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*PROS AND CONS OF DATA COLLECTED USING A
CENSUS: THE EXPERIENCE OF THE CARIBBEAN
COUNTRIES*

MEASUREMENT OF DISABILITY

PROS AND CONS OF DATA COLLECTED USING A CENSUS: THE EXPERIENCE OF THE CARIBBEAN COUNTRIES

The 1990 round of censuses in the Caribbean was the first occasion on which questions on disability were introduced in the census. Prior to that various surveys and studies were done in the region in regards to specific aspects of disability, however comparisons were somewhat difficult due to the lack of standardized definitions. The census provided a very useful benchmark on the disabled population as well as the frame from which in-depth sample surveys and studies could be done on disability.

What is a population census?

A modern population census may be defined as the total process of gathering, compiling and publishing information on the people of a country or a specific area, which tells about their number, their age and sex, where they live, their level of education, whether or not they attend school, work and other such characteristics. In short, it relates to information on the total count of the population and its characteristics.

The total population of the country consists of all the persons falling within the scope of the census. In the broadest sense, the total may comprise either all usual residents of the country or all persons present in the country at the time of the census. The total of all usual residents is generally referred to as the *de jure* population and the total of all persons present as the *de facto* population.

Census as a means of data collection

The advantage of the population and housing census is that it is geared towards the coverage of the entire population of the country, and information is collected about social and economic conditions such as housing characteristics and employment for every person or household enumerated. Therefore the question about the **prevalence** of disability is asked of all members of the household.

The usefulness of the census lies in the fact that it provides data, which allows for cross-classification of disability with the demographic data and other socio-economic variables in order to provide a more comprehensive picture of the status and condition of persons with disabilities. For example, one is able to obtain data on the housing conditions of disabled persons, which is quite important especially for persons in the lower socio-economic strata.

In addition, disability is seen as a sensitive matter, taking into account cultural factors and with a census the individual sees the focus as getting a population count and is not averse to answering specific questions on disability however the same individual might be very reluctant in answering questions in a survey specific to disability. In countries such as the Caribbean where there is the tendency to keep persons with disabilities hidden or

parents are reluctant to go public the information is sometimes supplied by the neighbors. From the census therefore one is able to determine the change in the population of persons with disabilities over various time periods.

However because the matter of disability is a technical and specialized area, that is, it might require medical knowledge to determine the nature of the condition, the census does not allow for the in-depth questioning necessary. This would be better done through a survey, as there is a limit to the number of questions that can be accommodated on the census questionnaire. The limited number of questions regarding disability, which can be accommodated in a census, cannot provide a precise measure of the number of people with disability, especially among children. Data obtained in the census should therefore be considered as indicative or as a provisional estimate of the number of people with disability. Also, the census is not intended to and cannot be the medium for collecting this data in the amount of detail or with the level of precision that is required.

Surveys

Sample surveys, unlike censuses are not intended to enumerate every household or individual in the country. The census provides the frame for future studies as this enables the selection of samples with some knowledge of where the person with a disability is located. The data that the census cannot provide, including the study of changes between two censuses in some characteristics, could be obtained through sample surveys. The census provides benchmark data for measuring those changes in characteristics based on the results of such surveys.

The adoption of sampling will be more appropriate with regard to the training of interviewers in very technical/specialized areas. In the case of a census to attempt to train a large number of interviewers in the concepts and definitions relevant to this highly specialized area, and then to undertake the probing that would be required to obtain specific information pertaining to the nature of disability is neither practical nor possible.

Although sample surveys are designed to be representative of the population, where the incidence of disability is low, a much larger sample is required to produce more meaningful results, as the data from these surveys are sometimes not published because of the low frequencies observed. Despite this factor however due consideration has to be given to the cost incurred when administering a large survey.

In an effort to obtain data additional data on disability in Jamaica, in 2000 questions on disability were included in the Health module in the Survey of Living Conditions as an attachment to the Labour Force Survey. The Labour Force Survey is based on a two percent sample of the population. The frequencies observed in this survey were very low so it is unlikely that the data will be published.

Terminology

One of the major problems in comparing statistics on disabilities and handicaps from different sources is the lack of consistency in terminological uses and classification. For

example, with regard to census 2001, in Barbados, disability is defined as a “condition characterized by the complete or almost complete (75% or more) absence of a given body function”. In Trinidad and Jamaica the term is described as “any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered to be normal for a human being”. Antigua and Bermuda speaks to a “long-standing” condition lasting six (6) months and more. The problem is further compounded by the unsuitability of various instruments for assessing disability and handicap and by the scarcity of professionals to carry out the research. Obtaining information about disability has therefore been a difficult and time-consuming exercise, with the consequence that very little priority has been given to disability in health programs in the region.

There is a tendency for a chronic disease to be regarded as a disability by the population in general hence the concept of disability must be clearly understood by the interviewer to obtain the correct answers. In the context of the Caribbean where the incidence of hypertension and diabetes is fairly high there is uncertainty on the part of interviewers as to how to classify these persons. In an effort to address this problem in the 2001 census, a list of the main chronic diseases have been included in some of the countries example, Jamaica, Bermuda and St. Lucia so as to better determine if any of these conditions have resulted in a disability.

Training

The census is a poor mechanism for obtaining detailed data on complex characteristics, the investigation of which calls for special skills and training of the field staff. It must be taken into account that the matter of disability is a very specialized area requiring knowledge in many instances specific medical details. As a result of the technical nature of the questions specialized training is required.

More emphasis has to be placed on training on the concepts so that interviewers will have a better understanding of the various categories used in the census. The concepts of mental retardation and intellectual disability posed a problem and would require further specialized training of census personnel by health professionals. This was evident in the results of the 1991 census of Jamaica; it was observed that persons who were identified in the category slowness at learning or understanding had University/tertiary level education as the highest level of educational attainment.

Based on the results of the 1991 census of Jamaica, in instances where interviewers were uncertain of the category to score the type of disability “Other” or ‘Not stated” was entered thus resulting in a large number of persons being placed in the “Other” category. Thus, pointing to the need for more extensive training regarding the concepts. The time lag in the analysis of the data on disability did not allow for follow up field checks.

Results

In designing the census questions on this topic, the Caribbean countries follow the recommendations of the U.N. to use the 'disability' approach, rather than the 'impairment' or 'handicap' approach. A screening question is asked to identify persons with a disability, which limits their activities, and a list of specific types is listed for scoring the answer. For example, most countries asked:

“Does -----suffer from any longstanding illness, disability or infirmity? Or Do/Does -----have any problems with any of the following?”

The census results in these countries showed the incidence of disability being under ten (10) percent. This round of censuses provided a very useful benchmark, as there was not a comprehensive set of data on disability prior to this. However, using the WHO figure of 10% as the international guide the local disability NGO's were dissatisfied with the proportion recorded for the population with a disability as experienced in Jamaica where the figure was approximately 5%. This dissatisfaction was recorded against the background of the absence of any comprehensive register of disabled persons to add some validity to their claim. However there is some merit to this, as the inclusion of persons with disabilities in institutions would have increased the figure.

In analyzing the data, data on socio-economic factors were distorted because of the disability and aging factor. To address the problem additional questions would be required such as the onset of disability, which is a very important variable in terms of the analysis of the data. In the previous census this question was not included, however, for the 2001 census some countries, for example, St. Lucia and Antigua have included the question “At what age did this disability begin?”

Limitations of the census

A major limitation of the census is related to the difficulty in covering the institutional population. Census information on persons in institutions are generally limited to age and sex which in most instances are taken from administrative records. The fact that there is the likelihood of disabled persons living in institutions has to be considered.

The approach for census generally is to identify those where access is possible and speak directly to the respondents. These are then asked the questions. Those where no access is possible and the basic (age and sex) information is taken from administrative records, are likely to be the ones where disability is more prevalent. The following are the main institutions identified :

- Correctional Institutions
- Mental Institutions
- Homes for Children, the Aged, Infirm and Needy

- Hospitals and Homes providing specialized care, Cancer Hospitals and other hospitals for chronic ailments and Homes for Incurables
- Hospitals and Homes for the Blind, Deaf and other Handicapped

It is this latter type that the census of Jamaica will attempt to cover in 2001

The census of 1991 in Jamaica did not identify these persons in the institutionalized population, which would result in an increase in the number of the disabled population. However the census scheduled for September 2001 in Jamaica will attempt to get answers to the disability questions in respect of persons resident in certain types of institutions but this poses a major challenge.

RECOMMENDATIONS

- **Harmonization of concepts and definitions**

There is at present no mechanism for routine collection of comparable disability data among Caribbean territories. The standardization of concepts and definition will facilitate analyses requiring the use of data from the census and sample surveys and will also help in evaluating coverage in the two operations. The level of reported prevalence of disability is largely determined by the operational definition of disability used.

- **Promotion of the ICIDH**

In the Caribbean there is need for the dissemination and promotion of the usage of the ICIDH among statisticians, researchers and users (including NGO's) of the data on disability so that there can be greater harmonization and to facilitate comparisons on an international/regional basis also for the development of social policy and legislation.

The users have to be sensitized to the limitations of census data. There is a general non-acceptance of the data and because the topic is so emotional, it sometimes makes rational discussions difficult.

- **Training**

There is need for more training in the research and use of disability data for statisticians and users also more interaction between the statisticians and the users.

- **Conducting more surveys**

There is the need for more detailed and specific information on disability, which would be better obtained through surveys.

- **Institutional Population**

The development of a strategy to cover the institutional population of persons with disabilities in studies is necessary.

CONCLUSION

The census can provide an indication of the prevalence of disability in the population, this is valuable information as in many countries it is the only available source of information on the frequency and distribution of disability in the population, at the national, regional and local levels.

Census results can provide baseline data and may be useful for investigating small-area variations in the prevalence of disability as well as utilizing the data for the monitoring and evaluation of national programmes and services concerning the equalization of opportunities, rehabilitation and prevention of disabilities.

Bibliography

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