

**IMPROVING STATISTICS ON PERSONS WITH DISABILITY:
CURRENT INITIATIVES OF THE UNITED NATIONS STATISTICS DIVISION**

Paper submitted by UNSD¹

Introduction

The work of the United Nations Statistics Division (UNSD) on disability statistics discussed in this paper covers two broad areas: the compilation and dissemination of data and the development of methods for data collection and compilation. The objectives of this work are to improve the use of the available disability data, to produce methodological guidelines for use by countries and to promote and improve the collection of data in countries. However, these are not easy tasks. The production of disability statistics requires links between substantive and methodological fields, including for example the requirements of policy makers and planners, the conceptual framework of the ICIDH-2, its implementation in national statistical activities and the development of appropriate statistical methods. Some guidelines and recommendations are now emerging but an immense amount of work remains before countries have adequate data for planners and policy makers and internationally comparable statistics are available.

1. The United Nations Disability Statistics Database (DISTAT)

The United Nations Disability Statistics Database (DISTAT) is a global database including statistics, indicators and textual information from national data collected on disability issues. DISTAT version 2 covers 179 national studies on disability from 100 countries across all regions of the world. The database is intended to promote the broader dissemination and use of disability statistics and indicators especially among non-statisticians concerned with disability issues. A second objective is to provide a comprehensive easily accessible source of information

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on the methods used in national studies to facilitate the development of better practices in collecting and compiling data on disability.

When completed, DISTAT version 2 will contain statistics and indicators on various topics by age, sex, type of disability or impairment; it will include also the social, economic and living conditions of persons with disability in terms of school attendance, educational attainment, employment and marital status. To the extent possible, comparative data are presented for the population without disabilities for information on the social, economic and living conditions.

Information on prevalence rates from DISTAT version 2 will soon be available at the web site of United Nations Statistics Division (<http://www.un.org/Depts/unsd/>). The rates are presented by age and sex, and when available, on rural and urban areas of residence. To aid in the interpretation of the data, the questions used in national studies are presented with the data. Work is continuing to finalize DISTAT version 2 for dissemination in the first half of next year.

According to information available in DISTAT, the number of countries collecting data on disability has increased significantly in the past few decades although this increase has been due mainly to the inclusion of a question or questions on disability in a census. There are great differences among studies in the concepts used to define disability, the data collection instrument and how the disability concepts are operationalized. These methodological differences have led to a wide variation in estimates of the prevalence of disability obtained in various studies which in general range between 0.2% and 20% and make it difficult to compare across studies and countries.

Most of the studies in DISTAT are from a census. Especially for developing countries, this is the only source of data on disability as detailed surveys are very costly. The questions countries use in a census usually refer to only a few specific types of impairments, and generally, the resulting rates of disability are not higher than 2 per cent. Fewer countries use a survey to collect data on disability. Among those that do, there are significant differences in the instrument used. Investigating disability in a survey often involves piggy-backing a few questions on impairments on a household survey that is not a disability survey. There are some countries, however, that have used detailed questionnaires to investigate disability in a survey. They include the United States, the United Kingdom, Australia, Canada, the Netherlands, New Zealand and Spain. For this latter group of countries, the estimated rate of disability ranges from about 12% to 20%, probably reflecting the wide variations between them in the scope and content of questions used to measure disability.

In both censuses and surveys, there are differences among countries in how the population with disability is conceptually defined as reflected in the questions used. National definitions differ both in meaning and scope. Countries that include only a limited number of severe impairments in the questions define the population with disability narrowly. Other countries using detailed questions either on impairments (such as Australia and the Netherlands) or on activity limitations (such as Canada and New Zealand), define the population with disability more broadly and the resulting data identifies a higher proportion of the population as having disabilities.

For the countries included in DISTAT, use of the ICIDH classification as a basis for defining the population with disability and for formulating questions has differed greatly between countries. The ICIDH has not been applied in most censuses as the questions used have tended to focus on a few severe impairments. For a growing number of countries, however, the original ICIDH framework has formed a basis for preparing disability questions in surveys. Still there are great differences in the scope and contents of the questionnaires, that is, in the number of ICIDH items included on the questionnaire, and also in the way the questions are formulated.

2. *Principles and Recommendations for Population and Housing Censuses*

The United Nations *Principles and Recommendations for Population and Housing Censuses, Revision 1*², issued in 1998, includes disability as a topic that may be covered in censuses. The number of countries collecting data on disability in a census has grown dramatically in the past few decades, and for many countries, a census represents the only national source of information on the frequency, distribution and social and economic situation of persons with disability. The recommendations provide guidance on how to define the population with disability, how to develop the questions to be used, and on possible tabulations. The recommendations for tabulations of data on disability include not only prevalence rates by gender and age and type of disability, but also tabulations comparing persons with and without disability on key social and economic characteristics, such as marital status, school attendance, educational attainment, activity status, and occupation.

As results of the 2000 round of censuses become available, the Statistics Division will analyze and assess the methods used, with particular interest placed on countries using these most recent guidelines.

3. *The Manual for the Development of Statistical Information for Disability Programmes and Policies*

This publication is a non-technical guide intended mainly for use by programme managers and others concerned with the production and use of statistical information for implementing, monitoring, and evaluating disability policies and programmes. It offers definitions of basic disability concepts and recognizes the importance of continued development of standard terminology and an internationally recognized system for defining and classifying the situation of persons with disability. The *Manual* also discusses the major sources of existing data and statistics on disability, attributes to consider in appraising their quality, and how the data can be used for programme planning and evaluation including in the field of rehabilitation and human functioning, with an emphasis on their quality. It also includes an overview of approaches for collection of disability statistics and steps required to initiate new data collection efforts, as well as on acquisition and uses of information on disability in especially difficulty situations, such as emergency and refugee relief situations.

² United Nations Publication, Sales No. E.98.XVII.8.

4. *Guidelines and Principles for the Development of Disability Statistics*³

The “Guidelines and Principles for Disability Statistics” is another UNSD publication concerned with the production and compilation of statistics and indicators on the situation of persons with disabilities. This publication builds on the *Manual* and also on the section on disability in the census recommendations. It addresses special issues raised by collecting, tabulating and disseminating statistics on persons with disabilities in surveys and in censuses. The “Guidelines” are aimed mainly to national statisticians to assist them in responding to the growing demand for data on disability. The special issues related to planning, collecting, processing and evaluating disability data are covered. Modules are provided on different topics to allow countries to choose and use, depending on their capabilities, resources and interests, only what they want on such topics as use of censuses, and of surveys to collect data on disability, use of sampling for a disability data collection activity, and collecting disability data in institutions. To improve the policy relevance of the data, a section is provided on the dissemination and uses of disability data.

The “Guidelines” provide a broad starting point or introduction to the special methodological considerations required to collect and compile statistics on populations with disability. But the treatment of many key topics is limited. First, it is limited with respect to the ICIDH-2. While the ICIDH-2 classification is close to being finalized, it will be several years before the new ICIDH concepts can be transformed into valid and reliable survey instruments and still longer before these instruments will be used in national data collection programmes. Further, much work is needed on many of the special issues related to the operational requirements of data collection. For example, interviewing persons with disabilities can pose a number of special problems that are only beginning to be addressed by research. Inadequate attention is also given to the measurement of the consequences of disability, that is the Participation Dimension in the ICIDH-2. The work and planned work of UNSD to address these gaps is described below.

5. UNSD is engaged in the analysis of the data included in the upcoming version of DISTAT. The purpose of this analysis is to study the variability of the data expressed as a percentage of persons with disability in terms of:

- methods of data collection (survey, census)
- questions used in the study (specific, generic), and
- definitions (approach, items included in questions)

Similar questions and methods will be analyzed in order to understand if similar approaches have similar results in different countries. Data collected through surveys and censuses in a few developing countries will also be analyzed in more detail to study the performance of questions used to identify persons with disability.

6. *Participation in the DISTAB project*

³ Unedited copies of this document may be obtained by contacting me: telephone: (212) 963-7845; fax:

The main purpose of the disability tabulations or DISTAB project is to examine the usability of the ICIDH-2 for coding disability survey and census data. National data based on the recommended tabulations on disability in the United Nations *Principles and Recommendations for Population and Housing Censuses, Revision 1*⁴ are being back coded using the terminology and coding categories of the ICIDH-2, Beta 2, and are evaluated for comparability and reliability.

DISTAB is a United States National Center for Health Statistics initiative co-chaired by Paul Placek and Gerry Hendershot (geh2@cdc.gov), and includes about 15 collaborators. The project is well underway and includes comparative data and collaborators from national disability surveys from the U.S. (Paul Placek, Gerry Hendershot, Kristine Mulhorn, Don Lollar, and others), Canada (Renée Langlois), France (Catherine Barral and Dominique Velche), the Netherlands (Marijke de Kleijn de Vrankrijker), South Africa (Margie Schneider, now of WHO) and the United Nations Statistics Division (Margaret Mbogoni).

Canada is using the 1991 Health and Activity Limitation Survey; France is using the 1999 Enquete handicaps, incapacites dependance questionnaire a l'aidant principal; Netherlands is using the 1997-98 Netherlands Health Interview Survey; South Africa is using the 1998 Questionnaire for People with Disabilities, and the U.S. is using the 1994-95 National Health Interview Survey on Disability. This effort represents Study Five (the evaluation of ICIDH-2 using surveys) among the eight WHO Beta-2 studies.

To make the data between the participating countries comparable, decisions were made on what tables to produce based on the availability of data on particular questions for the countries concerned, and on the age categories to use for the tabulations. A decision was made to produce tabulations on 10 broad categories of hearing, seeing, body movement, movement activities, gripping, personal care, IADLs, producing messages, behavioral and psychiatric disabilities, and learning disabilities. Within each of these broad categories the disability items used by the countries are assigned ICIDH-2 codes and compared between the countries, as are the questions used in the surveys. Specific survey questions are back coded to ICIDH-2 to search for coding gaps and classification difficulties.

The results of the DISTAB project have shown that most disability items included in the questions of the five countries can be coded into the ICIDH-2. For some items, however, the exact ICIDH-2 codes could not be established. For example, no ICIDH-2 codes could be found under the Activities Dimension for the sensory activity items of seeing and hearing, and neither for reaching, bending and intra-personal mental health problems. The analysis of the tabulations also revealed, however, that sometimes, the way the questions were formulated made it difficult to back code the items using the ICIDH-2 codes.

Based on the analysis of the tables and the coded items, two sets of recommendations were made. The first set is on recommendations to the WHO on how to revise the classification based on the finding of the DISTAB project with regard to gaps identified in the classification. The second set of recommendations is on what countries need to do to make disability data more comparable, specifically in the area of questionnaire design. With regard to the second set of

⁴ United Nations Publication, Sales No. E.98.XVII.8.

recommendations, the DISTAB group has recommended that the United Nations Statistics Division convene a gathering of international experts on questionnaire content and statistical methods to make recommendations with particular reference to questionnaire design so as to improve precision of measurement and achieve greater international comparability of the data. The DISTAB group is working towards the meeting to be hosted by the United Nations Statistics Division (see below).

7. *Next steps*

As a next step toward improving disability research methods, the United Nations Statistics Division, in collaboration with several national agencies of the United States and other partners, intends to organize a meeting on questionnaire design and statistical methods in the field of disability statistics during the first half of next year. The meeting would bring together a broad array of experts from both developed and developing countries representing national statistical offices, international organizations, research institutions, and non-governmental organizations working on the collection and use of disability data. Discussions made during the meeting will be used to identify areas of major concern for UNSD future methodological work in disability statistics.

UNSD is also planning to carry out a regional training workshop on disability statistics in Asia next year. The goal of this workshop is to strengthen national capabilities to produce and use relevant data to answer policy-related questions on disability. The United Nations “Guidelines and Principles for the Development of Disability Statistics” will provide the main training tool for the workshop. Participants will include both producers and users of disability statistics and the workshop will cover the process of producing disability statistics, specifically the steps ranging from planning to analysis and dissemination of the data.