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**Draft of the Section on Human Functioning and Disability for the revised 2010**  
**Programme on Population and Housing Censuses**

**(Report of Technical Subgroup 1-3)\***

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## Draft of the Section on Human Functioning and Disability for the revised 2010 Programme on Population and Housing Censuses

A census can provide valuable information on disability in a country. In many countries, it is the only available source of information on the frequency and distribution of disability in the population at national, regional and local levels. Even in countries that can afford special population based disability surveys or disability modules in a general population or health survey, Censuses can provide information for investigating small area variations in the prevalence of disability. These 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 framework and terminology**

In 2001 The World Health Organization (WHO) issued the International Classification of Functioning, Disability and Health (ICF) (ref) which is the successor of the International Classification of Impairments, Disabilities and Handicaps issued in 1980 (ICIDH) (ref). The ICF is a classification system offering a conceptual framework, conceptual definitions, terminology, definitions of terms, and a set of codes.

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

Functioning and disability which includes the components:

- body functions and body structures (impairments)
- and activities (limitations) and participation (restrictions),

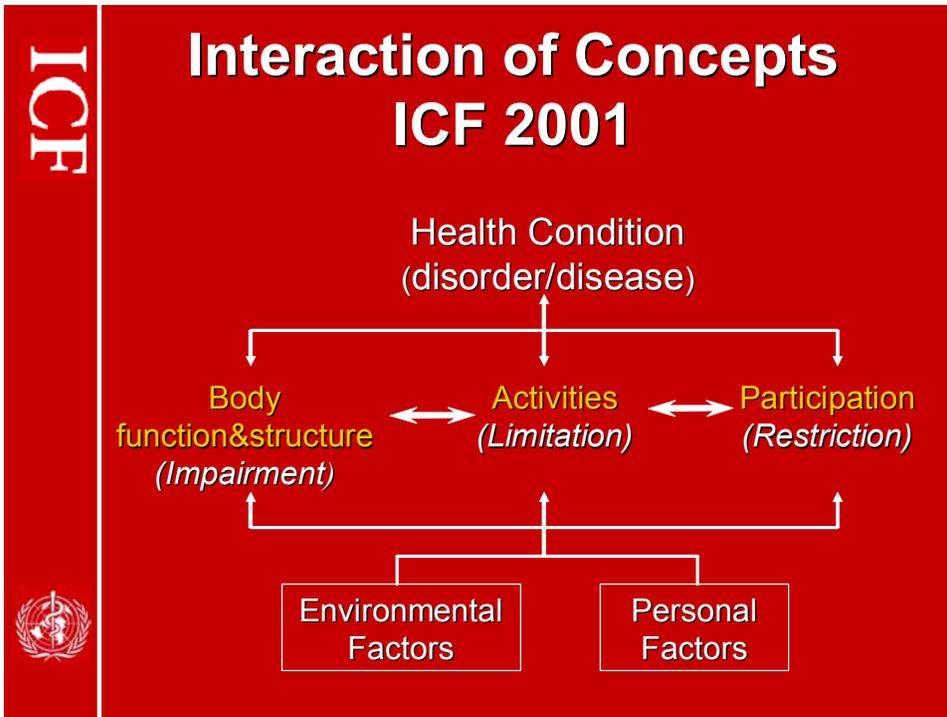
Contextual factors which includes the components:

- environmental factors
- personal factors.

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

### *Interactions between components of the ICF*

The interactions between the parts and components are reflected in the following model.



*Main concepts, terms and definitions*

The main concepts, terms and definitions of the ICF are:

- Body functions are the physiological functions of body systems (including psychological functions).
- Body structures are anatomical parts of the body such as organs, limbs and their components
- Impairments are problems in body function or structure such as a significant deviation or loss
- Activity is the execution of a task or action by an individual
- Activity limitations are difficulties an individual may have in executing activities
- Participation is involvement in a life situation
- Participation restrictions are problems an individual may experience in involvement in life situations
- Functioning is the umbrella term for body function, structure, activity and participation
- Disability is the umbrella term for impairment, activity limitation and participation restriction
- Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their life
- Personal factors are the particular background of an individual's life and living and comprise features of the individual that are not part of a health condition or health states, such as gender, race, age, fitness, lifestyle habits, coping styles, social

Contextual factors background, education, profession, etc. The ICF does not include a classification of personal factors represent the complete background of an individual's life and living including two components, being environmental factors and personal factors which may have an impact on the individual with a health condition and that individual's health and health related states.

The content of the ICF is illustrated by the first-level or parent categories (chapter headings) of each of the classifications included in the ICF.

Body functions:

- 1 Mental functions
- 2 Sensory functions and pain
- 3 Voice and speech functions
- 4 Functions of the cardiovascular, haematological, immunological and respiratory systems
- 5 Functions of digestive, metabolic and endocrine systems
- 6 Genitoury and reproductive functions
- 7 Neuromusculoskeletal and movement related structures
- 8 Functions of the skin and related structures

Body structures:

- 1 Structures of the nervous system
- 2 The eye, ear and related structures
- 3 Structures involved in voice and speech
- 4 Structures of the cardiovascular, immunological and respiratory systems
- 5 Structures related to the digestive, metabolic and endocrine systems
- 6 Structures related to the genitourinary and reproductive systems
- 7 Structures related to movement
- 8 Skin and related structures

Activity and Participation<sup>1</sup>:

- 1 Learning and applying knowledge
- 2 General tasks and demands
- 3 Communication
- 4 Mobility
- 5 Self-care
- 6 Domestic life
- 7 Interpersonal interactions and relationships

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<sup>1</sup> At the time the revision process of the ICIDH was in a final stage it seemed to be possible to distinguish activity and participation at the level of definitions. However it was not possible to reach agreement about the related classifications. For this reason there is one classification for activity and participation (domains) with four suggestions how to use this in an activity or participation mode

- 8 Major life areas (such as education, work and employment, economic life)
- 9 Community, social and civic life

#### Environmental factors

- 1 Products and technology
- 2 Natural environment and human-made changes to environment
- 3 Support and relationships
- 4 Attitudes
- 5 Services, systems and policies

Personal factors are mentioned as important factors but are not classified in the ICF. For health conditions (disorder, disease, injuries and congenital causes of disability) reference is made to the ICD-10 [full reference .....] and the ICECI [full reference .....].

In order to specify the functioning and disability situation of a person, qualifiers are available to indicate the extent and level of functioning/disability and the environmental factors as being facilitators or barriers. The advantage of the ICF is the broad spectrum offered from the body function/structure (impairment) point of view up to the participation one including the influence of environmental factors. It is recommended to use this broad spectrum as often as possible.

#### **Disability question sets**

A census format offers limited space and time for questions on any 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. The Washington Group on Disability Statistics, a UN City Group which focuses on proposing international measures of disability is developing short sets of disability questions which can be included in censuses and extended sets to be recommended for inclusion in population based surveys. The aim of the recommended sets is to improve comparability of disability data across countries.

The work of the Washington Group has provided recommendations for developing the purpose or use of measurement in censuses and household surveys. The purpose of the census or survey will then link to the conceptual dimension that is best suited to inform that purpose.

The World Programme of Action concerning Disabled Persons (WPA)<sup>2</sup> 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. Based on discussions at the first meeting of the WG, a tentative outline of purposes and measurement concepts was developed (see [www.cdc.gov/nchs/citygroup.htm](http://www.cdc.gov/nchs/citygroup.htm) for detailed information on the Washington Group activities). These elements were crafted into a draft of a disability measurement matrix

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<sup>2</sup> *World Programme of Action concerning Disabled Persons*, United Nations, New York, 1983.

presented at the second WG meeting. Elaboration of the matrix identified both individual and population or aggregate level purposes and matched them to general disability concepts.

The Washington Group identified three major classes of purposes for measuring disability at the population level: 1) to provide services, including the development of programs and policies for service provision and the evaluation of these programs and services; 2) to monitor the level of functioning<sup>1</sup> in the population; and 3) to assess equalization of opportunities. 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. Monitoring levels of functioning in the population, including estimating rates and analyzing trends, is considered a primary health and social indicator, which characterizes the status of the population. 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<sup>3</sup> in all aspects of life. All three of the objectives are consistent with the World Programme of Action concerning Disabled Persons, which outlines major goals for policy formulation and program planning, internationally. 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<sup>3</sup>, promoting optimal levels of functioning<sup>1</sup>, and equalizing opportunities for participation.<sup>2</sup>

Both the WG and the WPA are consistent in their emphasis on the importance of assessing equalization of opportunities. While assessment of equalization of opportunities might seem to require measurement of activities and participation, such an approach does not help to identify 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 our methodological problems.

In the equalization of opportunity approach, The WG recommends careful measurement of the primary basic activities, required for simplest to the most complicated aspects of life, separately from organized activity, representing elements of participation. 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. This separation 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*.

In order to address this purpose, we need to start by identifying persons who are at greater risk than the general population of experiencing restrictions in performing specific tasks or participating in role activities. This group would include persons who experience limitations in basic activity functioning whether or not they use assistive devices, have a supportive environment or have plentiful resources. It would include persons who do not experience limitations in the specifically measured tasks or participation activities because the necessary accommodations or adaptations have been made at the person or environmental levels. The latter group would still 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 current level of accommodation might not always be available or might not continue to produce the same level of functioning.

Of the four major dimensions identified in the ICF Model, body structure and function, Activity, Participation and Environment, the use of an Activity-oriented set of questions is recommended to capture the basic activity elements required for a good measure of the risk of participation restrictions. At the body structure, body function level, the domains are very specific to the organ or body level and require medically detailed information of the respondent that may not be available. Measures of activity reflect the purposeful actions of the individual, the collaboration of the mind and body to accomplish the range of actions necessary to survive. Measures of activity provide a range of options at the person level from such basic activities as the ability to walk to more complex activities that require more or greater integration of the body functioning through the direction of the mind. The building blocks of these more complicated activities include that mind body interaction to accomplish the functioning capacity required by the more complex tasks and activities. Participation measurement, the most complex element of the model is also influenced by the environmental characteristics which aren't easily measured in any data collection process. The intervention of these environmental characteristics or resources obscure the effective measurement for the purpose of equalization of opportunity by only providing information on persons with restrictions for the current moment based on how their basic activity functioning interacts with the social or physical context of the participation venue. Finally, the environmental element of the model is descriptive of the context or circumstances of the individual's activities or participation and while an important intervening element does not identify what the individual brings to the experience.

#### Essential domains:

It has been 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, suitability for self-report and parsimony. The set of domains should capture the definition of disability that is being operationalized. Other suggested criteria include the importance of the domain in terms of public health problems. Based on these criteria the WG recommends four basic domains which are considered to be essential domains. These include the areas of walking, seeing, hearing and cognition..

Walking fulfills the criteria of cross-cultural applicability and parsimony 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.

While seeing also represents a public health problem, self report of seeing limitation is more problematic, particularly when individuals use glasses to correct for 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. 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.

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.

A final consideration when constructing this basic set of domains for questions is to keep the domains separate through separate questions. 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.

#### Additional domains:

There are additional physical functioning domains that could be included in a set of Census questions depending on the space available. There was a suggestion that communication be used as the domain rather than hearing since it is a broader concept including hearing, speaking and understanding. Other domains that might be included, depending on space, include upper body functioning of the arms, hands and fingers and mental/psychological functioning. While identifying problems with mental /psychological functioning in the population is a very important element of measuring disability for the stated objective, questions that would 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. Other domains that should be considered for inclusion include all aspects of communication and learning. Questions on basic activity functioning domains that are particularly important in a specific country may be added to the core set for all countries.

#### Limitations of Small Question Sets

The Washington Group has developed this question set for use on national Censuses for gathering information about limitations in basic activity functioning among national populations. The questions were designed to provide comparable data cross-nationally for populations living in a great variety of cultures with varying economic resources. The objective was to identify persons with similar types and levels of limitations in functional activities regardless of nationality or culture. It was not our purpose to identify every person with a disability within every community. We recognize that this 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.

The census format requires that a limited number of questions be devoted to any one statistic that needs to be produced. For the reasons of simplicity, brevity and comparability, the choice was made to identify domains of basic activity limitations that are found universally, which are most closely associated with social exclusion, and which occur most frequently. The information that results from the use of these questions is expected to:

1. Represent the majority, but not all persons with limitation in basic activity functioning in any one nation.
2. Represent the most commonly occurring basic activity limitations within any country.
3. Capture persons with similar problems across countries.

The proposed questions identify the population with functional limitations that have the potential to limit independent participation in society. The intended use of this data would 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.

Use of Census questions for making prevalence estimates

Holding for additional material

Use of Census questions as a screener for other surveys

Holding for additional material