews, the respondent did not answer the core

question, and therefore the open-ended question was not asked. In 213 of the 353 interviews with an answer to the core question, an answer was elicited for the open-ended question. Therefore, the following comments are based in those answers.

In the great majority of the interviews, that is in about 198, the answer provided to the open-ended question confirmed the information provided in the core question. In only 7 interviews, the answers provided were not specific. In those interviews the respondent answered “because that’s the truth” and “that’s it”. In 1 interview there was an indication of inconsistency between the answer to the core question and the open-ended question.

In 158 of the 160 interviews in which the respondent reported not having difficulty caring for him/herself and also answered the open-ended question, the answer provided to the open-ended question only confirmed the answer to the core question, without adding additional information such as, for example, “because I have no difficulty”, “a good persons does not have any problem”, “thank God I can do it”. In the case of 1 interview in which it was said that the respondent “did not have difficulty”, in the answer to the probing of the open-ended question the following response was elicited: “he does not bathe by himself because of his age”, showing an inconsistency in the answers to the two questions. In only 1 case the respondent reported that: “life has taught me to be careful with problems”, thus revealing confusion regarding the goal of the question.

Among the 16 respondents who reported having “some difficulty” in this topic and who answered the open-ended question, no inconsistencies were found; only one respondent said he had “some difficulty”, but when answering the open-ended question he said that “sometimes he does not like to bathe”, showing confusion regarding the objective of the question, aimed at capturing physical problems that limit a person’s ability to take care of him/herself.

In 10 interviews in which “much difficulty” was reported and the core question was also answered, only 1 answer to the core question mentioned that the respondent “is schizophrenic and cannot always care for himself”. In the other interviews the answer to the open-ended question only confirmed the answer to the core question.

Two of the 38 respondents who answered in the core question “that they cannot take care of themselves at all” reported in the open-ended question that they are quadriplegic and the others have limitations due to the most varied reasons, the main ones being advanced age or serious illness, such as stroke and cerebral palsy. Eleven respondents did not answer the open-ended question.

Communication

In 57 of the total of 406 interviews, the respondent did not answer the core question, and therefore the open-ended question was not asked. In 216 of the 349 interviews with an answer to the core question, some response to the open-ended question was obtained. Therefore, the following comments were based in those responses.

In the great majority of the interviews, that is in about 200, the answer

provided to the open-ended question confirmed the information provided in the core question. In a few cases the answer obtained was not specific, however the number of questions such as “that’s it” and “because that’s the truth” was larger than in the previous questions. In one interview the respondent said he was tired of answering the same questions. In some case the respondent associated the difficulty communicating with shyness, dislike for conversation or being grumpy, but the majority associated it with physical, emotional or mental problems, or simply mentioned being able to understand (or not) or being understood.

In about 50 of the 154 interviews in which the respondent reported not having difficulty communicating and also answered the open-ended question, the answers were such as “I don’t have it” or “None”, without adding additional information that would help understand the reasons for the answer. In the majority of the remaining interviews, the respondents made comments that illustrated their ability to communicate, resorting often to expressions such as “I am communicative” and “I am articulate”. In only one interview the respondent reported being used to his problem, which suggests there is a communication problem even if it was not reported in the core question.

Five of the 21 respondents who reported “some difficulty” communicating and who answered the open-ended question reported physical problems with speech or hearing. The majority of the other respondents only mentioned difficulty understanding without, however, adding other information.

In 25 interviews in which “much difficulty” communicating was reported and the core question was also answered, the great majority of respondents reported physical, mental or emotional problems such as difficulty talking or hearing, Down’s syndrome, schizophrenia or depression. In only one interview the respondent reported a dislike for conversation, suggesting that the question may not have been well understood.

Ten of the 26 persons who cannot communicate at all did not answer the open ended question. Among the answers given, the great majority justifies the inability to communicate due to the difficulty with speech and/or hearing. In several interviews the respondent reported that communication only takes place through crying, smiles or looks, which in a certain way is contradictory because it reveals that the person is capable of communication, albeit very basic.

Body Structures and Functions

In 56 of the total of 406 interviews, the respondent did not answer the core question, and therefore the open-ended question was not asked. In 201 of the 350 interviews with an answer to the core question, some response to the open-ended question was obtained. Therefore, the following comments were based in those responses.

In the great majority of the interviews, the answer provided to the open-ended question confirmed the information provided in the core question. It was rare to obtain a non-specific answer such as “that’s it” or “because it’s true”. Compared to the other modules, this had the lowest percentage of non-specific answers.

The majority of respondents in the 162 interviews in which they reported not having any of the disabilities mentioned and answered the open-ended question confirmed the answer given to the core question. However, in about 15 cases the respondent explicitly mentioned “not having paralysis” or “having the limbs in perfect shape”, which suggests that they focused their understanding on just one part of the question. Some respondents reported having “paralysis in one arm”, “partial cerebral palsy”, aside from other impairments such as visual or mental problems, spine problems, arthritis, among others, which are not included in the response categories presented in this thematic module. In some interviews the response suggests that there is a problem, however there is not enough information to identify the problem because the answers are such as ‘I cannot do everything’, “is better after the surgery”, “had a stroke...”, “makes movements with limitations”, “can feel the leg but have no strength to walk”, among others.

The great majority of the 14 respondents who reported permanent total paralysis and who answered the open-ended question mentioned that they were completely disabled or quadriplegic. In the remaining cases, the reason why the person is paralyzed was mentioned, for example, “was in a car accident”. In only one case the respondent mentioned his complete inability to walk, which could be due to paralyzed legs or missing limbs, although no additional information is available.

Of the 17 respondents who reported having permanent paralysis of the legs and who answered the open-ended question, the great majority of the answers to the open-ended question confirm the existence of difficulty, but only in four the answer confirms the type of disability reported. In the remaining answers the respondent mentioned problems walking or being on their feet, that the person is sick or has dystrophy, difficulties that can be associated to other disabilities. In two interviews the response category selected is not correct, since the respondents reported being quadriplegic or having paralysis in one side of the body.

In four of the 5 interviews in which respondents reported having permanent paralysis in one side of the body and who answered the open-ended question, the respondent barely provided the reason why they have the difficulty: “because of a stroke”.

Of the 3 respondents who reported a missing leg, arm, hand, foot or thumb, and who answered the open-ended question, all described the type of disability.