Content Analysis of Questions Regarding Disabilities in the 65 Years and Older Population in the Census 2000, the Puerto Rico Community Survey 2006 and the Puerto Rican Elderly Health Conditions 2003.

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"Not everything that can be counted counts;

and not everything that counts can be counted."

- Albert Einstein

Introduction:

The accelerated growth of the population over 65 years has been experienced by many countries. This has generated concerns in many sectors at a global level, and requires a change of public policy strategy. In Puerto Rico, this growth has been observed consistently since the middle of the last century. The growth of the population aged 65 years or more is attributed to declining fertility and mortality ^(6, 13, 16, 17, 20, 24, 25, 41). New advances in medicine and public health are an integral part in this change. The ageing of the population has a major impact on the planning of health services, housing and economic support. The vertiginous increase of the elderly population results in political, economic and social problems that most governments are not prepared to assume. Socially and culturally speaking, the ageing process implies changes in physical and mental capacities. That is why a change in public policy is needed to benefit the elderly population who live with disabilities. The problem for this population is compounded when we include poverty as a variable into the analysis. By not being able to completely care for themselves, the elderly tend to fall under poverty levels. Governments should temper their public policy to meet the needs presented by this population. This demographic phenomenon challenges us to be creative and proactive for the benefit of this particular group.

The Americans with Disabilities Act was passed in 1990. It defined a disability as, "a physical or mental impairment that substantially limits one or more major life activities" ^(21, 39). Until 1990, the U.S. Census Bureau, with regard to disability, only asked whether a person "had a condition that made it difficult to work at a job or business", or "received federal benefits based on an inability to work" ^(22, 23). In the 2000 Census, questions regarding different categories of disabilities were incorporated into the survey; these categories were physical, mental and sensorial disabilities (32, 33, 36, 40). After the 2000 Census, the Census Bureau designed a survey to provide communities with a fresh look at how they were changing. This project was called the American Community Survey (ACS). Concerning Puerto Rico, it was named the Puerto Rico Community Survey (PRCS). The PRCS collects information such as age, race, income, commuting time to work, home value, veteran status, and other important data from Puerto Rican households ^(34, 38). Another study in Puerto Rico, the "Puerto Rican Elderly: Health Conditions (PREHCO)" project aims at providing quality data concerning: health status, housing arrangements, functional status, transfers, work status, migration, income, childhood characteristics, health insurance, use of health services, marital history, labor history, mistreatment, sexuality, etc, of older adults (aged 60+). PREHCO is a representative sample (4,293) of the 60 years and older population ⁽²⁶⁾.

This paper analyzes the discrepancies in the results from the 2000 U.S. Census, 2006 Puerto Rico Community Survey and 2002 PREHCO concerning disability with regard to sex, poverty level and education in the 65 years and older population of Puerto Rico. Differences are expected according to all the variables considered. A content analysis should help in understanding the discrepancies in disabilities in terms of methodology, wording of the questions, time of year, and the person who answers the questionnaire, among others.

Methodology:

This research is of a descriptive nature, which also implemented a content analysis technique. The data collected from three different studies: the 2000 Population and Housing Census, 2002 Puerto Rican Elderly Health Conditions, and 2006 Puerto Rico Community Survey. For the 2000 Census, the 5% public use micro data sample ("PUMS") was utilized. This sample is taken from the long-form questionnaire which collects information on economic activities, education levels, travel to work patterns, infrastructure, and purchasing power, among others, for the purpose of obtaining a summary of the current state of the Island.

The self-administered questionnaire completed by the householder or any member of the household, was returned by mail; this methodology was first use in 2000. For previous years this information was gathered by the field representative. The sample consisted of 189,828 people. The response rate for "mail back" was 52.6 percent. This is without taking into consideration the responses by phone and home follow-up, which are the next steps after not having responded to the questionnaire by mail. After no response follow up operation (NRFU), coverage improvement follow up operation (CIFU) and coverage edit follow up operation (CEFU), the accuracy of Census 2000 was 95.6 percent^{*}.

^{*} Bureau of the Census 2000 Puerto Rico Population Census, Carters vs. US Department(307f.3d1084) Technical Summary of A.C.E. Revision II - 4/4/03 DSSO Census Procedures and Operations Memorandum Series Q64.

Was also used the "PUMS" for the Puerto Rico Community Survey (PRCS) of 2006 ⁽³⁷⁾. It was created as part of the restructuring effort for the Census 2010, as it replaces the long-version that was used in the Decennial Census. This survey produces estimates on population and housing characteristics. As well as the Census of Population and Housing, the PRCS is also self-administered by the householder or any other member of the household. The data is collected monthly and is published annually according to the size of the geographic areas. The overall response rate for the 2006 PRCS was 97.5 percent and had a sample size composed of 34,746 persons ⁽³⁸⁾.

For the purposes of comparison, we used the "Puerto Rican Elderly: Health Conditions" (PREHCO) project database ^{*}. The project objective is to describe the health status of adults aged 60 or older in Puerto Rico. It is sponsored by the National Institute of Aging and the Pan American Health Organization. This project uses a stratified and multistage sample, which is representative of the 60 years and older non-institutionalized group living in Puerto Rico in 2002. The face to face interview was accomplished through the use of laptop computers and audio recorders. To determine if the "target" is capable to answering the interview, the "target" was submitted to a cognitive test. If the individual passed the minimental, the interview would continue. In the case that the "target" was not able to pass the minimental, a substitute informant ("proxy") who was aware of the "targets" " health conditions, would be chosen to answer the interview ⁽²⁶⁾.

During the fieldwork for these project 20,665 homes were visited, from which were obtained 4,291 interviews from "targets" and 1,045 from spouses, for a total of 5,336 interviews. Of all the interviews conducted, only 12.5 percent required the use of "proxies". The overall response rate was 93.9 percent. The questionnaire includes

^{*} www.prehco.rcm.upr.edu

sections on demographic and socioeconomic characteristics, mental health, functional status, use of health services, among others ⁽²⁶⁾. (See table 1)

Table 1⁽¹¹⁾

Feature:	Census 2000	PRCS 2006	PREHCO
Sample Frame	Household	Household	Household
Institutional	Included	Included	Excluded
Population			
Respondent	Household or family	Household or family	Target or Proxy
	member respondent	member respondent	
Ages Included in the	All ages	All ages	60 years and older
Survey			
Operational Mode	Self Report Mail	Self Report Mail	Computer Assisted
	Back Questionnaire	Back Questionnaire	Interview
Design	Cross sectional	Cross sectional	Cross sectional
Years Studied	2000	2006	2002
Complete Sample	189,828 personas	34,746 personas	4,291personas

U.S Census Bureau, Census 2000, Technical Documentation; U.S Census Bureau, PRCS 2006, Technical Documentation ;General Report - PREHCO 2002/03

The samples used in this study were: the 2000 Population and Housing Census with 21,223 persons aged 65 or more, the 2006 Puerto Rico Community Survey with 5,773 persons and the PREHCO study with 3,297 persons in this age group ^(26, 35, 37). The variables compared in this study are: sex, age, poverty levels, years of schooling completed, and type of disability. Age was grouped into five year age-groups, ranging from 65 to 85 years. The poverty thresholds used were those published by the U.S. Census for the years mentioned in each of the different studies.[†]

[†] Poverty Thresholds consulted from www.census.gov/hhes/www/poverty/threshld/thresh02.html

i ty.

	Census 2000	PRCS 2006	РКЕНСО
Sensorial	16. Does this person have any of the following long- lasting conditions:a. Blindness, deafness, or a severe vision or hearing impairment?	15. Does this person have any of the following long- lasting conditions:a. Blindness, deafness, or a severe vision or hearing impairment?	 G. 114ck Is the person being interviewed blind? G.115 How is the persons' vision with and without eyeglasses, contact lenses or intraocular lenses? G.123ck Is the person being interviewed deaf? G.124 How is the persons' hearing with and without the use of a hearing aid?
Physical	 16. Does this person have any of the following long- lasting conditions: b. A condition that substantially limits one or more Basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying? 	 15. Does this person have any of the following long- lasting conditions: b. A condition that substantially limits one or more Basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying? 	Anyone who answers affirmatively to any of the 17 questions from Section I that are asked to the "Target" and any of the 11 questions asked to the "Proxy" from Section Z, from the questionnaire. (See Appendix)
Mental	 17. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: a. Learning, remembering, or concentrating? 	16. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities:a. Learning, remembering, or concentrating?	Did the person pass or not the Minimental exam.(See Appendix 3)
Self Care	17. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in	16. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing	I.9 Due to of a health condition, do you have difficulty eating?I.10 Due to a health condition, do you have difficulty getting dressed

	doing any of the following activities:	any of the following activities:	and undressed by yourself?
	b. Dressing, bathing, or getting around inside the home?	b. Dressing, bathing, or getting around inside the home?	I.11 Due to a health condition, do you have difficulty using the toilet?I.12 Due to a health condition, do you have difficulty walking from one side of the room to the other?
			I.13 Due to a health condition, do you have difficulty getting in and out of bed?
			I.14 Due to a health condition, do you have difficulty bathing or showering?
			(No Data for Proxys)
Able to Go Out	17. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing	16. Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing	I.2 Due to a health condition, do you have difficulty arriving at places using some means of transportation?
	any of the following activities:	any of the following activities:	I.3 Due to a health condition, do you have difficulty buying food or clothes?
	c. Going outside the home alone to shop or visit a doctor's office?	a. Going outside the home alone to shop or visit a doctor's office?	Minimental.

U.S Census Bureau, Census 2000, Questionnaire ;U.S Census Bureau, PRCS 2006, Questionnaire; PREHCO 2002/03, Questionnaire. *Table design by Authors.

In order to make comparable the three studies, only the 65 years and older group living in household were selected, since PREHCO does not include people who lived in group quarters ⁽²⁶⁾. The 2000 Census and 2006 PRCS use the same variables pertaining to disability ^(36, 38). Using 2002 PREHCO data, dichotomic variables were calculated so that they would be comparable to the ones utilized in the 2000 Census and 2006 PRCS.

Census and PRCS define sensorial disability as blindness, deafness or a severe vision or hearing impairment. In order to create a variable comparable to this definition,

blind persons, those unable to hear as well as those who even with eye glass or hearing aids, their vision and hearing capacity was bad were grouped.

Mental disability is defined by both the 2000 Census and 2006 PRCS as having difficulty with learning, remembering or concentrating ^(36, 38). Anyone who did not pass a cognitive exam or minimental was considered to have difficulty with learning, remembering and concentrating. PREHCO validated this minimental which measures cognitive ability in adults older than 60 years; with no or low level of education. ^(26, 27). In addition, this variable includes aspects from the Census and PRCS definition. (See Appendix 1)

In order to compare physical disability, which the Census defines as a condition that substantially limits one or more basic physical activities such as walking, stair climbing, stretching, lifting or carrying ⁽³⁶⁾, a variable was created with the individuals who replied affirmatively to any of the questions related with basic and instrumental activities of daily living contained in the sections of the PREHCO questionnaire. (See Appendix 2)

Self Care was defined in the 2000 Census and 2006 PRCS as having difficulty in dressing, bathing and walking around the house ^(36, 38). The variable created from PREHCO brought together people who because of a health condition had difficulty eating, dressing and undressing alone, using the toilet, walking from one side of the room to the other, getting in and out of bed, and taking a bath or shower ⁽²⁶⁾; making this variable comparable with the definition from both the Census and PRCS. Since these questions were answered only by the people who answered the interview without a proxy,

this variable does not take into consideration the functional status of all persons aged 65 or more.

The variable able to go out was defined as those who had difficulty to go shopping and go see a doctor by themselves ^(36, 38), by both the 2000 Census and 2006 PRCS. It was considered that the questions in PREHCO which inquired about those who had difficulty arriving at places using some means of transportation, those who had difficulty buying food or clothing and those who didn't pass the minimental ⁽²⁶⁾ would be comparable with Census and PRCS. (See table 2)

Results:

The initial analysis of these three surveys, reported that the 65 years and older population with at least one disability increased from 58.6% in 2000, to 62.6% in 2006. In contrast, the results for that same variable in PREHCO were 47.2%. The proportions of women with at least one type of disability are the highest in all three surveys ^(26, 35, and 37). (See Table 3)

Variables:	Census 2000	PRCS 2006	PREHCO
Disability:	58.6	62.6	47.2
Sex:			
Male	55.5	57.4	42.1
Female	61.0	66.6	51.2
Age:			
65-69	45.8	49.8	33
70-74	52.8	55.0	38.6
75-79	64.1	67.4	52.7
80-84	73.5	78.8	62.9
85-89	80.7	87.4	74.1
90-94	88.8	90.5	84.8

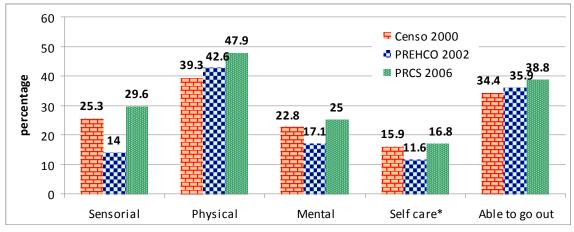
Table 3:

Poverty Level:			
Above	54.04	56.8	36.6
Under	64.7	70.0	56.4
School:			
No School	73.2	79.0	79.4
Elementary	65.7	73.1	55.5
Middle School	58.2	63.5	42.8
High School	55.6	53.9	37.3
More Than High School	44.9	50.3	30.8
Type of Disability:			
Sensorial	25.3	29.6	14.0
Physical	39.3	47.9	42.6
Mental	22.8	25.0	17.1
Self Care	15.9	16.8	11.6
Able to Go Out	34.4	38.8	35.9
Sample:	n = 21,223	n = 5,773	n = 3,297

U.S Census Bureau, Census 2000, 5% PUMS; U.S Census Bureau, PRCS 2006, PUMS; PREHCO 2002/03 Data Base. *Table designed by Authors. *PREHCO Self Care not included Proxies.

In addition, lower percentages were observed for all types of disabilities in PREHCO, compared with the 2006 PRCS. For example, the percentage of people 65 years or older with a physical disability in 2002 PREHCO was 42.6%, in 2006 the PRCS estimated it to be 47.9% ^(26, 35, 37). (See Graphic 1)

Graphic 1



Percentage of Disabilities by Type of Disability CENSO 2000, PREHCO 2002, PRCS 2006.

U.S Census Bureau, Census 2000, 5% PUMS; U.S Census Bureau, PRCS 2006, PUMS; PREHCO 2002/03, *PREHCO Self Care not included Proxies.

Furthermore, the data shows that the graphic having at least one type of disability increases with age (Graphic 2) and decreases depending on the level of education for all surveys (Graphic 3). This trend was observed in the 2000 Census and 2006 PRCS. In PREHCO, this trend is similar but with lower percentages, sharing a similarity with the consulted literature in this field ^(2, 5, 8, 9, 10, 11, 18, 19, 28, 29, 31). This study also found that as education increases, the percent of people with at least one type of disability decreases.

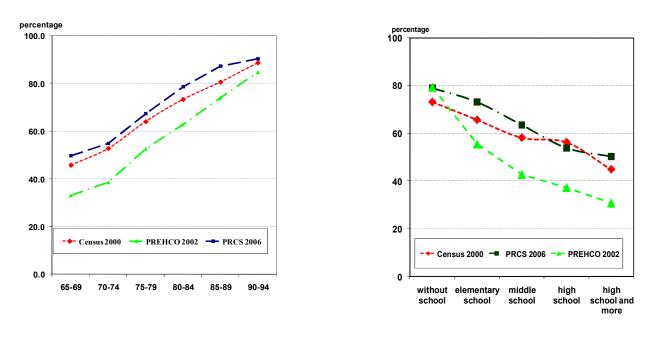
Graphic 2

Percentage of persons 65 years and more with

any disability by age group in Puerto Rico:

Census 2000, PREHCO 2006 y PRCS2006.

Percentage of persons 65 years and more with any disability by schooling in Puerto Rico: Census 2000, PREHCO 2002 and PRCS 2006.



U.S Census Bureau, Census 2000, 5% PUMS 5% PUMS U.S Census Bureau, PRCS 2006, PUMS PUMSPREHCO 2002/03, Data Base

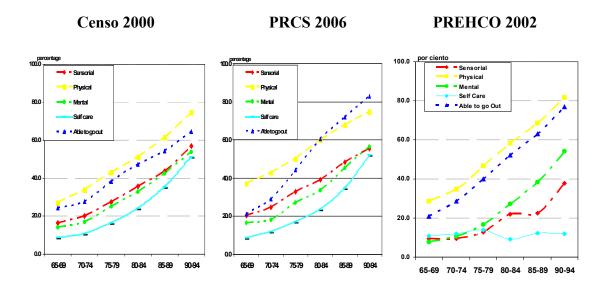
U.S Census Bureau, Census 2000, U.S Census Bureau, PRCS 2006, PREHCO 2002/03, Data Base

Although PREHCO maintains lower proportions in all types of disabilities in all age groups, this figure nearly matches Census and PRCS as age increases (Graphic 2); the opposite is true for education. The Census, PRCS and PREHCO reported very similar proportions when seniors lacked schooling, particularly the first two databases just mentioned. As education increases, the curve from PREHCO moves away from the others, to the extent that, the proportion of older adults with more than high school education in PRCS is twofold the proportion obtained in PREHCO (Graphic 3) ^(2, 5, 8, 9, 10, 11, 18, 19, 28, 29, 31)

A quantitative analysis showed that different type of disabilities increased with age ^(2, 5, 8, 9, 10, 11, 18, 19, 28, 29, and 31). This is evident in the Census and PRCS. Physical disability is very similar for both Census and PRCS. In PREHCO however, although there are more questions related to ADL's and IADL's than those in Census and PRCS, a lower proportion of people with some type of functional limitation was found (Graphic 4). For PREHCO, self-care curve is different because it does not account the answers of the proxies

Graphic 4

Percentage of person 65 years or more by type of disability and age group Puerto Rico: Census 2000, PREHCO 2002 and PRCS 2006.

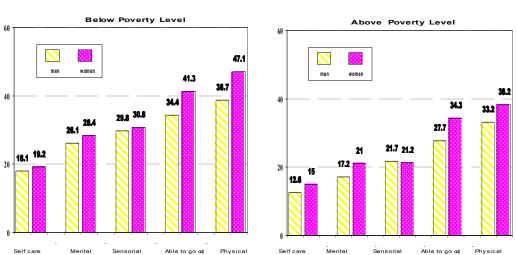


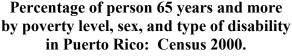
U.S Census Bureau, Census 2000, 5% PUMS; U.S Census Bureau, PRCS 2006, PUMS; PREHCO 2002/03, *PREHCO Self Care not included Proxies.

The analysis on disability and poverty level for all the surveys showed that, disability is higher in those who live below poverty level. On the other hand, the proportion of those who live above the poverty level lower. When sex is considered, women who live below the poverty level have a higher percentage of disability, compared to men in the same category of disability. In Census and PRCS, women above the poverty level have a higher percentage than men, except in sensory disability where the percentage of men was higher ^(2, 5, 8, 9, 10, 11, 18, 19, 28, 29, 31). (Graphic 5) (Graphic 6).

The results from PREHCO showed the disadvantage of women in all types of disabilities and levels of poverty. Under poverty level women had the highest percentage for all disabilities, except for sensory and mental disabilities. (Graphic 7).

Graphic 5

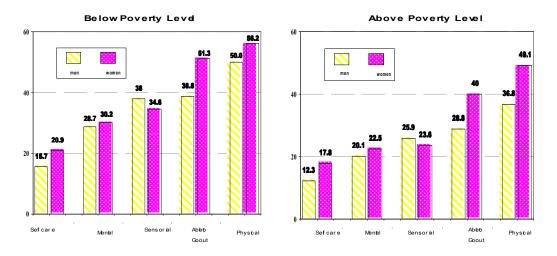




U.S Census Bureau, Census 2000, 5% PUMS; U.S Census Bureau, PRCS 2006, PUMS; PREHCO 2002/03, Data Base

Graphic 6

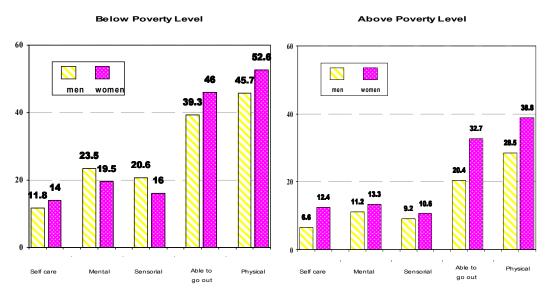
Percentage of person 65 years and more by poverty level, sex, and type of disability in Puerto Rico: PRCS 2006.



U.S Census Bureau, Census 2000, 5% PUMS; U.S Census Bureau, PRCS 2006, PUMS; PREHCO 2002/03, Data Base

Graphic 7

Percentage of person 65 years and more by poverty level, sex, and type of disability in Puerto Rico: PREHCO 2002.



U.S Census Bureau, Census 2000, 5% PUMS; U.S Census Bureau, PRCS 2006, PUMS; PREHCO 2002/03, Data Base *PREHCO Self Care not included Proxies.

Likewise, PREHCO data also shows the disadvantage of women in all types of disabilities whether they were below or above the poverty level, with the exception of mental and sensorial disabilities for those who live below the poverty level, where their percentage is lower to that of men.

Discussion:

In view of the fact that the decennial Census, PRCS and PREHCO were conducted in close proximity of one another, it was anticipated that these studies would share similar trends in the increase of disabilities by age. In addition, it was expected that the difference in percentages for disability would be minimal. But after examining the results, these showed that there were in fact discrepancies between them. Although there were differences between the 2000 Census and 2006 PRCS, both surveys followed a similar trend. These differences may be explained by the changes in age structure of the population.

Moreover the PREHCO results show significant deviations from the Census and PRCS. Disabilities in PREHCO are lower regardless of age. Several factors could be taken into account to explain these differences. The 2000 Census and 2006 PRCS are aimed at the entire population. An adult of the household may complete the self-administered questionnaires, although it is understood that it is mostly the householder who issues the response. In the 2000 Census, householders represented 67.1 percent of persons who live in household and 2006 PRCS had 57.8 percent of householders. Therefore, the information that describes a considerable part of this population comes from the data provided by a proxy that may or may not have knowledge of the peculiarities of all household members.

Often the instructions of these questionnaires sent by mail are not necessarily clear, especially when translation is taken into consideration. This lack of precision, with little probability of clarification, allows for the terms of these questions and the alternatives for the responses, to be misleading. Therefore, this allows for the premises outlined in the questionnaire to be interpreted in a broader form. As information from the PREHCO interview is managed with a computer, this is considered a direct interview. In this scenario, the interviewer may clarify under standardized instructions, any doubts that may arise to the interviewe. So the responses obtained circumscribe themselves more to the intention of the question, and answers of the premise.

Another important aspect that might explain this difference is the kind of question or the construction of the question. Although the word "disability" is not part of the vocabulary used and the word "impairment" is used only once, the Census and PRCS described a disability as: a long-term condition, a condition that limits, or a difficulty in carrying out any activity. Thus, the definition of the Census could lead to a substantially broader interpretation. On the other hand, PREHCO addresses the disability issue from a health condition standpoint.

The Census and PRCS questionnaires are designed to gather information in the United States, thus responding to its idiosyncrasies. The Census and PRCS translate literally the premises, without taking into account the different Hispanic vocabularies which may vary according to country and region. Conflicts stemming from the translation of questionnaires used by the Census tend to alter the content of the question and answer accordingly. One example of this is the word "reach", which translated outside the

cultural context by the Census, is defined as the word "estirarse[‡]", when the correct translation for this word would be, "alcanzar[§]", in question 16b (Census) & 15b (PRCS) of the questionnaire "Does this person have any of the following long-lasting conditions A condition that substantially limits one or more Basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?"^(1,3,4,7,14,15,30). It is important to consider that the 65 years and older population in this study has low levels of education and has a substantial proportion below the poverty level.

Political and economic aspects can also intervene in the differences from the Census and PRCS compared to PREHCO. To receive a communication from the Federal Government, by mail, by telephone or even personally can intimidate respondents, indistinctly from the legal and methodological clarifications that may be included in the instructions. Given the colonial status, hence economic dependence, of the Island with the United States, a substantial portion of Puerto Ricans receives federal aids.

In other words, for the purposes of receiving federal funds: MEDICARE, MEDICAID, Veterans and Social Security among others; people may exaggerate their condition for fear of receiving less or possibly losing all the aids from these institutions.

Although PREHCO used as reference contemporary studies of its kind, the instrument was adapted to the social and cultural context of the Island. This was carried out through focus group discussions, which ensured that the vocabulary used is not misleading the intent of the study. In addition, respondents signed an informed consent, which explicitly referred to the reliability of information management. This means that the information collected will be used solely for research purposes. It should be pointed

[‡] "Estirarse" = to stretch, in Spanish. § "Alcanzar" = to reach, in Spanish.

out that studies conducted by academic institutions, especially if it comes from the University of Puerto Rico dealing with health issues have prestige among the population. Thanks to this, it is not perceived as threatening. None of the three surveys emphasizes the words "disability" and "impairment". Another aspect that should be taken into consideration is that even in addressing the issue as a "long-term condition" or "difficulty due to health problems," the cultural and social conception of the term disability is associated with genetic problems or illness. In older people it is difficult to raise any conditions or difficulty, because they feel neglected or rejected as productive entities. This age group views the difficulties associated with ageing as part of a natural process and not as an "impairment" or "disability".

Prior to the 2000 census, the information was gathered was using a questionnaire developed by a committee composed of different census data users in Puerto Rico. This committee was organized by the Census Bureau in the Planning Board of Puerto Rico. Therefore the instructions, the terms, the wording of the questions, the expressions on assumptions, the vocabulary used, among other, take into consideration to the social, cultural, political and economic Puerto Rico.

The political reality of the Island influenced this practice. The government of 1992 requested the use of the questionnaire used in the mainland to collect data in the Island, adversely affecting this important aspect of the census operation. With this political aim, the opportunity to negotiate the content of questions was lost. Therefore, the Island lacks of valuable data collected through this instrument. This is important because, Puerto Rico does not participate in many of the surveys that provide information necessary for decision-making and research. The Island joined the ACS through the PRCS recently but it does not participate of other surveys such as: NHIS, AHEAD, MCBS, National Long Term Care Survey, LSOA, National Institute of Aging, and NHANES.

Conclusion:

The figures offered by PREHCO seem to correspond more with the reality of adults older than 65 in Puerto Rico. PREHCO is a study aimed at people aged 60 or over with the aim of documenting the health status of this sector of the population. The instruments used were adapted to the cultural and social aspects. In addition the minimental was validated for the people of this age group with low levels of schooling (important consideration when it comes to aged adults). The methodology used by PREHCO better guarantees that the answers are more sincere and correct, since among others, only 12.5 percent of the interviews from PREHCO were answered by a proxies. As mentioned earlier PREHCO data showed a lower prevalence of disability with respect to those obtained by the Census and PRCS. This finding is consistent with several studies indicating that the prevalence of disability is declining in this sector of the population ^(2, 5, 8, 9, 10, 11, 18, 19, 28, 29, 31)

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