

COMMENTS ON THE PROPOSED PURPOSE OF A GENERAL DISABILITY MEASURE

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In developing countries as Perú, on the topic of people with disabilities, the most important question that we have to solve is ***What is the number of persons in the population with disabilities that there is in the country?***

Our last census shows a small number (1,3 percent of the total population) and most of the organizations for disabled people think that this number is far away from the “real number”. Other statistical research made by the National Institute of Rehabilitation shows three different figures on the topics of Deficiency (45%), Disability (31%), and Handicaps (13%).

When some official institution or Non Governmental Organization wants to make a proposal or any project for people with disabilities, they really don't know what figure best suits their purpose.

In this context, the WG “Proposed Purpose of an Internationally Comparability General Disability Measure” would be useful for improving the way that National Institutions of Statistics measure this subpopulation.

Identification of Purposes

As the WG paper says, first of all we have to understand that is not possible to measure the “real (or true)” population with disabilities, indeed we can get at least a “proxy”, very useful for practical purposes. If we are clear in the definition of the purpose of measurement and in the operationalization of it, we can get a measure suitable for the objectives of given authorities, policy makers and other users, an important tool for their work.

The WG suggests the use of the International Classification of Functioning and Disability (ICF) to help in the measurement and the idea is good. However at this point is important to notice that in developing countries the ICF has not been used enough, which means that it might not be easy for all countries to understand how to use it.

In the paragraph related to the identification of purposes it is explained how the World Programme of Action concerning Disabled Persons (United Nations, New York, 1983) and the work developed by the WG coincide on the criteria that the selected purpose should meet. These are Relevance and Feasibility, the first one refers to the purpose of the measure and its importance on determining the future actions of policy related to people with disabilities. The second one is concentrating on the set of questions that countries will use to collect data.

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We must not forget that for developing countries the census is the only way to collect data on disability matters, so National Statistical Offices have to be very careful with the questions they use. For example in Perú, in the last two censuses it was allowed to introduce only one question and in cases like this it became more difficult to choose the best one.

The UNSD and the WG are in a good position to recommend a suitable set of questions that can meet the two criteria that satisfied both purposes: attend countries needs of a general measure and allows international comparability, since they have examined the questions used in developing and developed countries.

The Position Paper chose the ***Assessment of equalization of opportunity*** as the purpose for a general measure. This approach separates the measurement of impairment from participation limitation by focusing on the measurement of impairment and we agreed with the explanations given to understand the arguments. Although, we think that the main problem is how to operationalize this concept into a questionnaire (through a set of questions) that allow us to be closer to the true subpopulation we are trying to measure.

About the transition to Measurement appendix: Conceptualization, Operationalization and Measurement

The ICF model provides the conceptualization of disability, body structure and function, activity and participation, and environment, nevertheless we are not yet ready to transition from the concepts to the operationalization of them.

As the ICF is not well known yet, we have contacted the staff of the National Institute of Rehabilitation who specialize in issues of disability and understand better how the ICF could help to operationalize concepts into questions to get a measure on disability.

Together we have arrived to some conclusions:

- i) All the components of the ICF refer to the same generic scale. This is a common feature that allows comparability between levels of disabilities in spite of its reference to body structure and function, or activity and participation, or environment.
- ii) The ICF recommends that people who want to use it need to be trained by experts of the WHO. For instance, National Statistical Offices that are in charge of making census and sample surveys, don't have specialists in this issue, so they may have difficulty using the ICF for preparing a suitable set of questions.
- iii) The transition from concepts to empirical measures has to be done by professionals from National Statistical Offices, specialized in censuses and

surveys and specialists from health institutions that are familiarized with the use of the ICF. We are sure that together they could do a great job.

Brussels, February 19, 2004