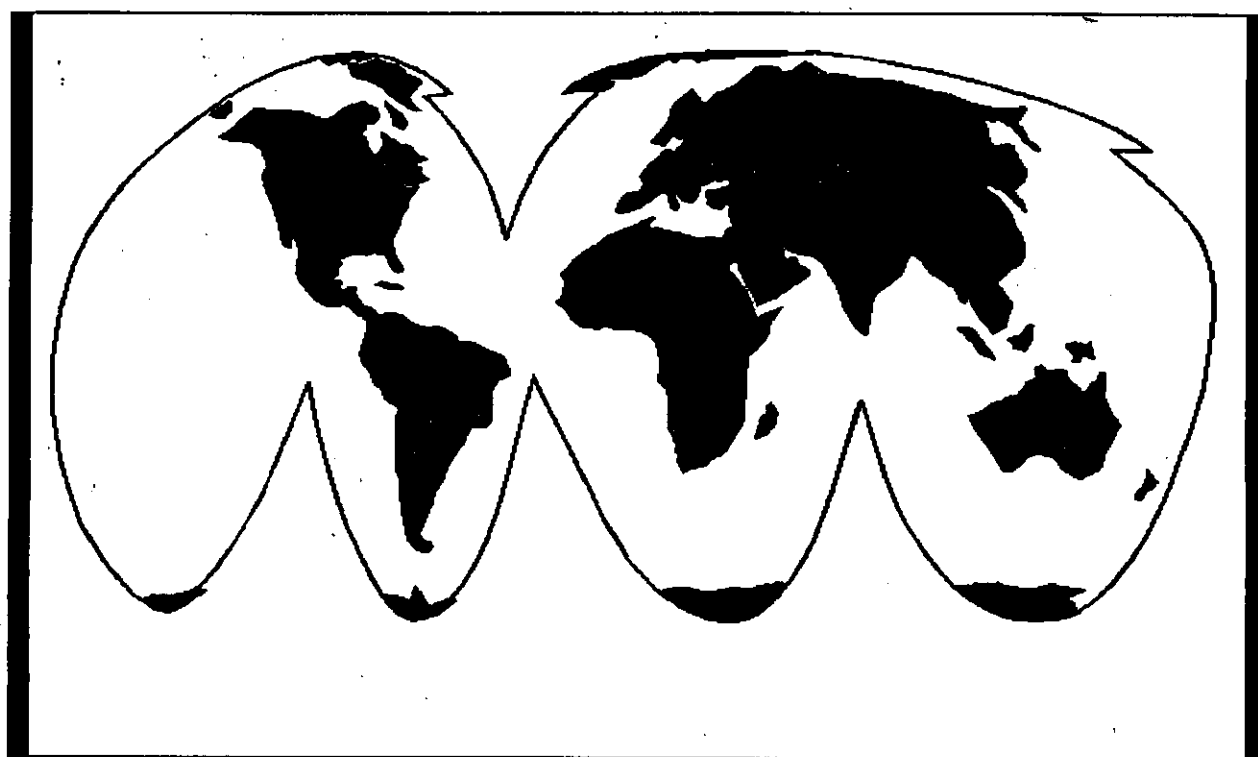


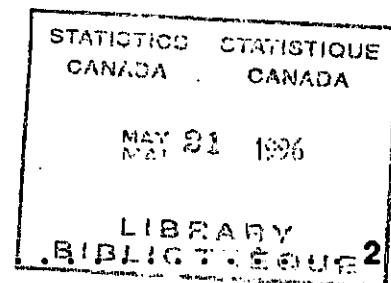
Report of the International Workshop on the Development and Dissemination of Statistics on Persons with Disabilities



October 13-16, 1992, Ottawa, Canada

**Organized by Statistics Canada and the
United Nations Statistical Division**

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INTRODUCTION

1. The International Workshop on the Development and Dissemination of Statistics on Persons with Disabilities was organized jointly by the Statistics Canada and the United Nations Statistical Division (UNSTAT). The objectives of the Workshop were to provide a forum for the discussion of national work and to consider the need for international standards and recommendations on disability statistics. Another goal was to address the concerns of producers of disability statistics, including survey directors and major data users in both government offices and research centres, regarding the need for comparability and quality of disability data. The Report of the Workshop, which is based upon the discussion and experience of participants, will be submitted as a background paper to the forthcoming United Nations Expert Group Meeting on Disability Statistics planned in November 1993.
2. The workshop was held in the Simon Goldberg Conference Room at Statistics Canada from 13 to 16 October 1992. Prior to the opening of the workshop, participants observed the public release and related presentations of the first set of results of the Health and Activity Limitation Survey (HALS) conducted by Statistics Canada in 1991.
3. Opening addresses were delivered at the workshop by Dr. Ivan Fellegi, Chief Statistician of Canada and by Mr. William Seltzer, Director, UNSTAT.
4. The workshop was attended by experts from Canada, Australia, Hungary, Netherlands, Philippines, Sweden, Tunisia, United Kingdom, and the United States of America. Representatives of the United Nations Statistical Division, of the World Health Organization (WHO), and of the International Labour Organization (ILO), and the Office of the Special Representative of the Secretary General for the Promotion of the United Nations Decade of Disabled Persons were also in attendance (see also Annex 2 to the report).
5. Mr. J. van den Berg (Netherlands) was elected Rapporteur in particular to draft a set recommendations of the workshop. Mr. John Coombs (Statistics Canada) and Mr. Kottai Gnanasekaran (UNSTAT) served as co-Chairmen.
6. The agenda of the workshop is shown in Annex 1.

PART ONE SUMMARY OF DISCUSSION

I. DISABILITY DATA COLLECTION IN COUNTRIES

This item was considered on the basis of presentations by participants of national data sources and methods of collection of disability statistics in their respective countries (see also Section IV below and Annex III). Data available for countries were noted to vary in scope, coverage and particulars regarding disability. Also, methods of obtaining national data differed among countries attending the workshop. Excepting one or two countries attending the workshop that reported to rely largely upon the population censuses for disability data, all others had conducted one or more surveys concerning disability. They included Australia, Canada, Hungary, Netherlands, Philippines, Tunisia, Sweden, and United Kingdom. The surveys were generally of household type and formed part of an existing periodic survey such as a population survey, a labour force survey or a health survey.

The coverage of population in those surveys were noted to differ a great deal; some were surveys of handicapped persons and some were surveys of disabled and aged persons. Most of the surveys excluded the young population, particularly children below five years of age. Participants frequently emphasized the need to cover also the institutional population and children in compiling statistics of disability, and discussed activities in some countries to cover these groups.

Personal interviews was the instrument used in collecting data. One or two countries informed the Working Group of new instruments like the mail-out questionnaire, Computer Assisted Telephone Interview (CATI), and others including audio and video technology and their possible use in future surveys.

With respect to concepts and definitions of disability, national surveys that were conducted in the early 1980s adopted terminology and standards from social security, health care, and other administrative programmes which foremost required the data for their specific uses. In other instances, the definitions were found to be less clear, as was the case with regard to disability statistics from censuses. Surveys conducted in late the 1980s were, however, found to base their concepts and definitions on the ICIDH and related terminology. The cases in point were those of Australia, Canada, Hungary, Netherlands, Philippines, and United Kingdom.

Canada, for instance, undertook the first disability survey in 1983. The inclusion of disability questions in the 1986 and 1991 Censuses helped to identify a sample population for the post-censal and the 1986 and 1991 Health and Activity Limitation Surveys (HALS). The Canadian surveys reflected the principles applied in ICIDH. Further, the Canadian approach to collection of disability statistics was unique in the sense that HALS was built on questions asked in the population census which helped established the universe of persons with disability for designing and carrying out the post-censal HALS.

The 1986 and 1991 HALS were also found to be very comprehensive and collected a wide range of information. Information collected included technical aids used and needed, barriers to employment, education, leisure, transportation, expenses related to disability, accommodation, etc. In addition, selected socio-demographic characteristics collected through the census were transferred to the HALS database to provide a more comprehensive profile of HALS respondents.

Participants also informed the workshop of several approaches followed in surveys concerning the collection of information on the severity of handicap. Some surveys identified the severity as profound, moderate, mild, etc., while some measured the severity on a point scale.

The workshop was also informed of the reference period followed in national disability surveys. In some surveys, the use of six months was noted. The appropriate reference period was underscored by participants as a significant issue in disability surveys since it would affect the quality of data. In this connection, the collection of longitudinal data was emphasized by some participants.

Participants noted that the common goal of standards for disability data collection challenges countries and/or organizations to state clearly their objectives, and to acknowledge the underlying policies, and financial and political agendas, that drive their statistical programmes. The International Labour Organization, for example, emphasized its need for statistics on barriers and work opportunities among people who are disabled, and the World Health Organization stated its need for national and sub-national statistical standards for monitoring community-based rehabilitation programmes. The representative from the Office of the Special Representative of the Secretary General for the Promotion of the United Nations Decade of Disabled Persons noted the continued need for broad-based statistics on this issue, at the most basic level.

II. INTERNATIONAL COLLECTION AND DATABASE DEVELOPMENT

The United Nations International Disability Statistics Database (DISTAT)

Participants were briefly apprised of the United Nations International Database on Disability Statistics (DISTAT). The goal of DISTAT is to document and prepare an international compilation of data on disability collected by countries around the world. It displays the type of data that have been collected according to twelve major demographic and socio-economic variables concerning disability, including age, sex, residence, marital status, educational attainment, economic activity, type of living arrangements, household characteristics, causes of impairment, and special aids used by disabled persons. A comprehensive overview describing the goals and concepts of national practices, and summary tables are also provided in the database.

Since 1970, there has been a steady increase in the number of countries documented in DISTAT. Disability statistics are collected by various countries through population and housing censuses, through household surveys covering subjects such as labour force and population, socio-economic surveys, special disability surveys, health and medical surveys, and surveys on family expenditure. Data are also collected in national registries and through administrative data collection systems.

A major concern faced by DISTAT has been concepts and definitions concerning disability used by countries. Another major concern has been the scope as to whether the data needs of policy-makers are being met and/or whether additional needs exist for emerging policies and the growing interest in disability issues.

Few international guidelines or recommendations exist in this area. Much of the national work documented in DISTAT shows how diverse disability concepts and definitions are which are used by countries to identify persons with disabilities and how such practices affect the data.

The proportion of people with disabilities ranges from a low of 0.2 percent to a high of 20.9 percent among 55 countries presented in DISTAT, version 1. This high degree of variation in disability rates is considered due in part to the national selection and the use of impairment and disability definitions and codes.

Analysis of the data available in DISTAT has further shown that census, survey and registration estimates of the proportion of persons with disabilities vary according to the type of method used to identify such persons. Two major methods refer to impairment or disability status. Impairment questions relate to the loss or abnormality of organs or anatomical structure (for example, blindness, deafness, amputations, etc.). Disability questions relate to restrictions or reduced performance of function or activity at the level of the person (for example, difficulty seeing, walking, climbing, grasping, feeding oneself, bathing, dressing, toileting, etc.). In general, the proportion of persons with disabilities is lower when impairment rather than disability questions are used in surveys. When impairment questions are used for screening purposes, the resultant disability rates for men are also generally higher than those obtained for women. In contrast, when disability screening questions are employed, rates are less divergent for women and men.

Findings of DISTAT have shown that regional, and even national comparisons of disability rates may be misleading unless the methodological differences between data collection systems are taken into account. The countries of Africa and Asia, which generally implement impairment screening questions in their censuses, survey and registration systems in order to identify disabled persons, report lower rates of disability than do the countries of Europe and North America, which generally use disability screening questions to identify this group.

Analysis of socio-economic characteristics indicates that even though the way in which countries measure educational attainment, or economic activity, or marital status is quite similar, the educational and occupational data on disabled persons cannot be readily compared owing to strong differences in the way in which disabled people have been defined.

These findings underscore the necessity of international guidelines and survey standards for data collection on disability so that rates may be more comparable, and more meaningful, both within and across countries.

One major international event impacting on survey and programme planning has been the United Nations World Programme of Action concerning Disabled Persons (WPA), adopted by the United Nations General Assembly at its thirty-seventh session in 1982 (resolution 37/52). The purpose of the WPA is to promote effective measures for the prevention of disability, for rehabilitation, and the realization of the goals of full participation of disabled persons in social life, and for the development of equality. The major areas of action for addressing these goals were viewed as prevention, rehabilitation, and equal opportunity.

At the same time that the WPA was being formulated by the United Nations, the World Health Organization was preparing the trial International Classification of Impairments, Disabilities and Handicaps (WHO, 1981). The broad concepts of the ICIDH were recognized by the drafters of the WPA and were included in its goals for improvement in the concepts and language for describing people who have impairments, disabilities or handicaps. Impairments are defined as any loss or abnormality of psychological, physiological or anatomical structure or function. Disabilities are defined as "any restriction or reduction in function resulting from an impairment, which impacts on a person's ability to perform an activity in the manner or within the range considered normal for a human being". Handicaps are defined as the description and classification of disadvantages that result from the interaction of people who are disabled with discouraging environments. Handicap occurs when people with disabilities encounter cultural, physical or social barriers which prevent their access to the various systems of society that are available to other citizens, thereby resulting in confinement, isolation, reduced mobility, reduced communication, reduced social interaction, etc.

III. CONCEPTS AND DEFINITIONS USED BY COUNTRIES

Governments and countries which have referred to the World Programme of Action concerning Disabled Persons and who recognized the language of the ICIDH, generally propose that the following concepts and topics be included when designing their database.

1. Impairments for the study of prevention;
2. Disability for planning programmes in rehabilitation;
3. Handicap for assessing human rights and equalization of opportunity.

Some work has also been done on global indicators to reflect the shift away from straight-forward counting of people with disabilities to viewing impairments, disabilities, and handicaps as shared national experiences, using statistics which enable one to look at the distribution of each of these across the life cycle, and across a wide range of comparable experiences, e.g., school attendance, work, marriage, income generation, and the like.

The workshop considered that it was important to look at how countries were driven in terms of formulating their conceptual rubrics and definitions to collect data. In this respect, discussions focused on the various ways in which screening questions were formulated among the countries present at the workshop.

It was generally viewed by participants that disability questions were useful topics for screening people into surveys, supplemented by more specific questions concerning the presence or absence of some impairments and diseases that would likely be associated with disablement, as a way of reducing false negative responses to the disability questions.

For example, in the Australian 1981, 1986 and 1988 national surveys of disability, a mixture of survey screening questions on impairments, disabilities, and handicaps were used in order to define their disabled and handicapped population. For the planned 1993 survey, additional questions had been proposed which would ask about long-term treatment with medication, and head injuries with long-term effects. It would also screen for specific diseases, including Alzheimer's, Dementia, asthma, heart disease, arthritis, etc. Australia did not use the terms disability or impairment in the specific survey questions, but referred to "long-term health conditions" instead. A follow-up study of their survey showed that about one-third of persons who had a disability responded negatively to all the survey disability screening questions. These false negatives were, for the most part, people who had mild disabilities.

Canada was using the "activities of daily living" concepts to determine their disabled population. One of the problems they encountered in survey planning was the difficulty in making the concepts and definitions of disability operational so that they would be understood by the population at large. Another problem was how to define disability among children.

For measuring disability among children, the 1991 Health and Activity Limitation Survey of Canada used a combination of questions about diseases, the use of technical aids, attendance at a special school, and limitations in activity considered normal for a child at that age. A question about learning disability was also fielded. Among adults, direct interviews took place; among children, questions were asked of the parent/guardian. In the institutions survey, questions were the same as for the household survey, and were asked through direct interviews with institutionalized individuals. About 50% of people in institutions responded for themselves; the others were interviewed by proxy.

Similar to Australia, Canada undertook some follow-up analysis to compare the variations in methods used for inquiring disability prevalence (i.e., proxy versus non-proxy response, census versus survey response). It was noted that for both proxy and non-proxy responses to survey questions, response rates were similar for the categories of moderate and severe disability. The category of mild disability, however, had lower response rates with proxy than with non-proxy interview techniques.

Hungary and Netherlands also used the ICIDH framework for their screening questions. In the case of Hungary, the survey was focused upon dysfunctional attitudes and behaviour in the work place that lead to employed persons exiting the work-force and receiving disability benefits. Netherlands screened by impairment, rather than disability. Specific questions about activity limitation, for example, were asked of persons who reported impairments of their arms, legs, etc. Interviewers, in both cases, were not specialists, but were regular interviewers who had received special instructions and training.

In the Philippines census of 1990, two screening questions were used: (i) Does a member of the household have a physical/mental disability? and (ii) What type of disability does this person have? A total of eight categories of impairments were coded, including the "other" category. From a population of 60 million, only 1.5% reported having a disability and 25 percent of those persons who reported being disabled were included in the "other" category. In this case, the interviewers had been left to interpret the screening questions themselves. This rate of disability is lower than the rate of disability obtained in the 1980 National Disability Survey of the Philippines, i.e., 4.4 %.

In its Survey of Living Conditions, Sweden used a disability screen that asked if respondents were dependent on assistance, especially in their residences and daily activities owing to either a physical or mental impairment. In addition, Sweden asked specific questions about diseases associated with disability that they knew to be underestimated. From these results, the survey categorized survey respondents into 12 broad disability groups. In addition to the Survey of Living Conditions, Sweden has also conducted a special study of young persons with disabilities. This sample was taken from the National Record of Disability Pensions. In this case, most of the youth had a severe disability associated with either mental or physical impairments.

Tunisia geared its 1992 National Survey of Disability so that it was focused upon the goal of prevention. In their disability screen, they asked respondents about their performance of a number of essential activities. Specialized interviewers with medical backgrounds were employed. For children under seven years of age, different questions were asked. A follow-up survey was implemented to check for false negatives, using medical personnel to do the follow-up survey. This survey, at the time of the workshop, was still being fielded.

The United Kingdom used disability measures based upon the concepts of the ICIDH for their National Survey of Disability. Disability (and severity) were measured first, and then respondents were asked about their extent of handicap. Priority was given to reduce false negatives, so a broad screening net was used in order to be more inclusive. In all, 32 screening questions on disability were asked of households, and five specific questions were asked to identify children with disabilities. Most questions focused upon daily activities, and in the case of mental impairments, upon services received including whether the person had ever seen a psychiatrist. Children were asked if they attended special schools, and a general screen on "normal development" was asked to identify children. The adult survey questions were also asked of children, with some adjustments for suitability to younger age groups. A follow-up survey checked for elderly persons who might have been missed in the general screen. One issue that the survey team noted was that the exact wording of the questions was particularly important when distinguishing between moderate and mild levels of disability. Severe disability was the most robust.

Several different factors are driving the need for disability statistics in the United States. First, prevention: by the year 2000, the goal of the United States is to increase individuals' "quality-adjusted life years;" second, rehabilitation: income support and maintenance and medical care to those persons who might be eligible for these services and under what conditions; third, attention to equalization of opportunity has been highlighted by the recently enacted Americans with Disabilities Act (ADA). In addition to the census question on disability, since 1957 the United States has been using the "limitation of activity" criterion in their national Health Interview Survey (HIS). The ordering of the screening questions for the HIS survey is as follows: first, is there a limitation of activity? and second, what is the impairment that causes it? Plans are currently being made to implement a nation-wide disability survey in 1993.

Throughout the discussion of survey and census methods, participants gave attention to the distinctive as well as the common features of the surveys of their respective countries. Consideration was also given to what drives their surveys. For example, is it a question of costs? If so, what are these cost factors? It is a question of the level at which data are being collected? Are the data collected from social surveys, or censuses, comparable to those collected from health surveys? Is it inevitable that they must be incomparable? One major issue is to work toward some common goals for the purpose of data collection as a way to increase comparability of statistics across nations. This is a very difficult objective, given that different countries and/or organizations are driven by different policies, and financial and political agendas.

IV. DATA NEEDS AND METHODS FOR COLLECTION

Issues of practicality abound when trying to simplify the presentation of disability results from surveys and censuses. The most over-riding question asked by policy-makers and planners is how many people are disabled and what percent of the population is disabled? Even when planners do not want to be dependent upon disability data that have been collected in the census, reality dictates that population censuses are consistently being used to produce national disability figures. In post-war situations, collection of disability data through population censuses is a major vehicle for countries. Generally, it is agreed that the census has a limited role in being able to screen for disability, and that this role needs to be outlined in detail and some rigour. This, in turn, must be backed up by the development of training materials for enumerators, supported by designs for post-censal survey operations, and prepared in writing for dissemination in the form of census methods handbooks.

A distinction in national disability estimates according to severity levels has been tried by several countries as a way of recognizing the diversity of conditions and issues affected by disability; yet even then, the demand for a single estimate has led to the presentation of a single figure describing the proportion of the population that is disabled. Even when it is unintended, countries are described according to their census estimates of disability, owing to that lack of national figures based upon more reliable survey data.

Sampling design issues are critical. Research that needs to be conducted includes preparing methodologies of disability data collection for developing and developed countries. Thus far, the United Nations has no census recommendations on the topic of disability for use in population censuses. Countries find themselves in a trade-off situation with other competing topics in the census questionnaire. There is no general agreement concerning whether to screen for disability during the household listing operation, in the short-questionnaire on household members of the population census, or in the long-questionnaire of the population census. The problem of what questions to include in the census was viewed as a matter of priority accorded to the disability topic by countries. Data user-groups show concern about the disability question being implemented in the census because it might be difficult to count accurately the disabled population. In the case of Canada, these concerns were taken care of by the census question being followed by the HALS post-censal survey on disability.

Interest was shown by participants in discussing further the pros and cons of attaching a disability survey on a health survey or on a population census. There were two factors to be concerned: first the question of costs; and second, the question of statistical methods. Canada, for example, noted that basing a disability survey on the population census had enabled it to get five times the sample at only twice the cost (excluding the cost of the census itself). One alternative proposed is to do a disability survey in its own right as opposed to piggy-backing on another established survey. In order to use the census to screen a population, a disability question must be agreed upon by all concerned, and an appropriate mechanism (especially government allowances and/or regulation) that enables a follow-up survey to be conducted. Participants also raised the question whether it was better to sample

at the level of the person or the household. Canada used the person as a sampling unit; Netherlands sampled households. It was pointed out that in developing countries, household surveys had been difficult to conduct because of extensive rural land masses. In this case, areal sampling could be taken at the level of provinces, as was done in China.

In United Kingdom, the use of mailing address lists as a national framework, and in Tunisia the use of medical registries, were noted. In Sweden it was described that each person in their national registry was assigned a number at birth. Special authority is required to link files with this number, and with different registries. In Australia, under the Privacy Act, all survey documents and files must be destroyed after data processing, making data linking complicated. Participants posed the question as to whether there is an address framework or registry that is consistently available in different countries that could be used while maintaining the privacy of sampled individuals. The question was viewed from the perspective of costs, methodology, efficiency, and privacy. Essentially, participants in the workshop wanted to find whether good sampling frames could be found in the event of not using censuses for sample selection.

In Australia, there is both a disability survey and a health survey, and they are kept separate so as not to overload the health survey and to reduce the probability of respondent fatigue. Surveys of institutions are also utilized. Surveys of care givers were suggested by both Australian and Canadian participants.

The question of stratification used in sampling design led to a discussion on user's needs and the amount of detail required to suit those needs. Geography and age were two stratification variables used by Canada. Children were defined as under 15 years of age, to be consistent with the labour force definition of the economically active population. Canada's size made geography an important stratification variable. It had to be determined whether there was a sub-population in the disability population for whom data would need to be provided, and whether or not there was a representative sampling of that sub-population in HALS.

The surveys held in United Kingdom were stratified by age. Tunisia noted that there were serious cost implications to gathering data from all geographical areas of the country and therefore their strategy was to choose a geographical area that was most representative of the country as a whole and then to take a sample in that area. Participants also raised the question whether there should be some stratification at socio-economic levels.

The workshop was informed by Canada that the issue of sub-populations within a country brought into question whether one culture (or area) would respond differently to a particular question than would another culture (or area). On the advice of Aboriginal people, some of the questions on agility in the Aboriginal Peoples Survey of Canada had been modified in order to be able to test the same motor movement but within a culturally specific context.

The workshop also considered issues of technology as a special factor in data collection in the area of disability. For example, a question was posed whether the technology associated with Computer Assisted Personal Interviews (CAPI) or Computer Assisted Telephone Interviews (CATI) was especially useful to disability surveys. The survey in the Netherlands succeeded in using CAPI for field work and almost all the interviewing was done with lap-top computers. However, the use of this technology for data collection was considered to be costly and could only be recommended for those countries/institutions conducting many surveys. This technology was also used in Sweden and found to be costly. The use of portable computers led to some problems with poor light conditions and user discomfort. In general, the technology of CAPI/CATI was not considered to be exceptionally useful or necessary for work in the area of disability.

V. COMPILATION, TABULATION AND DISSEMINATION OF DISABILITY STATISTICS

The workshop underscored a need for description of core variables for data analysis. Australia identified three major areas for core tabulations: namely, i) the demographic characteristics of age, sex, and marital status; ii) the area of ethnicity through the study of ancestry and language spoken at home; and iii) the standard social and economic variables of education, employment and income.

In addition, the derived variables of disability were identified: (i) the topic of handicap, self-help, mobility, transport, and access to education; (ii) severity of handicaps i.e., mild, moderate and severe (profoundly severe to be added in future surveys); and (iii) disability assessment through measure of disabling conditions, use of technical aids, help received (who provides help, their relationship to the person who is disabled, etc.). These basic core cross-tabulations led to an extensive analysis resulting in four major publications covering the overview, a description of the domestic situation, and the special issues on elderly persons and on care-givers. Hungary, in its survey, explored the interaction of the person and his or her work environment. They utilized variables which summarized dysfunctional attitudes at work and also inadequate coping strategies leading to work disability among persons who were identified as experiencing mental impairment (serious neurosis and/or severe depression).

Netherlands also used the core variables of age, sex, severity of disability, educational attainment, income, and the use of technical aids. The need for much more multi-variate analysis of the data was emphasized so that some of the relationships among types of disability might be more readily recognized, including further study of the extent to which multiple impairments and/or disabilities have an impact upon the situation of disabled persons.

The Philippines, using census data, produced a single cross-tabulation showing age, sex, and nature of disability by the smallest geographic level i.e., the village. Other cross-tabulations could be produced upon the request of a government agency.

Tunisia had not yet prepared its cross-tabulations scheme. It is interested in exploring how to classify or group mental impairments. Hungary indicated that mental impairment was described and analyzed according to one's inability to work because of headaches, insomnia, anxiety, anger, etc. This was also measured in terms of severity.

Sweden had produced publications on disability related to reduction in heart function, lung function, asthma, allergy, diabetes, mobility, vision, hearing, and use of assistive devices, all cross-tabulated by sex, age, and other socio-economic variables.

United Kingdom tabulated according to disability and not impairment. Standard cross-tabulations were prepared according to age, sex, residence, ethnic origin, type of disability, education, and income.

Very little data imputation was being done by countries. Non-response rates were small, and usually presented under a category of "non-response" or "not ascertained." Population estimates were provided from the survey data of Australia, Netherlands, United Kingdom, United States, and Canada.

Dissemination of data was largely through survey reports and publications of basic cross-tabulations supported by text. For major clients, a range of services were available including special tabulations and other electronic presentations (on tapes and/or diskettes) for countries such as Australia and Canada. The United States produced annual reports that were redesigned every ten years which presented disability according to four levels of severity, and according to age-related levels of activity such as play, school, work, and home. Oral presentations of survey results are presented to interested groups by a number of countries. Data are sent to archives by the United States and are kept in an electronic database by Canada.

Disability indicators are beginning to be developed by a number of international organizations. DISTAT identified selected areas of common disability topics. National statistics on these topics were published in the United Nations Disability Statistics Compendium. The European office of the World Health Organization has also made inroads in this area and a list of disability indicators has been published. Some inroads have also been made through the work of the Healthy Life Expectancy International Network of REVES, which has worked to produce a disability-free life expectancy estimate. These initial activities have already brought attention to the fact that standard classifications should be used, such as the ICIDH, in order to increase the clarity and comparability of results.

Participants were informed about the United Nations Expert Group meeting on disability statistics planned for November 1993 which would consider a draft outline of the methods for the measurement, collection, and dissemination of disability statistics. Based upon the comments at the meeting, the draft report would be revised and published by the United Nations. Data collection in the area of disability would then be periodically reviewed by the United Nations in order to ascertain the usefulness of the report and emerging issues in improving national and international disability statistics.

PART TWO

CONCLUSIONS AND RECOMMENDATIONS

I. POLICY-RELATED ISSUES

- 1.1 In light of the World Programme of Action concerning Disabled Persons (WPA) adopted by the United Nations General Assembly in 1982 (Resolution 37/52), increasingly it is recognized that statistics on disability should support examination of policy-related issues. Disability data collection will often have multiple purposes: national surveillance, monitoring of equal opportunities for work, education, health care, independent living, assessing social security systems, determining disability benefits, setting priorities for prevention programmes for primary health care, maternal and child health, and accident prevention. All areas require disability statistics.
- 1.2 The entire issue of "What drives statistics" was reviewed in some detail during the round-table discussions of the workshop. The goals of national surveys were shown to be very diverse. Some aim at producing general baseline disability statistics, others are more tailored to the need for evaluating legislative programmes, some seem primarily research-oriented. There are data needs with regard to surveillance of disability, and also with regard to the planning of programmes, i.e. prevention, rehabilitation and human rights or equal opportunity.

Identifying data needs

- 1.3 With respect to identifying the need for disability data, a great variety in national procedures was reported. Some countries used a consultation model, organizing a committee or council of potential users in order to reach compromise between the various demands. Giving these groups a draft questionnaire at an early stage greatly facilitated the decision-making on the content and goals of the surveys. In other cases, the identification of data needs was derived from new legislation, requests of (national and/or local) governmental organizations such as social security organizations, special interest groups such as organizations of disabled persons, and also requests of the private sector, especially industry for production of assistive devices. It is important to recognize that tensions between groups demanding data exist in

many cases and these might seriously complicate the formulation of data collection goals. Plans must be made to reach a compromise between the various demands. Consultative councils have proved to be very useful.

- 1.4 It is becoming increasingly recognized that it is essential to include organizations of people with disabilities and other interested organizations working on the issue of disability in survey planning, for the development of concepts, questionnaires, and for the consideration of language and fielding strategies, as well as for planning public relations and education campaigns about the surveys' goals.

- 1.5 In summary it was shown that policy issues with respect to evaluating programmes for disabled people give rise to data needs which are then translated into survey questions, ultimately resulting in the production of new statistical data making possible the evaluation of programmes.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH)

- 1.6 In order to develop a common international monitoring framework, data collection in censuses and surveys are encouraged to utilize the World Health Organization International Classification of Impairments, Disabilities and Handicaps (ICIDH) as their standard. Reference is also made to the concepts used in the United Nations World Programme of Action concerning Disabled Persons, specifically the goals of prevention, rehabilitation, and equal opportunity. Such a common framework as that provided by the combined use of the ICIDH and the World Programme of Action conceptually links policies for reducing impairment, disability, and handicap with the three major goals of prevention, rehabilitation, and equalization of opportunity to address a broad spectrum of disability-specific policy and research topics.
- 1.7 The ICIDH has already been a framework and standard reference for national work. In many national surveys it has become an established procedure to use the broad concepts of the ICIDH. However, the way in which surveys make the ICIDH concepts and definitions operational appears to be quite different. Further work is therefore required on harmonization in this area.

II. TOPICS FOR COVERAGE

Severity scales

- 2.1 Severity is relevant for measurement of impairments, disabilities, and handicaps. It was not reported across all three concepts in every survey. Usually ordinal categories were labeled: mild, moderate, severe (severe is sometimes broken down further, especially when large proportions of the persons being studied are elderly). Various threshold levels were used. How to apply severity measures and to define thresholds needs further elaboration. So as to improve international comparisons, standards for the incorporation of severity levels in ICIDH was recommended. Countries should then report how they made these severity levels operational in their surveys.
- 2.2 For the overall measure of disability and specific disabilities, at least three or four levels of severity should be distinguished and then tabulated against demographic variables such as age, sex, marital status and household composition. This approach should also be used for impairment and handicap. Severity by socio-economic variables such as education, income, and occupation should be displayed (preferably standardized by age and sex). Other topics that attention should be given in tabulations include information on the need for assistance, type of care provider or personal assistant, and disabling conditions.

Technical aids/assistive devices

- 2.3 Increased attention should be given to the presentation of results on special assistive devices for the reduction of disability and handicap. A standard and efficient classification of assistive devices should be used in data collection procedures. Reference was made to the newly devised Technical Aids for Disabled Persons Classification (ISO 9999), available in English and French from the International Standardization Organization (ISO) in Geneva, or through national standardization institutes. Tabulations should be provided showing the use of these devices by specific disability groups, age, and sex. Attention should also be given to the production of standardized tables showing the need for such devices.

Cause of impairment or disability

- 2.4 When assessing the cause of impairment or disability, the cause is usually reported in terms of codes relating to the International Classification of Diseases (ICD), with special attention given to external causes, or the E codes. Assessing cause would not preclude asking questions concerning specific illnesses or chronic conditions, as needed by countries for specific issues of disease monitoring.

Multiple disabilities

- 2.5 Multiple disabilities have been handled in several ways (i) identifying and tabulating persons by some of the most common combinations of disabilities (ii) tabulating persons by the number of disabilities, (iii) computing a severity score for each person consisting of a weighted sum reflecting the severity of each disability. These three approaches appear to have different analytical meanings, and should be further assessed. Some analysis was reported showing that especially the occurrence of multiple disability increased the probability of "perceived" handicap.

Mental health

- 2.6 Increased measurement in the area of mental health has been reported by countries. The necessity of including this topic in surveys was generally endorsed. Mental health includes the study the long-term consequences of disease and injury, e.g., Alzheimer's, dementia, schizophrenia, and brain-injury. This also includes the study of impairments such as depression, manic-depression, intermittent loss of consciousness, neurological dysfunction, and limited cognition. It also includes the study of the entire array of disabilities that have resulted from psychological impairments, or impairments of the mind i.e., various limitations in activity.

Disabilities, as defined and classified in the ICIDH, are not divided according to mental or physical characteristics. It is important to note that the distinction between mental and physical is only made at the level of the organ, or the impairment level of the ICIDH. The topic of learning disability, for example, would not be included under the rubric of psychological impairments but should, instead, be considered as an independent category of disability, or activity limitation, which may be linked with psychological impairments or other impairments of the mind, or may be linked to physical impairments. The study of handicap associated with mental health would include issues of discrimination and social isolation.

III. DATA COLLECTION METHODS

Data collection methods: piggy-backing on national surveys

- 3.1 National surveys may also be used for attaching special disability modules, as was done in the Labour Force Survey of Canada in 1983-1984 and in the Health Interview Survey of Netherlands in 1986-1988, and is proposed for the HIS Survey in 1993-94 of the United States. This is especially useful for exploring new topics concerning disability, and also for supplementing information provided in basic census work on the topic of disability. However, the extent to which the resultant prevalence rates of disability from these various types of surveys are affected by being embedded in other issues such as health, living conditions, or labour force participation, etc., is not yet completely understood.

Data collection method: Census planning

- 3.2 With respect to censuses, it was generally agreed that the census questionnaire used for complete coverage of the population should not be overloaded with detailed specialized questions on disability (or for any topic for that matter).
- 3.3 If a country uses a short form for complete coverage, and a long form for a sample coverage to collect data on other topics, the disability topics should be explored in the long form. Although the scope would be limited for practical reasons, basic information on the type of disability is useful, and cross-classifications with other demographic, social, and economic characteristics might improve sample design and make survey sampling frames more efficient. Census results may also be useful for considering small-area estimates of disability that could not be considered when using survey data because of sample size limitations.

Administrative files or registries

- 3.4 The sole use of administrative files or registries for screening was not encouraged because in many cases these lack completeness of coverage, and because of issues of privacy. However, with appropriate protection of privacy, administrative files may be a useful frame for supplementing samples selected by other screening methods.
- Survey research methods

- 3.5 The recommendations of international organizations and research groups such as WHO, REVES, Council of Europe, and WHO-Euro/Netherlands CBS "Consultations to develop common methods and instruments for health interview surveys," are useful sources of information for survey planning in the area of disability.

Survey screening and the screening process

- 3.6 Surveys are often in two main parts. There is an initial screening process, then there is a second round of interviewing for detailed disability items. The general strategy is to "throw a broad net" for screening so as not to miss any positives. The screening usually contains disability items, with selected impairments or even disease items added, to avoid false negatives. Screening questions like the ones used in censuses should be as broad as possible. Nevertheless, it was advised to use more extensive screens whenever possible so as to reduce false positives and negatives.
- 3.7 With respect to the relation between the two basic approaches of disability or impairment screens, both were viewed as important possible strategies for structuring the interview. A review of disability surveys shows that they tend either to have a focus on impairment/disability through description of functional limitations, or they focus on disability/handicap through description of activity restrictions and activities of daily living. These approaches need to be reviewed for increased agreement on a common core set of topics to increase comparability of data and for preparation of standard global indicators of disability.
- 3.8 Experience with using a special disability screen was also reported and proven to be satisfactory. In summary, it was agreed that all three screening methods (broad census questions, more detailed modules in surveys, and special screens) have proved to be acceptable. Choices largely depend upon practical issues of cost, efficiency, and opportunity.
- 3.9 The large majority of surveys and censuses are using regular interviewers and not physicians or other health specialists for screening procedures, nor are specialists being used for determining responses to the more detailed disability questions at the second stage. In the few exceptional cases where specialists were used at the second stage, the extent to which this changes the prevalence is not yet completely understood.

Sampling strategies and scope of surveys

- 3.10 Attention was paid to survey methodology to ensure that adequate information is obtained from all segments of the population. Notably absent from the scope of disability surveys are people who reside in prisons. Persons residing in health institutions are increasingly included in national disability surveys. Consideration should be given to the need for proxy or interpreted interviews in order to increase the scope of survey coverage.
- 3.11 Decisions on stratification depended upon the precision demanded for certain areas or population groups within the country. Unless practical restraints prove decisive in some cases, stratification was seen as a useful tool for improving statistics for specific areas or special population groups.
- 3.12 It was reviewed whether censuses could be used as a screening device to provide efficient sampling frames for post-censal national surveys of disability. Statistics Canada showed that the use of simple screening questions in the census improved the efficiency of sample selection, thereby reducing survey costs. Because the use of a limited number of screening questions can lead to false negatives, a sufficient sample of people who gave negative responses to the screen should be re-screened in the second round. Disabilities among children appear to be especially under-reported by the Canadian census screening question. Mild disabilities appear to be the most unstable when measured over time.

The interviewing process

- 3.13 Personal interviews were generally seen as most the appropriate because mail and telephone procedures in many cases are not applicable for communication with people who have hearing or speaking disabilities and the like. Proxy interviews were only recommended where personal interviews are not possible for reasons such as serious difficulty in speaking, or other severe limitations of communication. It was recognized, however, that resource limitations may not permit use of personal interviews and self-response in some cases. And in such cases, the use of proxy, mail and telephone techniques can provide useful information.
- 3.14 The use of CAPI (Computerized Assistance in Personal Interviews) was reported already by at least four countries. Practical problems related to large-size questionnaires and ergonomic difficulties for interviewers were reported, as well as positive experiences such as increased efficiency, reduction of errors in data collection, and the increased speed in data processing. Disability was not singled out as an area of research especially needing this technology in order to be carried out.

- 3.15 The use of different questionnaires for sub-populations (especially with regard to age groups) was reported and recommended. There was also concern for adapting questionnaires when different cultures exist in one country. Limited experience in this area was reported.

Testing the validity and reliability of results

- 3.16 Substantial research has been done by central statistical offices, and other offices collecting data on the evaluation of their findings, including studies of the validity and reliability of results. To facilitate the more wide dissemination of these reports UNSTAT was asked to explore possible mechanisms.

IV. PLANNING THE DISSEMINATION AND ANALYSIS OF DATA

Planning the basic cross-tabulations

- 4.1 Core tables should be identified for production by all, thereby increasing international comparability of baseline results produced as standard output. It was also recommended that agreement be reached on standard terminology when presenting these core tables.
- 4.2 Attention should be given to more than simple cross-tabulation of disability survey results. Data should also be used for in-depth secondary analysis including the use of such multivariate techniques as the standardization by means of regression techniques, cluster analysis, and factor analysis.
- 4.3 Consideration to the units of analysis might provide alternative avenues for studying disablement at numerous conceptual levels, i.e., through the experience of individuals who are disabled through the household having at least one disabled person, or even through community characteristics. Linking data from diverse data sets should also be considered in order to study individuals, households, and communities.
- 4.4 Disability-free life expectancy (DFLE) estimates using life table techniques on cross-sectional national data sets have been produced increasingly in recent years because these have proved to be an appealing way of presentation. The sources of age-specific disability rates used in the calculation of DFLE should be clearly explained, using ICIDH terminology.

Data dissemination: micro-data files

- 4.5 Statistical offices should be encouraged to provide micro-data files on disability (protected against identification) for use by others. Special requests for additional ad hoc tabulations should be responded to efficiently and at a low cost. A capacity to provide this service should be provided even long after the survey has taken place. It was recommended that an international organization such as UNSTAT should take responsibility in storing country data files for future international comparative analyses.
- 4.6 Strategies to meet the variety of user needs were further elaborated. They included printed publication of all results; release of micro-data tapes shortly after data collection, production of data bases accessible by external users; production of ad hoc cross-tabulations on request; and the creation of small-area estimates.

Data dissemination process: Publications

- 4.7 Publications of survey results should be widely disseminated to potential users through statistical offices. For international exchange, publications or reports (also containing the questionnaire) are sometimes useful with an English translation.
- 4.8 In the survey report, an explanation should be provided showing how the variables used to describe disability were derived from survey questions. It should also be shown how variables relate to the ICDH by means of a correspondence table.
- 4.9 Attention should be given in survey reports to the rationale underlying the design and implementation of surveys for comparisons of research work within and across countries. Participants should continue to identify common features and distinctive topics in their particular surveys.
- 4.10 Standard errors and/or confidence intervals of survey results should be given whenever possible by countries in their survey reports, and the publication of these is encouraged. Advanced techniques for the imputation of missing data were considered not generally useful because item non-response was smaller than one percent as a rule, and therefore not conceived of as a major problem.

International dissemination process: DISTAT

- 4.11 Standardized descriptions of disability data collection procedures should continue to be produced in DISTAT. Consideration should be given, on a trial basis, to providing statistical offices with standard forms for preparing descriptions of their survey work for inclusion in DISTAT. These standard forms should ask for details concerning definitions and concepts used, research designs, reasons for conducting the survey, and so forth.

- 4.12 There is an increasing need to compare national disability statistics across time periods and within countries. The number of national surveys on this topic have increased, and disability is becoming an issue that is being taken up in regular survey rounds. Consideration should be given to archive data and to maintain these earlier works that have been completed for future comparison.

Annex I
DAY 1 - AGENDA

October 13

- 08:30 - 09:30 Release of the 1991 Health and Activity Limitation Survey (HALS) data.**
A presentation on the first results of the HALS will be held at Statistics Canada in the Jean Talon Conference Room, for employees and other interested parties. Delegates to the International Workshop are invited to attend this presentation prior to the start of the workshop.
- 09:30 - 10:00 Coffee and Registration in the Simon Goldberg Conference Room**
- 10:00 - 10:05 Call the meeting to order**
- 10:05 - 10:15 Opening remarks by Dr. Ivan Fellegi, Chief Statistician of Canada, Statistics Canada**
- 10:15 - 10:25 Opening remarks by Mr. William Seltzer, Director, Statistical Division, United Nations**
- 10:25 - 10:35 Logistics**
- 10:35 - 12:10 Round table presentation by delegates**
Each delegate will be asked to make a 5 minute presentation outlining his/her role in the area of disability statistics as well as a description of the types of collection activities completed, underway and/or planned.
Delegates are encouraged to bring relevant documents with them for display and discussion.
- 12:15 - 13:30 Lunch in the Executive dining room**
- 13:30 - 14:00 Presentation of DISTAT**
Dr. Mary Chamie of UNSTAT will provide a demonstration of the UN Disability database. This demonstration will highlight the difficulty which exists in the derivation of comparable disability data from different countries.
- 14:00 - 15:00 Concepts and definitions - theoretical and operational**
Delegates will be asked to discuss the theoretical frameworks and definitions used in their disability data and how these concepts were operationalized and validated. Of particular interest will be the questions used to identify:(1) children with disabilities(2) adults with disabilities(3) persons with "mental" disabilities
- 15:00 - 15:15 Health break**
- 15:15 - 17:15 Concepts and definitions - theoretical and operational (continued)**
- 17:30 - 19:30 Reception in the Simon Goldberg Conference Room**

October 14

08:30 - 09:00 Coffee and croissants

09:00 - 10:30 **Data needs identification**

Delegates will be asked to discuss the process used to identify the key issues to be served by the data and their translation into specific questions.

10:30 - 10:45 Health break

10:45 - 12:00 **Methods for data collection**

Issues to be covered in this session include:

- (1) Data source (i.e. - census, survey, administrative files, registry)
- (2) Collection methodology - telephone, mail and personal interview
- (3) Use of proxy respondent
- (4) Response rates and response bias
- (5) Use of technology (e.g. - CAPI, CATI)

Mrs. Adele Furrie, Director, Post-Censal Surveys Program, will present Statistics Canada's experience using a census approach and a follow-up survey approach.

12:00 - 13:00 Lunch in the Executive dining room

13:30 - 15:00 Methods for data collection (continued)

15:00 - 15:15 Health break

15:15 - 16:30 **Other data collection and methodology issues**

Issues to be covered in this session include:

- (1) stratification
- (2) different questionnaires for specific sub-populations
- (3) promotion of the survey
- (4) language/literacy concerns

18:30 Informal dinner at Adele Furrie's home

October 15

08:30 - 09:30 Coffee and Croissants

09:00 - 10:30 **Compiling and tabulating disability statistics**

(1) Core variables

(2) Derived variables - e.g. nature and severity

(3) Standard cross-tabulations

(4) Other tabulation issues

10:30 - 10:45 Health break

10:45 - 11:30 **Methods used for the dissemination of data**

Delegates are encouraged to bring with them their dissemination plans and samples of their products.

11:30 - 12:00 **United Nations Compendium**

Mary Chamie will provide an overview of the Compendium and describe the activities underway to update DISTAT and related materials.

12:00 - 13:30 Lunch

13:30 - 21:00 Excursion

October 16

08:30 - 09:00 Coffee and croissants

09:00 - 09:30 Delegates' review of workshop recommendations

09:30 - 10:30 Detailed review of recommendations

10:30 - 11:30 Discussion of future follow-up

11:30 - 12:00 Closing ceremony

**Annex II
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Annex III

National and international disability data and statistical reports referred to by participants during the workshop.

Australia

Australian Bureau of Statistics

Handicapped Persons: Australia, 1981. Prepared by R. J. Cameron, (ABS Catalogue No. 4343.0) Canberra, 1984.

Disabled and Aged Persons: Australia 1988 (ABS Catalogue No. 4118.0), 1989.

Disability and Handicap: Australia 1988 (ABS Catalogue No. 4120.0), 1990.

Careers of the Handicapped at Home: Australia 1988 (ABS Catalogue No. 4122.0), 1990.

1989-90 National Health Survey: Summary of Results, Australia (ABS Catalogue No. 4364.0), 1991.

Domestic Care of the Aged (ABS Catalogue No. 4212.0), 1992.

Australian Institute of Health

Health Expectancies in Australia 1981 and 1988 Colin Mathers, (Australian Government Publishing Service, Canberra), 1991.

Australian Trends in Disability-free and Handicap-free Life Expectancy Colin Mathers, Australian Institute of Health, Canberra, Australia (Paper presented at the Fourth International Workshop of the Network on Health Expectancy REVES), Leyden, Holland 10-12 June 1991.

Canada

Statistics Canada

Health Division and Department of the Secretary of State. Social trends analysis directorate.
Report of the Canadian Health and Disability Survey 1983-1984. 1986.

Profile of Disabled Persons in Canada 1986.

Comparisons of the Results from the 1986 Census and the Health and Activity Limitation Survey for Persons with Disabilities Residing in Households Adele Furrie. October 3, 1989.

The 1986 Health and Activity Limitation Survey: Children and Youth with Disabilities in Canada
Prepared by Denise Avard, Canadian Institute of Child Health.

Special Topic Series: The Health and Activity Limitation Survey (HALS), 1986-1987(Listed by title below):

Blindness and Visual Impairment in Canada, 1990.

Selected Socio-economic Consequences of Disability for Women in Canada, 1990.

Barriers Confronting Seniors with Disabilities in Canada, 1990.

Profiles of Persons with Disabilities Residing in Health Care Institutions in Canada, 1991.

Leisure and Lifestyles of Persons with Disabilities in Canada, 1991.

Canadians with Impaired Hearing, 1992.

Netherlands

Netherlands Central Bureau of Statistics

The Physically Handicapped in the Netherlands 1971/1972. (English summary of gehandicapten wel geteld parts 1, 2, 3). The Hague, staatsuitgeverij, 1986.

Physical Disability in the Population of the Netherlands 1986/1988. (Netherlands institute for research on social welfare) 1990.

"Netherlands Health Interview Survey Questionnaire on Disability 1986-1988" Paper prepared by J. van den Berg and K. Gorter, for the third session of the Committee on the Rehabilitation and Resettlement of the Disabled, Committee of Experts for the Application of the WHO International Classification of Impairments, Disabilities and Handicaps, Council of Europe, Madrid 20-23 June 1989.

Netherlands Health Interview Survey: 1981-1991. The Hague, Netherlands, SDU publishers, CBS publications, 1992.

"Results of Two Methods to Determine Health Expectancy in the Netherlands in 1981-1985", Soc. Sci. Med. Vol. 32, No. 10, pp. 1129-1136, (Printed in Great Britain), 1991.

Netherlands Central Bureau of Statistics and WHO Regional Office for Europe, Second Consultation to Develop Common Methods and Instruments for Health Interview Surveys, 18-20 September 1990, Voorburg, Netherlands. 1990.

Philippines

National Census and Statistics Office.

1980 Census of Population and Housing: Philippines. Vol. 2 National summary. Manila, 1983.

Listing of interviewing forms having a disability questions in various censuses and surveys:

1990 Census Evaluation Survey: Main Questionnaire CES Form 2, June 1990.

1990 Census of Population and Housing: Common Household Questionnaire (CPH Form 2, May 1, 1990).

Sample Household Questionnaire (CPH Form 3, May 1, 1990).

Institutional Population Questionnaire (CPH Form 4, May 1, 1990).

National Commission concerning Disabled Persons, in co-ordination with the Ministry of Health.

National Disability Survey. 1983.

Department of Social Welfare and Development

Questionnaire for the Barancay/Community Profile for the Consolidated Family Survey (Date of survey not provided).

Sweden

Statistics Sweden

Living Conditions: Disabled Persons. Report No. 41. S-11581 Stockholm, 1984.

Less Known Groups of Handicapped People Prepared by Gunilla Davidson. (Living Conditions Report 73), 1992.

Disabled Persons 1975 - 1989 (Living Conditions Report 74.), 1992.

Trade Union Membership and Activity 1980 - 1989 (Living Conditions Report 75), 1992.

Working Conditions, Health and Sickness Absenteeism 1975- 1989 Prepared by J. Vogel, H. Kindlund, F. Diderichsen. (Living Conditions Report 78). 1992.

Tunisia

Institut national de la statistique

Recensement general de la population et des logements, 8 mai 1975. vol. III, Caracteristiques demographiques, tableaux et analyses des resultats du sondage au 1/1oeme.

Republique Tunisienne, Ministere des Affaires Sociales, Institut de Promotion des Handicapes, Service des Recherches

Enquête Nationale de Dépistage et de Diagnostic des Incapacités et des déficiences, Tunisie, 1992: Les Documents de l'enquête:

Document No. 1 Protocole de l'Enquête.

Document No. 2 Le Questionnaire "Dépistage des Incapacités" (Version Française)

Document No. 3 Le questionnaire "Dépistage des incapacités (Version Arabe dialectalé)

Document No. 4 Cahier d'enregistrement pour le dépistage des incapacités

Document No. 5 Guide de l'enquêteur pour le dépistage des incapacités

Document No. 6 Instructions aux enquêteurs.

Document No. 7 Manuel de codage pour les diagnostics positif et étiologique des déficiences.

Document No. 8 Aide mémo pour les diagnostics positif et étiologique des déficiences.

Document No. 9 Cahier d'enregistrement pour les diagnostics positif et étiologique des déficiences.

Document No. 10 Plan du sondage.

Document No. 11 Scénario de l'enquête sur le terrain.

United States of America

Department of Commerce, Bureau of the Census

1980 Census of Population. vol. 1, United States Summary: Characteristics of the population: General, Social and Economic Characteristics. Suitland, Maryland, 1983.

1990 Census of Population. (Disability data were not yet available).

Department of Health and Human Services, Public Health Service, National Center for Health Statistics

Current Estimates from the National Health Interview Survey: Data from the National Health Survey, series 10, No. 150. 1985.

Advance Data from Vital and Health Statistics of the National Center for Health Statistics:

"Developmental, Learning and Emotional Problems: Health of Our Nation's Children, United States, 1988", (Prepared by N. Zill, C. Schoenborn), No. 190, Nov. 16, 1990.

"Disability and Health: Characteristics of Persons by Limitation of Activity and Assessed Health Status, United States, 1984-88", (Prepared by P. Ries and S. Brown) No. 197, May 21, 1991.

"Serious Mental Illness and Disability in the Adult Household Population: United States, 1989", (Prepared by P. Barker, R. Manderscheid, G. Hendershot, S. Jack, C. Schoenborn, I. Goldstrom.) No. 218, September 16, 1992.

"Assistive Technology Devices and Home Accessibility Features: Prevalence, Payment, Needs and Trends" (Prepared by M. LaPlante, G. Hendershot, and A. Moss), No. 217, September 15, 1992.

National Institute on Disability and Rehabilitation Research (NIDRR)

Data on Disability from the National Health Interview Survey 1983-1985, Prepared by M. LaPlante. An InfoUse Report. Washington D.C. 1988.U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR), Disability Statistics Abstract:

"People with Work Disability in the U.S.", No. 4., May 1992.

People with Disabilities in Basic Life Activities in the U.S.", No. 3, April 1992.

United Kingdom

Office of Population Census and Surveys (OPCS)

1981 Census England (H Form for Private Households)

1991 Census England (H Form for Private Households)

National Survey of Disability 1985-88

Report 1. The Prevalence of Disability Among Adults (Prepared by J. Martin, H. Meltzer, D. Elliot), (September, HMSO, ISBN 0 11 691229 4), 1988.

Report 2. The Financial Circumstances of Disabled Adults Living in Private Households (Prepared by J. Martin and A. White), (November, HMSO, ISBN 0 11 691235 9), 1988.

Report 3. The Prevalence of Disability Among Children (Prepared by M. Bone and H. Meltzer) (February, HMSO, ISBN 0 11 691250 2), 1989.

Report 4. Disabled Adults: Services, Transport and Employment (Prepared by J. Martin, A. White, H. Meltzer) (March, HMSO, ISBN 0 11 691257 X), 1989.

Report 5. The Financial Circumstances of Families with Disabled Children Living in Private Households (Prepared by M. Smyth, N. Robus) (May, HMSO, ISBN 0 11 691264 2), 1989.

Report 6. Disabled Children: Services, Transport and Education (Prepared by H. Meltzer, M. Smyth, N. Robus). (May, HMSO, ISBN 0 11 691266 9), 1989.

Martin, J., and D. Elliot. "Creating an Overall Measure of Severity of Disability for the Office of Population Censuses and Surveys Disability Survey", **J. R. Statist. Soc. A** (1992) **155** Part 1, pp. 121-140.

United Nations

World Programme of Action Concerning Disabled Persons, United Nations Decade of Disabled Persons 1983-1992. The World Programme of Action was adopted by the United Nations General Assembly at its 37th regular session on 3 December 1982, by its resolution 37/52.

United Nations Statistical Division

Disability Statistics Compendium (ST/ESA/STAT/Ser.Y/4), Sales No. E.90.XVII.17, (Available in English, French and Spanish).

United Nations Disability Statistics Data Base, 1975 - 1986: Technical Manual (ST/ESA/STAT/Ser.Y/3), Sales No. 88. XVII.12 (Available in Arabic, Chinese, English, French, Spanish).

Development of Statistics of Disabled Persons: Case Studies (ST/ESA/STAT/Ser.Y/2), Sales No. 86.XVII.17 (Available in Arabic, English, French, Russian, Spanish).

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