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Comments on the 'Proposed Purpose of an Internationally Comparable General Disability Measure'

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The World Programme of Action concerning Disabled Persons outlines major goals for policy formulation and program planning, at the International level. 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.

Thus, the three major goals defined in the Programme of Action are **equalization of opportunities, rehabilitation and prevention** and in this line the authors discuss the Model to be used as a theoretical frame to analyse and measure the population with disability.

The study analyzes the purposes that a general disability measure should address and provide a rationale for the choice based on relevance across countries with respect to policy and feasibility of implementation with special attention to international comparability of data. The result is the decision upon the selected purposes for the general disability measure which the Washington Group (WG) must develop.

It is consensual the utilization of the **International Classification of Functioning and Disability (ICF)** as a framework for the implementation of the measures.

It also was discussed that the possible purposes of the harmonized mensuration, to be meaningful at the International level could be:

1) 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.

2) To monitor the level of functioning in the population,

Monitoring levels of functioning includes estimating rates and analyzing 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.

3) To assess equalization of opportunities.

The assessment of equalization of opportunities involves monitoring and evaluating the effect of anti-discrimination laws and policies, and programs designed to improve and equalize the participation of persons with impairments in all aspects of life.

In the paper, each of the three major purposes for measurement at the population level was evaluated for their **international relevance** and **feasibility of implementation**.

The important condition consensual for the WG was the need for a clear link between the purpose of measurement and the operationalization of the indicator.

Evaluation of purposes

The group analyzed the three purposes and concluded that the first two purposes satisfied the criteria for **relevance** but did not meet the criteria for **feasibility** of implementation in a way to permit the use of a small set of questions and to assure international comparability.

In the equalization of opportunity approach it is important to measure the impairment separately from the organized activity as a component of participation. This separation allows differentiating the purpose of monitoring functioning in the population and the purpose of assessing equalization of opportunity.

The authors show that the purpose of assessing equalization of opportunities meets the criteria for **relevance and feasibility of implementation** using a small set of questions that allow the possibility to achieve internationally comparable results.

The authors propose the assessment of equalization of opportunity as the purpose for the first general disability measure to be developed by the WG.

Benefits

Benefits of choosing this purpose include identification of a **broad subpopulation**, which can be further described using detailed information obtained via extended survey sets.

A small set of questions can be standardized and proposed to the countries, considering for the implementation, the particularities of each country.

Limitations

The general disability measure developed to suit the proposed purpose may not suit other purposes. It also does not provide a comprehensive assessment of disability or identify the “true” disabled population.

This approach is also lacking in **information about the possible mechanisms** that facilitate or impede participation. Some elements of those mechanisms could be included in extended survey sets, **such as use of assistive devices and access to personal assistance**.

In Brazil, some groups participating of the NGO's on Disability and other related Organizations are not encouraging the identification of a **large subpopulation** of people with disability. They argue that it is almost impossible to put into practice policies addressed to such a large population. It is worth to say that they are also against the restricted concept used in the past. It seems possible to deal with the problem considering several levels of severity, allowing, if necessary, to identify a subgroup of the broad subpopulation.

Transition to Measurement

The authors evaluate that:

The ICF model and classification scheme as it is currently constructed provides component concepts of the model, general definitions of those components as well the universe of domains that make up those components.

It also provides operationalization categories or what can be interpreted as empirical representations associated with the domains for all the components of body function and structure, activity and participation and environmental factors.

The ICF does not indicate the measurement questions or other possible methods of evaluation of the empirical representations,

It doesn't provide a way to combine the measures to create a **scale or index** that can be used in analysis as a representation of the combined empirical elements used to reflect the particular domain.

Measuring Impairment

A complete measurement of impairment as it is defined in the ICF, is not possible to be achieved. Even if it were, the restriction in the number of questions would allow the inclusion of only a minimum set.

The first task is to define what elements of body function and structure are most relevant to the relationship between the person and the environment so that they can contribute to the experience of disability.

Measuring Activity and Participation

There are large sets of questions and different approaches that reflect the components of activity and participation.

The authors show that there are at least three levels of measurement to address the experience of the individual with disability that are elaborated in the ICF.

The activities can be conceptualized as measuring basic **willful actions**, or the ability to perform **specific tasks**. In the second case the individual is motivated to combine physical movement, intellectual activity, and use of assistive devices in an organized process in order to reach a specific goal.

Finally, the individual would be involved in an **organized activity**. This is a more complex level of measurement from the Activity domain of the ICF and would represent the ongoing willful action and specific task completion necessary to perform activities which involve interaction with other people at some level of negotiation.

The Brazilian Experience

The Brazilian Population Census 2000 introduced five questions to measure disability in a broad concept. We also introduced the assessment of the level of severity of the impairment. The results were encouraging, in the sense that we think that we are able to implement measures recommended by the WG. The cross tabulations of socioeconomic and educational characteristics with demographic characteristics and impairments were meaningful, and the idea of harmonizing the questions seems feasible, specially after the success of the Mercosur plus Bolivia and Chile Common Population Census.

General Comments

The conclusion of the paper is absolutely compatible with the trend of the argumentation presented at the WG Meetings, and also with the experiences of the countries which are more and more interested on the theme. The necessity of harmonized data between countries is a

major goal of the Statistical Community, not only for disability, but for other important variables, as socio-economic characteristics, level of education, etc.

The big task is the transition to Measurement, and the possibility to arrive to a “true” compatible system.

Comments on the Implementation of the Measure

It is absolutely consensual the necessity for Harmonization of concepts and procedures to have meaningful and comparable measures.

But it is also clear that, even having found a purpose and an implementation simple and adequate, cultural differences between countries will continue to affect comparability. This is part of the challenge, and show the necessity of continuous work.

Some of the discussions maintained show us the need to have the Census and Surveys teams understanding the purpose of the measure. In this sense, we can think in a campaign addressed to the Statistical Agencies, and also to have the possibility of training people of the technical and operational teams, not only on the rationale and purpose of the measure, but also on the practical ways of implementing and evaluating the process and the results.

In this sense, it is important to agree on a minimum concrete set of questions recommended to insert in Censuses and Surveys. It is clear that the final form of the questions must be operationalized by the countries according to local characteristics.

The experience with the Mercosur Common Census has shown us how important is accompanying all the phases of the operation, being it a Census or a Survey.

We also consider important encouraging to perform the Pilot tests in a harmonized way, and to help in the way to analyze the results.

The Documentation on the results of the tests is very important: it can help other countries with similar characteristics not to loose time testing in a way that didn't work well for the neighbor.

Another important task that should be harmonized is the Editing and Imputation of the new variables. On this subject we don't know if it is possible to achieve consensus, but at least it should exist recommendations on best practices on the subject.

It is also recommended a kind of “harmonization” of the evaluation of the data. The idea is to provide standardization of a minimal set of checks to be performed at the country level, and also to discuss the special conditions of the country which lead to different results.

Considering the data together with statistical measures on the precision of the results is always important to establish comparisons.

Once again the experience with Mercosur project showed us how the harmonization work conducts to the optimization of the Methodological, Human and Technological Resources of the countries for execution of the Census or Survey.

Finally, it is important to keep documentation on the limitations on comparability due to cultural and contextual factors for each one of the participating countries.

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