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Considering issues related to the collection of information of disability, maternal mortality and HIV/AIDS mortality in the census*

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I. DISABILITY INFORMATION

1. For decades censuses have failed to produce reliable and comparable information on the extent of disability in the general population. Disability prevalence rates generated from census data range from 0.2% to 33% as compiled from the United Nations Statistics Division's Disability Statistics (http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp). One of the reasons for this high degree of variation was the lack of a common definition for disability as well as lack of standard methods.

2. The main purpose of collecting disability information in censuses is to obtain information on the overall number of people with disabilities. The census, however, is not an appropriate data collection vehicle to identify in great detail the type of disability.

3. Currently most of the countries collect, in their censuses, impairment data based on specific and familiar diagnostic situations (e.g., blindness, deafness, paralysis, movement, co-ordination and body strength, mental handicap etc). The disability prevalence rates obtained through this impairment-based approach are generally very low and are often criticised for not reflecting the true extent of disability in the population.

4. With the endorsement of the International Classification of Functioning, Disability and Health (ICF) by all 192 WHO Member States in 2001 a common framework became available. Since then, the World Health Organization (WHO), in collaboration with other United Nations agencies and individual Member States are engaged in a series of activities to promote and facilitate the use of the ICF framework in censuses. Most importantly, the United Nations Washington Group on Disability Statistics has taken the ICF as a basis for its efforts to develop a set of global census questions. At the regional level the WHO is collaborating with the United Nations Economic and Social Commission for Asia and the Pacific (UN-ESCAP) and the United Nations Economic and Social Commission for Western Asia (UN-ESCWA) in workshops and projects to improve disability statistics using the ICF framework. Similarly, the meeting on health status conducted by the United Nations Economic Commission for Europe (UN-ECE) also based its approach on the ICF.

5. With the ICF model, not using "impairment" based head count approach, this variance could be overcome. ICF is based on a spectrum of human functioning. There are meaningful thresholds of difficulties in functioning. For example a person can have full vision, good vision with negligible decrements, may be in need of correction eye glasses or lenses, or may need additional assistance because they may not be able to see the light. Accordingly the census should include a set of simple and direct questions which include the most parsimonious set of ICF domains. For example:

Do you have difficulties in any of the following areas of functioning:

a. *Mobility (e.g. walking, going out of house)*
b. *Vision (reading a document, seeing a person across the road)*
c. *Hearing- Communication (hearing another person, talking)*
d. *Taking care of your self (washing your self, going to toilet)*
d. *Remembering where you left your important things (keys, money)*

6. The ICF domain set selection criteria should include:
   (i) importance in terms of public health burden,
   (ii) psychometrics and feasibility,
   (iii) suitability for self-reporting,
   (iv) cross-population comparability,
   (v) explain large part of the People with Disabilities (PWDs) as defined by impairments.

These questions can reliably assess the classical groups of disability and the population prevalence could be better determined both in terms of magnitude and type of disability.

II. MEASURING MATERNAL MORTALITY

7. Maternal mortality is recognized as an important national and country indicator reflective of health system performance, the status of women and social and economic development. Reduction of maternal mortality is a Millennium Development Goal, and was included in the programmes of action of the International Conference on Population and Development in 1994,[1] the Fourth World Conference on Women in 1995,[2] the five-year follow-up conferences and special sessions of the United Nations General Assembly[3] and the World Fit for Children in 2002.

8. The inclusion of maternal mortality reduction in the recommendations of these global conferences creates a demand for sound data that can be tracked on a regular basis, a demand that is, in practice, difficult to satisfy. In developing countries where statistical systems are weak, there is neither complete registration of deaths nor medical certification of cause of death. In such settings, population-based surveys can be used to identify maternal deaths and calculate levels of maternal mortality. However, because maternal deaths are relatively rare events, very large sample sizes are needed to produce a stable value of the maternal mortality ratio. In order to reduce sample size requirements, researchers have developed indirect methods that obtain information about both the respondents themselves and their adult sisters. While these "sisterhood" approaches reduce sample size requirements, they still have sizeable confidence intervals and do not provide a current estimate of maternal mortality but one centered at some point prior to the survey, generally some 3-4 years prior to data collection. Furthermore, because of the small numbers of maternal deaths, it is impossible to calculate differentials in maternal mortality by key demographic and socio-economic stratifiers such as age, residence, education, wealth etc. This seriously limits the value of the maternal mortality ratio for policy-making and prioritization.

9. Monitoring trends presents particular difficulties: because of wide margins of uncertainty it is unclear whether changes in the maternal mortality ratio represent real change or are simply an artefact of the data collection method.

[1] Programme of Action of the International Conference on Population and Development, Cairo, 1994
[2] Programme of Action of the Fourth World Conference for Women, Beijing, 1995
[3] UN General Assembly. Report of the Ad Hoc Committee of the Whole of the Twenty-first Special Session. A/S-21/5/1/add.1. I July 1999

10. In recent years, there has been increasing interest in the potential of the decennial censuses to generate data on maternal mortality.[4] At the Safe Motherhood Technical Consultation that took place in Colombo, Sri Lanka, in 1997 as well as during the five-year follow-up to the International Conference on Population and Development in New York in 1999, attention was drawn to the potential of the census to permit better measurement of maternal mortality.[5] A number of countries have attempted to use the census to measure maternal mortality. In 2001, Measure Evaluation undertook a review and assessment of these experiences and made recommendations for further work in this area.[6]

11. The advantage of the census lies mainly in the large numbers involved; sampling errors are eliminated or greatly reduced. Moreover, the census can generate data at both national and subnational levels and can provide information on inequities in maternal mortality by geographic region, by socio-economic status, and by characteristics of the woman.

12. If the census has already been placed to include questions on recent household deaths, the additional cost of identifying pregnancy-related deaths will be small. The extra questions on timing of adult female deaths relative to pregnancy, childbirth and the postpartum period would, in a typical developing country, be used in less than 1% of households.

13. A further advantage of the census is that standard demographic methods can be applied to evaluate the quality of the data and corrections may be possible to adjust for omissions and other data quality problems. On the other hand, the census may miss maternal deaths that result in the break-up of the household.

14. The fact that the census takes places only every 10 years would appear to limit its usefulness for monitoring purposes. However, this problem is less serious than would at first appear. Given the slowness of the rate of change of maternal mortality, and the wide margins of uncertainty surrounding estimates generated through household surveys, it is not worthwhile to repeat such surveys more than once every ten years or so. The use of process indicators for monitoring progress is recommended instead.[7] The census can thus serve as an occasional check of the validity of the process indicators for monitoring and can also be used to validate other data sources including household surveys, civil registers and facility data.

III. HIV/AIDS mortality

15. The most recent review of the availability of trend data on HIV/AIDS related mortality from censuses, vital registration and surveys was published by John Blacker in July in *AIDS* 2004, 18: supplement 2. Censuses increasingly play an important role in documenting the age and sex-

[4] Stanton C et al. Every death counts: Measurement of maternal mortality via a census. Bulletin of the World Health Organization, 79(7):657-664

[5] Key Actions for the Further Implementation of the Programme of Action of the International Conference on Population and Development 1999

[6] Hill, K. et al. Measuring maternal mortality from a census: guidelines for potential users. Measure Evaluation and WHO, July 2001

[7] WHO/UNICEF 1997 The sisterhood method for estimating maternal mortality: guidance notes for potential users. WHO/RHT/97.28 UNICEF/EPP/97.1

specific mortality changes that are occurring in countries severely affected by the AIDS epidemic. Such information is crucial for the documentation of dramatic mortality changes that occur over time, and complement information generated by surveys, vital registration systems, demographic surveillance studies and research.

16. The inclusion of more specific questions about the cause of death may not give good results in censuses. While censuses would be able to collect reliable information on well-definable acute causes of death such as maternal death or injuries, validation studies have shown that reporting of the causes of death through questions to relatives of the deceased person often suffer from low levels of sensitivity and specificity. AIDS requires multiple questions and exclusion of other causes of death. The stigma associated with AIDS further complicates the reporting of AIDS as a cause of death which has been shown in several studies. It is not possible to simply ask whether the person died of AIDS.

17. Work on trying to improve the diagnostic algorithm using verbal autopsy questions is ongoing and increasing use of verbal autopsy questions in sample vital registration systems is to be expected. This effort, combined with improving medical certification of causes of death, is considered the best way to collect cause-specific information. At least as important however, is the careful documentation of the levels, trends and differentials in age and sex specific mortality rates in the censuses and surveys.