ST/ESA/STAT/SER.F/38

DEPARTMENT OF INTERNATIONAL ECONOMIC AND SOCIAL AFFAIRS
STATISTICAL OFFICE and
CENTRE FOR SOCIAL DEVELOPMENT AND HUMANITARIAN AFFAIRS

STUDIES IN METHODS Series F No. 38

DEVELOPMENT OF STATISTICAL CONCEPTS AND METHODS ON DISABILITY FOR HOUSEHOLD SURVEYS

UNITED NATIONS
New York, 1988

NOTE

Symbols of United Nations documents are composed of capital letters combined with figures. Mention of such a symbol indicates a reference to a United Nations document.

GENERAL DISCLAIMER

Details and percentages in tables do not necessarily add to totals because of rounding.

ST/ESA/STAT/SER.F/38

UNITED NATIONS PUBLICATION

Sales No. E.88.XVII.4

01000

ISBN 92-1-161291-8

Manufactured in the United States of America

PREFACE

The present publication is one in a series of technical reports and special statistical studies prepared by the United Nations on development of statistics and indicators on disabled persons.

By its resolution 37/52 of 3 December 1982, the General Assembly adopted the World Programme of Action concerning Disabled Persons in preparation for the United Nations Decade of Disabled Persons, 1983-1992, and following up the International Year of Disabled Persons, 1981. The World Programme of Action recognizes the importance of statistics on disabled persons as a foundation for policy planning and implementation, monitoring, analysis and research. Specifically, it states:

> "Member States should develop a programme of research on the causes, types and incidence of impairment and disability, the economic and social conditions of disabled persons, and the availability and efficacy of existing resources to deal with these matters". (29, para. 185)*
>
> "The Statistical Office [of the United Nations Secretariat] is urged, together with other units of the Secretariat, the specialized agencies and regional commissions, to co-operate with the developing countries in evolving a realistic and practical system of data collection based either on total enumeration or on representative samples, as may be appropriate, in regard to various disabilities, and in particular, to prepare technical manuals/documents on how to use household surveys for the collection of such statistics, to be used as essential tools and frames of reference for launching action programmes in the post-IYDP years to ameliorate the condition of disabled persons". (29, para. 198)

The United Nations Decade of Disabled Persons and the World Programme of Action concerning Disabled Persons have thus brought needed attention to an area of statistics that was often ignored or whose importance and significance were underestimated in the past. The need for statistics is also highlighted in a recent overview of disability issues prepared by the United Nations Secretariat in Disability: Situation, Strategies and Policies. (29a)

Two technical reports have been prepared by the United Nations Secretariat on the development of statistics of disabled persons. The reports are in response to the recommendation in the World Programme of Action on co-operation with the developing countries in evolving a system of data collection in regard to disabilities. The two reports were initially reviewed in draft form by the Expert Group on Development of Statistics on Disabled Persons, which met at Vienna from 2 to 6 April 1984, and were subsequently revised to take into account the recommendations of the experts, as well as comments and suggestions of the United Nations regional commissions, interested specialized agencies and other national and international experts. 1/

---

* Numbers in parentheses refer to numbered references at the end of the present report.

The objectives of the two reports are complementary. The present study reviews the development of statistical concepts and methods concerning disability for use in household surveys, based on selected national and international experiences and views, with the objective of assisting countries in developing their own survey work. The second report, Development of Statistics of Disabled Persons: Case Studies, (31) was prepared to evaluate sources of statistics which had already been collected on disabled persons in five countries on their ability to estimate the numbers and distribution of disabled persons and to assess their social, economic and geographical circumstances, and to demonstrate how to make effective use of statistics on disabled persons where such statistics have been collected.

Taken together, the two reports provide convincing evidence of the practicality and usefulness of collecting statistics on disabled persons through the use of population census and household survey techniques, and present examples, illustrations and suggestions for improvement of methods of data collection, presentation and analysis. It is hoped that the material will assist users and producers of statistics and indicators on disabled persons in developed and developing countries in devising and applying methods of data collection and analysis suitable to the social and cultural circumstances of each country. It is also hoped that during the Decade of Disabled Persons improved statistics and their dissemination will facilitate the adoption and implementation of more effective policies and programmes concerning disabled persons, pursuant to the objectives of the World Programme of Action.

Other reports are being prepared by the United Nations Secretariat on statistics of disabled persons and are to be issued in 1988. These are concerned with global compilation of national census and survey of statistics on disabled persons collected since 1975 in the United Nations Disability Statistics Data Base, and methods of selection, compilation and interpretation of principal statistical indicators on the situation of disabled persons. 2/

The programme on development of statistics on disabled persons of the Statistical Office of the United Nations Secretariat has been established in co-operation with the Centre for Social Development and Humanitarian Affairs, also of the United Nations Secretariat. Supplementary financial support for this work has been provided by the International Disabled Persons Trust Fund. The present report was drafted by Derek Duckworth, Research Fellow, Health Services Research Unit, University of Kent at Canterbury, England, as consultant to the United Nations Secretariat. J. N. Tewari assisted in drafting the final revisions, as consultant to the Secretariat, based upon the comments of the Expert Group.

Comments and suggestions concerning the present report are welcome. They should be addressed to the Director, Statistical Office, United Nations Secretariat, New York, NY 10017.

Notes

1/ The following experts participated in the meeting in a personal capacity: Janusz Bejnarowicz (Poland); E. F. Ching'anda (Malawi); Derek Duckworth (United Kingdom of Great Britain and Northern Ireland); Eloisa de Lorenzo (Uruguay); Sri Poedjastoeti (Indonesia); Muniera A. Al Quettami (Kuwait); Borhan Shrydeh (Jordan); and J. N. Tewari (India). The report of the Expert Group meeting has been issued as document ESA/STAT/AC.18/7, in English and Arabic.

2/ "Development of statistics and indicators for monitoring the implementation of the World Programme of Action concerning Disabled Persons, and illustrative statistics and information on sources from the United Nations Disability Statistics Data Base" (mimeo., June 1987) has been issued as a working paper by the Statistical Office for general distribution and comment. It is based on documents submitted to the Global Meeting of Experts to Review the Implementation of the World Programme of Action concerning Disabled Persons at the Mid-point of the United Nations Decade of Disabled Persons, held at Stockholm from 17 to 22 August 1987 (CSDHA/DDP/GME/4 and CSDHA/DDP/GME/CRP.1).

CONTENTS

Annexes

List of tables

CONTENTS (continued)

Figures

INTRODUCTION

In adopting the World Programme of Action concerning Disabled Persons in 1982, the General Assembly expressed a renewed commitment to promote effective measures for prevention of disability, rehabilitation and the realization of the goals of equality and full participation of disabled persons in social life and development. (29) Prevention, rehabilitation and equalization of opportunities leading to the integration of disabled persons into the mainstream of society are major themes of the World Programme of Action. It establishes concrete objectives in these areas for the United Nations Decade of Disabled Persons, 1983-1992, drawing on the experience of the United Nations, Governments and non-governmental organizations in the field of disability.

The World Programme of Action recognizes that statistics on disabled persons are essential for policy analysis, action and monitoring. It calls on the Statistical Office of the United Nations Secretariat to co-operate with countries "in evolving a realistic and practical system of data collection" on disabled persons and emphasizes in this connection the role of household surveys "for the collection of such statistics, to be used as essential tools and frames of reference for launching action programmes in the post-IYDP years to ameliorate the condition of disabled persons". (29, para. 198) This emphasis on household surveys for data collection on the situation of disabled persons is consistent with the rapidly emerging importance and pace of development of household surveys over the past decade for collecting data on all aspects of living conditions, as exemplified by world-wide interest and participation in the National Household Survey Capability Programme of the United Nations. While household survey programmes must be carefully developed in conjunction with other important data sources in countries, they play a central, strategic role in providing statistics giving an integrated picture of social and economic conditions as they affect individuals, households and special population groups.

The present report reviews the development of concepts and methods for collecting and compiling statistics on disabled persons and on their social and economic situations, primarily through population censuses and surveys, drawing on selected national experiences. The purpose of the report is to encourage a working dialogue between statisticians and planners concerned with disability in order to develop survey methodologies that utilize concepts of disability which can be used in programme planning and are reasonably statistically and conceptually comparable in the framework of a national household survey programme.

For quantification to be most successful a number of important methodological issues must be taken into consideration by the survey planner and disability specialist, who must in turn make every effort to present the issues clearly to the public and to more general analysts and policy makers both before and after a survey is undertaken. One of the most important of these issues and one which has caused major difficulties in applied statistical work in this field is how to define and measure disability for statistical purposes. As far as basic definitions are concerned, the present report argues that the conceptual framework and specific concepts and definitions of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), issued by the World Health Organization (WHO) for trial purposes in 1980, (46) are the clearest and most consistent available and should therefore be widely used as the starting point for development of basic standards, though considerable flexibility is needed in their application in surveys and censuses.

ICIDH is intended to accommodate descriptions of the altered physical and/or mental state of an individual by physicians, scientists, planners, the public and even by persons affected. This is not an easy task, as disability is described differently by various interest groups. For example, disability is diagnosed by physicians, labelled in lay terms by communities, observed and experienced by family members and by the individuals involved. Planners and legislators concerned with national welfare and financial expenditures often describe disability through its influence on the system as well as through the social system's ability to accommodate the evolving needs of a variety of special population groups, for example, age-structural shifts in the population, changes in life expectancy, household income patterns, unemployment, school retention rates, welfare and disability benefits and health expenditures, housing requirements, and access to public transport.

As a point of departure for bringing together so many different points of view, ICIDH is indispensable as a comprehensive reference classification, but is none the less subject to modifications and further improvements as inadequacies and limitations emerge and are clarified in various applications. ICIDH will inevitably be modified as it is further applied on medically diagnosed populations (hospitals, clinic records and medical research populations) on the one hand, and on lay reports of disabilities in surveys and national registration campaigns on the other. The requirements for classifying impairments for the two major groups of ICIDH classification users are very different, yet not totally incompatible. It is beneficial to try to accommodate both in one classification system, using one to four digit codes to allow for variation in detail and description of impairment.

The application of ICIDH in household surveys also poses problems specific to survey methodology. First, ICIDH is intended to be all-encompassing. Applied literally, it seems clear that a very large percentage of any population studied in detail would be found to be impaired or disabled. However, how to restrict the classification in practice to a limited population of impaired or disabled persons considered to be especially significant from some given analytical or policy standpoint is a question that the classification itself does not answer and for which there has been to date limited systematic, as opposed to ad hoc, experience in country work. Second, ICIDH is intended to encompass a wide range of disability limitations. At one extreme it provides technical concepts and definitions based on medical terminology and practice ("impairments"), and at the other, it covers limitations in the normal roles of individuals in society ("handicaps"), which may be as much or more a function of social and environmental constraints as of medically defined impairments. In between these extremes are "disabilities" (limitations in physical and mental functions), which cover major and minor long-term restriction of the individual as a single organism. Naturally, thorough and detailed application of such a wide range of concepts and definitions in statistical work requires such a range and depth of training and experience as to be totally impractical on a large scale.

On the other hand, there is clearly an important need for macro-information on disablement experience in societies - total numbers of persons seriously affected and information on their general condition and on their household, social and economic circumstances. Without this general picture of the overall situation of disabled persons in a society it is statistically inappropriate and potentially highly misleading to generalize from small-scale studies and other partial information. Thus, it appears that large-scale sample surveys have a significant role to play in collecting statistics on disabled persons.

The present report is mainly concerned with analysing the conceptual and practical problems that have been encountered in using household sample surveys to collect statistics on disabled persons and with ways of dealing with the problems. However, various technical issues are not dealt with in detail within the scope of the present study. Examples of statistical areas requiring further study and methodological development are sampling techniques, methods of statistically and analytically integrating data from different sources and data-processing. Specialized publications and experts in such areas should be consulted for detailed guidance on these topics (see, for example, 37 and 37a). In some cases, further work on these issues in relation to disability issues is required.

Overall, it is useful to emphasize three basic lessons of the present report at the beginning. First, problems of defining disability must be addressed and resolved at the survey planning stage if the data collected are to be meaningful. Second, household surveys are only one source of data on disabled persons; complementary sources also should be fully tabulated and analysed in order to obtain the maximum quantity and quality of information at least cost.

Finally, the two major disadvantages of household surveys in collecting data, namely, the relative smallness of the target population within the sample and the difficulties of bringing to bear analysis by trained medical personnel on the medical aspects of impairments in the population covered, are offset by two major advantages. First, a well-designed survey will give a good overall picture within which more specialized information can usefully be fitted, and secondly, household surveys are by far the most effective and least costly way of collecting relatively detailed information not just on the disabled person's own condition but also on the social and economic circumstances and environment. The present report, along with many other reports prepared in connection with the United Nations Decade of Disabled Persons, stresses that disability and handicap are not just medical phenomenon but also reflect the interaction of health circumstances with social, cultural and environmental conditions. Ultimately, it is only by collecting statistics both on disabled persons and on the circumstances in which they find themselves that their effective integration in society can be adequately addressed.

I. SCOPE, OBJECTIVES AND USES OF DISABILITY STATISTICS AND INDICATORS

One of the first objectives commonly cited when plans for disability statistics are discussed is the perceived need for information to estimate the overall size of the problem that disability presents. For example, the World Programme of Action concerning Disabled Persons states that "more than 500 million persons in the world are disabled as a consequence of mental, physical or sensory impairment", (29, para. 2) including 400 million disabled people living in developing areas.

The figures are based on the assumption that on the order of 10 per cent of the population is affected by a disability, but the actual numbers may be much higher - as high as 20 per cent has been mentioned for some developing countries - or lower, depending not only on real differences among countries but also and very significantly on the definition of disability used and how it is applied.

Estimates of numbers in the tens and hundreds of millions serve to emphasize the magnitude of the task of coping with the human challenge implied by disability but are hardly reliable or detailed enough for planning and policy formulation. For example, survey data are needed to compare the situation of disabled persons living in households with those living in institutions, by type of household and type of institution. Such statistical information is very important for planning community rehabilitation programmes, such as the one recommended by the World Health Organization. (47)

In addition to comparisons of different living arrangements, community-based rehabilitation programmes might benefit from survey statistics on ways that households, institutions and communities provide living and work arrangements suitable to include disabled persons in daily activities. Topics which might be covered in a household survey to study community integration of disabled persons include:

(a) Modifications made by the family to include the disabled persons in daily living, for example:

(i) Special child-care arrangements when required;

(ii) Provision of special aids, mats, chairs, ramps and the like built with locally available materials, when appropriate, in order to include the disabled person in daily household activities;

(iii) Provision of special accommodations, where needed, to include a disabled person at meals with the rest of the family;

(iv) Arrangements as needed so the disabled person can move from room to room in the home;

(b) Modifications made by the local school programme to include disabled children who are of school-age:

(i) Is the child allowed by the teacher (or school system) to attend the local school?

(ii) Is the child who attends school able to sit with the other children?

(iii) Can the child participate in the play activities of other school children?

(iv) Can the child participate in the basic educational programme offered by the school?

(c) Modifications made by neighbours to include the disabled person in social activities:

(i) Is the person generally greeted with acceptance or ridicule?

(ii) Has the disabled person visited a neighbour's home in the past week?

(iii) Do the neighbours include the disabled person in holiday visits and the like?

(d) Modifications by local health care workers and the primary health care programme to address the disabled person's medical and health needs:

(i) Has the disabled person ever visited or been visited by a health worker concerning the disability?

(ii) Has treatment or assistance been made available?

(iii) If so, describe;

(iv) Is essential medical care given and the disabled person visited regularly?

(e) If working age, modifications made in the work-place:

(i) Can the disabled person work in a place appropriate to his or her age and social circumstances, for example, home, fields, stores and factories?

(ii) Have modifications been made in the work-place in order to accommodate the disability?

(iii) What kinds of modifications were made so the disabled person could function productively, for example, transport to work, adjustments in the work programme, inclusion in general work activities?

(f) Who are the members of the community who have been especially skilled or helpful in arranging the modifications required in order to maximize the integration of the disabled person into the family and community? What have they done?

When covered in this way, disability statistics are no longer viewed as just a head-count of disabled persons, but as an opportunity to study the magnitude of the problem among families and communities to accommodate a wide range of human behaviours and needs, including those of disabled persons and their families.

The absence of disability statistics at the national level often leads to the use of estimates being produced which attempt to describe the entire picture of disability through one or two numbers, that is, the total population of disabled persons in a nation more soundly based. As statistics are collected and analysed, new numbers emerge which often differ significantly from the earlier estimates. Definitions of disabilities and considerations such as age and sex profiles of countries and illness and accident patterns, strongly affect the number of persons identified as disabled in any programme. Ultimately, however, once the size of the problem is broadly outlined and some basic statistics have been compiled on the numbers of disabled in a country, more detailed statistical profiles of disabled persons, their families and communities must be prepared for policy formulation and programme planning purposes. In many data collection programmes, this analytical work has been incomplete, for various reasons, but if policy formulation and programme planning requirements are kept firmly in mind at all stages of work on disability statistics, there will be little danger of collecting data and presenting statistics for their own sake. Rather, data will be collected and statistics derived from them for determining the policies of national Governments, local authorities and other institutions to cope more effectively with disability's causes, circumstances and effects.

A. Objectives of collecting disability statistics

Identification and elaboration of specific needs and objectives in collecting disability statistics are essential prerequisites to the design of a data collection and compilation programme.

The potential uses of statistics on disabled persons include:

(a) Public education and awareness;

(b) Assessing the need for programmes, action plans and policies;

(c) Planning and formulating action programmes;

(d) Allocating resources for programmes;

(e) Geographical distribution of resources;

(f) Monitoring and evaluation;

(g) Assessing programme and policy output and impact on the level and quality of life of disabled persons.

Community action of the kind advocated in the WHO manual on community-level rehabilitation mentioned above (47) is one essential programme approach. At the same time, it is also clear that many of the major causes of disability in developing countries - particularly malnutrition, diseases such as polio and leprosy and, in recent years, work, road and home accidents resulting directly or indirectly from industrialization, not to mention wars - cannot be eradicated by community rehabilitation alone. (30, p. 17) Statistics on causes of disability and on its prevention are also necessary. National surveys provide the more detailed statistics required on the numbers, distribution, problems and needs of disabled people living within their own borders, for programme implementation and policy formulation.

Key elements at the design stage of a survey are the definition of disability adopted for statistical measurement purposes and the methods of measurement selected. Inevitably, the specification of a statistical definition must take account of widely varying concepts of disability, each one often influenced by particular administrative applications and cultural practices and perceptions. A specialist on disability in the United States has stated the following:

> "Rational approaches to policy problems of disability require some level of common agreement on both the conceptual basis and the measurement of disability. Service organizations, however, define disability in a variety of ways, depending on their interests, orientation, objectives, or jurisdiction. The limitations of specific programme criteria emphasize the need for inclusive and comparable measurements of disability in order to examine the relationship and the effects of public policy." (4a, p. 319)

Thus, in order to establish a common ground for meeting a variety of objectives, development work on statistics on disabled persons should be clearly oriented to specific purposes and should be based on a clear conceptual framework. A sound conceptual framework is needed to promote ongoing improvement and ensure continuity of the statistics. The concept and scope of the definition of disability adopted in any data collection programme are fundamental in setting the scope and coverage of the whole data collection process and hence should not be considered as purely definitional matters.

B. Scope of statistics on disabled persons

Prevalence statistics concerning the numbers of disabled people, disaggregated in various ways, such as sex, age group, impairment and disease, region and socio-economic group or occupation, are the basic "intelligence" concerning disability that policy makers and planners require. In addition, incidence statistics are required for certain of the resulting specific series. Only on the basis of such knowledge can the requirements of medical and social services and policies to meet the needs of the disabled be calculated. In addition, as has been suggested in the previous section, the statistics can only be of maximum usefulness when they also extend to the study of social, economic and environmental characteristics of disabled persons and to environmental hazards which have been found to cause disability.

Information on the services already in existence and their availability and use among disabled persons is needed. Disability statistics related to the incidence of diseases and impairments will also be required to enable service administrators to monitor use and impact and to ensure the efficient and effective use of scarce resources.

The range of the disability statistics that might be developed is limited by the resources available for gathering the data and the requirements of those who wish to use them. A useful starting point is to study some of the reports of national household surveys covering disability that have been undertaken. Several of these are reviewed in annex I below. The 1968-1969 Survey of the Handicapped and Impaired in Great Britain, for example, shows how wide-ranging disability and statistics related to it can be. It also illustrates how a survey of disability and related circumstances and conditions is likely to originate in the desire of a Government to acquire information about a large group of people with disadvantages and to evaluate the measures that might appropriately be taken by a central authority on their behalf. Many more examples are given in the United Nations report on the Development of Statistics of Disabled Persons: Case Studies (31).

Each country will have its own priorities and circumstances to take into account in the collection and presentation of disability statistics and will wish to co-ordinate disability statistics gathered by household survey methods with whatever other health statistics might be available. The main topics to be covered in such surveys were considered by the United Nations Expert Group on Development of Statistics on Disabled Persons (31a) and their suggestions are given in table 1 below, subject to further research and field trials. The experts recommended that the topics covered in sections IV and V of the table, concerning social, economic and environment characteristics and distribution and use of services and support, should be viewed as important areas of concern with respect to the World Programme of Action and its mandate for monitoring and evaluation. Items I to IV in section V of the table are intended to shed light on efforts to counter the barriers that lead to handicaps. Even among this limited list of topics, it is likely that priorities will have to be set and a selection will have to be made. This matter is discussed in detail in chapter IV.

For the preparation of table 1, the Expert Group reviewed several working papers and drafts of technical reports on the development of disability statistics using censuses and surveys, and generally supported the concepts of impairment and disability set forth by the World Health Organization. However, it noted that the scope of topics in the International Classification of Impairments, Disabilities and Handicaps required modification in order to take into account measurement of principal social, economic and environmental concepts and the goal of equalization of opportunity set out in the World Programme of Action concerning Disabled Persons. Thus, the Expert Group recommended measuring handicaps with social, economic and environment characteristics, including environmental obstacles and accessibility, as shown in section IV of table 1. The United Nations framework for the integration of social, demographic and related statistics is used in this section of the table to provide a comprehensive arrangement of subject-matter using accepted statistical nomenclature for organization and implementation of social and economic topics in survey work. Statistical measures of social equality, economic opportunity, marginality and socio-economic status of special population groups are strongly interrelated in their methodological and conceptual development. The use of an integrated framework encourages the development of disability statistics not simply to study the disabled but also to study the comparative situation of women, men, children, youth, the elderly, displaced persons, new migrants, rural households and large metropolitan communities concerning disability.

Table 1. Topics concerning disability for use in household surveys

---

Topics and classification

I. PRESENCE OF IMPAIRMENTS a/

Physical

Sensory

A. Aural

Includes impairments of auditory sensitivity

B. Language

Includes impairments of language functions and speech

C. Ocular

Includes impairments of visual acuity

Other physical impairments

D. Visceral

Includes impairments of internal organs and of other special functions, such as sexual organs and mastication and swallowing

E. Skeletal

Includes impairments of head and trunk region, mechanical and motor impairments of limbs and deficiencies of limbs

F. Disfiguring

Includes disfigurements of head and trunk regions and disfigurements of limbs

Mental and psychological

G. Intellectual and other psychological impairments

Includes impairments of intelligence, memory, thinking, consciousness and wakefulness, perception and attention, emotive and volitional functions and behaviour pattern

Table 1 (continued)

Topics and classification

Generalized and other impairments

H. Generalized, sensory and other impairments

  1. Multiple impairment

    Physical only

    Other impairments

  2. Other impairments, such as severe impairment of continence, undue susceptibility to trauma, metabolic impairment and sensory impairments

II. PRESENCE OF DISABILITIES

Physical

A. Locomotor

  Includes ambulation and confining disabilities

B. Communication disabilities

  Speaking

  Listening

  Seeing

  Other disabilities

C. Personal care

  Includes excretion, personal hygiene, dressing and feeding

D. Body disposition

  Includes domestic disabilities, such as preparing and serving food and care of dependants, and body movements disabilities such as fingering, gripping and holding

E. Dexterity

  Includes daily activity disabilities, such as use of doors, domestic appliances and windows, and manual activity disabilities, such as fingering, gripping and holding

Table 1 (continued)

Topics and classification

Social

F. Behaviour

Includes awareness and disabilities in reactions

G. Situational

Includes dependence and endurance and environmental disabilities relating to tolerance of environmental factors

Other disabilities

H. Particular skills disabilities and other activity restrictions.

III. CAUSES OF IMPAIRMENT

Causes suitable for inquiry in sample surveys should be determined taking into account the main body of the international classification for diseases, injuries and causes of death (ICD), b/ and health conditions and feasibility of implementation in each country. An illustrative basic classification is given below. ICD codes are given in parentheses.

A. Infectious and parasitic diseases (I)

B. Congenital anomalies and perinatal conditions (XIV, XV)

C. Injury (XVII)

1. Motor vehicle accidents (E810-E825)
2. Other transport accidents (E800-E807, E826-E848)
3. Other accidents and accidental poisoning (E850-E949)
4. Injury resulting from operations of war (E990-E999)
5. Other external causes

D. Other diseases and conditions.

Table 1 (continued)

Topics and classification
IV. SOCIAL, ECONOMIC AND ENVIRONMENT CHARACTERISTICS c/ (includes environmental obstacles and accessibility)
A. Sex, age
B. Marital status
C. Household and family characteristics, or living in insitutions
D. Education and training
E. Employment
F. Income and consumption
G. Other health and nutrition characteristics may include variables such as height, weight and calorie intake
H. Housing and environment
I. Geographical distribution
J. Leisure and culture
K. Social participation
V. DISTRIBUTION AND USE OF SERVICES AND SUPPORT d/
A. Primary health care
B. Prevention of treatment of accident or trauma
C. Maternal and child health and family planning
D. General health services
E. Education (general, special)
F. Employment opportunities
G. Rehabilitation (vocational)
H. Compensatory economic measures and social security and pensions
I. Counselling and public information (community and family attitudes and behaviour)

Table 1 (continued)

Topics and classification
J. Legal protection of equal and non-segregated opportunities
K. Provision of equal mobility opportunities
L. Elimination of environmental barriers
M. Provision of technical aids and equipment
N. Provision of services for independent living

a/ Based on International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Disease (World Health Organization, Geneva, 1980). Unduplicated figures on persons having impairments and disabilities should be given in survey results. Incidence (that is, onset of impairment or disability within some specified period) might also be considered.

b/ World Health Organization, Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death (Ninth Revision), vols. I and II (Geneva, 1977 and 1978).

c/ Based on Social Indicators: Preliminary Guidelines and Illustrative Series (United Nations publication, Series M, No. 63, Sales No. E.78.XVII.8).

d/ Integrated and segregated services and facilities should be distinguished where possible.

C. Definitions of disability

Clearly, disability statistics are concerned with disability, but disability is a term which is not always used consistently and many definitions have been offered over the years.

One definition which conveys well a widely accepted meaning of disability is that laid down in article 1 of the Declaration on the Rights of Disabled Persons. It reads:

> "The term disabled person means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of a deficiency, either congenital, or not, in his or her physical or mental capabilities."

This definition obviously focuses on the idea that a disabled person has certain incapacities as a result of physical or mental deficiencies and that these incapacities are "disabilities". However, another well-established usage of the term disability focuses rather on the deficiencies themselves. For example, "disability" in statistical tables often relates to bodily abnormalities, defects and impairments, that is, the deficiencies which, according to article 1, result in disability.

As these and many other definitions have been widely used, the meaning of "disability" statistics has seldom been consistent among different surveys. As a result, the use of different concepts, classifications and definitions has sometimes resulted in misunderstanding of the significance of disability statistics in the past and has often tended, through such misunderstanding, to hinder national and international co-operation in the collection, dissemination and use of statistics on the subject.

In 1980, however, the World Health Organization put forward a scheme of definitions for trial use in the International Classification of Impairments, Disabilities and Handicaps (ICIDH). (46) In this scheme, "impairments" relate consistently to the defects of structure or functions of the body which give rise to personal inabilities to perform necessary activities, i.e., "disabilities". In turn, both "impairments" and "disabilities" give rise to "handicaps" or disadvantages in various aspects of social life.

Since 1980 there have been trial applications of ICIDH in various practical contexts, including surveys, as well as considerable discussion and analysis of the problems and prospects of using ICIDH effectively (see, for example, 46a). It is beyond the scope of the present report to examine this experience systematically, but reference will be made to some specific experiences in household survey work which relate to the use of ICIDH in that field. The Statistical Office of the United Nations Secretariat is currently preparing a much more complete review of the use of ICIDH or of compatibility with it in surveys in 55 countries.

One of the earliest explicit attempts to use ICIDH in a national survey was in Australia in its 1981 survey, (1) and a recent, comparable experience is provided by Canada. (1a) Among the developing countries, the results of the 1976-1977 survey of disability in Indonesia have been intensively analysed using concepts and classifications in ICIDH. (11a) The influence of ICIDH in the differentiation of impairments, disabilities and handicaps and the delineation of particular disabilities to be surveyed is evident in the survey of disabled persons in India in 1981. (5)

ICIDH will be discussed in detail in chapter III, sections C to E. At this point it should be stressed that while ICIDH was never intended to be applied in the full form in surveys, both the conceptual framework and the specific definitions and classifications which it provides are an indispensable point of reference for all statistical work in this field. Thus, as far as possible, the trial definitions of WHO will be used from this point on in the present report. It should be understood, however, that in referring to any particular survey, that survey's use of the terms will be applied with appropriate explanation. In cases of ambiguity, where the WHO definitions are not intended, the terms "impairment", "disability" and "handicap" will be put within quotation marks, or in some cases, the word "disablement" will be used as a general term.

There is, however, an important and acceptable reason for seeming variations in the concept of disability. Disability is not just a property of individuals as they are in themselves; it is also "a relationship between an individual and his or her environment". (46) That is, it is the individual's environment, which includes his social milieu as well as physical surroundings and natural phenomena, that significantly determines whether and to what extent an impairment (using the WHO terminology) results in particular disabilities and handicaps. Thus, as the Expert Group on Development of Statistics on Disabled Persons emphasized, it is important to measure not just impairments and disabilities, however defined, but also the social and physical circumstances in which disabled persons are found.

Another appropriate reason for accepting differences in operational definitions in planning and implementing a survey is the legitimate desire to focus on one or another group of disabled persons for policy purposes. In certain societies, different groups of people will be likely to experience disability and handicap and in varying degrees of severity, and surveys should be so adapted to national conditions that they focus on the people of greatest concern to policy makers in a given situation. Hence, in the United Nations report on the Integration of Disabled Persons into Community Life, though the apparent wide variation in the results of different surveys is emphasized, this is not necessarily regarded as evidence of unreliability in procedures or results. (30, p. 13) It is pointed out, for example, that a recent survey in Spain had as its main focus those disabled people in specific categories covered by the country's social security system. All these people were by any definition very severely disabled, hence the estimates of the numbers of "disabled" people were relatively low, amounting to only about 3 per cent of the population. By contrast, in the survey in Australia mentioned above, when "causes of disability", that is, diseases, disorders, injuries and illnesses which had resulted in an impairment, were regarded as the central focus of the statistics obtained, then some 23 per cent of the civilian population could for certain purposes be regarded as "disabled". Such differences are acceptable as long as the policy objectives which give rise to them are clearly identified and explained.

D. Disability as a health indicator

The possibility of using various statistics, including those relating to disability, for indicators of health is the subject of much current discussion on the nature, use and scope of health statistics. The discussion starts from the idea that good health is a concept which is not easy to measure directly. Hence, one common approach to compiling health statistics has been to produce series on mortality or series relating to measurable concepts of ill health, for example, on specific diseases.

Detailed statistics on mortality experience in specific populations have been compiled routinely in some countries for up to 200 years or more, either through the analysis of census data or by civil registration and other similar data. Only rarely and in most cases only recently, even in the developed countries, have data been collected which relate to impairment and disability. It is probably a result of this relative novelty in collecting and analysing disability data and constructing disability indicators that certain other health indicators, such as the infant mortality rate, nutritional status, child mortality rate, immunization rates, life expectancy at a given age, and maternal mortality rate, are regarded as essential, while indicators on impairments and disabilities are rarely cited.

A rationale for the development of indicators has been outlined by the World Health Organization. (45, p. 6) The rationale begins with a suggestion that many developing countries will find it possible to compile indicators on mortality rates for specific diseases, particularly communicable diseases. These rates can serve as indicators of the health situation in the same way as does the infant mortality rate. Next, as countries begin to extricate themselves from the burden of communicable diseases, their populations will increasingly experience cancer, cardiovascular diseases and accidents. In addition, as diseases which do not shorten life expectancy to any great extent become more prominent in health experience, indicators such as cause-specific mortality rates become less adequate by themselves as indicators of health. In the United States, for example, it has been suggested on the basis of fragmentary data that work disability rates among males have increased rather than decreased as mortality rates have gone down. (3a, p. 185) In other words, a decline in mortality is not necessarily associated with a decline in work disability, or more generally, decreasing mortality may be more likely to be accompanied by declining health status of those remaining alive than be a sign of improving health in a given age group.

Under these circumstances morbidity indicators, commonly expressed in statistics in terms of the incidence and/or prevalence of specific diseases and injuries, become crucially important. Of greatest importance in the present context is measurement of chronic health conditions and the related impairments. Such indicators of morbidity, including impairments, are of considerable importance in assessing health conditions in detail and in health planning.

Using the WHO global definition of health, disability statistics, as distinguished from morbidity and impairment statistics, focus upon the health consequences in terms of functional limitations and activity restrictions from diseases, disorders and injuries. However, as has already been pointed out, the term disability is often used to refer to abnormalities, defects and impairments generally, that is, impairment as defined in the WHO terminology. When the focus in household surveys is on a general concept of disablement, cutting across impairment, disability and handicap in the WHO terminology, then the specific term disability is clearly meant to include only those consequences of disease and injury which are reflected in restrictions on a person's daily living and social activities. If this disablement concept is adopted, then the usefulness of the resulting statistics from household surveys, whether for health indicators or more directly to guide planning of disability policies and services, is maximized.

II. SOURCES OF STATISTICS ON DISABILITY AND THE ROLE OF HOUSEHOLD SURVEYS

The United Nations Handbook of Household Surveys (Revised Edition), (32) prepared by the Statistical Office of the United Nations Secretariat, provides technical information and guidance to personnel in national statistical services charged with planning and implementing household sample survey activities. Some of the material in the present chapter is drawn from the Handbook, but the nature of disability is such that many of the general principles applicable to household surveys have to be modified when applied in this context.

In the present chapter, sections A and B consider population censuses, household surveys and other sources of statistics on disabled persons and disabilities. The complementarity of the various sources is emphasized. The unique advantages and disadvantages of household surveys in this field are summarized in section C. Later chapters will deal with issues such as how disability can be defined and how statistics of disability can be collected, tabulated and evaluated.

A. Population censuses and household surveys

Household surveys are among the most important instruments for collecting statistics on populations, but, like all data sources, they are most effective when developed in a complementary way with other key sources of data. In the Development of Indicators for Monitoring Progress Towards Health for All by the Year 2000, mentioned in chapter I, (45) it is suggested that household surveys can be more effective as alternative sources rather than primary sources for providing information to planners, policy makers and administrators on technical health subjects. In many developing countries, however, the appropriate primary sources are still poorly developed, such as civil registration, hospital records and epidemiological studies, and the household survey may be the only available source with national coverage. Some of the advantages and disadvantages of household surveys in this context are considered below and reviewed in detail in two other United Nations technical studies: The Role of the NHSCP in Providing Health Information in Developing Countries (36) and the Development of Statistics of Disabled Persons: Case Studies. (31)

Developed countries that undertake continuous household surveys have had many years of experience of conducting population and housing censuses. Such censuses are considered essential for developing a firm statistical base for surveys of various kinds, including household surveys, because the population census provides a broadly based inventory of a nation's human resources. Usually, only when such a base has been established can a sample household survey be fully effective, since one of the major purposes for which a household survey can appropriately be used is for updating census data between censuses.

Thus, as is pointed out in the Handbook of Household Surveys (Revised Edition) and the United Nations Principles and Recommendations for Population and Housing Censuses, (33) censuses and surveys are complementary. Censuses provide infrequent but geographically detailed cross-section data, while surveys provide much more frequent time-series that reflect continuous changes in a community. Another complementary aspect of censuses and surveys mentioned in the Handbook is that censuses are used to obtain data on a wide range of topics relatively superficially, while surveys can explore fewer topics, perhaps even only one topic, more deeply by means of questions probing into details which might be of particular importance at the time the survey is planned and undertaken.

In planning a household survey, therefore, it is essential first to study any available census data. In addition, it may be wise to consider the inclusion of census-type questions on, say, basic demographic data, since the answers from the census provide a check on the accuracy of the household survey (and vice versa). Moreover, as subsequent tabulations and analyses will require that the answers to the questions on disability in the household survey be related through cross tabulation with the basic demographic data (such as sex), it is necessary that both the demographic and the disability data be collected for each individual in the survey.

The extent to which censuses and surveys are complementary when they are compared as vehicles for collecting disability data is discussed at length in a report of the Office of the Registrar General and Census Commissioner for India. (6) The report considers the results obtained from a question on disability included in the houselisting operations which were a part of the 1981 census of India. The question was intended to collect information on the number of persons who were "totally blind, totally dumb and totally crippled separately for rural and urban areas at different administrative levels". The outcome of the exercise is described as providing a framework for later detailed investigation by other agencies, giving a broad idea of the problem in different parts of the country.

Beyond this, however, the report is critical of the quality of the data provided by the question. It seems that a question about "physical infirmities" had been included in censuses of India from their inception in 1872 until 1931, when the then Census Commissioner pointed out the deficiencies in the returns. His successor supported that view in 1941 and, until 1981, no attempt was made to gather disability data by census. On the 1981 data, the present Census Commissioner comments that "the experience of attempting to determine the number of people suffering from specific disabilities ... supports the view taken earlier that the census operations do not lend themselves to the ... identification of people with special characteristics of this nature". He concludes, "at best all that the census can provide is a frame on the basis of which further sample surveys would be carried out". (6, pp. 72-73)

As was mentioned in chapter I above, a household survey using experienced and trained staff was undertaken separately by the Indian National Sample Survey Organization (NSSO) in India. Like the census, the survey took place in 1981, specifically in response to the International Year of Disabled Persons. Unlike the census, however, it focused exclusively on disabled people. Even so, its scope was limited to certain specifically defined aspects of disability, namely, visual, communication and locomotion disability, although the opportunity was also taken to collect information on the behaviour patterns and developmental milestones of all children aged 5-13 years so that the extent and prevalence of delayed mental development could be determined.

The survey schedules used were very detailed so that a great deal of data was obtained from which the prevalence and incidence of the specific disabilities looked at could be determined for selected states of India. The differing approaches of the census and survey resulted in significant differences in the estimates obtained:

> There is wide divergence between the estimates of disabled persons obtained from the present inquiry and the broadly comparable counts available from the 1981 census. The estimated number of visually disabled persons having no light perception per 100,000 population was estimated at 219 for the rural areas of the country and at 135 for the urban areas as against the census proportions of 84 and 35, respectively, for the rural and urban areas. Against the census proportions of 39 dumb persons [that is, lacking speech] per 100,000 population for the rural areas of the country, and 21 dumb persons for the urban areas, the estimates from the present inquiry came out at 142 for the rural areas, and 102 for the urban areas. (5, para. 7.26)

It should be pointed out, however, that analysis of census results, even when underenumeration has occurred, can shed important light on the underlying demographic distributions, as shown in the United Nations case studies. (31) In addition, the directions of results are confirmed in censuses, for example, rural rates are higher than urban, and age and sex strongly influence disability rates.

B. Other sources of disability data

Some information about a survey population will probably be available in various administrative records, but disability data from such sources are likely to be incomplete, which is, in any case, part of the justification for undertaking a household survey on the subject. Most administrative records in developed countries, much less in developing countries, are incomplete, inconsistent and limited in scope. For example, in an investigation of the quality of administrative records relating to disabled people, a search of the records of 15 agencies expected to be involved in helping them was carried out in Canterbury, England, in 1972. (41) The five statutory registers of "handicapped" people were also examined because, in Britain, under the provisions of the Chronically Sick and Disabled Persons Act of 1970, local authorities like the City of Canterbury keep registers of handicapped people eligible for the kinds of help available from the Personal Social Services. The search followed a three-stage survey of every household in Canterbury, aiming to identify all impaired people living in the community. A marked disparity in the lists was evident: 1,608 disabled persons were identified in the survey and 907 names were held in the registers; only 586 persons were on both lists. Of the 586 on both lists, 402 were assessed as "handicapped" (that is, more severely disabled) in the survey, but, in the survey overall, 770 people were so identified.

In Britain also, registers are kept of the disabled for employment purposes. Registration is voluntary and the advantages to be gained by registering are often regarded as minimal. Hence, under-registration is usual and the registers suffer from the same defects of omission as the local authority registers.

In New Zealand the same kind of problem is noted in a report of the Department of Health. (16) Registers are kept of certain diseases and disorders, namely, cancer, blindness, congenital anomalies and hydatids (tapeworms). There is also registration of sterilization and neonatal births and further information about the existence of disability can be derived from routine sources on notifiable diseases and conditions and hospital inpatients and outpatients treated. However, in spite of evident under-registration, it is still suggested in the report that these sources "provide a valuable insight into the frequency of the more serious conditions and their incidence at specific ages in each racial group". It is also suggested that these sources of data could be supplemented by population interviews and health examination surveys enabling trends in morbidity to be promptly and easily identified.

The New Zealand Department of Health is clearly sanguine about the possibilities of employing certain kinds of records to supplement the results of surveys - or surveys to supplement records. The revised Handbook of Household Surveys suggests that, for such an approach to be effective, the two data sources, that is, registers and household surveys, must be integrated at the outset at least through the use of comparable concepts and definitions. However, quite apart from the problems mentioned above, the administrative data generated by a health care system are usually inevitably limited to the data relating to people who make contact with that system. Hence, household surveys will still be required to provide data which administrative sources cannot supply.

Overall, it is suggested in the Handbook that surveys are most effective when other data sources have reached their limit, that is:

(a) When census information is out of date or in insufficient detail for planning or other purposes or does not cover the topics needed;

(b) When other continuous sources such as administrative records are incomplete or non-existent or are not conceptually compatible with the data requirements;

(c) When certain analytically important relationships (such as household and family relationships, determination of household incomes and the like) which are not normally revealed in other data systems must be explored.

C. Advantages and disadvantages of household surveys

This topic is also considered in the revised Handbook of Household Surveys. Perhaps the main positive argument for the use of household surveys as sources of health and disability data is one which is drawn from what some see as the main weakness of the household survey - its reliance on the recall of respondents. Regardless of the need for certain kinds of information, there is little point in seeking it in a household survey if there is small likelihood that it can be supplied with acceptable accuracy by the respondents. However, though self-report may be unreliable in this way, it is able to tap those aspects of disability experience which are most clearly perceived by the disabled themselves or by those who care for them in the community.

In its susceptibility to description by self-report, disability contrasts somewhat with the experience of disease. The latter requires medical expertise to identify it in a way which might lead to a perception of how it may be cured. Generally speaking, impairments, almost by definition, are much less responsive to purely medical intervention. Sometimes, the best that can be hoped for is amelioration of pain and the enriching of social relationships. Medical expertise will play a part in the first of these processes at least, but lay perceptions are obviously required for the second, and they may be the most valid or authentic way of describing them. Household surveys have the potential to tap lay perceptions and, therefore, to explicate the more subjective elements in social processes. Other sources of disability data - hospital records for instance, by their objective, "impersonal" nature - cannot do this.

As an example, one may consider blindness, a significant cause of disability in many developing countries. Even hospital services cannot always make an accurate medical assessment of this condition, since the equipment that may be required to measure exactly visual acuity or field of view accurately may not be available. However, in the context of household surveys, visual disability and handicap of both the activity restriction produced and its social consequences may be measurable by self-report. Indeed, it may be that self-report is the best method available for measuring these aspects of disability and therefore for building up disability statistics in household surveys.

Once again a balanced view is required in which household surveys are seen as one among several complementary approaches to data collection. The reliability of the data gathered by household surveys depends in no small degree on a clear identification of what is being surveyed. Thus, disability presents a special problem in part because lay insights, not being couched in systematic terminology nor based on consistent theoretical perspectives, are bound to be unreliable and inconsistent. Yet, as was pointed out in chapter I and is discussed in detail in the evaluation of census and survey data in India, (6) even at the basic level of counting the numbers of the disabled the precise identification of what counts as disability or as being disabled is vital. When we move to attempting the formulation of clear categories of disability analogous to the categories of disease there are more problems. Then, as disability, certainly more clearly than disease, is a concept which, in some of its aspects, is capable of gradation into degrees, it is necessary to consider degrees or scales of disability such that severe disability experience can be distinguished from those less severe.

Another major difficulty of using household surveys as a method of gaining information is that they are relatively expensive. When financial resources are limited there is often a desire to maximize the information gained by bringing as many topics as possible within the scope of a given survey. However, to the extent this is done, there is the obvious danger that the amount of detail obtained on each individual topic may be too limited for the kind of secondary analyses which statisticians may have in mind to meet the requirements of policy makers. A possible compromise is that of using a common core of topics in each successive survey and supplementing this on a rotating basis by various modules related to specific topics, among which disability and health topics may well be included. This practice, which has been followed for many years in India, has another advantage beyond the saving of money: interviewers and respondents are less likely to be overburdened than if every topic is included in a single round.

A list of the advantages and disadvantages of using household surveys for data collection is given in the report of the World Health Organization on the Development of Indicators. (45, para. 156) Table 2 below presents an adaptation of this list. Some of the advantages and disadvantages will be mentioned in later chapters, but at this point it may be suggested that the advantages of household surveys are such that, even if every country had an ideal data collection system, it is unlikely that household surveys would be totally supplanted by other data sources. However, one must also be aware at the outset that all surveys are demanding of skills, experience and other resources for such major operations as sampling, development of good questionnaires and interviewing. Hence, there is a marked emphasis in the revised Handbook of Household Surveys on building up a survey team and making use of the experience of other countries.

A final point about the relative advantages and disadvantages of a household survey can be made by referring to the General Household Survey (GHS) in the United Kingdom that began in 1971. (20) The approach used in that continuous survey illustrates how, in some respects, the balance of advantage is towards surveys that are part of a continuing programme and not used on an ad hoc basis. The use of ad hoc methods, in which a survey on a particular subject takes place at a particular time with no follow up envisaged, means that a new start has to be made every time a survey is contemplated. Even developed countries can seldom afford to recruit new staff for such periodic special efforts. Thus, the British survey of 1968-1969 discussed in annex I was, and still is, the only comprehensive disability survey that has ever been undertaken in a major part of the United Kingdom. At the present time, a new survey with a focus on eligibility for disability benefits is under consideration, but there is no certainty that it will take place. To explain why this should be so, it suffices to point out the expense of undertaking a survey on this scale and the need to be sure that there will be a clear pay-off of the utility of the information gained, given that a substantial data base about the disabled of working age was built up in 1969 and that some information on relevant groups is available from other sources.

Table 2. Advantages and disadvantages of household surveys for collecting health data a/

Advantages and disadvantages

Advantages

(a) Health information can be related to other household information collected simultaneously, leading to analyses which would not be possible if the same information was collected from other sources;

(b) Information which lies outside the scope of official health services can be collected by direct questioning of the population, e.g., utilization of health care resources from the private sector;

(c) Data on morbidity and disability conditions not requiring health care but restricting activity can be derived only from this source;

(d) Morbidity and disability conditions not receiving health care and reasons for non-utilization of health services can be investigated in this way. These are particularly important for identifying socio-economic and cultural factors influencing accessibility of services;

(e) Estimates of coverage by various services can be checked by querying actual usage;

(f) Scientific sampling methods can provide estimates for the computation of population-wide rates and ratios.

Disadvantages

(a) Surveys based on probability sampling are difficult and expensive to organize and execute properly in the absence of an established national survey programme;

(b) Information on past diseases and other events reported by the respondent is subject to memory lapse and deliberate omission;

(c) Conditions that rarely occur or that show large variations in the population require large sample sizes or clustering techniques in sampling procedures for more precise estimates;

(d) To provide adequate data on indicators for small areas or population groups requires large sample sizes, and extensive disaggregation by subnational areas may require virtually complete coverage rather than sampling;

(e) Surveys conducted as one-time activities seldom lead to a permanent, routine data collection procedure.

---

a/ Adapted from Development of Indicators for Monitoring Progress Towards Health for All by the Year 2000 (World Health Organization, Geneva, 1981).

To summarize the discussion in this chapter, it has been argued that household surveys are particularly appropriate to gather information on disability topics. The reasons can be summarized by the argument presented most clearly in the WHO publication on International Classification of Impairments, Disabilities and Handicaps (ICIDH). (46)

The argument begins with the idea that every country, whatever its stage of social and economic development, needs quantitative information on the health status of its population, the use made of the health and social services, and the socio-economic and environment factors that affect health. Depending on its intended uses, the information may be needed at the national, regional and local levels. In certain countries, some of the data containing this information may be routinely generated by their health and social services. In other countries, few data may be produced by these services or they may be so rudimentary as to provide no opportunity for generating such data. In addition, even with the most complete and efficient organization of routine administrative statistics in the health and social services, there are bound to be significant gaps in the data produced. For example, health services can usually only generate data referring to actual users of the health care system. The characteristics of non-users and the reasons they give for non-utilization can only be derived from other sources - particularly household surveys.

Internal data generated by the health services of a country are often incomplete in other ways. The data produced are usually of two types. First, there are data on morbidity experience gathered by individual doctors and held by them in patients' personal records. Secondly, there are data, derived more particularly from hospital records, which are the by-product of internal administrative requirements. The data relate to such matters as hospital beds, personnel, waiting lists and patient loads in the different sectors of the system. A distinctive characteristic of these sources of data is that not only do they generate only data relating to users of the existing system, but they are also the product of that system and therefore reflect its requirements and assumptions. As a result, they cannot easily be used to evaluate that same system by acting as a basis for framing questions of utility, relevance, appropriateness and effectiveness. Again, additional data, ideally derived from some other external independent source, such as a household survey, are required. In addition, morbidity data generated by health services on disability are not likely to refer to anything more specific than the rather vague concept of disability as the more permanent long-term consequence of certain diseases and disorders, such as diabetes and stroke and of injuries. Hence, the disability data drawn from the different parts of the health system, or even from the records of different hospitals or health workers, are liable to have such an imprecise reference as to be comparable only with difficulty.

Thus, comprehensive disability statistics need to be generated from a system such as household surveys using precise definitions of the concepts on which information is required and from which statistics can be constructed. Definitions provided in ICIDH were outlined in chapter I and are discussed further in chapter III below, beginning with section D.

III. COLLECTING DISABILITY STATISTICS IN A HOUSEHOLD SURVEY PROGRAMME

A. Planning the survey

The collection of data in household surveys is a topic that has been examined at length in many standard textbooks and in the United Nations Handbook of Household Surveys (Revised Edition). (12, 32 and references in each) The various matters which require attention during the planning and execution of household surveys are discussed in general terms in the Handbook under the subheading entitled "Survey preparation". Each stage of survey work is listed and these are subsequently discussed in detail. An example of the application of survey organization principles to a specific context which overlaps with health matters is the World Fertility Survey (WFS). Certain manuals, studies and reports produced by the World Fertility Survey are relevant both to the content of this chapter and to other chapters of the present report. For example, part two of the Survey Organisation Manual issued by the World Fertility Survey, which deals with the planning and organization of a national survey, provides a useful check-list of the basic planning decisions which have to be made if a household survey is to be conducted correctly. (11) Parts of the list relevant to this section are shown in table 3 in a slightly abbreviated form. All the matters listed are considered in this and other World Fertility Survey manuals.

An introduction to the development of small-scale surveys for agencies with limited experience in conducting surveys has been issued by WHO and the International Epidemiological Association (IEA). (48) The guide describes step-by-step in an easily readable format the planning and organizing that has to take place when a local community survey of health topics is undertaken. Table 4 shows a slightly modified and abbreviated version of the operational chart which precedes the detailed description of how such a survey should be planned and conducted in that source. Table 3 emphasizes much more the tasks of preparing documents, recruiting staff and organizational and operational issues, while table 4, in contrast, brings out planning and policy matters which should be considered carefully in survey preparation.

Finally, the Expert Group on Development of Statistics of Disabled Persons particularly stressed the following fundamental procedures for improving the quality of survey data:

(a) Enumerator recruitment on the basis of demonstrated data collection skills in interviews and regular training and rechecking of performance;

(b) Recruitment and training of effective supervisors for field operations;

(c) Pilot testing of all procedures and questionnaires and post-enumeration surveys and analysis;

(d) Comparison of results using different questions, definitions and methods of data collection (e.g., self-report compared to medical examination);

(e) Quality checks at each stage of data handling;

(f) Continuous refinement of questions and coding and related techniques on the basis of field results to achieve maximum simplicity and consistency in the application of concepts, classifications and definitions.

Table 3. Planning decisions for a national household survey a/

Preparation for survey
A. Establishing the survey organization
B. Preparing documents
Developing, adapting, translating questionnaires and manuals
Printing questionnaires and manuals for pre-test
Designing and printing control sheets
Deciding on coding procedures
C. Sampling
Selecting area sample and mapping (where required)
Recruiting and training enumerators and supervisors
Listing households or dwellings (where required)
Selecting the household or dwelling sample
D. Conducting the pre-test
Recruiting and training pre-test interviewers and supervisors
Studying pre-test results and correcting documents
E. Printing of questionnaires and manuals for main survey
F. Field staff and field work
Recruiting and training supervisors and interviewers
Household schedule
Individual questionnaire
G. Coding and editing
Recruiting and training coders and editors
Conducting coding, editing and processing

---

a/ Adapted from Survey Organization Manual, World Fertility Survey, Basic Documentation No. 2 (International Statistical Institute, The Hague, 1975), pp. 34-35.

Table 4. Operational chart for planning and organizing a survey covering health topics a/

Check-list for planning and organization

Planning

1. Recognize and define the needs and problems.
2. Decide what information is required to deal with them.
3. Inquire whether this information is already available; study and use any available information.
4. Decide whether a survey can succeed in getting the information required.
5. List the main questions the survey is to answer.
6. Outline the methods by which the information can be obtained.
7. Decide on the time required for the field work.
8. Decide on the sampling plan.
9. Estimate the survey costs and modify the survey plan, if necessary.
10. Make the final decisions on the survey, especially:
    (a) Essential information to be collected;
    (b) The scale of the survey.
11. Design and write out:
    (a) The questionnaire;
    (b) The sampling plan;
    (c) The interviewer instructions.

Organizing

1. Prepare the community for the survey.
2. Test the survey methods.
3. Train the interviewers.
4. Undertake the field work.
5. Abstract the information.
6. Write and distribute the survey report.

---

a/ Adapted from Planning and Organizing a Health Survey, W. Lutz, ed., (World Health Organization and International Epidemiological Association, Geneva, 1981), pp. 5-7.

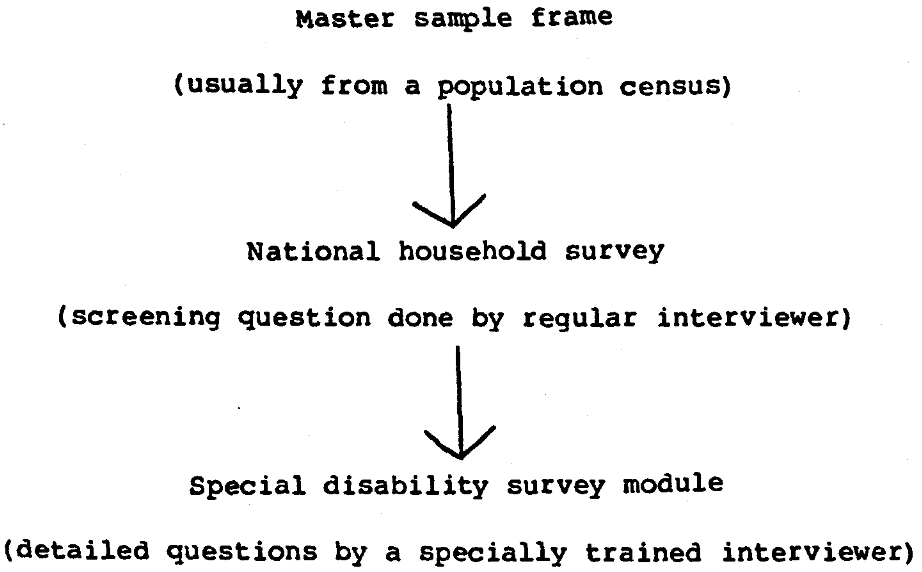
The topics discussed in the present chapter mainly concern issues which arise particularly and specifically when data concerned with disability and closely related subjects are collected. These include sample design, development of sampling procedures and making disability concepts and definitions operational in the survey.

B. Sampling in a survey covering disability topics

Sampling is one of the most highly technical tasks in any survey. The United Nations has published A Short Manual of Sampling (35) and a technical report, Sampling Frames and Sample Designs for Integrated Household Survey Programmes, (37) and WHO and IEA have provided a companion manual to Planning and Organizing a Health Survey, (48) mentioned in the previous subsection, entitled Sampling: How to Select People, Households, Places to Study Community Health. (49)

In the latter manual, it is pointed out that sampling in a developing country will normally begin with the search for a list or sampling frame of area units whose boundaries are reasonably well defined and whose population size is, ideally, less than 200 households in each area. Quite often the sampling frame is based on the population census. A sample of these units, numbering upwards of 100, comprises the area sample. The next operation is listing the households in each area. Then about one in 10 to one in 5 of these are selected for the main survey. However, this procedure is insufficient for a disability survey since it is likely that only about one in 5 of the sample households will be identified as containing an eligible person or persons. In developed countries, the problem may be overcome by undertaking an initial postal "sift" in which a letter and a form are sent by mail to a sample of households taken from some established register or sampling frame. It is intended that the forms should be returned by post so that they can be analysed to identify the disabled for interview. If the response is less than 80 per cent, a sample of non-respondents should be called on to check on the representativeness of the postal responses.

These suggestions are taken from a survey guide designed by survey officers who worked on the Survey of the Handicapped and Impaired in Great Britain. (24) The guide sets out, in language suitable for numerating persons who are not necessarily statisticians, a method for adjusting the sample of addresses based on the electoral register to provide both a good household sample and a representative sample of individuals of all ages. The main principle illustrated by the suggested sampling procedure is the likelihood that some kind of first stage identification of disabled persons must be undertaken prior to their being interviewed. In a developing country also, some procedure of this kind will be needed. As section C of table 3 implies, it is highly desirable to use listings from a master sampling frame or established household survey programme as a basis for the initial "sift" to identify households with disabled persons. There is probably no alternative in a developing country to using specially trained enumerators for this screening. One design typically used by household surveys, as in Canada (1983) and in Egypt (1979-1981), is to include in a labour force survey or a health survey the screening question on disability, which is then followed up with a more detailed interview by a specially trained interviewer. Thus, the design looks like the following:



This type of design significantly reduces the amount of effort that is expended, discussing disability in households not having a disabled person.

That disabled people make up only a small part of the population as a whole also has consequences for the disaggregation of data after the survey has been conducted. This matter is discussed in detail in chapter IV and in the United Nations case studies. (31)

C. Collecting disability statistics in continuous surveys

In chapter II, in which the possibilities of using household surveys for collecting disability data were examined, no clear distinction was made between the types of household surveys for this task. The reason is that, to date, most survey investigations of disability which are more than superficial have been on an ad hoc basis. Usually, it has been decided to do a one-time survey of disability so that rehabilitation and other services can be planned more effectively. Hitherto, few replications of disability surveys have been attempted. Some form of regular survey of disability would be ideal, but generally, continuous surveys are used to supply information on such a range of topics that few disability questions can be incorporated in them. The Health Interview Survey (HIS) in the United States of America is one example of a continuing survey of health conditions, including disability. (39) Most continuous national survey programmes cover topics such as employment and income, population and demographic characteristics and perhaps housing on a regular basis.

In continuous surveys, because data gathering is taking place all the time, a general framework of questions relating to specific important issues can be maintained and within this framework, health and disability topics can be included on a regular though not necessarily continuous basis. The advantages of this approach are, on the planning and operations side, the use of a flexible pre-existing infrastructure, including staff, sampling frame and skills, and on the subject-matter side, the ability of the survey to supplement other sources of data, to provide time-series in different fields and to show how these interact.

Clearly, the main strength of a continuing survey is its ability to cover these themes regularly and at the same time to produce information on them as closely as possible to the needs of different departments of administration. Another strength is, of course, that it will be capable over time of maintaining a general framework from which continuing series of statistics can be produced. Questions which are asked periodically can be used to construct time series and produce intercensal data.

D. Disability concepts, classifications and definitions in household surveys

1. General issues

Some consideration has already been given to the definition of disability in chapter I and further consideration is given to conceptual issues in the present chapter. Where surveys covering disability are concerned, certain points must be stressed repeatedly.

The first of these points is that the delimitation of the concept of disability on which the survey focuses is particularly difficult. Clearly, the main focus of a survey must depend on its aims, but the delimitation adopted is always likely to be influenced by the meanings generally accepted in the society within which the survey is conducted. It is probably for this reason that it is emphasized that the definitions in the survey in India of disabled persons were adopted for the specific purpose of the inquiry, which was "to estimate the prevalence and incidence of acute disabilities in the population". (5)

A second reason for difficulties in delimiting disability in survey work is that in any society the general notion is a broad one, covering at least "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being", to quote the definition used in both the survey in India and ICIDH. In order to limit its scope, the survey in India focuses only on three areas of disability - visual, communication and locomotor - and defines the disabilities to be measured within these areas very precisely.

The third point is that while careful selection and definition are essential, the true and actual focus of a disability survey does not depend so much on the formal definitions decided on during the planning of the survey as on the operational definitions implied by the actual questions asked during the survey, the way they are interpreted by the respondent and the ways the responses are interpreted and recorded by the interviewer.

The Survey of the Handicapped and Impaired in Great Britain illustrates the point well. The formal definition of "handicap" in this survey was expressed as the "restriction of activity or disadvantage caused by impairment". However, if the interview schedule is examined, the questions asked by which the handicapped were identified focus almost entirely on restrictions in activities, particularly those associated with physical rather than sensory or mental impairments. Many other questions were asked about disadvantages of various kinds, such as housing deficiencies, but the count of the handicapped was based only on the answers given to the restriction of activity questions. Hence, the estimate of some 1.1 million handicapped people 16 years of age and over living in private households in Great Britain must be interpreted as relating to the people with the kinds of activity restriction covered by the questions asked, taking into account the additional stated restrictions by age and private households.

In the survey in the United Kingdom, the discrepancy between stated intention and implementation was not liable to mislead since the restriction was thought through during planning and attention was drawn to it in the survey report. It was intended from the outset to concentrate on the physically disabled, since the personal social services provided by the local authorities were primarily directed to meet the needs of that particular group.

In order to provide countries with a more general, carefully developed basis for defining and classifying disabilities in national work, ICIDH was developed in the 1970s and issued for trial use in 1980. This classification, the underlying conceptual framework and ways of using these in survey work are described below. Some national experiences which predated ICIDH are described in annex I, section A.

2. Some problems of conceptualizing disability

In chapter I of the present report, the wide scope of disability statistics was pointed out. In order to maintain clarity in the terminology, it has been found necessary to analyse disability experience in a way that reflects the different aspects of that experience. Thus, the WHO trial terminology, in which impairment, disability and handicap are distinguished and precisely delineated in detailed definitions, has been deliberately constructed with the aim of achieving clarity and precision.

There is nothing new about trying to construct clear definitions as opposed to merely accepting the traditional usages reflected in speech or in dictionaries. The use of constructed definitions is a standard technique adopted by planners of surveys designed to measure the prevalence of conditions, like disability, for which precise formulation of concepts is needed. Instead of taking as a starting point the usual rather vague notions of real-life experience of disability and then looking for indicators which serve to measure it more or less exactly, it is often preferable to construct a definition or several definitions that are precise and detailed enough to be used as a basis for operational statistical series, definitions and indexes.

To assess needs and count the disabled in the community, a concept of disability is required that is related both to the needs and to the experience of the people whom it is desired to count. In addition, since both needs and disability experience and needs related to this experience are matters of degree, a definition is required that is capable of assessing the extent of people's disabilities, not just whether they can be regarded as disabled or not. Only by finding a conceptual framework with these properties will the concept of disability used in the survey have the potential to provide adequate indicators of either disability status or the needs of disabled people.

A convenient starting point is to distinguish between disabling conditions and disability experience. These terms are not synonymous. Blindness is a disabling condition, but the experience of being blind is inadequately summarized whether for planning or allocation of benefits by classifying people with blindness as "blind". The point is that blind people differ widely among themselves in their disability experience, so that individuals who are blind have differing special needs related to their blindness. Both their experience and their needs depend just as much on their age and adaptability, their families and their homes, their community, whether city or village, and the environment it provides, as on the condition of blindness in itself. In addition, the intrinsic and extrinsic aspects of the experience are interrelated in such a way that the experience cannot adequately be summarized by recording the medical and environmental information separately.

In addition to the difficulties of adequately conceptualizing the experience of disability, there are several popular uses of the term itself which can lead to misunderstandings when disability data are examined and interpreted. For that reason particularly, it was decided at the outset of the Health Interview Survey programme in the United States to use the term disability only in conjunction with other words, for example, "work disability", which made the meaning clear. Other terms were also introduced with specific, more limited meanings, such as "restricted activity day", "workless day", and "chronic mobility limitation". None the less, the published description of the survey (39) emphasizes that the survey definitions are not new. Rather, they have a long history which can be traced back at least as far as surveys conducted in the early 1920s. Even so, the process of development of the concepts and definitions in the United States survey is continuing, and a part of the programme is to conduct research that will lead to concepts that are more objective, more explicit and more useful. In this way the concepts and definitions used are kept in touch with "real-life" disability experience.

Survey definitions of disability, therefore, can never be totally definitive for the long term, even though stability in definition is bound to make comparison easier. Rather, definitions and concepts must be framed to respond to accepted usage and understanding, on the one hand, and to the necessity of clear-cut definitions for use by survey workers, on the other.

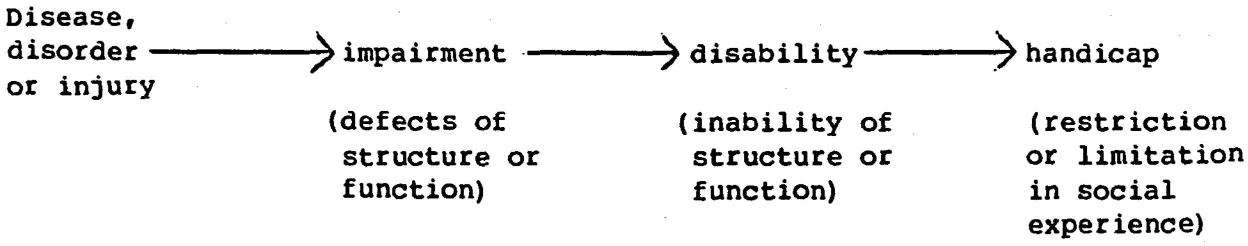
Similarly, it is necessary to keep in mind that the definitions used should be sensitive to perceived needs for social and health services and policies. For instance, the United States survey programme was set up because certain institutional needs were becoming evident. There was social pressure for more long-term provision for disabled people in hospitals and nursing homes. Moreover, a need for additional facilities for home-nursing and rehabilitation was being felt. It was therefore necessary for the survey team to conceptualize disability in such a way that those among the disabled who would be likely to benefit from the new services would not be inadvertently left out. To give a simple example, it is not very helpful to conceptualize disability solely on inability to undertake paid work if the need for services among people who are retired or out of work is a main focus of the study.

E. The conceptual framework of the International Classification of Impairments, Disabilities and Handicaps

Considerations such as those discussed above convey a broad lesson for those concerned with setting up surveys. This is simply that the conceptualization and definition of terms concerning disability are more fundamentally problematic than is sometimes realized. Ultimately, surveys are undertaken in order to study particular social issues and contribute to social policy. But before a problem can be studied a conceptual or definitional framework is needed. One aspect of such an analysis is the conceptualization of the key elements within the issue. The study of social issues always requires prior and explicit attention to definitional problems and to the intellectual framework within which a particular study or survey is being carried out. It is not enough to plunge into the "facts" and think that one will automatically draw out conclusions which can then be applied or made useful to the policy maker. An explicit conceptual framework within which to set the observations and out of which to develop adequate definitions of the phenomena under investigation is always required.

The conceptual scheme adopted in ICIDH provides a clearer conceptual framework than any previously proposed. This conceptual scheme is shown in figure 1.

Figure 1. Conceptual scheme of the International Classification of Impairments, Disabilities and Handicaps



For all its seeming simplicity, the scheme requires careful study in order to be fully understood. The concept of temporal or causal sequence expressed by the arrows from left to right is useful in understanding the four elements of the conceptual framework, but cannot at the present stage of research be applied as a fully developed description of disablement experience. Difficulties in this sequential interpretation arise in both theory and practice at several points. First, it is extremely difficult to draw a clear dividing line between each of the conceptual elements. Many conditions, particularly from the perspective of the disabled person, combine aspects of each element which are indistinguishable. This makes the development of separate but consistent classifications for the four elements extremely difficult. Even at the most basic level of specifying the links between diseases and injuries, and impairments, there have been considerable difficulties. Second, as Disabled Peoples' International in particular has emphasized, there are many factors which crucially affect the experience of disability and handicap besides the underlying diseases, injuries and impairments. To take a simple example, persons with serious vision impairments may or may not be disabled, depending on the practicality and availability of corrective services. Handicap in leading a normal life, in turn, may or may not be experienced depending on the social and economic circumstances in which the individual finds oneself and one's interaction with these circumstances.

With these unresolved issues in mind, prospective users of ICIDH should read carefully the introduction and the first chapter, entitled "The consequences of disease", in the manual describing the classification as a whole. (46) Much of the introduction is concerned with the need for a classification of disease consequences and an outline of the stages in its development. It is made clear, however, that during the construction of the classification, the attempt to reconcile what seemed to be a valid method of classifying disease consequences with the hierarchical method of classifying disease in the WHO International

Classification of Diseases, Injuries and Causes of Death (ICD) led to insuperable difficulties:

> It soon emerged that difficulties arose not only from nomenclature but also from confusion about the underlying concepts. After clarification of these ideas, it became apparent that a single scheme conforming to the taxonomic principles of ICD was unsatisfactory. Whilst impairments could be dealt with in this manner, a synthesis of the different dimensions of disadvantage could be accomplished only by making arbitrary and often contradictory compromises between the various dimensions or roles identified. The principle was therefore advanced that a classification of handicap had to be structured differently, based on ordination of the different states of each dimension.

The final result is that ICIDH is, in reality, three classifications: one of impairments, that is, defects of structure or function, one of disabilities, that is, inabilities of function or performance, and one of handicaps, the subsequent losses of opportunity and disadvantages in certain important dimensions of health and social experience.

The first section of the ICIDH manual spells out formally the definitions of impairment, disability and handicap, and shows how these concepts can usefully be conceived as "planes of experience" following the onset of disease or injury. The definitions and their characterizations and the description of how the planes of experience are likely to manifest themselves are given in annex II to the present report. As regards disability, for example, the definition reads as follows:

> In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

The main emphasis is on the restriction of abilities in the form of deficits in composite activities and behaviours, such as difficulties in undertaking personal care. A more general definition might also include limitations in bodily functions, that is, for example, the inability to move one's arms, which could lead to loss of ability to undertake personal care. In ICIDH, limitations in bodily function of this kind are assimilated in the concept of impairment.

The examples given on pages 30 and 31 of the ICIDH manual should also be examined because they make clear that the graphic representation in figure 1 shows only a theoretical case. As discussed above an impaired person may be disabled without being handicapped. The ICIDH conceptualization shows explicitly the intermediate role of disability between impairment and handicap. In other words, there may be great disparity (low correlation) between degrees of disability and subsequent handicaps experienced by impaired individuals and it is precisely this disparity which should be measured, as a basis for policy. Clearly, policy can seek to intervene at many points in the disablement process, and the ICIDH framework is useful in identifying and describing these points and in measuring their importance. They include prevention and control of diseases and injuries which lead to impairments, treatment of impairments to prevent or control disability, minimization of disability through rehabilitation and other services, and minimization of handicap through equalization of opportunity.

F. Using the International Classification of Impairments, Disabilities and Handicaps in surveys

An attempt to apply the concepts of ICIDH in a national survey was made in Australia in 1981. (1) In planning that survey, it was considered that the question on handicaps in the 1976 population census yielded inadequate data because the question had various meanings for different people. In addition, previous surveys undertaken by the Australia Bureau of Statistics had not focused clearly on handicapped persons in the ICIDH sense. As a result, in the new survey a methodology was implemented in which an attempt was made to take the ICIDH concepts and definitions as the starting point for the survey definitions and their operationalization in the questionnaire and coding schemes.

Not surprisingly, it was not possible to meet this goal completely. There is still some lack of concordance between the ICIDH concepts of impairment, disability and handicap and those used in the survey. Nevertheless, examination of the definitions stated in the report on Australia is instructive because it again shows that in planning a survey it is best to spell out precisely conceptual definitions as well as operational definitions. In the survey a disabled person was defined as a person who had for at least six months one or more disabilities or impairments from a given list. Similarly, a disabling condition was a condition which caused one or more of the impairments and disabilities in the list. The list, which is shown in table 5, has some value in its own right as an indication of what aspects of impairment and disability might be made the focus of a household survey.

Table 5. List of impairments and disabilities surveyed in Australia

Impairments and disabilities
Loss of sight (even when wearing glasses or contact lenses);
Loss of hearing;
Speech difficulties in native language;
Blackouts, fits, or loss of consciousness;
Slowness at learning or understanding;
Incomplete use of arms and fingers;
Incomplete use of feet and legs;
Long-term treatment for nerves or an emotional condition;
Restriction in physical activities or in doing physical work;
Disfigurement or deformity;
Need for help or supervision because of a mental disability;
Long-term treatment or medication (but individual was still restricted in some way by the condition being treated).

Source: Australia Bureau of Statistics, Survey of Handicapped Persons 1981 (Canberra, 1982).

One of the original intended applications of ICIDH was for use alongside ICD to facilitate data collection within the health care system following a detailed examination and interview of the individual patient. Technical applications such as this one have been discussed in a series of meetings convened by the World Health Organization and the Economic Commission for Europe. The realities of the household survey do not permit anything even approximating such a detailed approach. Nevertheless, the ICIDH conceptual scheme, because of its description of the significant different planes of experience associated with chronic disease or injury, is a more adequate representation of disability experience than most other conceptualizations now available. To the extent that its definitions can be operationalized in survey instruments which can be used by the survey team available, the ICIDH conceptual scheme seems to provide a way forward for future household surveys in all countries.

As all those readers with experience of household surveys will recognize, the proviso that the definitions can be operationalized in survey instruments which can be used, that is, can be reliably administered to the envisaged respondents by the survey team available, is extremely important. It is for this reason that survey field experience is important and that this chapter and annex I of the present report include some discussion of the lessons that have been learned about operationalizing disability concepts within surveys of practical measuring instruments.

G. Measuring the degree of disability in a household survey

An important characteristic of disability which makes it difficult to give a categorical answer to any question concerning numbers of disabled people is that it is a phenomenon capable of categorization into degrees. One disabled person is always, in some sense, more or less disabled than another. A household survey which does not come to terms with this problem is likely to provide inadequate information, since people who are severely disabled are likely to have different needs than those who are mildly disabled.

Recently, ad hoc surveys of the disabled, therefore, make some attempt to form operational definitions of degrees of disability. A simple example is provided by the 1981 Survey of Handicapped Persons in Australia. First, handicapped persons were defined as a subset of the disabled as follows:

> A handicapped person is a disabled person aged 5 years or more who is further identified as being limited to some degree in his/her ability to perform certain activities or tasks in relation to one or more of the following five areas:
>
> (a) Self-care;
>
> (b) Mobility;
>
> (c) Communication;
>
> (d) Schooling;
>
> (e) Employment.

Disabled persons aged under 5 years were all regarded as being handicapped. (1)

Then, for self-care, mobility and communication, three levels of handicap were defined as follows:

(a) Severe handicap - personal help or supervision required or the person is unable to perform one or more of the activities;

(b) Moderate handicap - no personal help or supervision required, but difficulty in performing one or more of the activities;

(c) Mild handicap - no personal help or supervision required and no difficulty in performing any of the activities, but uses an aid.

If it can be implemented, a degree of disability or handicap classification of this kind increases the value of disability survey data considerably, especially if the categories identified as more severely disabled or handicapped can be equated with priority groups with special needs.

A good example of such a priority group, which the United Kingdom survey was intended to identify, was that group of disabled people who were thought likely to be the target group for the Attendance Allowance which was being planned at the time the survey was undertaken. The group was described as requiring a considerable degree of attention or supervision from others if their basic needs were to be met. They were described in the survey as "very severely handicapped (needing special care)", a respondent being deemed to need special care "if his condition was such as to make him dependent on someone else for the performance of living activities which occur more than once a day".

In order to identify this special group, every questionnaire was scrutinized by the research staff of the survey. The questionnaires were then divided into three categories on the basis of criteria supplied by the Department of Health and Social Security. People in categories lower on the handicap scale were classified by total scores on the index of self-care included in the survey schedule. The full details of the method of assignment of disabled persons to the special group and other handicap categories are described in an appendix to the survey report which extends to more than eight printed pages. However, survey designers in developing countries will almost certainly wish to avoid the complexities of the British classification of handicap. One way of doing this would be to confine the analysis of degree of disability to the three categories of the Australia survey within any particular dimension or type of disability or handicap. Another strategy, used in the Indian survey, is to draw a fixed dividing line between those who are to be counted as disabled and those who are not. Thus, for visual disability, "a person was treated [as] visually disabled if he/she did not have light perception [with] both eyes taken together or he/she had light perception but could not correctly count fingers of a hand (with spectacles if he/she used spectacles) from a distance of 3 metres in good daylight".

H. Disability topics in continuous surveys

Health is an obvious topic for inclusion in continuous surveys. In the General Household Survey in the United Kingdom, one of the four parts of health experience always covered is that of illness, which is divided into chronic and acute, these being established by two separate questions. The question about chronic illness asked in 1971 was the following:

> Do you suffer from any long-standing illness, disability or infirmity which limits your activities compared with most people of your own age?

The meaning of disability in the question is not precisely specified. However, the intention behind the question as a whole is to find out the proportion of people in the sample who, at the time of interview, considered that a medical condition limited their activities in some way, corresponding to the ICIDH concept of disability. It should be pointed out, however, that survey respondents were asked if they "suffer from" any such illness or disability, but some individuals will not perceive themselves as "suffering from" but rather, perhaps, coping with these attributes. Undoubtedly, the wording of the question affects the response rate.

Some valuable additional considerations are suggested in the General Household Survey, Introductory Report: (20)

> ... differences in attitudes, judgements and intelligence can affect response to this question. For example, some people may adapt so well to a disability, adopting a new and tolerable way of life, that they no longer consider it a limitation, while others may never be able to make this adjustment. Secondly, some people may be less willing (or able) to adopt a sickness role than others. Again, the availability of services may help to prompt awareness of disability and availability of services is not evenly spread. Finally, it is a measure which is closely tied to expectations of the fullness of living and, as such, may vary as social conditions change.

The point being made is that disability is not a "pure fact", that is, it is not value free. What counts as disability in Britain may not count as such in a developing country, because there are issues of policy surrounding the concepts being presented. Hence, the operationalization of disability and related concepts adopted will in no small measure influence the magnitude and significance of the results obtained.

In the General Household Survey, Introductory Report, an attempt is made to compare the 1971 data of the General Household Survey on chronic illness with data from the 1968-1969 survey in the United Kingdom and data from the Health Interview Survey in the United States in 1970. It is reported that the United Kingdom survey found 8 per cent of persons aged 16 or over with impairment as defined in the Health Interview Survey, compared with as many as 20 per cent of persons aged 15 and over in the General Household Survey. A possible reason for this observation was sought in the form of the main "disability" question in the 1971 General Household Survey. It seems that some informants were replying to the question, "Do you suffer from any long-standing illness, disability or infirmity which limits your activities compared with most people of your own age?" before the interviewer had finished asking it. Hence, a small study was undertaken in which the question was broken down as follows:

> "Do you suffer from any long-standing illness, disability or infirmity?"
>
> If YES, "Does this limit your activities compared with most people of your own age?"

The effect of splitting the question was to lower the overall proportion of chronically sick people on the General Household Survey definition substantially. The rates for 1972 now approximate very closely to those found in the United States study except among the elderly, where General Household Survey rates are markedly lower. This lowered rate can be explained by the emphasis now given to the phrase "compared with people of your own age". It seems that this phrase may be causing the elderly to regard quite serious limitations as common among people of their own age with the result that they answer "no" to the second part of the question when they themselves have quite severe limitations. The lesson conveyed by this instructive example is the overwhelming importance of attention to detail in the wording of the question. The questions asked operationalize the conceptual definitions envisaged, and even quite minor changes in wording can influence the results obtained considerably.

IV. ILLUSTRATIVE SERIES AND CLASSIFICATIONS

In this chapter, examples will be given of variables and classifications in household surveys covering aspects of disablement which have been conducted in a few developed and developing countries. Work in India and Nepal is described in detail since these surveys can serve to illustrate most of the practical points that need to be made.

As was discussed in the previous chapter, the lack of time-series data on disablement in part relates to the difficulty of obtaining information by specialized interviewers. Accurate series are produced only if precisely the same questions within the same interview framework are used to elicit responses. In addition, as ad hoc surveys, in contrast to censuses, are usually designed to elicit information on specific current issues, it seldom happens that surveys on a particular topic replicate a framework and questions used previously.

One set of surveys of disablement which attempted to meet the conditions necessary for the production of accurate time-series data was undertaken by the National Sample Survey Organization in India, and, even with these, reservations have been expressed about the comparability of the results. (5, p. 2 and appendix 1) The possibility of constructing true time-series of certain aspects of disablement so that change can be measured accurately is obviously an important issue for future study and research now that the availability of a stable set of definitions has made the undertaking more feasible.

A. Examples of variables on disabled persons from surveys

Household surveys covering disablement that have been conducted in developed countries during the past 20 years have resulted in a formidable collection of statistics relating to these countries. For example, the contents of tables of statistics relating to the Survey of the Handicapped and Impaired in Great Britain are summarized in table A-1 in annex I below. Altogether, 360 tables were produced on personal characteristics, impairments and handicaps, work and leisure activities, qualifications and housing of the disabled 16 years of age and over living in private households in Great Britain. In addition, the tables enable the provisions made for the disabled by local authority health and welfare services to be examined.

Some of the in-depth questions used in this survey cannot easily be generalized to other developed or developing countries, where these require specialized skills and training of interviewers and coders, extensive data processing capabilities and knowledgeable respondents. For example, interviewers in the United Kingdom survey asked respondents to supply the medical diagnosis of their main disabling condition in such a way that the diagnoses could later be classified in broad ICD groupings. In a developed country and in a relatively small-scale survey such as this one, confined to adults in the community with mainly physical disabilities, obtaining accurate diagnoses of the common disabling diseases from the self-reports of disabled persons is feasible. (40) When survey-takers have access to substantial medical expertise and the survey is carefully limited to a few widely understood impairments causing disability, a similar view can be taken:

> It is ... plausible to postulate that at least in cases of acute disabilities, the results of the sample survey method would be broadly in accord with those which could have emerged had the clinical test been carried out by medical experts. (5, p. 12)

However, if it is desired to extend the survey to impairments whose origin is less widely understood by laymen, the information required cannot easily be acquired with accuracy.

Examples of topics in household surveys covering disablement are given in table 6 below, based on surveys in Canada, Lebanon and Zimbabwe.

Table 6. Illustrative topics from selected national surveys covering disability

	Canada	Lebanon	Zimbabwe
Presence of impairments Presence of disabilities	Nature and degree of disability Dependency and degree of dependency in daily activities (adults) Conditions limiting participation in normal activities (children)	X	X Age at onset Mobility
Causes of impairment	X	X	X
Social economic and environment characteristics			
Sex, age	X	X	X
Marital status	X	X	
Household family characteristics, or living in institutions	X	X	
Education and training	X	X	X
Employment	X	X	X
Income and consumption			
Other health and nutrition characteristics			
Geographical distribution	X	X	
Housing and environment	X		
Leisure and culture			
Social participation			
Others		Siblings deceased, birth order Father's and mother's social and economic characteristics and degree of blood relationship	
Distribution and use of services and support	Use of and need for aids and prostheses Access to transportation Income assistance and extra expenses	Training and rehabilitation	Type of treatment (formal, traditional)

Sources: *Report of the Canadian Health and Disability Survey, 1983-1984* (Statistics Canada, Ottawa, 1986); questionnaire for the Survey of the Handicapped in Lebanon, 1980-1981 (Lebanon, Office of Social Development), as translated from Arabic in *Development of Statistics of Disabled Persons: Case Studies*, Series Y, No. 2 (United Nations publication, Sales No. E.86.XVII.17), pp. 130-142; *Report on the National Disability Survey of Zimbabwe 1981* (Department of Social Services, Harare, n.d.).

In developing countries, the main constraints in surveys covering disablement have always been skills and finance. Thus, what is surveyed in a particular developing country should always relate closely to the priorities identified in that country, and the statistics should be developed so as to assist in designing and implementing programmes in a cost-effective fashion. The interrelations between services for prevention, rehabilitation and health care, on the one hand, and housing, sanitation and education services, on the other, should be brought out by the statistics so that cost-effectiveness can be analysed. (19) At the same time, it is essential to limit the scope of any survey to topics that can realistically be covered using available resources.

B. National sample survey in India

This survey has been mentioned several times in previous sections, but its scope can conveniently be outlined here. In 1981, during the International Year of Disabled Persons, the Ministry of Social Welfare of India requested a country-wide sample survey on disabled persons to complete vital gaps in the information base concerning disability. A working group of experts decided that the best advantage would be gained by limiting the survey coverage to visual disability, communication disability and locomotor disability. It was also decided to collect information on behaviour problems and developmental milestones for all children aged 5-14 years, regardless of whether or not they were physically disabled, so that the extent and prevalence of delayed mental development could be examined. Then, to put the data obtained into context, basic demographic data on sex, age and place of residence were noted together with data relating to other characteristics, depending on the particular disability surveyed. The scope of the survey was limited in two main ways: first, it was limited to what policy makers considered to be essential to complete serious gaps in the information base regarding disablement, and secondly, it was limited by what experienced survey workers considered feasible. Even this limited coverage resulted in a report containing in excess of 100 tables, which, along with some 60 pages of explanation, discussion and comment, provides data giving a reliable and detailed national picture of the prevalence and incidence of the particular disabilities surveyed.

The actual characteristics surveyed can best be identified by examining the inquiry schedules issued to field staff. More than half the document containing the schedules is taken up by the schedules for the household listing and the records of family group formation. The data obtained are linked with those in the survey of disabled persons proper through variables providing particulars of specialized institutions exclusively for disabled persons and through other variables identifying disabled persons in the visual, communication and locomotor categories within households. In the disabled persons survey itself, household, demographic and disability data are gathered in considerable detail. It is not easy to summarize the characteristics concisely, but table 7 lists the column variables which provide demographic and summary disability data relating to each person within each household. The coding employed in certain columns is also described at the foot of the table.

Table 7. Disability survey: characteristics surveyed within households, India

Characteristic of disabled person
1. Serial number
2. Name
3. Relation to head of household
4. Sex
5. Age at last birthday
6. Marital status
7. Usual (work) activity status
8. Visual disability
9. Communication disability (5 years and above)
10. Locomotor disability
11. At least one of the disabilities in lines 8-10
12. Whether parents of the disabled member have common ancestors
13. Type of blood relationship
14. Degree of physical disability

<u>Codes</u>

13 Member's mother is first cousin of member's father

Member's mother is member's father's sister's daughter

Other blood relation

14 Total

Can function with only aid/appliance/help

Can function without aid/appliance/help

Source: India, Report on Survey of Disabled Persons (National Sample Survey Organization, New Delhi, 1983).

Table 8 below lists the disability variables and coding for each person having a visual disability. In the schedule used, data are sought relating to additional characteristics cross-referenced with both the household data shown in table 8 and the household list data.

Table 8. Disability survey: visual disability characteristics relating to each disabled person, India a/

Characteristic of disabled person

---

10. Whether having light perception (yes, no)

11. Having light perception but with both eyes open cannot count fingers at a distance of 3 metres or 10 feet in good daylight (with spectacles, without spectacles)

12. Whether normally using spectacles (yes, no)

13. Whether having visual disability from birth (yes, no)

14. If code 2 against 13, since when (years) having difficulty in moving around

15. Whether visually disabled during last year (yes, no)

16. Probable cause of visual disability, as known

17. If code 1 against 16, type of eye disease as known

18. Whether can read Braille alphabets (yes, no)

19. Whether treatment taken (yes, no)

20. If code 2 against item 10, reason for no treatment

21. If code 1 against item 10, how soon treatment commenced after having difficulty in moving around (months)

22. Type of treatment taken

Codes

16 Cause of visual disability

Eye disease
Sore eyes during first month of life
Sore eyes after one month
Severe diarrhoea before the age of six years
Small pox
Injury
Old age
Others.

Table 8 (continued)

Codes	Characteristic of disabled person
17	Type of eye disease Cataract, glaucoma, corneal opacity, eye infection (inner eye), eye haemorrhage (inner eye), high power of glasses, other eye diseases, not known.
20	Reason for no treatment Place where treatment available not known Place of treatment known but treatment expensive Treatment not deemed to be necessary for economic independence, personal independence, others (specify).
22	Glasses only, medicine only, surgical operation, others.

a/ Extract from the Report on Survey of Disabled Persons (National Sample Survey Organization, New Delhi, 1983).

C. Characteristics surveyed in other developing country household surveys concerning disability

Many survey projects on disability were undertaken or planned in connection with the International Year of Disabled Persons. Many of these are listed in the United Nations *Disabled Persons Bulletin* for 1982. This publication, though it concentrates on work in Africa, also mentions initiatives elsewhere. For example, the English version of the WHO manual, *Training Disabled Persons in the Community*, (47) is being field-tested in at least 10 countries and a French version is being produced. Some other surveys and similar studies in Africa, many associated with the International Year of Disabled Persons, are listed in table 9. Many of these studies were assisted by United Nations organizations.

Table 9. Population censuses and surveys in Africa which collected data on disability, 1974-1985

Country	Census or survey
Benin	1983-1984 census a/
Botswana	1983 survey
Cameroon	1985 survey
Cape Verde b/	1980 census
Central African Republic b/	1975 census
Comoros b/	1980 census
Egypt b/	1976 census and 1979-1981 Health Interview Survey
Ethiopia b/	1979-1981 Survey of Disabled Children
Kenya b/	1981 National Survey of Disabled Persons
Libyan Arab Jamahiriya	1984 census
Madagascar	1974-1975 census
Malawi	1983 survey
Mali b/	1976 census
Seychelles	1979 Survey of children
Sudan	1983 census
Swaziland b/	1983 Survey of the Handicapped
Togo	1981 census
Tunisia b/	1975 and 1984 censuses
Zaire	1984 census
Zambia	1980 census, 1982 survey of children
Zimbabwe b/	1981 National Disability Survey

Source: Statistical Office of the United Nations Secretariat, Disability Statistics Data Base.

a/ Covered disabled persons not economically active.

b/ Results are included in the United Nations Disability Statistics Data Base.

In Nepal, to mark the International Year of Disabled Persons, a sample survey of disabled persons was undertaken in 1980 in co-operation with the United Nations Children's Fund (UNICEF) and WHO. (13) The physical disabilities covered were visual, auditory, limb, head, neck and spine. Mental retardation was also covered and graded as severe, moderate and borderline.

The report adopts the following classification of disabilities in the presentation of data:

Visual	1. Blind 2. Visually handicapped 3. One eye blind 4. One eye visually handicapped

Auditory	1. Deaf
	2. Hearing handicapped
	3. Deaf-mute
Upper limb	1. Both arms crippled
	2. Left arm crippled
	3. Right arm crippled
	4. Both arms severed
	5. Left arm severed
	6. Right arm severed
	7. Finger defective
Lower limb	1. Both legs severed
	2. Left leg severed
	3. Right leg severed
	4. Both legs crippled
	5. Right leg crippled
	6. Left leg crippled
Head, neck, spine	Head, neck and spine
Mental retardation	1. Severe
	2. Moderate
	3. Borderline

Disabilities are defined for the purpose of the survey in rather general terms. Specific mention may, however, be made of the following definition and gradation of mental retardation given in the report:

(a) Severe: A person who, despite good physical condition, is incapable of doing normal daily self-care activities consistent with age is considered to have severe mental retardation;

(b) Moderate: A person who is in good physical condition and is capable of taking care of himself, but cannot do ordinary reading or writing or adjust to a situation needing ordinary skills consistent with age is considered to have moderate mental retardation;

(c) Borderline: A person who is in good physical condition and is capable of taking care of himself and doing ordinary reading and writing, but cannot cope with a situation needing moderate intelligence or skill is considered to have borderline mental retardation. (Categorization of borderline and moderate mental retardation, as defined, gives good level to the investigator.)

Persons with disability were identified by sex, age, area of residence, type or site of disability, cause of disability, work undertaken and family size. It is evident from the tables in the report of the survey that many of the topics listed in table 1 above were covered. The variables chosen for examination, as judged from the reported tables of data, are listed in table 10 below. A particularly interesting feature of the Nepal survey is that the views of "panchas" (local leaders) and social workers were sought about the relation of disabled persons to their families and society and about the need for rehabilitation programmes. The main value of the survey is seen as indicating areas in which preventive and rehabilitation programmes will have the greatest effect. This survey is documented in considerable detail, and the final report is therefore of considerable value for countries undertaking similar surveys in the future.

Table 10. Topics and characteristics surveyed in disability survey in Nepal

Topics and characteristics
<u>Background variables</u>
Sex, age, region, family size
<u>Disability variables</u>
Type of disability or impairment:
Visual
Auditory
Upper limb
Lower limb
Head
Neck and spine
Mental retardation
<u>Cause of disability</u>
Congenital defects
Acquired defects
Accidents
<u>Handicap variables</u>
Employment of disabled person
Attitudes of local leaders and social workers towards disabled persons:
Liability towards family and society
Desirability of rehabilitation
Willingness to contribute to rehabilitation programme
Persons to be contacted for launching rehabilitation programmes

Source: Nepal, Report on the Sample Survey of Disabled Persons in Nepal (1980).

D. Characteristics surveyed in developing countries in community-based rehabilitation surveys

The guide for local supervisors which is part of the WHO manual, Training Disabled Persons in the Community, (47) includes a straightforward description of how disabled people who need training might be located and identified and how their progress might be assessed. Survey questions, often requiring no more than a yes/no answer, are suggested as well as simple tests. The tests are clearly explained. For example, the test for visual disability used in the Indian survey (item 11 in table 8 above) is described in four steps accompanied by illustrations as follows:

1. Stand at a distance of 3 metres in front of the person. Hold up three fingers of one of your hands;
2. Tell the person to hold up as many fingers as you have held up;
3. If the person holds up three fingers, he/she does not have difficulty with seeing.

In some cases during trial use of the manual, the suggested questions and tests have been incorporated into a formal questionnaire. An example produced by the Institute of Health Research and Development of the Department of Health in Jakarta, Indonesia, incorporates detailed check-lists with comprehensive coverage. The conceptual scheme on which the questionnaire is based is similar to the 1975 draft of ICIDH. In this scheme, functional limitations are differentiated as intermediary between impairments and disabilities.

In the questionnaire of the Indonesian survey, the questions are explained for the benefit of the interviewer in various ways. For example, the first "chronic impairment" asked about is coughing. In the "comments to questions", a person with a cough is described as one "who coughs every or almost every day with or without expectorate, due to chronic bronchitis, asthma, emphysema, tuberculosis or other lung disease". The first "mental health impairment" question relates to "withdrawal, isolation, non-communication and/or avoidance of social contact; difficulty in mixing with others; liking to sit by themselves; you have to make an effort to engage them in normal activities". The comment on this question is that it is "supposed to screen out simple schizophrenia without positive florid symptoms. Here are included people with gradual slow loss of social interests, school performance or personal hygiene, apathetic, withdrawn into their own inner world, self-preoccupied and non-productive".

The Indonesian survey was an ambitious one and needed people trained in health matters for its administration. A survey with this amount and level of detail is clearly likely to be much more feasible on a small scale rather than nation wide. However, the WHO manual provides simple material which can easily be adapted to a variety of local or national conditions.

E. Some problems of categorization

The World Fertility Survey provided widely used guidelines for household survey work at all stages from planning to disaggregation and cross-classification of the data gathered. (8) As noted there, the basic series to be compiled from any survey will consist of selected rates, means and frequency distributions of dependent variables within major demographic subgroups. In other words, in a basic survey of disablement, the variables listed in table 1 under impairments, disabilities and handicaps will be classified according to sex, age and residence.

Stated in this way the required categorizations and cross-categorizations seem straightforward. Nevertheless, surveys of disablement present peculiar problems of disaggregation and cross-classification. The UNICEF Bulletin (38) gives an example to illustrate these. For this example a survey (or part of a survey) covering 2,000 households is taken as the starting point. In such a survey, with an average family size of, say, 5.5, 11,000 persons are covered. At most, about 10 per cent of the persons can be expected to have a disability or impairment, that is, about 1,100 persons maximum. However, a typical household survey can only be expected to pick up some of these people. Limited identification of impairments and disabilities occurs for many reasons. For example, mental disablement is difficult to identify and some kinds of physical or sensory disablement are also likely to be overlooked. Partial hearing loss is particularly difficult to identify in a general survey. As a result, the Bulletin suggests that the resulting effective sample of disabled persons in this example might only be about 350 persons.

With an "N" of only 350, the possibilities for disaggregation are limited, so it is essential to avoid classifications which are too detailed and to eliminate those which are unnecessary. The Bulletin illustrates problems which arise from too detailed disaggregation by pointing out that if a disablement variable for the effective sample of 350 is split into six categories and cross-classified by sex and age, even if the latter is only a binary split (children/adults, say), the average cell size would only be 15. Six age cohorts would reduce the average cell size to five.

A cautionary exercise is therefore recommended. This consists of drawing up trial tabulations of the kind proposed for the World Fertility Survey before a disablement survey is carried out. Then, if the expected number of cases per cell is calculated, the possibilities of disaggregation can be assessed and the expectations for the survey reviewed accordingly.

F. Disaggregation and categorization - some examples

While the World Fertility Survey guidelines on variables, disaggregation and cross-tabulation are very useful for disability statistics as well, disablement presents its own peculiar problems to the classifier, perhaps the main one of which is that many aspects of disablement are a matter of degree as well as of type. Loss of vision or hearing, for example, are often partial so that a simple binary categorization of hearing simply results in inaccurate description and unreliable data. In both theory and practice, when a binary division is used for continuous survey variables, the results produced are less reliable than if a graduated scale is used. (3) What should be done is simple to state but quite difficult to operationalize: no more or fewer categories should be used than the purpose of the survey requires. For example, if a survey is undertaken to find out how many pairs of spectacles are required in a community, upper and lower limits of sight can probably be defined between which spectacles are useful and outside the limits which spectacles are of comparatively little use. The following examples of categorizations of disability variables are contained in the survey in India:

Visual disability is effectively graded as:

Can count fingers without spectacles
Can count fingers with spectacles
Cannot count fingers with light perception
Cannot count fingers with no light perception

Hearing disability is graded:

No disability
Moderate disability
Severe disability
Profound disability

No tests are indicated for hearing disability.

In the more in-depth Indonesian survey, which was related to the WHO community-based rehabilitation project, a binary division is used for sensory limitations. The survey administrators are asked to include among those who experience hearing difficulties "persons who are hard of hearing of such a degree that they cannot hear whispered words at a distance of 2 metres". The instruction to "cup your hand before your mouth when you test" is also provided. Similarly, among those who experience difficulty in seeing, "persons who cannot see and recognize objects of the size of a matchhead or grain of rice at a distance of one metre" are to be included. Not included are "persons who have simple myopia, hyperopia or presbyopia". Persons should use glasses if they have them.

The schemes described above show how disaggregation and categorization of disablement variables is approached empirically in household surveys. What is feasible is decided in the light of the mode of administration of the survey and the aims of the survey are adjusted accordingly. It seems unlikely that within the household survey mode categorization and measurement of either ocular impairments or visual disability as conceived in terms of, say, ICIDH could be envisaged except in a drastically simplified form.

Nevertheless, what can be accomplished by well-chosen categorization and disaggregation can be easily illustrated. The distributions in table 11 are taken from an account of hearing disorders in a four-centre stratified sample of the British population. (2) They show the variation of auditory impairment and disability by age, sex and socio-economic group in this sample.

Table 11. Percentages of persons with various disabilities by age, sex and socio-economic groups, United Kingdom of Great Britain and Northern Ireland

A. Percentages of people whose hearing levels (averaged at 0.5, 1, 2, 3 khz) were 25, 35 and 45 dB HL, in the better ear, by age

Age group	Percentage with hearing level greater than or equal to: 25 dB	35 dB	45 dB	Average hearing level dB HL, better ear
17-20	3	2	0	6
21-30	1	1	0	5
31-40	5	2	1	9
41-50	10	4	2	12
51-60	23	10	6	18
61-70	34	17	12	24
over 71	74	49	25	34
All	17 + 2.2	8 + 1.5	4 + 1.2	14

B. Percentages of people with three degrees of hearing impairment, by sex

Sex	Percentage with hearing level greater than or equal to: 25 dB	35 dB	45 dB	Average hearing level dB HL better ear	worse ear
Male	20	9	5	15	21
Female	14	8	55	13	19

Table 11 (continued)

C. Percentages of people with three degrees of hearing impairment, by socio-economic group

Socio-economic group	Percentage with hearing level greater than or equal to 25 dB	35 dB	45 dB	Average hearing level dB HL better ear	worse ear
I	4	0	0	9	11
II	11	4	3	12	17
IIIn	13	6	3	12	16
IIIm	20	12	8	17	23
IV	25	12	7	16	23
V	11	6	3	15	23

D. Difference between sexes adjusted for age, noise exposure and socio-economic group over threshold and SLin tasks

Task	Differences (female minus male) between sexes: better ear	worse ear	
Threshold (250 Hz)	1.96	2.33	db HL
Average threshold: (.5, 1, 2, 4 khz)	0.34	0.25	db HL
Average threshold: (6, 8 khz)	-4.29	5.80	db HL
Sentence identification in noise test (SLin)	5.12	4.26	% correct

Source: A. C. Davis, "Hearing disorders in the population: first-phase findings of the MRC national study of hearing", in M. E. Lutman and M. P. Haggard, Hearing Science and Hearing Disorders (London, Academic Press, 1983).

Part of the author's comments on these data is as follows:

> There are two reasons for documenting the variation in measures of auditory dysfunction with age, sex and socio-economic group (SEG). Firstly, it is interesting (e.g., to planners of audiological services) to look at the marginal distribution or at least a cross-tabulation of two of these explanatory variables. For example, it is useful to know that there is a high probability of a hearing impairment for men whose occupation corresponds to SEG IV. Secondly, it is highly desirable to be able to build a model of the causal effect of various environmental variables on hearing impairment. To do this, account must be taken of other explanatory variables which might actually mediate any apparent effect. For example, sex differences in hearing impairment could conceivably be explained largely in terms of differences in noise exposure, so the effect of noise exposure must be held constant when making this kind of comparison. Comparison of parts C and D of table 11 will make this point. (Parts A, B, and C) present the marginal distribution of average hearing level, and the proportion of people with average hearing levels greater than or equal to 25, 35, 45 dB HL, over age, sex and SEG.
>
> The sex differences in auditory impairment shown [in part B of table 11] have been broken down further to look at the frequency-dependent nature of this difference and also the extent to which these may affect auditory disability. (Part D of table 11) shows the difference (females minus males) between the sexes after taking into account the different structure of age, noise immission rating (NIR, a cumulative index of noise exposure) and SEG for the two sexes. The significant difference for mid-frequency thresholds is about 2 dB in table 11 (part B) but is reduced by this control procedure to 0.3 dB here. That is to say, the sex difference was probably a manifestation of different levels of noise exposure rather than a fundamental sex difference. However, there remain differences at low frequency (men less impaired) and at high frequency (women less impaired). Noticeably, the advantage that women have at high frequencies is carried over to the auditory disability measure. (2, pp. 52-55)

Further analysis undertaken on the relation of socio-economic group and disability when age, sex, and noise-intensity ratio are controlled suggested a clear dichotomization of the SEGs into manual and non-manual workers.

V. EVALUATION, TABULATION AND DISSEMINATION OF RESULTS

Once the field work in a survey is completed, it may seem that the major part of the survey programme has been completed, but in fact many more critical and difficult phases of work must still be done. In this chapter various aspects of the processes of evaluation of results, preparation of reports and dissemination will be considered where disablement is the subject of the survey.

A. Evaluation

The first task, checking and editing the questionnaires, consists mainly of ensuring (a) completeness - that there is an answer to every question, (b) accuracy - that there are no inconsistencies or arithmetical errors, and (c) uniformity - that the interviewers have all interpreted questions and instructions in the same way. Some of the procedures can be done by computer, other procedures are routine but require scrupulous individual care.

The next task is coding, during which the responses to the questions are put into meaningful categories. Generally, the set of categories, that is, the coding frame, shall have been established along with the survey questionnaire. However, it may have been modified in the light of analysis of a small number of pre-test interviews. Possible variations in coding work should also be investigated routinely. The results of experiments on coder variability suggest that unreliable coding may be responsible for misleading data more often than is generally appreciated. Hence, a proper evaluation of survey data will include an investigation of the reliability of the coding process. The statistical advisers and experts of the World Fertility Survey suggested that both the procedures (such as coding) and the data themselves should be systematically evaluated, and that a report of this evaluation should be prepared so that future performance in the conduct of both field work and the analysis and reporting of results will be improved (7, 10).

To evaluate the data collected, tests of the reliability of the recorded responses made in the course of the survey should be undertaken. One way in which this can be done is to repeat the administration of the questionnaire on a small scale using a new sample of people drawn from the original population. Less expensive procedures may also be possible. Thus, interviews could be repeated with different interviewers with part of the original sample; or the responses to background demographic questions common both to the disablement survey and to any other survey that may have been conducted on a sample drawn from the same population could be compared. Similar data from other external sources of information, such as previous social surveys, census figures or other sources of disablement data, such as those discussed in chapter I, might be compared with the survey data to highlight discrepancies for subsequent investigation.

Such comparisons are reported in the discussion of the question on physical handicap in the 1981 census of India. (5) Estimates of the numbers in certain categories of handicapped per 1,000 population estimated by the National Social Survey Organization (NSSO) on the basis of a sample survey conducted in 1973-1974 are compared with those enumerated in the 1981 population census during the house-listing operations conducted in 1980. The results are shown in table 12 below.

Table 12. Number of handicapped per 1,000 population, India

Blind		Dumb		Crippled		Total	
NSSO	Census	NSSO	Census	NSSO	Census	NSSO	Census
1.26	0.73	0.61	0.42	1.10	0.55	4.43	1.70

Source: India, Report on Survey of Disabled Persons, National Sample Survey Organization (NSSO), thirty-sixth round, July-December 1981, No. 305 (New Delhi, 1983), p. 68.

The wide discrepancies shown in the table reveal the problems of making comparisons when disability data are involved. The main explanations suggested are (a) that the NSSO survey definitions are wider than those used in the census, and (b) that the operational methods differ. The census question was put to respondents only during house-listing, while the survey question was put to respondents by trained survey staff who had received instruction on the methods appropriate to the subject of the survey and who were provided with a survey schedule that permitted a certain amount of probing and checking for the authenticity of the replies. However, the census report also observes that surveys can be discrepant with one another, not merely with censuses. The following example given derives from certain Indian states and union territories:

> For example, the estimated (number of) handicapped persons per 1,000 population of Himachal Pradesh according to the 24th Round, for rural areas was 5.17 and for urban areas 0.50. But according to the 28th Round, this proportion ... went up to 11.84 for rural areas and 3.50 for urban areas. (6)

Six other states and territories listed show similar differences. The main reason suggested for the differences is the "built-in difficulties of enumerating special characteristics of populations of this nature". It is also suggested that discrepancies between similar data derived from surveys undertaken by NSSO and the Indian Council for Medical Research (ICMR) can also be explained by these difficulties.

Hence, while comparisons between survey data, on the one hand, and census and other data, on the other, should be made, discrepancies are to be expected. Possibilities of comparisons that might be undertaken are outlined in a report of WHO. (43) The report is mainly concerned to emphasize that survey data should, whenever possible, be related to other sources of information. However, it is also pointed out that not only those data which relate to the main substantive concern of the survey should be used in comparisons. As has been observed above, "disability" data from different sources can appear widely discrepant, but data on basic demographic characteristics, perhaps derived from preliminary listing procedures, can also be compared. An example given in the WHO report is that the age and sex structures observed in a survey sample of households can sometimes be checked against similar demographic data obtained from other sources.

B. Tabulation

Standard textbooks advise that, in principle, tabulation may consist of nothing more than a systematic arrangement of counts of the number of cases falling into each of several classes - so many with this impairment, so many with that and so on. In a small survey, it seems clear that such uncomplicated counts can be done by hand. In large surveys, especially when cross-tabulations, perhaps in the form of three-way tables, are required, the use of a machine tabulator or, better, a computer using standard programmes, is probably essential. Nevertheless, in principle, tabulation is not generally regarded as requiring great statistical expertise. However, part of the forbidding aspect of statistical reports in the eyes of users of surveys can often be attributed to poor presentation, in particular poor tabulation, of data. Hence, any of the modern relatively elementary texts on statistics emphasize principles of tabulation. An example of a list of such principles taken from a modern text used by students in the United Kingdom is given below in table 13. Extensive examples of tabulations in the field of disability are given in the United Nations publication Development of Statistics of Disabled Persons: Case Studies. (31)

Table 13. Principles of good tables

Principles

1. Every table should have a short explanatory title and a note on the source of the information.
2. The unit of measurement should be clearly stated and, if necessary, defined in a footnote.
3. Use different rulings to break up a larger table.
4. Wherever they are applicable insert both column and row totals.
5. If the volume of data is large, two or three simple tables are better than one cumbersome one.
6. Before drafting a table, be sure what it is to show. Keep in mind that most people find it easier to absorb figures in columns than in rows.

Source: F. Owen and R. Jones, Statistics, 2nd ed. (Stockport, Polytech Publishers, 1982).

The principles in table 13 are not rules. For example, because of the expense, even a developed country might not follow principle 3 in a printed text. In addition, principle 5 should be treated with care; several tables concerned with a single variable often can only be replaced by one compound table. Thus, in a double or two-way table, one variable, usually that with the greater number of values, is listed vertically and the other horizontally.

As background for the analysis of survey data on disabled persons, basic age and sex distribution of the populations represented by the sample (national, regional and so on), for example, using five-year age groups, should be prepared. This kind of preliminary tabulation for a survey of disability is liable to be overlooked, but is always valuable because the prevalence of disability in a community and the degree of disability of individuals are invariably associated with the age-structure of the community. The reason is that both the extent and degree of disability are often associated with increasing age. Moreover, the prevalence of particular impairments and causes of impairment within certain age cohorts is correlated with sex. Hence, within a community, it is invariably important to cross-tabulate sex and age-distributions as a preliminary to the substantive tabulations. Preparing this kind of background table as a matter of course in national surveys will also facilitate comparisons between countries.

Basic two-way tabulations from the survey data will mainly take the form of cross-tabulations according to the dependent impairment, disability and handicap variables. In general, the dependent variables will be cross-tabulated according to three basic demographic variables - sex, age and area of residence. Complicating factors are, as has been pointed out, that the demographic factors interact, that disabilities and handicaps do not just randomly occur and that, when they are present, they are present to various degrees. Hence, many of the more useful tables in a report will take the form of three-way cross-tabulations.

The standard way of presenting such tables is to repeat one of the variables in successive subtables or panels. Examples could be multiplied using additional breakdowns by sex, age, area of residence and so on, along the lines given in table 1 in chapter I, above. Thus, it becomes clear why there are invariably so many tables in a report on disability. Information is likely to have been obtained on many significant impairment, disability and handicap variables and, in addition, the distribution of many of these variables in relation to the three basic demographic variables is likely to convey more meaningful information to policy makers and planners. Finally, tabulations should be prepared to show the extent of certain disabilities and handicaps among different sectors of the population.

C. Dissemination

Conventionally, the final step of a survey so far as it concerns the survey statistician is "to present its results, details of its methodology, any necessary background information and the conclusions drawn from the results, in some kind of report". (12, p. 407) The form of the report will depend on the type of reader for which it is intended. The present report, for example, is intended for both producers and users of statistics on disabled persons, to encourage a dialogue among them and to inform them of national and international experience concerning disablement, so that surveys can be undertaken which meet the requirements of Governments for accurate information about disablement. The World Fertility Survey Guidelines for Country Report No. 1 recommend that the country reports should be presented in two stages. (8) The first stage report is primarily addressed to administrators and policy makers. It should describe the field work and present only basic results. It should contain a minimum of multi-variable analyses and complex data evaluation. It is only later that a report or reports whose primary audience is researchers and statisticians are produced.

In the general considerations relating to the first-stage report, World Fertility Survey experts suggest that the report should be released quickly with a frank statement that the quality of its tabulations will be assessed in further detail and adjustments made in later reports. The main reason for this approach is that Governments are often concerned with decisions that have to be made within a fairly short time-limit, in part because of intense short-term public pressures on policy makers, partly because Governments may have a fixed timespan and in part because legislation itself is time-consuming. (18) For example, even though the time-scale for implementing "Health for All by the Year 2000" may seem virtually infinite, some progress must become evident in the short term if the goal is to be reached. The main implications of the recommendations of the World Fertility Survey are that the first report should be produced as quickly as possible, should not be over-technical and should be directed primarily at policy makers.

Recommendations issued by the United Nations go even further than those of the World Fertility Survey, suggesting that a preliminary report should first be issued, followed by a general report. Later, technical reports should be produced. (34) On the preliminary report the recommendations are as follows:

> A preliminary report is often required to make available data of current interest as rapidly as possible; such results may relate to selected important characteristics sometimes based on a sub-sample of the full sample. It should contain a brief statement concerning the survey methods and the limitations of the data. As a very minimum, information should be given concerning the size of the sample, the method of selecting the sample and discrepancies observed between external and internal data. Fuller details can be given in the general and technical reports on the survey.

Under arrangements in which only one report, ostensibly for all audiences, is produced, the report often has little impact. At least two possible reasons for this have been identified in a report on dissemination produced for the United Kingdom Department of Health and Social Security. (4) One reason is simply that the rule that the first report should not be overly technical and should be directed at policy makers is often ignored. It seems that, in the United Kingdom, research reports are evaluated in the first instance mainly by the peer group of scientists, hence workers are pressed into writing primarily for their specialist peers. To the extent that research and survey reports overlap, the same could be true of survey reports.

The other reason is simply that modes of dissemination are often faulty; it is sometimes as if they are lost in the post. The United Kingdom report suggests that to overcome this problem seminars should be arranged. These should both be carefully planned and delivered to carefully selected audiences. It is suggested that on the national scale seminars of this kind are highly cost-efficient methods of transmitting information.

The United Kingdom report also stresses the role of information and general public relations services to arrange for articles in house journals such as, in the United Kingdom, <u>Health Trends</u>, which disseminates information about work done under the auspices of the Department of Health and Social Security. Publications cited elsewhere in the present report, for example, the <u>Social Statistics Bulletin</u> published by the Eastern Africa Regional Office of UNICEF (38) and the WHO/International Epidemiological Association's guide to planning and organizing a health survey, (48) show that, with backing from international agencies, valuable information about disability and disability surveys in developing countries could be inexpensively produced and disseminated in a readily understandable form.

In order to address common dissemination problems, the Expert Group on Development of Statistics on Disabled Persons listed the following ways of bridging the gap between statisticians and policy makers, programme planners and specialists:

(a) Co-ordination and exchange of ideas at the highest level;

(b) Co-ordination and exchange of ideas at the working level through such activities as seminars, staff training programmes and informal contacts;

(c) Active involvement of policy makers and programme planners in the development of long-term programmes of censuses and surveys from the design stage to data evaluation, analysis and dissemination;

(d) Development of avenues for increased participation of statisticians in the design and execution of services and in training programmes concerned with disabled persons, for example, as part of staff training for surveys covering disability topics;

(e) Increased efforts to guide planners to phrase their goals in such a way that they can be measured more readily;

(f) Continued relations and interaction between users and producers, even after survey procedures are completed, including follow-up of the report. Creative examples should also be prepared in order to show the value of data.

Annex I

SELECTED NATIONAL EXPERIENCE AND PRACTICES

In this annex, selected national experience in planning and implementing surveys covering disability is examined. Most of the experience reviewed here predates the International Classification of Impairments, Disabilities and Handicaps (ICIDH), hence the terms used and their definitions follow the usage adopted in each national study discussed. This experience provides useful historical background on the development of the concepts in ICIDH. The ICIDH terminology issued for trial purposes in 1980 (46) is discussed in chapter III, sections G, H and I, of the present report.

A. Approaches to defining disability preceding the International Classification of Impairments, Disabilities and Handicaps

It is an obvious truism that almost all significant real-life concepts can be defined in many different ways. Disability is no exception to this rule, and during the past 20 years many definitions of this concept have been suggested. However, quite apart from being different from one another, not all the definitions have proved to be particularly useful in practice. One carefully expressed definition of disability is to be found in work undertaken for the World Health Organization about 10 years ago. It reads as follows:

> Disability is an existing limitation in one or more activities which in accordance with the subject's age, sex and normative social role are generally accepted as essential, basic components of daily living. [a]

This definition provides some indication both about what might count as a disability - a limitation in activity - and about the kind of questions that might be included in a survey of disability. However, the trouble with all definitions, even detailed ones like this, is that a word of doubtful meaning is being defined in terms of other words which might also be doubtful in meaning. For example, what counts as an activity "generally accepted as an essential component of daily living" will differ from country to country. Is watching television or listening to the radio such a component? And again, what is to be counted as an activity? Is "watching" or seeing an activity, or must the seeing and the watching be directed towards specific objects - the television and the radio?

Hence, the definition above is not adequate by itself, and, as is pointed out in the report presenting it, one must proceed further to formulate operational definitions which inform the survey designer of the "operations" that have to be undertaken to obtain the information he requires about disability. The example given of an operational definition derived from the above conceptual definition is:

> All examined subjects will be rated by the examining physician as to the expected degree of limitation in the essential basic components of daily living, the impairment to which the limitation is attributable, the prognosis for the impairment and a summary judgement of the degree of disability.

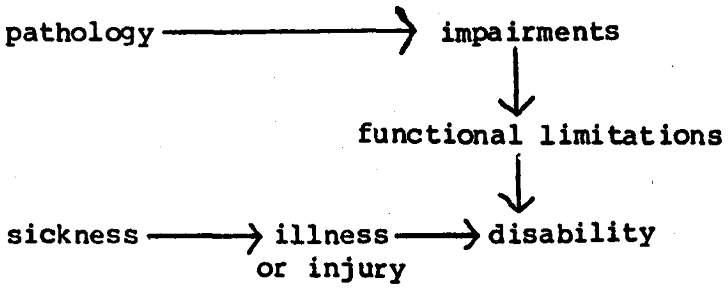
In practice, operational definitions are not usually spelt out formally to this extent. Rather, as is discussed in the present report, especially on surveys, the actual questions asked and, indeed, the whole survey procedure operationalize the working definition. Thus, over the years, a variety of approaches to the conceptualization and definition of disability have been studied and tested for various purposes, including surveys, prior to the adoption of the WHO classification for trial purposes, issued in 1980. Several of these are described below.

1. Experience in the United States of America

A brief review of some important definitions concerning disability in the United States is provided in one of the basic handbooks related to the long-standing Health Interview Survey organized by the National Center for Health Statistics. (39) The handbook suggests that in the early 1960s the term disability was most often used to refer to a medically defined condition that interfered with the ability to work. This usage led to a classification of disabling conditions of "temporary partial", "temporary total", "permanent partial" and "permanent total". Hence, total blindness, total deafness or the loss of a leg by accident or amputation would generally be classified as "permanent total" disability conditions. The classification acquired legal significance through its application of defining eligibility for compensation when not being able to work. However, its usefulness in this particular legal and administrative context does not mean that a similar classification will be appropriate for community household surveys. In undertaking those surveys, we are more likely to be interested not so much in benefits as in estimating the wider need for health and social service provision. To assess this need, all the disabled in the community must be counted, not just those who are totally disabled and not just the "work disabled" - those who are having difficulty in undertaking or keeping their jobs because of their disabilities.

One rather elaborate framework of disability experience differentiates several "disability" concepts, among them impairments, functional limitations, illnesses and disabilities. b/ Disabilities are defined as "forms of behaviour that evolve in situations of long-term impairment that have resulted in functional limitation". The concepts listed above are then linked together in a "model" of how disability "works", that is, of disability or disablement experience. This can be represented by the terminological scheme in figure A-1. Though this is too elaborate for direct use in surveys, it reminds us how important it is to be careful about conceptualizing precisely the definitions we operationalize, that is, use as a basis for formulating survey questions.

Figure A-1. An illustrative model of disablement experience



2. Experience in the United Kingdom

Less elaborate terminological schemes than that outlined above must be used in surveys of disability, but the good effects of careful definitions and the bad effects of the reverse are always evident. In the United Kingdom survey of 1968-1969 special attention was paid to careful definition. At the outset of the report of the survey a reluctance to use the term disabled to describe certain groups of impaired people is evident. However, a close reading of section 1.1, entitled "Definitions", of the initial survey report shows how strong the pressures were to revert to "disabled" to describe these groups and, indeed, to use "disability" instead of "impairment" because of both popular and official usage.

The main reason stated for preferring "impaired" to "disabled" and "impairment" to "disability", however, was the general tendency in Britain to equate the term disability and disabled with the more severe visible conditions: "reference to the 'disabled' is more likely to conjure up a picture of someone in a wheelchair, a spastic, or someone 'crippled with arthritis' than someone with tuberculosis, or who is totally deaf, or a bronchitic". (21)

The definitions of impairment and handicap proposed for and used in the survey were as follows:

"Impairment" is:

(i) Lacking part or all of a limb or having a defective limb, or

(ii) Having a defective organism or mechanism of the body which stops or limits getting about, working or self-care;

"Handicap" is the disadvantage or restriction of activity caused by disability.

In addition, another term, "disablement", was defined as "the loss or reduction of functional ability". The described relationship of this term to impairment suggests that it was being used as an alternative to "disability" when reference was intended to disability experience rather than to the disabling condition causing that experience.

There is no doubt that the definitions, developed in 1967, result in too many inconsistencies to be regarded as good models. However, though they are not entirely clear and consistent, they were formulated so that the competing claims of policy makers for specific information about people's ability to perform self-care activities and of survey workers for conceptual clarity could be reconciled. This process of reconciliation is essential if the results of a survey are to be of maximum practical use.

A meritorious feature of the definitions was that they had within them the nucleus of a theoretical framework required for conceptualizing those aspects of disability experience with which the survey was concerned. Thus, the idea is expressed that impairment, itself caused by disease or injury, "results in handicap, as far as self-care is concerned". Similarly, the idea is expressed in terms of examples that when handicap is defined solely in terms of disadvantage, and when the notion of functional limitation is expressed by some other term, then it is clear that only some impaired people are functionally limited (that is, "disabled") and only some disabled people are "handicapped":

We have said the short-sighted or diabetic person is impaired, but not necessarily disabled in that they are able to correct with aids or drugs. Similarly, a disabled person, that is someone who has a reduction of functional ability, may not find such a reduction places him at such a disadvantage as to render him handicapped.

The overall impression of the process of definition given in this report is that two competing views of disability experience are being kept in mind. One view is that impairment (as defined there) might lead to handicap defined by restriction of activity and disadvantage in such a way that the handicapped could be conceived as a subset of the disabled. This view can be represented by the following scheme or model:

$$\text{disease} \xrightarrow{\text{may lead to}} \text{impairment} \xrightarrow{\text{may lead to}} \text{handicap}$$

A rather similar model of the process of disability has also been used in the Wellington, New Zealand, survey. In this survey, the impaired and the handicapped are regarded as subsets of the disabled. In addition, the impaired and handicapped are distinguished, as in the survey carried out by the Office of Population Censuses and Surveys, primarily by their degree of disability but also by an elaborate classification in which the degree of ability to undertake self-care, dependency on walking aids, the extent of sensory problems and the ability to attend work are all taken into account.

The other model of the disability process latent in this work is that impairment (defined in a wide sense suggested by preliminary studies) might lead to disability (defined as functional ability), and that disability might lead to handicap (defined as disadvantage only). This view can be represented as follows:

$$\begin{array}{c}\text{disease}\\\text{or injury}\end{array} \xrightarrow{\text{may lead to}} \text{impairment} \xrightarrow{\text{may lead to}} \text{disability} \xrightarrow{\text{may lead to}} \text{handicap}$$

This second conceptualization is a prototype of the conceptual scheme and model of the experience of disease consequences formulated in ICIDH and shown in annex II to the present report.

3. Experience in the Netherlands

Another survey of the disabled or, more precisely, of the "physically handicapped", was carried out in the Netherlands in 1971-1972. Once again, a working definition of the concept being studied - that is, physical handicap - is provided, but in this survey an attempt was made to produce an explicit operational definition said to be based on a more theoretical definition drawn from a number of sources. Although the account of the transposition from these theoretical (working) definitions to the operational definition used suffers somewhat in translation from Dutch to English, the careful attention to definition and clear specification of both the concepts which the survey is intended to include and those which it excludes is noteworthy:

> A physical defect is a state of imperfection of the body which can be objectively defined by a physician. In connection with a defect a handicap can make itself manifest in the form of an impediment or complex of impediments which limits or hinders the functioning of the individual. A handicap can manifest itself in the form of a physical, social and social-psychological impediment. ... physical defects can exist without constituting a handicap, but ... conversely a person may have a handicap though there is no evidence of physical defect. This study is limited to those persons who have a handicap in the sense of a physical impediment (functional disorder) in conjunction with a physical defect. It would thus in this instance be correct to speak of "persons with a physical handicap in conjunction with a physical defect". For the sake of brevity we shall however speak of "physically handicapped persons".
>
> There are of course people who are physically handicapped in the sense of our definition who also suffer from a form of mental handicap. These mentally and physically handicapped persons have not been included when drawing up the survey results. (15)

In comments on the conceptualization and results of the survey, it has been explained that the definitions and terms used were established around 1970, and that an internationally accepted system of terms, such as is provided by ICIDH, was not then available. As a result, this survey of the "physically handicapped" was not based on a coherent model of disability experience. Rather, it was limited to persons with certain kinds of functional disorders or impairments and some of the disabilities and handicaps resulting from them. c/

In addition, because the relationship between the disorders and impairments surveyed and what is now regarded in ICIDH as handicap was inadequately conceptualized, insufficient insight was gained into the disability factors determining the need for care services and housing provisions. Instead, need was inferred only from the wishes which respondents were invited to express during the survey interviews. Apart from their lack of explicit connection with disability experience, subjective expressed needs of this kind are largely related to the respondents' knowledge of the services available, while planning requires need to be based on accurate knowledge of what services are likely to be available in the future.

In general, therefore, the conceptualization of disability in surveys to date has centred largely on impairment, and has led to an emphasis on prevalence studies of the more easily recognizable physical impairments and some of the disabilities and handicaps which result from them.

4. Experience in India

The survey in India, already discussed in chapter IV, was marked by clear definitions of the entities surveyed and a focus on either disability or impairment depending on the entity. The starting point was, in fact, the ICIDH definition of disability: "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being". The disabilities surveyed were:

(a) Visual disability: lack of ability to execute tasks requiring adequate visual acuity operationalized in terms of an inability to count fingers of a hand from a distance of 3 metres in good daylight (the ability to perceive light was also investigated);

(b) Inability to hear, or the possession of speech or voice defects. The classification used was fairly complex. Thus, hearing disability was classified by degree into total, profound, severe and moderate and by various operational criteria, while speech defects were classified into no speech, unintelligible speech, stammering, speaking with abnormal voice and other (nasal voice and articulation defect). This speech classification obviously implies that a nominal classification of speech defects is imposed on a threefold ordinal classification (no speech, the middle range of defective speech and speech);

(c) Locomotor disability: inability to execute distinctive activities associated with moving both himself and objects from place to place. However, the classification of detected locomotor disability proceeded according to course - paralysis, deformity of limb, amputation, dysfunction of joints of limb and deformity of body other than limb.

It seems clear, therefore, that though the broad ICIDH definition of disability was adhered to, the actual disability classification was only used in the simplest possible way and only three or four of the areas represented by the first-digit classification of disability were surveyed. Later, classification proceeded purely pragmatically, presumably so that only the information actually required by Government would be obtained.

B. Survey of the Handicapped and Impaired in Great Britain (1968-1969)

A wide-ranging survey of the "handicapped and impaired" was conducted by the staff of the Office of Population Censuses and Surveys (OPCS) in 1968-1969 in the United Kingdom. The survey took place because, in the 1960s, the needs of disabled people were at the forefront of public discussion. Earlier small-scale surveys, often undertaken by university researchers on behalf of private institutions, had drawn attention to the connection between poverty and disability. The OPCS survey built on the foundations provided by the earlier surveys. It was primarily designed to give reliable and up-to-date information about the seemingly straightforward matter of the number of disabled people in Britain. The aim of the survey was described more precisely to estimate "the number of 'handicapped' people aged 16 and over, living in private households in Great Britain". Because of the relative independence of local authorities from the central government in the United Kingdom in health matters, it was also designed "to examine what local authority health and welfare services are being made available to those people to assist them to overcome their disablement as far as possible". In any event, the survey was extended at the planning stage to cover yet other matters, such as the housing conditions of disabled people and the effect of their disablement on their ability to find suitable employment, their social life, their leisure activities and the numbers that might qualify for the new kinds of financial benefit that were being planned.

To give an idea of the wide coverage of the survey, table A-1 shows the content of the 44 tables of statistics presented in the introduction of the main survey report. The tables relate to the entire sample of people identified as "impaired" or "handicapped" in the population surveyed. Other tables not listed here relate to various subgroups of the sample. In the three volumes of the report there are 368 tables of statistics altogether. A broad categorization of these is shown in table A-2.

Table A-1. Content of basic tables in the report of the Survey of the Handicapped and Impaired in Great Britain a/

Table	Titles
1	Estimated numbers of men and women in different age groups, living in private households, who have some impairment
2	Proportion per 1,000 of men and women in different age groups, in private households, with some impairment
3	Estimated number of impaired men and women living in different areas
4	Estimated proportion of impaired men and women in regions
5	Proportion of men and women aged 65 and over in the population aged 16 and over, in different regions
6	Main cause of impairment
7	Estimates of men and women with specific diseases of the central nervous, circulatory and respiratory systems and diseases of bones and organs of movement
8	Estimated numbers and cumulative frequencies of men and women with varying degrees of handicap
9	Degree of handicap of impaired people in different age groups, and estimated numbers
10	Estimated numbers of men and women of different ages who are very severely, severely or appreciably handicapped
11	Estimated numbers of impaired persons in different areas with varying degrees of handicap
12	Proportion per 1,000 of men and women in each area who are very severely, severely or appreciably handicapped
13	State benefits received by the impaired
14	Proportion in each category of handicap who are head of household

Table A-1 (continued)

Table	Titles
15	Household composition of those in different categories of handicap
16	Household composition of the impaired aged 16 to 64 compared with those aged 65 and over
17	Mobility of those with different degrees of handicap
18	Proportion per 1,000 aged 16 and over in different areas who have limited mobility
19	Proportion of people with different degrees of mobility and handicap who are also living alone
20	Estimates of the number of handicapped men and women in different age groups living alone
21	Proportion of those with varying degrees of handicap having various walking aids
22	Proportion of people using various types of walking aids
23	Proportion of impaired people in different areas having regular general practitioner attention (elderly and non-elderly shown separately)
24	Proportion of people with varying degrees of handicap having attention from a general practitioner regularly
25	Proportion of handicapped people in different areas having regular general practitioner attention (elderly and non-elderly shown separately)
26	Frequency of regular general practitioner visits to or from the handicapped in different areas (cumulative frequencies shown)
27	When the elderly and non-elderly handicapped last saw their general practitioners (regular and non-regular visits combined)
28	When handicapped people in different areas last saw their general practitioner (cumulative frequencies shown)
29	Proportions of men and women in different age groups using drugs for their condition
30	Estimated weekly cost of drugs prescribed for those with different degrees of handicap
31	Proportion of people with different degrees of handicap who are on the local authority register (general classes)

Table A-1 (continued)

Table	Titles
32	Proportions of elderly and non-elderly men and women in different categories of handicap who are on the local authority register
33	Proportions of registered handicapped and impaired people in different age groups
34	Proportion of very severely and severely handicapped people who are registered, living alone and with others
35	Proportion of people with different degrees of handicap and mobility who are registered
36	Proportion of people with different degrees of handicap registered in different areas
37	Number of different health and welfare services helping persons with varying degrees of handicap
38	Proportion of people with different degrees of handicap receiving help from health and welfare services
39	Health and welfare services of the handicapped who are living alone
40	Household composition of handicapped people who have no health and welfare services
41	Proportion of handicapped people with different degrees of handicap benefiting from various health and welfare services who are on the local authority register, compared with the non-registered handicapped
42	Income distribution of elderly and non-elderly impaired with single incomes
43	Income distribution of elderly and non-elderly impaired with joint incomes
44	Household composition of people with single incomes of different amounts

---

a/ United Kingdom, Office of Population Censuses and Surveys, Handicapped and Impaired in Great Britain (Part I), A. I. Harris, ed. (London, Her Majesty's Stationery Office, 1971).

Table A-2. Categories of tables in the report of the Survey of the Handicapped and Impaired in Great Britain a/

Coverage of tables	Number of tables
Basic tables in introduction b/	44
"The impaired housewife"	17
Work and non-work activities	122
Work, education and qualifications	52
Housing	72
Benefits	47
Miscellaneous	14
Total	368

a/ United Kingdom, Office of Population Censuses and Surveys, Handicapped and Impaired in Great Britain (Part I), A. I. Harris, ed. (London, Her Majesty's Stationery Office, 1971).

b/ Listed in table A-1.

C. A simplified survey schedule - the United Kingdom local authority surveys

In most respects, the United Kingdom survey of 1968/1969 provides an object lesson on how a large-scale *ad hoc* survey might be conducted if sufficient resources of finance and personnel are available. Subsequent to organizing the national survey, staff of the Office of Population Censuses and Surveys prepared a first version of the guidelines mentioned in chapter III above on the conduct of sample surveys of the disabled. (24) Survey workers in developing countries will find that the revised version of the guidelines is a useful supplement to the World Health Organization (WHO)/International Epidemiological Association (IEA) booklet providing guidance on how to organize a survey in a local area, since it states clearly what can and what should not be changed to suit local conditions, knowledge or language.

The guidelines were devised so that local authorities could inform themselves of the number of chronically sick and disabled persons in their area as required by the 1970 Chronically Sick and Disabled Persons Act and subsequent legislation. In the guidelines, the recommendations for conducting a survey are divided into three stages. Stage 1 describes the postal sift mentioned above in chapter III. Stage 2 describes how the main survey questionnaire can be used to identify various at-risk groups, such as the following:

(a) The very severely, severely or appreciably handicapped (based on mobility and self-care);

(b) Those whose visual acuity is so low that vision is less than 6/24;*

(c) Those who are not able to communicate with the interviewer due to deafness, speech inadequacies or mental conditions;

(d) Children needing special care or educational facilities;

(e) Elderly people (70 or over) who are impaired, but not necessarily as handicapped as in (a) above.

Finally, in stage 3 it is shown how data on which to plan services might be collected.

Unfortunately, the task of implementing the surveys was delegated by many local authorities to workers inexperienced in the tasks required. In 45 per cent of the local authorities there were no persons with research qualifications of any kind to supervise or conduct the study. Overall, qualified researchers supervised only one quarter of the studies and wrote one fifth of the reports.

However, it is possible under certain circumstances for volunteers, such as schoolchildren, to distribute the first-stage postal questionnaire. In the carefully organized Canterbury survey described below, schoolchildren were used, but only under the close supervision of their teachers. However, published criticisms of some other aspects of the local authority studies are instructive. They have been summarized thus:

> Over a third of the problem formulations were inadequate, as were almost half of the research designs. Over half the reports were poorly presented, and a third were less than 10 pages in length. Almost two thirds of the reports had four frequency tables or less (a quarter had none) and over a half had four or less cross-tabulation tables (a quarter had none) ... Whereas half of the authorities defined "handicap" the same as in the national survey or using criteria of their own, half had no definition. (17)

Other comments draw attention to the importance of every local authority conceptualizing and operationalizing the definition of handicap in the same way. The variations between the surveys in the proportion of people identified as handicapped depended much less on geographical variability than on whether any definition of handicap at all was used. It seems that nearly all those authorities who obtained a result which differed widely from the national figure of 6.5 per cent did not specify any definitions of impairment and handicap.

The defects in local surveys demonstrate by their absence the importance of a close relationship among trained staff, good methodology and reliable and usable

---

* On a Snellen chart for testing distance vision, the line of type for "normal vision" is such that a healthy eye should easily read it at the prescribed distance of the chart, usually 6 metres. If the patient can read this line his vision is described as 6/6. On a 5-metre chart the line of type above the "normal" line should be legible at 9 metres and the line above that at 12 metres and so on. The vision of people who can only read these lines is described as 6/9, 6/12 and so on.

results. Even the excellent handbook produced by OPCS staff could not help those with no training or experience in survey work to organize a good survey.

One local authority which had the resources to undertake a well-conducted survey was the small county borough of Canterbury, which was able to obtain help from the Health Services Research Unit at the University of Kent. That part of the report of this survey which describes the way in which it was conducted emphasizes the crucial features which ensured its success. Three points from this description, which also serve to summarize the remarks regarding the conduct of disability surveys by less-experienced workers made above seem applicable in a wider context:

(a) The use of large numbers of voluntary helpers, prepared to help under supervision and trained for their tasks;

(b) Detailed and prompt checking of the quality of the work by scrutiny of all forms as they were returned to the office;

(c) Use of previously developed forms and questionnaires (although there were some adaptations to the latter). (25)

Another useful product of the Canterbury Health Services Research Unit is an interviewers' manual. (27) It was designed in the first instance for instructing interviewers taking part in a study of elderly people leaving hospital. However, the advice given can be generalized for other kinds of surveys so that it serves as an example of the kind of manual that should be produced for interviewers before a disability survey. It is essential that all interviewers, not just the relatively inexperienced, should have a manual to study before they embark on survey interviews. It should be emphasized, however, that such a manual is not a substitute for proper training and continuous monitoring by supervisors. This point was also emphasized in the World Fertility Survey.

Notes to Annex I

a/ S. B. Slater and others, "The definition and measurement of disability", Archives of Physical Medicine, No. 40 (1974), pp. 421-428.

b/ S. Z. Nagi, "Some conceptual issues in disability and rehabilitation", in M. B. Sussman, ed., Sociology and Rehabilitation (Ohio State University Press).

c/ M. W. de Kleijn-de Vrankrijker, "The physically disabled in the Netherlands - evaluation of the 1971-72 survey", International Rehabilitation Medicine, No. 2 (1980), pp. 172-176.

Annex II

EXCERPTS FROM THE INTERNATIONAL CLASSIFICATION OF IMPAIRMENTS, DISABILITIES AND HANDICAPS (46)

A. Impairment

1. Definition

In the context of health experience, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function.

(Note: "Impairment" is more inclusive than "disorder" in that it covers losses - e.g., the loss of a leg is an impairment, but not a disorder.)

2. Characteristics

Impairment is characterized by losses or abnormalities that may be temporary or permanent, and that include the existence or occurrence of an anomaly, defect, or loss in a limb, organ, tissue, or other structure of the body, including the systems of mental function. Impairment represents exteriorization of a pathological state, and in principle it reflects disturbances at the level of the organ.

3. Classification of impairments

List of two-digit categories:

1. Intellectual impairments
2. Other psychological impairments
3. Language impairments
4. Aural impairments
5. Ocular impairments
6. Visceral impairments
7. Skeletal impairments
8. Disfiguring impairments
9. Generalized, sensory, and other impairments.

B. Disability

1. Definition

In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

2. Characteristics

Disability is characterized by excesses or deficiencies of customarily expected activity performance and behaviour, and these may be temporary or permanent, reversible or irreversible, and progressive or regressive. Disabilities may arise as a direct consequence of impairment or as a response by the individual, particularly psychologically, to a physical, sensory, or other impairment. Disability represents objectification of an impairment, and as such it reflects disturbances at the level of the person.

Disability is concerned with abilities, in the form of composite activities and behaviours, that are generally accepted as essential components of everyday life. Examples include disturbances in behaving in an appropriate manner, in personal care (such as excretory control and the ability to wash and feed oneself), in the performance of other activities of daily living, and in locomotor activities (such as the ability to walk).

3. Classification of disabilities

List of two-digit categories:

1. Behaviour disabilities
2. Communication disabilities
3. Personal care disabilities
4. Locomotor disabilities
5. Body disposition disabilities
6. Dexterity disabilities
7. Situational disabilities
8. Particular skill disabilities
9. Other activity restrictions.

C. Handicap

1. Definition

In the context of health experience, a handicap is disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

2. Characteristics

Handicap is concerned with the value attached to an individual's situation or experience when it departs from the norm. It is characterized by a discordance between the individual's performance or status and the expectations of the individual himself or of the particular group of which he is a member. Handicap thus represents socialization of an impairment or disability, and as such it reflects the consequences for the individual - cultural, social, economic and environmental - that stem from the presence of impairment and disability.

Disadvantage arises from failure or inability to conform to the expectations or norms of the individual's universe. Handicap thus occurs when there is interference with the ability to sustain what might be designated as socially defined roles.

3. Classification

It is important to recognize that the handicap classification is neither a taxonomy of disadvantage nor a classification of individuals. Rather, it is a classification of circumstances in which disabled people are likely to find themselves, circumstances that place such individuals at a disadvantage relative to their peers when viewed from the norms of society. The following is a list of handicap dimensions:

1. Orientation handicap
2. Physical independence handicap
3. Mobility handicap
4. Occupation handicap
5. Social integration handicap
6. Economic self-sufficiency handicap
7. Other handicap.

References

1. Australia, Bureau of Statistics, Survey of Handicapped Persons 1981 (Canberra, 1982).

1a. Canada, Statistics Canada, Report of the Canadian Health and Disability Survey, 1983-1984 (Ottawa, 1986).

2. A. C. Davis, "Hearing disorders in the population: first-phase findings of the MRC national study of hearing", in M. E. Lutman and M. P. Haggard, Hearing Science and Hearing Disorders (London, Academic Press, 1983).

2a. Disabled Peoples' International, A Voice of our Own, Proceedings of the First World Congress of Disabled Peoples' International, held at Singapore, 30 November-4 December 1981, K. S. Miller and L. M. Chadderdon, eds. (University Centre for International Rehabilitation, Michigan State University, East Lansing, Michigan, 1982).

3. D. Duckworth, The Classification and Measurement of Disablement (London, Her Majesty's Stationery Office, 1983).

3a. Jacob Feldman, "Work ability of the aged under conditions of improving mortality", in Consequences of Mortality Trends and Differentials, Population Studies, No. 95 (United Nations publication, Sales No. E.85.XIII.3).

4. M. D. Gordon and A. J. Meadows, The Dissemination of Findings of DHSS-funded Research (Leicester Primary Communications Research Centre, University of Leicester, 1981).

4a. Lawrence Haber, "Some parameters for social policy in disability: a cross-national comparison", in Milbank Memorial Fund Quarterly; Health and Society, summer 1973, pp. 319-340.

5. India, National Sample Survey Organization, Report on Survey of Disabled Persons, thirty-sixth round, July-December 1981, No. 305 (New Delhi, 1983).

6. __________ Office of the Registrar-General and Census Commissioner, Census of India 1981, Part VIIB, The Physically Handicapped, P. Padmanabha, ed. (Delhi, Controller of Publications, 1983).

7. International Statistical Institute, World Fertility Survey, The Fiji Fertility Survey: A Critical Commentary on Administration and Methodology, M. A. Sahib and others, eds., Occasional Paper No. 15 (The Hague, 1975).

8. __________ Guidelines for Country Report No. 1, Basic Documentation No. 6 (The Hague, 1977).

9. __________ Interviewers Instructions, Basic Documentation No. 8 (The Hague, 1975).

10. __________ Strategies for the Analysis of WFS Data, Basic Documentation No. 9 (The Hague, 1977).

11. __________ *Survey Organization Manual*, Basic Documentation No. 2 (The Hague, 1975).

11a. Kenneth Manton, J. E. Dowd and Max Woodbury, "Conceptual and measurement issues in assessing disability cross-nationality; analysis of a WHO-sponsored survey of the disablement process in Indonesia", *Journal of Cross-Cultural Gerontology*, January 1986, pp. 339-362.

12. C. A. Moser and G. Kalton, *Survey Methods in Social Investigation*, second edition with supplementary bibliography (London, Heinemann, 1979).

13. Nepal, *Report on the Sample Survey of Disabled Persons in Nepal* (1980).

14. __________ Ministry of Health and World Health Organization, Blindness Prevention and Control Programme, *The Epidemiology of Blindness in Nepal* (draft) (Kathmandu, 1982).

15. Netherlands, Central Bureau of Statistics, *The Physically Handicapped* (English summary of *Gehandicapten Wel Geteid*), parts 1, 2 and 3 (The Hague, Staatsuitgeorerij, 1976).

16. New Zealand, Department of Health, *Physical Disability, Results of a Survey in the Wellington Hospital Board Area*, A. Jack and others, eds. (Wellington).

17. __________ *Trends in Health and Health Services* (Wellington, 1980).

18. L. J. Sharpe, "The social scientist and policymaking: some cautionary thoughts and transatlantic reflections", paper given at the Political Studies Association Annual Conference, Oxford, 1975.

19. A. Sonis, "The strategic approach: priorities in Holland", in *Measurement of Levels of Health* (World Health Organization, Regional Office for Europe, Copenhagen, 1979).

20. United Kingdom of Great Britain and Northern Ireland, Office of Population Censuses and Surveys, *General Household Survey, Introductory Report* (London, Her Majesty's Stationery Office, 1973).

21, 22, 23. __________ *Handicapped and Impaired in Great Britain (Part I)*, A. I. Harris, ed., *Work and Housing of Impaired Persons in Great Britain (Part II)*, J. R. Buckle, ed., *Income and Entitlement to Supplementary Benefit of Impaired People in Great Britain (Part III)*, A. I. Harris and others, eds. (London, Her Majesty's Stationery Office, 1971 and 1972).

24. __________ *Sample Surveys in Local Authority Areas*, revised edition, A. I. Harris and E. Head, eds. (London, 1974).

25. __________ University of Kent, Health Services Research Unit, *The Canterbury Survey of Handicapped People*, M. D. Warren, ed., Report No. 6 (Canterbury, 1974).

26. __________ *Handicapped People in the Community. A Survey of Agencies Reports in Canterbury*, M. D. Warren, ed. (Canterbury, 1974).

27. __________ *Interviewers' Manual* (Canterbury, 1975).

28. United Nations, Vienna Affirmative Action Plan, contained in "Report of the World Symposium of Experts on Technical Co-operation among Developing Countries and Technical Assistance in Disability Prevention and Rehabilitation", held at Vienna, 12-23 October 1981 (IYDP/SYMP/L.2/Rev.1).

29. __________ World Programme of Action concerning Disabled Persons, adopted by the General Assembly by its resolution 37/52 of 3 December 1982.

29a. __________ *Disability: Situation, Strategies and Policies* (United Nations publication, Sales No. E.86.IV.9).

30. __________ *Integration of Disabled Persons into Community Life* (United Nations publication, Sales No. E.81.IV.1).

30a. __________ *Manual on the Equalization of Opportunities for Disabled Persons* (ST/ESA/177).

31. __________ *Development of Statistics of Disabled Persons: Case Studies*, Series Y, No. 2 (United Nations publication, Sales No. E.86.XVII.17).

31a. __________ Report of the Expert Group on Development of Statistics on Disabled Persons, held at Vienna, 2-6 April 1984 (ESA/STAT/AC.18/7).

32. __________ *Handbook of Household Surveys (Revised Edition)*, Series F, No. 31 (United Nations publication, Sales No. E.83.XVII.13).

33. __________ *Principles and Recommendations for Population and Housing Censuses*, Series M, No. 67 (United Nations publication, Sales No. E.80.XVII.8).

34. __________ *Recommendations for the Preparation of Sample Survey Reports (Provisional Issue)* (United Nations publication, Sales No. E.64.XVII.17).

35. __________ *A Short Manual on Sampling, Volume 1, Elements of Sample Survey Theory*, Series F, No. 9, Rev. 1 (United Nations publication, Sales No. E.72.XVII.5).

36. __________ Department of Technical Co-operation for Development and Statistical Office, *National Household Survey Capability Programme - The Role of the NHSCP in Providing Health Information in Developing Countries*, NHSCP Technical Study No. 3 (DP/UN/INT-81-041/3).

37. __________ *National Household Survey Capability Programme - Sampling Frames and Sample Designs for Integrated Household Survey Programmes, Preliminary Version* (DP/UN/INT-84-014/5E).

37a. __________ *National Household Survey Capability Programme - Survey Data Processing: A Review of Issues and Procedures* (DP/UN/INT-81-041/1).

37b. __________ Economic Commission for Europe, Conference of European Statisticians, and World Health Organization, Regional Office for Europe, Report of the fourth joint meeting on health statistics, held in Geneva, 20-23 October 1986 (CES/AC.36/41-EURO/ICP/HST/116/41).

38. United Nations Children's Fund, Eastern Africa Regional Office, *Social Statistics Bulletin* 37, (Nairobi, 1980).

39. United States of America, National Center for Health Statistics, *Health Survey Procedure* (Washington, D.C., Department of Health, Education and Welfare, 1964).

40. M. D. Warren, "Interview surveys of handicapped people: the accuracy of statements about the underlying medical conditions", *Rheumatology and Rehabilitation*, No. 15 (1976), pp. 295-302.

41. __________ *Handicapped People in the Community; A Survey of Agencies Reports in Canterbury* (Canterbury, England, Health Services Research Unit, University of Kent, 1974).

42. P. H. N. Wood, "The language of disablement: a glossary relative to disease and its consequences", *International Rehabilitation Medicine*, vol. 2, No. 2 (1980), pp. 86-92.

43. World Health Organization, "Basic principles of surveys as part of primary health care information systems", W. Lutz, ed. (Geneva, 1982, WHO/HS/NAT.COM/82.379).

44. __________ "Common framework and format for monitoring progress in implementing the strategies for Health for All by the Year 2000" (Geneva, 1982).

45. __________ *Development of Indicators for Monitoring Progress Towards Health for All by the Year 2000* (Geneva, 1981).

46. __________ *International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relating to the Consequences of Disease* (Geneva, 1980).

46a. __________ Report of the Meeting of Principal Investigators for Testing the Classification of Impairments, Disabilities and Handicaps (ICIDH), held in Voorburg, The Netherlands, 24-28 June 1985 (DES/ICIDH/85.23).

47. __________ *Training Disabled Persons in the Community: An Experimental Manual on Rehabilitation and Disability Prevention for Developing Countries*, E. Helander, P. Mendis and G. Nelson, eds. (Geneva, 1983, DPR/80.1, Version 2).

48. __________ and International Epidemiological Association, *Planning and Organizing a Health Survey*, W. Lutz, ed. (Geneva, 1981).

49. __________ *Sampling: How To Select People, Households, Places to Study Community Health*, W. Lutz, ed. (Geneva, 1982).

كيفية الحصول على منشورات الأمم المتحدة

يمكن الحصول على منشورات الأمم المتحدة من المكتبات ودور التوزيع في جميع أنحاء العالم . استعلم عنها من المكتبة التي تتعامل معها أو اكتب إلى : الأمم المتحدة ، قسم البيع في نيويورك أو في جنيف .

如何购取联合国出版物

联合国出版物在全世界各地的书店和经售处均有发售。请向书店询问或写信到纽约或日内瓦的联合国销售组。

HOW TO OBTAIN UNITED NATIONS PUBLICATIONS

United Nations publications may be obtained from bookstores and distributors throughout the world. Consult your bookstore or write to: United Nations, Sales Section, New York or Geneva.

COMMENT SE PROCURER LES PUBLICATIONS DES NATIONS UNIES

Les publications des Nations Unies sont en vente dans les librairies et les agences dépositaires du monde entier. Informez-vous auprès de votre libraire ou adressez-vous à : Nations Unies, Section des ventes, New York ou Genève.

КАК ПОЛУЧИТЬ ИЗДАНИЯ ОРГАНИЗАЦИИ ОБЪЕДИНЕННЫХ НАЦИЙ

Издания Организации Объединенных Наций можно купить в книжных магазинах и агентствах во всех районах мира. Наводите справки об изданиях в вашем книжном магазине или пишите по адресу: Организация Объединенных Наций, Секция по продаже изданий, Нью-Йорк или Женева.

COMO CONSEGUIR PUBLICACIONES DE LAS NACIONES UNIDAS

Las publicaciones de las Naciones Unidas están en venta en librerías y casas distribuidoras en todas partes del mundo. Consulte a su librero o diríjase a: Naciones Unidas, Sección de Ventas, Nueva York o Ginebra.

Litho in United Nations, New York
00262—February 1988—3,000
ISBN 92-1-161291-8

01000

United Nations publication
Sales No. E.88.XVII.4
ST/ESA/STAT/SER.F/38