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Manual for the Development Of Statistical Information for Disability Programmes And Policies

(incorporates corrigendum)

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The term “countries and areas” as used in the text of this publication also refers, as appropriate, to territories or areas.

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PREFACE

The World Programme of Action concerning Disabled Persons 1/ was adopted by the General Assembly in its resolution 37/52 of 3 December 1982. In paragraph 198 of the World Programme, the Statistical Office, Department of International Economic and Social Affairs of the United Nations Secretariat, was urged together with other units of the Secretariat, the specialized agencies and regional commissions, to cooperate with the developing countries in evolving, inter alia, a realistic and practical system of statistical data collection. The system for collection was to be based either on total enumeration or on representative samples, as appropriate, in regard to various disabilities, and, in particular, to prepare technical manuals and documents on how to use household surveys for the collection of such statistics. These resources were to be used as essential tools and frames of reference for launching action programmes to ameliorate the condition of persons with disabilities on a world-wide basis.

In 1988 the Statistical Office completed a computerized database called "United Nations Disability Statistics Database" (DISTAT, version 1). DISTAT contains disability statistics from national household surveys, population censuses, and population or registration systems. It is the first international database of its kind and includes data from 55 nations. Basing its work upon national statistics available in DISTAT, the Statistical Office prepared in 1990 the first international compendium of disability statistics. 2/ The *Disability Statistics Compendium* provides national data on 12 major topics about people with disabilities, including age, sex, residence, educational attainment, economic activity, marital status, household characteristics, causes of impairment and special aids used.

The *Manual for the Development of Statistical Information for Disability Programmes and Policies* responds to the increasing demand for guidelines and comparable national and international disability statistics. It is written specifically for the use of programme managers and others concerned with the production and use of statistical information for implementing, monitoring and evaluating disability policies and programmes. It intends to define basic concepts such as impairment, disability and handicap and to promote progress in comparability and usefulness of information. It specifically presents and discusses the major possible sources of existing data on disability, considering also some aspects of their quality. It provides suggestions for the development of statistical information and for obtaining and using it even in especially difficult situations, such as emergency and refugee relief situations. Special

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1/A/37/351/Add.1 and Add.1/Corr.1, annex, sect. VIII, recommendation 1 (IV).

2/*Disability Statistics Compendium*, Statistics on Special Population Groups, Series Y, No. 4 (United Nations publication, Sales No. E.90.XVII.17).

attention is given to the major uses of statistical information on disability for purposes of programme planning and evaluation.

The draft *Manual* was prepared by Maureen Durkin, with the assistance of Nandini Hawley, both acting as consultants to the Statistics Division of the Department for Economic and Social Information and Policy Analysis of the United Nations Secretariat, and in collaboration with the Rehabilitation Unit of the World Health Organization. The *Manual* was revised based upon a review by the United Nations Expert Group Meeting on the Development of Impairment, Disability and Handicap Statistics, hosted by Statistics Netherlands and held in Voorburg, Netherlands, 7-11 November 1994 (the report of the Expert Group Meeting is contained in document ESA/STAT/AC.47/6).

Support for the *Manual* was provided by the Swedish International Development Authority (SIDA).

Comments and suggestions concerning the *Manual* are welcome. They should be addressed to the Director of the Statistics Division, DC2-1420, Statistics Division/DESIPA, United Nations, New York 10017, United States of America.

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INTRODUCTION

Many nations are beginning to recognize the rehabilitation needs and civil rights of people with disabilities as well as the impact of impairment, disability and handicap* on national indicators of health, education and economic prosperity. Consequently, policy makers, planners and programme managers in all sectors are requesting information in these areas. Informational needs range from basic counts of the number of people with disabilities in the population to material on complex issues such as the differences in quality of life between people with and people without disabilities.

In recent decades, the collection of data and the production of statistical information on topics relevant to rehabilitation and disability have proliferated. A myriad of programmes administering rehabilitation services to people produce statistical information based on administrative data. In addition, national census and survey programmes within different government sectors are producing increasing amounts of information on impairment, disability and handicap.

Unfortunately, in many instances the information produced fails to meet the needs of policy-making and programme development and evaluation. A major reason for this is that much of the current statistical information is produced without the benefit of a common terminology or standard procedures and guidelines. Consequently, elements of information from various sources are rarely comparable. In addition, the quality, completeness and detail of existing statistical information on impairment, disability, or handicap often fall short of what is required to answer important policy questions or to address specific programme planning needs.

The present manual is intended to provide background information and suggestions for a more systematic approach to data collection and development of statistical information related to disability. The aim is to promote progress in the comparability and usefulness of information. The emphasis is on quantitative data and statistical information. The manual was written specifically for programme managers producing and using statistical information to implement, monitor and evaluate disability policies and programmes. It defines key terms and concepts in the field and describes methods for obtaining and using the relevant statistical information.

- Programme managers often have very basic questions calling for statistical information on topics related to disability and rehabilitation. The most basic question commonly asked is: **How many people with disabilities are there in the population?**

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* The terms impairment (reduced function of an organ or body part), disability (reduced function and activity of a person) and handicap (the social, economic and cultural circumstances that place persons with impairment or disability at a disadvantage relative to their peers) are used here in accordance with definitions given in the *International Classification of Impairments, Disabilities and Handicaps*. 1/

Before this question can be answered, decisions must be made about how disability will be defined and measured and what methods used to count or estimate the number of people with disabilities.

- Few users of statistical information on disability, however, would be satisfied with knowing only the total number of people affected. Once the basic question is answered, a host of additional questions arise. For example, planners of rehabilitation programmes will need to know: **What kinds of disability do people in the population have, and how frequent is each kind?**

- To target services appropriately, they will also need to know: **How does the frequency or prevalence of disability vary by age group, gender and geographical area?**

  By computing the prevalence of disability in different geographical areas of a country (using a common definition of disability and common methods), one might find that some areas have higher prevalence rates than others; these areas should be targeted by rehabilitation programmes.

- In health planning, an example of a question that might be asked is: **How many people with disabilities are without access to the special appliances or aids that they need?**

  To answer this question, one must define "special appliances or aids", identify the population of interest (people with disabilities who need special appliances or aids) and determine who, within the population of interest, does not have access to needed appliances or aids.

- In education, planners might ask: **What percentage of school-age children with disabilities are in school?**

  For this question, the population of interest (the denominator) is the number of children of school age who have disabilities, including both those in school and those not in school; the numerator includes only those children of school age with disabilities who do attend school. To interpret the answer to this question, one would need to compare the figure obtained with the percentage of school-age children without disabilities who are in school. This requires filling in the following table with information about all children of school age in the population.

	Number of school-age children	Percentage attending school
With disability		

With no disability

- In the labour sector, an example of one question that might be asked is: **What percentage of adults with disabilities are economically active, and how does this compare with the percentage for other adults?**

  For this question, the population of interest (the denominator) includes all adults, with and without disabilities. To answer the question, the nature of disability and economic activity must be defined and ascertained. Standard and internationally accepted definitions of, and methods of ascertaining, the status of economic activity have been developed (described in the United Nations *Principles and Recommendations for Population and Housing Censuses*). 2/ Comparable definitions and methods have yet to be developed for disability; the *International Classification of Impairments, Disabilities, and Handicaps*, 1/ described in chapter I and currently under revision, is a preliminary attempt to define and classify impairment, disability and handicap.

- Within the ministry or department of social welfare, planners may ask: **How many people with disabilities receiving social services require full-time care from a family member or other person?**

  The answer to this question is critical to understanding the full economic impact of disability. The question cannot be answered without systematic information on the number of people with disabilities in the population and the extent to which they depend on others for care.

- The National Council on Disability in a country may wish to know of the barriers faced by persons with disability. It may ask: **Can people with disabilities use public transport available to others? If not, what are the reasons that they cannot use it?**

  Answers to these questions are necessary for knowing how environments must be further adapted to include persons with disabilities. Ramps, elevators, Brailling of instructions for transportation, and alternative seating arrangements on public transportation are examples of modifications that may be made.

This manual is intended to assist managers in producing and making use of statistical information in order to address questions such as those highlighted above. It is increasingly recognized that statistics on impairment, disability and handicap (IDH) should support policy-related issues. IDH data often have multiple purposes: national surveillance; monitoring opportunities for work, education, health care, and independent living; assessing social security systems; determining disability benefits; setting priorities for prevention programmes for primary health care, and maternal and child health; and preventing injury.

National statistical workshops and seminars can be used to increase the awareness of government offices and policy makers of the usefulness of impairment, disability and handicap statistics for policy formulation, programme planning and implementation.

Overview of subsequent chapters

Chapter I	Provides background information on four trends that have emerged in the development of disability statistics. It also defines basic concepts such as impairment, disability and handicap.
Chapter II	Describes the major sources of existing data and statistical information on disability and discusses attributes to consider in appraising their quality.
Chapter III	Provides an overview of approaches to data collection within the field of disability; this information is important to consider when collection of additional data is necessary.
Chapter IV	Discusses the major uses of statistical information on disability for programme planning and evaluation.
Chapter V	Discusses the acquisition and uses of information on disability in especially difficult situations, such as emergency and refugee relief situations.

I. BACKGROUND AND DEFINITIONS

A. The emerging four trends

Four trends in disability policy have brought about the need for the present manual:

(a) Trend 1: Recognition of the human rights of people with disabilities;

(b) Trend 2: An expansion of community-based rehabilitation (CBR) services for people with disabilities;

(c) Trend 3: The development of a standard terminology and of an internationally recognized system for defining and classifying the consequences of disease processes and injuries. These consequences are seen as being present at:

(i) The level of the organ or body part (for example, brain, spinal cord, limb or other body part): impairment;

(ii) The level of the person (for example, in learning, speaking, walking or other activity): disability;

(iii) The level of interaction of persons with society or the environment (for example, family relations, occupation or other social relations): handicap;

(d) Trend 4: A rapidly increasing demand for information and survey research in the expanding field of rehabilitation and human functioning. This fourth trend is accompanied by major advances in computer technology which will enable larger and more complex information systems.

The present chapter provides an overview of each of the four major trends mentioned above.

1. Trend 1: Recognition of the human rights of people with disabilities: recent initiatives

- 1975 The United Nations formally recognized the need to protect the rights of persons with disabilities, with the proclamation by the General Assembly, in its resolution 3447 (XXX) of 9 December 1975, of the Declaration on the Rights of Disabled Persons.

- 1982 The World Programme of Action concerning Disabled Persons (adopted by the Advisory Committee on the International Year of Disabled

Persons at its fourth session, Vienna, 5-14 July 1982, and contained in document A/37/351/Add.1 and Add.1/Corr.1, annex, sect. VIII, recommendation 1 (IV)) was adopted by the General Assembly in its resolution 37/52 of 3 December 1982. In that resolution, the Assembly (along with a number of individual nations in their policies) formally recognized the rights of disabled persons to equal opportunities, full participation in economic and social activities, and equal access to health, education and rehabilitation services.

The objectives of the World Programme of Action concerning Disabled Persons are:

(a) To promote effective measures for the prevention of impairment, disability and handicap;

(b) To extend rehabilitation services to all in need;

(c) To achieve the goals of equal opportunities and full participation for all people with disabilities.

Prevention of impairments is to be achieved through:

(a) Avoidance of war;

(b) Improvement of the educational, economic and social status of the least privileged groups;

(c) Identification of types of impairment and their causes;

(d) Improved nutritional practices;

(e) Early detection and prompt treatment of medical problems;

(f) Health education;

(g) Protection from environmental hazards.

Strengthening of rehabilitation is to be achieved by:

(a) Respecting the individual strengths, abilities and integrity of people with disabilities;

(b) Using resources within families and communities of people with disabilities in order to implement rehabilitation;

(c) Providing rehabilitation services whenever possible within the natural environment, with backup support when necessary from referral agencies and institutions;

(d) Integrating rehabilitation services with other services to increase their accessibility.

Equalization of opportunities is to be achieved through:

(a) The extension to people with disabilities of the same opportunities enjoyed by people with no disability for:

(i) Education;

(ii) Employment;

(iii) Participation in social and political groups, religious activities, intimate relationships and family life;

(iv) Access to housing, financial and personal security, and public facilities;

(v) Freedom of movement.

The adoption of General Assembly resolution 37/52 is an indication of recent gains in worldwide recognition of disability, as well as an impetus for nations and communities throughout the world to include disability in their agendas for socio-economic development and to provide improvements in the quality of life of disabled persons.

- 1993 The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities were adopted by the General Assembly in its resolution 48/96 of 20 December 1993. These rules, contained in the annex to that resolution, provide a basis for international cooperation and an instrument for policy-making and action for persons with disabilities (box I.1). Several countries have responded to the above-mentioned Assembly resolutions by passing national legislation with goals similar to those of the World Programme of Action concerning Disabled Persons.

Box I.1. Summary of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities

Rules 1-4: Preconditions for equal participation

1. Awareness-raising and public education
2. Medical care
3. Rehabilitation
4. Support services

Rules 5-22: Target areas for equal participation, and implementation measures

5. Accessibility
6. Education
7. Employment
8. Income maintenance and social security
9. Family life and personal integrity
10. Culture
11. Recreation and sports
12. Religion
13. Information and research
14. Policy-making and planning
15. Legislation
16. Economic policies
17. Coordination of work
18. Organizations or persons with disabilities
19. Personnel training
20. National monitoring and evaluation of disability programmes in the implementation of rules
21. Technical and economic cooperation
22. International cooperation

2. Trend 2: Community-based rehabilitation (CBR)

Community-based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities.

CBR is implemented through the combined efforts of people with disabilities, their families and communities, and the appropriate health, education, vocational and social services.

Prior to the 1980s, formal rehabilitation was provided primarily by professional staff based in hospitals or institutions, where people with disabilities were often segregated from the rest of society. Today, model services for people with disabilities are community-based and emphasize integration into all aspects of society; they also aim towards the enhancement of functional abilities and the provision of improved access to rehabilitation. CBR and other models are being developed and implemented to extend appropriate rehabilitation services to a wider population and to involve the larger community in rehabilitation planning. Successful CBR programmes emphasize the role of persons with disabilities, and their families and communities, in the rehabilitation process. CBR also includes the development of a system of referral services provided through health, education, social and vocational programmes. In addition, CBR programmes promote the equalization of opportunities through the removal of physical and social barriers that prevent the participation of people with disabilities in education, work or social activities. A goal of CBR is community adaptation and modification to facilitate the inclusion of persons with disabilities in daily living.

In a CBR programme, people with disabilities and their families are responsible for carrying out training activities to increase self-care, communication and mobility. Communities are responsible for becoming more open and adaptable to the needs of persons with disabilities and for providing opportunities for employment and vocational training. Children with disabilities attend the local school. Community leaders work to remove barriers to social integration. A community worker is available to provide basic information and guidance for these activities. Rehabilitation personnel provide information to community members so that they understand the causes of disability and alternative ways in which communities can provide rehabilitation services and social integration.

The community does not work alone for the rehabilitation of its members. Skilled training procedures or equipment or appliances not available within the community may be provided through referral services. Personnel from health, education, social and vocational referral services also provide training and information for the community rehabilitation worker, who works directly with people with disabilities and their families.

The World Health Organization (WHO) has developed a manual consisting of training modules and guidelines to assist with the process of developing, implementing and evaluating a CBR programme. 3/

CBR programmes collect information about people with disabilities that is needed for programme planning, monitoring and evaluation. This is discussed in the final section of this chapter, which concerns information systems.

3. Trend 3: Definition and classification of impairment, disability and handicap

Lack of agreement on concepts and terms has long limited the development of disability statistics at the national and international levels. In 1980, WHO issued the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH). 1/ This classification was developed to facilitate the collection of essential statistical information for policy and programme development and for evaluation. ICIDH is currently being revised and efforts are under way to achieve the implementation of common definitions. A goal of ICIDH is to replace the unstandardized and often pejorative terms used to refer to people with disabilities with more precise, objective and internationally recognized terminology. This, in turn, should allow a more scientific approach to the collection and use of statistical information on this subject.

ICIDH is analogous in some ways to the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10), tenth revision, 1992, 4/ which is also published by WHO and used throughout the world to classify and code mortality and morbidity data (that is, cases of diseases and injuries resulting in medical care and/or death). ICIDH provides a system for categorizing and coding not diseases and injuries themselves, but rather the long-term consequences of diseases and injuries in terms of impairment, disability and handicap. Table I.1 provides a summary of the ICIDH concepts with examples of each of them.

Table I.1. Summary of ICIDH concepts with examples

Impairment (organ, body part)	Disability (person)	Handicap (societal level)
Amputated leg	Walking limitations	Unemployment
Partial sight	Difficulty in reading the printed page	Inability to attend school
Loss of feeling in fingers	Difficulty in grasping or picking up small objects	Underemployment
Paralysis of arms and legs	Limited movement	Homebound state
Impaired voice function	Limited ability to speak	Social isolation
Hearing loss	Difficulty in understanding speech	Reduced interaction
Mental retardation	Slow learning	Social isolation

A survey of impairment, disability and handicap may aim, for example, to estimate the number of persons with impairments or disabilities or who experience handicap. Surveys vary according to which concepts they cover. A survey of the three components casts a broad net so that policy makers and analysts can distinguish subpopulations for the purposes of planning and implementing programmes. Table I.2 provides a summary of the major categories and one-digit codes of ICIDH. The ICIDH manual provides two-digit codes to present information that is more detailed and specific.

Table I.2. Summary of ICIDH concepts and categories

Concept	One-digit category
Impairment (I): organ or body-part level	1. Intellectual
	2. Other psychological
	3. Language
	4. Aural
	5. Ocular
	6. Visceral
	7. Skeletal
	8. Disfiguring
	9. Generalized, sensory, and other
Disability (D): personal level	1. Behaviour
	2. Communication
	3. Personal care
	4. Locomotor
	5. Body disposition
	6. Dexterity
	7. Situational
	8. Particular skill
	9. Other activity restrictions
Handicap (H): societal level	1. Orientation
	2. Physical independence
	3. Mobility
	4. Occupation

5. Social integration

6. Economic self-sufficiency

7. Other

Source: WHO, *International Classification of Impairments, Disabilities, and Handicaps* (Geneva, WHO, 1980).

To further convey the distinction between impairment, disability and handicap, as well as the nature of the classification of these phenomena, three additional examples are given below. For each ICIDH code used, a complete explanation of the code is available in ICIDH. For example, disability code #40 (Walking disability), as defined in ICIDH, includes the measurement or assessment of ambulation on flat terrain; it excludes negotiation of discontinuities in terrain (d codes 41-43). Such a specific description allows for relatively accurate and measurable comparisons of human behaviour across surveys and across time.

A missing lower leg (Impairment code 75.6, "Transverse deficiency of lower leg") will most likely result in locomotor disability or restricted ability to walk (Disability code 40) if there is no access to technical aids or prostheses. Access to effective rehabilitation and proper fitting of a prosthesis can greatly reduce the severity of this disability. An associated handicap might include exclusion from school and other social activities (Handicap code 4, "Occupation"), restricted employment opportunities (Handicap code 4, "Occupation"), and restricted opportunities to marry or engage in recreational, religious and other activities (Handicap code 5, "Social integration"). The degree of handicap would depend both on the severity of disability and on the attributes of the social and physical environment. In an environment where the rights of people with walking disabilities are respected and where there are ample ramps, access to prosthetic devices and other alternatives to climbing stairways and platforms, walking disability may result in minimal or no handicap.

Brain dysfunction is an impairment that may be the consequence of an injury. More specifically, the impairment may be mental retardation (Impairment codes 10-13), which can result, for example, in a self-awareness disability (Disability code 10) or a disability in talking (Disability code 21). Here again, the level of disability and handicap can be modified by access to rehabilitation and according to various attributes of the social and physical environment.

A disease or injury that affects the eye may result in low vision (Impairment code 53.2). This might result in a seeing disability such as difficulty in seeing over long distances (Disability code 27, "Other disability in seeing and related activities"), or in a different type of disability such as difficulty in climbing stairs (Disability code 42, "Climbing stairs disability"). Access to corrective lenses might prevent disability in the presence of impairment. A handicap may result if a person is dismissed from his or her job on the assumption that reduced vision will make it impossible for that person to perform his or her work.

Survey results throughout the world show that people who have impairments and/or disabilities often find themselves in circumstances that are handicapping and that result in social disadvantage entailing low literacy levels, fewer employment opportunities, reduced access to public buildings and transport, higher rates of institutionalization, and social isolation and rejection. 5/, 6/ Measurement and assessment of handicap can be included in surveys and other data-gathering efforts.

Much of the description of handicap in surveys is achieved through the direct comparison of population groups. Handicap may be assessed in terms of differences between people with and people without disabilities, by indicators such as social isolation, unemployment and illiteracy. For example, if 80 per cent of the population with disabilities and 10 per cent of the total population were socially isolated, the gap between people with and people without disability might be viewed as large and the social integration handicap severe among persons with disability.

Modern statistics on disability may be collected and reported with the ICIDH categories and terminology in mind. For implementation of CBR, information is needed, particularly on the dimensions of disability and handicap; information on impairment may also be useful. It should be kept in mind that handicap is due to the interaction of disability and barriers in the social and physical environment; its measurement may thus require information on each of these elements. Social barriers include attitudes and policies that are against inclusion of people with disabilities within various contexts. Physical barriers include inaccessibility of public and private places and transportation to people in wheelchairs, and lack of information services for people with vision and hearing disabilities. For planning and evaluation of policies, information is needed on the presence of these barriers as well as on the frequency of impairments, disabilities and handicaps. Future collection of statistical information in accordance with the concepts of ICIDH will also help to identify gaps and practical problems of the system and help future efforts to improve the ICIDH system.

Current work in the WHO/ICIDH revision process encompasses broadening the three concepts to include the full range of possibilities, both positive and negative, thus reducing value judgements made about any particular state. The revised ICIDH may refer to:

(a) Anatomical structure and organ function to describe impairment;

(b) Ability and activity to describe disability;

(c) The process of accommodation resulting from interactions between people and their social, economic and cultural environments to describe handicap.

These same explanations could guide the work of survey research in seeking descriptions of impairment, disability and handicap experiences.

4. Trend 4: Development of statistical information and survey research

The *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, adopted by the General Assembly in 1993 (resolution 48/96), state that States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities (sect. III, rule 13). The Standard Rules call for the promotion of comprehensive research on all aspects of the subject, including obstacles that affect the lives of persons with disabilities, through the use of national censuses and household surveys and database development. States are asked, at regular intervals, to:

(a) Use national censuses and household surveys to collect statistical information concerning the living conditions of persons with disabilities;

(b) Consider establishing a data bank on disability to produce statistical information on available services and programmes as well as on the different groups of persons with disabilities, with proper respect for privacy and personal integrity;

(c) Support programmes of research on the causes, types and frequencies of disabilities, the availability and efficacy of existing programmes and the need for development and evaluation of services and support measures;

(d) Adopt terminology and criteria for the conduct of surveys in cooperation with organizations of persons with disabilities;

(e) Facilitate the participation of qualified persons with disabilities in data collection and research;

(f) Support the exchange of research findings and experience;

(g) Take measures to disseminate information on disability to all political and administrative levels within national, regional and local spheres.

Various national statistical offices have begun to focus on informational needs with respect to impairment, disability and handicap.

With policies in place such as the Standard Rules and the World Programme of Action concerning Disabled Persons, statistical offices in all nations are being called upon to provide useful statistics on disability, handicap and related topics so that compliance with policies and the effects of policies can be monitored. Measures are specifically needed on:

(a) Nature, frequency and population distribution of impairments, disabilities and handicaps;

(b) Exposure to risk factors for impairments;

(c) Interventions of prevention programmes and adherence to preventive measures;

(d) Access to, and use of, rehabilitation services by persons with disabilities and their families;

(e) Improving resources for rehabilitation;

(f) Reducing barriers to full participation by people with disabilities.

Monitoring of the Standard Rules has begun at the international level through the development and use of the United Nations Disability Statistics Database (DISTAT), completed in 1988. DISTAT monitors national statistical information covering the Standard Rules and the way in which the relevant topics are being covered is presented in table I.3 below. Similar data-collection and analysis systems are increasingly being developed at the national level for proper monitoring and evaluation of national rehabilitation programmes.

In table I.3, the topics of DISTAT and the particular Standard Rule with which they are associated have been placed side by side. The current procedure in the Statistics Division of the United Nations is to work with existing national statistics and to see how much can be learned from them, while simultaneously preparing procedures for their future improvement.

Table I.3. Topics of DISTAT associated with any particular Standard Rule

Standard Rule	Topic of DISTAT mirroring national data being compiled on disability
	Area 1. General description of the census or survey methodology in each data source
Rule 1. Awareness-raising	Table 1. Censuses and surveys having a question indicating disability status
Rule 2. Medical care Rule 3. Rehabilitation Rule 4. Support services	Table 21. Services or treatment received, by impairment and disability status, age group and sex
Rule 5. Accessibility	Table 20. Aids and/or personal assistance used for reducing disabilities, by impairment and disability status, age group and sex
	Area 3. Assessing the equalization of opportunities
Rule 6. Education	Table 8. Educational attainment and current school attendance, by impairment and disability status, age group and sex
Rule 7. Employment	Table 9. Economic activity, by impairment and disability status, age group and sex
	Table 10. Occupation, industry, employment and status of the not economically active population, by impairment and disability status and sex
Rule 8. Income maintenance and social security	Table 14. Household and personal income, by impairment and disability status, age group and sex
	Area 4. Social integration, household and family membership
	Area 6. Other special topics
Rule 11. Recreation and sports Rule 5. Accessibility	Table 22. Examples of special topic tables based on national data collection, including tables on social isolation, community attitudes towards disability and persons with disability, transportation and problems encountered in the home (data file)

Standard Rule	Topic of DISTAT mirroring national data being compiled on disability
Rule 13. Information and research	Table 2. Sources of data for censuses and surveys having a question indicating disability status

		Table 3. Country classifications and International Classification of Impairments, Disabilities and Handicaps (ICIDH) codes used in disability cross-tabulations for censuses and surveys having a question indicating disability status
Rule 13.	Information and research	Table 6. Impairment and disability status of population by age group and sex
		Table 7. Urban/rural residence by impairment and disability status, age group and sex
		Area 5. Describing the disability experience
Rule 13.	Information and research	Table 15. Presence of an additional impairment and/or disability, by impairment status, age group and sex
		Table 16. Age at onset of impairment, by impairment and disability status, age group and sex

Below is a summary figure derived from table I.1 in *Disability Statistics Compendium* 5/ showing the extent to which statistics and information on the various Standard Rules were covered by countries entered into the first round of DISTAT.

From this graph it may be seen that censuses focus mostly on topics such as age group, sex, urban/rural differences, educational attainment, economic activity and occupation, industry and employment (A1-A5). Few censuses collect data on the disability experience topics. Surveys, on the other hand, tend to cover a broader range of the Standard Rules disability topics. The most common disability experience data found in surveys are on cause of impairment, severity of impairment/degree of disability, services/treatment received and special disability issues. Future surveys may provide an opportunity to broaden the coverage of Standard Rules topics.

The Statistics Division of the United Nations continues to search through national data sets to see if they include statistical information related to the topics selected. If they do, it is entered into DISTAT. If not, the table remains blank for the particular country concerned. Similar data compilation activities, based upon DISTAT, may be completed at the national level, compiling all existing data sets meaningfully into a database to support monitoring of the policies and procedures of rehabilitation, equalization of opportunity and prevention activities at the national level.

One set-back in the development of DISTAT is that, because there is no recommended minimum data set for countries to use, all the individual reports or studies must be gleaned for their statistical data on impairment, disability and handicap and then be placed in some logical order through the use of the World Programme of Action concerning Disabled Persons, the Standard Rules and ICIDH, before their results can be compared. This activity is further complicated because there are currently few analysts or research centres using these data for the necessary production of estimates and the smoothing out of crude results through the use of statistical techniques.

In the future, it is likely that countries will encourage the United Nations to develop procedures for providing a basic minimum data set for worldwide use, subject to the preparation of guidelines and recommendations for the inclusion of the topic of disability in national population censuses, household surveys and administrative registries. Such a minimum data set would increase the comparability of national and community-level data and also would provide better standardized national data for inclusion in DISTAT.

Several countries have responded to General Assembly resolutions by passing national legislation with goals similar to those of the World Programme of Action concerning Disabled Persons and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. National monitoring of these topics will become increasingly important to policy makers and programme planners.

B. Putting policies and concepts into a common framework

In order to develop a common framework, those undertaking censuses and surveys are encouraged to use the WHO *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) as a standard reference and to use the concepts included in the World Programme of Action concerning Disabled Persons, specifically relating to the goals of prevention, rehabilitation and equal opportunity. This approach conceptually links policies for reducing impairment, disability and handicap with the three major goals of prevention, rehabilitation and equalization of opportunity in order to address a broad spectrum of policy and research topics (see also *Disability Statistics Compendium*, chap. I).

Governments and countries that have referred to the World Programme of Action concerning Disabled Persons and recognized the language of ICIDH generally propose the following concepts and topics for inclusion when designing their database:

(a) Impairments for the study of prevention;

(b) Disability for planning programmes in rehabilitation;

(c) Handicap for assessing human rights and equalization of opportunity.

Table I.4 below indicates how the three WHO/ICIDH components and the three United Nations goals complement each other. Shaded cells show the orientation of the main activities of prevention, rehabilitation and equalization-of-opportunity programmes.

Table I.4. Survey strategy for monitoring disability programmes and policies

	World Programme of Action concerning Disabled Persons		
ICIDH	Prevention	Rehabilitation	Equalization of opportunities
Impairments	I_p	I_r	I_e
Disabilities	D_p	D_r	D_e
Handicaps	H_p	H_r	H_e

The table provides a simplified description of survey strategy for monitoring disability programmes. Essentially, people with disabilities are identified through the description of impairments and disabilities. Programmes are planned and implemented to reduce impairments through the prevention of disease and accidents and through the general study of the cause of impairments, as well as through medical and health care for reduction in loss of function (cells I_p and I_r). An inoculation campaign for the prevention of infectious diseases, such as poliomyelitis, is an example of an impairment prevention programme (cell I_p); to the extent that such a programme aims to immunize the total population regardless of ability to pay, it is also an example of an equalization-of-opportunities programme (I_e). In other words, it is an equal-opportunity programme to increase access to preventive services for the reduction of impairments. Programmes are also planned and implemented that aim to reduce disabilities through early intervention and physical therapy, or that attempt to reduce barriers for persons with disabilities through the production and distribution of special aids to increase the mobility, the vision or the communication possibilities of such persons (cells D_r and D_e).

Prevention of handicaps, as shown in cell H_p, would involve working to reduce factors that isolate persons with disabilities (lack of services, negative community attitudes, prejudice towards persons with disabilities), whereas rehabilitation goals (cell H_r) might be to increase opportunities for independent living, community-based rehabilitation programmes, modified transport arrangements, public media programmes, and so on, so as to reduce the above-mentioned negative influences. Equalization-of-opportunity programmes addressing handicaps (cell H_e) would concentrate on organizing opportunities for full participation and integration of persons with disabilities as national and international citizens.

Chapters II through V of this manual provide suggestions and examples for collecting and using statistics on these topics.

II. REVIEW AND APPRAISAL OF EXISTING STATISTICAL INFORMATION

A. Review of existing data

The present chapter provides an overview of the major sources of existing statistical information that can be searched to develop a profile of a population with respect to impairment, disability and handicap. Such profiles help identify priorities for rehabilitation programmes and policies. Readers are encouraged to seek, evaluate and use existing information to the extent possible before initiating new data-collection efforts on these topics.

The following are some examples of profiles developed from existing sources of data in two countries, namely Mauritius and Viet Nam.

Example 1:

> In Mauritius, community-based rehabilitation (CBR) programme records in 1990 showed that approximately 400 Mauritius residents had received CBR services. According to social security statistics, on the other hand, 14,000 residents received disability pension benefits that year. Both these figures were much lower than those from the 1990 national population and housing census which showed that 27,852 people or 2.6 per cent of the population had been identified as having a disability and that about 10 per cent of households reported at least one member with disability. 7/, 8/, 9/, 10/ Thus, the 400 residents who had received CBR services represented less than 2 per cent of the total number identified by the census as having disabilities. The 14,000 residents receiving disability pension benefits were only half of the total number reported by the census as having disabilities.

Example 2:

> In Viet Nam, census data show chronic illness and disability to be an important cause of not being economically active. Retirement and being a full-time student are other causes. Approximately 22 per cent of not economically active adults have a disability, and approximately 5.7 per cent of the total population aged 13 years or over are both not economically active and possessed of a disability. 9/, 11/ Information is not available from the census on the frequency of disability in economically active persons or among children aged 13 or under.
>
> Survey data from parts of Viet Nam show that in some Vietnamese communities, loss of a limb (amputation) is considered a major impairment in terms of warranting rehabilitation planning. Because such surveys only cover one type of impairment, the importance of

amputation relative to other impairments cannot be determined. According to a survey reported in 1992 of communities in four provinces, the highest prevalence of amputation was observed in Danang province, where it is estimated that 5.4 of every 1,000 persons in the population have lost a limb. Most of the amputations are war-related (77 per cent); involve men (81 per cent); affect the age group 15-59 (84 per cent); and involve civilians (62 per cent). Among 737 persons with amputated limbs interviewed in Qui Nhon province, more than 50 per cent were in need of artificial limbs, more than two thirds were in need of crutches or wheelchairs, and one third were in need of physical therapy. Information on economic activity and disability among residents of Viet Nam who had lost a limb was not collected in the survey. 11/

Notes of caution

- When using existing published reports, keep in mind that the terms "impairment", "disability" and "handicap" as well as others are often used interchangeably, or in ways that differ from ICIDH definitions as laid out in chapter I. When these terms are referenced, it cannot be assumed that they correspond to concepts and definitions of ICIDH. Users of existing data must find out how the data were collected, how questions were worded, and what definitions and criteria were used, before they can know whether a particular example pertains to impairment, disability or handicap.

- National studies show large variations in reported prevalence rates of disability, ranging from 0.2 to 20.9 per cent. The high degree of variation in prevalence is due in part to differences in the types of definitions and categories regarding impairment and disability used in different countries, and even by different agencies within a country.

  It has been shown that surveys identifying people who have mainly severe impairments such as total blindness, complete deafness, serious mental retardation and loss of a limb result in low overall prevalence rates (ranging from 0.2 to 5 per cent of the population). Surveys identifying persons with disabilities through broad questions about difficulty with respect to seeing, hearing, moving from room to room, climbing stairs, and other activities, result in higher prevalence rates (ranging from 8 to 17 per cent of the total population) (see chap. II, subsection A.3 of the *Disability Statistics Compendium*). Some surveys begin by identifying all persons with a disability experience that is broadly defined, such as difficulty seeing even when wearing corrective lenses. Among persons who report having a disability, further probe questions about their personal experience with specific and severe impairments may then be asked. This approach uses both disability and impairment concepts to identify the population of concern.

In reviewing existing data, it is important to identify what was measured (for example, impairment, disability) and to be aware that the prevalence rates and numbers and types of persons identified will differ accordingly. Table II.1 and figure II.1 illustrate how the concepts used influence the resultant prevalence rates.

Table II.1. Prevalence rates of impairment and disability per thousand population by age group and sex

ICIDH concepts used	Country or area	Data-collection year and type	Age group	Impairment/disability rate		
				Both sexes	Males	Females
	IMPAIRMENT (I)					
I	Qatar	1986(C)	All ages	1.7	1.3	2.6
I	Egypt	1976(C)	All ages	3.0	4.4	1.6
I	Bulgaria	1989(R)	16 or over	3.5	4.1	2.9
I	Singapore	1985(S)	All ages	3.9	a/	a/
I	Kuwait	1980(C)	All ages	4.4	5.0	3.5
I	Pakistan	1981(C)	All ages	4.5	3.8	5.3
I	Sri Lanka	1981(C)	All ages	4.9	5.8	4.0
I	Bangladesh	1986(C)	All ages	5.2	6.2	4.1
I	South Africa	1980(C)	All ages	5.5	6.0	5.1
I	Thailand	1986(S)	All ages	7.3	8.5	6.1
I	Hong Kong	1981(C)	All ages	8.4	0.0	0.0
I	Iraq	1977(C)	All ages	9.3	11.2	7.2
I	Syrian Arab Republic	1981(C)	All ages	10.2	12.3	8.0
I	Panama	1990(C)	All ages	13.4	14.8	11.9
I	Turkey	1985(C)	All ages	13.7	16.7	10.6
I	Zambia	1980(C)	All ages	16.2	16.7	15.6
I	Bahrain	1981(C)	All ages	17.0	10.8	8.7
I	Comoros	1980(C)	All ages	17.0	19.4	14.6
I	Brazil	1981(C)	All ages	17.2	a/	a/
I	Cyprus	1982(C)	All ages	22.0	24.0	20.1
I	Botswana	1991(C)	All ages	22.4	a/	a/
I	Mauritius	1990(C)	All ages	26.4	27.7	25.0
I	Japan	1987(S)	18 or over	26.7	a/	a/

ICIDH concepts used	Country or area	Data-collection year and type	Age group	Impairment/disability rate		
				Both sexes	Males	Females
I	Mali	1987(C)	All ages	27.5	29.4	25.6
I	Netherlands Antilles	1981(C)	All ages	28.6	32.6	24.9
I	Malawi	1983(S)	All ages	29.0	a/	a/
I	Hungary	1988(S)	16 or over	34.0	25.6	41.2
I	China	1987(S)	All ages	49.0	48.5	49.4
	DISABILITY (D)					
D, I	Germany	1991(R)	All ages	84.0	94.0	75.0
D	United States	1990(S)	16-64	89.6	93.7	85.6
D, I	Poland	1988(C)	All ages	98.6	94.0	103.0
D, I	Netherlands	1986(S)	5 or over	115.0	94.0	136.0
D, I	Sweden	1988(S)	16 or over	120.0	106.0	135.0
D	New Zealand	1980(S)	15 or over	130.0	a/	a/
D	Canada	1986(S)	All ages	132.4	127.0	137.5
D, I	United Kingdom	1986(S)	16 or over	142.0	121.0	161.0
D, I	Spain	1986(S)	All ages	149.8	133.4	165.4
D, I	Norway	1991(S)	16 or over	a/	140.0	220.0
D, H, I	Australia	1988(S)	All ages	156.0	160.0	152.0
D	Finland	1986(S)	15 or over	170.0	130.0	200.0

Source: DISTAT.

Note: C stands for census; R for registration; and S for survey.

a/ Data unavailable.

Some general sources of existing statistical information relevant to impairment, disability and handicap are:

(a) Administrative data: including from social security, CBR programmes, special education, health offices, and other sources;

(b) Censuses and surveys: including population and housing census and survey programmes, labour-force surveys, surveys of living conditions, and other sources.

This chapter provides further information about each of these sources.

1. Administrative data relevant to impairment, disability and handicap in the population

Social security services, rehabilitation programmes and other services for people with impairments or disabilities usually maintain records of all persons served. These records constitute administrative data routinely collected by agencies responsible for health, education, labour, social security and other activities. For purposes of rehabilitation planning, two kinds of administrative data may be considered:

(a) Service records

Service records constitute a record of individuals receiving specific rehabilitation and related services. For example:

- The numbers and characteristics of children enrolled in regular school systems who receive special educational services;
- The number and characteristics of children enrolled in special education programmes;
- The number of people receiving CBR support services according to the specific service received.

(b) Registries

Registries are lists of individuals identified systematically from various monitoring sources as having an impairment, disability or specific health problem, and who may or may not be receiving services. Health-related registry data are often checked medically to confirm an underlying condition. Examples of such data are:

- The number of children with cerebral palsy;

- The number of congenital malformations per thousand live births;
- The number and characteristics of persons seeking rehabilitation services;
- Registered lists maintained by the Ministry of Social Welfare of persons needing rehabilitation services according to type of service needed;
- The number of persons receiving economic compensation or social services for serious impairments.

Registries may be continuous or one-time efforts.

(i) Continuous registries

Continuous registries may be characterized as follows:

(a) They are regularly updated so that each year persons are reported to be one year older: If persons no longer need rehabilitation, they are removed from the list;

(b) If persons on the list die, they are removed from the list and the cause of their death recorded;

(c) Addresses are changed when registered people move to a new residence;

(d) They are costly and require regular staffing and constant administrative and financial attention.

(ii) One-time registries

One-time registries may be characterized as follows:

(a) They record all persons found during a particular time period who report that they have an impairment or a disability, or experience handicapping situations;

(b) Their information is not necessarily adjusted annually for changes in age or residence, or at death; nor is it adjusted when individuals no longer need services, or if the type of service needed has changed;

(c) New persons identified by service programmes may be added to the list;

(d) Data are not necessarily representative of the population of persons needing services and, therefore, are not good substitutes for probability surveys;

(e) They cost less than continuous registries, but their information rapidly becomes outdated and invalid.

Therefore, in the search for registry data, it is important to check if the registry is continuously updated.

Administrative information from service records or from registries is often available in the form of summary tables of agency reports. Sometimes information is also provided through summary tables of persons newly registered or receiving services over the last year. This information may be processed in a computerized form after removal of personal identifiers, so that the frequency of people with impairments, disabilities and handicaps served by various programmes can be tabulated while confidentiality remains protected.

(c) Country example of administrative data: Mauritius 7/, 8/, 9/

In 1991, the Ministry for Social Security and National Solidarity, more specifically, the National Council for the Rehabilitation of Disabled Persons, of Mauritius, requested a question on disability in the national census:

(a) Purpose: to provide necessary information on all persons with impairments in the country for the purpose of planning services and increasing public awareness;

(b) Goals:

(i) Goal 1: To increase public discussion and education about disability, to inform the public about available rehabilitation programmes, and to plan for the removal of environmental barriers in architecture, transport and communication systems that created handicapping conditions for persons who had disabilities;

(ii) Goal 2: To provide financial support to persons who were medically certified as having an impairment that had caused at least a 60 per cent reduction in function and who needed the assistance of another person for their usual daily activities.

The existing sources of administrative data were:

(a) The national registry of Mauritius;

(b) CBR service records.

(i) National registry

The National Pension Plan provides the following financial support for persons who have a medically certified impairment: a retirement pension for persons who are deaf; who are paralysed totally; or who have a permanent impairment of at least 60 per cent and need the assistance of another person for their usual daily activities (dressing, eating, going shopping and getting around).

Pensions are as follows: 9/

Pension type	Amount (Mauritian rupees)
1. Age-related	
a. age group 60-74	1 040
b. age group 75-89	1 170
c. aged 90 years or over	3 620
2. Impairment/"invalid"	520
3. Additional, for persons with impairments who need the assistance of another person for their daily needs	433

The mortality of persons with serious impairments who register for the pension plan is accounted for through the death registry.

(ii) CBR service records

In populations served by rehabilitation programmes, rehabilitation service records provide a valuable source of administrative data related to disability.

Box II.1. An example of a national programme for community-based rehabilitation (CBR)

The CBR programme in Mauritius was initiated by the Ministry of Health in 1990. This programme, which intends to become a national one, has hitherto covered a population area of only 21,000 in the Flacq district. The programme was managed by a CBR team consisting of two physicians, a physical therapist and an occupational therapist. In 1990, 15 family planning workers were trained for one year to become CBR workers. From 1991 to mid-1993, these workers carried out CBR activities two days per week and worked as community health workers three days per week. A second group of 14 workers from the family planning programme completed the one-year training programme in June 1993. The 15 part-time workers were equivalent to 6 full-time workers, or 1 full-time worker for a population area of 8,800.

Programme activities

These include:

(a) Home visits;

(b) Working to integrate school-age children with disability who are not attending school into the local school system;

(c) Arranging for unemployed and/or not economically active persons with a disability to be occupied with work or other social and economic activities of the community;

(d) Referring persons who need additional services.

To identify people with disabilities who are in need of services, the CBR worker goes to each house in his/her area. Questions are asked to determine whether there are members of the household with disabilities associated with:

(a) Mobility;

(b) Hearing/speaking;

(c) Mental illness;

(d) Seeing;

(e) Mental retardation/epilepsy;

(f) Multiple disabilities.

Service records

In preparation for identifying people with disabilities, the community worker drafts a map of the area (see figure), which is filled in as the CBR worker carries out the house-to-house visits.

Island: Mauritius; district: Flacq; village: Bramsthan

Households with one or more persons with a disability are identified. For such households, a form is completed and a file indicating the name of the head of the household and the composition by sex and age group (0-14, 15 or over) is established. The confidentiality of individual and household information on disability must always be maintained. The exact location and other identifying information of households requiring rehabilitation services are never to be published or disseminated for a purpose other than that of service provision.

Each person identified as having a disability is assessed using a questionnaire (form 2 as contained in annex II.1) from the manual *Training in the Community for People with Disabilities* 3/ about activities that reflect the person's ability to perform self-care activities, communicate, and participate in play, school, household, social and work activities.

The severity of functional limitations is recorded in form 2, which is later used to record progress made by an individual with respect to the activities listed. The CBR workers using this system for grading progress indicated that the three levels of severity listed in the manual were insufficient, and that they preferred a five-level system such as the one shown in annex II.1.

Since rehabilitation workers at the community level are not expected to diagnose underlying conditions or diseases that may cause impairments or disabilities, they do not maintain records on causes. However, the physicians who supervise the CBR programme see each person identified and note the underlying condition, if established. They maintain a record of two causes in particular: cerebral palsy and cerebrovascular accidents.

All records are maintained at the area health centre; copies of the notes of visits are left in the households so that these records will be kept both by the family and by the health centre.

Reporting system

Since the CBR programme has been established in the localities surrounding one area health centre, all records are kept at that centre. No system of reporting to regional or national levels has yet been established. This will be done when the programme expands.

Data from records at the area health centre are analysed to provide the following information:

(a) Total number of households;

(b) Number of households including one or more persons with a disability;

(c) Number of persons with a disability according to type of disability (as noted above), sex and age group (0-15, over age 15);

(d) Number of people with disability who require rehabilitation services, according to the above categories.

Even though the CBR programme was originally intended for national coverage, it only pertained to the Bramsthan area in the Flacq district. The findings in this programme do not represent the actual situation for the country as a whole. Caution must be exercised when collecting and comparing data to compile a national population profile with respect to impairment, disability and handicap.

2. Censuses and surveys

It is important for all nations to collect information on impairment, disability and handicap in their populations. The United Nations Expert Group Meeting on the Development of Impairment, Disability, and Handicap Statistics, held in November 1994, 12/ recommended that countries that had never surveyed their populations with respect to impairment, disability and handicap, or had not done so recently, consider doing so in their next census round or in a survey. The recommendations from this meeting also emphasized the importance of rapid processing and dissemination of the results of impairment, disability and handicap surveys.

An important activity associated with all census and survey work on impairment, disability and handicap is to identify affected persons according to specific definitions and concepts. In censuses and surveys, "screening" is used to identify affected persons (see box II.2).

(a) Screening

Just as the definitions and concepts used for administrative data are shaped by the types of programmes and services administered, the definitions and screening questions used in censuses and surveys are largely determined by the choice of concepts used in the policy formulation and programme services of countries.

A broad impairment, disability and handicap question may be included in censuses in order to identify the possible population for a more detailed follow-up survey. Such broad and non-specific screening questions should be designed to have a high degree of sensitivity (annex II.1); but they may have low specificity, and should not be used alone to estimate the prevalence of a specific condition. The follow-up survey can contain a detailed set of questions to identify the various types of impairment, disability or handicap.

It has been suggested that before a response is counted as indicating an impairment, disability or handicap, it should be determined that the limitation indicated has had a duration of at least six months. Thus, a question designed to detect impairment, disability or handicap should include the qualification that the limitation must have lasted, or be expected to last, for six months. Some questionnaire modules specify a minimum duration for the underlying health condition (that is, the disease or injury that caused the impairment, disability or handicap). It is recommended that the minimum duration should relate to the limitation itself rather than to the underlying condition.

Box II.2. What is screening?

Screening is a strategy to increase efficiency in identifying individuals who may have an impairment or disability that cannot be identified from administrative records. It is also a strategy used by surveys to identify characteristics of persons or households. Instead of examining every individual in the population for the presence of disability, screening allows one to identify a smaller subpopulation that includes most of the people in the population with a disability. More detailed information, which is generally more expensive to obtain than the screening results, is then obtained by questioning only the individuals in a subpopulation.

A screen for disability is a procedure such as a question, a set of questions or a performance test used to sort the population into two groups, a "negative" group and a "positive" one. The "negative" group consists of people who are not likely to have a disability. The "positive" group consists of people who are likely to have one.

If the screening procedure were perfectly accurate, each of the persons screening "negative" would not have a disability and each of those screening "positive" would have one. In practice, screening procedures are not perfectly accurate. Rather, a disability screen is intended as a rapid and low-cost method of identifying persons likely to have a disability and distinguishing them from the majority in the population who are not likely to have one. In general, a positive screening result for disability must be confirmed using more detailed questions and/or other procedures before the person is considered to have a disability.

There are a number of ways to screen for impairment and/or disability in surveys. The way to identify persons in censuses may be less elaborate and simpler than methods used in surveys. Some censuses have screened only for impairments (Bahrain, 1981; Sri Lanka, 1981); others primarily for disability (Canada, 1983/84); some for specific handicapping situations (institutionalization, unemployment of working-age adults or school non-attendance of children) (Mexico, 1980). 5/ Some specialized surveys have used screens covering impairment, disability and handicap concepts (Spain, 1981; Australia, 1981). 5/ Screening questions may use a broad range of culturally appropriate expressions to ask about functional limitations and need not follow the logic of the categories of ICIDH. Once persons are screened in as positive, the precise categories of ICIDH that describe their impairments, disabilities or handicaps may be used.

In specialized disability surveys and in health and medical surveys, tests of performance or aptitude or diagnostic tests may be used to validate general questions. Such tests are not routinely used in survey modules for labour-force, living conditions and other population and demographic surveys, but they are often used in health surveys and may be useful in surveys of impairment or disability.

Handicap screens may also be used in surveys. One general approach to questions of handicap is to ask persons with impairments and/or disabilities to describe the conditions under which they experience handicap (for example, when using public transport, at work, or during social events). It may also be useful to estimate levels of handicap among countries or areas through comparative analysis of the socio-economic situations of persons with disabilities with respect to other populations. Comparisons may be made in terms of educational attainment, school attendance, marital status, residence and employment.

At least five different screening approaches have been used by census programmes to collect information about impairment, disability and handicap:

(a) One general question;

(b) A check-list of specific impairments or disabilities;

(c) Counts of the number of persons experiencing handicap;

(d) Probe questions following a general question;

(e) Surveys dedicated to impairment, disability or handicap.

Each of these five approaches is described or exemplified below.

(i) A general question or item (asked of everyone)

This approach may be used in a general population census or survey.

Example 1A:

Are you limited in the kind or amount of activity that you can do because of a long-term physical condition, mental condition or health problem:

___ (a) At home? (No; Yes)

___ (b) At school or at work? (No; Yes)

___ (c) In other activities, for example, transportation, leisure-time activities? (No; Yes)

Example 1B:

Do you have any long-term disabilities or handicaps? (No; Yes)

Example 2:

Is (name of person) limited in his/her daily activities (at home, at work or at school) because of a long-term physical or mental condition (lasting six months or more)?

No ___

Yes ___

(ii) A check-list of specific impairments or disabilities (completed for everyone)

Censuses may also provide a list of likely impairments and/or disabilities from which the respondent may choose. One or more questions is asked about one or more specific impairments or disabilities for each person enumerated. For example, national censuses have asked about the presence of deafness and hearing problems in the population (Tunisia, 1975; Denmark, 1976; Finland, 1978; Comoros, 1980; Bahrain, 1981; Peru, 1981; Netherlands, 1981; Sweden, 1981) and/or about blindness or other vision problems (Bahrain, 1981; Comoros, 1980; Egypt, 1976; Hong Kong, 1981; Indonesia, 1980; Kuwait, 1980; Mali, 1976; Netherlands Antilles, 1981; Pakistan, 1981; Panama, 1980; Peru, 1981; Sri Lanka, 1981; Tunisia, 1975; Turkey, 1975). 5/ These questions may be laid out in a list of choices, as in the two examples given below.

Example 1: Impairment-oriented question

Does the person have any long-term impairments, disabilities or handicaps?

No ___
Yes ___. Check all that apply:

___ Incomplete use of legs, feet

___ Incomplete use of arms/fingers

___ Partial or total loss of sight even with glasses

___ Partial or total loss of hearing

___ Partial or total loss of speech

___ Slow development/learning difficulties

___ Behavioural problem/mental impairment
___ Other. Specify ___________________________

Example 2: Disability-oriented question

Is (name of person) limited in his/her daily activities (at home, at work or at school) because of a long-term physical or mental condition (lasting six months or more)?

No ___
Yes ___. Has difficulty in (check all that apply):

Seeing ___ (Even with glasses, if worn)

Hearing ___ (Even with hearing aid, if used)

Communicating ___ (talking, conveying information, listening)

Moving ___ (walking, climbing stairs)

Standing ___ (unable to stand for a short time)

Grasping ___ (using fingers to grasp or handle objects)

Intellectual ___ (difficulty learning, retardation)

Emotional ___ (psychological, behavioural problems)
Other ___ Explain ______________________________

Figure II.2 below shows data from one census (Mauritius 7/) that focused upon serious impairments through the use of a single census question, and also data from one survey (Canada 13/) that focused more broadly upon mild, moderate and serious disability through the detailed use of 21 questions. It can be seen that the 21-question disability screen resulted in much higher prevalence rates than the single-question approach to impairment.

A useful check-list within a population census is one that is applicable to people of all ages (children, the working population, the elderly). It may be necessary to design separate check-lists for different age groups.

(iii) Counts of the number of persons experiencing handicap (namely, people with limited roles, such as institutionalized populations and people who are unemployed)

Some censuses screen on a simple handicap question, or on a question about the circumstances of persons with disabilities, or on a description of relationships that have evolved, involving, for example, not economically active status or unemployment among adults, illiteracy, and lack of school attendance among children. For example, national censuses in Belize (1980), the Central African Republic (1975), Cuba (1981), Guyana (1980), Myanmar (1983), the Philippines (1980), Venezuela (1981) and Viet Nam (1989) have asked about serious impairment among not economically active working-age adults. 5/ From these data, the proportion of not economically active severely impaired persons in the population, or that of children not attending school who are seriously impaired, may be estimated. The problem with these measures is that no comparison with economically active impaired persons may be made, nor can account be taken of the number of children with serious impairment who do attend school. In this case, the proportion of persons with impairments who are not handicapped by being not economically active or excluded from school remains unknown.

The 1980 national census in Mexico included serious impairments as a reason for not attending school. The results show that 2.6 per cent of the total population of female children ages 6-14 not attending school and 2.9 per cent of the total population of male children ages 6-14 not attending school had impairments (table II.2). 14/ What is not known is the percentage of children in age group 6-14 who were impaired and in school, nor the percentage of all children not attending school, so that these figures could be compared with the percentage of children with disabilities not attending school. Thus, these data do not show to what extent children with impairments were less likely to attend school than children without impairments.

Table II.2. Children not attending school, Mexico, General Census of Population and Housing, 1980, by sex, age group and number with impairments

Age group	Total	With serious impairments	
		Number	Percentage
		Males	
	2 314 005	66 025	2.9
6-8	698 191	32 855	4.7
9-11	267 633	16 645	6.2
12-14	1 348 181	16 525	1.2
		Females	
	2 386 598	63 288	2.6
6-8	680 081	30 497	4.5
9-11	272 758	15 265	5.6
12-14	1 433 759	17 526	1.2

Source: *Disability Statistics Compendium*, Statistics on Special Population Groups, Series Y, No. 4 (United Nations publication, Sales No. E.90.XVII.17), sect. IV, table No. 1, section dealing with Mexico. (Original data from Instituto Nacional de Estadística Geografía y Informatica, 1984, *X censo general de población y vivienda, 1980*. Resumen general abreviado. 1984.)

One way to avoid this problem is to ask separate impairment/disability/handicap screening questions among all children, and to ask also about school attendance of all children, thereby allowing for full comparisons as shown below:

	Total population of school-age children	School-age children with serious impairments
Attending school		
Not attending school		

(iv) Probe questions (asked specifically of only those persons who said yes to the screening question)

In this approach, a general screening question about impairment or disability is asked of everyone enumerated. For persons identified as possibly having an impairment or disability ("screening positive"), more detailed questions are asked to confirm the presence of an impairment or disability and to obtain more detailed information. Further probes may also be asked of a sample of persons who were not identified by the screening question as having an impairment or disability, in order to ascertain whether the screening question excluded a person with an impairment and/or disability who should have been included in the survey.

(v) Surveys specifically dedicated to impairment, disability or handicap

Such surveys are rarely undertaken because their cost is greater than that incurred through including impairment, disability or handicap questions in the national census or in surveys. When a survey is specifically dedicated to collecting information on impairment, disability and handicap, the quality and detail of information can be maximized. One example is *The survey of disabled Americans of the International Center for the Disabled*. 15/ This survey of a representative sample of 1,000 Americans with disability over age 16 collected information on educational attainments; income; employment and occupation; participation in social and recreational activities; mobility; personal satisfaction; attitudes; barriers to full participation and equal opportunities; age of onset, nature and severity of disability; and many other topics.

Surveys devoted to impairments or disabilities may also focus specifically on the causes and types of impairment, nature and severity of disability and handicap, and treatment and rehabilitation history and needs. One example is the Viet Nam survey of amputation impairments mentioned above. 11/ This survey asked about the causes of impairment and also about needs for prostheses, crutches, wheelchairs and physical therapy.

Increased attention must be given by countries to the collection and presentation of data on special assistive devices for reduction of disability and handicap, using the newly devised International Organization for Standardization (ISO) Technical Aids for Disabled Persons Classification (ISO 9999). 16/ Survey questions concerning technical aids must be consistent with ISO 9999 levels of generalization and at the same time should refer to technical aids actually available to a given population. Tabulations may be produced showing the use of these devices by specific subgroups. Attention should also be given to the production of standard tables showing the need for technical aids. After 1995, the revised version of ISO 9999 will be available in English, French, German, the Nordic languages and Dutch, from ISO in Geneva.

(b) Censuses

In a number of countries, the population and housing census has been used to collect information about the three concepts, impairment, disability and handicap.

Box II.3. What is a census?

A census is a count or enumeration of every person in the population. Census programmes operated by national Governments conduct official population and housing censuses on a regular basis, usually every 10 years. In addition to counting the population, censuses collect information about social and economic conditions such as housing characteristics and employment for every person or household enumerated.

In modern times, census data for each household are collected in a standard form or questionnaire so that identical questions are asked of every household. Data for each household and household member are written in the standard form either by an adult member of the household or by a trained interviewer who obtains the information about each household by interviewing an adult member. The data or responses to the questions are later computerized and aggregated so that summary tables and other statistical information can be produced at national, regional and local levels. Published information from national censuses is confidential in most countries and generally cannot be linked back to individual persons or households.

Census questionnaires used for complete coverage of the population cannot be overloaded with detailed and specialized questions on a particular type of subject-matter. Census programmes often use short and long forms of the census questionnaires. The short form is for complete coverage of general topics. A probability sample from the population is selected to receive the long form. The long form includes all questions in the short form plus supplemental questions for more detailed coverage of specific topics. Questions more detailed than a single general question regarding impairment, disability and handicap may be included in the long form.

The census can provide a valuable source of information on the frequency and distribution of impairment or disability in the population, at regional, national and local levels. It is well-documented fact, however, that censuses have problems with underenumeration of persons with mild disabilities and of disabilities in children. 13/ Provided these problems of underenumeration are taken into account, the population and housing census can provide baseline information from which to proceed. It can also provide a sampling frame for more detailed studies of disability. 13/ Census results may also be useful for investigating small area variations in the prevalence of impairment and/or disability; these often cannot be investigated in sample surveys because of sample size limitations.

Census sampling

In this approach, an impairment or disability question is systematically asked of a sample of households included in the census rather than of all individuals or households.

Box II.4. What is a sample?

A sample is a subset of a given population. Information obtained from a properly selected sample of the population is used to make an estimate for the population as a whole. Sampling lowers costs, so the estimate is more efficient than a complete census of the population would be. The sample estimate will be accurate if the sample units are selected in accordance with probability methods and the methods of data collection are valid. The sample estimate will be reliable if the sample size is large enough (see box II.6 below on sample size) and the data-collection methods are reliable (see box III.13).

Box II.5. What is a probability sample?

A probability sample is a selection of units from a given population in accordance with certain mathematical tenets. The first tenet is that every person or household in the parent population must have a known, though not necessarily an equal, chance of selection in the sample. The second tenet is that the chance of inclusion must be non-zero. Geographical areas or population groups that are hard to enumerate cannot be arbitrarily excluded from having a chance of selection, or else the sample will be biased and will not constitute a bona fide probability sample. Many techniques are used to produce a probability sample, starting from a current, complete sampling frame, which is usually the population census. These techniques include systematic or random sampling, multi-stage sampling, stratified sampling, and cluster sampling. When probability methods are strictly adhered to in the execution of a survey, the resulting estimates enable the user to infer characteristics with quantifiable "degrees of confidence" of the entire population from which the sample was drawn.

Box II.6. What is sample size?

Sample size is probably one of the most important considerations in the design of a sample survey for disability statistics. This is because disability is a rare characteristic (less than 10 per cent prevalence) in many, though not all, populations. Even in a population where overall disability is not a rare occurrence, the disability survey (or module) will seek to profile many different types of disabilities. The sample size for each type of disability that is a key measurement objective of the survey will have to be large enough to provide a reliable estimate. There are mathematical formulae that sampling statisticians draw upon to calculate the sample size needed for a survey, provided the precision of the desired estimate can be fixed in advance. a/, b/. For example, one may wish to estimate the prevalence of vision impairment with "sampling" error of plus or minus 3 percentage points. In general, the sample size needed to estimate, say, the proportion of blind persons, would be much higher than that needed to estimate the proportion of persons wearing glasses because blindness is much less prevalent in the population than the wearing of glasses.

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a/ P. S. Levy and S. A. Lemeshow, *Sampling of Populations: Methods and Applications* (New York, New York, John Wiley and Sons, 1991).

b/ S. K. Lwanga and S. A. Lemeshow, *Sample Size Determination in Health Studies, A Practical Manual* (Geneva, WHO, 1991).

An example of sample size implications:

> Suppose the true prevalence of hearing disability in a population is 5/1,000 or 0.5 per cent. In a representative sample of 50 individuals selected from that population, there could not be one half of a person (0.5 per cent of the sample) with a hearing disability: the most likely number of persons with hearing disabilities included in the sample would be either 0 (giving a prevalence of 0/1,000) or 1 (giving a prevalence of 2 per cent or 20/1,000). Not only are 0 and 20 widely different (unstable) prevalence estimates, but both are far from the true prevalence of 5/1,000.
>
> Suppose instead of a sample size of 50, one was able to include a representative sample of 5,000 individuals. In theory, this sample could by chance include no individuals with hearing disabilities, all individuals with hearing disabilities (provided the population was large enough) or any number with hearing disabilities in between these

two extremes. In practice, however, the sample would likely include between 20 and 30 individuals with hearing disabilities, and therefore yield prevalence estimates within a fairly narrow range of 4/1,000 to 6/1,000, close to the true prevalence of 5/1,000.

Some census programmes use a systematic sampling approach to collect information about impairments, disabilities and/or other characteristics in the households selected to receive the long census form (see annex II.1). Because the questions added to the long form are given to a sample of households, usually selected systematically (for example, every tenth or twentieth household), the impairment or disability information can then be generalized to the entire population, using statistical techniques, to obtain an estimate of the frequency of impairment or disability in the population. This approach was used in the 1990 population and housing census of the United States of America.

(c) Sample surveys

In situations where there is a regular programme of national household surveys, disability information may be obtained from a variety of sources, including demographic and health surveys and surveys of education, living conditions, family expenditure, labour force participation, nutrition, special populations, institutions and other areas.

Box II.7. What is a sample survey?

A sample survey is a method of gathering information from a sample to learn about the population from which the sample has been drawn. Sample surveys do not attempt to enumerate all households or individuals in a population, as censuses do. Instead, they gather information from a probability sample of households or individuals that have been selected to represent a larger population or subpopulation. Sample surveys are similar to censuses in at least three other respects, in that (a) the information is collected using standard forms and with identical questions so that the information collected from individuals or households is comparable; (b) the information collected is computerized; and (c) frequency tables and other statistical information are produced, providing estimates of population frequencies.

Sample surveys are often conducted by countries on a regular basis (annually, quarterly, monthly or even weekly) to take account of yearly or seasonal trends in health, living conditions, labour, agriculture and other characteristics. A cost-effective way of developing social and health statistics is to incorporate impairment, disability and handicap questions into ongoing or planned demographic, household and health surveys. An efficient means of collecting survey information about impairment, disability or handicap is to make use of a survey devoted to a broader topic and attach questions on the above topics to it.

Panel or repeated surveys may be used to obtain information on the transition from impairment to disability, or from disability to handicap, or on recovery from disability. Such information is important for studying the dynamics of functional limitations in a population and for planning services. The time interval between survey waves should be larger than six months but no larger than two years.

(i) Collection of information from surveys

The first three approaches and the fifth approach to gathering disability information in population censuses (namely, (a) one general question, (b) a check-list of specific impairments or disabilities, (c) counts of the number of persons experiencing handicap and (e) surveys dedicated to impairment, disability or handicap) can be used within the context of a sample survey. Surveys that gather information on impairments, disabilities and/or handicaps, regardless of which approach to collecting the information is used, are particularly valuable when the information is collected and presented in accordance with the principles, definitions and distinctions of ICIDH. The Health and Activity Limitations Surveys of Canada carried out by Statistics Canada between 1986 and 1991, 13/, 17/-21/ the Australian survey of 1988 22/ and the National Survey of Impairments, Disabilities and Handicaps in Spain 23/ are notable for having been undertaken in accordance with ICIDH. Examples are shown hereinafter for the purpose of illustrating the more detailed screening modules of disability (D) and handicap (H) used in specialized national impairment/disability/handicap (IDH) surveys.

The 22 questions in annex II.2 have been used in several Canadian surveys. 13/, 17/-21/ These questions are not asked consecutively. Additional questions are asked after each screening item. An example of the more detailed pattern used in the questionnaire is shown in the example below. The screen questions were asked of everyone surveyed and the probe questions only of those who were screened in as "yes" or positive for the specific disability.

Example:

1. Do you have any difficulty hearing what is said in a conversation with one other person?

   No ____ If Yes ____
   Are you completely unable to do this? Yes/No

2. Do you have any difficulty hearing what is said in a group

conversation with at least three other people?

No____ If Yes ___

Are you completely unable to do this? Yes/No
If Yes is given for either question, ask the following:

3. What is the main condition or health problem that causes you difficulty hearing?

Specify. ____________________________________

4. Which one of the following is the best description of the cause of this condition?

(a) Existed at birth

(b) Work environment

(c) Disease or illness

(d) The natural ageing process

(e) Psychological or physical abuse

(f) Injury, at home

(g) Injury, motor vehicle

(h) Injury, work-related

(i) Other, please specify. _________________________

(j) Don't know

5. Are you able to hear what is being said over a telephone?

(a) Yes, with an aid

(b) Yes, without an aid

(c) No, not able
(d) Don't know

6. I would like to ask you about your use of special or technical aids or services for persons who are deaf or hard of hearing.

Do you now use a/an:

___ Hearing-aid

___ Telecommunications device for the deaf (TDD)

___ Oral interpreter or sign-language interpreter

___ Flashing alarms or visual alarms

___ Volume control telephone

___ Computer to communicate

___ Message relay service provided by a telephone company
___ Other. Please specify ________________________

(ii) Two-phase surveys

This consists in a screening followed by a clinical examination or performance test to confirm the presence or absence of impairment, disability and/or handicap.

In this approach, a brief and low-cost screening method (such as a questionnaire) is used in phase one to identify a subgroup of the population in which there is a high prevalence of the condition of interest (for example, disability). In phase two, individuals screened as positive are referred for clinical examinations and for performance tests to confirm the presence or absence of the condition. Information about the specific cause of disability or underlying conditions may also be obtained during the phase two examination. This two-phase approach, using the ten questions (annex II.3) as the screen in phase one, has been used in several countries to screen for serious disabilities in children. 24/-27/

3. Joint use of census and survey approaches

The national censuses of Canada in 1986 and 1991 included a few simple questions on impairment and disability. The questions asked in 1986 were as follows: 13/

> Are you limited in the kind or amount of activity that you can do because of a long-term physical condition, mental condition or health problem:

(a) At home? (No, I am not limited; Yes, I am limited)

(b) At school or at work?
(c) In other activities, for example, transportation to or from work, leisure time activities?

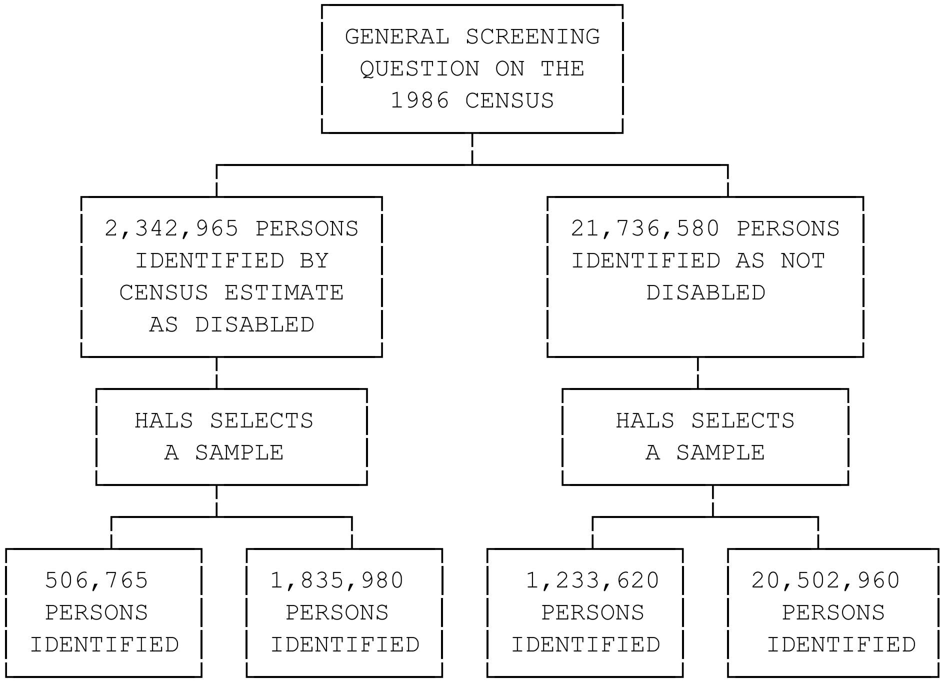
(d) Do you have any long-term disabilities or handicaps? (No, Yes)

The purpose of these questions was not to estimate the frequency of impairment or disability from the questions alone: it was to define a sample of individuals likely to have a disability. Following the census, a national sample survey based upon the census results was prepared. Those screened positive in the census and thus considered likely to have disabilities were then asked the 22 Health and Activity Limitation Survey questions (see annex II.2). A sample of persons who screened negative in the census were also included in the sample survey.

The survey results provide detailed information on the occurrence of true positive, false positive, true negative and false negative responses to the census questions, as well as detailed information on impairments, disabilities, handicaps and other characteristics of persons identified as having a disability (see box II.8). 13/, 17/-21/

Box II.8. Estimates of persons with disabilities residing in private households, as reported by the 1986 Census of Population and the Health and Activity Limitation Survey (HALS), Canada a/

The number of persons with disabilties identified in the Census was 2,343,000 as compared with 3,070,000 in the Health and Activity Limitation Survey (HALS). There were an estimated 1,836,000 persons who answered yes to both the Cnesus and HALS (Yes/Yes in the following tables). This Yes/Yes component accounted for 78 per cent of the Census estimate and 60 per cent of the estimate from HALS.



a/ A. Furrie and Statistics Canada, *Comparison of the Results from the 1986 Census and the Health and Activity Limitation Survey for Persons with Disabilities Residing in Households* (Ottawa, Statistics Canada, 1989).

4. Where to find census and survey data on impairment, disability and handicap

- National central statistical offices or census bureaux are responsible for conducting and disseminating the results of the national census.

- National statistical offices and census programmes may also conduct sample surveys that include questions on disability-related topics.

  To find out about these data, one could visit the statistical office or census bureau and ask whether or not previous national censuses or surveys had included any questions on impairment, disability or handicap. Statistical office staff may not necessarily be aware of all disability-related information that has been collected in the past. Even when one is told that disability data have not been collected, it is best to probe and review summary reports until it can be confirmed that no information has been collected in recent years. If it can be determined that data on disability, impairment or handicap have been collected, one should find out as much as possible about the specific question(s) asked and the approaches used to collect the data. Copies of relevant reports, compilations and tabulations should be obtained.

- The national library is another source of census and survey information. A reference librarian may be able to provide assistance in locating census materials and identifying references to data collected on topics relevant to disability.

- Government ministries, departments and agencies responsible for health, labour, education and social welfare also conduct surveys and disseminate results that may include information on disability and related topics.

- Universities are often involved in the design and implementation of sample surveys. In such cases, it may be possible to obtain information on survey results from university libraries, departments or individual faculty members.

- A convenient international reference to census and survey information related to disability is the *Disability Statistics Compendium*, published in 1990 by the United Nations. 5/ This publication includes referenced summaries, descriptions and tables of statistical information on disability from censuses and surveys in 55 countries. It is based on an ongoing computerized data bank known as DISTAT, which currently contains statistical information from over 100 countries and is maintained by the Statistics Division of the United Nations.

B. Evaluating existing statistical information on

disability topics

Three questions must be addressed in evaluating statistical information on disability and related topics:

1. Does the information pertain to impairment, disability and/or handicap?

   To determine this, it is necessary to find out how the information was collected. If the source of information is a census or survey, what questions were asked and how can these questions be interpreted in terms of ICIDH categories and definitions? If the source of information is service records, by what criteria does one get selected to receive services? If the data source is a registry, what are the inclusion criteria for cases in a registry? Case definitions and criteria may not be apparent from summary reports. It is often necessary to speak with staff members responsible for data collection, and obtain copies of any manuals produced for a given programme, which describe those definitions and criteria.

2. How accurate is the information collected?

   For this, one needs to review the census and survey questions or case inclusion criteria, and also find out if any pretesting and validation work was done to estimate the sensitivity, specificity and predictive value of the questions asked (see annex II.4). Another way of assessing accuracy is to review the data to see if they are consistent with what is known about disability. This approach, however, must be used with caution, since existing knowledge may be inaccurate.

3. What can the available information reveal about people with impairments, disabilities and handicaps in the population?

   To be useful for developing a profile of disability in a population, data are needed not only on the total number of persons in the population with disability, but also on a number of attributes. Depending on the purpose of the survey, it may be useful to obtain information on the following attributes:

   (a) Demographic characteristics: these include age and sex, and may include marital status, household characteristics and urban/rural residence;

   (b) Socio-economic characteristics: these include education, employment status, occupation and housing conditions;

   (c) Cause: external factors and underlying conditions. Surveys may wish to describe causes or external factors affecting disability to the extent that they are known. This is especially important for planning prevention and public education programmes. Surveys usually use a two-part procedure to explain the underlying diseases or other causes of impairment, disability or handicap. In the beginning, people are often asked a general question to find out what happened. In this case, the purpose is to find out the cause of the impairment or disability. Second, people may be asked to describe, if known, the underlying condition associated with their impairment and/or disability. (The cause of the underlying condition may be unknown to, or not understood by, the respondent. Age at onset is also useful to know and may be used to estimate the incidence of impairments or disabilities; but for conditions with a gradual onset, incidence may not be readily known. The two-phase survey approach (described in subsection A.2.c (ii) above) is especially useful for obtaining medically verified diagnostic or causal information.) General categories of causes include:

(i) Nutritional deficiencies (for example, iodine, vitamin A, folate or calcium deficiency);

(ii) Inherited genetic conditions (for example, Huntington's chorea, muscular dystrophy, phenylketonuria);

(iii) Chromosomal disorders (for example, Down's syndrome);

(iv) Injury or trauma (for example, from motor vehicle injuries, warfare);

(v) Infections (for example, poliomyelitis, meningitis);

(vi) Other conditions (for example, arthritis, diabetes);

(d) Nature and severity of impairment, disability and handicap: the nature of impairments, disabilities and handicaps can be described using ICIDH categories. Severity of disability can be described in terms of degree of functional limitation (annex III.1);

(e) Use of special aids: these include technical aids (for communication, moving about, listening, seeing, accomplishing fine motor tasks, and other activities) in order to reduce the level of disability and handicap for persons with a given impairment;

(f) Access to and use of rehabilitation and other services: these include special education, physical therapy, occupational therapy and other interventions to reduce impairment and disability in persons with impairments. They may also include general education, vocational training and other interventions to increase opportunity.

An important step in evaluating existing data on disability and related topics for a population is to develop a profile of what is known about disability in that population from the existing information. The profile should contain as much information as possible about frequency of disability in the population by age, gender and other demographic categories, socio-economic characteristics of people with disabilities compared with others in the population, major causes of impairment in the population and nature and severity of disabilities and handicaps associated with each cause, access to and use of special aids and rehabilitation services by people with disabilities, barriers to full participation and equal opportunities for people with disabilities in the population, and other information perceived as relevant. The accuracy of the information used in developing the profile should be considered and gaps in the information identified. In this process, specific needs for collecting additional information may be identified. Chapter III provides guidelines for the collection of additional information on disability and related topics when this is found necessary.

Annex II.1

INDIVIDUAL ASSESSMENT/PROGRESS FORM (FORM 2)*

Note: The reliability and validity of this form have not been tested (see box III.13). Some of the questions are age-specific.

Registration Number ....

Name ....
Region .... District ....
Community .... Sex .... Age ......
Number of months in the programme ....
Type of disability ....

Task	Present level	Date
1. Feeds himself or herself? (including eating and drinking)	5. ___ Alone	.....
	4. ___ With little help	.....
	3. ___ With some help or sometimes	.....
	2. ___ With a lot of help	.....
	1. ___ Not at all	.....
2. Keeps himself or herself clean? (including washing, bathing and cleaning teeth)	5. ___ Alone	.....
	4. ___ With little help	.....
	3. ___ With some help or sometimes	.....
	2. ___ With a lot of help	.....
	1. ___ Not at all	.....
3. Uses the latrine?	5. ___ Alone	.....
	4. ___ With little help	.....
	3. ___ With some help or sometimes	.....
	2. ___ With a lot of help	.....

1. ___ Not at all .....

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* This is a revised version of form 2, as presented in Ture Jonsson, *OMAR in Rehabilitation: A Guide on Operations Monitoring and Analysis of Results (Draft for Field Testing)* (United Nations Development Programme (UNDP) Interregional Programme for Disabled People, 1994). The original form, with 23 questions, is contained in the manual *Training in the Community for People with Disabilities* (Geneva, WHO, 1989).

Task	Present level	Date
4. Dresses and undresses?	5. ___ Alone	.....
	4. ___ With little help	.....
	3. ___ With some help or sometimes	.....
	2. ___ With a lot of help	.....
	1. ___ Not at all	.....
5. Understands simple instructions?	5. ___ Easily	.....
	4. ___ With little difficulty	.....
	3. ___ With some difficulty	.....
	2. ___ With great difficulty	.....
	1. ___ Not at all	.....
6. Expresses needs?	5. ___ Easily	.....
	4. ___ With little difficulty	.....
	3. ___ With some difficulty	.....
	2. ___ With great difficulty	.....
	1. ___ Not at all	.....
7. Understands movements and signs for communication?	5. ___ Easily	.....
	4. ___ With little difficulty	.....
	3. ___ With some difficulty	.....
	2. ___ With great difficulty	.....
	1. ___ Not at all	.....

8. Uses movements and signs for communication that others understand?

5. ___ Easily .....

4. ___ With little difficulty .....

3. ___ With some difficulty .....

2. ___ With great difficulty .....

1. ___ Not at all .....

Task	Present level	Date
9. Lip-reads?	5. ___ Easily	.....
	4. ___ With little difficulty	.....
	3. ___ With some difficulty	.....
	2. ___ With great difficulty	.....
	1. ___ Not at all	.....
10. Speaks?	5. ___ Easily	.....
	4. ___ With little difficulty	.....
	3. ___ With some difficulty	.....
	2. ___ With great difficulty	.....
	1. ___ Not at all	.....
11. Sits? (including sitting up from a lying-down position with technical aid)	5. ___ Alone	.....
	4. ___ With little help	.....
	3. ___ With some help	.....
	2. ___ With a lot of help	.....
	1. ___ Not at all	.....
12. Stands? (including standing up from a sitting position)	5. ___ Alone	.....
	4. ___ With little help	.....
	3. ___ With help	.....
	2. ___ With a lot of help	.....
	1. ___ Not at all	.....
13. Walks at least 10 steps? (with	5. ___ Alone	.....

Task	Present level	Date
help of walking aids or of a person)	4. ___ With little help	.....
	3. ___ With help	.....
	2. ___ With a lot of help	.....
	1. ___ Not at all	.....
14. Moves inside the home? (including walking, crawling using trolley, wheelchair and so forth, or with help of a person)	5. ___ Alone	.....
	4. ___ With little help	.....
	3. ___ With help	.....
	2. ___ With a lot of help	.....
	1. ___ Not at all	.....
15. Moves around the village? (including walking, crawling using trolley, wheelchair and so forth, or with help of a person)	5. ___ Alone	.....
	4. ___ With little help	.....
	3. ___ With help	.....
	2. ___ With a lot of help	.....
	1. ___ Not at all	.....
16. Has aches and pains in the back or the joints?	5. ___ Very rarely or not at all	.....
	4. ___ Sometimes, but can still work	.....
	3. ___ Disturbs work but not sleep	.....
	2. ___ Disturbs sleep	.....
	1. ___ Cannot work at all because of pain	.....
17. Shows strange or unusual	5. ___ Never	.....

Task	Present level	Date
behaviour?		
	4. ___ Yes, but rarely (once a month or less)	.....
	3. ___ Yes, sometimes (once a week)	.....
	2. ___ Yes, often (every day)	.....
	1. ___ Yes, regularly (several times every day)	.....
18. Plays like other children of the same age?	5. ___ Yes	.....
	4. ___ Plays slightly below his/her age	.....
	3. ___ Plays much below his/her age	.....
	2. ___ Plays very much below his/her age	.....
	1. ___ Does not play at all	.....
19. Goes to school?	5. ___ Yes, in a regular class	.....
	4. ___ Yes, in a special class/unit in a regular school	.....
	3. ___ Yes, in a special school/institution	.....
	2. ___ No, but receives informal education	.....
	1. ___ No, receives no education	.....
20. Performance in school? (contact the teacher)	5. ___ Excellent	.....

Task	Present level	Date
	4. ___ Above average	.....
	3. ___ Average	.....
	2. ___ Below average	.....
	1. ___ Much below average	.....
21. Joins in family activities?	5. ___ Yes, very often	.....
	4. ___ Quite a lot	.....
	3. ___ Sometimes	.....
	2. ___ Very seldom	.....
	1. ___ Not at all	.....
22. Joins in community activities?	5. ___ Yes, very often	.....
	4. ___ Quite a lot	.....
	3. ___ Sometimes	.....
	2. ___ Very seldom	.....
	1. ___ Not at all	.....
23. Does household activities?	5. ___ Yes, all	.....
	4. ___ A lot, but not all	.....
	3. ___ Some but not all	.....
	2. ___ Very few	.....
	1. ___ Not at all	.....
24. Has sufficient skills for income-generation?	5. ___ Yes	.....
	1. ___ No	.....

Task	Present level	Date
25. Has work, or an income?	5. ___ Full-time work with adequate income for his/her needs	.....
	4. ___ Full-time work but inadequate income for his/her needs	.....
	3. ___ Part-time or seasonal work or some income	.....
	2. ___ Very infrequent work or income	.....
	1. ___ No work and no income	.....

Annex II.2

SAMPLE DETAILED SCREENING MODULE USED IN NATIONAL IMPAIRMENT, DISABILITY AND HANDICAP SURVEYS: CANADIAN 1991 QUESTIONNAIRE*

I am going to ask you a series of questions about your ability to do certain activities even when using specialized or technical aid. Please tell me about only those difficulties that have lasted or are expected to last six months or more.

1. Do you have any difficulty hearing what is said in a conversation with one other person?

2. Do you have any difficulty hearing what is said in a group conversation with at least three other people?

3. If yes, What is the main condition or health problem that causes you difficulty hearing?

4. Do you have any difficulty seeing ordinary newsprint, with glasses or contact lenses if usually worn?

5. Do you have any difficulty seeing clearly the face of someone across a room (that is, from 4 metres or 12 feet), with glasses or contact lenses if usually worn?

6. If yes, What is the main condition or health problem that causes you difficulty seeing?

7. Do you have any difficulty speaking and being understood?

8. Do you have any difficulty walking 350 metres or 400 yards without resting (about three city blocks, about half a kilometre or a quarter of a mile)?

9. Do you have any difficulty walking up and down a flight of stairs (about 12 steps)?

10. Do you have any difficulty carrying an object of 4.5 kilograms for 10 metres or 10 pounds for 30 feet (for example, a bag of groceries)?

11. Do you have any difficulty moving from one room to another?

12. Do you have any difficulty standing for more than 20 minutes?

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*Statistics Canada, *1991 Health and Activity Limitation Survey for Institutions (Adults)* (Ottawa, Statistics Canada, 1991). Interview form 04.

13. When standing, do you have any difficulty bending down and picking up an object (for example, a shoe) from the floor?

14. Do you have any difficulty dressing and undressing yourself?

15. Do you have any difficulty getting in and out of bed?

16. Do you have any difficulty cutting your own toenails? (That is, is it physically difficult for you to cut your own toenails?)

17. Do you have any difficulty using your fingers to grasp or handle (such implements as pliers or scissors)?

18. Do you have any difficulty reaching in any direction (for example, above your head)?

19. Do you have any difficulty cutting your own food?

20. Because of a long-term physical condition or health problem that has lasted or is expected to last six months or more, are you limited in the kind or amount of activity you can do? ... (a) in the residence or institution? ... (b) in other activities, outside the residence or institution, such as travel, sport or leisure?

21. Learning new things or reacting to new situations is sometimes more difficult for one person than for another. From time to time, EVERYONE has difficulty remembering the name of a familiar person, or learning something new, or he or she experiences moments of confusion. However, do you have any ongoing difficulty with your ability to remember or learn?

22. Because of a long-term emotional, psychological, nervous or psychiatric condition, that is, one that has lasted or is expected to last six months or more, are you limited in the kind or amount of activity you can do ... (a) in the residence or institution? ... (b) in other activities outside the residence or institution such as travel, sport or leisure?

Annex II.3

TEN QUESTIONS FOR SCREENING SERIOUS CHILDHOOD DISABILITY*

1. Compared with other children, did the child experience any serious delay in sitting, standing or walking?

2. Compared with other children, does the child have difficulty seeing, either in the daytime or at night?

3. Does the child appear to have difficulty hearing?

4. When you tell the child to do something, does he/she seem to understand what you are saying?

5. Does the child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?

6. Does the child sometimes have fits, become rigid, or lose consciousness?

7. Does the child learn to do things like other children his/her age?

8. Does the child speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words)?

9A. For three to nine-year-old children ask: Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?

9B. For two-year-old children ask: Can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?

10. Compared with other children of his/her age, does the child appear in any way mentally backward, dull or slow?

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*S. Zaman and others, "Validity of the Ten Questions for screening serious childhood disability: results from urban Bangladesh", *International Journal of Epidemiology*, vol. 19, No. 3 (1991), pp. 613-620.

Annex II.4

ASSESSING THE ACCURACY OF A SCREEN: CONCEPTS OF SENSITIVITY, SPECIFICITY AND PREDICTIVE VALUE

To assess the accuracy of a screening procedure, both a screening result and a criterion rating based on a more definitive assessment than the screen (such as a clinical examination) must be obtained for a sample of individuals. The screening result and criterion rating are then cross-classified as in the following two row-by-two column table:

Criterion rating

Screening result	Disability present	Disability absent
Positive	True positive	False positive
Negative	False negative	True negative

A reasonably accurate screen is one that has:

- High sensitivity;
- High specificity;
- High predictive value. a/

Definitions:

(a) Sensitivity is the proportion or percentage screened positive among those with a disability (the number of true positives divided by the sum of the number of true positives and the number of false negatives);

(b) Specificity is the proportion or percentage screened negative among those with no disability (the number of true negatives divided by the sum of the number of true negatives and the number of false positives);

(c) Positive predictive value is the proportion or percentage with a disability among those screened positive (the number of true positives divided by the sum of the number of true positives and the number of false positives).

Examples:

Suppose 1,000 people were screened for disability with a single question and later evaluated using a more expensive and accurate method to determine whether or not they truly had a disability, and the following results were obtained:

Criterion rating

Screening result	Disability present	Disability absent
Positive	45	150
Negative	5	800

Sensitivity = 45/(45 + 5) = 0.90 or 90 per cent

Specificity = 800/(800 + 150) = 0.84 or 84 per cent

Positive predictive value = 45/(45 + 150) = 0.23 or 23 per cent

True prevalence of disability = (45 + 5)/1,000 = 50 per 1,000 or 5 per cent

Is this a reasonably accurate screen?

The answer to this question requires judgement and depends on the purpose of the screen. If the screen is designed for a fatal disease that can be cured if detected early, the screen will be reasonably accurate only if its sensitivity is 100 per cent and its positive predictive value greater than the prevalence of the disease in the general population. In other words, if one is screening for a fatal condition that is curable if detected early, the screen should not miss even a single case, and the prevalence of the disease in those screening positive must be higher than the prevalence of the disease in the general population to make the screening procedure worthwhile.

If the purpose of the screen is to estimate the prevalence of disability in the population, a sensitivity of 90 per cent may be considered quite acceptable. A positive predictive value of 23 per cent when the prevalence of disability in the population is 5 per cent is acceptable only if the following conditions hold:

(a) Positive screening results are followed by additional questions or assessments to distinguish true positives from false positives;

(b) The proportion of the population screening positive is relatively small so that follow-up is required for a relatively small proportion of the population;

(c) The cost of the screening procedure per person screened is much less than the cost of obtaining the criterion rating.

If the screening approach was used in a census to obtain an estimate of the number of people with impairments or disabilities in the population, a sensitivity of 90 per cent and a positive predictive value of 23 per cent would be acceptable and the screening procedure worthwhile if the above three conditions held.

Note that:

(a) Without condition (a), the prevalence of disability in the population estimated from the screening question would be inflated nearly fourfold (195 per 1,00 instead of the true prevalence of 50 per 1,000);

(b) With condition (a) and no follow-up of the majority screening negatives, the prevalence of disability in the population would be estimated to be 45 per 1,000 which is very close to the true prevalence;

(c) Without conditions (b) and (c) above, it may be more cost-effective to obtain criterion ratings for everyone in the population than to implement the screening.

Note also that estimates of the sensitivity and positive predictive value of a screen can be made only if both screening results and independent criterion ratings are obtained for a sample of individuals so that the results may be cross-classified in a two row-by-two column table. If the condition being screened for is rare (that is, of less than 10 per cent prevalence), it will be necessary to obtain criterion ratings for a large sample with negative screening results in order to assess sensitivity. b/

Notes

a/ *Teaching Health Statistics: Twenty Lesson and Seminar Outlines*, S. W. Lwanga and C.-Y. Tye, eds. (Geneva, WHO, 1986).

b/ M. S. Durkin and others, "Validity of the ten questions screen for childhood disability: results from population-based studies in Bangladesh, Jamaica and Pakistan", *Epidemiology* (May 1994).

III. DEVELOPMENT OF DATABASES: INITIATING NEW SURVEY WORK

In order for impairment, disability and handicap to be adequately considered in the planning and development of social policies and programmes, there is a need for baseline statistical information on the frequency of disabilities in various subgroups of the population, the living conditions and service needs of people with disabilities, the underlying causes of impairment, and other related topics. The purpose of the present chapter is to provide information and initial steps for the production of statistical information to plan, monitor and evaluate policies and programmes:

(a) To improve the quality of life of people with disabilities;

(b) To increase opportunities and participation of persons with disabilities;

(c) To reduce the incidence of disease and trauma that cause impairments and disability.

Before statistical information can serve these purposes, relevant indicators of frequency, circumstances such as handicap, and rehabilitation needs must be agreed upon and guidelines for measuring those indicators developed and implemented. Proposed indicators are described in subsection D.2 of this chapter.

Chapter II of this manual stresses the importance of using existing statistical information as much as possible to develop a profile of disability in one's population. In the process of reviewing all existing sources of data and developing a profile, one may find that sufficient information is being produced by census, survey and administrative programmes to compute required disability indicators. Alternatively, one may find critical gaps and limitations. The suggestions put forth in this chapter are intended for situations in which a need to produce new information has been identified. Considerable work is yet to be done to develop internationally recognized and accepted definitions and criteria as well as instruments for measuring disability and related concepts. It is hoped that the following suggestions will stimulate progress in these areas. As progress is made, the suggestions will of course require revision.

A. Suggestion 1: Consulting people with disabilities

It is essential to consult organizations of people with disabilities and other interested organizations on the following issues:

- Development of questionnaires;

- Consideration of ethical issues, language and fielding strategies;
- Public relations and education campaigns regarding the survey.

Persons with disabilities, organizations that represent them and proxy informants such as family members and carers can be asked to describe their experiences with handicap so that these experiences may be taken into consideration in the planning of survey questions.

B. Suggestion 2: Reviewing ethical standards

Any plan to produce statistical information on disability in a population should conform to basic and internationally recognized ethical standards for survey and epidemiological research. These include:

- Voluntary and informed consent: Unless anonymous administrative data are to be used, participation in the study should be voluntary, the decision not to participate should have no unfavourable repercussions for potential participants, and potential participants should be informed of these arrangements prior to agreeing to participate in the survey;
- Confidentiality: All data collected should be kept confidential and not used in any way that could cause harm or embarrassment to participants. The names of individuals providing data are never to be used in materials prepared for distribution;
- Referral to services: A strategy should be developed in advance of the survey to provide referrals of individuals identified during the course of the survey who are in need of medical or rehabilitation services. It is imperative that false promises of services not be allowed during the fieldwork of the survey;
- Adherence to quality standards for surveys and data collection: Failure to adhere to standards for data collection could result in data that are not useful, resulting in a waste of public funds as well as of the time and effort of survey participants and field staff;
- Dissemination of results: Failure to analyse the data collected and publish or otherwise disseminate the information obtained in a timely fashion results in waste of valuable resources expended in planning and implementing the data-collection procedures;
- Protection of survey participants from potential harm: Data-collection procedures that could potentially harm participants should

be avoided. The safety of individual participants in a survey takes precedence over potential benefits to be gained by the population as a whole as a result of the information collected. 28/

C. Suggestion 3: Defining the population of interest

The population is the universe about which information is desired. When information is wanted on the frequency of disability, the population may consist of all persons in a nation or other geopolitical unit, such as a region, a district, a province, a city, a health district or another unit. The population may be further defined by age group (for example, children ages 0-14, persons over age 15, persons over age 65); occupational group (for example, agricultural workers, construction workers, office workers); and other special groups (for example, ethnic groups, immigrants, refugees, homeless people). If information is needed on the prevalence of disability in a country, the population would be the entire population of the country, not only a subpopulation with disabilities. If information is needed on the use of technical aids by people with impairments or disabilities in a country, the population would include all people with impairments or disabilities in the country. Defining as precisely as possible the population of interest is a first step in evaluating and developing statistical information on disability.

D. Suggestion 4: Defining the domains of interest

A domain of interest refers to the specific information that is needed about a population. It can be defined in terms of:

(a) Topics;

(b) Indicators;

(c) Research and policy questions.

1. Topics

The most basic statistical information about disability is its frequency and distribution in the population:

(a) The number of persons with disability according to age group, sex and type of disability;

(b) The overall or crude prevalence of disability (number of people with disabilities per 1,000 people in the population);

(c) The prevalence of disability in each age group (0-4, 5-9, 10-14, 15-19, 20-29, 30-39, 40-49, 50-59, 60-69, 70-79, 80-84, 85 or over);

(d) The prevalence of disability in males and females, by age group and for all ages and by urban/rural residence.

Detailed information about disability in the population that may be further required includes:

(a) The prevalence of specific types of disabilities, including serious difficulties in seeing, hearing, walking or moving about, doing manual tasks, speaking, communicating, learning and thinking (these can be defined and classified using broad or detailed ICIDH categories and codes); 1/

(b) The underlying conditions and causes of impairments and disabilities in the population and the extent to which causes are known. Broad categories of the causes of impairments are given below. (Within these broad categories, specific factors may operate during various stages of life (prenatal, perinatal, postnatal or later). Each of these broad categories can be further categorized according to specific underlying conditions and/or diagnoses, which can be coded using WHO'S *International Classification of Diseases*, Ninth revision (ICD-9) 29/ or WHO'S *International Statistical Classification of Diseases and Related Health Problems* (ICD-10), Tenth revision, 1992. 4/) The broad categories include:

(i) Infectious and parasitic;

(ii) Genetic;

(iii) Nutritional;

(iv) Injury and trauma;

(v) Other diseases and conditions;

(c) The severity, estimated duration (outlook), age at onset of disability. Categories and codes for severity and duration are proposed in ICIDH 1/ and summarized in annex III.1. The ICIDH severity scale includes six levels of disability severity. A 10-level severity scale was used in national disability surveys carried out in the United Kingdom of Great Britain and Northern Ireland; 30/

(d) The previous use by people with disabilities of medical and rehabilitation services, personal assistance and assistive technology as well as current needs for these;

(e) The impairments associated with the disabilities identified; experience with handicaps associated with the disabilities identified;

(f) The quality of life of people with disabilities (living conditions, health, social and economic conditions);

(g) The barriers to full participation by, and equal opportunities for, people with disabilities (prejudice, absence of environmental modifications to enable mobility, issues of integration and independent living);

(h) Public attitudes towards disability and towards government responsibility to protect the rights of people with disabilities;

(i) Social and economic characteristics not mentioned above, including marital status of an adult with disability or of the parents of a child with disability; household income and expenditures; leisure activities; and school attendance;

(j) General health and nutritional characteristics, including height, weight, caloric intake, medical history and current health status;

(k) Current access to and use of services for primary and secondary health care, family planning, rehabilitation, compensatory economic measures, counselling and employment. 31/

2. Indicators

An indicator is a summary measure of a population characteristic used to measure changes or monitor progress with respect to national goals or programme targets.

The design and production of indicators of disability

The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities indicate that Governments assume the ultimate responsibility for the collection and dissemination of information on living conditions including obstacles that affect the lives of persons with disabilities. The WHO member States of the European region prepared indicators to evaluate and monitor the regional targets of the Global Strategy for Health for All by the Year 2000 (EURO/HFA) 32/ and included the following impairment- and disability-related indicators.

Box III.1. Strategy for health for all, European region a/

EURO/HFA target 3: Better opportunities for people with disabilities

- Percentage of persons with disabilities of working age engaged in occupational activities (EURO/HFA indicator 3.2)

EURO/HFA target 4: Reducing chronic diseases

- Number of days of temporary disability per person per year, by age and sex (EURO/HFA indicator 4.1)
- Percentage of the population experiencing different levels of long-term disability, by age and sex (EURO/HFA indicator 4.2)
- Disability-free life expectancy (DFLE) b/ at birth and at ages 1, 15, 45 and 65, by sex (EURO/HFA indicator 4.5)

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a/ See WHO, *Health for All Targets: The Health Policy for Europe*, updated ed., Health for All Series, No. 4 (Copenhagen, WHO Regional Office for Europe, 1993).

b/ A synthetic indicator of mortality/disability, following the initial work by Statistics Canada and l'Institut national de la santé et de la recherche medicale (INSERM) of the network on health expectancy (Réseau d'espérance de vie en santé (REVES)). See J. M. Robine, "Estimating the value of disability-free life expectancy (DFLE) for Western countries in the last decade: how can this new indicator of health status be used?" *World Health Statistics Quarterly*, vol. 42, No. 3 (1989), pp. 141-150. In French.

It is generally agreed that the type of information requested for the EURO/HFA targets will have to be met largely through surveys.

In 1993, the framework for the third monitoring of progress towards Health For All issued at the global level included an additional disability-related indicator, jointly developed by the Statistics Division of the United Nations and WHO:

Box III.2. Disability-related indicator a/

The number of people identified as having one of the following types of disabilities:

(a) Seeing;

(b) Hearing;

(c) Speaking;

(d) Moving;

(e) Learning/comprehending;

(f) Other (to be specified).

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a/ WHO, *Implementation of Strategies for Health for All by the Year 2000*, third monitoring of progress: common framework CFM3 (WHO/HST/GSP/93.3) (Geneva, 1993).

A similar indicator has been developed with the United Nations Children's Fund (UNICEF), WHO and the Statistics Division of the United Nations for use in assessment of progress towards the aims of the World Summit for Children. 33/ It is shown below:

Box III.3. Health goals of the World Summit for Children

GOAL: Improved protection of children in especially difficult circumstances.

Indicator: The total number of persons with disability, specifying the number having serious difficulty, of a duration of at least six months or of an irreversible nature, in age groups 0-4, 5-14, 15-19, and 20 or over):

- Seeing
- Hearing/speaking
- Moving
- Learning/comprehending
- Having strange or unusual behaviour

- Other disability

The total disability rate: Rate per 1,000 children age groups 0-4, 5-14, and 15-19, and adults aged 20 years or over.

Countries are also encouraged to report recent rehabilitation service coverage by type and age group. These indicators are currently being developed.

The basic requirements for the development of any disability indicator include:

- A definition of disability;
- A means of identifying persons with disabilities;
- Valid estimates of disability prevalence rates by age group and sex.

An example of the way in which indicators may be derived from the basic cross-tabulations of survey research on disability is provided below. This example assumes that only three basic cross-tabulations are available.

Table III.1. Population by major geographical location, sex and type of disability, if any

Geographical area, municipal ward or village council area	Total	Not with disability	Persons with disability				
			Total with disability	Type of disability			
				(1)	(2)	...	...
Total country							
Both sexes							
Male							
Female							
Major region or geographical area							
Both sexes							
Male							
Female							
And so on ...							
Both sexes							
Male							
Female							

Table III.2 is particularly important when planning CBR programmes, since it offers information on the number of persons in each major geographical area (such as province, major city, or municipality) who report a disability. This table could be additionally supported by a more detailed cross-tabulation showing the age distribution of persons with disability in each area where CBR programmes are being planned. The prevalence of disability could thus be compared among each of the areas.

Table III.2. Population by urban/rural residence, type of disability, age group and sex

	Total	Not with disability	Persons with disability	
			Total with disability	Type of disability
Total country				
Both sexes				
All ages				
0-4				
5-9				
10-14				
15-19				
20-24				
25-29				
30-34				
35-39				
40-44				
45-49				
50-54				
55-59				
60-64				
65-69				
70-74				
75-79				
80-84				
85-89				
90-94				
95-99				
100 or over				
Male				
Age groups ...				
Female				
Age groups ...				
Urban				
Both sexes				
Age groups ...				
Male				

- Age groups ...
- Female
- Age groups ...

Rural

- Both sexes
- Age groups ...
- Male
- Age groups ...
- Female
- Age groups ...

And so on ...

From table III.3, the following statistics and indicators requested by WHO and UNICEF and by the European Community may be produced:

(a) The number of persons in the country reporting a disability, according to age and sex (urban and rural areas);

(b) The prevalence of disability per 1,000 population (males, females and total population, as well as for urban and rural areas);

(c) Disability-free life expectancy (DFLE) or the estimation of average years of life lived without disability for the total population (male, female, total population; at birth, at age 65). 34/ The production of this synthetic indicator also requires information about age-specific mortality of the population;

(d) Percentage of total life spent with disability: a ratio based upon DFLE that compares the percentage of estimated years with disability with the total expected years of life;

(e) Age-sex pyramid of disability, based upon the number of males and females in each age group;

(f) Sex ratio of persons with disability, or the ratio of males with disability to females with disability.

Box III.4. Example of using cross-tabulations to produce an indicator

EURO/HFA target 3: Better opportunities for people with disabilities

- Percentage of persons with disabilities of working age engaged in occupational activities (EURO/HFA indicator 3.2)

One would request the cross-tabulation (table III.3) showing the population aged 15 years or over with disabilities according to age, sex and current activity status.

From table III.3, when completed, the following indicators can be prepared:

(a) The percentage of persons with disability of working age engaged in regular occupational activities;

(b) The percentage of women and men with disability who are unemployed;

(c) The sex ratio of employed persons with disability (employed males with disability/employed females with disability).

The purpose of these examples is to demonstrate that a number of important disability indicators may be produced with the use of two or three basic cross-tabulations from censuses or surveys. It is imperative to anticipate the statistics to be developed from each tabulation requested, so that the analysis remains feasible both financially and in terms of available staff within a given time-frame.

Table III.3. Population with disability aged 15 years or over, by sex, age group and current activity status

	Total	Current activity status										
		Currently active										Not stated
		Total	Employed	Unemployed			Not currently active					
				Total	First job seeker	Worked before	Total	Household duties	Studies	Retirement	Other	
Total population with disability												
Both sexes												
Total												
15-19												
20-24												
25-29												
30-34												
35-39												
40-44												
45-49												
50-54												
55-59												
60-64												
65-69												
70-74												
75 or over												
Male												
All age groups ...												
Female												
All age groups ...												
Disability type I and so on												
Both sexes												
All age groups ...												

UNICEF/WHO recommend that disability prevalence rates be estimated separately for the age groups 0-4, 5-14, 15-19, and 20 or over, for males and females, and for rural and urban populations. They also recommend that countries report recent rehabilitation service coverage by type and age group. 33/ Specific and detailed guidelines for measuring disability and for calculating disability prevalence and programme coverage must still be developed.

When a formal statistical indicator pertaining to disability has been agreed upon, the indicator itself defines the domain of interest. An example is the indicator mentioned above: prevalence of disability in the population. The guidelines for this indicator specify that it should represent the estimated number of people with a disability in designated age groups per 1,000 people in those respective age groups in the population, using agreed concepts and definitions of disability.

There is significant and increased attention being given by the international community and by Governments to the development of global indicators relevant to disability. All indicators should be presented in as value-free a manner as possible. The wording should be carefully considered to avoid the erroneous implication that people who experience functional limitations are of lesser worth.

It is recommended that DFLE 34/ and life expectancy estimates be implemented as core indicators in health statistics. Estimates of the proportion of life expectancy with impairment, disability and/or handicap can then be derived. The sources of age-specific impairment, disability and handicap rates used in the calculation of DFLE should be clearly explained, using ICIDH terminology. 35/

3. Research and policy questions

Statistical information is useful ultimately if it can help answer important research or policy questions. The best way to delineate domains of interest is to phrase the question or questions one eventually wants to answer and define the specific information needed to answer those questions. Questions relevant to disability range from basic ones about frequency and distribution in the population to those concerning specific rehabilitation needs, or the impact or success of public policies or programmes. Several examples of research or policy questions calling for statistical information on disability are given below, along with the respective domains of interest.

Example:

Research or policy question	Domain of interest
How does the prevalence of disability vary by age, sex and urban/rural residence?	Prevalence of disability in each age group (number with and without disabilities in each age group), for males and females, urban and rural area
How do people with disabilities compare with others in terms of major socio-economic indicators?	Within specific age groups, mean values and frequencies of people with and without disabilities in terms of years of education; literacy; household income, expenditures and assets; housing conditions; occupational rankings
How has national legislation to facilitate equal access of people with disabilities to opportunities affected the physical mobility of people with disabilities?	Changes over time (before and after enactment of the legislation) in indicators of mobility of people with disabilities. Possible indicators of mobility include participation in activities such as school, organized recreational activities, work outside the home and social events; number of people with disabilities using public transportation, libraries, museums and other facilities; and survey results concerning people's perceptions of changes in distances covered
What proportion of people with disabilities in need of rehabilitation services are being served?	Estimates of the number of people with disabilities in the population, and the number within this group who are using the services
What are the reasons for non-use of rehabilitation services by people with disabilities?	Reasons given by people with disabilities and their families, by service providers, and by administrators, for not using the services; estimated frequency of each reason
What are the average number of years of life expectancy with a moderate/severe disability for women and men? According to type of disability? What percentage of total life expectancy is spent with disability?	Estimates of life expectancy with and without disability by sex

E. Suggestion 5: Reviewing existing sources of information

The importance of a thorough review of existing sources of information by the agencies responsible for the collection and dissemination of information on disability in the population cannot be overstated. Too often, surveys to collect new data on disability are planned and undertaken without making use of what is already known.

Box III.5. A national example of "no existing data"

Recently, a ministry in a country applied for international funds to plan, carry out, and disseminate the results of a large survey to determine the prevalence of disability in the population and obtain information about the economic activity of people with disabilities. The applicants specified that the work needed to be completed within six months of the application date. In response to this application, the funding agency asked the applicants to provide a summary of current information on disability in their country, and to identify the specific needs for additional information. The applicants responded that they were unaware of any previously collected data or published statistical information on disability in their country. This response provoked a reviewer of the application to compile a preliminary summary of previously published information on disability in the country. No fewer than five major sources of existing information were identified:

(a) The national census;

(b) A national demographic survey;

(c) A demographic sample survey focused specifically on people with disabilities;

(d) A labour force survey;

(e) A national survey of disabilities in children.

It was clear from the existing information that persons with disability were much less likely than the general population to be economically active, and this was what the ministry had initially hoped to determine. The final response to the application was that the information could be obtained with little cost and within the six-month time constraint by using existing sources of information.

The above example serves to reinforce the importance of thoroughly reviewing existing information before considering proposals for additional data-collection efforts. Three main advantages of using existing data are:

(a) Time. The work involved can be done in much less time than that required to plan and carry out new data collection and analyse the results;

(b) Cost. The cost is much less than that of a new survey or any other data-collection effort;

(c) Identification of specific needs for additional data collection. Specific gaps and needs for additional information can be identified so that new data-collection efforts can complement, expand upon and improve rather than duplicate previous ones. Thus, review of existing sources of data is a critical step in identifying specific needs for additional data collection.

F. Suggestion 6: Time projections

With few exceptions, the decision to collect new data for the purpose of developing useful population information is a long-term commitment. If the decision is made to collect census data on disability by adding or modifying questions in the national census, initial steps must be made several years in advance of the census date. Furthermore, an additional few years will elapse after the census data have been collected before those data are processed and the required statistical information is available for public use. For national censuses undertaken every 10 years, it is recommended that contacts be made with the statistical office responsible for carrying out the census, and a proposal drafted for inclusion or modification of questions on disability at least six years prior to the anticipated date of the census. Therefore, the decision to use the national census and post-censal household survey programmes as a means of developing statistical information on disability in a population involves a minimum 10-year commitment.

Sample surveys

These are generally a much more rapid and efficient means of producing statistical information than population censuses. Nevertheless, the time between initial planning and release of the information from a sample survey can be as long as five or six years. The actual time requirements will be a function of factors such as:

- Amount, complexity and accuracy of the information required;
- Ease with which a sample can be selected and individuals contacted;
- Extent to which the survey can incorporate previously developed methods of data collection (for example, previously tested questionnaires, tests of functional abilities, administrative records);
- Size of the sample required.

Rapid methods for estimating the prevalence of serious childhood disabilities in populations with limited professional resources (the ten questions (annex II.3) and disabilities in adult populations (the 22 basic questions (annex II.2) have been developed and tested in several countries. 24/ Using these methods and given a well-trained and motivated survey and assessment team, reasonably accurate estimates of prevalence can be made within a two-year period.

Attaching a set of disability questions onto a sample survey that has been prepared for another or related topic can constitute a particularly efficient use of the sample survey method to collect data on disability. However, this approach, too, requires ample advance planning. First, it is necessary to contact the agency responsible for carrying out the survey to find out when the next survey is likely to be scheduled. Agencies responsible for ongoing or regularly scheduled surveys include ministries or departments of labour, health, education and social welfare, as well as central statistical offices and other agencies and organizations. Typically, the final questions and forms for a sample survey are prepared and approved at least one year prior to the start of the fieldwork (data collection). Therefore, the initial contacts and proposals to include questions on disability may need to be made two or three years in advance of the start of the survey fieldwork.

One-time or ad hoc surveys can also take three to five years to complete, including time for preparation, fieldwork, data processing and analysis, and production of a report.

Ongoing sample survey programmes have important advantages over ad hoc or one-time surveys for the collection of data on disability. One advantage is that ongoing survey programmes can make maximum use of the resources initially expended, including the time and other resources used in preparing for the data collection as well as the trained personnel and other resources dedicated to collecting, processing and analysing the data on a regular basis. Another advantage of ongoing survey programmes is that they offer opportunities to learn from previous experiences, so that the quality and usefulness of the information produced can be advanced with each new survey. A third advantage of ongoing survey programmes is that they allow for ascertainment of changes over time in key indicators. Analysis of changes over time in indicators such as frequency of various types of disability, severity of disability, quality of life, opportunities and participation of people with disability, and rehabilitation needs of a population can play a critical role in programme and policy evaluation.

G. Suggestion 7: Considering how the data will be used to provide information or to answer a question, before finalizing plans for data collection

Several steps are involved between the initial plan for data collection and the release of a report containing statistical information. These include:

(a) Data collection;

(b) Coding;

(c) Data entry;

(d) Data processing;

(e) Statistical analysis;

(f) Interpretation;

(g) Preparation of a report.

Box III.6. Data collection

In constructing statistical information for a population, data must be collected on relevant variables for all individuals or a representative sample of individuals in the population. Three general methods of collecting data on disability are:

(a) Abstracting data from administrative records or linking them from computerized files;

(b) Filling out questionnaires or forms designed for collecting data from what individuals say or think;

(c) Observing behaviour, physical features, test performance or laboratory or examination results.

To ensure successful data collection, standard procedures must be developed, tested and followed; persons following the procedures must be trained in advance and monitored throughout the data-collection process; and routine spot checks should be made to assess the quality and completeness of the data.

Box III.7. Pretesting

The importance of pretesting and trial use of the questionnaire cannot be overemphasized. Pretesting the questionnaire means that time is spent trying out the interview, timing how long it takes to do the interview, and observing the interview as it occurs. Notes are taken and summarized by the observer and by the person doing the interview about the way in which the questions were received; misunderstandings that occurred; and language that was not understood.

During the pretest, one would check to see that the covering page of the questionnaire is adequate; that the screen for adults and children is working appropriately; that people are not embarrassed or insulted by the questions; that people have answers to the questions being asked (for example, not all people know the exact medical diagnosis of the underlying condition causing an impairment); and that appropriate questions are asked.

Box III.8. Questionnaires

A questionnaire is a standard form containing questions or items of information and an instrument for systematic data collection. The purpose of a questionnaire is to ensure that comparable data are collected from all individuals in the sample. Questionnaires can be self-administered by the respondent (the individual for whom data are being collected) if the respondent is literate and capable of filling out the questionnaire. They can also be administered as a personal interview by trained interviewers. Self-administered questionnaires cost less to administer, but personal interviews are necessary in many circumstances to enhance the accuracy and completeness of the data. Questionnaires can be relatively structured, meaning that structured answers or options are provided for the respondent to choose from or tick off. An example of a structured question is:

Does the child have difficulty (check all that apply):

__ Seeing
__ Dressing
__ Understanding
__ Hearing
__ Feeding
__ Communicating
__ Walking
__ Talking
__ Other

The questions on a questionnaire can also be open-ended, meaning that the respondents are encouraged to answer the questions in their own words and to provide whatever information comes to mind. An example of an unstructured question is:

> Please describe what you see to be the child's functional limitations, by which I mean the basic functions or activities that the child has trouble performing when compared with other children of his/her age.

In general, highly structured questionnaires are preferable for obtaining systematic data for statistical analysis. For categorical variables, the responses on structured questionnaires can be pre-coded (assigned numerical codes).

Box III.9. Data entry

Data entry involves transferring the coded data from forms or questionnaires into a computerized format. Personal computers and commercially available software packages may be used. Several steps can be taken in the data entry process to ensure accuracy entailing clearly designed forms, routine spot checking of data entered by comparing them with data recorded on the forms, and use of data entry programmes that check the data for logical consistency and out-of range values. To prevent accidental loss of data, a backup file of data previously entered should be made periodically during each data entry session. In addition, daily and weekly backup files should be made of all data collected.

Box III.10. Data, databases, variables and coding

Data are the observations or facts used to construct statistical information. A database is a compilation of data, and is usually computerized. Variables are factors about which data are collected and for which numerical values have been assigned. Age, sex, presence of disability, type of disability, severity of disability, previous use of rehabilitation services, and current need for rehabilitation are examples of variables that might be included in a disability database.

To be useful for developing statistical information, data must be systematic and quantitative. "Systematic" implies that the variable has been well defined and that the same structured method is used to collect the data for every individual in the sample. Systematic collection of data is necessary to ensure that the data are comparable from individual to individual. "Quantitative" implies that the data have been given numerical values. Some variables are inherently numerical or quantitative, such as age, height, weight, and test scores. Other variables are qualitative (categorical) and must be given an arbitrary numerical code before they can be analysed statistically. Examples of qualitative variables with arbitrarily assigned numerical codes are:

Variable	Value and code
Disability present	No = 1
	Yes = 2
	Not known = 9

Box III.11. Data processing

Data processing involves the creation of summary tables or graphs that indicate the frequency of completed forms or questionnaires along with frequencies corresponding with each data item. Below is an example of a frequency table from the 1988 Survey of Disabled and Aged Persons conducted by the Australian Bureau of Statistics. a/

Frequency of severe disability by age

Age group	Number	Percentage
5-14	53 300	10.4
15-29	44 900	8.8
30-44	73 200	14.3
45-59	85 400	16.7
60-69	85 800	16.8
70 or over	169 000	33.0
Total	511 600	100.0

In addition to simple frequency tables, data processing involves the preparation of cross-tabulations of two or more data items (variables). The following cross-tabulation is from the 1988 Survey of Disabled and Aged Persons conducted by the Australian Bureau of Statistics. a/

Frequency of severe disability by age and living arrangement

Age group	Number (percentage) living alone	Number (percentage) not living alone
5-14	(not available)	
15-29	1 796 (4.0)	43 104 (96.0)
30-44	2 708 (3.7)	70 492 (96.3)
45-59	6 832 (8.0)	78 568 (92.0)
60-69	9 181 (10.7)	76 619 (89.3)
70 or over	56 108 (33.2)	112 892 (66.8)
Total	82 367 (16.1)	429 233 (83.9)

The goal of data processing is to prepare the information collected for statistical analysis, interpretation and reporting.

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a/ I. Castles, *Carers of the Handicapped at Home, Australia, 1988* (Canberra, Australian Bureau of Statistics, Commonwealth of Australia, 1990).

Box III.12. Statistical analysis

Statistical analysis involves calculating estimates of population characteristics from data collected for a sample from the population. [a] Some examples of statistical estimates relevant to impairment, disability and handicap are given below.

Survey estimates should be accompanied by corresponding estimates of sampling error, at least for the major variables obtained in the survey. These are used to construct confidence intervals around the estimates to indicate the range in which the "true" population value lies, while remembering that the survey is based on a sample rather than on the entire population. In comparing two different estimates - for example, the proportion of females with disabilities with that of males with disabilities - tests of statistical significance should be carried out to ensure that the observed difference has not occurred owing to chance, again as a result of the fact that samples were used to generate the estimates.

The steps to be taken to obtain statistical estimates depend on the study design and sampling method and are described in textbooks of statistics and survey methodology. The goal of statistical analysis is to facilitate the interpretation and policy recommendations to be made from the data collected. The results of statistical analysis should be summarized in a written report for distribution to the appropriate audiences.

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[a] S. W. Lwanga and C.-Y. Tye, eds., *Teaching Health Statistics: Twenty Lessons and Seminar Outlines* (Geneva, WHO, 1986).

Examples:

- The total number of people with disabilities in the population;
- The proportion of people in the population with a disability. This proportion may be expressed as the number of people with a disability per 1,000 people in the population (in other words, prevalence);
- The prevalence of specific types of disability;
- Data from programmes with reference to school attendance, labour force participation, services received, and participation in family and community life;

- Survey reports of services received (namely, educational, health, social);

- The range of expenditures on rehabilitation services per capita (for example, from a minimum of zero to a maximum of $10,000);

- The ratio of the prevalence of disability in one group versus that in another (for example, prevalence in homeless people versus that in people with established homes).

A useful strategy in preparing for data collection is to think through the steps from data collection, processing and analysis to report writing. Each step should be planned with all subsequent steps in mind. For example, the questionnaire and other data-collection procedures are developed after a thinking through of the following: how the data will be processed and analysed, and the nature of the statistical information that will eventually be reported. All aspects of the data-collection plan must be reviewed in terms of whether or not they will result in a data set that is useful for providing the information needed, or for answering the policy question posed. In the process of thinking about how the data will be used, one may identify ways in which the data-collection plan could be revised. Perhaps the initial plan called for collection of data that would never actually be used, or omitted the collection of data that would be essential to obtaining the information of interest. Deficiencies and flaws in the data collection plan can often be rectified only if anticipated in advance. The temptation to change the procedures for data collection in mid-course, after the data collection has begun, should be avoided because enormous difficulties may arise in the analysis if the data collected before and those collected after a change in data-collection procedures are not comparable.

H. Suggestion 8: Assessing the quantity and detail of the data to be collected

A balance must be maintained between the need for simplicity and the need for detail. Simplicity of field procedures and of the data to be collected is necessary to ensure that the essential data are obtained, that the fieldworkers and computers do not become overwhelmed, that the individuals providing information are willing and able to provide it, and that the information is eventually used. A great deal of the time, effort and expense of a data-collection programme occurs in the planning phase, in recruiting and training field staff, in selecting a sample, and in making contacts with households and individuals in the sample. Once contact has been made and an interview is in progress, very little extra time and effort may be required to ask each additional question. Decisions regarding how many questions can and should be asked requires judgements about the quantity of information needed and about the resources available for collecting and processing the data.

I. Suggestion 9: Deciding how precise and accurate the statistical information needs to be

Box III.13. Reliability and validity of measurement tools

Reliability refers to precision. Data are reliable if they are consistent and repeatable. If a question such as "Do you have a disability?" elicits different answers when given to the same people on different occasions and when there has been no change in their true status, the question and the data generated are said to be unreliable or imprecise. In order to be useful for producing statistical information, data must have a high degree of reliability. The reliability of a survey question can be assessed by administering the questions on repeated occasions to a sample of individuals and measuring the degree of agreement.

Validity refers to accuracy. Data are valid or have validity if they reflect the truth. A question or other method of measuring has validity if the data it produces are reasonably accurate. A very reliable question can have either good or poor validity, but a very unreliable question cannot have good validity. For example, if you ask a sample of individuals to state their weight and get consistent responses on two occasions you may conclude that the question is reliable. To determine its validity, it would be necessary to compare stated responses with a criterion such as actual measures of weight. Reliability is a necessary, but not sufficient, condition for validity. Useful statistical information on disability must be based on data that have a high degree of reliability as well as validity.

In general, greater resources are required to produce information that has high reliability and validity than to produce information that is cruder or less accurate. For some purposes, relatively crude estimates of the frequency of disability across large population areas may be sufficient. For other purposes, highly accurate information for provinces or even villages may be required. It would be useful if producers of statistical information on disability could provide evidence of reliability and validity to allow potential users to assess the quality of the information. Whenever possible, sampling errors of survey estimates should be presented so that users are knowledgeable of the degree of certainty associated with any estimate.

Another way of defining the reliability and validity of a measure is in terms of the amount of error it contains. Two broad sources of error in data collected in sample surveys are:

(a) Sampling errors;

(b) Non-sampling errors.

1. Sampling error

Sampling error is the difference occurring by chance between the value estimated on the basis of data collected from a sample and the true value in the population. The difference between the estimated and true values can be estimated using theories and methods of probability statistics, provided that a method of probability sampling was employed. Estimates that contain a large amount of sampling error are considered to have low reliability and therefore poor validity. Sampling error depends on the sampling, design and the size of the sample as well as the frequency or variability in the population of the characteristic to be estimated. If the purpose of a survey is to estimate the prevalence of disability in the population and if the true prevalence is very low, the effect of sampling error on the prevalence estimate can be reduced and minimized by increasing the size of the sample, provided a given probability sampling design was used.

2. Non-sampling error

Non-sampling errors are discrepancies between the information obtained and the true information desired about a population; they are independent of sample size and cannot be reduced simply by increasing the size of the sample. There are many potential sources of non-sampling errors in data pertaining to disability. "Non-response" or a situation involving missing information occurs when information cannot be obtained for some of the people in the sample. If information is missing for a large portion of the sample and the individuals for whom the information is missing are different in terms of disability characteristics from those for whom the information is not missing, the data collected will be biased and not representative of the true characteristics of the population. Other kinds of non-sampling errors occur when:

(a) The informant or person providing the information gives incorrect information either unintentionally (perhaps because he or she did not understand the question owing to poor wording or inappropriate language, because the response options were not appropriate, or because he or she did not know the correct answer) or intentionally (perhaps to conceal true information);

(b) The data-collection procedures are not followed consistently by field staff;

(c) Errors occur in coding;

(d) Mistakes are made during computer entry of the data.

In estimating the prevalence of disability in the population, a relatively crude approach, giving results that cannot be assumed to be highly accurate, is to ask one household member if anyone in a household has a disability. Somewhat more accurate information may be obtained by inquiring separately about each individual being surveyed (or asking an informant who knows a given person well) about the presence of disability. The most accurate approach may be to undertake performance or functional examinations of everyone in a sample. The decision of how accurate the information must be to be useful involves weighing the costs and benefits and selecting the most accurate method that one can afford to implement, subject to the costs and time allowed for the results.

J. Suggestion 10: Using probability sampling when appropriate and considering types of sampling and sample size (see box II.5 for definition of probability sampling)

Collecting data on a sample rather than on the entire population has important advantages if the population is large: it can be done in a relatively short time and with fewer resources; the accuracy and completeness of the data can be enhanced and non-sampling error minimized by focusing the data-collection efforts on a relatively small number of units. Sampling error can be accounted for in the analysis if a probability sampling method has been used.

K. Suggestion 11: Enhancing comparability between different sources of information (census, survey, service records, registries)

In developing a statistical profile of disability in a population, it is useful and necessary to select information from various sources. The usefulness of the profile for evaluation and decision-making will be enhanced if comparable definitions and categories have been used in producing the information from different sources. For example, one may want to estimate rehabilitation service coverage as a ratio of the number of people receiving services to the number of people with disability in a population estimated from a sample survey. This approach is valid only if comparable definitions are used in obtaining the numerator and denominator of this ratio.

L. Suggestion 12: Reviewing and making use of previous work on the validity of various methods of collecting data on disability

- Previous work with children has shown that the questionnaire approach may not be as sensitive for detecting even severe seeing and hearing disabilities not previously identified as for detecting cognitive and motor disabilities. 27/ Therefore, it is suggested that whenever possible, performance testing of vision and hearing be done to detect impairments. 36/ Simple and low-cost performance tests of vision and hearing impairments have been prepared by WHO. 37/ The WHO test for vision impairment in infants and children aged three years or under is presented in box III.14. Additional suggestions for performance testing are given in the Guide for Local Supervisors of the WHO manual *Training in the Community for People with Disabilities*. 3/ Once a vision or hearing impairment is detected, it may be possible to make inferences about the presence of disability. For example, if the vision test has detected very low vision in a child and the child does not wear corrective lenses, it could be inferred that the child has a seeing disability.

Box III.14. Test for vision impairment in infants and children aged three years or under

Let the mother sit down and hold the child on her lap.

Hold a burning candle or torchlight 30-50 centimetres (cm) (12-20 inches) in front of the child.

Move the candle from side to side and up and down.

If the child's eyes follow the light, then the child is able to see.

If the child's eyes do not follow the light, repeat the test three times.

If the child's eyes do not follow the light, then the child may have difficulty seeing.

- Previous work has also shown that accurate detection of even severe disabilities in children requires special approaches. 24/, 38/ If a questionnaire or interview approach is used, the questions must be:

(a) Developmentally appropriate, taking into account the age of the child and the abilities expected of a child of that age;

(b) Culturally appropriate, asking about abilities that are expected of children in the child's culture;

(c) Answered by an appropriate respondent, that is, an adult who knows the child well;

(d) Worded in appropriate language, or language that is clear, simple, unambiguous and easily understood by the respondent. Special efforts may be necessary to facilitate successful communication, particularly if the respondent is not literate or has a communication disability.

M. Suggestion 13: Assessing costs of collecting, processing and disseminating new statistical information, and sources of funding

The costs of a survey or other data-collection effort should be estimated in advance so that funding can be secured and the project completed without interruption. Costs are estimated in terms of requirements for:

- Personnel (salaries, benefits, administrative costs);
- Transportation;
- Equipment (for example, computers, printers, telephones, measuring equipment);
- Supplies (for example, stationery, printing, computer supplies);
- Other expenses (for example, telephone charges, food, lodging).

To minimize costs, locally available resources should be used whenever possible. Often personnel paid from other sources can be used. To obtain funding for a survey or other data-collection project, it is necessary to submit a formal proposal with a budget indicating anticipated expenditures and their justification. Guidelines for preparing proposals and budgets may be provided by the funding source. Suggestions for preparing proposals and budgets for surveys are also provided in survey and research handbooks. 39/-41/

Advance planning and incorporation of a disability survey within a regularly planned national census or survey can reduce costs considerably. When this is done, ad hoc budgeting is not required, as the expenses of the survey are included in the regular data-collection programmes of national planning commissions and related ministries (see suggestion 6 above).

When proposing a survey, it is useful to consider the costs of not doing the survey. Disability has multiple costs in terms of lost productivity, lost income, quality of life, and resources required to provide services. If the survey can lead to reductions in disability and handicap, one could argue that it is an investment that will more than pay for itself over time.

N. Suggestion 14: Dissemination of survey results

Statistical offices are encouraged to provide microdata files on impairment, disability and handicap for use by others. These files should be void of personal identifiers. Rapid response by statistical offices to special requests for ad hoc tabulations will facilitate the use of data for planning and policy.

An important consideration in the dissemination of statistical reports is their accessibility to people with impairment, disabilities and handicaps. This may require large-type, Braille, audio formats including audiovisual cassettes, American Standard Code for Information Interchange (ASCII) computer disks, and special computer programmes and interfaces for people with intellectual impairments.

It may be useful to include questionnaires in their original language in survey reports, with explanations of how the variables used to describe functional restrictions were derived from the survey questions, and to show how variables relate to ICIDH by means of a correspondence table.

There is a need for production of reports for different audiences including the general public and the media; people with disabilities and advocacy and support organizations; policy makers including government and business officials; and other statistical organizations, locally and internationally.

Additional tabulations covering the life experiences of people with impairments, disabilities and handicaps are encouraged, particularly data on social and community participation and quality of life. Such tables may include the frequency of going shopping, to theatres, or travelling, and civic and recreational activities.

Adequate documentation published in a report of the survey methods, with field names and locations, file organization, editing procedures that have been performed, and other manipulations that have been carried out, will ensure appropriate use of the data set, including secondary analyses.

Annex III.1

MEASUREMENT OF SEVERITY AND DURATION

Severity is particularly relevant for measurement of disabilities and handicaps. Usually ordinal categories are labelled: mild, moderate, severe (severity is sometimes broken down further, especially when large proportions of the persons being studied are elderly). For impairments, all that may be needed is to know whether impairment is present or not. In countries where grading scales of impairments are used for provision of services, or for disability benefits, then questions concerning these grading scales may be needed in surveys that are assessing services received. For the overall measure of the prevalence of impairment, disability and handicap, and also for estimation of specific disabilities, three or four levels of severity may be distinguished and then tabulated against demographic variables such as age, sex, marital status and household composition.

A. Example of disability severity ratings: optional fourth digit for ICIDH a/

Digit		
0	No disability	No disability present (that is to say, the individual can perform the activity or sustain the behaviour unaided and on his/her own without difficulty)
1	Difficulty in performance	Difficulty present (that is to say, the individual can perform the activity or sustain the behaviour unaided and on his/her own but only with difficulty)
2	Aided performance	Aids and appliances necessary (that is to say, the individual can perform the activity only with a physical aid or appliance)
3	Assistance performance	Need for a helping hand (that is to say, the individual can perform the activity or sustain the behaviour, whether augmented by aids or not, only with some assistance from another person)
4	Dependent performance	Complete dependence on the presence of another person (that is to say, the individual can perform the activity or sustain the behaviour, but only when someone is with him/her most of

the time)

B. Rules for assignment of ICIDH disability severity codes

1. Categorize an individual according to activity performance, taking account of aids, appliances and assistance needed to permit this level of accomplishment.

2. The aids and appliances that it is intended should be provided or prescribed should not be taken into account; this would then permit use of the scale as a rough measure of what was accomplished once such aids or appliances had been provided.

3. If doubt is experienced about the category to which a disability should be assigned, rate it to the less favourable category (that is, the one with the higher number).

C. Example of disability ratings: ICIDH optional fifth digit disability outlook codes

Digit		
0	No disability	No disability present
1	Recovery potential	Disability present but diminishing, and recovery without ultimate restriction in functional performance expected
2	Improvement potential	Disability present but diminishing, though the individual is likely to be left with residual restriction in functional performance
3	Assistance potential	Disability in stable or static state, but functional performance could be improved by provision of aids, assistance or other support
4	Stable disability	Disability in stable or static state with no outlook for improvement in functional performance
5	Amelioration potential	Disability increasing, but functional performance could be improved by provision of aids, assistance or other support
6	Deteriorating outlook	

8 Indeterminable outlook

9 Outlook unspecified

D. Rules for assignment of ICIDH disability outlook codes

1. Categorize an individual according to the outlook for his/her activity performance (that is, disability status), and not for the prognosis of the underlying impairments, except to the extent that disability may correlate closely with the outlook for the impairments, and taking account of aids and appliances, modification or adaptation of the immediate environment, and assistance received from other persons.

2. The aids or adaptations that it is intended should be provided or prescribed should not be taken into account; this would then permit use of the scale as a rough measure of what was accomplished when such an aid or adaptation had been provided. (Note: the ordination of this scale according to the potential for intervention determines that categories reflecting a potential for assistance or amelioration have lower numbers than the corresponding stable or deteriorating categories; thus provision of assistance or amelioration is likely to lead to reassignment to a category with a higher number, since no further potential for improvement can be assumed.)

3. If doubt is experienced about the category to which a disability should be assigned, rate it to the less favourable category (that is, the one with the higher number).

Notes

[a] WHO, *International Classification of Impairments, Disabilities, and Handicaps* (Geneva, WHO, 1980).

IV. USING STATISTICAL INFORMATION TO PLAN AND EVALUATE REHABILITATION PROGRAMMES

Information on disability and rehabilitation in the population is required for planning and evaluation of relevant programmes and policies. The present chapter discusses the use of information for planning, specifically for planning rehabilitation programmes and policies aimed at enhancing functional abilities, integration within society and quality of life of people with disabilities (sect. A). It also emphasizes the importance of evaluating the programmes and policies implemented and provides suggestions for using information as the basis of an evaluation (sect. B). It concludes with a list of specific suggestions and methods for using information on disability and rehabilitation for both planning and evaluation purposes (sect. C).

Within settings where resources are scarce and needs unlimited, the costs of collecting and processing the information must be justifiable. This is possible only if active and sustained efforts are made to put the information acquired to use for planning and evaluation, the ultimate aim being optimal use of resources in the community.

The skilful use of information for planning, evaluation and proposal development may also result in the procurement of additional resources for rehabilitation programmes. Once resources have been committed to a rehabilitation programme, an evaluation employing information on the impacts, successes and weaknesses of the programme is needed to facilitate ongoing commitment to the programme within the community and from governmental and other potential funding agencies. Thus an investment in the acquisition of useful statistical information for planning and evaluation will more than pay for itself if it results in programme expansion and procurement of additional financial and other resources.

Box IV.1. Planning and evaluation as a process

<u>Initial planning</u>	<u>Implementation</u>	<u>Evaluation</u>	<u>Further planning</u> ...
Situation analysis	Programme policy	Process or progress impact	Situation analysis
Objectives		Efficiency	Objectives
Activities		Effectiveness	Activities

A. Information for initial planning

The three phases of planning encompass the processes of:

(a) Analysing the current situation (the situation analysis);

(b) Setting objectives;

(c) Planning activities.

Information is fundamental to each of these phases of the planning process. Before disability will be seriously addressed in government plans and policies, information must be presented showing its importance within the context of the nation's overall health, quality of life and economic situation, as well as the feasibility of proposed solutions. The situation analysis should allow planners to determine whether changes are warranted and feasible as well as the relative priority of a given problem. Three sets of criteria have been outlined by the United Nations Development Programme (UNDP), by which government planners in many countries determine priorities. These have been adapted and expanded for presentation here:

Box IV.2. Information in a situation analysis designed to influence allocation of government resources for rehabilitation and prevention of disability a/

1. Magnitude of the problem and the need for programmes:

   (a) Incidence/prevalence of disability in the population;

   (b) Severity;

   (c) Duration;

   (d) Impact on the health, economic productivity and quality of life of affected individuals and families;

   (e) Availability of services;

   (f) Use of services;

   (g) Unmet needs for services.

2. Technological feasibility:

   (a) Availability of effective technical solutions;

   (b) Time required to obtain trained technical and management personnel.

3. Political and economic feasibility:

(a) Public awareness and concern;

(b) Likelihood of achieving community involvement;

(c) Costs of available solutions;

(d) Budgetary resources.

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a/ Adapted from E. Helander, *Prejudice and Dignity: An Introduction to Community-Based Rehabilitation* (New York, UNDP, 1993).

The situation analysis for government planning of rehabilitation programmes would ideally involve a review of information to assess each of the criteria outlined in box IV.2. In other words, it would involve a review of information to answer questions such as the following:

(a) How many people in the population have disabilities?

(b) What is the prevalence of serious disability in the population?

(c) What percentage of households have a member with a disability?

(d) What segments of the population are most affected by disability?

(e) To what extent are people with disabilities receiving effective rehabilitation services?

(f) To what extent do people with disabilities experience handicap (for example, unemployment, exclusion from school, social isolation)?

(g) What interventions would be feasible and appropriate to help enhance the functional abilities and quality of life of people with disabilities?

(h) Who should be targeted by new or expanded programmes?

(i) What resources could be mobilized for the purpose of CBR?

By almost any measure of magnitude (prevalence, duration, severity, impact on individuals and families), impairment, disability, and handicap have enormous social, economic and public health significance. 5/, 6/ Available statistical information from many countries indicates disability prevalence rates of 15 per cent or higher (DISTAT). Because disability increases with age, the overall prevalence rates of impairment, disability and handicap tend to increase as a population ages. In general, people with disabilities have less access to education, and are more likely to be unemployed and live in poverty than people without disabilities. 6/

Numerous programmes and technical solutions have been developed to improve the capacities, quality of life and productivity of people with disabilities. The manual *Training in the Community for People with Disabilities* 3/ provides information on some practical and accessible solutions (namely, community-based rehabilitation) for people in communities.

Programmes and technical solutions also exist to prevent new cases of disability in the population. These include:

(a) Immunization programmes (for poliomyelitis, rubella and other infections that can result in long-term disability);

(b) Prenatal screening and care programmes (to prevent and manage complications of pregnancy and birth that may result in childhood disability);

(c) Nutritional supplementation programmes (for iodine, vitamin A, folic acid, and calcium deficiencies, in particular);

(d) Environmental and technological interventions to prevent toxicities and injuries, and educational interventions (to reinforce a variety of disability prevention programmes).

Information showing the political and economic feasibility of implementing a programme may include documentation of public concern and commitment, anticipated costs of the programme, and demonstration that the costs can be met with available funds. Public concern can be inferred to some extent from statistics showing the number of households in the community that are affected by disability. More direct information or indicators showing public concern, however, may be difficult to obtain before the establishment of a community-based rehabilitation programme. Expressions of public concern are likely to be suppressed in settings that lack rehabilitation services, owing to prejudice and a lack of public awareness that potential solutions exist. 42/ Once a rehabilitation programme has been established and its effectiveness made known in a community, public awareness and commitment are likely to increase.

Successful community-based rehabilitation depends on inputs from family members or other individuals to facilitate home-based programmes. Therefore, a situation analysis in preparation for a community-based rehabilitation programme should address questions about the availability of potential persons with sufficient time, commitment and ability to provide the necessary services. The cost of community-based rehabilitation programmes can be contained by relying largely on existing resources and structures in the community. 3/, 42/

In the process of planning a new or expanded programme, the ability to obtain comprehensive and accurate information for the situation analysis will determine the success of the planning process and, ultimately, that of the programme. If information is unavailable for a segment of the population, it will be difficult to plan services for that segment. For example, if information on the prevalence of disability in Ireland were limited to that displayed in figure IV.1, which includes only disabilities among not economically active people over age 15 or over, it would not be possible, based on this information alone, to make informed decisions about the rehabilitation needs of the population as a whole. Disabilities in children would not be represented in this data source, and disabilities in women and retirees might be undercounted.

To plan programmes addressing a particular need, information must be obtained on that need, and the information must be sufficiently complete, accurate and detailed. For example, a survey in Viet Nam on the frequency and rehabilitation needs of people with amputated limbs, completed in 1992, provided a comprehensive source of information for planning services to meet the needs of amputees in the community 11/ and may also be useful for persuading governmental and other agencies of the need to allocate resources for programmes and policies addressing the needs of amputees.

The planning process culminates in a set of objectives along with decisions about what steps will be taken to achieve each one. The situation analysis provides the necessary background for a clear statement of the objectives of a programme or policy. The objectives should be justifiable in light of priorities identified and attainable in light of existing resources and technical solutions and politico-economic circumstances. In addition, a useful statement of goals and objectives is one that is clear and unambiguous.

Decisions about steps to be taken to achieve a given set of goals should specify how resources will be allocated to meet the goals. In planning a rehabilitation programme, the plan should state the goals of the programme and identify who will be served (the number of clients and a description of the clients in terms of age, gender, types of impairments and disabilities, severity of disability and handicap), what resources will be mobilized, and what techniques will be used.

B. Information for monitoring and evaluation

Monitoring should be viewed as an ongoing, necessary and integral part of every social programme, 43/ including programmes relevant to disability. Evaluation is rarely performed annually, as it is too costly. However, when an evaluation is done, it should be done thoroughly. Evaluation can also be done on a periodic basis to determine if the objectives are being met. The broad purpose of an evaluation is to document the occurrence and effects of a programme in terms of concepts such as:

- Effectiveness;
- Process;
- Impact;
- Efficiency.

On the basis of the evaluation, decisions are made about whether continued support of, and participation in, the programme are justified. A successful evaluation makes use of information to help achieve this.

To enable useful evaluations of community-based rehabilitation programmes, an information system based on systematically collected data should be built into all programmes from their inception. Evaluation is a natural extension of planning. When a planning process has resulted in changes such as the establishment of a new programme, modifications in an existing programme, or the implementation of a policy, an evaluation is done to measure progress that has been made towards programme or policy goals.

- The process or progress of a programme refers to its implementation and day-to-day operations. A process evaluation documents the extent to which programme implementation has occurred and the extent to which the targeted population has participated. Examples of questions to be addressed are:

(a) What percentage of the targeted population is being reached by the programme?

(b) How often are assessments of function made?

(c) How many persons have been trained to work in the programme?

- The effectiveness of a community-based rehabilitation programme refers to the extent to which the programme has caused improvements in functional capacities, quality of life and integration of people with disabilities in the community. At a macro- or societal level, the effect of a programme is often referred to as its impact.

Evaluation of the impact may employ statistical indicators of desired outcomes. Measures of these indicators over time help to determine what (if any) impact the programme has had with respect to its objectives. Impact evaluations of community-based rehabilitation programmes might involve assessments of the degree to which a programme has achieved community participation. Community participation is a goal of every community-based rehabilitation programme because social integration of people with disabilities is unlikely to be achieved without it, as is demonstrated in a document issued by WHO. 44/ Well-established and tested methods of measuring community participation and other outcomes of successful community-based rehabilitation programmes are not yet available. Suggested methods are described in the final section of this chapter.

- Efficiency refers to a programme's outcomes relative to its costs or inputs.

Inputs	include resources or costs in terms of money, time, personnel, equipment, supplies and other resources required to establish and operate a programme.
Outcomes	include the number of individuals and families served and the benefits of the services provided in terms of improved functioning, increased productivity, satisfaction and other factors.

An efficiency evaluation weighs the impact of a programme against its costs or the resources used. One way to evaluate efficiency is to assign monetary values to both the costs and the benefits of a programme and then to determine whether the benefits have outweighed the costs. A weakness of this approach lies in the difficulty of assigning monetary values to all costs and benefits. Another approach is to compare two or more programmes in an attempt to determine which programme or programmes achieve the most benefits for a given cost, that is, which programmes are most cost-effective or cost-beneficial. For countries that cannot conduct such studies, it should at least be possible to analyse how the costs have been apportioned.

Table IV.1, reproduced from the above-mentioned WHO document on CBR and health care referral services, 44/ lists several components of the information to be gathered for evaluation of CBR programmes along with brief descriptions of each component and the sources of the information.

The remainder of this section of chapter IV provides suggestions for a uniform minimum database and information system to be incorporated into community-based rehabilitation programmes so as to facilitate useful, low-cost and comparable evaluations.

Table IV.1. Information to be gathered for programme evaluation

Component	What to analyse	Source of information
Effectiveness	Degree to which targets and objectives have been met compared with Planned objectives and targets Special focus: people with disabilities	Reports of activities and documented results of activities Field observations and interviews compared with Original programme objectives and targets
Progress	Schedule of programme activities implemented or in progress compared with Planned schedule	Reports on programme activities Field observations and interviews compared with Original broad and detailed programme plans Original schedules of activities at all levels
Impact	Overall effect on health and social development of people with disabilities	Review of situation analysis through policy and programme review
	Special focus: people with disabilities and the community	Field observations and interviews
Efficiency	Impact of programme compared with Resources used	Reports on the results of activities Field observations and interviews compared with Audits and documentation showing resources invested
Relevance	Situation analysis, problems, and programme priorities compared with Broad objectives	Documents containing background information prepared by the national planning committee

1. Process or progress evaluation of community-based rehabilitation programmes

Detailed suggestions with forms and a computer programme for process evaluation of CBR programmes have been prepared by UNDP in A Guide on Operations Monitoring and Analysis of Results (OMAR). 45/ When computers are not available, at the community level, form 2 (annex II.1) from the OMAR manual can be used without the aid of a computer. This form can be modified with separate entry slots for dates so that progress may be shown on one form. Examples of questions for process evaluation of a CBR programme 45/ include:

(a) Has the local supervisor for your community visited all households to locate and identify members with disabilities?

(b) Have you formed a committee in your community for rehabilitation?

(c) Have you started training programmes for all the people in your community who need and want training?

(d) Have you written all the records needed for the people in the programme, including the assessments?

The OMAR manual also includes the form (annex IV.1) for use in process evaluation.

2. Evaluation of the effectiveness of community-based rehabilitation programmes

An effective programme is one that results in improvements in the ability of people with disabilities to carry out activities of daily living, participate in school or work, earn an income, participate in social activities, and function within a community setting. 44/ An effective educational programme may be one that results in a change in community interaction so that many more persons with disabilities are included in social, educational and recreational community activities. Data on several desired outcomes of a programme collected at baseline (at the time of the first encounter of a person with disability with the programme or the time of a community's first exposure to a public education campaign), and again at each follow-up assessment, can be used to provide information on the degree to which improvements have been achieved. These same questions can also be asked in surveys, to be compared with programme reports.

Form 2 (see chap. II, annex II.1) can be used to collect uniform baseline and follow-up data for each participant in the programme. By following the eight steps given below, summary statistics can be produced from the responses to the 25 questions (obtained for all or a representative sample of clients), providing direct evidence of the effectiveness of the programme:

1. Assign a unique registration or identification number for every individual in the programme and enter this on the assessment form completed at each visit.

2. Enter the date of assessment on each form completed.

3. Code the responses to each question on the assessment form as follows: 5 = alone or easily; 4 = with little help, or with little difficulty; 3 = with some help or sometimes or with some difficulty; 2 = with a lot of help or with great difficulty; 1 = not at all; and 9 = missing information.

4. Remove forms that have questions with missing information (responses coded 9) from the analysis.

5. Score each completed form by summing the responses to the 25 questions.

6. Sort the forms by individual and by date.

7. Determine whether or not the scores from forms completed at successive visits show (a) a decline (indicating improved functioning); (b) no change; or (c) an increase (indicating reduced function), coinciding with increased duration of participation in the programme.

8. Summarize the results by counting the number of participants that fall into each group.

Note that:

(a) Similar steps can be followed for each question separately as well as for the total score;

(b) These steps are best carried out using a computer, after the data from the assessment forms have been entered into a computer database.

A hypothetical example of summary statistics from forms completed for 750 participants in a community-based rehabilitation programme is given in table IV.2.

The hypothetical results in table IV.2 suggest that the percentage showing improvement increases with increasing numbers of visits. Such a finding would be consistent with the hypothesis that the programme's effectiveness increases with increases in the duration of programme participation. These results can be compared with survey data showing the number or proportion of people with disabilities reporting that they had actually received services in the past year.

Further insight into the effectiveness of a programme and the reasons for lack of improvement in some individuals may be gleaned from analyses of different strata or subgroups within the overall group evaluated. Possible ways of subdividing the group into subgroups is by sex (males, females), age group, and case group based on diagnostic categories, causes of disability, severity levels or services received. Such an analysis might show that the programme is having more beneficial effects for one subgroup than another, and this may point, in turn, to a need to reinforce efforts to benefit a particular subgroup. It may also show that cases with decreasing function (for example, the 10.2 per cent in table IV.2) are restricted to a subgroup with conditions likely to cause progressive disability even when effective rehabilitation services are provided.

Table IV.2. Example: effectiveness of a hypothetical community-based rehabilitation programme - summary statistics based on the individual assessment/progress form

	Number	Percentage
Participants served	1 275	
Participants served but lacking complete information for at least two visits	525	
Participants included in the evaluation	750	
Among the 750 included in the evaluation		
Participants who showed improvement	254	33.8
Participants who showed no change	420	56.0
Participants who showed a decline	77	10.2
Participants with two visits only (235) showing improvement	47	20.0
Participants with three visits (250) showing improvement	88	35.0
Participants with four or more visits (265) showing improvement	119	45.0
Participants among the 750 included in the evaluation showing improvement on each question		
1.Feeding	188	25.1
2.Dressing		
3....		
4....		

Note: The period covered by the evaluation was three years. The average number of visits per participants was 3.4.

3. Evaluation of community participation

Indicators of community participation include the percentage of people with disabilities in the population who are served by the programme, as well as involvement of community leaders and other members of the community, including people with disabilities, in actions to promote rehabilitation of members of the community with disabilities. 5/ These actions may be aimed at increasing awareness about rehabilitation within the community, making environmental modifications so that physical barriers are removed to allow people with disabilities to have access to public facilities, integrating children with disabilities into local schools, providing training and jobs for people with disabilities, or assisting individual families who have a member with a disability. 44/

Client satisfaction and client assessments of the extent to which their rehabilitation needs are being met may also be evaluated in surveys.

4. Study designs for evaluation of impact

Evaluations of the effectiveness or impact of a rehabilitation programme should employ a scientific study design to enable the evaluator to determine whether (a) the programme goals have been met; and (b) whether changes observed (such as improved function, reduction in handicap) are due to the programme or to some other factor. The strongest scientific study design is a true experiment. A randomized clinical trial is an example of such an experiment. In a randomized trial, individuals are randomly assigned to two or more different situations (for example, different services). At baseline, the group characteristics of individuals randomly assigned to different service groups are similar. If differences in function between the different groups are observed after some time, these differences are assumed to represent the effect or impact of the service. The randomized clinical trial approach is often used to determine whether a specific drug or service is efficacious (in other words, whether it produces the desired effect), but this design is usually impractical for evaluating the impact of a programme that involves implementation of many techniques.

A variety of quasi-experimental study designs have been employed to evaluate the impact of social programmes, 46/ including family planning programmes. 40/ Quasi-experimental designs are used when the experimental technique of randomly assigning subjects to different treatments or regimens is not feasible for ethical and/or practical reasons. These types of designs have not yet been widely used to evaluate the impact of community-based rehabilitation programmes.

An example of a quasi-experimental study design that could be useful in impact evaluations of community-based rehabilitation programmes is the non-equivalent control group design. This design is similar to the experimental clinical trial except that the different service groups are self-selected or selected by convenience rather than randomly assigned. For example, using this design, one may measure outcomes such as "performance of activities of daily living", "participation in society" or "attitudes towards people with disabilities" in two communities before and after the establishment of a community-based rehabilitation programme in one of the communities. The community with no programme is considered the control community. Some time after implementation of the programme in one community, repeat measures of the same outcomes are made in both communities. Impact of the community-based rehabilitation programme is then assessed in terms of the degree of improvements in outcomes in the intervention community relative to the control community. Methods of testing for statistical significance of presumed impacts and of controlling for baseline differences between the two communities are described by Cook and Campbell. 46/ Other quasi-experimental designs that may be useful for evaluating the impact of rehabilitation programmes are described in detail also by Cook and Campbell, 46/ and summarized by Fisher, Laing and Stoeckel. 40/

Impact evaluations of infectious disease prevention programmes may compare the incidence or prevalence of a disease in a population before and after implementation of a programme, and measure the impact of the programme in terms of the percentage reduction in incidence or prevalence. Similarly, the impact of a family planning programme may be measured in terms of the percentage reduction in fertility after initiation of a programme to reduce fertility. We caution that it may be inappropriate to measure the impact of a community-based rehabilitation programme in terms of a percentage reduction in the number of people reported to have a functional limitation following implementation of a programme. This is because one goal of community-based rehabilitation is to raise public awareness of disability and enhance the social roles of people with disabilities. In achieving such a goal, a successful community-based rehabilitation programme is likely to result in actual increases in the reported prevalence of functional limitations in the populations (see sect. D, note of caution, at the end of this chapter).

A review of summary statistics for specific questions may reveal specific strengths and weaknesses of the programme, and/or information about specific needs of the programme's participants or clients.

5. Evaluation of programme efficiency

All income to the programme from government and non-government sources as well as all expenses of the programme should be documented, including recurrent and capital expenses (costs). Recurrent costs include salaries; maintenance of equipment, buildings, and vehicles; ongoing educational programmes; and costs for referral services. Capital costs include buildings, equipment, vehicles and training.

To evaluate the efficiency of a programme, overall costs should be compared with the total number of people served (coverage) and with indicators of the extent and quality of services provided as well as indicators of the benefits achieved. The evaluation of how well the programme is meeting its goals, whether or not more can be done with the resources available, and what additional resources are required involves reviewing information and making judgements regarding the value of costs and benefits.

C. List of specific suggestions for using information on disability and rehabilitation for planning and evaluation

1. Opt for the minimum amount, detail and accuracy of the information that is needed to evaluate the programme. The costs of producing information increases sharply with its detail and accuracy. Resources should not be diverted from provision of services to information systems and planning unless this can be justified.

2. To be useful for comparative purposes, information must be comparable (over time and geographical areas, as appropriate). If baseline assessments are not comparable with follow-up assessments (for example, if different questions were asked at baseline and at follow-up assessments), the information will be less useful for evaluating progress. If information from different communities or subgroups is not comparable, the information will be of limited use for identifying priorities or comparing outcomes.

3. Users of information need cross-tabulations and appropriately refined categories to address complex policy questions or plan an appropriate programme. Data collection and analysis should be done in close proximity to the site of usage of the information. Users should be involved in data collection to ensure that the information is useful for purposes of planning and evaluation.

4. Part of planning is defining precisely what information is needed. A match between what the information system provides and what information is needed for planning is necessary.

5. Within a context of scarce resources and unlimited needs, planning becomes a question of determining how best to allocate resources. What programme or technique will produce the most benefit with the limited resources available?

6. Specific information needed for planning:

    (a) Indicators of disability:

- Prevalence;
- Incidence;
- Incidence and prevalence of major causes of disability;
- Age distributions of people with and without disabilities;
- Sex differences in prevalence;
- Geographical differences;
- Social class and ethnic differences;

(b) Indicators of quality of life, economic stability, handicap of people with disabilities, social attitudes, public policies, met and unmet needs;

(c) Indicators of resources, their level, type and distribution (finances, personnel: voluntary and paid, trained and untrained, buildings, equipment, supplies, training, transportation), sustainability of programmes.

7. Specific information needed for evaluation: number of people served, number of people still needing services and not served, process, impact and efficiency, number of people served per provider. Guidelines may need to be developed to measure client satisfaction and reduction in handicap.

8. Analysis: transforming data into information.

9. Presentation: numbers, tables, descriptions, charts, graphs.

10. In planning and evaluation of community-based rehabilitation programmes, we ask these questions:

    (a) What are the goals and objectives?

    (b) Who are the clients?

    (c) How will goals be achieved?

    (d) What progress has been made?

    (e) How should the goals be revised?

Note of caution

The prevalence of reported disability in a community may actually increase in response to a successful community-based rehabilitation programme. This is because one community-based rehabilitation programme goal is to increase awareness of disability, acceptance of people with disabilities, and visibility of people with disabilities within the community. A successful programme could therefore cause an increase in the prevalence of reported disability in the community as measured by a survey or administrative records. Thus, both decreases and increases in estimated prevalence of disability should be interpreted cautiously as indicators of the effectiveness of a programme. Reductions in prejudice and stigma associated with disability could make it easier for people to report disability in surveys. Improved services for people with disabilities will increase the administrative prevalence of disability (that is to say, the number of people with disabilities receiving services). Increased recognition, sensitivity and knowledge, especially with respect to mild disability, may also result in increased prevalence of reported disability. Changes in the frequency of causes of disability, such as war, famine, natural disaster, and epidemics, could result in increased prevalence of reported and actual disability even in settings well served by comprehensive community-based rehabilitation programmes. Because of the difficulties in measuring the impact of rehabilitation programmes, it is especially important to conduct ongoing process evaluations of implementation, as well as evaluations of impact on intermediate outcomes, such as public awareness of disability and acceptance of people with disabilities.

Annex IV.1

QUESTIONNAIRE (FORM C)

(To be used by the person responsible for the programme at
the national or regional level)

A. The person interviewed/supplying information is:

Name _____________________________ Function ______________________________

B. Name of interviewer _______________________________ Date __________________

1. Is there a national policy and a national plan on rehabilitation?
___ Yes (enclosed) ___ No

2. Are there written national guidelines for non-governmental organizations working with rehabilitation? ___ Yes (enclosed) ___ No

3. What are the objectives of your programme?

(Enclosed)

4. What has been achieved so far?

5. What has not been achieved and why?

6. How many persons with disabilities have been identified? How many of those identified need rehabilitation? How many of those identified are actively involved in your programme?

7. How has cooperation and coordination with other rehabilitation partners been carried out? What is the experience?

8. How is the Government supporting the programme?

9. Have organizations of people with disabilities/parents been involved? How? What is the experience?

10. What major problems or constraints have affected the programme? What corrective measures have been taken?

11. What training of staff has been provided?

12. How has the problem of the need for transport to reach the beneficiaries been solved? What is the experience?

13. Has the programmes had any unforeseen effects or problems?

14. Can the programme continue without international assistance? If so, specify.

15. What are the most important findings of the programme?

16. What, if any, are the lessons learned from this programme?

The OMAR manual can be obtained by writing to:

Interregional Programme for Disabled People
Division for Global and Interregional Programmes
United Nations Development Programme (UNDP)
Palais des Nations
CH-1211 Geneva 10
Switzerland

V. INFORMATION ON IMPAIRMENTS, DISABILITIES AND HANDICAPS IN ESPECIALLY DIFFICULT CIRCUMSTANCES

Especially difficult circumstances include refugee camps and emergency relief situations for communities exposed to armed conflicts, famine, and natural and human-induced disasters.

The aftermath of emergency situations as well as ongoing political violence often impose especially difficult circumstances on communities for extended periods. These circumstances, not uncommon in the world today, appear to be increasing in terms of both incidence and impact on human life. 47/

Statistical information on disability in these situations is scant. Yet the incidence and prevalence of impairments and disabilities are clearly increased in communities under such conditions. This is because one or more of several interrelated causes of impairment and disability is likely to be increased: severe physical and psychological trauma and stress, infectious diseases, nutritional deprivation, inadequate medical care, and disruption of family and other support systems.

The purposes to be served by statistical information in these situations can be categorized as immediate, post-immediate or long-term. 48/

Immediate purposes:

- To document the number of people with impairments and disabilities, among non-combatants and combatants, and to assess immediate needs;
- To provide emergency relief and humanitarian assistance for immediate medical rehabilitation and emergency survey procedures for baseline assessment;
- To document the need for prompt and effective prevention and rehabilitation programmes.

Post-immediate purposes:

- To produce low-cost technical aids and prostheses and to encourage technology transfer in this area;
- To encourage the use of some aspects of community-based rehabilitation, including training of trainers for personal assistance to people with disabilities and measures to facilitate the independence of people with disabilities;

Long-term purposes:

- To plan and design transport, housing and public structures to provide accessibility for all persons;

- To adopt any legislation necessary to protect human rights of persons with disabilities and take action to prevent further violation of human rights as a major cause of disability;

- To integrate people with disabilities (including persons with moderate disabilities, people with less obvious disabilities, households having a person with disability and elderly persons with disabilities) into the planning and management of all programmes and activities and avoid the institutionalization of people with disabilities;

- Ensure programmes of vocational training, education, legislation on civil rights and health care, and respond to the needs of people with disabilities.

Information on who is at risk for disability and on the specific rehabilitation needs of the community is required to plan appropriate interventions. In the absence of this information, there may be a tendency for relief efforts to focus on the assessment and prevention of mortality to the exclusion of long-term impairment and disability. The number of people with impairment and disability may increase several months after the acute emergency, owing to the impact of mental and physical wounds, ongoing mine injuries, food shortages, and breakdown in infrastructure and routine public health services such as immunization programmes to prevent poliomyelitis.

The major differences in information needs between especially difficult and more ordinary circumstances stem from the fact that in emergency situations the response must be more rapid and the data gathering and processing must often be done with extraordinarily limited resources (including personnel with very minimal, if any, training, and no readily available sampling frame).

A. Principles and recommendations for acquiring useful statistical information on disability in emergency situations

1. Use of rapid and low-cost methods

To develop information on disability in especially difficult circumstances, it will be necessary to rely on whatever resources are available. These may include a small team of people with sufficient skills to interview, observe and record information. To identify people with impairments and disabilities, it may be possible to rely on full assessments, and necessary to estimate probable impairment and disability. The following brief set of screening questions for this purpose has been proposed by the Office of the United Nations High Commissioner for Refugees: 49/

- Is anyone having trouble taking care of himself or herself?
- Do you know anyone who has difficulty walking, using his or her arms or legs, seeing, hearing, speaking or learning?
- Do you know anyone who sometimes has seizures?
- Do you know anyone who has problems because of sometimes acting in strange ways?

2. Sampling frame

To be able to use sampling as a means of improving the speed and efficiency of information gathering, it is necessary to have a sampling frame or listing of everyone in the population. When populations have been displaced or when there is substantial migration in or out of the population, there may be no sampling frame from which to select a probability sample. In such a situation, one should make use of whatever counting is being done, for example in planning for food and housing, in order to find out something about the size and structure of the population.

3. Thorough and valid case-finding

Within the population or sample about which information is to be collected, every effort should be made to identify all persons with disabilities using direct interviews and observations. The "key informant" approach (which assumes that a few people in the community will know of all those with disabilities and be able to identify them) is not very useful because it will miss many people even with serious disabilities. 50/

4. Comprehensiveness

Information on a range of topics will be needed. These include:

(a) Causes of disability;

(b) Availability of resources for rehabilitation;

(c) Potential for and barriers to long-term follow-up and provision of medical care;

(d) Indicators of handicap such as evidence that people with disabilities are being excluded from educational, employment and recreational opportunities.

B. Uses of statistical information in emergency relief situations

Statistical information on disability in refugee and other emergency relief situations is vital for at least three purposes:

1. Prevention of impairments

Knowledge of the causes of impairments, and the relative frequency of each cause in a community, serve as the basis for identifying priorities for prevention. For example, identification of dietary deficiencies such as iodine, vitamin A and folate deficiency as causes of childhood neurodevelopmental and vision impairments in a vulnerable community could lead to implementation of nutrition supplementation programmes to prevent these impairments in the future.

Information on the extent to which basic public health measures such as child immunization, sanitation and prenatal care are being implemented is useful for identifying preventable causes or impairments. In addition, information is needed on the number of people in need of urgent medical care so that a timely response can be made and impairments prevented.

2. Prevention of disability

To prevent and minimize disability after impairment has occurred, the community will need long-term community-based rehabilitation programmes. These programmes must provide appropriate training, technical aids and prosthetic aids. The goals are for people with disabilities and their families to achieve self-sufficiency, social integration with people without disabilities, and active participation in decision-making and in the planning and implementation of appropriate rehabilitation services.

3. Prevention of handicap

Handicap occurs when people with disabilities do not have the equivalent access to resources and equivalent opportunities, relative to their peers. To assess handicap, information may be collected on the degree to which people with disabilities have equal access to resources and equal opportunities, and the extent to which they are being included in decision-making processes and resource allocation. The Office of the United Nations High Commissioner for Refugees has developed extensive guidelines for refugees with disabilities. 49/, 51/ A first step in preventing handicap is to assess the extent to which these guidelines are being followed. The following are particularly relevant to prevention of handicap: 49/

(a) Integration

With respect to integration:

(a) "Under no circumstances should action be taken that might identify or establish refugees with disabilities as a separate or isolated population";

(b) "Teachers in the schools attended by refugee children should be encouraged to include children with disabilities in their classes whenever possible";

(c) "Action to promote the social (and economic) integration of refugees with disabilities need not be delayed pending medical or specialized rehabilitation measures";

(d) "The objective of community-based rehabilitation ought to be:

(i) The 'empowerment' of the person with disability or the family of the child with disability;

(ii) Full social integration of the people with disabilities".

(b) Self-sufficiency

With respect to self-sufficiency:

(a) "Negative attitudes and ignorance, in most parts of the world and at all levels of society, are serious obstacles to the attainment of self-sufficiency by refugees with disabilities";

(b) "Efforts should be made to incorporate people with disabilities in existing or planned vocational training and income-generating activities for the general refugee population".

(c) Participation

With respect to participation:

"Active participation of persons with disabilities in general community affairs, as well as in matters of immediate concern to them, should be encouraged".

(d) Opportunities

With respect to opportunities:

(a) "Refugee children with disabilities should be encouraged and helped to complete as much of their schooling as possible";

(b) "Not only teachers, but parents and school authorities will need to cooperate in making education accessible to refugee children with disabilities";

(c) "Access by persons with disabilities to social, recreational, cultural and religious activities is dependent as much on attitudes as on mobility";

(d) "A programme of rehabilitation is not just about providing for skills or career training, but should aim to make available as wide a range of opportunities as possible to persons with disabilities".

In summary, statistical information in especially difficult circumstances is used to ensure that the needs of people with disabilities are not overlooked in resource allocation and infrastructure development. The information is used to ensure that funds are earmarked for rehabilitation, as well as for the construction of buildings and transport systems suitable for people with movement restrictions and other functional limitations.

C. Other suggestions for collecting information

- Use developmentally and culturally appropriate methods to identify disability and to collect other information.
- Recognize that normal family and other support systems may not be available to facilitate rehabilitation and that information on alternative support systems and the feasibility of community-based rehabilitation in each setting should be collected.
- Find out about resources, programmes and policies of the host country that might be extended to refugees with disabilities. 49/
- Compare the situation of people with disabilities with those without disabilities, to assess special needs in a given setting, and to identify if the special needs of people with disabilities are any different from those of people without disabilities.
- Assess the frequency of depression and other emotional problems in the community. Populations in emergency situations are at increased risk of depression and post-traumatic distress syndrome, which can be disabling and interfere with mobilization of the community to overcome the difficulties it faces. A 20-question self-reporting questionnaire (box V.1), has been developed for this purpose and is used to identify individuals needing mental health services in disaster situations. 52/, 53/

Box V.1. The self-reporting questionnaire

1. Do you often have headaches?
2. Is your appetite poor?
3. Do you sleep badly?
4. Are you easily frightened?
5. Do your hands shake?
6. Do you feel nervous, tense or worried?
7. Is your digestion poor?
8. Do you have trouble thinking clearly?
9. Do you feel unhappy?
10. Do you cry more than usual?
11. Do you find it difficult to enjoy your daily activities?
12. Do you find it difficult to make decisions?
13. Is your daily work suffering?
14. Are you unable to play a useful part in life?
15. Have you lost interest in things?
16. Do you feel that you are a worthless person?
17. Has the thought of ending your life been on your mind?
18. Do you feel tired all the time?
19. Do you have uncomfortable feelings in your stomach?
20. Are you easily tired?

- In assessing disability and handicap, interview information should be supplemented with actual observations of functional abilities, of who has access to resources and of who is participating in community affairs.

- When impairments, disabilities and handicaps are identified, try to find out if they preceded or followed the onset of the emergency situation. This will make it possible to estimate the frequency of disability due to the difficult circumstances, and to evaluate what happens to people with disabilities when they are put into refugee and disaster-type situations.

- Find out whether the special needs of people with disabilities are being taken into account in infrastructure development (that is, construction of buildings, doorways, railings, sidewalks, ramps, toilets, transport).

- Determine the amount of resources that will be required to meet the needs of people with disabilities in refugee and disaster-type situations, so that funds can be requested.

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