



Economic and Social Council

Distr.: General
18 July 2014

Original: English

Economic Commission for Europe

Conference of European Statisticians

Group of Experts on Population and Housing Censuses

Sixteenth Meeting

Geneva, 23-26 September 2014

Item 12 of the provisional agenda

Demographic, household and family characteristics and disability

Demographic characteristics and disability - Draft text for the Conference of European Statisticians Recommendations for the 2020 census round

Note by the UNECE Task Force on Demographic, household and family characteristics, and the UNECE Steering Group on Population Censuses

Summary

This document presents the draft text on demographic characteristics and on disability for the new Conference of European Statisticians Recommendations for the 2020 Round of Population and Housing Censuses. It was prepared by the UNECE Task Force on Demographic, household and family characteristics and the UNECE Steering Group on Population and Housing Censuses (in cooperation with the Washington Group on Disability Statistics) based on the first proposal discussed at the September 2013 meeting of the UNECE-Eurostat Group of Experts on Population and Housing Censuses, and on further discussion within the Task Force and the Steering Group.

NOTE: The present version of the document shows, using the “track changes” function, the changes between the text of the CES Recommendations for the 2010 census round, and the draft text of the CES Recommendations for the 2020 census round. It should be noted that the order of some topics within the chapter was changed between the 2010 and the 2020 census round recommendations.

I. Demographic characteristics

A. Introduction

~~2041.~~ The demographic characteristics of sex, age and marital status are core variables, which are often used to classify ~~or base~~ other information from the census to help in the understanding of various socio-economic and demographic issues. In the case of sex and age, it is considered important that this information be available for every person for whom census information has been collected. It is therefore recommended that where this information is incomplete it be derived or imputed for census purposes rather than report it as being 'not stated'.

2. The population census provides an opportunity to collect data for estimating fertility and mortality at national and sub-national levels in a cost-effective manner. The investigation of fertility in population censuses is particularly important in countries lacking a reliable system of vital statistics because of the opportunity the data provide for estimating vital rates that would not otherwise be available. Even in countries with complete birth registration, some of the topics ("children born alive", "children living", and "age at marriage or union") are equally appropriate because they provide data that are not easily available from registration data, such as cross-tabulation with socio-economic characteristics.

Sex (core topic)

~~2053.~~ The sex of each person should be recorded in the census. Sex is, together with age, the census topic that is most frequently cross-classified with other characteristics of the population. Therefore, it is fundamental that information on sex is as complete and accurate as possible. If information on sex is missing, an imputation based on other individual or household entries should be made.

~~206. Many countries in the region have identified the need for further development in gender analysis. It is therefore important that countries ensure that the various definitions and classifications for data on educational attainment, economic activity status, occupation, position in the family and household, etc. are appropriately used in the census. The same data for both men and women should be provided for all appropriate topics.~~

4. The sex (male or female) of every individual should be recorded in the census questionnaire. Sex disaggregation of data is a fundamental requirement for gender statistics. For many socio-economic and demographic characteristics that could be collected through a census, such as education, economic activity, marital status, migration, disability and living arrangements, there are generally variations by sex. Sex, together with age, represents the most basic type of demographic information collected about individuals in censuses and surveys, as well as through administrative recording systems, and the cross-classification of these data with other characteristics forms the basis of most analyses of the social and demographic characteristics of the population as it provides the context within which all other information is placed.

Age (core topic)

~~2075.~~ To obtain information on age, it is recommended that information on date of birth ~~is collected~~ be collected. This yields more precise information than collecting data on exact age at the time of the census. Collecting information on the date of birth allows the

tabulation of data in two ways: by year of birth and by completed years of age. Date of birth also allows the calculation of age to be made in respect of points in time other than at census day. Given that age is one of the most important variables collected in a census, used in many tabulations and analyses, it is fundamental that information on age ~~is~~ be as complete and accurate as possible. ~~Particular attention should be given to the older ages.~~ If information on age is missing, imprecise or contradictory, imputation based on other individual or household entries should be made.

6. In countries where exact date of birth may be difficult to collect for a significant proportion of the population, the instrument can be modified to allow calendar quarter or season of the year to be substituted. In census questionnaires with specifically designed responses boxes for day/month/year, such write-in responses as season of the year would not be codable. Impossible ages, e.g. children older than their parents, should be edited. If age in years is collected attention must be given to parents incorrectly reporting their infant's ages in months. Additionally, care should be taken in collected information for the elderly as misreporting can be more common at the older ages.

~~2087.~~ Many countries in the region have identified children, the youth and the elderly as particular population groups for which various types of census data will be required. The types of data on children and youth that are likely to be of interest include topics such as family type (two-parent or one-parent family), family income, economic activity of parents, and school attainment and/or educational attainment of parents. For the elderly, data on marital status, economic activity status, position in the family and household, disability, and type of living quarters are illustrations of some of the topics cross classified by age and sex, and that are likely to be of interest to countries. It is recommended that countries ensure that the definitions and classifications planned to be used in the census for these and other topics of interest are appropriate for the dissemination of those data on children, youth and the elderly that will be required. ~~Attention needs to be paid to the accuracy of the information, particularly for the elderly.~~

Legal marital status (core topic)

~~2098.~~ Marital status is defined as the (legal) conjugal status of each individual in relation to the marriage laws (or customs) of the country (that is *de jure* status).

~~2109.~~ Information on the legal marital status of each person should be collected at least for persons aged 15 and over. However, since the minimum legal age (or the customary age) for marriage varies between countries and since the population may also include young persons who have been married in other countries with lower minimum ages, ~~it is recommended to collect~~ the collection of the data for all persons: is encouraged.

~~2110.~~ The following classification of the population by marital status is recommended:

- (1.0) Never married
- (2.0) Married
- (3.0) Widowed and not remarried
- (4.0) Divorced and not remarried

~~2121.~~ It should be noted here that insofar as this recommended classification of legal marital status is concerned, all persons living in consensual unions should be classified as never married, married, widowed or divorced in accordance with their *de jure* (legal) status.

~~21312.~~ In countries with legal provision for registered/legal partnership (for opposite-sex couples and/or same-sex couples) or where same-sex couples can legally marry, additional categories may either be included in the category of the "married", ~~or~~ for example

~~_____ (2.1) Opposite-sex husband/wife/spouse~~

~~_____ (2.2) Same-sex husband/wife/spouse~~

~~13. Alternatively, the above classification may be expanded to include them explicitly (for example: (5.0) Person living in a registered/;~~

~~_____ (1.0) Never married~~

~~_____ (2.0) Married~~

~~_____ (2.1) Opposite-sex husband/wife/spouse~~

~~_____ (2.2) Same-sex husband/wife/spouse~~

~~_____ (3.0) Registered or other legal partnership; (6~~

~~_____ (3.1) Opposite-sex partner~~

~~_____ (3.2) Same-sex partner~~

~~_____ (4.0) Person living Widowed and not remarried~~

~~_____ (5.0) Divorced and not remarried.~~

~~14. Obviously, the choice of terms actually used for "husband/wife/spouse" must be appropriate to the language and the culture. Many languages lack a gender neutral word for "spouse." However, in a registered/choosing terms, one must remember that opposite-sex couples may prefer different terms from same-sex partnership). However, couples. Regardless of the approach chosen, it is suggested/strongly encouraged that a thorough testing program be conducted prior to introducing this possibly sensitive latter category.~~

~~21415. A separate category for "legally separated" could be considered in countries where the legislation includes provisions for this status, as different/being distinct from "married" or "divorced".~~

~~21516. In countries where the group of persons whose only, or latest, marriage has been annulled is substantial in size, a separate category may also be considered for this group. When a separate category is not considered for this group, the individuals should be classified according to their marital status prior to the annulled marriage.~~

De facto marital status (non-core topic)

~~216. Countries which have experienced increases in the number of persons living in consensual unions may wish to collect information not only on the de jure status but also on the de facto status. In some countries it is already possible to identify registered partnerships, as this category may have status equivalent to legal marriage.~~

~~21717. De facto marital status is defined as the marital status of each individual in terms of his or her actual living arrangements within the household enumerated. It is suggested regardless of that person's legal marital status. It is recommended that information on this topic be collected for persons of the same age categories as those for whom information on the legal status was/is collected.~~

~~21818. The suggested/recommended classification is:~~

~~(1.0) Person living with spouse or partner (registered or in a consensual union-) having usual residence in the same household~~

~~(2.0) Person not living with spouse or partner (registered or in a consensual union) having usual residence in the same household.~~

21919. Two persons are taken to be partners in a consensual union when: they have usual residence in the same household, they are not married to, nor are in a registered/legal partnership with, each other, and they have a marriage-like relationship to each other. People in such a relationship are also known as "cohabiting partners".

22020. An optional distinction within category (1.0) between (1.1) "Person living ~~in an~~with opposite-sex ~~partnership~~spouse or partner" and (1.2) "Person living ~~in a~~with same-sex ~~partnership~~spouse or partner" should be considered by countries that would like to ~~collect~~produce data on same-sex ~~partnerships~~couples.

22121. It is to be noted that information on *de facto* marital status can also be derived from information collected on topics related to household and family characteristics of persons, characteristics of family nuclei and characteristics of private households, based on the relationship to the reference person question or the full household relationship matrix in countries adopting a traditional census where ~~the~~such a matrix is used. Where such matrix is not used, a ~~separate~~specific question would need to be asked.

22. It is recognised that in countries where census information is derived from administrative registers, data on consensual unions may not be available.

23. [NOTE: Some members of the task force proposed to add a new cross-classification of legal and de facto marital status, whereas others were not in agreement. The meeting may wish to discuss whether the following cross-classification should be included in the recommendations or not] For those countries wishing to cross classify *de jure* and *de facto* status, the following classification is suggested:

(1.0) Never married(1.1) Person living with partner (registered or in a consensual union) having usual residence in the same household(1.2) Person **not** living with partner (registered or in a consensual union) having usual residence in the same household(2.0) Married(2.1) Person living with spouse or partner (registered or in a consensual union) having usual residence in the same household(2.2) Person **not** living with spouse or partner (registered or in a consensual union) having usual residence in the same household(3.0) Widowed and not remarried(3.1) Person living with partner (registered or in a consensual union) having usual residence in the same household(3.2) Person **not** living with partner (registered or in a consensual union) having usual residence in the same household(4.0) Divorced and not remarried(4.1) Person living with partner (registered or in a consensual union) having usual residence in the same household(4.2) Person **not** living with partner (registered or in a consensual union) having usual residence in the same household**Total number and sex of children born alive (non-core topic)**

2224. Information on total number of children born alive can be collected in the census by countries that plan to use it to calculate estimates of fertility based on indirect techniques. If this topic is included in the census, it is suggested that information on total number of live-born children be collected for all women age 15 and older. In populations where significant fertility occurs at younger ages, the lower limit should be adjusted accordingly.

2225. The data collected on total number and sex of live-born children should, in principle, include all children born alive during the lifetime of the women concerned up to the census date (that is excluding foetal deaths)- and stillbirths. Adopted children should not be included. The number recorded should comprise all live-born children whether born of the present or prior marriage(s), whether born of consensual or other unions or by a single mother, within country or abroad, and regardless of whether or not such children are living at the time of the census, or where they may be living. ~~It is recognized that it may not be possible to specify in the enumeration instructions that all children including those not born in a marriage or in a consensual union should be included.~~

Date(s) of legal marriage(s) of ever-married women: (i) first marriage and (ii) current marriage (non-core topic)

22426. Information on dates/duration of marriage is valuable for fertility statistics and extends the knowledge that can be derived from data on number of live-born children. In the case of women who have been married more than once, information may be obtained on the dates of both the first marriage and the current marriage.

27. For women who are widowed, separated or divorced at the time of the census, 'date of/age at/number of years since dissolution of first marriage' should be collected. Information on dissolution of first marriage (if pertinent) provides data necessary to calculate 'duration of first marriage' as a derived topic at the processing stage. In countries in which duration of marriage is reported more reliably than age, tabulations of children ever born by duration of marriage yield better fertility estimates than those based on data on children born alive classified by age of the woman. Data on duration of marriage can be obtained by subtracting the age at marriage from the current age, or directly from the number of years elapsed since the marriage took place. Some countries may find it useful to also collect the order of the current marriage.

Date(s) of the beginning of the consensual union(s) of women having ever been in consensual union: (i) first consensual union and (ii) current consensual union (non-core topic)

22528. Information on dates/duration of consensual union, as well as information on dates/duration of marriage, is valuable for fertility statistics and extends the knowledge that can be derived from data on number of live-born children. In the case of women who have been in consensual union more than once, it is suggested to obtain information on the dates of both the first and the current consensual union. Information on dates/duration of consensual union(s) can be combined with the information on the date(s) of legal marriage(s).

29. It should be recognized that the beginning, and thus the beginning date, of a consensual union may be imprecise.

II. Disability

A. Introduction

44530. A census can provide valuable information on disability in a country. For countries that do not have regular special population-based disability surveys or disability modules in on-going surveys, the census can be the only source of information on the frequency and distribution of disability in the population at national, regional and local levels. Countries that have a registration system providing regular data on persons with the most severe types of impairments, may use the census to complement these data with information related to the broader concept of disability based on the International Classification of Functioning Disability and Health (ICF) as described below. Census data can be utilized for planning programs and services (prevention and rehabilitation), monitoring disability trends in the country, evaluation of national programs and services concerning the equalization of opportunities, and for international comparison of the disability prevalence in countries.

Disability status (non core topic)

~~44631.~~ Disability status characterises the population to those with and without a disability. Persons with disabilities are defined as those persons who are at greater risk than the general population for experiencing restrictions in performing specific tasks or participating in role activities. This group would include persons who experience limitations in basic activity functioning, such as walking or hearing, even if such limitations were ameliorated by the use of assistive devices, a supportive environment or plentiful resources. Such persons may not experience limitations in ~~the specifically measured~~ tasks, such as bathing or dressing, or participation activities, such as working or going to church, because the necessary adaptations have been made at the person or environmental levels. These persons would still, however, be considered to be at greater risk for restrictions in activities and/or participation than the general population because of the presence of limitations in basic activity functioning and because the absence of the current level of accommodation would jeopardise their current levels of participation.

~~447.—32.~~ A comprehensive measure to determine disability would include six domains of functioning: walking; seeing; hearing; cognition; self-care and communication. It is, however, recommended that the ~~following 4~~first four domains be considered as essential in determining disability:

- ~~i. — Walking;~~
- ~~ii. — Seeing;~~
- ~~iii. — Hearing; and~~
- ~~iv. — Cognition.~~

~~A comprehensive measure would include all domains (see paragraph 468).~~

If countries wish, then self-care and communication may also be considered as additional domains.

B. Disability framework and terminology

~~44833.~~ In 2001 The World Health Organization (WHO) issued the International Classification of Functioning, Disability and Health (ICF)¹ which is the successor of the International Classification of Impairments, Disabilities and Handicaps issued in 1980 (ICIDH)². The ICF is a classification system offering a conceptual framework with conceptual definitions, terminology and definitions of the terms, and classifications of contextual components associated with disability including both participation and environmental factors.

~~44934.~~ The ICF distinguishes multiple dimensions that can be used to monitor the situation of individuals with disability. The system is divided into two parts each with two components;

- (1.0) Functioning and disability, which include the components:

¹ International Classification of Functioning, Disability and Health (ICF), Geneva, World Health Organization, 2001.

² International Classification of Impairments, Disabilities and Handicaps (ICIDH), Geneva, World Health Organization, 1980.

- (1.1) Body functions and body structures (impairments); and
- (1.2) Activities (limitations) and participation (restrictions).
- (2.0) Contextual factors which include the components:
 - (2.1) Environmental factors
 - (2.2) Personal factors.

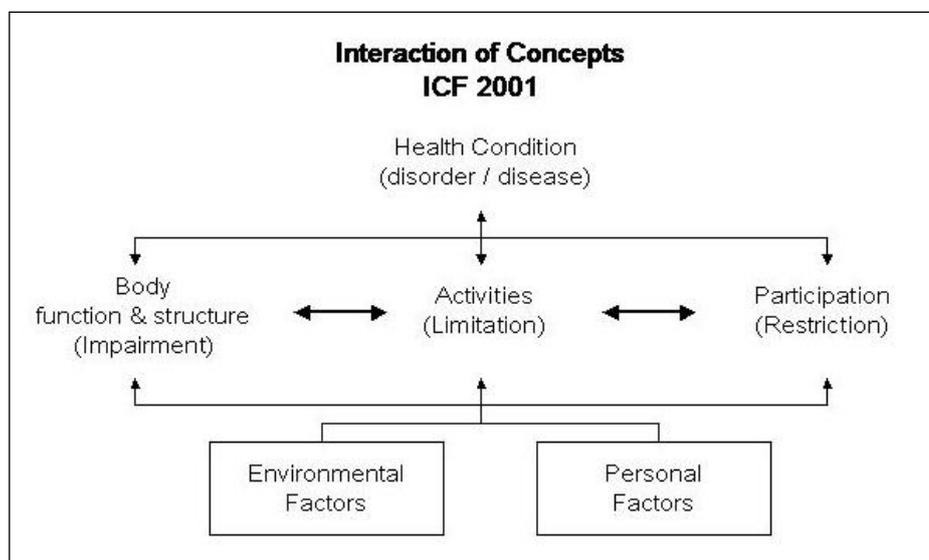
45035. The ICF provides classification schemes for all these elements except for personal factors.

1. Interactions between components of the ICF

45136. The interactions between the parts and components are shown in Chart 31.

Chart 31

Interaction of disability concepts



45237. The main structure of the classification is ~~reported in Appendix III~~ available on the web page of the ICF hosted on the WHO website³.

2. Use of the census to measure disability at aggregate level

45338. A census format offers only limited space and time for questions for one topic such as disability. Since the ICF offers several dimensions for use to develop a census measure, it is best to focus on a few of those dimensions, leaving the remaining dimensions for use in more extensive household surveys. Short sets of disability questions, which can be included in censuses and extended sets to be recommended for inclusion in population-based surveys

³ <http://www.who.int/classifications/icf/en/index.html>

are being developed and tested⁴. The aim of the recommended sets is to improve comparability of disability data across countries.

~~454. The World Programme of Action concerning Disabled Persons (WPA)⁵ provides a valuable guide for conceptualizing the uses of data on disability. The three major goals of the World Programme of Action are equalization of opportunities, rehabilitation and prevention.~~

45539. Three major classes of purposes for measuring disability in a census are:

(a) To provide services, including the development of programs and policies for service provision and the evaluation of these programs and services. The provision of services at the population level includes, but is not limited to, addressing needs for housing, transportation, assistive technology, vocational or educational rehabilitation, and long-term care;

(b) To monitor the level of functioning in the population. Monitoring levels of functioning includes estimating rates and analysing trends. The level of functioning in the population is considered a primary health and social indicator, which characterizes the status of the population in a society;

(c) To assess equalization of opportunities. The assessment of equalization of opportunity involves monitoring and evaluating outcomes of anti-discrimination laws and policies, and service and rehabilitation programs designed to improve and equalize the participation of persons with impairments in all aspects of life.

45640. The intent of these purposes for measurement is consistent with that of the World Programme of Action concerning Disabled Persons (WPA)⁶, which provides a valuable guide for conceptualizing the uses of data on disability. The WPA outlines three major goals for policy formulation and program planning, internationally: equalization of opportunities, rehabilitation and prevention. The common goal is to promote the participation of persons with disabilities in all aspects of life by preventing the onset and consequences of impairments, promoting optimal levels of functioning, and equalizing opportunities for participation.

45741. The assessment of equalization of opportunity is the purpose that can be best achieved in a census. It is this purpose that is being measured in the topic Disability Status considered when determining Disability Status (see paragraph 31) [NOTE: The cross reference will be updated based on the paragraph numbering of the final version of the recommendations].

45842. The definition outlined in disability status (see paragraph ~~446~~31) [NOTE: The cross reference will be updated] requires that disability be defined in terms of limitations in basic activity functioning, and not by that would place a person at greater risk than the general population of restricted performance or participation in the organized activities (such as educational attendance or work participation).

43. While assessment of equalization of opportunities might seem to require measurement of both activities and participation, such an approach does not help to identify

⁴ The Washington Group on Disability Statistics (WG), a UN City Group which focuses on proposing international measures of disability is developing ~~has developed~~ these questions. See www.cdc.gov/nchs/citygroup.htm. http://www.cdc.gov/nchs/washington_group.htm for updates on the questions

⁵ ~~World Programme of Action concerning Disabled Persons, United Nations, New York, 1983.~~

⁶ ~~World Programme of Action concerning Disabled Persons, United Nations, New York, 1983.~~

changes in the level of participation in the population in response to changes in opportunities. It only reflects the circumstances of those who because of unfriendly environments or lack of assistive devices are experiencing restrictions in participation. Approaching the assessment of equalization of opportunity by recognizing the link between a basic level of activity and subsequent participation can reduce some of the methodological ~~problems~~ challenges.

~~459~~44. Disentangling the conceptual dimensions of basic activity limitations that result from impairment, from the more complex activities associated with participation provides the opportunity to determine the intervening mechanisms that facilitate or interfere with performance of tasks and organized activity. At the analysis stage, people who are identified with and without disabilities on the basis of their ability to perform basic activities can be compared in relation to their participation in organized activities (such as school and work). This comparison can assess the equalization of opportunities. The separation between activities and performance differentiates approaches for the purpose of monitoring functioning in the population and for the purpose of assessing equalization of opportunity. —When assessing opportunity equalization, *the connection between the conceptual elements is made during analysis*, whereas for monitoring functioning *the connection is done during data collection*.

~~460~~45. Within the framework of the ICF Model and its four major dimensions (body structure and function, activity, participation and environment), an activity-oriented set of questions, located at the simplest and most basic level, should be used to capture the basic activity elements required for a good measure of the risk of participation restrictions.

~~461~~46. The adoption of an activity-oriented approach is also used in the European Health Status Module developed by Eurostat. ~~The module has been developed~~ within the European Statistical System ~~and although~~. ~~Although it~~ has been designed for more extended data collection activities such as ~~health interview surveys~~ the European Health Interview Survey, it still can be used to identify questions to measure activity limitations in a census. This module also includes the Minimum European Health Module (MEHM)⁷. ~~—, a set of three general questions characterizing three different concepts of health (self-perceived health, chronic morbidity and activity limitations).~~

~~462~~47. Given the ~~sensitivity and the~~ complexity of disability definition and measurement, and, in certain cultures, the sensitivity attached to identifying as having a disability, it is recommended that several functional activity domains be ~~identified where~~ defined whereby people can ~~be asked~~ respond to questions about their ~~ability to perform in such domains~~ difficulty performing those activities rather than ~~enquire about~~ directly enquiring whether or not they have a general disability status.

3. Essential domains:

~~463. The set of domains should capture the definition of disability that is being operationalized.~~ ⁴⁸. It is suggested that only those domains that have satisfied a set of selection criteria be eligible for inclusion in a short set of questions recommended for use in Censuses. Criteria for inclusion include cross-population or cross-cultural comparability,

⁷ The following link refers to the methodological manual for the European Health Status Module Interview Survey (EHIS wave 2), which includes model questions and guidelines on the Minimum European Health Module (MEHM)—
http://forum.europa.eu.int/Public/irc/dsis/health/library?l=/reports/healthsinterviewsurvey/questionnaire_translation_detailed&sb=Title (see pages 13 to 17):
http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-RA-13-018/EN/KS-RA-13-018-EN.PDF

suitability for self-reporting and space on the census form. Other suggested criteria include the importance of the domain in terms of public health problems. Based on these criteria, four basic domains are- considered to be essential domains. These include ~~the areas of: walking, seeing, hearing~~ and cognition. In addition, if space permits, two other domains have been identified for inclusion, self-care and communication. It is highly recommended that all six domains be operationalized if possible. The domains of walking, seeing and hearing are also included in the European Health Status Module.

46449. Walking fulfils the criteria of cross-cultural applicability and space requirements for comparable data since walking is a good indicator of a central physical function and is a major cause of limitation in participation. It is also a basic area of activity functioning that can be self-reported.

46550. While seeing also represents a public health problem, self-reporting of seeing limitation is more problematic, particularly when individuals use glasses to correct visual impairments. Similar difficulties are associated with asking about hearing activity. The most direct way to deal with assistive devices like glasses and hearing aids without contributing to confusion over answering such questions is to ask the questions about difficulty hearing or seeing without any devices or assistance.

46651. However, devices, such as glasses, provide almost complete accommodation for large proportions of those with impaired functioning and the numbers with the impairment can be very high. It is often argued that asking about seeing without the use of glasses greatly increases the number of persons with disabilities and makes the group too heterogeneous, that is, the group would include persons at very little risk of participation problems along with those at great risk. An alternative is to ask questions on difficulty seeing even *with* the use of glasses if they are usually worn and difficulty hearing *with* the use of hearing aids if these devices are used.

46752. Of the four essential domains, cognition is the most difficult to operationalize. Cognition includes many functions such as remembering, concentrating, decision making, understanding spoken and written language, finding one's way or following a map, doing mathematical calculations, reading and thinking. Deciding on a cross culturally similar function that would represent even one aspect of cognition is difficult. However, remembering and concentrating or making decisions would probably serve the cultural compatibility aspects the best. Reading and doing mathematical calculations or other learned capacities are very dependent on educational systems within a culture.

4. Additional domains:

53. In additional to the four essential domains, two other have been identified for possible inclusion: self-care and communication. The self-care domain is intended identify persons who have some problems with taking care of themselves independently. Washing and dressing represent self-care tasks that occur on a daily basis and are considered to be basic activities.

54. The purpose of the communication domain is to identify persons who have some problems with talking, listening or understanding speech such that it contributes to difficulty in doing their daily activities. Two aspects of communication are considered: understanding others (receptive communication) and being understood by others (expressive communication). Communicating (understanding/been understood) refers to the exchange of information or ideas between two people through the use of language. They may use their voices for their exchange or make signs or write the information they want to exchange.

468. There55. Beyond the six domains identified here, there are additional physical functioning domains that could be included in a set of ~~Census~~census questions depending

on the space available. Other domains that might be incorporated include upper body functioning of the arms, hands and fingers and psychological functioning. While identifying problems with psychological functioning in the population is a very important element of measuring disability for the stated objective, questions that attempt to represent mental/psychological functioning would run into difficulty because of the levels of stigmatization of such problems within a culture. This could jeopardize the whole set of questions.

5. Census questions

46956. It is recommended that special attention be paid in designing census questions to measure disability. The wording and the construct of questions greatly affect the precision in identifying the people with disabilities. Each domain should be asked through a separate question⁸. The language used should be clear, unambiguous and simple. Negative terms should always be avoided. The disability questions should be addressed to each single household member and general questions on the presence of persons with disabilities in the household should be avoided. If necessary, a proxy respondent can be used to report for the family member who is incapacitated. The important thing is to account for each family member individually rather than ask a blanket question. Scaled response categories can also improve the reporting of disability. -The census questions on disability endorsed by the Washington Group include four response categories (a. No - no difficulty; b. Yes – some difficulty; c. Yes – a lot of difficulty; d. Cannot do at all), and disability prevalence is determined based on any response that is “a lot of difficulty” or “cannot do at all” for any of the questions.

47057. The European Health Status Module (see paragraph 46146) **[NOTE: The cross reference will be updated]** includes a set of standard questions for various domains and can be used as source to develop census questions in three of the four core domains (seeing, hearing, and walking). There is also a set of questions for use on national Censuses for gathering information on the four essential domains⁹. The questions have been designed to provide comparable data cross-nationally for populations living in a great variety of cultures with varying economic resources. The objective is to identify persons with similar types and levels of limitations in functional activities regardless of nationality or culture. It is not the purpose of these questions to identify every person with a disability within every community. The questions may not meet all the needs for disability statistics, nor will it replicate a population evaluated across a wider range of domains that would be possible in other forms of data collection or in administrative data.

47158. The information that results from measuring disability status (see paragraph 44646) **[NOTE: The cross reference will be updated]** is expected to:

- (a) Represent the majority, but not all persons with limitation in basic activity functioning in any one country;
- (b) Represent the most commonly occurring basic activity limitations within any country; and
- (c) Capture persons with similar problems across countries.

⁸ When domains are combined such as asking a question about seeing OR hearing, respondents frequently are confused and think they need to have difficulty in both domains in order to answer yes. In addition, having the numbers with specific limitations is useful for both internal planning and for cross national comparisons.

⁹ For more information see the Washington Group Web-site:

www.cdc.gov/nchs/citygroup.htm http://www.cdc.gov/nchs/washington_group.htm

47259. The questions identify the population with functional limitations that have the potential to limit independent participation in society. The intended use of these data would be to compare levels of participation in employment, education, or family life for those with disability versus those without to see if persons with disability have achieved social inclusion. In addition the data could be used to monitor prevalence trends for persons with limitations in the particular basic activity domains. It would not represent the total population with limitations nor would it necessarily represent the ‘true’ population with disability, which would require measuring limitation in all domains.

C. Use of Census to screen for disability and follow-up with other surveys

47360. Countries that are planning specialized surveys on disability may want to use the census to develop a sampling frame for these surveys and include a screening instrument to identify persons who will be interviewed subsequently. The definitions and the instruments used for this purpose are very different from the ones used to assess equal opportunities. The main purpose of a screening is to be the most inclusive as possible in order to identify the largest group of people who could be further studied. The screening question should be designed so that false negatives¹⁰ are minimized, while false positive¹¹ should be less of a concern.

47461. Within the framework of the ICF, the census screening may include all of the three main dimensions of body structure and function, activity, and participation. This will allow for keeping a broad approach to the follow-up survey where the different aspects of disability can be better studied.

47562. The same recommendations highlighted in paragraphs 469-47256-59 [NOTE: The cross reference will be updated] should also be considered when a screening module is designed.

47663. Before embarking in using the census to develop a frame for a follow-up survey, it is important that the legal implications of using the census data for this purpose are fully considered. Respondents should be informed that the data may be used for follow-up studies and national authorities responsible for ensuring the privacy rights of the population may need to be consulted in order to obtain their approval.

¹⁰ Persons who have disabilities but are not identified in the census as having disabilities.

¹¹ Persons who are identified with disabilities in the census but in reality ~~the~~they do not have disabilities (as assessed in the largest instrument used in the follow-up survey)