

**United Nations Statistics Division
United Nations Children's Fund
Statistical Office of the European Communities
Centres for Disease Control and Prevention
of the United States of America**

ESA/STAT/AC.81/2-2
22 May 2001

**International Seminar on the
Measurement of Disability**

**New York
4-6 June 2001**

*Niels Kr. Rasmussen:
Overview of Datacollection practices
in 29 developed Countries*

Overview of Datacollection practices in 29 developed Countries

(draft)

Niels Kr. Rasmussen

Niels Kr. Rasmussen
National Institute of public health
25 Svanemollevej
DK 2100 Copenhagen
Denmark

Phone: +45 39207777
Fax: +45 39208010
e-mail: nkr@dike.dk

Purpose.

The purpose of this paper is to present results from two recent inventories of general multipurpose population surveys that measure prevalence of disability in developed countries. The purpose of the inventories has been to assess the comparability of existing surveys regarding measurement of disability and eventually point to possibilities for improving comparability.

The overall conclusion is that although most surveys seemingly have the same theoretical and methodological background, the ways in which the different surveys both define and measure disability vary significantly. It is only to a very restricted degree and between a rather few countries that comparability exists, based on which one could rely on when making comparisons regarding the prevalence of various aspects of disability.

The two inventories referred to are:

“Survey data on disability” 1999, Eurostat Working Papers, and “An inventory of health and disability-related surveys in OECD countries” 2000, OECD occasional papers.

Background

Traditionally, monitoring of health in a nation has used a variety of indicators – from indicators of mortality and medically defined conditions, diagnoses (the medical expert perspective), over indicators of restriction of functioning, fulfilment of daily activities and social roles due to ill-health or age-related impairments (the social surroundings’ perspective), to indicators of the individual’s own evaluation or perspective on his or her own health. Applying all these perspectives simultaneously signifies that different perspectives on health yields different pictures of health and with different applications, and that disease and ill-health have no major interest in and of themselves, unless it is recognised by the individual and society due to their harmful consequences on daily life.

Furthermore, there is increasing interest in mapping, monitoring and analysing social inequality in health or health gaps between different social groups in Europe and other industrialized countries, along with increasing interest and political awareness of developing policies and interventions to combat the health gaps. Recent comparative studies indicate that European countries have substantial and unexpected socio-economic differences and inequality in health status, morbidity and mortality. Further, contrary to what was expected, the countries with long traditions of extensive policies on health and social welfare have just as great inequality as, or even greater inequality than, countries with less developed welfare policies. The studies do not explain the possible reasons and the relatively poor comparability of existing data on health and morbidity does not allow comparative studies at a level that might shed light on this problem.

Two major sides of social differences appear: There are the differences caused by socially different living conditions and lifestyles, and the differences regarding the risk in experiencing adverse consequences of ill-health/ disability, a risk that is significantly higher in certain social groups than in others. In societies with a very high level of competitiveness in the labour market, stressing highly efficient labour, there is a high risk that disability will lead to marginalisation and social exclusion, especially among those groups that primarily have qualifications for performing manual labour.

This issue is on the agenda in the European Union and in many member states, but it is almost impossible to obtain a valid basis for creating a comparable picture of the situation in both the single nations compared to the international situation, and of the overall international situation. Due

to problems with disability statistics, both regarding the prevalence of disability and the rate of employment and economic activity among those with a disability, assessing the magnitude of the problem and monitoring is nearly impossible.

Therefore, several initiatives have been established with the aim of improving disability statistics. One of them is the initiative of EURO-stat to commission The National Institute of Public Health, Denmark to produce an inventory of disability related recent surveys in the European Union ("Survey data on disability" 1999, Eurostat Working Papers).

Another recent initiative is that of OECD to produce a similar and extended inventory of surveys in the OECD countries.

Methods

The EUROstat inventory identified 16 surveys among 11 EU-countries. Inclusion criteria were that the surveys should be either national or regional and that they should include a major component focusing on disability. Some of the identified surveys were regular disability survey or surveys with a special focus on disability and the living situation for the disabled, whereas the majority of the surveys were multipurpose health interview surveys to be carried out on a broad representative sample of the general population. Some of the surveys were labour force surveys focusing especially on the situation of persons with disability in the labour market. Most of the surveys included people of all ages and were regularly undertaken (ranging from annually to every 10 years). Sample size varied from 5000 to 80000 and all but 1 postal survey were conducted through face-to-face interviews.

The OECD-inventory identified a total of 30 national surveys from 23 countries, including most of the surveys in the EUROstat inventory.

The questions or variables in the surveys relevant for the inventories were defined very broadly.

The EUROstat inventory used the following list of disability and disability-related indicators, as the intention was to cover a broad range of questions:

- self-reported acute or chronic sickness, illness or impairment
- limitations in daily activities (e.g. paid/unpaid work, education, household chores, leisure and social activities)
- functioning (e.g. physical mobility, self-care, sensory impairment)
- work participation (e.g. job changes or reductions caused by ill-health)
- occupational status (e.g. unemployed, on sick benefit or social welfare, early retirement).

The OECD-inventory covered the following health and disability dimensions:

- General chronic illness and specific conditions
- Mental health
- Pain
- Selfcare
- Mobility
- Communication/senses
- IADL (instrumental activities of daily living)
- Work/social activities
- General limitations in usual activities

The inventories firstly examined whether these variables were measured in the various surveys, and having established this, a detailed examination was performed as to how the specific questions were formulated, in order to assess to which degree the questions and answer categories were identical or different.

Results

General

A varying conceptual definition of disability was found. But whether this is a problem with consequences for comparability depends on whether the different definitions have been logically converted/translated to concrete measurement instruments. It is a question whether it has been the case.

Despite the striving for conceptual clarity the factual development of an instrument cannot go further than the clarity of the language used by the respondents. This is a basic dilemma in using self-report methods that it needs to use the commonsense terms. This dilemma is being reflected in the problem between measuring capacity and performance. From a theoretical point of view performance measurement might be preferred to performance measurement, whereas asking about actual behaviour and events might provide the most reliable responses, whereas asking about capacity implies an imaginary or test situation producing less reliable responses.

Common for most of the surveys studied is a clear reference to some kind of disability model or theory reflected in the list of variables presented in the inventories, and that is a model of the type, which lied behind the ICIDH-classification.

Specifics

Both inventories identified the usual problems in comparability:

Different chronic conditions asked about, different wordings used for the same chronic conditions.

Some used the Latin terms for illness/disease, while other used others common sense.

Different recall periods were used

Different wordings in the questions

Different aspects of activity limitations, number and type measured

Qualifiers/scales – without and with help.

A fundamental shortcoming of this type of analysis that is performed on survey instruments is that many have been translated from a non-English language into English. First, it is not known whether the translations are correct and, secondly, even if the translations are correct, it is not known whether the meaning of the questions is identical to or refer to same type of phenomena in different cultures using different languages.

Discussion – perspectives

Both inventories conclude as many other inventories of health surveys have done: It is only to a very limited extent that comparisons can be performed cross nationally on the basis of the national surveys.

What is the solution? Eventually, it looks as if the easiest solution would be to develop a new gold standard of high scientific quality that had the same validity across cultures and that could create consensus in the health, statistical, epidemiological and other communities.

Meanwhile, this approach has a serious condition/qualification that must be fulfilled. Is it possible to develop instruments that are universally identical across different cultures and languages? What comprises high scientific quality? Experience has shown that in the field of questionnaires it is difficult to identify, on a scientific basis, one or more methods that are definitively more scientifically correct than others and that can obtain consensus. Establishing comparability between surveys is much more related to practical coordination, communication and networking than to pure science.

Many countries have already established their own tradition of measuring disability, or are in the process of doing so. However, due to the lack of generally accepted and formulated standards, countries are measuring disability in rather different ways. In order to use an international standard and, therefore, develop greater comparability, it is important that the individual countries can see an advantage/gain:

1. Development of instruments which are clearly better, or at least not any worse, than those that are currently being used.
2. An experience of gain or sense in producing internationally comparable data
3. A conviction that the transition to the new instruments is followed loyally by all partners in an international collaboration

It is the opinion of the author, that a sound process for making viable compromises between consideration of national trends and international comparability implies an experience of a national gain/profit in adopting an international standard and approximation of an individual country's survey instruments can only be successful through a continuous collaboration and an organic development of good models to be copied.

As an alternative to harmonisation through the development and use of identical instruments, it has often been suggested that post-harmonisation be used. What does this mean? Different statistical methods have been proposed. Some of the more advanced methods proposed relate to rescaling techniques, when different instruments and answer categories or scales tend to produce different distributions of responses in different population. The assumption behind using these kinds of techniques is that the phenomenon under study has comparable or identically "true" distributions in the different populations and cultures that are being studied, and that a notion of a "true distribution" is valid. This assumption needs to be tested but the only way to test it is by using the instruments under investigation or other instruments that do not rely on self reporting, i.e. examinations by others, doctors or other professionals. However, when using examination instruments, we restrict ourselves to measuring only what could be observed by others, which is basically performance rather than capacity.

An especially difficult problem to overcome when dealing with self-report instruments is the problem of translangual comparability. The two inventories have examined instruments, of which many have been translated into English from a variety of other languages. Basically, we do not know what these instruments are really measuring because we do not know the foreign language and the connotation of the different words and terms. A group of methods that could create a better understanding of the meaning of the questions and of the phenomena that are actually being studied are the so-called qualitative interview and observational methods, focus-group-encounters etc. These approaches could shed light on the situations and mechanisms that result in respondents' answers and reactions to the instruments. Unfortunately, there has been some methodological antagonism between the statistical/epidemiological and the anthropological/qualitative approach, in that at one group's approaches and methods have been refuted by the other.