Department of Economic and Social Affairs
Statistics Division

Guidelines and Principles for the Development of Disability Statistics

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PREFACE

The present publication, Guidelines and Principles for the Development of Disability Statistics, is one of two recent United Nations reports concerned with the development of statistics and indicators on the situation of persons with disabilities. These reports were prepared in response to the recommendations of the World Programme of Action concerning Disabled Persons[1] and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.[2] In particular, the World Programme of Action urges the Statistics Division

> together with other units of the United Nations Secretariat, the specialized agencies and regional commissions, to cooperate with the developing countries in evolving a realistic and practical system of data collection based either on total enumeration or on representative samples, as may be appropriate, in regard to various disabilities, and in particular, to prepare technical manuals/documents on how to use household surveys for the collection of such statistics.

Both reports provide guidance on the development of statistics on persons with disabilities; however, each has clearly distinct purposes. The first report, Manual for the Development of Statistical Information for Disability Programmes and Policies,[3] published in 1996, was written specifically for programme managers and others concerned with the production and use of statistical information for implementing, monitoring and evaluating disability policies and programmes. Special attention is given to the major uses of statistical information on disability for purposes of programme planning and evaluation. As a user-oriented manual, it defines basic concepts and provides guidance on the possible sources of existing data on disability. Suggestions are given for the development of statistical information and for obtaining and using it even in especially difficult situations, such as emergency and refugee relief situations.

The present volume builds on the *Manual* and also on the section on disability as a new topic in the recent United Nations publication, Principles and Recommendations for Population and Housing Censuses, Revision 1.[4] Oriented to statisticians, *Principles and Recommendations* provides guidelines and principles for collecting, compiling and disseminating statistics on persons with disabilities. Examples are included from both developing and developed countries. Although technical in approach, this publication is useful to managers of disability programmes, as they are essential partners in developing objectives for a data collection activity and the use of the resulting data. Researchers in the disability field may also benefit from the general information on methods.

Wil Ooijendijk and Jose Geurts prepared an earlier version of Guidelines and Principles for the Development of Disability Statistics as consultants to Statistics Netherlands and the United Nations Statistics Division (UNSD). It was reviewed by an expert group meeting organized by the UNSD and hosted by Statistics Netherlands at Voorburg, Netherlands, 7- 11 November 1994. Adele Furrie, formerly of Statistics

Canada, undertook additional work with funds received from the Swedish International Development Agency (Sida). In Chapter I of this publication, the section on the "International Classification of Functioning, Disability and Health – ICF" was prepared by the Classification, Assessment, Surveys and Terminology Team of the World Health Organization. In Chapter II, the section on "Evaluationg and improving the quality of the results" was prepared by Anthony Turner. Chapter III of this publication consists of detailed sections, which were substantially developed by the following persons: (a) censuses: Jose Geurts, with comments and additions by Adele Furrie; (b) surveys: David Keer, with contributions from the following persons on specific subtopics: (i) mental disorders, by Howard Meltzer; (ii) causes of disability, by W. Davidse; and (iii) services and support, by Jose Geurts; (c) sampling: Anthony Turner; and (d) institutional population: Renee Langlois.

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NOTES

1. The World Programme of Action concerning disabled Persons was adopted by the General Assembly in its resolution 37/52 of 3 December 1982. The Programme of Action may be viewed on the United Nations web site on persons with disabilities, at www.un.org/esa/socdev/enable/diswpa00.htm.

2. *The Standard rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations publication, Sales No. E. DPI/1454).

3. *Manual for the Development of Statistical Information for disability Programmes and Policies* (United Nations publication, Sales No. E.96.XVII.4).

4. *Ptinciples and Recommendations for Population and Housing Censuses, Revision 1* (United Nations publication, Sales No. E.98.XVII.8).

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ABBREVIATIONS

ACASI	audio computer-assisted self-interview
ADLs	activities of daily living
CAPI	computer-assisted personal interviewing
CASI	computer-assisted self-interview
CATI	computer-assisted telephone interviewing
CBR	community-based rehabilitation
CFM3	The Common Framework for the Third Monitoring of Progress of Strategies for Health for All by the Year 2000
deft	sampling design effect
DFLE	disability-free life expectancy
DFLE/LE	ratio of disability-free life expectancy to total life expectancy
DISTAT	United Nations Disability Statistics Database DISTAT-2 (under preparation)
EUROSTAT	Statistical Office of the European Commission
GP	General Practitioner
HALS	Health and Activity Limitation Survey
ICD	International Classification of Disease
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ICIDH-2	International Classification of Functioning, Disability and Health
INSERM	Institut National de la Santé et de la Recherche Médicale (French Institute of Health and Medical Research)
ISO	International Organization for Standardization
ISO 9999	International Standard ISO 9999, technical aids for disabled persons
LE	life expectancy
NHIS	National Health Interview Survey
OPCS	Office for Population Censuses and Surveys
PIN	personal identification number
pps	probability proportionate to size
REVES	Reseau Esperance de Vie en Santé (International Network on Health Expectancy)
Sida	Swedish International Development Agency
TTY	teletypewriter
UNICEF	United Nations Children's Fund
UNSD	United Nations Statistics Division
WHO	World Health Organization

USING THE GUIDELINES

Guidelines and Principles for the Development of Disability Statistics has been prepared to meet the growing needs of national statistical services in the field of disability. Over the past several decades, national efforts to collect disability statistics have increased significantly. However, this increase is due mainly to the inclusion in the census of a question or questions on disability. Some countries have included a special module on disability in an ongoing survey, usually a health survey. Only a few countries have undertaken a special disability survey. National registers of persons with disabilities are rare, and another problem is the lack of international standards to guide the production and compilation of statistics in the field of disability. As a result, the quality, completeness and detail of existing statistical information are usually inadequate for national policy and programme needs. The present publication provides technical guidance to help countries respond to the growing demand for data.

A review and assessment of national studies was an essential part of the preparation of *Guidelines*. This review was facilitated by the United Nations Disability Statistics Database (DISTAT). The second version of this database (DISTAT-2), currently under preparation, includes data from over 100 countries. The methodological information, such as definitions of the target population and screening questions in DISTAT-2 and in the underlying national reports, provide examples that are included in *Guidelines.*

The focus of *Guidelines* is selective. It is not a general manual on censuses and surveys but takes up only the special issues raised by collecting, tabulating and disseminating data on persons with disabilities. Further, it recognizes that inadequate attention has been given to many of the special issues relating to the operational requirements of data collection. For example, interviewing persons with disabilities for household surveys can pose a number of special problems that are only beginning to be addressed by research. Inadequate attention is also given to the measurement of the consequences of disability—the dimension of "handicap" in the original International Classification of Impairments, Disabilities and Handicaps (ICIDH) and the component of "Participation" in the International Classification of Functioning, Disability and Health (ICF).[1] The development of guidelines on a number of other topics will depend on future testing and evaluation.

The scope of the present publication is also necessarily limited with respect to the ICIDH. While the ICF classification has been finalized, *Guidelines* could not fully reflect the methods required to implement the ICF in national data collection programmes. It will be several years before the concepts in ICF can be transformed into valid and reliable survey instruments and still longer before these instruments will be used in national data collection programmes. The approach used in *Guidelines* is to integrate the concepts of

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[1] *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) (Geneva, World Health Organization, 1980); and *International Classification of Functioning, Disability and Health—ICF, Final Draft, Full Version* (Geneva, World Health Organization, 2001).

the ICF, to the greatest extent possible, within the existing experience on the development of disability statistics.[2]

The "Introduction", Chapter I, describes relevant international framework specifically the Standard Rules on the Equalization of Opportunities for Persons with Disabilities[3] and the ICIDH, both the original version and ICF. The Standard Rules inform statisticians of the range of topics that need to be studied, and the ICIDH and ICF provide a conceptual basis for the definition and classification of disabilities. Chapter I also describes the various opportunities for collecting disability statistics in the programmes of censuses, household surveys and administrative registries and includes the strengths and shortcomings of each.

Chapter II, "General issues in planning and organizing the collection of data on disability", is a guide to the basic steps in the data collection process, from planning to data processing and evaluation, focusing on the special issues related to disability.

Chapter III, "Modules: methodology for disability data collection", contains detailed sections on censuses, surveys, special topics in surveys, sampling and the institutional population. Since use of this handbook will depend on the capabilities, resources and interests of the country, chapter III has a modular structure. For ease of reference, additional material for some of the modules is presented in annexes at the end of *Guidelines*.

Chapter IV, "Dissemination and use of disability data", addresses the use of disability statistics for policy purposes.

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[2] *International Classification of Functioning, Disability and Health—ICF*, Final Draft, Full Version (Geneva, World Health Organization, 2001).
[3] *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations publication, Sales No. E.DPI/1454).

CHAPTER I. INTRODUCTION

A. INTERNATIONAL RECOMMENDATIONS

For many years, national population censuses and household surveys have included questions about disability in their interview schedules. Historically, national interest in disability has largely concerned assessing its long-term effects upon survivors of civil strife, war, famine, accidents and disease. However, the demand for statistics on persons with disabilities has increased greatly as a result of the International Year of Disabled Persons in 1981, the World Programme of Action concerning Disabled Persons,[1] the United Nations Decade of Disabled Persons from 1983 to 1992, and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.[2] Not only has this legislation made it more important to produce statistics, but the required statistics have also been broadened to include sociodemographic and economic factors; environments, their access and their accommodations for persons with disabilities; technical aids; and personal assistance.

The World Programme of Action concerning Disabled Persons calls for "an analysis of the situation of disabled persons ... within the context of different levels of economic and social development and different cultures" (para. 3). It also recommends that Governments should ensure the full participation of persons with disabilities in social life and development, and that such persons should be provided with opportunities equal to those of the whole population, including participation in education, employment, social and political groups, religious activities, intimate relationships and family life; access to housing, financial and personal security, and public facilities; and freedom of movement.

The Standard Rules elaborate further and imply a strong "moral and political commitment on behalf of States to take action for the equalization of opportunities for persons with disabilities .... Areas of decisive importance for the quality of life and for the achievement of full participation and equality are pointed out" (para. 14).

The Standard Rules address the following:

1. Preconditions for equal participation: specifically, rules concerning awareness-raising, medical care, rehabilitation and support services;

2. Target areas for equal participation: specifically, rules concerning accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion;

3. Implementation measures: specifically, rules concerning information and research, policy-making and planning, legislation, economic policies, coordination of work, organizations of persons with disabilities, personnel training, national monitoring and evaluation of disability programmes in the implementation of the Standard Rules, technical and economic cooperation, and international cooperation.

4. Monitoring mechanisms: ways to identify obstacles and suggest suitable measures to contribute to the successful implementation of the Standard Rules.

The rights and opportunities of persons with disabilities were also addressed by the International Conference on Population and Development in 1994 (paras. 6.29-6.33),[3] the Fourth World Conference on Women in 1995, (para. 106),[4] the World Summit for Social Development in 1995 (commitments 5 and 6),[5] and the Convention on the Rights of the Child in 1989 (Article 23).[6]

Implementation and monitoring of the Standard Rules and the global conferences and conventions place great demands for data on countries and on international organizations. In order to learn the number of persons with disabilities in a country as well as monitor equality of opportunity and achievements made, in terms of economic, social, political and cultural rights, an enormous amount of good quality statistical data is required.

B. THE INTERNATIONAL CLASSIFICATION OF IMPAIRMENTS, DISABILITIES, AND HANDICAPS (ICIDH)

In statistics, the conceptual framework of the ICIDH provides standardized concepts and terminology that can improve questionnaire design and provide a standardized coding/classification framework for data compilation. The use of a common framework also contributes to greater comparability of data at the national and international levels, thereby increasing the relevance of the data to a wide set of users. Section 1 below refers to the original ICIDH and section 2 introduces the second version of this international classification, based on the final draft of April 2001. Section 3 gives examples of how the ICIDH has been applied to the design of questions in disability data collection.

1. The three *ICIDH* concepts of disablement

The original ICIDH has three interrelated, yet distinct dimensions: impairment, disability and handicap. Each dimension forms a separate part of the ICIDH classification, which describes the response to or experience of the consequences of disease, injury, or disorders at the levels of the body, person or society, respectively. The diagram below shows the links among the concepts of disease or disorder, impairment, disability and handicap.
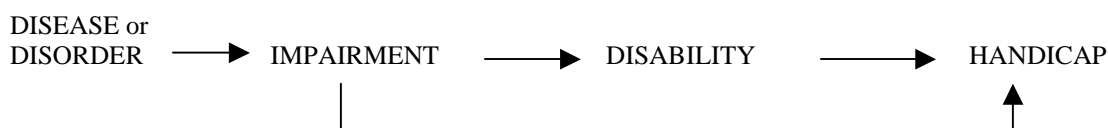
DISEASE or
DISORDER ⟶ IMPAIRMENT ⟶ DISABILITY ⟶ HANDICAP

The first version of the ICIDH does not fully describe or model the "process" of disablement because the situation is more complex than represented here. For instance, handicap may result from impairment without the presence of a disability. Also, the sequence can be interrupted at any stage. Thus, one can be impaired without having a disability, or have a disability without experiencing a handicap.

Box 1 presents definitions of the three ICIDH dimensions, while Box 2 presents a summary of the categories at the one-digit level for each of the three classifications. More detailed information on the three ICIDH classifications may be found in the *International Classification of Impairments, Disabilities, and Handicaps.*[7]

Box 1. Definitions of the three ICIDH concepts

Impairment:

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

Disability:

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

Handicap:

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

> *Source*: *International Classification of Impairments, Disabilities, and Handicaps* (Geneva, World Health Organization, 1980 and 1993).

The impairment dimension describes the biomedical status of the body and is characterized by losses or abnormalities that may be either temporary or permanent. It includes the existence or occurrence of an anomaly or defect, or loss of limb, organ, tissue or other structure of the body. It also includes defects in a functional system or mechanism of the body, including the systems of mental function. In laymen's terms, "impairment" describes some part of an individual's body that is missing or that does not function "normally". "Blind", "deaf", "mute" and "paralyzed" are words that are often used to describe persons with specific types of impairments. The impairment dimension

is the most detailed of the three ICIDH dimensions. It is comprised of nine categories relating to body structures and functions. Each of the nine categories is further subdivided into more detailed types of impairments.

The disability dimension refers to the effects an impairment may have on an individual's ability to perform the activities of daily life. An individual with an impairment may not experience any disability; alternatively, an individual may have a disability as a direct consequence of an impairment; or a disability may be a psychological response to an impairment.

In the original ICIDH, knowing that an individual has an activity limitation because of an impairment is an important first step in being able to determine if there are any interventions that could be undertaken to alleviate or reduce the limitation. Assessing the severity of the disability is viewed as a next step and is dealt with in a supplement to the disability subcategories.[8]

The handicap dimension is a classification of circumstances in which persons with impairments and/or disabilities find themselves when they interact with others within their society. Handicap refers to any discordance between the individual's performance or status and the expectations of the particular group of which she/he is a member. Handicap represents the social and environmental consequences for the individual stemming from the presence of impairments and/or disabilities. Societal differences in defining handicap are relevant, as the valuation is dependent on cultural norms; a person may be handicapped in one group and not in another. The ICIDH handicap classification is comprised of six key dimensions of experience that have been designated as "survival roles". The classification is structurally different from the other two ICIDH dimensions. The items related to handicap are not classified according to individuals or their attributes but according to the circumstances in which persons with disabilities are likely to find themselves, circumstances that can be expected to place such individuals at a disadvantage in relation to their peers when viewed in relation to the norms of society.

Box 2. Categories of the three ICIDH dimensions at the one-digit level		

IMPAIRMENT (I-CODE)   **DISABILITY (D-CODE)**   **HANDICAP (H-CODE)**

IMPAIRMENT (I-CODE)	DISABILITY (D-CODE)	HANDICAP (H-CODE)
1. Intellectual	1. Behaviour	1. Orientation
2. Other psychological	2. Communication	2. Physical
3. Language	3. Personal care	3. Mobility
4. Aural	4. Locomotor	4. Occupation
5. Ocular	5. Body disposition	5. Social integration
6. Visceral	6. Dexterity	6. Economic self-sufficiency
7. Skeletal	7. Situational	7. Other
8. Disfiguring	8. Particular skill	
9. Generalized, sensory and other	9. Other restrictions	

2. The International Classification of Functioning, Disability and Health—ICF

The ICIDH has been revised under the direction of the World Health Organization. The International Classification of Functioning, Disability and Health, or ICF, provides a broader theoretical framework for classifying health-related human functioning than the original ICIDH. The original ICIDH was based on a model in which impairment, disability and handicap were causally linked as consequences of disease or disorders at the levels of the body, person or society, respectively. The ICF moves away from the concept of "consequences of disease" to a "components" approach of human functioning. In this approach, there are no assumptions related to causal relationships between the different components of human functioning. ICF uses the concept of functioning to refer to all body functions, activities and participation as an umbrella term, and the concept of disability as an umbrella term for impairments, activity limitations or participation restrictions.[9] Disability represents impairments at the level of body function or structure; activity limitations at the level of the person and participation restrictions at the level of life situations in the societal context. Box 3 presents operational definitions of the components and table 1 presents an overview of the key components of the ICF. Information on the ICF is available on the World Health Organization web site at http://www.who.int/icidh.

Box 3. Definitions of the ICIDH-2 components

In the context of health:

Body Functions are the physiological functions of body systems (including psychological functions).
Body Structures are anatomical parts of the body such as organs, limbs and their components.
Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual.
Participation is involvement in a life situation.
Activity limitations are difficulties an individual may have in executing activities.
Participation Restrictions are problems an individual may experience in involvement in life situations.

Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

Source: *International Classification of Functioning, Disability and Health – ICF,* Final Draft, Full Version (Geneva, World Health Organization, 2001).

TABLE 1: OVERVIEW OF KEY COMPONENTS OF ICIDH-2

	Body Functions & Structures	*Activities and Participation*	*Environmental Factors*	*Personal Factors*
Domains	1. Body functions 2. Body structures	Life areas (task, actions)	External influences on functioning disability	Internal influences on functioning disability
Constructs	Change in Body function (physiological) Change in Body structure (anatomical)	*Capacity* Executing tasks in a standard environment *Performance* Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	The impact of attributes of the person
Positive aspect	Functional and structural integrity Functioning	Activity Participation Functioning	Facilitators	Not applicable
Negative aspect	Impairment Disability	Activity limitation Participation restriction Disability	Barriers/hindrances	Not applicable

Source: *International Classification of Functioning, Disability and Health—ICF,* Final Draft, Full Version (Geneva, World Health Organization, 2001).

The original ICIDH model implied a causal connection between impairments, disabilities, and handicaps, unmediated by environmental factors. This led to confusion between disease conditions and impairments, since the impairment level appeared to be nothing more than a consequence of disease conditions, rather than, as intended, a distinct phenomenon that can be assessed independently. Further, the causal model always failed to capture the fact that handicap can lead to the creation of disability as well as impairment.

The ICF model avoids these and related confusions by presenting a multidimensional and interactive process. Disablement is seen as a dynamic interaction between health conditions and other personal factors (such as age, sex, personality or level of education), on the one hand, and social and physical environmental factors on the other hand. The arrows are all bidirectional, indicating the mutual interaction between all components of the disablement process. Early on in the revision process it was decided that the ICIDH-2 should be as flexible as possible in its model to accommodate different approaches, different research demands and different users. Box 4 presents a graphical representation of these intersections in the ICF model.

Box 4.   Current understanding of interactions between the components of ICF

Health condition
(Disorder or disease)

Body Functions and Structures   Activity   Participation

Environmental factors   Personal factors

Source: *International Classification of Functioning, Disability and Health—ICF*, Final Draft, Full Version (Geneva,. World Health Organization, 2001).
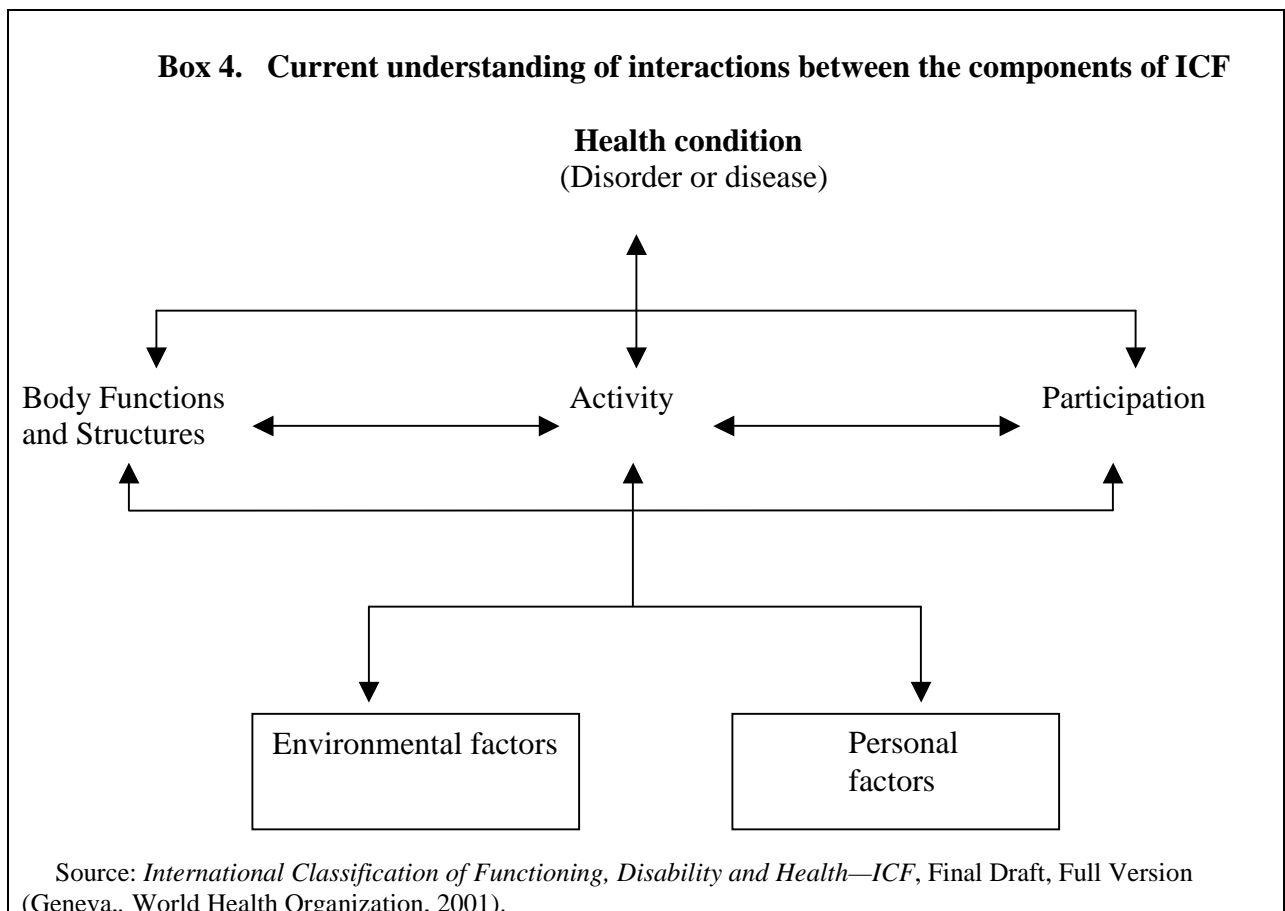
The original ICIDH was criticized as unsuitable, without specific modification, for data collection.[10] The impairment categories were phrased in medical terminology rather than ordinary, everyday language and could not be easily used in a questionnaire based on self-reporting of one's condition rather than medical assessment. The ICIDH was also criticized as being culture-specific, including, for example, such phrases as "pouring tea".

In the ICF each item or category has been operationally defined so that users have no difficulty distinguishing parallel items in the two components. Care has been taken to

avoid using the same word or phrase to identify similar items in the two components of Body Functions and Body Structures, and Activity and Participation. Nouns are used to denote body functions and structure, such as "speech functions", while activities are formulated as verbal nouns with an "ing" ending, such as "talking". The participation items are defined by interactive phrases such as "involvement in", "engagement in"or the like.

The ICF is presented in two versions in order to meet the needs of different users for varying levels of detail. The full version has four-digit levels of detail for each of the components, and the short version consists of only the first two digits. The short form, which has no more than 100 categories for each component, is much easier to use.

Another aim of the revision of the ICIDH is to develop general principles to classify human functioning and disability; specifically, the principles of universality, neutrality and parity, as explained below:

Universality**:** disability is not an intrinsic or defining feature of a subset of human beings (and as such is not analogous to other human differences such as gender and race), but is a universal condition of humanity itself. Since epidemiologically all humans are at risk for disablement in the course of their lives, the ICF needs to encompass all health conditions.

Neutrality**:** The ICF is a classification of functioning and disability, and strives to capture the levels of disability in as neutral a language as possible with no use of negative or depreciatory terms.

Parity**:** this principle asserts that, except in limited instances, no predictable correlations exist between health conditions and aspects of disablement. Persons with mental or physical disease may experience the same or different activity limitations and participation restrictions. It is inaccurate and prejudicial to associate certain forms of disablement with "mental" as opposed to "physical" health.

In contrast to the original ICIDH, the ICF includes psychological and intellectual function terms. The revised version includes an extensive description of both general and specific mental functions, as well as, in the activity and participation component, items on mental functioning related to learning, applying knowledge and undertaking tasks.

In the revision process, World Health Organization Collaborating Centres from around the globe conducted extensive "cultural applicability research" and linguistic analysis on the various drafts of ICF. Major aims of the revision process were to make the ICF culturally applicable and user-friendly across a wide range of potential users and uses to develop the best international terminology and to achieve a common language of disability for data collection purposes.

Since the revised ICF is different from the original ICIDH, a conversion table will be developed to convert data based on the original classification to the revised categories. The possibility of converting data from the old into the new classification means that issues of the comparability of data based on the two classifications are being addressed. As part of the ICF preparatory activities, the National Center for Health Statistics/Centers for Disease Control and Prevention of the United States of America, in collaboration with the United Nations Statistics Division and a number of countries, undertook a project to examine the usability of an earlier draft of the ICF for back-coding census and survey data from the original ICIDH.

3. *Application of the ICIDH in disability data collection*

An essential starting point for the development of guidelines for data collection is the experience of countries. As census questions have generally been limited to a generic question, the ICIDH has not been applied in most censuses, although the use of the ICIDH was recommended in a recent United Nations census guide.[11] However, in surveys, the ICIDH framework based on the original classification has formed a basis for defining the population to be studied and also for designing disability questions in a number of countries. Unfortunately, during the preparation of this set of guidelines, experience had not yet accumulated on the use of the ICF.

Statisticians, in applying the ICIDH, are working on issues that have also been addressed in the preparation of the ICF. They have translated the ICIDH concepts into simpler, non-technical language that can be understood by respondents. For example, instead of asking respondents if they have a "disability in detailed visual tasks", the question has been reworded as "Do you have difficulty clearly seeing the face of someone across a room/a road, with glasses or contact lenses if usually worn?" Nonetheless, the original ICIDH remains a useful starting point for developing questions on disability for the surveys and censuses now being planned. In surveys, questions using the original ICIDH are based mainly on the disability dimension, which is defined as difficulty in performing the basic activities of daily living such as seeing, hearing, walking and reaching. These questions, with some revision, can also be used in implementing the ICF, as the disability dimension of the original ICIDH is generally analogous to the Activity concept of the ICF. However, in the ICF some of the categories have changed. For example, seeing and hearing, which were originally part of the disability dimension, are now part of Body Functions, and are no longer Activity items. As a result, some modifications to the questions are required in order to follow the ICF categories. Modifications to the questions will also need to take into account the concept of severity, which is expressed through "qualifiers" (numeric codes that specify the extent or magnitude of the functioning or disability in a particular category) in ICF. These modifications will be discussed in Chapter II. The codes in the sample questions below refer to the dimensions of the categories of the original ICIDH.

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In the United States of America, the National Center for Health Statistics included a set of questions to identify specific impairments and disabilities in its 1994 National Health Interview Survey. These questions included the following:

Does anyone in the family have serious difficulty seeing, even when wearing glasses or contact lenses? (Seeing disability - D25 to D27)

Does .... have serious difficulty learning how to do new things that most people their age are able to learn? (Knowledge acquisition disability - D15)

Does .... have a problem with their sense of taste, such as not being able to taste salt or sugar or with tastes in the mouth that shouldn't be there, like bitter, salty, sour or sweet tastes*?* (Impairment of taste I69.2)

The 1986/1988 Health Interview Survey of the Netherlands included 30 questions that identified specific impairment and disabilities. Examples of some of the questions are given below:

Does .... have any difficulty in walking? (Walking disabilities - D40)

Does .... suffer from backache? (Back pain - I96.3)

Does .... suffer from dizzy spells or loss of balance? (Impairment of vestibular and balance function - I48)

Can .... hear loud noises, such as the horn of a car? (Other listening disability - D24).

In the Surveys of Disability in Great Britain conducted for the Office of Population Censuses and Surveys (OPCS) from 1985 to 1988, disability was classified along the lines of the ICIDH, but with some differences where the ICIDH was considered to be either too detailed or not detailed enough for the purpose of the study.[12] The following are examples of the screening questions asked to identify individuals for further questioning:

ADoes anyone in your household have the following difficulties due to long-term health problems or disabilities, either physical or mental?≅:

Difficulty walking for a quarter of a mile on the level (Walking disability - D40)

Great difficulty walking up or down steps or stairs (Climbing stairs disability - D42)

Difficulty bending down and straightening up, even when holding on to

something (Retrieval disability - D52)

Difficulty using arms to reach and stretch for things (Reaching disability - D53)

Great difficulty holding, gripping or turning things (Gripping disability - D63; Holding disability - D64)

Difficulty recognizing a friend across the road, even if glasses or contact lenses are worn (Disability in detailed visual tasks - D26)

Difficulty hearing someone talking in a quiet room (Disability in listening to speech - D23)

Severe suffering from noises in the head or ears (Impairment of perception - I23)

Although a growing number of countries have used the ICIDH framework in the preparation of questions to screen for disability, great differences still exist in the scope and content of the questionnaires. Both the number of ICIDH disability items included on the questionnaire and the way the questions are formulated differ between countries. These differences in part relate to the size of the ICIDH disability classification. Since the number of disabilities covered in the classification is very large, the investigator must select which ones to include and which not to include, and the original classification gives no guidelines on how this selection should be made.

C. DATA SOURCES ON DISABILITY

A country may collect data on disability through each of the three main types of national data collection systems: surveys, population censuses and administrative records.

1. Surveys

Sample surveys are not intended to enumerate every household or individual in the country; rather, they are designed to be representative of the population under study. Using sampling procedures, selected households or individuals are intended to be statistically representative of the total population. Surveys cover many different and often specialized topics such as health, welfare, labour force, agriculture and other socio-economic issues. The majority of surveys are household-based; however, in studying the population with disabilities it is also important to include the institutional population.

Surveys can be used to collect data on disability either by conducting a special disability survey or by including a module on disability in another survey. The two types of surveys are discussed in more detail in Chapter III under "Surveys."

2. *Population censuses*

In most national statistical systems, population censuses are the principal sources of statistics on population and its characteristics. A census is a nationwide activity with every person enumerated separately and their characteristics recorded separately. Universal enumeration, an essential feature, permits population censuses to provide useful demographic, economic and social data for small geographical areas, which would not be possible with a sample survey. A population census is a complex and costly undertaking that the majority of countries are normally able to organize and conduct at ten-year intervals.

Using the census to collect information about a certain segment of the population is not a new concept, although census organizers typically try to avoid using the census to collect anything other than basic demographic information. However, with the high cost of data collection and the increasing need for social, economic and demographic information, many countries are examining their census as a possible means to obtain other needed information. Although a broad range of topics is included in a census, most can be covered only briefly because of budgetary, personnel and time constraints. Disability is increasingly a topic investigated in a population census. For the first time, the United Nations *Principles and Recommendations for Population and Housing Censuses, Revision 1*,[13] includes disability as a topic that may be covered in censuses. Census recommendations on disability issues are covered in more detail below.

3. *Advantages and limitations of using censuses and surveys to collect disability data*

Each method has advantages and disadvantages in relation to its use for collecting disability data. The advantages and limitations of censuses and surveys for the study of disability are summarized in table 2. The choice of method(s) is determined not only by the type and amount of information needed but also the resources available. For example, in many countries, particularly in the developing regions, although the quality and coverage of census data on persons with disabilities is likely to be limited, the inclusion of disability in a census is often the only possible option given the available resources.

Table 2. Advantages and limitations of using censuses and surveys to collect disability data

A. Censuses

Advantages	Limitations
Data can be tabulated for small, local areas.	The subject matter is limited to basic socio-economic and demographic characteristics. Limited range and depth of interview are possible on the special situation of disabled persons.
Prevalence rates can be calculated for small geographical areas because data are also gathered about the population at risk.	
Detailed descriptive cross-tabulations are not subject to sampling errors. The study of causes of disability in local areas is, however, subject to limitations from the number of observations involved.	Data collection is infrequent, i.e., usually every 10 years. In addition, the time between data collection and data dissemination can be considerable.
	The disabled in institutions may not be included in the census population or at least not in descriptive tabulations; sometimes only the non-institutionalized population is covered.
Underlying factors found in different areas may be attributable to small numbers of observations rather than to any pattern of causality for that area.	Problems of non-response may be significant, given the complexity and sensitivity of the question and the limitation of the census instrument.
If disability questions remain comparable, they can be useful for time-series analysis of disability rates.	
The numbers of persons with disabilities are usually large, and therefore more detailed cross-tabulations can be prepared.	It is very costly and time-consuming to ask 80-90 per cent of the total population a question that is likely to be answered negatively, in order to identify the 1-20 per cent that has disabilities.
Censuses and surveys can provide a useful sampling frame for research on persons with disabilities that are otherwise difficult to find, such as blind persons and those who are deaf or mentally impaired.	Given the massive training requirements for a census, enumerators may be limited in the amount of training received on the subject of disability, which needs specific guidelines.
Comparisons can be made between persons with and without disabilities.	Censuses are usually completed by one person for the household, and that person may not have full information on the disabilities of others in the household.

TABLE 2. (*Continued*)

B. Surveys

Advantages	*Limitations*
A survey offers greater flexibility in the depth and range of topics that may be covered. Special probes and tests may be designed to ensure that the disabled are identified.	Except with synthetic estimation techniques, the ability to analyze prevalence rates for many local areas is limited, owing to the limited sample size and subsequent sampling errors associated with desegregation for small areas.
Surveys are relatively easy to initiate, given the availability of a sampling frame and a survey-taking infrastructure.	A very large sample size is required to capture an adequate number of persons identified as having a disability since the incidence of disability is less than 20 per cent of any population.
There is greater control over the conditions of observation and the interview because of limited coverage geographically and a smaller number of interviews to be completed.	The coverage of the populations in unusual circumstances, such as institutionalized persons, members of secondary families, secondary individuals, homeless persons and refugee or nomadic populations, is typically very poor.
Design modifications may be tried in order to increase the power of the survey in locating disabled persons, such as co-ordinating probability sample selection with the use of a census, using registered population lists, stratifying at the sample stage or increasing the sampling fraction.	
Greater opportunity exists for supervision of fieldwork and specialized field training and for careful pre-testing of detailed questions about impairment.	
Measurement can be built in: eye tests, manual dexterity or steps, for example.	

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4. *Administrative records and registers*

Additional sources of data on disability include data collected in an administrative system set up for other or more general purposes as well as those obtained from a register intended to serve persons with disabilities. Many types of administrative recording and registration systems can potentially be used to obtain data on disability. These include population registers, vital registration systems, social security systems, registries of occupational injuries, rehabilitation programmes and other services for persons with disabilities.

Administrative records and registers can provide often unique information about persons with disabilities. Usually the information in these systems has been collected for reasons other than statistical, perhaps related to the administration of a particular programme or service for persons with disabilities who meet its specific criteria. However, some administrative record systems are maintained to provide information about programme implementation; this information may then prove useful for other purposes. For example, data collected by theUnited States Department of Education, Office of Special Education Programs, provide information on educational attainment for children in special education, such as graduation rates. These data are collected annually and can therefore serve as a useful source for trend data on the prevalence of specific impairments or disabilities, which may not be available through other sources.

This publication will not provide methodological guidance on administrative records and registers. The methods involved in establishing such systems may not be statistical. Furthermore, there may be legal problems in the use of administrative service records or registers for statistical purposes other than in support of the programme or service. A legal opinion regarding the rules or legislation under which the original data were collected may be required. Any legal opinion takes time to obtain, and significant costs may be incurred. However, in some cases, these barriers can be overcome and, particularly in conjunction with other data sources, administrative records can enrich our knowledge about trends concerning persons with disability.

A wide range of types of administrative records and registers have been used to generate data concerning persons with disabilities, including the following:

(a)   Belgium: disabled pupils in special education. This data source includes children and adolescents who are capable of receiving an education but who are not capable of following it in an ordinary educational establishment. The data are subdivided into four classes of students and are collected at the beginning of each school term;[14]

(b)   Greece: general scheme social security fund. This data source includes persons receiving an invalidity pension under the general scheme. In general, these are insured persons with a disability of at least 50 per cent as a result of a common disease (including psychiatric illness), an occupational disease or accident, or an accident

occurring outside of work. This insurance covers those individuals who were employees in the private sector. Data are available from this source on an annual basis.[15]

(c)   France: disabled adults grant (Allocation aux adultes handicapés—A.A.H). This data source includes disabled adults between the ages of 20 and 60 (or between 16 and 20 if they are no longer eligible for family allowances) whose disability is at least 80 per cent or, if the degree of disability is lower, are unable to carry out a profession because of their disability. The amount of the grant is dependent on whether or not an individual with a disability can work and what their income is. It is designed to provide all disabled adults with a minimum income. Annual data are available from this source.[16]

(d)   Ireland: domestic care allowance. This program covers seriously disabled children aged from two to sixteen who live at home and, because of their disability, demand a level of care and attention that is significantly higher than that normally required of a child of the same age. Annual data are available from this source. [17]

(e)   Mauritius: The National Pension Plan registry. The National Pension Plan provides financial support for persons who have a medically certified impairment, a retirement pension for persons who are deaf, or who are totally paralyzed, or who have a permanent impairment of at least 60 per cent and require assistance with their daily activities. [18]

(f)   On example of a continuous registration system aimed at serving persons with disabilities is the system in Germany. This system includes persons who are certified as disabled by the local authority (*Versorgungsamt*), and thereby qualify for special benefits. The local authority determines the degree of disability (or percentage of reduction in ability) on a scale ranging from 20 to 100, with a degree of 50 or more representing severe disability. Basic guidelines have been established, including an extensive breakdown types of disabilities and the corresponding degrees of reduction in ability. The degree of reduction is determined by taking into account the expected ability for a given age and how this has been affected as a consequence of physical and mental disorders. To be certified as disabled, the person submits an application (including medical reports) to the local authority. This authority, on the basis of the medical reports and the guidelines, determines the degree of disability, which may be the result of more than one disorder. From this registration system, statistics are compiled every two years at the regional and national levels only for the severely disabled (those with a degree of disability of 50 per cent or more). In addition, the registration system provides a basis for refining data collection methodology on disability for the micro-census.

Guidelines and Principles for the Development of Disability Statistics

Chapter I. Introduction

NOTES

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1. The World Programme of Action concerning Disabled Persons was adopted by the General Assembly in its resolution 37/52 of 3 December 1982. The Programme of Action may be viewed on the United Nations web site on persons with disabilities:
 www.un.org/esa/socdev/enable/diswpa00.htm

2. Adopted by the General Assembly in its resolution 48/96 of 20 December 1993 and published under the title, *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations publication, Sales No. E.DPI/1454).

3. *Report of the International Conference on Population and Development*, Cairo, 5-13 September 1994 (United Nations publication, Sales No. E.95.XIII.18).

4. *Report of the Fourth World Conference on Women, Beijing, 4-15 September 1995* (United Nations publication, Sales No. E.96.IV.13).

5. *Report of the World Summit for Social Development, Copenhagen, 6-12 March 1995* (United Nations publication, Sales No. E.96.IV.8).

6. The Convention on the Rights of the Child was adopted by the General Assembly in its resolution 44/25 of 20 November 1989.

7. *International Classification of Impairments, Disabilities, and Handicaps* (Geneva, World Health Organization, 1980 and 1993).

8. *Ibid.*

9 In *Guidelines and Principles for the Development of Disability Statistics*, the term "disability" is used as a generic term for impairments, activity limitations and participation restrictions. When used in connection with the original ICIDH, however, the term "disability" refers to the disability dimension of that classification.

10 See "Foreword" to the 1993 reprint of *International Classification of Impairments, Disabilities, and Handicaps* (Geneva, World Health Organization).

11 *Principles and Recommendations for Population and Housing Censuses, Revision* 1 (United Nations publication, Sales No. E.98.XVII.8).United Nations Publication, Sales No. E.98.XVII.8.

12. Jean Martin, Howard Meltzer and David Elliot, *OPCS Surveys of Disability in Great Britain: Report 1, The Prevalence of Disability among Adults* (London, Her Majesty's Stationery Office, 1988).

13. *Principles and Recommendations for Population and Housing Censuses, Revision* 1 (United Nations publication, Sales No. E.98.XVII.8).

14. Eurostat, *Disabled Persons: Statistical Data*, Second Edition (Luxembourg, Office for Official Publications of the European Communities), p. 10.

15. *Ibid.*, page 30.

16. *Ibid.*, page 47.

17. *Ibid.*, page 64.

[18]. *Manual for the Development of Statistical Information for Disability Programmes and Policies* (United Nations publication, Sales No. E.96.XVII.4), p. 27.

CHAPTER II
GENERAL ISSUES IN PLANNING AND ORGANIZING THE COLLECTION OF DATA ON DISABILITY

Whether data are collected in a census or in a survey, a number of general issues relevant to the topic of disability need to be addressed when planning and organizing a data collection effort. As a first step, clear objectives with respect to disability should be specified in the planning stage. In addition, information needs must be identified and the study population defined. In preparatory work, consultations with organizations of persons with disabilities and potential users of the data are essential. The effect of disability on all relevant design features must be considered in the preparatory stage. In the design of questions to identify persons with disabilities, significant experience has accumulated, although it is based on the original ICIDH. Such country experience is essential to the development of international guidelines and will be used to the degree possible, given the new approach of the ICF. With regard to other general issues of data collection design and operation, the technical complexities involved and the need for further research and national experience limit the scope of this chapter to a review of the points to be taken into account.

A. PREPARATORY ACTIVITIES

1. Identifying the objectives of the study

The development of plans for data collection should include, at an early stage, the preparation of a set of strategic aims and objectives. Study objectives, coverage in terms of the population of interest, and the topics to be investigated in relation to the population with disabilities are very different from one country to another. Box 5 provides examples from national data collection activities on disability.

Box 5. Objectives and population data coverage for a national data collection activity on disability: national examples

Examples of study objectives for the Philippines, China and India, as well as population and topic coverage from national data collection activities are given below.

1. Philippines, National Commission concerning Disabled Persons, National Disability Survey, 1980

Why?   Data were needed to

(a) Determine the number, distribution and characteristics of the population who are disabled in the 13 regions of the Philippines;
(b) Compare persons with and without disabilities;
(c) Study the prevalence of disability by region, sex, age, type and cause;
(d) Identify the needs and requirements of the population with disabilities for medical, nursing and rehabilitation services;
(e) Determine whether the disability was incurred at work or in the line of duty.

Who?   The study covered all population living in households. A person with a disability or disabilities was defined as an individual having

(a) A physical impairment, including language, aural, ocular, visceral, skeletal and disfiguring impairments;
(b) A mental impairment, including intellectual and other psychological impairments, such as mental retardation, psychosis, alcoholism, chronic depression or anxiety and convulsive disorders.

What?   What types of data were collected?

(a) Age and sex, marital status, residential status, relationship to the head of the household;
(b) Educational activities, highest level of educational attainment;
(c) Occupation, employment situation;
(d) Disability status;
(e) Type of impairment;
(f) Causes;
(g) Technical aids;
(h) Family's care of person with disabilities and family's economic situation;
(i) Needs of persons with disabilities.

Box 5. (*Continued*)

2. China, Ministry of Civil Affairs, National Sampling Survey on Disabled Persons, 1987

Why?   Data were collected to provide information on the number of persons by

      (a) Type of disability;
      (b) Regional distribution;
      (c) Causes of disability;
      (d) Medical treatment;
      (e) Rehabilitation;
      (f) Education;
      (g) Employment;
      (h) Marriage;
      (i) Family;
      (j) Participation in social life.

      Data were needed to provide a basis for drawing up legislation and national policies and programmes to improve the situation of persons with disabilities and to ensure that they have rights equal to those without disabilities.

Who?   The survey covered population living in households in the 29 provinces.

      Persons with disabilities were defined to include only those with (a) vision; (b) hearing; (c) speech; (d) mental; (e) limb; and (f) psychotic impairments.

What?   Data were collected on

(a) Type of impairment;
(b) Cause of impairment;
(c) Age, sex;
(d) Educational attainment of the person with a disability, and of the person's father and mother;
(e) Economic activity status, industry, occupation;
(f) Treatments received for the disability, and reasons for not receiving treatment;
(g) Willingness of the person with a disability or disabilities to go to school, be employed;
(h) Willingness of person with disabilities to take part in social activities, continue treatment, use prosthesis (for those with physical impairments), marry;
(i) The attitude of relatives of person with disabilities: do they regard him/her as a burden, wish he/she could be admitted into a special institution for persons with disabilities?

Box 5. (*Continued*)

3. India, National Sample Survey Organization, Department of Statistics, National Sample Survey of Disabled Persons, 1991

Why?   The National Sample Survey collected information on disability to

       (a) Build a database regarding the incidence and prevalence of disability in the country;
       (b) Identify interstate (provincial) variation in the rates;
       (c) Study the particulars of disability, such as the type or degree of disability, causes of disability, age at onset of disability and type of aid/appliance used;
       (d) Determine socio-economic and demographic characteristics.

In pursuance of the policy of the Government of India, data on disability were collected to review the status of the disabled in the country and to make a comprehensive rehabilitation programme.

Who?   The survey was carried out in 56,760 households throughout India.

Persons with the following physical disabilities formed the study population: (a) visual disability; (b) communication disability (such as a hearing disability or speech defect for individuals aged 5 years and over); and (c) locomotor disability.

The survey also covered the extent to which children aged 5-14 years reached different developmental milestones.

What?   Information was collected on

(a) Households with at least one disabled person;
(b) Household characteristics, such as age, sex, size, social group, industry, occupation, employment status, average monthly expenditure and type of housing;
(c) Disability characteristics such as type, number of disabilities, degree of disability, causes of disability, age at onset of disability and type of aid/appliance used;
(d) Type of blood relationship between parents of disabled persons.

The starting point for developing these objectives is to assess existing data and understand user requirements for data. A clear identification of disability data requirements can best be achieved through a series of meetings with advocates, groups

representing persons with different types of disabilities, and organizations that provide services and programs for persons with disabilities.

Generally, information needs identified by advocates who are not trained in statistics are stated in very general terms. The agency responsible for data collection must translate these general statements into detailed data requirements. This is usually an iterative process and can be facilitated by asking questions and providing examples to assist the requesting individuals and/or agencies with the process (see boxes 6 and 7 for examples of this type of communication).

Box 6.   **An example of communication between the data collection agency and users requesting information on employment opportunities for persons with disabilities**

Based on the knowledge that the project manager of the data collection activity has of the issues facing persons with disabilities in the country, he/she arranges to have a meeting with officials from the ministry/department of labour. There, the project manager might hear the following:

> There is increasing pressure from lobbying groups to develop an employment policy to ensure that adults with disabilities have access to employment opportunities. How many adults with disabilities are there in the population and what is their employment status as compared with the rest of the population?

In addition to some of the questions asked in the first meeting to determine definitions and needs, other specific questions might include:

> *How do you define "adult"?*

> *Do you need the information for the total adult population, or do you require   information by specific age groups?*

> *How do you define "employment"?*

> *Do you have another source of employment information for persons who do not have a disability? The need for employment information on persons without a disability was mentioned in your statement of information needs.*

There are two options that the data collection agency may wish to put forward to meet this need: (a) the possibility of using employment data for the total population that might be available from another source; or (b) extending the information-gathering exercise to include the collection of information about the employment status of adults who do not report a disability.

Discussions on this process should also include the scope of information on the characteristics of persons with disabilities, such as age, sex, education, income and labour force status, as well as the level of geographical detail. For the agency collecting the data, this additional information is very important in determining the method to be used to collect the information, as well as the cost of the undertaking. It is also important, at this stage, to decide on the coverage of the population with disabilities. Very often, data collection activities include only those persons residing in private households. In order

not to exclude a relevant portion of persons with disabilities, the team should consider all possible locations where persons with disabilities may live and then establish through consultation whether inclusion of these populations is a priority. Documentation of the decision-making process for inclusions and exclusions is an important aspect of this phase of the planning. The following represent some of the groups of persons that should be carefully considered for inclusion in the data collection activity: (a) persons residing in institutions; (b) persons living in remote areas; (c) nomads; (d) the homeless; and (e) refugees.

Box 7.   An example of communication between the data collection agency and users requesting information on technical aids

Typically the meeting is with the ministry/department that has the most pressing need for information, and the one that has indicated that funding might be available for the collection of such information. The information need may be expressed as follows:

> It has been decided that the health ministry is going to introduce a new program to ensure that persons with disabilities have access to the technical aids that they need. We need to know what they need.

Some questions to ask the user might include the following:

> What is your definition of a person with a disability?

Here, the data collection agency might give some examples, such as a person who has some difficulty paying attention, a person who has difficulty understanding spoken messages, a person who cannot walk because he is paralyzed, or an elderly person who has difficulty walking because of arthritis. It would be useful to have access to prevalence rates from other countries that used a similar definition, which would alert the user to the possible implications of using a particular definition.

> Do you need information about particular types of disabilities?

This part of the discussion helps to determine the amount of detail that will be required to identify the population of interest, as well as the size of the sample required.

> Do you need to know how long the person has had the disability and the cause of the disability?

Duration and cause are two pieces of information that are typically used by researchers when they are developing composite indicators of disability, such as disability-free life expectancy (DFLE). Examples of questions to use to determine cause and duration are

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Box 7: *(Continued)*

provided in chapter III, section B.5(a).

Do you want to include all ages: children, adults and the elderly?

It is important to cover each age group specified because the issues and requirements related to disability for each age group may be different.

What are the differences in the characteristics and situation of women and men with disabilities?

The data-collecting agency should ask users to identify issues relevant to gender to ensure appropriate coverage in the questionnaire.

Is it important to identify whether these individuals live in urban or rural areas, or in other geographical areas?

It is important to know if the information is needed at the country level only or if regional data will be required. This will have an impact on the sample size and the sample design.

What do you mean by technical aids?

The data collecting agency might want to ask users to identify the scope of technical aids that might be considered, such as hearing aids, glasses, wheelchairs, canes, seeing eye dogs or other aids.

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2. Consulting users and persons with disabilities, and examining relevant existing data

Statisticians are responsible for ensuring that the data they collect respond to the needs of users. Consultation with users will ensure that the final product meets those needs and interests.

Consultations with users are crucial at the outset to help identify the issues and topics to be addressed and should be continued at each stage of the process. Users should be consulted, for example, in the development of questions, in particular for ethical issues, language and fielding strategies as well as for planning publicity about data collection goals.

Users include government officials, researchers, legislators, persons with disabilities, and members of non-governmental associations and organizations that provide services to persons with disabilities. Researchers and representatives of non-

governmental organizations play a unique role in the consultation process by providing state-of-the-art information about their disciplines and about the issues facing disabled persons. Typically these individuals or associations do not have funds to contribute to the data collection process, but their understanding of issues and the needs of their members and their support are often critical to ensuring the success of a data collection exercise.

The form of these consultations may vary from informal discussions to workshops or seminars to formal meetings of consultative committees comprising producers and users. Different forms meet different objectives in the process, and different types of consultation will need to be explored.

Although crucial to the quality and usefulness of the data produced, there are also drawbacks to consultations with user groups. This procedure can lengthen the timetable for data collection and confront statisticians with competing demands and conflicting opinions from different user groups. However, on the positive side, a successful dialogue with users will identify crucial issues and information and, when the constraints of the producers are made clear, help users develop more realistic expectations about the data that can be collected.

Consultation with a broad range of individuals should also provide access to any relevant existing data. An important part of the planning process is to determine if there were any efforts in the past to collect information about the population with disabilities. Since data collection activities are often very expensive, it is important to identify and analyse studies already undertaken. Contact with other survey managers and the census manager would be an important first step in determining if disability data exist, and if there is any documentation as to the quality of the data and any problems that may have been encountered when collecting the data.

Some geographical regions within the country may have conducted a survey or census related to a specific disability issue. While this information may not be useful as a source for national data, the experience that was gained in the collection of such information may be valuable to the planning team.

Ministries and departments, and some advocacy groups and service providers often maintain administrative records, or registries, that are used to monitor and evaluate programmes and services. While there are often restrictions on access to these records, aggregated data may be used. Persons doing research on disability may also be a good source for determining the data that are available, as they may have already sought out sources in support of their research.

The sources identified should be documented in a standard format because they will be used in various stages of the data collection effort. They will serve as a resource for the planning team in the design of questionnaires, in developing procedures and training the data collection staff, and in validating the new data. They may also be used as additional information to complement the new data.

3. Publicity

When disability questions are included in a census or in an on-going survey, it is important for disability issues to be specifically addressed in the national publicity campaign that promotes the entire data collection effort. The publicity programme should be designed to highlight the importance of collecting data on persons with disabilities and to overcome any negative views associated with being identified as having a disability.

In places where disability is a stigma, people may be reluctant to report it. The publicity campaign is crucial in encouraging persons with disabilities to collaborate. The inclusion of information on the uses of the data to develop new programmes and policies for persons with disabilities, and assurances concerning the confidentiality of the information given are important. The public should also be informed that the data will not be used for any other purposes, such as taxation, assessment of pension benefits or regulation.

Organizations of persons with disabilities, the elderly and professional organizations should be involved. They can address the cultural attitudes and conditions of persons with disabilities living in their communities. Such organizations are also a good means for publicizing the importance of cooperation of persons with disabilities with the data collection effort.

4. Defining the population with disabilities

The definition of the population with disabilities is a key element in the design of a data collection activity, for it sets the scope and coverage of the whole data collection process. In data collection, the definition to be adopted for the population with disabilities should be based on the purpose and objectives of the study and should be discussed with various data users, experts in the disability field and groups representing persons with disabilities.

The experience of other countries can be important when assessing different methodologies and approaches to identify persons with disabilities. The United Nations Statistics Division web site on disability is a source of information on methodologies used as well as on basic prevalence rates obtained.[1] Country examples related to specific issues have been included in this handbook.

Countries, in their data collection activities, do not define persons with disabilities uniformly. National definitions differ in both meaning and scope, as the population with disabilities is highly influenced by the administrative applications of the data as well as cultural practices and perceptions.

At the international level, substantial improvement in terminology has occurred through the development, by the World Health Organization, of the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH)[2] and the *International Classification of Functioning, Disability and Health—ICF,*[3] which are covered in greater detail in chapter I. The revised ICF, introduced in chapter I, is an extension and clarification of the original version. Countries are encouraged to utilize the ICF as the basis for developing definitions of disability. This classification provides a conceptual framework that aims to improve clarity and precision in the definition and measurement of disability in the country, leading to the production of internationally comparable data on disability.

Based on the original version of the ICIDH, the use of the disability concept was recommended to define the population with disabilities in census questions as well as in household surveys.[4] Disability-based terms, which focus on difficulties experienced in the performance of daily activities, are generally easier to understand, especially for the respondent, than those based on the impairment concept. In addition, the ICIDH disability concept can be used to measure the consequences of ill health and its effect on the activities essential to daily living. By using this approach, it is possible to obtain information on the rehabilitation and adaptation needs of the population with disabilities and develop policies and programmes accordingly. The equalization of opportunities for persons with disabilities may also be addressed within this framework.

Activity in the ICF is analogous to the disability dimension of the original ICIDH. Activity gives a profile of an individual's functioning in terms of activities, from simple to complex (e.g., from basic watching and walking to undertaking multiple tasks). Concepts based on activity can be related to real life situations more easily than the concepts based on the component "Body Functions and Body Structures". The latter are concerned with body systems and seem more appropriate for the assessment of disability under clinical situations. Since the activity concept focuses on an individual's functioning in terms of executing tasks or actions in one's life, it is relevant for formulating social policy. For all of these reasons, a definition of the population with disabilities that is based on the activity concept is relevant for use in censuses and surveys.

A definition of the study population using the participation concept is also important, as it examines societal circumstances related to the involvement of an individual in various life areas, such as self-care, interpersonal interactions, learning and applying knowledge, communication and domestic life. Participation is analogous to the handicap dimension of the original ICIDH. However, since the handicap dimension was more complex and less developed than the other two dimensions, it was difficult to operationalize and apply in data collection activities on disability. Consequently, no country experience is available as a source of strategies to measure handicap or participation.

Participation in the ICF looks at the "lived experience" of an individual with a health condition in terms of involvement in the different life situations by trying to find out if the individual is taking part, being included or engaged in an area of life, being accepted, or having access to needed resources. The standard or norm against which an individual's participation is compared is that of an individual without a similar health condition (disease, disorder or injury, etc.) in a particular society. Participation is also concerned with whether environmental factors facilitate or hinder the involvement of the individual in that particular domain. Use of Participation to define the population of interest is especially relevant, considering that it can be used to assess equality as specified in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.[5]

It is important for groups representing persons with disabilities to participate in the process of defining the population with disabilities. Most of these organizations and associations have similar needs for information. However, the difficulty arises in how each defines the population with disabilities. Membership in most organizations and associations is defined by cause of disability or underlying condition. These associations include, for example, those persons with spinal cord injury, brain injury, cerebral palsy, mental retardation, arthritis and heart problems. Other associations define their population through the use of an aid, such as the wheelchair association; others deal with specific types of impairments, such as the association for the blind or deaf. The different interests of the various organizations will need to be coordinated and considered in developing a definition of persons with disabilities within the framework of the ICF.

When defining the population with disabilities (irrespective of the ICF component used), it is important to distinguish between temporary and long-term disability.[6] "Long-term disability" refers to chronic conditions and is the concept that is usually associated with the definition of the population with disabilities. To measure long-term disability it is necessary to set a minimum length of time of experience or expected duration of the condition(s) being measured. In order to exclude persons with a temporary disability, many countries have defined a disability in terms of "has lasted or is expected to last six months or more". The six-month criterion is arbitrary and has no scientific basis except that it has been used by a number of countries and appears to exclude individuals with a

temporary disability. "Temporary disability" refers to temporary restrictions in an individual's usual level of functioning. It aims to measure deviation from an individual's usual level of functioning (ill health), even if this usual level is already reduced. It includes such conditions as short-term illnesses, broken legs and pregnancy.

B. DESIGNING QUESTIONS TO IDENTIFY PERSONS WITH DISABILITIES

The design of questions to identify persons in the population with disabilities presents particularly complex problems. From the conceptual standpoint, there is no

universal definition of what constitutes a disability nor of who should be considered as having a disability. The ICIDH and more recently the ICF provide a multidimensional framework within which to define the population with disabilities, rather than a single clear definition. As used in the ICF, disability is an umbrella term that covers two components: (1) Body Functions and Body Structures; and (2) Activity and Participation. Consequently, it covers the physical, emotional and mental conditions associated with the functioning and structure of body parts; difficulties in executing tasks at the level of the individual; and problems of involvement in life situations at the level of the society. The ICF concepts of "impairment" (related to problems associated with body parts), "activity limitations" (related to problems with executing tasks), and "participation restrictions" (related to problems of involvement) are interrelated but not synonymous. The term "disability" takes on a different meaning depending on the concept being adopted.

Moreover, there is no one static condition of disability even when viewed from one conceptual ICF component. A disability is a result of the interaction between a person with a health condition and a particular environmental context. Individuals with similar health conditions may not be similarly disabled or share the same perception of their disability, depending on their environmental adaptations. For example, having access to technical aids, services or medication, or physical adaptation to the environment may allow individuals to overcome their disabling conditions. Disability is not an all-or-nothing phenomenon but involves degrees of difficulty, limitation or dependence, ranging from slight to severe. Questions should be designed to capture those with severe as well as those with less severe forms of disabling conditions and should take into account any assistive devices or accommodations that the person may have.

Given the complexity of the concept of disability, the comprehension of the questions by the respondent is a major problem.[7] Among the factors that affect the interpretation of questions on disability by the respondent are the specific wording of the question, the structure of the question and the form of presentation—whether the question is read by the respondent or is presented to the respondent by an interviewer. The wording of the question is particularly problematic: although one can standardize the language read by the respondent or the interviewer, standardization of language does not imply standardization of meaning. Respondents are likely to differ in their interpretation of terms and may sometimes overlook qualifying statements in the question. For instance,

use of terms such as "difficulty" may be subject to interpretation by the respondents, and when formulating a response, some may answer in terms of what they can do regardless of whether they do it (capacity or ability), while others may base their answers on what they actually do (actual performance).

Question wording and the range of activities covered affect the number of persons identified as having disabilities. Generally, the number of persons regarded as having disabilities will be higher if the instrument contains questions about a wider range of

activities.[8] Also, specific questions are more likely than generic ones to identify more persons with disabilities.

National data in the United Nations Disability Statistics Database (DISTAT2) show that differences in prevalence rates are affected by the following aspects of questionnaire design: (a) the type of questions used (generic versus specific); (b) the clarity of the question wording with regard to terms used; and (c) the scope of the questionnaire in terms of the number of items included. These factors are more important than whether a disability (ICIDH) or an impairment (ICIDH) concept is used in framing the question.

The following items are from questionnaires from three different countries that used an ICIDH impairment approach:

1. Australia: "Is there anyone in the household who has any loss of sight? Does anyone have loss of hearing? Does anyone have loss of speech? Is there anyone who has blackouts or fits or loses consciousness? Is there anyone who is slow at learning or understanding things? Does everyone have full use of their arms and fingers?" (Eight additional conditions are also listed);

2. Bangladesh: "Is there any blind/crippled/deaf and dumb/mad person in this household?"

3. Sudan: "Does anyone in this household, including very young children and women, have any long-term condition or health problem which prevents or limits his/her participation in activities normal for a person his/her age?"

Table 3 shows that for these countries the prevalence rates were highest when the question referred to a variety of specific conditions. In countries where the question referred to a limited list of severe impairments or referred only to severe ones, a lower prevalence rate was obtained.

TABLE 3. PREVALENCE RATES BY LEVEL OF DETAIL IN QUESTIONS USED IN SURVEYS OF SELECTED COUNTRIES

Country/Year of study	Total Population	Males	Females
Australia (993) [a]	18.0	18.4	17.6
Bangladesh (1982) [b]	0.8	0.9	0.6
Sudan (1992-1993) [c]	1.1	1.3	1.0

_____

[a] Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers* (Canberra, 1993).

[b] Bangladesh Bureau of Statistics, Demographic sample survey of 1982.

[c] Government of Sudan, Federal Ministry of Health, *Sudan Maternal and Child Health Survey 1992/1993, Principal Report* (Khartoum, Federal Ministry of Health; and Pan Arab Project for Child Development, League of Arab States, 1995).

Specifically, in Australia, where the prevalence rate is the highest, the questions referred to a variety of conditions based on the impairment classification of the ICIDH. In Bangladesh and in the Sudan, the use of generic questions may have led to a lack of clarity on the part of the respondents about the meaning of the question, and in Bangladesh the questions referred only to a limited list of severe impairments

The extent to which the instrument can be articulated, however, depends to a large extent on the method of data collection used and the resources available. In a population census, for example, the space dedicated to disability is limited, and the question(s) relating to disability therefore cannot contain an elaborate list of disability items. In a survey where the topic can be more extensively developed, the instrument can be better articulated and can explore more fully those aspects included in the definition of disability.

When developing questions, it is important to test whether they are culturally acceptable and in accordance with the agreed definition of disability. Barring cases of severe activity limitations or of visible impairments, the reporting of difficulty experienced in the performance of certain tasks (walking, bending, etc.) will be affected by cultural norms on what is normal and what is not. Questions need to be pre-tested, and this testing should be as broad-based as the budget allows. Consultation within the disability community is very important.

The cultural relevance of the question(s) takes different forms. First, each of the selected questions included in the instrument and in the questionnaire should be reviewed to determine if it is appropriate. For instance, whereas in some countries it is appropriate to ask whether the respondent has difficulty walking up and down a flight of stairs, it may be irrelevant in other countries. Second, the appropriateness of the questions for different cultural groups within the same country should also be reviewed, as words and/or phrases to describe specific types of disabilities may be acceptable in some communities but not in others. Also, a particular word or phrase may mean one thing in one part of the country and something different in another.

The design of the question merits careful consideration, as the shortcomings of a poorly designed question cannot be overcome during or after enumeration, and no amount of processing will improve data obtained through a poorly designed questionnaire. When developing the question or questions, the aim is to convert complex ideas and concepts into questions that are easily understood and correctly answered. The questions and the words should be clear, simple and appropriate so that people are not embarrassed or insulted by them. The use of specific medical terms in questions should be avoided. Poorly worded questions and/or confusing formats will generally result in unreliable information.

The nature of some of the disabilities to be investigated can pose challenges to the design of the questions. This is especially true when designing questions to identify disabilities associated with cognitive and psychological functioning. In this case, the disability may be a hindrance to the respondent's understanding of the questions asked and his/her accuracy in providing information. Also, given the sensitive nature of some of the disabilities, such as activities related to toileting or engaging in intimate relationships, the development of appropriate questions becomes even more challenging.

Questions designed for the data collection instrument should embody the definition of disability being used. Sometimes the questions used to operationalize the definition may not include everyone implied in the definition. However the population with disabilities is defined, questions must be carefully phrased in order to be able to identify the population of interest. These questions should be specific with regard to the disabilities included in the definition of the study population.

The instrument should be articulated so that the perception of the respondent is focused on the definition of "disability" as agreed upon for the data collection. The use of ambiguous terms should be avoided because the person being questioned may have his/her own idea about what "disability" is, reflecting the culture of the country; in many

cultures, people's general perception of their disablement is still linked to stereotyped impairments, such as not being able to see, hear or speak.

To avoid the use of broad generic and ambiguous terms, the ICF should be used to provide a framework for the definition of the population with disabilities and as a basis for concepts used in the design of questions. Chapter I.B.3, "Application of the ICIDH in disability data collection" and also chapter III.B.3, "Development of questions to identify persons with disabilities" provide country examples of the ways in which the original ICIDH classification items have been used to develop questions to collect data on disability.

The questions may use a broad range of culturally appropriate expressions, linked to the ICF categories, to ask about the disabilities of interest. Selection of the aspects that will be covered by the instrument will depend on the definition of disability adopted for the study and in particular on the relevance of these disabilities to planners and policy makers. When designing questions, it is important to distinguish between performance questions and capacity questions. Performance refers to what one actually does as part of everyday activities, whereas capacity refers to an individual's ability to do a certain task whether or not it is performed on a daily basis. The performance perspective is recommended in the design of screening questions.

When designing questions using the ICF, concepts based on the Activity and Participation component are preferable to those based on Body Functions and Body Structures. As stated above, terms based on the Activity concept are generally easier for the respondent to understand and relate to, while the Body Functions and Body Structures component is better suited for investigating disability in clinical settings (see above, chapter II, section A.4). However, the application of the ICF will be different in a census and a survey and this will be addressed in chapter III, section A and section B.

With the ICF, the categories of the classification are identified in neutral terms (see chapter I, section B.2) and cannot, without qualification, denote a disability. This is a major difference between the original ICIDH and ICF. To assess levels of disability, categories in all components of the ICF classification need to include a set of uniform "qualifiers" to measure the extent or magnitude of the problem (see annex 1).[9] For example, a code of "d430"—activities of lifting and carrying objects—must be accompanied by a qualifier to denote the degree of difficulty in executing this task. The World Health Organization's draft Disability Assessment Schedule (WHODAS II), which is described in greater detail in chapter III, section B.3 (a), relies on the ICF as a conceptual framework. The following are examples of some of items it includes:

Difficulty in standing for long periods, such as 30 minutes;

Difficulty in taking care of household responsibilities;

Difficulty in learning a new task, such as learning how to get to a new place.

The responses are recorded according to the levels of difficulty specified below:

None;
Mild;
Moderate;
Severe;
Extreme/cannot do.

The use of qualifiers in the design of screening questions poses difficulties when it comes to censuses owing to space limitations. More space for the question(s) is needed to accommodate the qualifiers in the questions.

C. GENERAL ISSUES IN DESIGN AND OPERATIONS

Special methodological concerns are raised by interviewing persons with disabilities. For example, some persons with disabilities may require proxy respondents. In addition, the mode of data collection needs to be sensitive to the different issues associated with interviewing those with physical, sensory, cognitive or psychological impairments. A comprehensive treatment of these issues awaits further research. The United States Interagency Subcommittee on Disability Statistics has noted the inadequate state of development of research methodology for collecting disability data. Given the new demand for the data, the Subcommittee has been charged to come up with action steps to respond to this problem. A number of new developments are taking place which should lead to an improved understanding of methods to collect data on disability.[10] However, based on the information now available, the present publication can only provide an introduction to some of the main methodological issues that must be addressed in collecting and processing data on the population with disabilities.

1. Choice of respondent

In any data collection activity, it is desirable to collect the information from someone who is well informed about the subject and able to perform respondent tasks. Often in survey or census interviews, the head of the household gives information not only about him/herself but also for the other members of the household. When collecting data on disability, the person with the disability is usually the best informed about his/her situation. This is especially true in relation to impairments and activities in the sensory areas, and to such topics as impairments of bladder and bowel function and activities relating to toileting, which people may wish to keep private even from other members of their family.

The particular type of disability itself may render it difficult for some to perform the tasks usually expected of a respondent, such as, hearing questions, interpreting their meaning and speaking responses. A person with loss of function in thought, hearing, perception or speaking, or someone who is very ill, might not be able to perform respondent tasks in the way usually assumed in non-disability interviews. For those who have a loss of hearing, for example, the use of sign language may not allow direct

interpretation, thus creating a potential for measurement error. These potential problems may create a dilemma in that the best informed person may not always be the best respondent. Many factors may affect the resolution of the dilemma, but when possible, barriers should be modified to provide for participation of the person with disabilities (see chapter II, section C.3 on "Mode of data collection").

When the sampled respondent is not competent to answer the questions, proxy informants may be used rather than lose information about the selected person. It is good practice to ask the intended respondent if the interviewer can approach someone else, as even persons with cognitive or psychological impairments may be competent to give permission. In institutional settings, it is worthwhile to collect data from both the intended respondent and a proxy informant. However, interviewing the intended respondent with a proxy alongside is not good practice because it may seem as if the interviewer is simply checking the respondent's answers.

When using proxy informants, the interviewer should choose someone who is knowledgeable about the subject, such as a relative or someone who provides daily care.[11] This is especially important when details are asked about services received, such as the kinds of medicines taken or the kinds of treatments received. Proxy informants are also routinely used for obtaining information about children and for collecting data when the intended respondent is not available at the time of the interview. However, proxy respondents should be used as a last resort.

2. Non-response

Non-response is a failure to obtain some information on some part of the sample population and happens for a variety of reasons, including refusals, persons not at home at the time of the interview, persons incapable of answering or unable to answer, or persons in mailed surveys who are not found. A probability sample can soon lose its representative character if a significant proportion of ultimate sample units are not interviewed owing to non-response; households (or individuals) that are not interviewed may represent situations that significantly differ from those who are interviewed. Estimation of non-response bias is explained below in chapter II section C.7(b).

Non-response can be a special problem with persons with disabilities. In addition to the general reasons for non-response, refusal to participate may be linked to the type of impairment of the intended respondents. For example, persons with advanced cases of dementia or profound mental retardation may refuse because they are incapable of answering the questions; depressed persons may be capable but not willing to participate in the data collection; persons with paranoia, obsessive-compulsive reactions or elective mutism may not want to talk to strangers as part of the nature of the disorder itself; mute or deaf persons may find it difficult to participate in a face-to-face interview.

Nevertheless, a recent study carried out by the United States National Center for Health Statistics found that the rates of non-response were lower in persons with more severe disabilities, ranging from 7.56 per cent among those with mild disabilities to 5.07 per cent for those with severe disabilities.[12] This relationship is also found in the components of non-response: (a) eligible persons who could not be contacted; and (b) others who could not be interviewed (table 4). Furthermore, when the data were analysed through a multivariable approach controlling the effect of age and education, the statistical results held. Respondents with moderate or severe disabilities were more likely than those with mild disabilities to respond. Drawing on other related research, the study suggests that persons with more severe disabilities are more likely to be at home and to have time to cooperate with the interviewers. In addition, as they may benefit from government-sponsored programmes, they are more likely to cooperate with a government-sponsored survey.[13]

TABLE 4. RATES OF NON-RESPONSE, NON CONTACT, AND NON-COOPERATION BY ACTIVITY LIMITATIONS1994-1995 U.S. NATIONAL HEALTH INTERVIEW SURVEY ON DISABILITY

	Dependent variable		
	Non-response (Eligible person not interviewed)	*Non-contact (Eligible person not contacted)*	*Non-cooperation (contacted person not interviewed)*
	Percentage (Standard error)		
Activity limitation			
Mild	7.56	3.26	4.27
Moderate	5.94	2.25	3.59
Severe	5.07	1.95	3.02

Source: Gerry E. Hendershot, Lisa J. Colpe, and Peter C. Hunt, "Person with disabilities: non-response and proxy response in the National Health Interview Survey on Disability." Paper presented at the International Conference on Survey Non-response. Portland, Oregon, 28-31 October 1999.

Sometimes, however, the problem of non-response is not due to the intended respondents but to other household members who act as "gatekeepers" to limit access to household or family members with disabilities. In this case, the sampled household members might be willing to serve as respondents if provided the opportunity. [14]

Training of the field staff may also help to minimize non-response among persons with disabilities. For instance, interviewers should be trained to explain during the interview the specific purpose of the interview and the ways in which the results are expected to be used. Interviewers should have a good attitude in dealing with, and should not be prejudiced against, persons with disabilities. Interviewers need sensitivity training

in asking questions on disability, coping with listening to people talk about their disabilities, and avoiding the use of negative or derogatory terms. Also, interviewers themselves should not be a source of non-response by making assumptions about the sampled respondent's ability to serve as a respondent based solely on cognitive capabilities and sensory, or other impairments. [15] In addition, they should be trained to deal with persons who may be uncooperative or unable to participate in the interview. If subjects either do not agree to participate or are incapable of doing so, there is a need for guidance on how and when to do proxy interviews. When feasible, self-completion questionnaires should be used for highly sensitive topics.

3. Mode of data collection

There are several modes of data collection: face-to-face interviews, self-completed questionnaires and interviews by telephone, as well as the computer-assisted versions of these three methods. Depending on the abilities of the persons being interviewed and the availability of various modes of data collection, a mode should be chosen that minimizes the barriers to full participation by respondents.

Face-to-face interviews are the most common method used to collect data on disability. They are often the only viable approach in developing countries owing to high illiteracy rates and weak mail and telephone systems. Such interviews usually achieve higher cooperation and response rates and more complete and consistent data because of the potential for interaction between the interviewer and the respondent, and the opportunity to probe for more adequate answers. Face-to-face interviews can, if necessary, be combined with other data collection modes, including direct observation, visual cues and self-administered questionnaires. However, face-to-face interviews are likely to be more costly than other data collection modes: interviewers need to travel to the respondent's residence, and the amount of time required for data collection may be greater than that required for telephone procedures.

Personal interviews are generally seen as the most appropriate mode of collecting data on disability because some procedures, such as telephone interviews, may not be applicable for communication with people who have a functional loss in hearing or speaking. In such cases, in-person interviews are preferable because sign-language interpreters can be used.

Alternative techniques using **direct observation and measurement** (disability examination) are sometimes used in elaborate surveys. For example, in an Indonesian survey of the disablement process conducted in 1976/1977, local physicians were used as interviewers because of their ability to select an International Classification of Disease (ICD) category for the reported or observed impairments.[16] China, for its 1987 National Sampling Survey on Disabled Persons, also used physicians of different specialities to interview persons identified as having an impairment in the initial screening of the

household survey. Physicians examined the respondents and made a diagnosis of the nature and the degree of impairment.

The majority of surveys and censuses use regular interviewers and not physicians or other health specialists to administer screening questions for disability. If the approach used to identify disability is linked to activity limitations or participation, there is generally no reason to involve medical experts. However, specialists can improve the quality of data related to impairments, although these procedures require a lot of time and money.

Self-enumeration is often used in more developed countries and also among the more literate populations of developing countries. The completion of the questionnaire (or parts thereof) is made by the respondents themselves as in Australia (1993 Survey of Disability, Ageing and Carers), Japan (1991 national survey of disabled persons), and the United States of America (1990 census). The questionnaires may be distributed by mail or hand-delivered and the completed forms either returned by mail or picked up by field agents. Questionnaires for self-completion may also form part of a face-to-face interview when the subject is sensitive (for instance, toileting). Generally, it is advisable to restrict the length of self-enumeration questionnaires in order to avoid confusion and reduce non-response.

An advantage of self-enumeration is the relatively low field cost, as only a minimum of staff and facilities are needed. A disadvantage is the need for a good mailing list. In addition, the absence of an interviewer during the data collecting process may result in lower cooperation and completion rates and less consistent responses. Postal screening methods can be cost-effective for identifying samples of small sub-groups, such as persons with disabilities, that can then be followed up with a more detailed interview.[17]

The need to make data collection cheaper and more effective has increased the use of **telephone interviews** in data collection in developed countries, such as the United States of America, Switzerland, Canada and Italy. Telephone interviews are generally inexpensive and can offer some of the advantages of direct interviews, such as securing more consistent responses. Also, since no travel is involved, it is not necessary to select "clustered" samples. Therefore, more reliable estimates may be obtained with a given sample size, or fewer interviews may be needed to meet a specified reliability standard. The control and monitoring of interviews is considerably easier than in a field operation. The strength of the telephone interview lies in its low cost and rapidity. Its weakness is its lack of visual aids, which has its consequences for the questionnaire design. [18] Also, telephone interviews, like face-to-face interviews, are dependent on the interviewer's skill in obtaining answers.

Telephone interviews present particular problems in situations where observation is helpful, as is often the case with information on disability. For example, interviews

with people who have a functional loss in hearing, who do not speak the local language or who have diminished mental functions can pose problems when conducted over the telephone. Also, research has shown that conducting a telephone interview with elderly persons may present special problems. [19]

Computer-assisted interviewing may be in the form of a computer-assisted personal interview (CAPI), computer-assisted telephone interview (CATI), computer-assisted self-interview (CASI), or audio-computer-assisted self-interview (ACASI). In the CASI mode, the respondent reads questions from a computer screen and enters responses on a key board; in ACASI mode the respondent has the choice of reading questions from a screen or listening to them on earphones and entering responses on a keyboard.

Use of computer-assisted modes of interviewing helps minimize or eliminate some of the problems of interview non-participation that arise for some respondents when traditional forms of data collection are used. A person with a loss of functioning in hearing, cognition or speaking may be better able to respond to some of these modes than others. For instance, a person with a loss of hearing cannot hear the questions read by an interviewer but may be able to read the questions from a CASI screen. A person who cannot see cannot read questions from a screen but can hear questions read by an interviewer or recorded on a computer.

A major advantage of computer-assisted modes of interviewing is that the computer selects the proper questions to be asked and makes it easier to skip those that do not apply to the particular respondent, thus assuring consistent answers. The process also makes data coding and processing faster since, at the end of the interview, the data are already entered in the computer, and there is no need for data editing. Unfortunately the introduction of computers in data collection requires significant capital investment in both skilled personnel and computer hardware, preventing the majority of the countries from using them in large-scale data collections.

Some combinations of the various data collection techniques are frequently used, such as when a survey starts with a self-administered questionnaire distributed by mail or with a random-digit dialing interview procedure including some disability screening questions, followed by a face-to-face interview to obtain much more detailed information or by a physical examination. For example, the 1971/1972 Netherlands health survey on health, illness and handicap was carried out in two phases. In the first phase, a very brief and simple questionnaire was sent by mail to a sample of persons. The second phase involved a more detailed follow-up interview of persons who had indicated on the mail questionnaire that they had physical impairments.

4. *Translation of questionnaires*

A problem arises when the language spoken by a sizeable proportion of the respondents is different from the official language of administration. In some countries and for some studies, the best solution may be to print the questionnaires in different languages. However, the use of different languages might adversely affect the standardization of questions; different languages do not always have words or phrases with exactly the same meanings. Furthermore, the meaning of disability-related problems can differ substantially between different cultures. In other situations, it might be necessary to teach the interviewers to formulate/translate the questions accurately into the vernacular, which may be an unwritten language. In this case, however, interviewers require very good training in order to avoid or minimize interviewer variability in posing and interpreting the questions. Interviewers need to be trained how to explain the purpose and the meaning of the questions in the vernacular as well as which alternatives to choose, what to say and what to do at different stages of the interview.

Sometimes different sub-groups of the population use different vocabularies of the same language. It is not good practice to use different questions or wording of questions for the different sub-groups because finding exactly comparable words is not easy and this makes it difficult to give instructions to interviewers as to when to use which version of the translated questionnaire. [20]

5. *Data processing*

This section reviews issues related to disability in the various steps of data processing: data entry, data editing, weighting adjustment and tabulation.

(a)   Data entry

Although the majority of questions have check boxes that are marked or coded or that have numerical values already entered, there are often some entries that require clerical coding at the processing stage, such as descriptions of health conditions or occupations. Since items requiring coding are usually of a more complex nature, the expertise of subject-matter specialists should be utilized in order to avoid incorrect interpretation of the responses. The development of a coding scheme that would translate the collected data into meaningful categories of disability is very important. In addition, instructional manuals should be provided for this purpose and coders should be given sufficient training and be adequately supervised. In general, existing internationally comparable coding schemes should be used to the greatest extent possible.

(b)   Data editing

Editing of information and imputing for missing or erroneous data are important steps in data processing. Special attention should be given to the editing of data on the

population with disabilities since individual characteristics may be different between the population with and that without disabilities. No special procedures may be needed when editing variables such as age, sex and place of residence as there may not be significant differences between the two population groups. Other variables such as education , occupation and relationship to head or reference member of household may be more directly linked with disability status. However, editing is not a simple matter, and the development of editing rules for disability data is a complicated task requiring knowledgeable professionals. For example, it should not be assumed that a blind person can't be a doctor or architect just because it seems inconsistent with what is normally expected.

Various approaches may be used to resolve content errors found when processing the data. Generally, the best procedure is to resolve the problem using information in the questionnaire. When errors cannot be resolved in this manner, the choice needs to be made between allowing an error to stand or making some kind of imputation. One approach to imputation is the Acold deck≅ procedure, whereby unknowns are replaced on the basis of a distribution of known cases. Another approach is the Ahot deck≅ procedure. In this procedure the missing information is assigned on the basis of the last known case in the same group. It might also be decided to use a kind of model to estimate a value for a missing value based on the answers to other questions from the survey. When editing data for a disability study, decisions on whether to impute values or to retain Aunknown≅ categories depend on a number of circumstances. Although imputation is a biased procedure, the retention of unknown categories in such basic characteristics as gender and age can create problems for analysts since there is a strong correlation between each of these variables and disability.

(c)   Weighting and non-response adjustment

An important aspect of data processing is the implementation of the weighting and estimation procedures. After data editing, the result is a "clean" file—one with as many errors as possible eliminated. Before this file can be used for tabulation and analysis, some additional procedures have to be applied. These procedures involve the application of weighing adjustments to the raw data records. There are two kinds of adjustments that should be considered. One is the so-called design weights, defined as the reciprocals of the probabilities of selection. These must be applied whenever the disability data come from a probability sample, especially when the latter is not self-weighting. Whenever the sample is selected in such a way that households or persons are selected with different probabilities, a technique that is frequently utilized when different strata are involved, then the sample is not self-weighting and the differential design weights must be computed and applied in order to inflate the data properly to produce the estimates. An example would be a disability survey in which urban households are selected at the rate of 1 in 100 and the rural households at the rate of 1 in 50; in this case the weights to be applied would be 100 and 50 respectively to the urban and rural households (and

persons). Another example of weighting is the selection of one-person households, that is, giving those in one-person households a greater chance of selection than those living in two- or three-person households. When all the sample units (households or persons) are selected with identical probabilities, the sample is said to be self-weighting. When that occurs, design weights are only required if survey totals are wanted; if the tabulations are restricted to proportions, the design weights need not be applied.

A second weighting adjustment, which is superimposed upon the design weights, is one that adjusts for non-response households and/or persons. This subject is considered in some detail below in section C.7, "Evaluating and improving the quality of the results".

(d)   Tabulation

In the data processing stage, the planned tabulations are prepared. Careful preparation of specifications is required for each proposed table. The specifications must spell out the codes or values, which comprise each listed category in the table and the location of this information on the computer record. Careful consideration has to be given to the choice of variables to be included in each of the tables. Disability data should always be cross-classified by both age and sex. The age and sex distribution of the study population is important because both the extent and degree of disability are often associated with increasing age, and also because the prevalence of particular impairments and causes of impairments within certain age cohorts is correlated with sex. [21]

A useful and often necessary step in processing data is the recoding of information or the creation of variables from a combination of the initial data elements. It is important to have a well developed list of analytically meaningful cross-classifications of disabilities. Cross-classification should be done at the tabulation stage rather than in the field by the enumerator; any groupings that are created at the data collection stage cannot be desegregated at the compilation stage.

If an individual has more than one type of disability, then tabulating these multiple occurrences in a meaningful way must be considered in tabulation design. For some tabulations, the basic unit is the number of individuals who have one or more disabilities, and each person is counted once in the population with disabilities. However, for some tabulations there is an interest in the distribution of the population with disabilities by type of disability generally cross-classified by other variables. Although the unit of analysis in such tabulations is still the person, the total number of persons with disabilities is less than the total number of disabilities, as some people may have multiple disabilities.

If there is an interest in the number of disabilities per person, the recommended way for presenting that information is to create a variable with the label Anumber of

disabilities≅. The number of disabilities that each individual has would then be counted and recorded in that variable. Each person within the population with disabilities would have one code assigned to this variable. For example, if an individual had an activity limitation in understanding spoken messages and another in walking, the number recorded in the derived variable, Anumber of disabilities≅, would be 2. This derived variable could then be cross-tabulated with other variables such as age, gender and employment status.

Some users may be interested only in individuals with a particular type of disability, such as persons with a mobility disability. To handle needs such as this, the database design team may consider the creation of a series of derived variables that have the values of Azero≅ or A1≅. Each derived variable would represent one type of disability, such as an activity limitation in walking, listening, speaking, using public transportation as a passenger or washing and drying oneself. Each record would be evaluated and the appropriate codes assigned to each of the derived variables. For example, if a person had a walking and a listening disability, then the derived variable Awalking≅ and the derived variable Alistening≅ would each be assigned the value of A1≅. The Ausing public transportation as a passenger≅, Aspeaking≅ and other derived variables would be assigned the value of Azero≅. The programmer would then select those records that had the desired derived variable equal to A1≅, and then he/she would tabulate the selected characteristics of that population.

In order to convey meaningful information to policy makers and planners, tabulations should be prepared to show the social and economic characteristics of persons with disabilities. Tabulations should also include the population without disabilities, the reference population against which the social integration and equalization of opportunities of persons with disabilities are assessed. Hence, in addition to the cross-classifications by age and sex, persons with disabilities by type of disability (and those without disabilities when applicable) should be cross-classified by other characteristics such as the following: (a) educational attainment; (b) school attendance; (c) economic activity status; (d) occupation; (e) status in employment; (f) industry; (g) marital status; (h) rural/urban area of residence; and (i) type of household.

6. Planning outputs and dissemination of data

The planning process should also include the development of the data analysis and dissemination plan. The plan should consider not only immediate data needs and standard publications but also other potential uses and analytical opportunities. Dissemination and analysis are discussed in more detail in chapter IV.

For planning purposes, three phases of analysis and dissemination should be considered. First, it is necessary to produce the planned tabulations and indicators required by the sponsor(s) of the data collection exercise. A detailed outline of the

planned tabulations and indicators will provide the main users with the opportunity to see what they will receive as initial output. This is another way to confirm the detailed specifications for the content of the questions, and the amount of detail that will be required with respect to cross-classifications of variables and geography. All tables included in the tabulation program may not have the same urgency. The main users should be asked to prioritize the tables to ensure that the most immediate needs are met as soon as the data become available.

The second phase involves the development and production of reports and other products to ensure that the data are made available to a wide spectrum of users. There are a variety of products that may be considered to ensure that the data are made available to as many users as possible. Typically, users can range from very sophisticated data analysts to members of the general public who are interested in understanding the issues of living with a disability.

Finally, the third phase consists of the secondary uses that are made of the data by researchers and other statistical agencies. Ensuring that the data and supporting documentation, such as the sampling frame, coverage, response rate, editing, and coding procedures, are available for users of the data for further analysis is an important part of the analysis and dissemination plan. It is important for the planning team to be aware of the work in the research community involving disability data and to inform the research community of the availability of the data.

7. Evaluating and improving the quality of the results

It is widely recognized that data from censuses and surveys are subject to error, both random and non-random, and that error occurs no matter how carefully the data collection processes are planned and executed. Whether the data on disability originate from a census or a survey, errors enter into the results from a variety of sources. Errors can and do occur, starting from the initial stages of the data collection plan through to the end result, and at all stages of operation in between. The many kinds of error that are present in varying degrees in census and/or survey data on disability include conceptual errors in designing and phrasing the disability questions, respondent errors, interviewer errors, non-response (already discussed in some detail above in section C.2), coding mistakes and other data processing errors, sampling variance, response variance and errors in sample coverage, including those arising when certain segments of the population are purposely excluded from the disability study.

It is incumbent upon the producers of the disability data to take appropriate steps both to control the errors and to assess their components. It is also incumbent upon the

users to be cognizant of the various errors affecting the accuracy of the results. Findings and results from the disability study, whether from a census or a survey, should be

accompanied by descriptions of their quality and limitations. This is essential for the proper use and interpretation of the data.

Survey and/or census error can be categorized in several different ways. These include errors of accuracy versus reliability, or variance versus bias, or the all-encompassing notion of total survey error, also known as mean square error. For the purposes of this publication the dichotomy, sampling error and non-sampling error will be used. An overview of the way in which both affect disability data collection, some steps that should be taken to control the errors and ways to measure them will be presented below.

(a) Sampling error

Sampling error is the error of random fluctuation in survey results that comes about when a sample, rather than the total population, is surveyed. Sampling error occurs in all sample surveys. If the disability estimates were generated from a sub-sample of a population census, then sampling error would also occur; but if the disability results came from the 100 per cent enumeration of a census, no sampling error would be involved.

The magnitude of sampling error in the disability survey depends primarily on the size of the sample used, but it also depends on other important features of the sample design including the stratification scheme, the number and sizes of ultimate clusters, and the allocation and distribution of the first-stage selection units. Sampling error decreases as the sample size increases. When sampling error is thought to be too large, a sure method of decreasing it is to increase the sample size of the survey, if the budget will allow it. Another method of decreasing sampling error in surveys is to refine the sample design by, for example, decreasing the cluster sizes (number of sample persons per cluster) with a compensating increase in the number of clusters to retain the same overall sample size.

Sampling error is evaluated by estimating the sampling variance. Mathematically, the sampling error, or standard error, of a survey estimate is the square root of the variance. Sampling variance occurs in a sample survey on disability because the particular sample of persons selected and interviewed is only one of all the possible samples that might have been chosen using the same sample design and selection methodology. It is important to obtain an estimate of the sampling variance for the main survey on disability variables; otherwise, an evaluation of the precision of the disability estimates is not possible. From the variances, the standard errors can be calculated easily by taking the square roots. These standard errors (precision measures) are then used to establish confidence intervals around the survey estimates. It is usually standard practice to double the estimated standard error in order to obtain intervals at the 95 per cent level of confidence.

As an example, if the survey estimate of total disability in the north-east region of a country is 8 per cent, and the estimated standard error is 0.5 per cent, then the confidence interval around the survey estimate at the 95 per cent level of confidence would be found by adding to and subtracting from 8 per cent twice the standard error, or 1 per cent. This would yield a confidence interval of 7-9 per cent. The interpretation of the confidence interval is that if the survey were to be repeated using all possible samples, under the same design and conditions, the estimate of total disability in the north-east region would fall in the interval between 7 and 9 percent 95 per cent of the time.

The method of calculating the sampling variances for a disability survey is highly dependent on the particular sample design that is used, but a necessary and sufficient condition is that the design must be based upon probability sampling techniques. There is no standard formula for the calculation of standard errors when complex sampling procedures are used, as would be the case for a disability survey. The calculation formula must be, in effect, derived from and faithful to the sample design. Shortcut methods that are found in general statistical packages for personal computers are inappropriate because they generally assume that the survey is based upon a simple random sample, which would almost never occur in practice for disability sampling. As a result, those packages would seriously underestimate the standard errors.

However, statistical software is available that has been specially designed to deal with the estimation of sampling variance and standard errors, plus other associated measures such as the coefficient of variation (standard error divided by survey estimate) and design effects (measure to show the ratio of variances for the sample design used in the survey compared to that of a simple random sample of the same size). Many of these software packages are freely available and they include the following:

Bascula	Statistics Netherlands (Voorburg, Netherlands)
CLUSTERS	University of Essex (Colchester, United Kingdom)
CENVAR	United States Bureau of the Census (Washington, D. C.)
WesVarPC	Westat, Inc. (Rockville, Maryland)
SUDAAN	Research Triangle Institute (North Carolina)
PC CARP	Iowa State University ((Ames, Iowa)
Generalised Estimation System	Statistics Canada (Ottawa)
Stata	Stata Corporation (College Station, Texas)

See Lepkowski and Bowles 1996 for an excellent review of these packages, including the conditions under which they should be used and information on their availability.[22]

(b) Non-sampling error

The concept of non-sampling error runs the gamut of survey errors that occur apart from sampling error. Non-sampling error is present in surveys and in censuses, whether sampling is used in the latter or not. Non-sampling error is basically survey (or census) bias, and most observers believe that it is generally of much greater consequence than sampling error, the latter of which is better understood and measured. Moreover, as mentioned above, sampling error can always be reduced by increasing the sample size, whereas non-sampling error cannot.

Many of the types of error mentioned in the opening paragraph of this section are in the non-sampling error category. These include conceptual errors, non-response, respondent and interviewer errors, coding mistakes and so on. They also include certain errors associated with the sampling process, such as coverage problems and biased selection procedures. In practice, it is often difficult and expensive to obtain good estimates of non-sampling error and virtually impossible to obtain an estimate of the total contribution that non-sampling error makes to the total survey error. Instead, strenuous efforts must be made to control non-sampling error, as opposed to measuring it in its entirety. Nevertheless, a number of statistical measures relating to non-sampling error, such as response rates, can be calculated and presented in the disability survey report to inform users of the quality of the results. In addition specialized studies may be undertaken, when survey budgeting permits, to measure particular components of non-sampling error, such as response variance.

In disability measurement a particular type of non-sampling error that can be very troublesome is that of conceptual error. This arises either from poor operational definitions in the survey or from poor wording in the survey instruments. Errors of this kind, when they occur, present problems of validity with the disability survey results. That is why it is very important to adopt disability definitions that are consistent, as much as possible, with international standards. In addition, it is also important to use survey protocols, instruments and questionnaire phraseology, notwithstanding the difficult requirements demanded by language translation, that have already been validated in various contexts and settings, including international forums. Another technique for controlling and reducing conceptual errors is through the careful use of pre-testing of the questionnaire, the importance of which has already been stressed a number of times in this manual.

The validity of the questionnaire may be pre-tested through cognitive interviewing. Cognitive interviewing or testing may take the form of either focus group research, in which a moderator leads a group of participants through a structured discussion, or observational studies, in which observers watch respondents complete forms in the environment where they would normally do this, such as in their homes. [23] This option of pilot testing the questionnaire offers the questionnaire designer an opportunity to evaluate the participants in terms of the time taken to read the instructions and the order in which questions are answered, as well as a greater understanding of how

respondents understand and interpret the questions. This feedback is important, for instance, to ensure that disability terms and concepts used in formulating the questions are clear and unambiguous and not easily misinterpreted by the respondents. This provides invaluable information for revising the data collection instrument. One drawback of this method is that such studies tend to be relatively expensive. Extreme caution should be exercised when interpreting the results because of small sample sizes, as problems with form design may not be detected, and the significance of the problems detected may be biased. It should also be borne in mind that testing conditions are not identical to census or survey conditions.

Non-response has already been discussed above in terms of its potentially serious consequences on the representativeness of the disability study. Every effort should be taken to keep non-response to a minimum. It is important for non-response bias to be estimated. This can be achieved by intensive methods using different procedures with a sample, such as 1 in 10, of non-responders. If this sample should exceed 10 or 12 per cent of the respondents, the disability results may be seriously biased. No matter whether the rate of non-response is large or small, information about it should be published in the report on the disability study. This would include rates of non-response for major areas or regions and its distribution by cause: refusal, no one at home, temporarily absent, other. In addition, investigating income historically has a high non-response rate; to minimize this, it would be better to ask such questions last so as not to alienate respondents.

Various adjustments for non-response can be made at the data processing stage, although it should be noted clearly that the adjustments do not remove the bias inherent in non-response. Whatever adjustment is made suffers from the fundamental assumption that the persons who did not respond have the same characteristics and distribution as those who did—an assumption that is rarely verifiable. One such adjustment is simply to Aweight up≅ the data to account for non-response by introducing an additional factor in the inflation, or weighting, procedure beyond the so-called design weights, the latter of which are the reciprocals of the probabilities of selection. The adjustment factor would typically be of the form, n/(I), where n is the number of households selected into the sample and I is the number interviewed.

Another adjustment technique that might be used is one that would apply when item non-response occurs. In that instance, when particular questions are not answered, item responses may be imputed by such techniques as basing the response on patterns of responses to other questions or by using the response from another questionnaire that is similar in certain prescribed ways. The report on findings, in addition to providing non-response rates, should also supply a description of the adjustment procedures used in the disability survey, including imputation rates for item non-response.

The influence that interviewers have on the disability study can contribute to error in many ways. If they fail to collect data from some of the sample households or from

eligible persons within households, non-response bias occurs. When interviewers do not fully understand the survey concepts, ask the questions inconsistently, record the answers erroneously or make up information, error obviously occurs. These influences affect disability data in different ways. When there is a lack of uniformity in the way interviewers apply the concepts, ask the questions or record the answers, survey variability is increased. For disability data on small areas, where few interviewers are assigned, this interviewer variance can be substantial, though it is usually negligible for large areas because many more interviewers are involved, and the effects tend to balance out. However, if most of the interviewers in a disability study carry out the work in a way that is different from what was planned, bias results. The bias then affects both small and large area aggregations of the data.

Controlling both interviewer variance and bias, as much as practicable, is an essential component of the disability survey and its operation. That is why it is very important to provide ample training on disability concepts and interviewing procedures. Again, the need for pre-testing cannot be over-emphasized. In addition, field supervisors should conduct direct observation of interviewers during actual interviews, especially at the beginning of a disability survey, so that bad practices can be corrected. Measuring interviewer variance and bias is, unfortunately, a complicated and expensive proposition, involving the use of randomized, inter-penetrating samples, and it is usually impractical to consider it unless the research budget for the disability survey is quite large. One type of study that is comparatively economical, however, and which is useful because it partially measures the contribution that interviewers make to response bias, is a re-interview survey. This will be covered below. First, however, it is necessary to consider respondent error.

Respondent error in a disability study can arise for many reasons: failure to understand fully the survey concepts and/or questions; lack of knowledge (especially when a proxy respondent is used); or wrong answers willfully given in the interview. The sensitivity of a subject can cause false reporting, and, in some cultures, disability is such a subject. Again, as has been stated so often, the necessity for careful pre-testing and pilot testing is essential in order to find and refine appropriate phraseology in the questioning, which can tap various disabilities in a survey mode without offending the respondents. Pre-survey publicity is useful in this regard also, as is a carefully-worded introduction that the interviewer should use when first requesting the sample persons to cooperate in the interview.

The task of measuring respondent error is a difficult one. Usually the survey research team will have to settle upon getting measurements of certain components of respondent error. A reverse record check is a useful tool for finding out about certain types of respondent error before the disability survey is undertaken, so that the questionnaire can be modified accordingly to reduce the error. The reverse record check entails selecting a small sample of known disabled persons, usually from an existing administrative register of some kind, and then administering the questionnaire to those

persons to ascertain whether the disability is reported. In studies of this type, the interviewer is often not informed that the particular subjects for the study are known to have disabilities, in order to minimize any biasing influence that the interviewer might contribute. The results of the record check are used to discover instances in which the questionnaire wording may be deficient, or if cultural taboos are inhibiting the respondents from giving accurate answers. As mentioned, this kind of study would be done a priori, as a planning tool for designing the disability instruments and survey procedures.

Use of a re-interview survey to study response variance or response bias will provide valuable information about the degree and nature of response errors. Whether variance or bias is studied depends upon the research objectives of the re-interview design, especially the questionnaire. If the objective is to study simple response variance, the design entails re-interviewing a sub-sample of the original disability survey respondents under conditions that are approximately the same as those of the original interview (same wording of the questions, same quality of interviewing staff). Under this approach the consistency of response is compared between the original and re-interview. The method is not intended to provide "true" responses, but rather to establish the degree of inconsistency in response. When the objective is to measure response bias in the initial interview, a preferred survey technique should be used in the design of the re-interview study. It is then assumed that the re-interview produces responses that approximate the truth more closely than those of the original survey. A re-interview involves the use of more detailed and probing survey instruments, better-trained interviewers and field reconciliation of observed discrepancies. Measurements of error in the response bias model are interpreted as deviations from the "truth", as opposed to deviations, or variance, across "trials" as in the simple response variance model.

It was mentioned above that some types of non-sampling error occur, perhaps paradoxically, in the sampling process. One type is sample selection error, which can happen whenever simple mistakes are made in applying sampling intervals to lists of households or when interviewers misapply sampling instructions in the field. The latter can be particularly problematic for disability measurement if interviewers, whether purposely or subconsciously, fail to follow prescribed procedures for random or systematic selection. This may affect the outcome in two ways: (a) households with disabled persons are consistently omitted; or (b) interviewers consistently obtain a disproportionately large number of non-interview cases from households containing persons with disabilities.

An important source of non-sampling error from the sampling operation is sample under-coverage. Under-coverage may happen in a number of ways, most of which are attributable to the sampling frame. If an area frame is used, which is usually the case for a national disability survey, some geographical areas may be excluded from the frame and, hence, excluded from the sample and the survey. They might include difficult-to-access areas such as remote, mountainous regions or areas in which civil unrest or other security

problems preclude survey-taking. The frame may also exclude certain groups of people, such as those residing in refugee camps or military barracks, boat people or nomadic peoples who have no fixed residences. Needless to say, persons in such excluded areas may have degrees of disability prevalence that are quite different from the survey population that is covered, and excluding them from the sample will cause estimation bias. Another important source of under-coverage, also attributable to the frame, occurs when an old frame is utilized without appropriate updating. Residential areas, including squatter camps on the outskirts of cities, are especially vulnerable to under-coverage when an old sampling frame is used.

Remedies to control or reduce both types of under-coverage—frame exclusions and obsolete frames—are available. The sampling staff can attempt to supplement the existing frame with auxiliary frames in order to cover population groups of the type mentioned above that might otherwise be excluded. This is especially important if the excluded groups are thought to have special problems or needs with respect to disability. Nomadic groups, for example, might be sampled from a separate frame constructed by making a list of water-points that the nomads use to water their animals. Similarly, a list of refugee camps could be compiled and sampled as a separate, auxiliary frame to the main frame. With regard to dealing with frame obsolescence, it is always important to update the frame periodically, every year or two. Making a new list of households in the sampled primary sampling units can achieve this.

It is not easy to measure errors due to sample under-coverage in a direct way. However, for the purpose of looking for evidence of under-coverage, indirect measurements may be made by comparing the disability survey results with other, independent studies, whether national or sub-national.

NOTES

[1] The United Nations Statistics Division web site on disability statistics is at http://esa.un.org/unsd/disability/.

[2] *International Classification of Impairments, Disabilities, and Handicaps* (Geneva, World Health Organization, 1980 and 1993).

[3] *International Classification of Functioning, Disability and Health–ICF,* Final Draft, Full Version (Geneva, World Health Organization, 2001.)

[4] *Principles and recommendations for Population and Housing Censuses, Revision 1* (United Nations publication, Sales No. E.98 XVII.8), p.93.

[5] Adopted by the General Assembly in its resolution 48/96, of 20 December 1993; available as *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations Sales publication E.DPI/1454).

[6] A. de Bruin, H.S.V. Picavet and A. A. Nossikov, *Health Interview Surveys: Towards international Harmonization of Methods and Instruments.* WHO Regional Publications, European Series, No. 58 (Copenhagen, World Health Organization, Regional Office for Europe, 1996).

[7] N. Mathiowetz, and G. S. Wunderlich, *Survey Measurement of Work Disability: Summary of a Workshop* (Washington, D. C., National Academy Press, 2000).

[8] J. R. McWhinnie, *Measuring Disability:* t*he OECD Social Indicator Programme*, Special Studies, No. 5 (Paris, Organization for Economic Cooperation and Development, 1982).

[9] *International Classification of Functioning, Disability and Health–ICF,* Final Draft, Full Version, (Geneva, World Health Organization, 2001).

[10] See N. Mathiowetz, and G. S. Wunderlich, *Survey Measurement of Work Disability: Summary of a Workshop* (Washington, D. C., National Academy Press, 2000).

[11] K. Dunnell, "Methodological issues in health interview surveys", in *Consultation to Develop Common Methods and Instruments for Health Interview Surveys, 21-23 June 1988* (Copenhagen, World Health Organization; and Netherlands Central Bureau of Statistics, Voorburg, the Netherlands, 1988).

[12] Gerry E. Hendershot, Lisa J. Colpe, and Peter C. Hunt, "Persons with disabilities: non-response and proxy response in the National Health Interview Survey on Disability", paper prepared at International Conference on Survey Non-response, Portland, Oregon, 28-31 October 1999 (http://www.jpsm.umd.edu/icsn/papers/Hendershot.htm).

[13] R. M. Groves, and M. P. Couper, *Non-Response in Household Interview Surveys* (New York, John Wiley and Sons, 1998).

[14] N. Mathiowetz, and G. S. Wunderlich, *Survey Measurement of Work Disability. Summary of a Workshop*.(Washington, D. C., National Academy Press, 2000).

[15] *Ibid.*

[16] Kenneth Manton, J.E. Dowd and Max A. Woodsury, "Conceptual and measurement issues in assessing disability cross-nationally: analysis of a WHO-sponsored survey of the disablement process in Indonesia, *Journal of Cross-Cultural Gerontology*, vol. 1, No. 4 (1986).

[17] Jean Martin, Howard Meltzer, and David Elliot, *OPCS Survey of disability in Great Britain: Report 1, The Prevalence of Disability among Adults* (London, Her Majesty's Stationery Stationary Office, 1988).

[18] E. Körmendi, and J. Noordhoek (1989) *Data Quality and Telephone Interviewing* (Copenhagen, Danmarks Statistik, 1989).

[19] Ibid.

[20] F. J. Fowler, Jr. *Survey Research Method,* Applied Social Research Methods Series, vol. 1. (Beverly Hills, California, Sage Publications, 1984), p. 52.

[21] *Development of Statistical Concepts and Methods on Disability for Household Survey* (United Nations publication, Sales No. E.88.XVII.4).

22. J. Lepkowski, and J. Bowles, "Sampling error software for personal computers", *The Survey Statistician*, No. 35 (December 1996), pp.10-17. *The Survey Statistician* is the newsletter of the International Association of Survey Statisticians (IASS). This article can be accessed on the Internet at http://www.fas.harvard.edu/~stats/survey-soft/iass.html.

[23] *Handbook on Census Management for Population and Housing Censuses*, Studies in Methods, Series F, No. 83 (United Nations publication, Sales No. E.00.XVII.15).

CHAPTER III
MODULES: METHODOLOGY FOR DISABILITY DATA COLLECTION

Chapter III consists of modules giving detailed methodological information on specific types and aspects of data collection. The modules cover the following topics:

1.   Censuses. This module presents general issues in the use of a population census to collect data on disability, information on questions for use in a census and the use of a census to screen for a follow-up disability survey.

2.   Surveys. This module includes information on survey questionnaire design for collecting data on disability. It also addresses the development of survey screening questions for the general population, children and the elderly. Owing to the specific nature of mental disability, a section has been developed on screening for this type of disability. In addition, the chapter includes information on other special topics that could be investigated in a survey on disability: the causes of disability, the environment, the use of technical aids, and services and support.

3.   Sampling for a disability survey. This module gives guidance on how to develop a sample for a disability survey and includes information on sampling frames, determination of sample size and sampling techniques.

4.   Institutional population. This module includes information on collecting disability data in institutional settings, ranging from lists of possible institutions to be considered in determining the questionnaire content to how to interview institutional residents.

A. CENSUSES

1. Investigating disability in a population census

For many countries, a census represents the only national source of information on the frequency, distribution and socio-economic situation of persons with disabilities. Questions to identify persons with impairments, disabilities and handicaps were included in censuses as early as 1930.[1] A review of data in the United Nations Disability Statistics Database, version 2 (DISTAT2) shows that in the past 25 years the number of countries collecting this type of data has increased, from about 19 in the 1970 census round, to 45 in the 1980, and to 80 in the 1990 census round. Information on the inclusion of disability questions in population censuses can be found in the *Principles and Recommendations for Population and Housing Censuses, Revision 1.*[2] Although *Principles and Recommendations* refers to the terms of the original ICIDH, it remains a valuable source of information on the use of censuses to develop disability data.

Discussions on including disability as a topic in a census must begin very early in the preparatory stage to allow for consultation with a broad array of data users in national, regional and local Government as well as with interested researchers, professional groups, community organizations, organizations of persons with disabilities and the general public. It is important to establish why the data are needed. Census data on persons with disabilities are collected mainly to study the socio-economic situations of these individuals, as well as to monitor the effect of disability programmes. In addition, details should be worked out concerning such issues as the nature of the information to be collected, the development of the disability question(s) to be used, the placement of the question(s) on the short or long census form and the additional materials required to support collection of the disability data. Additional training of field staff may be required to ensure that the concepts and definitions associated with the disability question(s) are well understood. Chapter II, Section C.1 above addresses other training issues, such as the need for sensitivity training related to interviewing persons with disabilities.

The addition of a question or questions to identify persons with disabilities in a census must be considered in the context of the total demands on the census. The choice of topics, the level of detail of the information to be collected and the corresponding questions to be asked must take into consideration the possible burden that may be placed on respondents. Public cooperation can be undermined by a questionnaire that respondents find too burdensome or that takes too long to answer. Adding questions on persons with disabilities to the census needs to be assessed in terms of these general considerations and the alternative possibilities for obtaining the data.

To avoid overburdening the respondents and overloading the census questionnaire, some countries use two questionnaires for their census, a long and a short form (such as the 1991 census of Canada). The short form contains only the main census questions to be asked of 100 per cent of the population, while the long form, which is distributed to a pre-selected sample of households, includes the same questions as the short form, plus a number of questions on special topics, such as disability, that are to be asked on a sample enumeration basis only. Therefore, if the question on disability cannot be included in the complete enumeration, countries may wish to include it in a questionnaire to be administered on a sample basis.

Among the many countries that have used the census to collect information on persons with disabilities, significant differences exist in the type and clarity of the questions used. The range of different questions used in censuses can be seen on the United Nations Statistics Division web site.[3]

2. Developing disability questions for a census

The following guidelines may be considered when formulating disability questions to be included in the census. General issues on the design of screening questions are addressed in chapter II, section B. Given the complexity of a census operation, it is important to minimize the explanatory material and training required for the enumerators. The number of additional probing questions to check on the accuracy or consistency of replies should also be minimized. To do this, the structure and the formulation of the questions must be easily understood by the respondents as well as by the enumerators.

In general, owing to space limitations, the way persons are identified in censuses as having a disability is less elaborate than the methods used in surveys. *Principles and Recommendations for Population and Housing Censuses, Revision 1*[4] proposes the inclusion of a disability-oriented question. With the development of the ICF, it is recommended that the activity concept, with some modification, should be used as a basis to investigate disability in a census. Chapter II, section B discusses in more detail the design of screening questions, and why the activity concept is recommended.

Use of a generic question, even when followed by a specific question on the type of disability, is discouraged because it tends to exclude persons with mild and moderate disabilities, persons with disabilities of a psychological nature, the aged and children.[5] For example, a generic question, such as, "Is there any person in this household who is disabled?" should be avoided, as the interpretation of the term "disabled" may differ among respondents. Rather, a question that lists specific categories based on the ICF should be used so that each person can check the presence or absence and degree of disability for each listed category. Listing different categories of the ICF in the question, as recommended, will help respondents understand whether they should identify themselves as having a disability. To eliminate the need for further coding and to expedite tabulation, the use of pre-coded, fixed response categories from which one or more answers can be selected is recommended. It might be useful to include one "other, not specified" response category on the list, where the respondent or enumerator can write the answer fully in case none of the categories corresponds with his/her specific limitation. This "other" response category is coded afterwards.

The recommended categories, based on the original ICIDH, include:

(a)   seeing difficulties (even with glasses, if worn);
(b)   hearing difficulties (even with hearing aid, if used);
(c)   speaking difficulties (talking);
(d)   moving/mobility difficulties (walking, climbing stairs, standing);
(e)   body movement difficulties (reaching, crouching, kneeling);

      (f)   gripping/holding difficulties (using fingers to grip or handle objects);
      (g)   learning difficulties (intellectual difficulties, retardation);
      (h)   behavioural difficulties (psychological, emotional problems);
      (i)   personal care difficulties (bathing, dressing, feeding);
      (j)   others (specify).

This list was developed taking into account country experience in items investigated in national studies that used the ICIDH as a guide to formulate questions. By representing six of the seven categories of the disability category of the ICIDH, these items are seen to capture as wide an experience of persons with disabilities as possible. A person is identified as having a disability if she/he indicates having difficulty with one or more of the categories included on the list. Countries may modify this list to suit national situations. However, it is important for the list to include categories relating to the experience of children and the elderly in order to identify disability among these categories of the population. For example, among children, problems with learning are of special importance, while among the elderly, the emphasis tends to be on difficulties with performing the activities of daily living.

Not all categories of the disability dimension in the original ICIDH translate into activity items in the ICF. Seeing, hearing and behavioural difficulties in the original disability dimension are included under Body Functions in the ICF. For seeing and hearing, the related category under Activity in the ICF, "Purposeful Sensory Experiences", includes "Watching" and "Listening". At this time, however, it would not be appropriate to change the recommended census question to make it fully consistent with the Activity items of the ICF. Most countries using a list of items in their census question on disability have included seeing and hearing problems. "Purposeful watching" does not have the same meaning. Given the space limitations of the census, further work is needed to operationalize these new categories to make them meaningful to respondents. For now, pending such work, countries should continue to use the question in the United Nations census recommendations.

The use of qualifiers should be taken into consideration when the ICF is used as a basis for disability questions in a census. However, owing to space limitations, it is generally not possible to include all seven qualifiers in the question. For more information on the ICF qualifiers, see chapter II, section B. An alternative proposal is to incorporate some of the qualifiers, such as "none", "mild and moderate", and "severe and extreme". Since the ICF has not yet been applied in census data collection efforts, what can or cannot be done is not clear. Experience gained as countries apply this classification will shape future international recommendations in this area.

The question or set of questions to be asked of the general population may take this form:

Because of a long-term physical or mental condition that has lasted or is expected to last six months or more, do you have difficulty .... ? (check all that apply)

	Yes	No
Seeing, even with glasses, If worn?		
Hearing, even with hearing aid, If used?		
Speaking (talking, conveying Information)		
Moving/mobility (walking, climbing Stairs, standing?		
Body movement (reaching, crouching, Kneeling)?		
Gripping/holding (using fingers to Grip or handle objects)?		
Learning (intellectual difficulties, Retardation)?		
Behavioural (psychological, emotional Problems)?		
Personal care (bathing, dressing, feeding)?		

Other? _____   Explain _____

The entire set of questions should be asked of each person who lives in the household or institution. It is not sufficient to derive disability data only from the questions asked on reasons for being economically inactive or not attending school. Special attention should be given to the disability status of persons living in institutional settings, since in many countries a significant number of persons with disabilities reside in institutions, such as chronic care hospitals and psychiatric institutions.

If the question on disability cannot be included in the short form, the country may consider placing it on the long form.

3. Additional topics on disability to be investigated in a census

A country may be interested in obtaining information on additional topics such as impairments from Body Functions and Body Structures, Participation, and the causes of

disability. Duration of disability is another important variable in examining the characteristics of persons with disabilities.

(a)   Impairments

For those persons who have been identified as having a disability, the specific loss or dysfunction of a body part can be analysed through the use of a carefully selected question on impairments related to Body Functions and Body Structures. Such a question would give information related not only to the nature of the impairment, such as the difficulty that a person has in climbing stairs, but also to its cause, such as heart function, muscle power functions or the structure of the pelvic region. Information related to impairments is relevant for prevention as well as for planning and implementing programs oriented to early intervention and rehabilitation.

With the ICF it is relatively easier to ask about Body Functions and Body Structures in questions because the terminology of this ICF component is greatly simplified compared to the impairment category of the original ICIDH. The categories of impairment in the ICIDH were difficult to understand because they were generally phrased in medical terms.

Many countries measuring disability through censuses have covered only severe impairments, such as blindness, deafness or mutism. However, the recommended approach would cover a wider set of persons with disabilities, as included in the screening question. Continuity between old and new census data may be achieved by investigating a subset of impairments associated with Body Functions and Body Structures. In this case, only a few categories of Activity and Body Functions and Body Structures may be included in the question in order not to overburden the census questionnaire.

(b)   Participation

Participation denotes the individual's involvement in life situations. It can be measured by collecting information on the functioning of an individual in various life areas. The standard or norm against which that individual is compared is that of an individual without disabilities in that particular society. Life situations may include learning and applying knowledge; general tasks and demands; communication; mobility; self care; domestic life; interpersonal interactions and relationships; major life areas; and community, social and civic life. Asking a question or questions on Participation is useful for obtaining information on the equal participation of persons with disabilities in society and on factors that act as barriers or facilitators to their participation. It is particularly useful because the census affords the possibility of comparing participation among those with and without a disability. Investigating Participation may not be feasible in a census because of space limitations. However, it can be investigated if the long census form is also used.

(c)   Causes of disability

Information on causes of disability is important for the planning and the evaluation of prevention programmes. owing to the limited space on a census questionnaire, information on causes may be obtained by asking about broad conditions, which either gave rise to or underlie the disability, rather than asking detailed questions concerning specific illnesses or injuries. Six main categories are recommended for use in the collection of data on causes of disability: (i) infectious and parasitic diseases; (ii) congenital anomalies and perinatal conditions; (iii) other diseases and conditions; (iv) injury (distinguishing motor vehicle accidents, other transport accidents, accidental poisoning, and injury resulting from accidental falls, fire, and operations of war); (v) other causes including natural and environmental factors; and (vi) cause not known

Although the categories on the short list may be sufficient for census purposes, a few additional subcategories could be included if in a country a particular disease (such as polio, leprosy or cataracts) or particular events (such as work accidents) are especially relevant.

4.   *Using a population census as a screen for a follow-up survey*

Census questions may be used as a screen for a post-census disability survey (see also chapter III, section C.4 "Use of two-phase sampling and post-stratification"). Box 8 presents the definition and characteristics of a screening question.

Box 8. A screening instrument to identify persons with disabilities

A screening instrument is a question or set of questions used to identify persons who will be interviewed subsequently with more detailed questions. Screening question(s) must be inclusive, that is, they must be general enough to capture not only those with severe types of disability, but also those with mild and moderate forms. This is important in order to ensure a wide and unbiased selection of persons with disabilities for the follow-up interview. Specifically, screening question(s) might identify a large number of persons who have difficulty seeing. Subsequent detailed questions might then establish that the number of persons who had a seeing disability at or above a specified level of severity was substantially lower.

If the screening procedures 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.

 A reasonably accurate screen is one that has the following characteristics:
(a) High sensitivity: 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) High specificity: 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) High predictive value: 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)

[a] Box 8 is based on *Manual for the Development of Statistical Information for Disability Programmes and Policies* (United Nations publication E.96.XVII.4), pp. 46-48. The *Manual* may be consulted for additional information and examples.

Two countries, Canada in 1986 and 1991, and New Zealand in 1996, have combined the census and survey for data collection by asking broad generic screening questions in the population census and using the responses to these questions to draw up a sample for a follow-up survey that uses more detailed and specific questions to obtain the information of interest. The follow-up survey included more detailed and specific questions in order to identify persons with disabilities in the population. In the 1986 and 1991 Health and Activity Limitation Surveys, Statistics Canada used at least 20 questions representing different types of activity limitations. Because the census uses a generic question, there is concern about under-coverage of individuals

with mild or moderate disabilities as well as children and elderly persons with disabilities. To counter this, the sample designs used in both Canada and New Zealand included a sample of persons who had responded "No" to the census screening question. In both Canada and New Zealand, the broad generic questions included on the census were intended to aid in the development of a sampling frame for the follow-up survey and not for estimating the prevalence of disability in the population.

In the 1991 population census of Canada, the following questions were asked:

1.   Because of a long-term physical condition or health problem, that is, one that is expected to last six months or more, is this person limited in the kind or amount of activity he/she can do:

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

(b) At school or at work?   ☐   No, I am not limited.   ☐   Yes, I am limited.

(c) In other activities e.g. transportation to or from work, leisure time activities?

☐   No, I am not limited.   ☐   Yes, I am limited.

2.   Does this person have any long-term disabilities or handicaps?

☐   No   ☐ Yes

The 1996 population census of New Zealand included the following questions on disability:

1.   Does a health problem, or a condition, you have (lasting 6 months or more) cause you difficulty with, or stop you doing:

Everyday activities that people your age can usually do;

Communicating, mixing with others or socializing;

Any other activity that people your age can usually do;

No difficulty with any of these.

2.   Do you have any disability or handicap that is long-term (lasting 6 months or more)?

☐ Yes   ☐   No

The importance of using a detailed questionnaire to collect data on disability is shown by the results of a comparison between the 1986 Canadian census and the 1986 Health and Activity Limitation Survey (HALS), as shown below;[6]

(a)   The general census question identified fewer persons with disabilities than the detailed questions used in the HALS survey.

(b)   The general census question was not an effective way to identify children with disabilities.

(c)   The general census question provided a good way to identify persons with severe disabilities, worked less well for individuals with moderate disabilities and very poorly for individuals with mild disabilities.

(d)   Persons with disabilities aged 15 through 64 identified in the census were less likely to be employed than their counterparts who were identified through the follow-up survey questions.

The results of the comparison between the 1986 Canadian studies presented above support the use of a specific and not a generic question, as explained above in section A.2 of this chapter, when using the census to collect data on the prevalence of disability in the population.

The timely selection of the sample as well as the identification of the names and addresses of the persons selected for the follow-up survey is very important. Both Statistics Canada and Statistics New Zealand included a sample selection operation as part of the initial processing of the census returns.

Other issues need to be considered when the census is used as a sampling frame for a follow-up survey. It is important to assess the legal considerations involved with access to individual census returns before pursuing this type of census/survey approach. Both Statistics Canada and Statistics New Zealand are centralized statistical agencies responsible for conducting both censuses and surveys. By contrast, in the United States of America, responsibility for collecting census data rests with the Bureau of the Census, while health surveys are the responsibility of the National Center for Health Statistics. This type of organizational arrangement can make accessing individual census returns more difficult, perhaps impossible. Even if a country has a centralized statistical agency, there may still be a requirement to obtain permission from a body within the country that has the responsibility for ensuring the privacy rights of the population.

B. SURVEYS

1. Approaches to collecting disability data in sample surveys

In planning a survey to collect information on disability, two broad possibilities may be considered: (a) a national disability survey; or (b) attachment of a special disability module ("piggy-backed") onto a household survey focused on another specific topic, such as the labour force, health and medical care, family expenditure or living conditions.

(a)   National disability survey

A national survey of disability is dedicated to the topic of disability. There are two main approaches to conducting such a survey: (i) by preparing a national sample of households, then screening all households selected into the sample for disability; or (ii) by screening for disability in a national census or in a national health, medical or labour force survey, then developing a national disability survey from these findings (such as the Canadian Health and Activity Limitation Surveys of 1986 and 1991 and the Egypt health and medical profile survey 1979-1981). If a person with a disability is found during the screening process, then a detailed interview is conducted. A smaller sample of people who report when screened that they have no disability are also selected to be further interviewed or tested in order to study the validity of both "Yes" and "No" responses to the screening question.

A national disability survey provides for the collection of detailed information about persons with disabilities, their families and their environment (at school, at home and at work). In this type of survey it is important to include questions used in other population surveys or censuses that can be used in comparing the population with disabilities to the population without.

While a special disability survey provides flexibility in terms of the length of the questionnaire and the opportunity for in-depth interviewing, it is a costly venture that is beyond the resources of many countries. Collecting the data using a disability module attached to an on-going survey will be the more reasonable alternative for most countries.

(b)   Disability module

An alternative survey design is to incorporate a series of questions (screening questions plus specific details about disability) directly into a national survey in a special module taking some portion of the total interview, as a "piggy-back" section. In this alternative, all interviewers must receive training concerning the disability questions, and all questions about disability are asked at the time of the national household survey interview. In addition, fewer details may be

sought about persons with disabilities because the disability item is only one part of the whole survey.

Using an on-going survey to collect data on disability also provides the opportunity to collect information on the population without disabilities. Such information permits an assessment of the equalization of opportunities for persons with disabilities as compared with those without. However, when disability questions are "piggy-backed" onto the questionnaire of another survey, consideration must be given to the amount of space available on the questionnaire and the potential length and complexity of the overall interview which could undermine the cooperation of the respondents.

2. Survey questionnaire design

This section examines issues that are relevant to both on-going household surveys that include a module on disability and disability surveys that are conducted separately. More general issues on questionnaire design are discussed in chapter II.

The quality of the information collected depends in large part on the validity and reliability of the questions. Questionnaire design is both an art and a science, and in the early stages of developing the questionnaire a number of issues must be considered in consultation with persons with disabilities and representatives of non-governmental organizations. Using these individuals and their families to test and refine questions is an excellent pre-test approach.

The purpose of the data collection determines the topics to be investigated. The specifics of the policy being formulated or programme being evaluated help determine the emphasis in the range of data items to be included in the survey. Typically, the survey will also include such questions as causes of disability, use of technical aids, employment, and need for and receipt of assistance with specified daily activities.

Great effort needs to be put into the formulation of questions. Decisions need to be made regarding the use of open or verbatim versus pre-coded response questions or a mixture of the two. With verbatim questions, respondents are asked open-ended questions, and the responses are recorded on the questionnaire and coded afterwards, whereas with pre-coded questions, the respondent selects one or more responses from a fixed list of categories provided on the questionnaire. Pre-coded questions make it easier for the respondents' answers to be recorded in appropriate categories, although they are more difficult to design because all possible responses should be included. Furthermore, interpreting and classifying the answers to open-ended questions requires more skill and additional effort on the part of both the interviewer and the investigator.

Questions should be clear, concise and unambiguous. A hastily developed questionnaire may result in the use of words, terms and concepts that are not universally understood and have multiple meanings.

Designing the questionnaire also involves the formulation of probing questions and questions to determine validity. Probing questions elicit additional information to ensure that the information provided is complete. For instance, instead of asking, "Are you limited in the kind or amount of activity that you normally can do because of a long-term physical condition, mental condition or health problem?", the respondent would be asked if he/she is limited in specific situations:—"at home?"—"at school or at work?"—"or in other activities, for example, using public transportation?" Validity questions are intended to check the accuracy or consistency of the respondent's answers. For example, the respondent might be asked, "Are you able to walk 100 metres without stopping?" If the answer is "No", the validity of the response would be checked with a question such as, "About how many metres can you walk without stopping?"

Another aspect of questionnaire design is the development of routing patterns and screening or filter questions to ensure that respondents are asked only those questions on the questionnaire that are relevant to them. Hence, it would not be appropriate to ask a 75-year-old individual questions intended to measure childhood disability. Routing is used, for example, when conditional questioning is necessary. In this case, a respondent is asked additional questions only if the answers on the "filter" or screening questions in the first stage have certain responses. This procedure is recommended for inquiries about mental health problems.[7] Owing to the problem of "response set", one should ask the filter questions on the disability domains before asking such questions as those on duration. This is because people realize very quickly that a "Yes" response leads to more questions and may give false negative responses. Overly complex routing of questions should be avoided, however, as it complicates the design of the questionnaire and increases the likelihood for mistakes on the part of the interviewer, or in the case of self-administered questionnaires, the respondent.

Since some disability topics tend to be sensitive, the order in which the questions are asked must be taken into consideration when designing the questionnaire. This point is important, both to ensure the accuracy of the information and to retain the interest and cooperation of the respondent. The more sensitive and difficult questions, such as those on incontinence or on the use of specific social aid programmes, should not be placed near the beginning but rather in the middle or near the end of the interview. Asking these questions at the beginning of the interview could make the respondent suspicious or defensive, thereby either ending the interview or producing false or evasive answers.

Designing questions also involves making a decision about whether the questions would be asked of each person in the sample (sample-person-style questions) or if one person would

answer questions on behalf of all the family or household members (family-style questions). In the first type, the questions are administered to a sample person or, perhaps, to a proxy for the sample person. Questions from the Canadian Health and Activity Limitation Surveys (1986 and 1991) and from the European Community Household Panel Survey (1994) are examples of sample-person based questions. Sample-person based questions rely on self-response; it is assumed that the sample person is most familiar with his or her own history of disability. When a proxy response is allowed, the proxy is usually a person who is very familiar with the health of the sample person. Examples of family-style questions include those from the Australian Survey of Disability, Ageing and Carers (1993) and the United States Survey of Income and Program Participation (1991/1992). Family-style questions ask one respondent about all family members living in the household. The respondent is usually a person who is knowledgeable about all family members. When asking family-style questions, it is important to follow up on any affirmative responses to identify the family member(s) with particular impairments or disabilities. Standard probe questions are "Who is this?" and "Anyone else?"

3. Development of questions to identify persons with disabilities

(a) Developing questions for the general population

Surveys provide an opportunity for a more in-depth study of disability in the population of interest, through the use of a more elaborate instrument than would be feasible with a population census. It is also possible in a survey to have questions on both of the components of functioning and disability which are Body Functions and Body Structures, and Activity and Participation.

In designing questions, the World Health Organization's *International Classification of Functioning, Disability and Health ICF* [8] should be used as guide. General issues relating to the design of disability questions are discussed in chapter II. Careful consideration should be given, however, to the categories chosen for inclusion in the questions, based on their relevance, clarity and measurability. Countries may therefore choose those items that are relevant to the objectives of the data collection activity. When necessary, the ICF categories chosen should be modified to suit local conditions in order to make it possible for respondents to understand the questions easily.

The questions should refer to specific ICF items and the use of generic and ambiguous terms should be avoided. As a general principle, instruments yield a higher number of persons with disabilities when they contain questions about a wider range of ICF items. The more detailed and probing the questions, the greater will be the proportion identified of persons with disabilities. Questions should also be designed to encompass the population included in the definition of the study or target population. In addition, when designing questions, it is important

to determine their relevance for all age groups to be included in the survey. These questions should be developed (and also tested) to take into account the different population groups, such as children and the elderly. In the development of the ICF, careful consideration has been given to making this classification applicable to all age categories of the population, including children and the elderly. Recommendations on designing questions for children as well as for the elderly are presented separately below.

In a collaborative effort with some countries and agencies, the World Health Organization is developing an instrument, the WHO Disability Assessment Schedule (WHODAS II) to assess disability in a variety of settings and cultures. The WHODAS II instrument, which is grounded in the conceptual framework of the ICF, seeks to determine the amount of difficulty encountered in activities that a person actually does as opposed to those he/she would like to do or those he/she can do, but doesn't. More information on WHODAS II can be obtained from their Web site at **http://www.who.int/ICIDH/whodas/index.html**. This instrument includes the following domains:

1. Understanding and communicating
2. Getting around
3. Self care
4. Getting along with people
5. Life activities
6. Participation in society

Within each domain, questions target specific activities and participation issues as follows:

1.   Understanding and communicating
   (a) Concentrating
   (b) Remembering
   (c) Problem solving
   (d) Learning new tasks
   (e) Communicating

2.   Getting Around
   (a) Standing
   (b) Changing body position
   (c) Moving round inside the home
   (d) Getting out of the home
   (e) Walking

3.   Self Care
    (a) Bathing
    (b) Dressing
    (c) Eating
    (e) Staying alone

4.   Getting Along with People
    (a) Interpersonal skills with….
    (b) People close to you (family, friends)
    (c) People not known at all (strangers)
    (d) Sexual activity
    (e) Making friends

5.   Life Activities
    (a) Household activities
    (b) Work
    (c) School

6.   Participation in Society
    (a) Community activities
    (b) Discrimination
    (c) Stigma/dignity
    (e) Impact on time, emotions, finances and family
    (f)Leisure

(b)   Identifying disability among children

Since children below a certain age cannot be expected to perform certain activities, and the inability to walk, speak or read is quite normal below a certain age, the development of questions to screen children for disabilities becomes problematic and challenging. Opinion is divided on how children should be treated in a disability data collection activity. It is argued, for instance, that children below 5 years of age should be left out of the study because at best only very global information can be gained about them.[9] Another possibility is to include children in the study, but to omit certain questions, and where possible to ask alternative questions.

Country practices on this issue differ. Some countries ask the same questions of children and adults (Egypt, Maternal and Child Health Survey*, 1991)*; others include questions intended to reflect the wide range of experiences of children either in a separate children's questionnaire or as a separate section on the main questionnaire (Canada, Health and Activity Limitation Surveys,

1986 and 1991; United Kingdom, OPCS Surveys of Disability in Great Britain, 1985/1988); and in some cases the same questionnaire is used for everybody but children are not asked certain questions (United States, National Health Interview Survey, 1994).

Annex 2 presents examples of questions used to identify for childhood disability in New Zealand (1996), the United Kingdom (1985-1988) and the United States (1994). The questions used differ by country, although in all three countries they were based on activity limitation. In addition, in New Zealand, unlike in the other two countries, questions were asked about the presence of some long-term health conditions or diseases that limited the child's activities.

In general there are no international recommendations on how to identify disabilities among children. However, as mentioned earlier, the ICF aims to make the classification applicable to children by making it less adult-oriented. This classification provides concepts covering particular aspects of disablement among children. Categories of interest in studying disability among children include: (i) activities of learning, such as focusing attention, (ii) communication activities, such as communicating with—receiving—spoken messages, (iii) interpersonal activities, including regulating behaviours within interactions, such as physical aggression, and (iv) engaging in major life areas, such as school-related responsibilities and privileges.

Durkin, and others,[10] developed a simple and cost-efficient instrument for measuring childhood disabilities that uses 10 questions to interview primary caretakers of children. The 10 simple questions, included in annex 2, have been tested in developing countries (Bangladesh, Pakistan and Jamaica) and are currently being used as an optional module in the UNICEF Multiple Indicator Cluster Survey, which is being undertaken to monitor the goals of the 1990 World Summit for Children.[11]

Overall, studies of the reliability and validity of these questions argue for their continued use with amendments, rather than using the more complex questions about limitations in daily activities and services or treatments received, or conducting performance tests.[12]

Further validity studies have shown that the 10 questions are useful as a general screen, but not for vision and hearing disabilities in populations where few affected children have previously been identified and treated. It has been suggested, for instance, that the 10 simple screening questions should be amended to include simple performance testing for children, at least for vision and hearing in areas where it is very likely that testing services are not widely provided to children.[13] In areas where services are more universally provided, these questions may be augmented with additional questions, asked of the child's caretaker, concerning previous treatment and testing of the child for vision and hearing problems.

(c)   Identifying disability among the elderly

Disability status among the elderly is best assessed by use of questions on activities of daily living (ADLs), such as bathing, eating, transferring, dressing and toileting. The term "activities of daily living" refers to a set of common, daily activities, the performance of which is required for personal self-care and independent living.[14] ADLs are therefore a measure of ability to perform and ultimately of the quality of life associated with functional status. Although persons of all ages may have problems performing the activities of daily living, prevalence rates are much higher for the elderly than for the non-elderly.[15]

The following questions asked in the 1985 Survey of Persons Aged 60 and Over in Households in Israel are an example of screening for disability among the elderly using questions on activities of daily living.

1.   Are you able (by yourself) without help:

        (a)   to dress and undress
        (b)   to take a shower or bath
        (c)   to get in and out of bed
        (d)   to eat (to cut food, etc.)?

2.   Are you able to cut your own nails without help?

3.   Incontinence: does it happen that you sometimes cannot reach the bathroom in time?

The 1989 Netherlands Health Interview Survey questionnaire contains the following question on ADL items for persons aged 55 years and over.

        Now I am going to read out a few activities that some people have difficulty with. Please indicate for every item whether you can perform it without difficulty, with difficulty, or with help from others:

        Eating and drinking;
        Getting in and out of a chair;
        Getting in and out of bed;
        Dressing and undressing;
        Moving towards another room on the same floor;
        Walking up and down the stairs;
        Leaving and entering the house;
        Moving along outside the house;

Washing your face and hands;
Washing your whole body.

To measure the disability status of elderly persons through questions on their functional capabilities requires the development of a set of culturally appropriate ADL items and other relevant disabilities. If possible, organizations of elderly persons should be consulted when choosing the items to be included. For example, whereas being able to "cut food" while eating is a way of life in some cultures, it may be inappropriate as an item to investigate disability status in other societies.

Another dimension that is relevant for assessing disability status among the elderly is cognitive ability. Persons with Alzheimer's disease and related dementias are examples of individuals with cognitive decline. These topics are discussed in the next section on measuring cognitive and psychological functioning, and specific measurement instruments are presented in annex 3.

The ICF provides a good resource for items to be used in screening instruments on ADLs and cognitive decline among the elderly. Examples of items that could be used include the following:

1.	For cognitive decline, activities associated with:
	(a)	Conversation
	(b)	Thinking
	(c)	Solving problems
	(d)	Carrying out daily routines
	(e)	Making decisions
	(f)	Focusing attention

2.	For activities of daily living, activities associated with:
	(a)	Washing oneself
	(b)	Caring for body parts
	(c)	Toileting
	(d)	Dressing
	(e)	Eating
	(f)	Drinking
	(g)	Walking
	(h)	Moving around
	(i)	Maintaining a body position
	(j)	Changing body position
	(k)	Transferring oneself

The data collected should distinguish, at a minimum, two categories of elderly persons with a disability: (i) those who can perform the activity with difficulty (this category can further be divided into those who can perform the activity with "some difficulty" and "great difficulty"; and (ii) those who need the assistance of others or of a device to accomplish the activity in question. The ICF provides for the assessment of the effect(s) of an individual's disability or disabilities on their need for assistance with ADLs and hence of their dependency, or lack of, on aids, appliances or helpers.[16] To assess the severity of a disability or disabilities, including ADLs, the ICF includes a set of "qualifiers" to be used in conjunction with each category to give the extent or magnitude of the limitation. Use of the ICF qualifiers to assess severity is addressed in annex 1. The qualifiers should be used with the ADL screening questions so as to ascertain the degree to which an individual's activity performance is limited.

4. Measuring cognitive and psychological functioning

In the development of the ICF, special attention was given to terms concerning psychological and intellectual functions. The ICF includes an extensive description of global and specific mental functions. Some of the categories included in the classification are:

(a)   Global mental functions such as orientation functions, intellectual functions, sleep functions;

(b)   Specific mental functions such as attention functions, memory functions, emotional functions and thought functions;

(c)   In the Activities and Participation component, basic learning activities, applying knowledge and major life areas.

What is needed is an instrument or instruments based on these categories of the ICF that can be used to measure cognitive and psychological functioning, and that encompass a broad area of functioning and cannot be assessed with a few simple questions. Instruments that cover these different areas will need to be much more extensive than the instruments that measure the areas of physical impairments, such as functional impairments in seeing or hearing.

From 1988 to 1992 Statistics Netherlands and the World Health Organization Regional Office for Europe organized a series of consultations to develop common methods and instruments for health interview surveys; this section is based on the report of those consultations.[17] Instruments concerning chronic mental conditions were recommended in that report and are reprinted in annex 3. Although based on the original ICIDH, these instruments

reflect the most recently agreed guide for country use in framing questions on chronic mental conditions. However, further work is necessary to develop instruments based on ICF.

The range of conditions that are included under the category of cognitive and psychological functioning is very large and extends from severe conditions such as mental retardation, schizophrenia, manic depression or dementia to minor psychopathology which includes anxiety, phobias and other neurotic symptoms. Severe psychological disorders have low rates of prevalence in the population. Less severe but potentially incapacitating forms of psychopathology are more common. These conditions affect well-being and create the risk of more serious psychological problems and life-threatening behaviour such as suicide, violence and substance abuse.

In measuring cognitive and psychological functioning in health interview surveys, a selection of cognitive and psychological items needs to be made since it is not possible to include all of the conditions now distinguished. The Statistics Netherlands/World Health Organization guidelines recommend prevalence, severity and duration as the criteria for selecting which cognitive and psychological conditions are relevant for public health policies and thus should be measured.[18] On this basis, instruments for the measurement of the following major chronic cognitive and psychological conditions are given: dementia, mental retardation (both referring to cognitive functioning) and   anxiety disorders, schizophrenia and affective disorders (referring to psychological functioning).

As the knowledge of respondents about these conditions is generally poor, the instruments need to be based on a symptom approach, which is generally time-consuming and requires face-to-face interviews. In general, the inclusion of these instruments makes high demands on the design and duration of health surveys.

Table 5 summarizes the instruments recommended by Statistics Netherlands and the WHO Regional Office for Europe for the three main categories of chronic cognitive and psychological conditions. A more recent instrument is also included for identifying mental health problems among children (Groningen Social Disabilities Schedule – GSDS). Selected instruments are reprinted in annex 3 with details of source, content, administration and scoring.

Table 5. Selected instruments for diagnosis of some chronic cognitive and psychological conditions

Condition	Population characteristics	Screening instrument	Diagnostic Instrument	Duration
Dementia	People ≥ 55 years	No screening questions	Iowa dementia test (a) Measurement of temporal orientation (b) Controlled Oral Word Association Test (c) Benton Visual Retention Test (MC version)	± 10 min
		Proxy version: 4 questions	A question on already diagnosed dementia or Alzheimer disease by a health professional	≤ 2 min
Mental retardation	People with Lower education And < 55 years	4 questions	Mini-Mental State Examination (14-55 years) Benton Visual Retention Test (MC version) (7-13 years and illiterate adults)	≤ 5 min 4-5 min
		Proxy version: 3 questions	One question about diagnosed mental retardation	≤ 1 min
Selected conditions Anxiety disorders Schizophrenia Affective disorders	People ≥ 19 years	Two-stage screening: GHQ-12 and 6 questions	Diagnostic Interview Schedule (DIS) Anxiety disorders Schizophrenia Affective disorders	20-30 min
		Proxy version: 6 questions	Diagnostic interview schedule (DIS) Anxiety disorders Schizophrenia Affective disorders	20-30 min 20-30 min
	Children of 6-18 years	6 questions	Adapted version of DIS (DIS-C) Or a proxy version for parents (DIS-Parent)	

Source: A. de Bruin, H.S.V. Picavet and A. Nossikov, <u>Health Interview Surveys: Towards International Harmonization of Methods and Instruments</u>, WHO Regional Publications, European Series, No. 58 **(**Copenhagen, World Health Organization, Regional Office for Europe, 1996), p.69.

5. Special topics (causes, duration, technical aids, environment, and services and support)

While estimates of the crude disability rate may indicate the magnitude of the problem, they are insufficient for understanding and for monitoring the situation of persons with disabilities.[19] Additional information is needed to better understand the situation of persons with disabilities in terms of prevention, rehabilitation, equalization of opportunities for education, employment, medical care, training, and social integration. The need for data on these dimensions is highlighted in the World Programme of Action concerning Disabled Persons[20] and in *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities.*[21] The required topics include the socio-economic and demographic characteristics of the study

population, such as age, sex, marital status, area of residence, education, work and living arrangements. Information is also needed on other topics that describe disability experience, such as causes of disablement, age at onset, use of technical aids and of services, and environmental barriers. The choice of the additional topics to include depends on the data priorities of the country in terms of its intended uses, and also on the financial cost of collecting the information.

(a)   *Causes and underlying conditions of disability*

Underlying conditions and causes of disability are important variables to be collected in a survey concerning persons with disabilities because these conditions and causes provide the health and medical explanation of the disability. This information is useful in developing preventive measures against disability. In addition, it is often of primary interest to organizations and associations of and for persons with disabilities since they often represent individuals with disabilities who have a particular underlying condition such as arthritis, multiple sclerosis or spinal cord injury.

Statistics on causes of disability may not reflect the proper medical diagnosis of the impairments or disabilities, but rather are a representation of the general population's understanding of the factors that caused their impairments or disabilities. This is shown in some of the responses or explanations given, such as "bewitched" or "due to evil eye".

Information on causes of disability is often obtained by asking a question about the cause of a reported impairment or activity limitation. The World Health Organization International Statistical Classification of Diseases and Related Health Problems, *Tenth Revision* (ICD-10)[22] is an essential source of information on the classification of external causes and of underlying conditions. It provides a classification scheme for external causes (injury, traumatic experience, illness, or congenital factor) as well as for underlying conditions, identified by a set of codes at the three - and four - character levels. "Underlying conditions" refers to medical or pathological conditions described according to disease, disorder or other morbid state, such as, neoplasms, mental and behavioural disorders, diseases of the respiratory system, musculoskeletal system, malformations, deformations and chromosomal abnormalities.

Data on causes of disability from national studies are generally not standardized through the use of any international classification system, thus creating variability in the presentation schemes. Countries do not always follows the World Health Organization International Statistical Classification of Diseases and Related Health Problems (ICD) when presenting data on cause, and some countries include diseases as causes of disablement. The causes of disability included in national studies may reflect what is considered important by a particular country.

In the 1991 Health and Activity Limitation Survey of Canada, persons were asked:

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

>   existed at birth
>   work environment
>   diseases or illness
>   natural ageing process
>   psychological or physical abuse
>   accident - at home
>   accident - motor vehicle
>   accident - work related
>   other, please specify
>   don't know

In the 1996 Household Disability Survey of New Zealand, the following question was asked:

Which ONE of the following is the BEST description of the cause of this condition?

>   disease or illness?
>   an accident?
>   your work environment?
>   it existed at birth?
>   the natural ageing process?
>   psychological or physical abuse?
>   or another cause? (Specify)
>   don't know

In the 1993 Australian Survey of Disability, Ageing and Carers, the question on cause merely asked, "What causes this ....*?*"

In the 1986-1988 Netherlands health interview survey, information on cause of disablement was collected using the following question:

What is the cause of this difficulty?

>   congenital or occurring during birth
>   illness or old age
>   an accident at work
>   an accident at home

a road accident
a sports accident
other accident
don't know/no answer

Based on information on country practices available in DISTAT-2, the United Nations Statistics Division has proposed a shortlist for classifying external causes (see box 9).

Box 9. Proposed short list of external causes of disablement

The external causes of disablement include the following:
(a) Infectious and parasitic diseases;
(b) Congenital anomalies and perinatal conditions;
(c) Other diseases and conditions;
(d) Injury:
    Motor vehicle accidents
    Other transport accidents
    Accidental poisoning
    Injury resulting from accidental falls, fire and operations of war
(d) Other causes, including natural and environmental factors.

When information is asked about causes or underlying conditions, it is advisable to avoid asking detailed questions that would require the information to be coded at the three-or four-digit level of the ICD-10. One must be selective about the conditions or diseases to be included on the questionnaire as most may be rare or unknown to most people. A disability survey is not the most appropriate vehicle for assessment of the prevalence of rare disorders since the latter are not reliably represented in a study population randomly selected from the general population unless the sample is extremely large. However, if information is needed, for example, about the age-specific prevalence of certain diseases among the young and the elderly, then sample size requirements should be adjusted accordingly to obtain an adequately representative sample.

The process of selecting the diseases and/or conditions to include should be based on their estimated prevalence, severity and indication of chronicity in the country, as well as on the possibility of asking questions about the disease or condition in question. When selecting diseases and conditions to include in the study, the codes at the three-digit level should be regrouped, as they are too detailed for inclusion in a disability survey. A number of diseases can be grouped together according to their ICD codes. From this group, a selection of diseases should be made based on their estimated prevalence.

When designing questions on causes, the following points should be considered:

(a)   During the interview the interviewer can read the list and show a card, both containing a number of possible causes. It is desirable to obtain the answers one by one. After each answer the interviewer may request further information about the particular disease or condition, if needed.

(b)   When questions are asked about diseases or conditions at the three- or even four-digit level, the answers will probably have a lower validity than if one uses main categories such as "existed at birth", or "work environment". Therefore, control questions such as "Has your doctor told you that?" or "Who told you that?" should be asked.

(c)   One should be careful about asking questions about diseases as "causes" of disability because of the very complex relation between diseases and disablement. In many cases it is not known to the people being interviewed whether or not the relation between (an) existing disease(s) and the disablement is a causal one. For this reason, the question should not be "Which disease is the cause of ... ?", but simply "What caused that …?".

(d)   In designing questions on cause(s) of disability, the possibility of multiple causes should be taken into consideration.

(b)   Duration of the disability

Some disabilities occur at birth, such as a deformed arm or Down's syndrome; others arise in early childhood with the onset of asthma or diabetes, which may result in some limitation in activity; others might occur as a result of an accident; while still other disabilities may not occur until much later in life with the onset of heart disease or cataracts.

Collecting information on duration of disability is a difficult undertaking. Unless the onset of the disability is linked to a specific event, memory recall can significantly affect the quality of the data. If the disability existed at birth, or was the result of a traumatic event, such as a war or an accident, then memory recall is not an issue. However, if the disability is related to the onset of a disease or health condition, and that onset occurred in the distant past, then memory recall becomes a factor.

Box 10 contains examples of questions on duration asked in national disability surveys.

Box 10. Examples of questions on duration of disability asked in national surveys	
Statistics New Zealand, 1996 Household Disability Survey	At what age did you first have difficulty doing this?
Statistics Canada, 1986 Health and Activity Limitation Survey	(a) At what age did you first have trouble doing this? (Adults - 15 and over) (b) At what age did this limitation begin? (Children - under 15) (c) At what age did .... first have this ...? (Children - under 15)
Ministry of Labour and Social Services, Zimbabwe, 1981 National Disability Survey	How old were you when the disability started?
Ministry of Culture and Social Services, and Institute for Development Studies, University of Nairobi, 1981 study, *The Condition of Disabled Persons in Kenya*	When did you become handicapped?

(c)   Technical aids, environment, and services and support

(i) Technical aids

It is essential to collect information on the need for, and use of, the assistive devices required for some types of impairments and activity limitations. This information can be used to monitor the situation of persons with such disabilities and observe their ability to live independently as well as benefit from rehabilitation.

Both the form of the questions on technical aids and assistive devices and their placement are important considerations in questionnaire design. A list of specific technical aids should be included. Asking open-ended questions on unmet need for such aids assumes that the person with the disability knows the range of technical aids or services that are available. However, that is rarely the case.

Below are a number of examples of questions on technical aids asked in national studies and an indication of the placement of such questions on the questionnaire. The 1991 Canadian Health and Activity Limitation Survey placed the questions concerning use of assistive devices for persons with seeing disabilities immediately following two questions that were used to identify this sub-population. If there was a "Yes" response to either of the two screening questions (those used to identify the population with seeing disabilities), the interviewer went on to ask the two follow-up questions. This approach reduced the respondent burden because these two additional questions were skipped for persons who answered "No" to both seeing disability questions. A similar approach was followed for the other types of disabilities. This way of asking for information on the use of assistive devices seems to be the standard procedure in all the countries for which questionnaires have been examined.

In the 1992 Tunisian survey, "Enquête nationale de dépistage et de diagnostic des incapacités et des déficiences", questions on the use of technical aids were built into the response categories for the questions on activity limitations. For example:

Can he/she, in a normal way, climb two flights of stairs without difficulty and without a technical aid or assistance from another person?

One of the responses:

Can climb the stairs while using a technical aid.

The approach was slightly different in the 1986 "Encuesta sobre discapacidades, deficiencias y minusvalias" of Spain. The following are some of the questions asked about hearing disabilities:

Is there anyone in this household who is unable to or has serious difficulty in following a conversation in a normal voice without the use of a hearing aid?

Of the persons mentioned, how many have overcome their difficulty by using a hearing aid?

New Zealand collected very detailed data on the use of and need for technical aids in its 1996 Household Disability Survey. For example, for those with a hearing difficulty, the following questions were asked:

I would like to ask you about your use of special or technical equipment or services for people who are deaf or hard of hearing. Do you use:

a hearing aid with T-switch?
another type of hearing aid?
a telecommunications device such as a teleprinter or TTY?
teletext?
hearing loop, FM or infrared system?
a sign language interpreter?
flashing alarms or visual alarms?
a volume control telephone?
a computer to communicate?
a fax machine?
some other equipment or service that I have not mentioned?

Is there any equipment or service for people who are deaf or hard of hearing which you need, but do not have? (Yes/No)

Which equipment or services do you need but do not have?

a hearing aid with T-switch?
another type of hearing aid?
a telecommunications device such as a teleprinter or TTY?
teletext?
hearing loop, FM or infrared system?
a sign language interpreter?
flashing alarms or visual alarms?
a volume control telephone?
a computer to communicate?
a fax machine?
some other equipment or service that I have not mentioned?

Why don't you have this equipment or service(s)? I will read you a list. Please answer "Yes" or "No" to each.

It is only needed occasionally?

The equipment or service is not available?
Your condition is not serious enough?
It is too costly or you cannot afford it/
You applied for financial help to get it but were not eligible?
You did not know you could apply for financial help or where to apply?
You have never been assessed?
Another reason?

These examples show differences in the questions asked, and also in the level of detail of the information collected. The New Zealand survey requested more detailed data than did the other two, and collected information on persons who needed but did not have technical aids. New Zealand also asked the following questions to collect information on the use of technical aids by children:

Does .... use any of the following equipment:

(a) A special buggy or a trolley?
(b) A standing frame?
(c) Any kind of braces, other than braces for teeth?
(d) A wheelchair?
(e) Crutches, walking sticks, a walking frame or any other kind of walking aid?
(f) An artificial leg, arm, hand or foot?

Does .... use any other kind of equipment because of a condition or a health problem that has lasted or is expected to last for 6 months or more? Don't count asthma inhalers, braces for teeth or grommets.

Survey questions concerning technical aids should refer to technical aids actually available to the given population, and must be consistent with International Standard ISO 9999, technical aids for disabled persons.[23] ISO 9999 comprises ten categories of technical aids:

Class 03	Aids for therapy and training
Class 06	Orthoses and prostheses
Class 09	Aids for personal care and protection
Class 12	Aids for personal mobility
Class 15	Aids for housekeeping
Class 18	Furnishings and adaptations to homes and other premises
Class 21	Aids for communication, information and signalling
Class 24	Aids for handling products and goods

| Class 27 | Aids and equipment for environmental improvement, tools and machines |
| Class 30 | Aids for recreation |

Tabulations of data on technical aids should include information not only on the actual use of these devices by specific sub-groups, but also on those showing the need for these aids.

(ii)   Environment

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.[24] The factors are external to individuals and can have a positive or negative influence on the individual's performance as a member of society, on the individual's abilities or on the individual's body function or structure. The environmental factors focus on two different levels:

a. Individual: in the immediate personal environment of the individual, including but not limited to settings such as home, workplace and school. It includes the physical and material features of the environment that an individual comes face to face with as well as direct personal contact with others such as family, acquaintances, peers and strangers.

b. Services and systems: the formal and informal social structures, services and overarching approaches or systems in the community or a culture that have an impact on individuals. These structures or systems include organizations and services related to the work environment, community activities, government agencies, communication and transportation services, and informal social networks as well as laws, regulations, and formal and informal rules, attitudes and ideologies.

Environmental Factors interact with the components "Body Functions and Body Structures" and "Activity and Participation". Disability is characterized as the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives. Because of this relationship, different environments may have a very different impact on the same individual with a given health condition. An environment with barriers, or without facilitators, will restrict the individual's performance; other environments that are more facilitating may increase that performance. Society may hinder an individual's performance because it either creates barriers (such as inaccessible buildings) or fails to provide facilitators (e.g., unavailability of assistive devices).

The ICF has developed a classification of environmental factors to show the extent of interaction between these factors and components of functioning and disability: Body Functions and Body Structures, and Activity and Participation. In data collection, Environmental Factors should be investigated in connection with these components to show whether the environment has a positive or negative influence on the individual's participation as a member of society, on the performance of activities by the individual or on the individual's body function and structures. As with the components of Body Functions and Body Structures, and Activity and Participation, Environmental Factors should be used in combination with "qualifiers" to denote the magnitude of facilitators or barriers. A negative qualifier, indicated by a decimal point, represents a barrier, while a positive sign denotes a facilitator. For example, the statistician, in investigating disability and including a question on walking activities (ICF code d450) may also be interested in finding out if the respondent has access to products for personal indoor and outdoor mobility and transportation (ICF code e140). The following qualifiers are recommended for use with Environmental Factors:

xxx.0	No barrier	(none, absent, negligible….)	0-4%
xxx.1	Mild barrier	(slight, low….)	5-24%
xxx.2	Moderate barrier	(medium, fair….)	25-49%
xxx.3	Severe barrier	(high, extreme….)	50-95%
xxx.4	Complete barrier	(total….)	96-100%
xxx+0	No facilitator	(none, absent, negligible….)	0-4%
xxx+1	Mild facilitator	(slight, low….)	5-24%
xxx+2	Moderate facilitator	(medium, fair….)	25-49%
xxx+3	Severe facilitator	(high, extreme….)	50-95%
xxx+4	Complete facilitator	(total….)	96-100%

xxx.8 Not specified barrier
xxx+8 Not specified facilitator
xxx.9 Not applicable

The final draft of the ICF includes the following categories of environmental factors:

1.   Products and technology: the natural or human-made products or systems of products, equipment and technology in an individual's immediate environment that are gathered, created, produced or manufactured;

2.   Natural environment and human-made changes to environment: animate and inanimate elements of the natural or physical environment, and components of that environment

that have been modified by people, as well as characteristics of human populations within that environment;

3. Support and relationships: people or animals that provide practical physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, place of work, school or at play or in other aspects of their daily activities;

4. Attitudes: the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs that influence individual behaviour and social life at all levels, from interpersonal relationships and community associations to political, economic and legal structures;

5. Services, systems and policies: (a) services that comprise the provision of benefits, structured programmes, operations, public, private or voluntary, established at a local, community, regional, state, provincial, national or international level by employers, associations, organizations, agencies or Government in order to meet the needs of individuals, including the persons who provide these services; (b) the systems that comprise the administrative control and monitoring mechanisms established by local, regional, national and international government or other recognized authorities, in order to organize services, programmes and other infrastructural activities in various sectors of society; and (c) the policies that comprise the rules, regulations and standards established by local, regional, national and international government or other recognized authorities, which govern or regulate the systems that control services, programmes and other infrastructural activities in various sectors of society.

Environmental factors are considered in Rules 5 through 12 of the Standard Rules, including accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion respectively.

Assessment of environmental conditions is necessary but seldom undertaken in surveys. For the most part, survey efforts fail to measure environmental factors as either facilitators or barriers to participation, but rather rely on self-identification of barriers and accommodations. The reliability and validity of these subjective approaches have not been measured and may in fact be low. There is also a tendency to ask about the experience with barriers, without investigating how often barriers are overcome. However, both obstacles and accommodations in the environment are important because most people, in their day-to-day activities, experience both barriers as well as accommodations.

Surveys of the elderly often contain detailed housing characteristics, including the presence of stairs, slopes, slip-resistant floors and other special features. The following are

examples of questions on environment taken from the United States of America 1994 National Health Interview Survey, Supplement on Ageing Questionnaire.

Because of a physical impairment or health problem, do you have any difficulty …

a.   Entering or leaving your home?
b.   Opening or closing any of the doors in your home?
c.   Reaching or opening cabinets in your home?
d.   Using the bathroom in your home?

Some residences have special features to assist persons who have physical impairments or health problems. Whether you use them or not, does your residence have any or these features?

Which special features do you need to get around this home, but do not have?

a.   Widened doorways or hallways?
b.   Ramps or street level entrances?
c.   Railings?
d.   Automatic or easy-to-open doors?
e.   Accessible parking or drop-off site?
f.   Bathroom modifications?
g.   Kitchen modifications?
h.   Elevator, chair lift, or stair glide?
i.   Alerting devices?
j.   Any other special features?

The following example is taken from the Australian 1993 Survey of Disability, Ageing and Carers.

Would you be able to use ALL forms of public transport, including trains, buses and ferries?   Yes   No

(Does/Do) your condition(s) make it at all difficult for you to use (the) public transport (that you can use)?   Yes   No

What are the reasons you do not use public transport?

What are the problems you have using public transport?

a. Getting to stops/stations;
b. Sight problems;
c. Getting into vehicles/carriages:
   Steps;
   Doors;
   Other;
d. Crowds, poor ventilation;
e. Lack of seating/difficulty standing;
f. Learning/behavioural problems.

(iii)   Use of services and support

Although in many countries administrative data on people with disabilities are routinely collected by agencies responsible for health care services, educational programmes, labour programmes, social security and other activities, such data are only partly useful for policy evaluation. Registration systems do not provide information about individuals with disabilities who need but are not receiving the service (the unmet need). They only provide information about individuals receiving services, such as the number of children enrolled in special education programmes or the number of people receiving community support services. If the service users can be classified according to whether or not they have an impairment and/or disability, then comparisons can be made between the two groups of users of the service.

Surveys are the most useful data source for collecting information about the distribution and use of services and support. Currently, no international survey standards are available for asking about services used and support received by persons with disabilities. One reason may be that access to and use of services, especially public services, differs greatly among countries, and therefore, questions relating to the "distribution and use of services and support" need to be adapted to the actual situation in each country. Annex 4 shows examples of questions that have been used in national studies to investigate these topics.

The Expert Group on Development of Statistics on Disabled Persons[25] proposed a list of topics related to the "distribution and use of services and support":

1. Primary health care;
2. Prevention;
3. Treatment of accident or trauma;
4. Maternal and child health and family planning;
5. General health services;
6. Education (general, special, vocational);
7. Employment;

8. Rehabilitation (including vocational);
9. Compensatory economic measures, social security and pensions;
10. Counseling and public education and information (community and family attitudes and behaviour;
11. Legal protection or equal and non-segregated opportunities;
12. Provision of equal mobility opportunities;
13. Elimination of environmental barriers;
14. Provision of technical aids and equipment;
15. Provision of services for independent living.

Information relating to these topics is relevant for policy makers and complements the administrative data already collected. For instance, health planners who are interested in the use of services and the unmet need for services, may ask, "How many people with disabilities are without access to a special service or lack special support which they need for independent living?" To answer this question one must define the special services and support, identify the population of interest (people with disabilities who need these special services or support) and determine, within the population of interest, persons who do not have access to the needed services or support.

Another question might be, "How many people with disabilities receiving social services also require full-time care from a family member or other person?" This information is critical to understanding the full economic impact of disability and for developing social policy directed to those who need the care as well as to the caregivers.

Planners within the ministry of education may ask, "Do children with disabilities have equal access to educational services?" To answer this question, information is needed about all children (both with and without disability) of school age in the population, who do and who do not attend school.

When collecting information on the use of services, it is important to define clearly the target population, which is largely dependent on the purpose of the study. The purpose of the data collection may be, for instance, to investigate the use of disability-specific services by persons with disabilities or to compare the use of health care services in general by persons with and without disabilities. While the need for and use of services by the institutionalized population or homeless persons may differ substantially from other persons, special attention should be paid to the inclusion of homeless and institutionalized population groups in the sample. The choice of the target population also defines which services have to be investigated in the survey. The relevant services for children are different from those for the working age population.

Proxy information on use of services and support is acceptable, especially when the intended informant is in some way a dependant of the proxy, as is the case with young children, the very ill or persons with particular types of disabilities.

Questions should be clear and easy to understand and, as much as possible, everyday language should be used. It may even be necessary, when the question(s) contain(s) a number of services or regulations not common to a great part of the population, to introduce the subject(s) to the respondents before beginning the interview or the specific part of the questionnaire. The questions and the response categories should be made as specific as possible, to ensure that the respondent interprets the questions in the way the researcher expects him/her to do. For example, instead of asking, "Did you make use of any primary health care services during the past three months?" specific services should be listed and the respondent asked about the use of each of the listed services. The use of pre-coded answer categories also speeds up data processing and is less error-prone compared to write-in entries, which must be coded when the data are being processed.

Attention should be paid to the reference period used in the questions. Research has demonstrated that in general information obtained using shorter recall periods is more accurate and less biased than that obtained using longer recall periods. The extent of the bias depends both on the recall period and the meaning of the specific subject for the respondent. Nevertheless, the reference period should not be too short, because this will lead to larger sampling errors (owing to the fact that fewer events will occur during shorter periods), and respondents are more likely to report an event which actually took place earlier. Complex and difficult-to-remember questions such as the use of prescribed or non-prescribed medicines (and the specific type of medicines used) should be restricted to a relatively short time span, such as two weeks. Use of primary health care services and additional questions relating to the reason why this service was visited or which treatment was received during the visit might make use of a somewhat longer reference period, such as two months. Events that occur less frequently, such as hospital admissions, may need a reference period of as much as one year to get enough positive cases.

To improve the reliability of the information collected, the accuracy or consistency of the answers given should be checked. For example, the respondent might be asked, "Did you visit your doctor during the past two months?" If the response is "No", the answer should be checked by asking, "When was the last time you visited your doctor?" If the answers are inconsistent, a further inquiry would be necessary for clarification. The actual date might also be added to the question, to make it easier for the respondent to understand. For example, the interviewer could ask, "Did you visit your doctor in the past two months, since ... (add actual date) ...?"

Before starting the investigation, however, the respondent should be cautioned that the inquiry will not lead to a fulfilment of the unmet need for services. Instead, the interviewers should give the respondents enough information about where they should go to apply for the help and the services they need.

C. SAMPLING FOR A DISABILITY SURVEY

1. Scope and purpose

There are two main types of surveys that have been undertaken to study disability. Each calls for a different sampling strategy. One type of disability survey is that which is intended to estimate both the prevalence of disability and the distribution and characteristics of all persons with disabilities. The other type of disability survey is that which is intended to study, variably, the characteristics, attitudes, perceptions and/or needs only of known persons with disabilities. Sampling methodology for the second type of survey is straightforward and will be discussed only briefly in this section. However, sampling methodology to estimate disability prevalence and distribution can be both complicated and challenging. Consequently, this section focuses most of its attention on sampling issues and on the measurement of the prevalence and distribution of disabilities.

The matter of sample design for a survey to measure disability rates and/or the distribution of disability by cause is a highly specialized topic. There are two reasons for this. First, a disability survey, unlike a general-purpose household survey such as one to study labour force activity or the general health conditions and characteristics of a population, is a limited-scope topic which requires dedicated, and perhaps even unusual, sample design procedures. In particular, the level of detail of information to be collected will affect the complexity of the sample design. Secondly, the body of international experience in design of samples for disability surveys is comparatively scarce, with only a few countries ever having attempted it, in stark contrast to many other types of household surveys. For that reason, there is less accumulated wisdom about what may constitute the optimum procedures for sampling to measure disability efficiently and reliably.

While it is felt that the readers of this handbook should be provided with some guidelines on sample design for a disability survey, development of a standard sample plan that could be used by countries contemplating a disability survey is not a plausible option for the handbook. This is chiefly because there are numerous conditions and circumstances, which are highly variable by country, that determine what an appropriate, practical sample design would be. These include the actual (or presumed) rate of disability in a country; the availability and quality of administrative records about persons with disabilities that might be of use in sampling; whether national or sub-national estimates (or both) are wanted; and whether an overall disability rate is

the main objective or, instead, rates by type of disability are seen as taking precedence. Moreover, it is not thought that it would be particularly useful to readers of this handbook to present a general primer on sampling per se, without a specific focus on disability, since such information can be better found elsewhere. [26]

The principal purpose, then, of this endeavour is to provide information on sampling issues that will help guide planners of national disability surveys to determine the general parameters of a suitable sampling scheme, rather than the specific details of its design. The latter, being highly specialized and somewhat complex, should be placed in the hands of a qualified sampling expert, who may have to be hired or contracted specifically for that purpose, depending upon the availability of such an individual at the national statistical organization or other institution carrying out the survey. The issues elaborated below include keys to determining the sample size for each of the two types of disability surveys mentioned above in the first paragraph. This section is followed by sampling topics dealing mainly with the first type of disability survey, one that is designed to estimate disability prevalence and the distribution of disabilities. Those topics cover various techniques for increasing the efficiency of sampling persons with disabilities, including how to make optimum use of area sampling together with list samples of certain categories of persons with disabilities in dual or multi-frame approaches; the use of two-phase sampling methods with questionnaire screening to signal likelihood for disability, used in conjunction with post-stratification; and the possibility of using very large clusters, which, while contrary to standard sampling practice, may actually improve sampling efficiency for disability measurement.

2. Keys to determination of sample size

The first question that a survey director usually confronts is how much the survey will cost. This query is universal no matter what the subject matter—income and expenditure survey, demographic survey, public opinion poll or disability survey. A critical determinant in the cost of a survey is, of course, its sample size. Unless the survey director herself is an expert in sample design, she will usually turn to the sampling expert to answer the cost-related question of how big the sample should be.

The sample size that is needed can be estimated mathematically if certain information is known. Often, however, the size of a sample for a survey is determined more or less by figuring the largest sample that can be accommodated within the available survey budget. For example, if, after subtracting certain fixed costs, $100,000 is available to conduct the fieldwork and process the results, and the cost per household is figured to be $50, then 2,000 households would be targeted as the sample size. Unfortunately, when the sample size is calculated in this way, precision or reliability requirements for the survey are not taken into account. Suppose the type of survey is a national public opinion poll, and it is decided that 2,000 households could be

surveyed because the budget would allow that many. It can be shown that this number could actually be too large a sample (by about double!) in terms of providing acceptably reliable results in most national-level public opinion polls. By contrast, for a survey intended to estimate a rare event such as maternal mortality, a sample size of 2,000 households would be woefully inadequate. It is important, therefore, to take note prior to sample selection of how precise the survey estimates should be in terms of fitting the intended policy objectives, so that the sample size can be calculated accordingly.

(a)   Sample size for a population of known persons with disabilities

The simplest survey, from the standpoint of sampling, is one where the universe of the population with disability is taken from one or more lists of persons known to have a disability. A probability sample of individuals from these lists is chosen in a simple and straightforward fashion, and the selected individuals are interviewed for the survey. Surveying such persons may not be simple, owing to poor addresses, erroneous listings and other problems. Nevertheless, sampling from such lists is not particularly problematic. It is only a matter of selecting a random or systematic sample, of whatever size deemed suitable, from a register or registers of persons with disabilities. Perhaps of greater concern, however, is that there is a danger in limiting a sample, even for the study of attitudes or needs, to known persons with disabilities. The results of such a sample are highly likely to be biased, inasmuch as they will exclude persons not known to have a disability.

As mentioned in the preceding paragraph a systematic or random sample can be chosen Aof whatever size deemed suitable≅. The difficulty, however, is to determine a suitable sample size for this universe of study, the known disabled. The answer to this question is that the size is not unlike that for an opinion poll, especially if only dichotomous variables at the national level are to be analysed (e.g., male/female, living above/below the poverty line, under/over 25 years old or opinions for/against certain therapies). In such an instance, a sample size of 1,000 persons is a good rule of thumb for providing very reliable results.

Of course, national level, dichotomous variables do not usually go far enough to satisfy most users or sponsors of a disability survey. Typically, a distribution is wanted (e.g., age groups, types of disability), as well as sub-national geographical breakdowns. In those cases, the sample size would have to be multiplied by a factor to provide suitably reliable data to take account of the more detailed analytical requirements. For example, if data for 5 geographical regions were wanted, all with equal reliability, the rule of thumb sample of 1,000 persons should be multiplied by about 5, to give 5,000 persons. This issue of increased sample size to satisfy detailed analyses is covered in much more detail in the sections below, with reference to the estimation of prevalence rates. However, the conclusions are the same for studying characteristics of known persons with a disability.

(b)   Sample size for estimating prevalence

The sample size needed to estimate disability prevalence is quite different from that needed to study the characteristics of known persons with a disability. The great majority of households that would be selected in a sample to estimate prevalence would not have a resident with a disability: for example, with a disability prevalence in a particular country of 5 per cent, 20 persons would have to be selected on average to locate one who has a disability. However, virtually all of the persons selected from lists of known persons with a disability would, in fact, have a disability.

In general, for any survey, in order to estimate the sample size mathematically for measuring rates, percentages or prevalence, it is necessary to specify how precise one wants the final results to be. This is not as easy as it may first appear, since all household surveys produce not just one result but hundreds, not all of which are wanted (or can be got) with the same precision. For example, the precision of an estimate of the unemployment rate in a labour force survey will always be less than the precision of the estimate of the proportion of the population in the labour force, since the former is a subset of the latter. Yet, both statistics are crucial estimates that a labour force survey would seek to measure, as are many others, such as the proportion employed in manufacturing, the proportion of unemployed persons who are out of work for more than two months, and so forth. The solution to estimating an appropriate sample size is sometimes found by ascertaining which of the list of most critical survey variables is the least prevalent, specifying the level of precision wanted for that variable and then figuring the sample size needed to measure it. Here the assumption is that survey estimates that are more prevalent in the population will then be measured with a precision that is at least as good as the least prevalent variable. [27]

In some respects the key variable for purposes of determining the sample size in a disability survey is not difficult to identify. For that reason, the sample size may be estimated fairly easily without resorting to the suggested solution cited in the preceding paragraph. The key variable in many disability surveys is simply the overall disability rate or prevalence: an estimate of the proportion of the population which is judged to have a disability of one type or another. While many other statistics and indicators can be measured in the survey, such as disability rates by type and by cause, the overall rate is most likely to be the estimate deemed the single most important statistic. To calculate the sample size then, it remains only to speculate on the size of the actual disability rate, always a somewhat paradoxical exercise since that is usually the reason the survey is being conducted in the first place. Nevertheless, to compute the required sample size, it is necessary to Aguess≅ what the disability rate is going to be, using whatever available information already exists.

The other parameters that are needed to calculate a sample size for a disability survey are the specified precision that the survey must attain, the confidence level required and an estimate of the sampling design effect, or *deft*. A good rule of thumb for the precision requirement is to specify a relative precision, also known as the coefficient of variation, of 10 per cent. The confidence level for most national surveys is usually taken to be 95 per cent (2 standard errors). D*eft* is covered in greater detail in the next subsection.

(i)   A plausible sample size

Box 11 illustrates the calculation of the sample size needed for a national survey intended to measure the prevalence and distribution of disability. The illustration is not intended to be a prescription for a particular country, since each country will have its own conditions and requirements.

Box 11. Illustration of a plausible sample size

If we assume, for illustration, that the estimated disability rate—the proportion, p, of the population with a disability—is 5 per cent, then our survey, taking account of the parameters discussed in the subsection above, would be designed to estimate the disability rate of 5 per cent plus or minus 0.5 per cent (10 per cent of 5 per cent) at the 95 per cent level of confidence. Another way of stating this is that the 95 per cent confidence interval of the point estimate, 5 per cent, would be 4.5 per cent - 5.5 per cent.

The actual formula for calculating the sample size also contains two other factors, but one of them can usually be ignored. These are the sampling design effect (*deft*) and the finite multiplier. The finite multiplier is equal to (N-n)/N, where N is the population size and n is the sample size. Because n is usually very small relative to N, this ratio is always very nearly 1, and for that reason it can be ignored. *Deft*, by contrast, can be large and must be taken into account when figuring the sample size.

D*eft* is important because national-level household surveys, especially in developing countries, are always based on personal interview, multi-stage, stratified, clustered designs, as opposed to simple random samples of a population. These additional complexities in the design account for *deft*, which, in effect, is the factor by which the sampling variance for a survey is increased over that which would come about if a simple random sample were used with the same sample size. Indeed, the value of *deft* for a simple random sample is 1.0. For a multi-stage, stratified clustered design *deft* will be a positive number for virtually any characteristic that one seeks to measure in a household survey. Sometimes the value of *deft* can be very large, such as 10 or greater (an example would be a survey to estimate internal migration where large clusters are used). In many developed countries, however, which have near total telephone penetration or virtually 100 per cent literacy, telephone and/or mail surveys can be conducted randomly without the need for using clustered designs.

A large value of *deft* occurs when the variable in question is said to be highly Aclustered≅. The interpretation of a value of *deft* of, such as 3.0, is that the sample variance is 3 times bigger than it would be if the survey were based on the same sample size but selected randomly. An alternative interpretation is that only one third as many sample cases would be needed to measure the given statistic if a simple random sample were used instead of the cluster sample with its *deft* of 3.0. Hence it is important in designing a household survey sample to strive for a design in which *deft* is small, usually in the range of 1.5 to 3.0. In some disability surveys it has been shown that urban communities are more Aclustered≅ with respect to disability than rural communities; hence the *deft* would be higher in the urban areas. This might suggest that an optimum sample plan would utilize smaller clusters in urban areas than rural ones, though this might not be an efficient approach unless reliable data are available on the urban/rural

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Box 11: *(Continued)*

values of *deft* for a country that is planning a disability survey. Poverty has also been shown to be correlated with disability, which would imply that areas with a high concentration of the poor might be separated out as a distinct stratum, for sampling purposes, to optimize the impact of *deft* on the sample design.

The total design effect reflects the stratification and the stages of selection, plus the number, average size and variation in the size of clusters that are used in the survey. Hence, the precise value of *deft* is a combination of all these influences. However, the factor that accounts for the great bulk of the *deft* value is the clustering effect, which is expressed as:

$$deft = 1 + \delta(\hbar -1), \text{ where}$$

deft is the design effect;
δ is the intraclass correlation for the statistic in question;
$\hbar$ is the (average) size of the cluster.

The intraclass correlation value, δ, is different for each statistic. It represents the likelihood that two elements in the same cluster have the same value, for a given statistic, relative to two elements chosen completely at random in the population. In household surveys using the personal interview, clusters are generally geographically defined areas containing a predetermined or expected number of households. A value of 0.05 for δ is interpreted, therefore, to mean that the elements in the cluster are about 5 per cent more likely to have the same value than if the two elements were chosen at random in the survey. The smaller the value of δ, the better the overall reliability of the sample estimate will be. Fortunately, for disability measurement, δ, while likely to be positive, is nevertheless probably very small—close to zero—since persons with a disability are not particularly Aclustered≅ in the same neighbourhoods, except those living in some urban settings as mentioned above or in institutions, which would be sampled in a different manner anyway. The latter is discussed below in the subsection 3(a) on the use of institutions as a list frame.

The other factor, which determines the overall value of *deft*, is $\hbar$—the size of the cluster. Since the two factors, δ and $\hbar$, are multiplicative, even when one is small, if the other is very large, then *deft* will also be large. As mentioned above, it is best to choose a cluster design whereby the overall *deft* is less than 3.0. To illustrate, if we assume that disability prevalence has an intraclass correlation, δ, of 0.02 among persons in the same cluster and, further, if we want the *deft* for our design to be 2.5, then the cluster size, in terms of the number of persons it should contain, would be calculated by rearranging the expression above as follows:

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Box 11: *(Continued)*

ñ = 1 + (*deft* - 1)/δ,

or

ñ = 76, the average number of persons the cluster should contain.

To figure the expected number of households that each cluster should contain, simply divide ñ by the average size of households. For example, with an average of 4.2 persons per household in a given country, our sample would be designed to provide clusters of approximate size 76/4.2, or 18 households.

For more information about *deft* see Kish (1965).*

To complete the illustration, assuming the values for the parameters as stated above, the necessary sample size for our disability survey can be calculated with the following formulation:

$$n = 4 \, (pq/\delta^2) \, f, \text{ where}$$

n = the sample size,
4 = the factor to provide a confidence limit of 95 per cent,

p = the estimated prevalence
  = 0.05,

q = 1-p
  = 0.95,

δ^2 = the required (specified) precision
  = $(.005)^2$
  = .000025,

f = shortened symbol for *deft*
  = 2.5.

Substituting, the value of n is 19,000.

* L. Kish, *Survey Sampling* (New York, Wiley, 1965).

(ii)   Sample size: persons versus households

It is important to recognize that the computation in box 11 gives the estimated value of n in terms of the number of sample persons needed. The task remains to compute how many sample households this would require, and that number depends on the average household size for the population (country) in question. For example, with an average household size of 4.2 persons, a total of 19,000/4.2, or about 4,500, sample households would be needed to estimate a 5 per cent disability rate, plus or minus 0.5 per cent at the 95 per cent level of confidence.

The above is only an illustration. Other specified parameters would yield different estimated sample sizes. If, for example, the production of estimates that were twice as reliable was desired—plus or minus 0.25 per cent instead of 0.5 per cent, at the 95 per cent confidence level (confidence interval of 4.75 per cent - 5.25 per cent)—then the sample size, n, would be four times bigger: 76,000 persons or 18,100 households. Similarly, if the design effect, *deft*, is bigger, then the sample size will be proportionately larger (a *deft* of 3.0, for example, would require a sample size 1.2 times larger than one where the *deft* is 2.5). In contrast, adopting a convention of accepting results at the 90 per cent level of confidence (which is equivalent to 1.6 standard errors) instead of 95 per cent (or 2 standard errors) would permit the sample size to be reduced from the factor of 4 in the above calculation to a factor of $(1.6)^2$, or 2.56, resulting in a sample about 64 per cent as large. It is clear, therefore, that changing the requirements and, thus, the specified parameters can have significant effects on the overall sample size necessary.

If the predicted disability rate that was used to calculate the sample size is considerably different from the actual rate, based on the survey findings, then the reliability and confidence interval will be quite different also. For example, if the estimate from the survey turned out to be 10 per cent instead of 5 per cent (from our illustration) the confidence interval on this estimate would be 9.32 per cent - 10.68 per cent instead of our hypothesized interval of 4.5 per cent - 5.5 per cent.

It is also important to note that the intraclass correlation, δ, may not be known in advance of the survey. Above, we have Aguessed≅ it to be about 0.02, and calculated the *deft* and n̂ accordingly. After a survey is conducted it is possible to calculate an approximate value of δ, which can then be used to help design the next survey more efficiently. For the design of the first survey, however, it may be necessary to rely upon estimates of *deft* and/or δ that may have been made from surveys conducted in other countries: this is a reasonable approach since there is no cause to believe that the Aclustering≅ of individuals with a disability is especially variable by country. For further information about the use of clusters for disability surveys see section (v) below.

    (iii)   *Augmenting the calculated sample size for sub-groups*

The above illustrations pertain only to sample sizes necessary to estimate a national-level, overall disability rate with a pre-specified precision. If an estimate is wanted for a disability that occurs with less frequency, such as the proportion of the population that is blind, then the requirements for sample size will be commensurately larger. Also, as mentioned above, determining the characteristics of the population with a disability by type of disability is likely to be an important policy objective and hence a survey objective as well.

In general, distributional statistics will not be very reliable unless there are several hundred cases in each parent cell; for example, if the survey is to produce estimates for each of 6 different types of disability, there should to be a minimum of 300 to 400 cases of each type in the sample. To do this requires samples very much larger than the one calculated in the illustration above; note, for example, that in the illustration the number of overall persons with a disability in the sample of 19,000 would be approximately 950, that is, 5 per cent of 19,000. To subdivide 950 cases into 6 or more types of disability for further analysis would yield very thin and not very reliable results by type of disability.

Hence, the calculated sample size may have to be multiplied by a factor of 2, 3 or even more to accommodate reliability requirements for sub-group estimates and distributions.

(iv)   Sample size for sub-national areas

The sample for a national-level estimate, when subdivided to examine sub-national areas, suffers from the very same reliability problem identified in the preceding subsection. As a result, a sample of 950 persons with a disability distributed among, 10 geographic regions of a country would give an average of less than 100 per region—too small to analyse meaningfully. Sub-national detail, however, is usually very important to policy-makers and administrators in those districts, and therefore they would require reliable information at that level.

Here, treatment of the sample size problem can be handled in one of two ways. First, it must be ascertained whether equal reliability is wanted in each region of interest. If so, the mathematical solution is to multiply the sample size needed for the national estimate by the number of regions. For example, if 4,500 households were needed overall and there are 6 regions, then about 27,000 households would be needed in the sample. This is because equal reliability by sub-area requires equal sample sizes in each such sub-area, since the precision of an estimate is a function of the absolute value of the sample size n and not the proportion that n is of the total population. In other words, for a specified precision, n is the number of cases needed no matter how large the population, whether the population is a single province/state in a country or the entire country (except for the finite multiplier effect explained above).

Multiplication of the simple size by the number of regions is usually an unacceptable solution when the number of sub-areas is large. Moreover, many countries

may not be interested in obtaining sub-national data that is equally reliable for each sub-area. To illustrate, if one region of a country is sparsely populated, it may not be regarded as sufficiently important for program planning as another that might contain 20 per cent of the nation's population; in such a case, surveying a large sample in the sparsely populated region may not be a strong policy objective, and hence there would be no measurement objective to do so. Alternatively, officials may decide that proportionate samples of the nation's regions better satisfy their objectives. This leads to the second solution.

The second solution pertains when equal reliability of results is not necessary for sub-national areas. Instead, the expected sample results would be examined in advance of the sample design to compare the relative reliability for regions, or other sub-areas of interest, if the sample is to be proportionately allocated geographically. If, for example, rural areas comprised 33 per cent of the nation's population, then 33 per cent of the national sample would be allocated to and selected in the rural domain. If the north-east region comprised 20 per cent of the population, then the sample in that region would also be, proportionately, 20 per cent of the total sample. In this way, the reliability of the results would be proportionately reduced in those areas relative to the national estimates. In the rural domain, per the example, the sampling error for the disability statistics would be approximately 74 per cent higher than the corresponding sampling errors for the national statistics, computed as the square root of the ratio of (1) 0.33); for the north-east region the sampling errors would be roughly 2.23 times greater, or, the square root of the ratio of (1) 0.2).

As mentioned, this kind of sampling variance analysis can be done prior to the survey, because it is only a matter of comparing relative sample sizes for domains (regions, urban/rural, and so on) versus the total sample (nation as a whole). If it is seen that important domains will yield results that are too unreliable to be analytically useful, then the sample size in those domains can be augmented, if necessary. Hence, the second solution might involve augmenting the national sample size, computed as in the illustration of subsections 2.(b)(i) and 2.(b)(ii), by increasing the sample households in certain important domains by some factor, usually contingent upon the overall survey budget, to permit the desired reliability for the domain estimate(s). A side effect of such augmentation would be that the reliability of the overall national estimates would also be improved.

(v)   Sample size considerations: summary

As explained at the beginning of section 2, the issue of sample size is perhaps the main consideration in designing a reliable and affordable disability survey when prevalence is more or less the principal measurement objective. The requisite sample size can quickly become implausibly large on several accounts. For example, the statistic, "disability prevalence", is usually a small if not rare phenomenon in most countries, and large samples are needed to measure it reliably. Moreover, the estimate of prevalence alone is not sufficiently informative, and the survey will nearly always seek to include a

considerable body of additional information about the distribution, types and causes of disability, which create even greater requirements for large sample sizes. Lastly, national surveys are increasingly seen in many countries to be too broad unless they can also provide the necessary estimates for important sub-national groups, including geographical subdivisions; the need for sub-national estimates can increase an already large sample size by orders of magnitude, especially if geographical data are wanted with equal reliability.

Consequently, it is important to seek ways of increasing the efficiency of sample design, so that sample persons with disabilities can be more easily located and interviewed. The next three sections introduce some of the techniques that can and should be employed in a disability survey to improve efficiency and, in some cases, lower costs.

3. *Optimum use of sample frames*

The quality of the sampling frame or frames—the materials from which the sample is selected—is vital for any household survey. A sampling frame should always adhere as closely as practicable to certain basic principles. The frame must bear a one-to-one correspondence with the target population of the survey in order for probability sampling to be achieved. This usually means that the frame must be as accurate and as complete as possible. It also means that the frame should be current, or else provision should be made to bring it up to date prior to sample selection.

In addition to these basic tenets of frame quality, special procedures exist that can be utilized advantageously to develop better sampling frames for disability surveys. The procedures involve the use of dual or multiple frames. These frames are presented below in terms of area frames and list frames.

Household surveys, except in rare instances, such as random digit dialling telephone surveys, are always based upon an area sample as a starting point. Area sampling implies the use of an area frame, one in which a complete and non-overlapping list of geographical areas of a country is available for sampling. A typical area frame might be the set of enumeration areas developed in the most recent population census. Such an area frame nearly always contains information such as the census count of persons or households in each area, which can be used to establish the probabilities of selecting the first stage sampling units.

In theory, a probability sample of areas, which can be chosen in various ways, is all that is needed to produce an unbiased estimate for disability prevalence (or any other social, demographic statistic of interest). With variations here and there, such a sample is typically selected using multiple stages, geographical stratification with systematic *pps* (probability proportionate to size) selection and final-stage clusters ranging in size from 5 to 50 (or sometimes more) households. Such a sample design, which has been and continues to be used in scores of countries for numerous sociodemographic surveys, is a classic area sample design.

The difficulty with relying solely on an area-based sample, as described above, is that it may be very inefficient for studying rare phenomena or attributes. A typical disability survey, where for many countries the prevalence rate may be 5 per cent or less, falls into such a category. The reason it is inefficient is that many households have to be interviewed, on average, to locate a single person with a disability. As mentioned above, if the overall rate is 5 per cent, only 1 person out of 20 canvassed in the sample will have a disability. Another way of looking at this, from the standpoint of the interviewer's work load in the field, is that if an interviewer's assignment area is a cluster of 40 households (or about 160 persons if there are around 4.0 persons per household), he/she would expect to find only 8 persons with a disability in the sample.

The point here is that thousands of households must be sampled and surveyed to find enough households containing persons with a disability to render reliable analysis. In the previous illustration, where the prevalence rate was about 5 per cent, 4,500 households would have to be surveyed, but this would yield only about 950 persons with a disability in the sample. That is a minimum number, since it does not take account of the larger samples that would be needed to study disability by type or to produce reliable sub-national estimates.

(a)   Use of institutions as a list frame

To improve the efficiency of sampling for disability, strong consideration should be given to using one or more list frames together with the area-based frame: not in lieu of, but in addition to. One type of list frame that should always be used by a country contemplating a disability survey is a list of institutions for the elderly and other health institutions providing long-term care. Compared to persons living in conventional dwelling units, persons with a disability will obviously disproportionately inhabit such institutions. A complete list of such institutions should be compiled to constitute an independent frame for sample selection in a disability survey. For further details on the collection of disability data in these institutions as well as a list of the basic types of institutions to include, see section D below. Depending on the number and size of such institutions, it may be necessary to select the sample in two stages: first, a sample of institutions selected with probability proportionate to size: and second, a sample of persons within the selected institutions.

Another type of institution that should be given strong consideration as an auxiliary list frame is orphanages, since they may also contain a disproportionately large number of children with various disabilities. It should be noted that residents of homes for the elderly, orphanages and long-term health care institutions would not be covered by the area frame anyway, so long as the household roster for the area sample uses a *de facto* approach (see more on this point below).

(b)   Advantages and disadvantages of combining list and area frames

In addition to institutions, other lists may be available to supplement the area frame: these lists would in fact overlap, in terms of coverage, with the area frame. These kinds of lists would be national or local registers of known persons with disabilities. They might be specialized registers focusing on a particular type of disability, such as one maintained by a national association for the blind.

As suggested above, sampling from such registers can offer the advantage of increasing the number of persons with a disability in the sample since a very high percentage of them, though probably not all, will indeed have a disability. However, not all the persons with a disability will be registered (on the various lists), and so the area sample is needed for complete coverage. Hence, the list frame is efficient but incomplete, while the area frame is inefficient but affords more complete coverage.[28]

Nevertheless, there are some disadvantages to using supplemental lists, and these should be taken into account in designing the sample for a disability survey. For example, use of lists requires preparatory work, such as checking on their accuracy and recency. If a potential list is known to be very much out of date, its utility as an auxiliary or supplemental frame may be insufficient to justify the cost of trying, often futilely, to track down the persons sampled from it. Preparatory work might entail having the list frame computerized before sampling. It may also be necessary to sort it in various ways, such as by geography, prior to sampling. Since it is not likely that Aclusters≅ could be established from registers, the sampling scheme would have to be a systematic random sample. This scheme has the disadvantage of spreading out the travel component of the survey and thus increasing costs. Travel can lead to a significant increase in survey expense; therefore, sample optimization should be used to find the right Amix≅ in terms of allocating the overall sample size appropriately among the list frame(s) and the area frame.

Another disadvantage of using supplemental lists is that, in order for the probabilities to be properly computed (and hence the survey weighting factors), it is necessary to Aunduplicate≅ the list and area frames. One way of implementing the necessary procedures for unduplication is by adding a question to the area frame sample questionnaire that asks whether any person with a disability identified from the area frame is also listed on a particular register (the one used for the supplemental list frame). When an affirmative response is given, the overall weight for that person must be adjusted to account for multiple probabilities of selection. A further disadvantage is that some individuals with a disability covered by the area frame may not know whether they are listed on the list frame or not, in which case a matching operation between the two frames might have to be performed to avoid coverage bias. Sometimes the process of unduplication through matching can be aided in countries where the population is assigned personal identification numbers. In this case it would be necessary to inquire about the PIN during the survey interview and the number would subsequently be used to help in matching. In any case, performing matching operations would add significantly to both the operational complexity and the cost of the survey.

Frame unduplication would not be necessary for persons selected from the list of institutions indicated above (homes for elderly persons, orphanages or long-term health care institutions). This is because the institution frame and the area frame are mutually exclusive and residents of institutions would not be in the area frame. It is important to ensure that, in completing the survey questionnaire, the household rosters of the area sample should include only de facto members of the household and not de jure members who actually reside in the institutions mentioned.

4. *Use of two-phase sampling and post-stratification*

A methodology that increases sampling efficiency for disability surveys is two-phase sampling. As the name implies, it features selection of the sample in two phases. The first phase is intended mainly to identify persons with disabilities, while the second phase is intended to gather pertinent information about them by interviewing a sub-sample of those identified.

The procedure entails the selection of a comparatively large sample of households in the initial phase, using conventional survey sampling techniques such as stratification, stages of selection, clustering and systematic random selection. The first-phase sample is then canvassed, and the sample households and their occupants are screened using a relatively short and simple questionnaire intended to gather only enough information to enable the first phase sample of households, or persons, to be post-stratified for further sampling and interviewing in the second phase. The simplified questionnaire used in the first phase is primarily a screening device, as mentioned. As such it would contain, in addition to basic household roster data and address location information, only those series of questions that are framed to screen whether a person has one or more disabilities.

With the responses obtained in the large first-phase sample, all the original households are then post-stratified into two strata. The first stratum would consist of any household in which at least one member responded affirmatively to one or more of the disability screening questions. The second stratum would contain all other households. In most countries, except those where the disability prevalence rate is relatively high, the great majority of households would be categorized into the second stratum. An alternative strategy would be to classify, or stratify, persons rather than households in this same manner.

The next step in the sampling operation would involve selecting a sub-sample in each of the two strata. In many situations it might be prudent to select 100 per cent of the sample households (or persons) in stratum 1, depending on the overall requirements for ultimate sample size. In stratum 2 a much smaller sub-sample, proportionately, would be selected, perhaps as small as 1 in 10 or 1 in 20. In any case, the optimum allocation for the sub-samples between the two strata can be calculated using standard techniques. [29]

It is important to remember two things about first-phase screening and post-stratification. First, while most of the persons stratified into the first stratum will ultimately turn out to have a disability (after the second-phase questionnaires are completed, coded and analysed), some of them nevertheless will not have any disability, since the screening questionnaire is by definition imperfect. Secondly, some of the individuals classified as not having any disability in stratum 2 will actually turn out to have one once the second-phase sample is implemented, again because of the imperfect nature of the screener and, hence, of stratification itself. In any event, a sub-sample of some size, even a very small one, must be selected in stratum 2 in order for unbiased estimates of disability prevalence to be made. This is inherent in the nature and theory of stratified sampling, which requires sample units to be selected from every stratum constructed for a survey.

In this way, the first-phase sample is a comparatively inexpensive field operation whereby a large sample of households, usually many thousands, is quickly canvassed for purposes of locating persons who, by virtue of the first-phase screening and post-stratification, have a high probability of having a disability. The detailed interview, which is considerably more expensive to administer, is then restricted mainly, but not exclusively, to such persons. Thus, two-phase sampling helps to realize efficiencies in the operation of the sample, which is intended to better identify persons with disabilities.

A variation of the two-phase technique for disability survey sampling can be used to advantage when population census data are appropriately exploited. The census itself is not a particularly useful vehicle for obtaining disability information, since the questions needed to do so are so detailed that it would place too great a burden on an instrument that is used for many other purposes. However, it is plausible to introduce one or two disability screening questions, as noted in the preceding paragraphs, into a census questionnaire. The responses to the disability screening questions could then be post-stratified for sub-sampling in the same manner as above, with a follow-up disability survey then undertaken at some point after the census. Hence, the census would not provide data per se about disability, but it would constitute an excellent frame for the implementation of a two-phase sampling method. A difficulty with the use of census records in this way is that often the census is confidential, to the point that names and addresses may not be available for subsequent use to select samples for follow-up surveys. Because disability increases with age, a systematic random sample, despite stratification and clustering, will give a large proportion of those in the old age groups, such as those over age 65. It is recommended to sub-sample the old population so that for a fixed sample size, proportionately more of the younger persons with disabilities are included.

5. The potential for use of large clusters in sample design

Subsection 2.(b)(i) above explored the influence of clusters on reliability, and hence the sample size, of surveys in general and disability surveys in particular. What was not mentioned is why clusters are used in the first place, since they have the negative

effect of lowering the precision of survey results. The reason is simple—travel cost. Again, this consideration is relevant only for personal interview surveys of the type normally conducted in developing countries; in developed countries where interview-by-mail or telephone surveys are heavily relied upon, the issue of travel costs and hence the use of clustered designs, does not pertain.

If a survey organization conducting a personal interview survey wants a sample of 5,000 households, it is cheaper to survey 50 households in each of 100 locations than 25 households in 200 locations. That is why simple random samples are never used in household surveys requiring in-person interviews. It would be prohibitively expensive to travel to 5,000 separate, and probably widely scattered, locations to conduct 5,000 interviews. Consequently, a sampling practitioner must always design a household survey sample in a way that balances the lower cost of cluster sampling against the increased sampling error it causes.

It was suggested above in subsection 2.(b)(i) that for a disability survey the design effect, *deft*, which measures the increase in sampling error whenever cluster sampling is used, may in fact not be very large for a survey mainly intended to estimate disability prevalence. Since it is thought that persons with a disability do not Acluster≅ together in the same households or neighbourhoods, then the intra-class correlation, one of the two multiplicative factors in the calculation of *deft,* should be very small.[30] It is not implausible to imagine that it may be as small as 0.005.

Consequently, the other factor, ñ, the average cluster size, could perhaps be allowed to be comparatively much larger than one would normally propose for a household survey. Most household surveys use clusters in the range of about 10-35 households, so that *deft* may be confined to a range of about 1.5 to 3.0. There is considerable room for variation here, depending on the particular characteristic being measured.

An example presented in subsection 2.(b)(i) suggested that δ among persons might be about 0.02, in which case a cluster size of around 76 persons (or 18 households if the number of persons per household averages 4.2) would yield a *deft* of 2.5. But what if the intra-class correlation is much lower? Table 6 gives some comparative values:

TABLE 6. COMPARISON OF CLUSTER SIZES FOR VARIOUS DESIGN EFFECTS (*DEFTS*) AND INTRA-CLASS CORRELATIONS (δ)[a]

Intra-class correlation (δ)	*deft* = 1.5	*deft* = 2.0	*deft* = 2.5	*deft* = 3.0
.005	101	201	301	401
.01	51	101	151	201
.015	34	68	101	134
.02	26	51	76	101
.025	21	41	61	81

[a] The interior values of the table show the cluster sizes that correspond to the design effects and intra-class correlations that apply to the sample design. For example, when deft is 2.0 and the intra-class correlation is .01, the size of the cluster must be 101.

The results from table 6 are expressed in terms of number of persons per cluster. They suggest that if δ for disability among persons is very small, then it is not unreasonable to use clusters as large as several hundred persons in a disability survey. Since the empirical values of the intra-class correlation may not actually be available, however, it is best to be on the conservative side and settle for cluster sizes that are smaller, perhaps 150 persons. Depending on the average size of households in a specific country, this number of 150 persons per cluster might translate into 30-50 households per cluster.

The implications for sample design and survey costs for disability surveys are quite significant. They suggest, for example, that whereas a traditional sample survey with a 10,000-household sample might normally be scattered among 400 clusters with a sample size of 25 households (in a two-stage design), for a disability survey this same sample size might be usefully restricted to only about half as many clusters. The size of the sample would then be doubled to 50 households, in countries where the average household size is comparatively low, and still the sample would produce quite reliable results. The savings in survey costs for visiting 200 locations instead of 400 would be appreciable. Thus, this sort of approach should be carefully considered when designing the sample for a disability survey. In addition, whenever information is available, such as from a prior disability survey, about the actual values of the design effect(s) and the intra-class correlation(s), these statistics should be used in designing the new disability survey. Even a previous multi-purpose survey, containing questions on disability could be used for this purpose if the design effects and intra-class correlations have been computed for the disability statistics.

6. General principles for disability survey sampling: summary

The principal, though not exclusive, focus of this section on sampling has been on national-level, as opposed to local-level, surveys and on sampling techniques to measure disability prevalence, as opposed to characteristics of persons already known to have disabilities. It is strongly suggested that whatever sampling strategies are adopted, probability sampling techniques should be used at every stage of selection. This is essential to ensure that the sample survey results can be used to make unbiased inferences about the larger population that the sample represents.

As a result of the low disability rate in most countries, a general-purpose sample design is likely to yield very few cases of persons with disabilities for analysis, unless the sample is very large. For this reason it is argued that sampling plans should encompass certain techniques that are specifically dedicated to the problem of disability measurement, in order to improve the efficiency of the design. For example, while an area sampling frame must be used for purposes of ensuring complete coverage in measuring disability prevalence, sampling efficiency in terms of increasing the number of persons with disabilities in the sample can be improved when the area frame is supplemented with, first, a list frame of institutional persons in long-term care facilities, homes for the elderly and orphanages and, second, other list frames from registers of known persons with disabilities of various types.

It has been shown that a plausible sample size for a national disability survey is on the order of magnitude of 4,500 households whenever the prevalence rate is low (around 5 per cent) and no detailed sub-analyses are wanted. Otherwise, 3, 4 or 5 times as many sample households might be necessary to obtain reliable sub-national and/or sub-group estimates.

The use of first-phase large samples together with the technique of post-stratification to identify likely persons who have disabilities, followed by sub-sampling for detailed interviews, is a viable area sampling strategy for measuring the prevalence and characteristics of persons with disabilities. A population census can also be used for this purpose, by screening for disability and then following up a sub-sample in a post-census disability survey. In this case, the census serves as a sampling frame. Abnormally large clusters, containing 50 or more households, may be a sensible sampling technique to use in countries where the intra-class correlation for disability is very low since the results would not be appreciably worsened in terms of reliability, yet the survey costs could be lowered substantially.

7. Country experiences: sampling schemes

A host of countries have undertaken disability surveys and studies of various sorts. Many of these have been limited to studies in which persons with known disabilities were sampled and interviewed. Such studies are useful for studying the characteristics, attitudes and needs of persons with disabilities, but they cannot be relied

upon to provide estimates of disability rates or prevalence. Moreover, because they are limited by definition to known persons with disabilities (those listed on various registers), the studies or surveys do not represent the characteristics or needs of persons with disabilities who are not known, creating an inherent bias.

Some countries have undertaken disability surveys intended to estimate the prevalence of disability, its distribution by cause and type, and other characteristics of the population with disabilities. It is useful to describe the sample designs that have been used in some of these surveys in order to illustrate some of the topics covered. The examples chosen, however, are not necessarily intended to represent best practice.

In Botswana a probability sample of nearly 8,800 households, comprising about 46,000 persons, was interviewed for the 1983 Primary Health Care Survey—while the health conditions that were included in the survey were broad-based, some of the questionnaire items dealt directly with disability. The sample design for the survey was well-conceived, but it was a general-purpose design intended to be used in a wide variety of integrated household surveys for Botswana, the first of which was the health survey. The sample was a multi-stage, stratified, clustered design based on the 1981 population census as its frame, in which about 200 primary sampling units were selected. The survey found that between 4.5 and 5.0 per cent of the population had a form of disability. This sample provided useful results on the magnitude of the population with disability at the national level, and as such it is a good illustration of the use of a general-purpose sample design for a special-purpose (disability) topic, even when the population under study is comparatively rare, so long as reliable sub-national estimates are not of paramount interest. No special procedures were introduced into the sample design to focus more specifically on the population with disabilities nor to augment the sample size for that sub-population, again because the chief objective of the survey was the health condition of the total population in general.

A contrasting illustration of a sampling scheme is provided by a survey undertaken in India that was specially designed to sample persons with disabilities. The sample plan entailed a two-phase sampling strategy. The first phase used conventional sampling methodology to stratify states, districts and urban/rural areas before selecting a *pps* sample of villages and urban blocks. The entire sample village or block was canvassed and listed, and a house-to-house inquiry was made regarding whether the household contained at least one member having at least one physical disability pertaining to vision, communication (for those 5 years and above) and/or locomotor skills. Responses were then post-stratified into two strata: those households with at least one affirmative response regarding the disability screen (stratum 1) and the residual households (stratum 2). In the first stratum, 100 per cent of the households were included in the second phase of the survey, while a sub-sample of 1 in 12 and 1 in 14 respectively of the rural and urban sectors were included from the second stratum. Thus we have an excellent illustration of how two-phase sampling with post-stratification and differential sampling rates from the two second-phase strata can be designed and implemented.

Another example of two-phase sample design occurred in Great Britain, but it also involved the use of dual frames. This was the 1986/1987 survey of blind and partially sighted adults. The survey utilized a two-phase sample in which the first phase consisted of 100,000 households selected randomly by the Office of Population Censuses and Surveys. Questionnaires were posted to the sample households. Of those who responded, a sub-sample was then further interviewed in the second phase, along with a sample of persons from a list frame, which consisted of the registers of blind and partially sighted people maintained by local authorities. Altogether, accounting for non-response, the final area sample consisted of 338 persons who fit the vision criteria and consented to be interviewed, while 312 persons from the local authority lists were included under the same conditions. In addition to illustrating two-phase sampling in conjunction with dual frames, this sample plan also illustrates another feature of disability survey sampling: for rare characteristics such as blindness, an enormously large initial sample may have to be screened.

Dual frames were also used by the United States in its 1994/1995 Disability Supplement to the National Health Interview Survey (NHIS). The area frame consisted of approximately 200 primary sampling units with clusters the size of 8 households, selected using conventional sample survey methodology for national household surveys (multi-stage, stratified and clustered sampling techniques). The list frame consisted of national social security administration records of persons with disabilities, sampled for the purpose of increasing the number of cases of such persons in order to build up the sample size for analysis. A distinctive feature of the United States survey is that the NHIS is a continuous weekly survey based on a sample that is additive over time. Hence, for the disability supplement the survey interviews were cumulated over a two-year period to ensure that the sample size was large enough for reliable analysis of the population with disabilities. In addition to illustrating dual frame usage, this survey shows how countries that make use of continuous surveys can increase sample size for rare populations (such as persons with severe disabilities) by cumulating the weekly, monthly or quarterly survey panels.

An interesting feature of the British survey mentioned above was its use of random, as opposed to cluster, sampling methods in selecting the target ("with disability") population. This was a cost-effective strategy in the British case because the interviews were conducted by mail rather than in person. For a different reason, random samples were also used in Israel in a cost-effective way, in order to study disabilities of young children and elderly persons. The survey, intended to study disability among 3-year old children, was selected entirely from a list frame. The frame consisted of all Jewish children born in 1980 and registered in family health centres. It was thought that these centres accounted for 95 per cent of the target population. The sample size was close to 9,500 children. A survey of persons 60 and older living in households was also conducted in Israel in 1985. This sample was based on the 1983 population census, from which about 4,000 households containing the target (elderly) populations were selected using stratified, systematic sampling. Clusters were not used even though this was a personal interview survey. These two surveys illustrate how Israel was able to use

essentially random samples of households without incurring undue survey costs, since travel within its territory does not involve great distances. The surveys also illustrate, respectively, (a) the effective use of list sampling, especially if the list covers close to 100 per cent of the target population, and (b) use of a population census as a sampling frame for disability surveys.

D. COLLECTING DATA ON DISABILITY IN INSTITUTIONS

In many countries a significant number of persons with disabilities reside in institutional settings, such as chronic care hospitals and psychiatric institutions. For example, findings from a 1988 survey of disabled and aged persons in Australia showed that 8 per cent of the persons with disabilities lived in a health establishment and that 93 per cent of the persons living in a health establishment had a disability.[31] Survey research in an institutional setting, however, presents a variety of challenges, ranging from operational considerations to ethical concerns.

1. Types of institutions to include

A wide range of institutions can be considered depending on the population that is covered. The following basic groups of institutions could be included:

For children:

(a)	Acute care hospitals;
(b)	Chronic care hospitals;
(c)	Psychiatric institutions ;
(d)	Treatment centres for children with disabilities;
(e)	Residential special schools, such as schools for deaf children;
(f)	Private and non-private group homes;
(g)	Private and non-private children's homes;
(h)	Orphanages.

For adults:

(a)	Acute care hospitals;
(b)	Chronic care hospitals;
(c)	Psychiatric institutions ;
(d)	Treatment centres for persons with physical disabilities;
(e)	Residential special schools;
(f)	Private and non-private group homes;
(g)	Special care homes;
(h)	Penal institutions and detention centers;
(i)	Military establishments.

For older adults:

      (a)   Acute care hospitals;
      (b)   Chronic care hospitals;
      (c)   Psychiatric institutions ;
      (d)   Private and non-private group homes;
      (e)   Nursing homes;
      (f)   Special care homes;
      (g)   Private and non-private residences for senior citizens;
      (h)   Geriatric institutions.

Not every institution is appropriate for inclusion. Various types of institutions will be selected depending on the objectives of the research. It is important to realize that research studies will reach different rates and conclusions depending on the inclusion or exclusion of certain types of institutions.

The Health and Activity Limitation Survey conducted by Statistics Canada in 1991 included six basic groups of institutions: nursing homes, residences for senior citizens, general hospitals, chronic care hospitals, psychiatric institutions and treatment centres for persons with physical disabilities. The 1985-1988 OPCS Surveys of Disability in Great Britain included the basic groups of hospitals, homes and other communal institutions in their design. Each of these groups was comprised of a variety of institutions ranging from private children's homes to convents and monasteries.

Finding sources for lists of institutions and compiling a list of institutions is difficult and often quite time-consuming. Possible options to obtain current and reliable lists of health-related institutions will vary by country. Some possibilities include acquiring lists from national ministries involved in the provision of services to persons with disabilities; regional or municipal health and community or social service authorities; associations of persons with disabilities; and researchers in the health field. If a combination of sources is used, the researcher will need to compile a list from the lists received, and make sure that the coverage and categories in use are compatible.

Population censuses also usually produce lists of institutions that can be used to determine the place of residence. These lists have the advantage of being complete, often computerized, and providing a classification of the institutions. However, they can be out of date if the survey does not take place immediately after the census.

2. *Drawing a sample of institutions and respondents*

Once decisions have been made regarding the types of institution to include in the survey, a sample of institutions must be selected. Often, the sample is stratified in terms of the size of the institution (i.e., the number of permanent residents) since institutions of various sizes will have different populations; the size thresholds will be established based on the number of residents. It is advisable to have good representation of all institutional

types selected for the study, as well as good representation of the different sizes of institution.

A sample of respondents is drawn from each selected institution in each size group, based on a listing of all residents provided by the institution. The number of respondents selected to be in the sample should depend on concerns regarding the response burden for the facility administrators and staff. Generally, large institutions have more staff available to assist the researchers and interviewers than do small ones. In Statistics Canada's 1991 Health and Activity Limitation Survey, sample sizes were set at 8 interviews for small institutions, 15 interviews for medium institutions and 45 interviews for large institutions. The size categories for the institutions varied from one province to another because of wide variations in the population levels of each province. In the 1986 OPCS survey of disability among adults living in communal establishments in Great Britain, a slightly different approach was adopted. In institutions with 80 or fewer permanent residents, one resident in every four was interviewed; in institutions with more than 80 permanent residents, one resident in twelve was selected for interview.

The institution's staff must be briefed as to which residents are targeted by the survey. For example, a definition of "permanent resident" must be provided to the staff so that they can assist in the selection of the sample if the survey means to collect data only from permanent institutional residents.

The staff of the institution may be responsible for drawing up the list of eligible residents, since institutional documents are confidential. This could be quite a burden in some institutions. Clear instructions should be provided to the contact person regarding the variables, such as date of birth and sex, that will be required to select the sample. Assistance from the research team may be required for institutions where staff is in short supply. Alternate methods should be considered, such as having the interviewer assist the institution in preparing the necessary paperwork, or having the interviewer do all pre-survey work personally when permitted to do so by the institution.

3. Enlisting the support of the institutions

Experience in the United Kingdom and in Canada has shown that preliminary contact with the institution, in writing, is very important. An information package concerning the survey and its objective should be sent to the chief administrator in advance of researchers or interviewers initiating verbal contact. The package might contain a letter of introduction, a description of the survey's objectives and methods, samples of the questionnaires to be used, and if possible, endorsements from associations of other facilities involved in long-term care provision or from health departments.

After the information package has been sent, a preliminary visit to the institution's administrator should be arranged to enlist cooperation. This initial visit should also serve to answer any questions or concerns and to identify the contact person within the institution who will be responsible for assisting in the sample selection.

Since institutions are concerned about the well-being of their residents, there may be reservations about participating in surveys, which are viewed as invasive or a burden on the participant. To help alleviate this situation, it is good practice to involve some institutions or associations in discussions while the research is being designed. For example, Statistics Canada was able to overcome the initial reticence of some associations with regard to its Health and Activity Limitation Survey by working out solutions to address their concerns. Since the associations felt strongly about not disclosing any information on the revenue levels or sources of their residents, these questions were removed from the form. Concerns for the confidentiality of the data were also addressed by using anonymous forms. When the survey's objectives were discussed with associations of hospital and long-term care institution administrators, these associations saw the potential for obtaining data that would be useful to them and agreed to endorse the survey.

4. Considerations when interviewing institutional residents

Most permanent residents of institutions have a health condition or some degree of disability that might preclude the use of a lengthy questionnaire. It is best to limit the number of questions to as few as possible. Although in some cases a follow-up visit may be permitted, it is best to try to conduct the interview in one session.

Interviewers should receive extensive training prior to the data collection exercise. They should be thoroughly familiar with the content of the questionnaire; the intent of the questions, so that they can properly prompt the respondent if the question is misunderstood; the flow of the questions; and the skip patterns if there are any. They should also be sensitive to the reactions of the respondents, some of whom may tire quickly or may not be comfortable taking part in a survey. Sensitivity training in dealing with persons with disabilities as regards language, alternate methods of communication and other concerns should also be provided. For example, oral and sign language interpreters may be required, and they should be provided when the need arises.

The timing and location of the interview should be decided upon in consultation with the institution's staff. The objective is to be as discreet as possible and to disrupt to the least extent possible the routines of the resident and the institution.

The use of proxy respondents comes up very often in surveys of institutional residents; because of various conditions or disabilities, some respondents may not be able to provide answers to questions. Older residents may be quite capable of answering questions, but may provide unreliable information because of failing memory or confusion. It is best to check with institutional staff for advice on the need for proxy interviews. This is a sensitive area, since some residents may feel capable of providing answers and feel slighted if they are not permitted to do so. Alternatively, it is possible that staff members might be too conservative in their estimation of a resident's abilities. If

a conflict arises between the desire of a resident and the opinion of the staff, it is best to interview the resident and verify the accuracy of the data with a proxy respondent.

Proxy respondents can be family members or staff members of the institution who have daily contact with the resident. It is quite probable that some proxy respondents will be unable to answer some questions, especially those regarding events that happened in the past. In this case, it is good practice to include a "don't know" category in the answer categories. Some questions may not be asked of proxy respondents; for example, if the survey includes some attitudinal questions requesting opinions, these should not be asked of the proxy respondent and a "not applicable" option should be provided on the questionnaire form.

When interviewing children residing in institutions, researchers should ensure that parents are advised of the survey, and that their consent is obtained prior to the interview. Some institutions may insist on having parents present during the interview, or on having parents respond to the survey themselves.

Notes

[1] *Population Census Methods* (United Nations publications, Sales No. 1949.XIII.4).

[2] *Principles and Recommendations for Population and Housing Censuses, Revision 1* (United Nations publication, Sales No. E.98.XVII.8).

[3] The United Nations Statistics Division web site on disability statistics is at **http://esa.un.org/unsd/disability**.

[4] *Principles and Recommendations for Population and Housing Censuses, Revision 1* (United Nations publication, Sales No. E.98.XVII.8).

[5] *Ibid.*

[6] A.D. Furrie, *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).

[7] A. de Bruin, H.S.V. Picavet and A. Nossikov, *Health interview surveys: Towards international harmonization of methods and instruments,* WHO Regional Publications, European series; No. 58 (Copenhagen, World Health Organization, Regional Office for Europe, 1996).

[8] *International Classification of Functioning, Disability and Health—ICF,* Final Draft, Full Version (Geneva, World Health Organization, 2001).

[9] Statistics Netherlands, *Physical Disability in the Population of the Netherlands, 1986/1988* (The Hague, 1990).

[10] M.S. Durkin, and others, "The validity of the Ten Questions screen for childhood disability: results from population-based studies in Bangladesh, Jamaica, and Pakistan". *Epidemiology,* vol. 5, pp. 283-289.

[11] Additional information on Multiple Indicator Cluster Surveys can be obtained from the Internet at **http://www.childinfo.org**.

[12] Mary Chamie, "Can childhood disability be ascertained simply in surveys?" *Epidemiology*, vol. 5, No. 3, pp. 273-275.

[13] Ibid.

[14] J. Kennedy, and M.P LaPlante, *A profile of adilts needing assistance with activities of daily living, 1991-1992.* (Washington, D.C., United States Department of Education, National Institute on Disability and Rehabilitation Research, 1997).

[15] Joshua M. Wiener, and others "Measuring the activities of daily living: Comparisons across national surveys", *Journal of Gerontology: Social Sciences*, vol. 45, No. 6, pp. S229-237.

[16] D. Duckworth, "Measuring Disability: the role of the ICIDH". *Disability and Rehabilitation,* vol. 17, No. 7 (1995).

[17] A. de Bruin, H.S.V. Picavet and A. Nossikov, *Health interview Survey: Towards International Harmonization of Methods and Instruments,* WHO Regional Publications, European series, No. 58 (Copenhagen, World Health Organization, Regional Office for Europe, 1996).

[18] Ibid., p.66.

[19] Mary Chamie, "Survey design strategies for the study of disability", *World Health Statistical Quarterly*, vol. 42, No. 3 (1989).

[20] The World Programme of Action concerning Disabled Persons was adopted by the General Assembly in its Resolution 37/52 of 3 December 1982. The Programme of Action may be viewed on the United Nations web site on disabilities: **www.un.org/esa/socdev/enable/diswpa00.htm**

[21] *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Naitons publication, sales No. E.DPI/1454).

[22] *International Classification of Diseases and Related Health Problems: Tenth Revision (ICD-10)* (Geneva, World Health Organization, 1992).

[23.] International Organization for Standardization, International Standard ISO 9999, "Technical Aids for Disabled Persons" (Geneva, ISO, 1992). Prepared by Technical Committee ISO/TC 173, Technical Systems and Aids for Disabled or Handicapped Persons.

[24] *International Classification of Functioning, Disability and Health—ICF,* Final Draft, Full Version (Geneva, World Health Organization, 2001).

[25] Report of the Expert Group on Development of Statistics on Disabled Persons, Vienna, 2-6 April 1984 (ESA/ST/AC.18/7).

[26] A. Turner, ASample and survey design strategies for household surveys on special subjects", E*stadistica,* vol. 42, No. 139 (Santiago, Instituto Interamericano de Estadistica, 1990).

[27] R. Tortora, AA note on sample size estimation for multinomial populations≅, *The American Statistician*, (Alexandria, Virginia, American Statistical Association), vol. 32 (1978), pp. 100-102; "Choosing the sample", chap. 4 in *Monitoring Progress Toward the Goals of the World Summit for Children: A Practical Handbook for Multiple-Indicator Surveys* (New York, United Nations Children's Fund, 1995).

[28] *Sampling Rare and Elusive Populations*, National Household Survey Capability Programme (New York, United Nations Statistical Division, 1993).

[29] G. Kalton, *Introduction to Survey Sampling*, Quantitative Applications in the Social Sciences Series, vol. 35 (Beverly Hills and London, Sage Publications, 1983); L. Kish, *Survey Sampling*, Wiley, (New York, 1965); M. Hansen, W. Hurwitz and W. Madow, *Sample Survey Methods and Theory* (New York, 1953).

[30] Clustering of persons with disabilities in households is not to be confused with clustering of such persons in institutions. Persons with disabilities in institutions would not be sampled using an area frame but rather would be selected by first choosing a sample of institutions and then a sample of the rosters of persons in the selected institutions. Following this procedure would minimize the effect of "clustering" on reliability of surveys of persons in institutions.

[31] Australian Bureau of Statistics, *Disability and handicap*, catalogue No. 4120.0 Canberra, Australian Bureau Statistics, 1990).

CHAPTER IV. DISSEMINATION AND USE OF DISABILITY DATA

Introduction

A census or a survey is not complete until the information collected is made available to users in a form suitable to their needs. Products should be developed in consultation with users so as to understand their needs. Potential users include the general public and the media, persons with disabilities and their advocacy organizations, non-governmental organizations, researchers, service organizations for persons with disabilities and policy makers. Users will range from sophisticated data analysts to members of the general public who are simply interested in the number of people living with a disability. Topics of interest to the different user groups include the following:

(a)   Simple differences in rates of disability between males and females;
(b)   Differences in service utilization between the population with and without disabilities;
(c)   Need for and current use of assistive technology;
(d)   Access to and participation in education and employment.

An important consideration when planning the dissemination of the data and the format of products is to make the data accessible to persons with disabilities who may not be able to use the standard products.[1] This may require large-type, Braille and audio formats, including audio-visual cassettes, as well as special computer programs and interfaces for people with intellectual impairments.

Whatever the means used to disseminate the results, it is important for the statistical agency to find out how its data are being used and what problems have been encountered in such use. Most users can supply adequate reasons for wanting certain kinds of information but find it much more difficult to describe their actual use.

To improve the utility of the data, the data collection agency should also inform potential users of the existence of the data and publications and how to obtain them. Materials should be developed to promote their use. Some examples are given below:

1.   Simple fact sheets providing highlights of the data. These can be easily produced and distributed through newsletters of disability organizations and over the Internet, as well as at annual national and international meetings of organizations and associations concerned with the issues facing persons with disabilities;

2.   A brochure providing an overview of the available data, a list of products and services and instructions on how to obtain the data or publication(s);

3.   A users' guide providing an overview of the data, including a list of the questions asked, the forms used in data collection, a review of the data collection methodology, definitions, a list of products and services connected with the data and instructions on how to request the data. Such a guide would be especially useful to researchers and

statistical agencies might be interested in conducting some secondary analyses, as it would contain background information regarding the study in question.

Concerning the data products, different levels or degrees of detail and analytical depth are desirable when presenting and disseminating the results because of the different levels of sophistication of the users. The data may be disseminated in various types of reports or publications, in unpublished tabulations for limited distribution, through microdata files or by on-line access to the data.

A. PLANNED TABULATIONS

Typically, the specifications for the planned tabulations are developed, in consultation with users, during the planning phase. The planned tabulations should be designed to serve as wide an audience of users as possible since many general users of data do not have the resources to carry out their own analyses tailored to their own requirements.[2] Chapter II includes more information on planning tabulations.

As a basic requirement, data by disability status should be presented by age and sex. If the data are not classified by single age or by standard five-year age groups, it is recommended that whatever age classification is adopted should make it possible to distinguish the following age categories: 0-14 (children), 15-59 (adults), and 60 and over (elderly). Other special issues to be considered when producing tabulations on persons with disabilities will be discussed in the following sections. These issues include:

(a)   Number of persons versus number of disabilities,
(b)   The socio-economic profile of persons with disability,
(c)   Comparisons of persons with and without disability.

1. Number of persons versus number of disabilities

In presenting data on persons with disabilities, it is important to be clear about what the data represent, disabilities or persons with disabilities. For example, in tabulations on type of disability, since an individual could report more than one type of disability, the row or column totals could exceed the number of persons included in the study. The column or row total, which represents the total number of disabilities rather than of persons, will be higher than the total number of persons with disabilities, and the difference between the two will depend on the number of persons with multiple disabilities. Tabulations showing type of disability should also present a corresponding total number of persons with disabilities to whom the information refers. Furthermore, each tabulation reporting type of disability should have a disclaimer cautioning the user about the fact that the row or column totals may be more than the total number of persons because of the occurrence of multiple disabilities.

To illustrate the extent of multiple disabilities, persons with disabilities may be categorized by number of disabilities. For example, if an individual has activity limitations in the areas of "lifting and carrying objects" and "undertaking a single task",

the number recorded in the derived variable Anumber of disabilities≅ would be 2. If an individual has activity limitations in "speaking", "learning to read", "thinking", and "transferring oneself", then the number recorded in the derived variable Anumber of disabilities≅ for that individual would be 4. This derived variable could then be cross-tabulated with other variables such as age, gender and employment status.

2. *The socio-economic profile of the population with disabilities*

To convey more meaningful information to policy makers and planners, tabulations should show the characteristics of persons with disabilities in terms of their disability experience as well as their socio-economic and environmental attributes. Tabulations may also present the population with disabilities desegregated by area of residence, such as by rural/urban residence. Additional tabulations covering the life experiences of persons with disabilities are encouraged, particularly data on social and community participation and quality of life. Depending on their relevance in the particular country, such tables may include the frequency of shopping trips, or theatre-going travel, and civic and recreational activities.

Consideration should also be given to defining the units of analysis that might provide ways to study disablement at numerous conceptual levels: through the experience of individuals who have a disability; through the experience of the household having at least one member with a disability; or even through community characteristics when available.[3]

The following are examples of tabulations that can be used to show the socio-economic profile of persons with disabilities:

(a)   Cross-tabulations of educational characteristics with age, sex, and type of disability would reveal any differences among persons with different types of disabilities in educational attainment, school attendance, or literacy;

(b)   Data on employment, when cross-tabulated with age, sex and type of disability, can measure the extent to which persons of either sex with different types of disabilities are being integrated into the labour market;

(c)   If collected, income data cross-classified by age, sex and type of disability can provide an indication of income security;

(d)   Data on marital status and living arrangements, when cross-tabulated with age, sex and type of disability, can measure the extent to which persons with disabilities are living alone or living with others.

The problem of comparability among those with and without disabilities in relation to education and employment cannot be over-emphasized. These aspects of social/economic status are often the first to suffer when someone becomes disabled. For

example, someone may have professional qualifications but never have been employed in that profession because of his or her disability. If the designation of socio-economic position depends only on current occupation, as it frequently does, it will not be possible to assign a meaningful socio-economic classification to that person. For this reason the socio-economic condition of persons with disabilities should not be based on a single indicator; additional dimensions should be considered.

3. Comparisons of persons with and without disabilities

If the data collection activity includes persons without disabilities, then data should be presented for the population with and without disabilities by socio-economic characteristics such as education, employment and marital status, and on other variables such as living arrangements, income and service utilization. This type of information would make possible a comparative analysis of the two population groups in order to assess the extent to which there is equality of opportunity as stated in various international policy documents, such as the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.[4] Also, if data have been collected on participation, such information would be useful in examining whether there are differences between the population with and without disabilities in terms of involvement in life situation, such as participation in education, work and employment, social relationships, community, and social and civic life.

At national as well as at local levels, the census provides an opportunity to examine the social, demographic and economic characteristics of the population both with and without disabilities. National surveys, multi-purpose surveys in particular, can also provide an opportunity for this type of comparison, especially given the scope and detail of topics likely to be investigated. In a detailed special survey of disabled persons there may not be comparable data about the non-disabled population. In this case it is important to include in the survey some questions used in other general population surveys or censuses in order to obtain data that can be used for comparison.

Any comparisons between the two population groups should control for those variables that may affect the analysis. Studies have shown that these include such variables as geographical location (urban/rural areas), age and sex. For example, the prevalence of disability in developing countries is likely to be higher in rural than in urban areas since persons with disabilities would be more likely to remain in rural areas and not to migrate to cities. Also, data generally show that disability increases with age, and that persons in the older age groups are more likely than either children or young adults to have chronic health problems or conditions that result in some limitation of activity.[5]

Lastly, issues of gender equality are an important item on the global agenda and are relevant in considering persons with disabilities. Since a woman with a disability can face a double barrier, analysis of the social and economic factors that measure equality of opportunity should include gender as a control variable. It is important, therefore, to

identify during the consultation process these and other factors, such as ethnic group, that are particular to a country's situation and that may affect the analysis.

4. Recommended tabulations

In *Principles and Recommendations for Population and Housing Censuses, Revision 1*,[6] the United Nations developed a set of tables that can be produced with census data on the prevalence of disability by gender, age and urban and rural residence. These include the following:

(a)   Total population, by type of disability, geographical division, urban/rural residence, whether living in household or institution, age and sex;

(b)   Households with one or more persons with disability, by type, size of household and urban/rural area;

(c)   Total population 15 years of age and over, by type of disability, marital status, urban/rural area, age and sex;

(d)   Population with disability, by cause and type of disability, urban/rural area, age and sex;

(e)   Population 5 to 29 years of age, by school attendance, type of disability, urban/rural area, age and sex;

(f)   Population 5 years of age and over, by educational attainment, type of disability, urban/rural area, age and sex;

(g)   Population 15 years of age and over, by activity status, type of disability, urban/rural area, age and sex.

This set of tables is also applicable to surveys. The additional tabulations that are possible with surveys include data relating to the following topics: (a) severity of disability; (b) age at onset/duration; (c) need for and use of technical aids; (d) environmental characteristics that are either facilitators or barriers to participation; (e) vocational training; (f) income and consumption; (g) social participation; and (h) access to and use of services and support.

B. REPORTS AND PUBLICATIONS

To meet the variety of user needs, different forms of reports and publications need to be planned. The complexity and detail of the reports should be tailored to suit the type of audience for which they are intended and include an overview for non-technical readers.

Timing the release of the various reports is important. It is recommended that an advance report, mainly directed at policy makers, should be released as soon as possible

after data collection to make available as rapidly as possible data of current interest. This report should not be overly technical in nature. It should be brief and present the highlights of the study. It should also include information concerning the method(s) of data collection as well as cautions about the coverage and validity of the data.

More detailed data as well as information on the study should be given in subsequent reports. In these detailed reports, data as well as analyses can be presented that compare the demographic as well as the socio-economic attributes of persons with and without disabilities. Normally, these reports and publications also contain descriptions of the methods used, including definitions, classifications, study coverage, questionnaires and estimates of the reliability of the data, as well as sampling design and sampling methods if relevant.

In addition, reports should contain an explanation showing how the variables used to describe disability were derived from the questions. It would also be useful to show how the variables relate to the ICF-2 by means of a corresponding table.

The following illustrate the types of reports and publications that could be issued to disseminate disability data:

(a)   Advance report: a brief substantive analysis or presentation of the data mainly for purposes of disseminating preliminary results of the survey or advance data. The advance report may contain tables, charts and brief analyses of data on the following:

(i)   The number of persons with disabilities and those without, by age and sex, and by major geographical division;
(ii)   The number of persons with disabilities, by age and sex, and by type of disability;
(iii)   The number of persons with disabilities, by age and sex, and by cause of disability.

(b)   Detailed report: a review of the interrelationships within the data, including comparisons among demographic, socio-economic and geographical groups. Tables in such reports should be analysed for statistically significant differences between population sub-groups (e.g., men and women, the population with disabilities and that without, adults and children) and trends over time, using appropriate statistical tests.

Ideally, the detailed report would present information not included in the advance report as well as some of the information previously published in the advance report but in greater detail. The information that could be presented includes:

(i)   Economic characteristics for persons with disabilities and those without, by age and sex, and by geographical area of residence (showing type of disability for the appropriate population);

      (ii)   Educational characteristics for persons with disabilities and those without, by age and sex, and by geographical area of residence (showing type of disability for the appropriate population);

      (iii)   Marital status for persons with disabilities and those without, by age and sex, and by geographical area of residence (showing type of disability for the appropriate population);

      (iv)   Other types of information related to the situation of persons with disabilities, such as the cause and severity of the disability, the use of technical aids, and the need for and availability of support.

A moderately detailed publication would typically include the following sections:

      a.   Summary section
      b.   Chapters or sections considering specific topics
      c.   Graphs and charts
      d.   Technical annex
      e.   Detailed tables.

      (c)   Specialized/ special topic reports: these reports, which are most often completed after the initial publication, may utilize not only the data being analysed, but also information from other sources relevant to the topic at hand. The objective is to discover among the whole array of statistics those measures that clearly and concisely depict the condition of interest. [7] One type of specialized report could be concerned with the development of social and economic indicators on the situation of persons with disabilities. The topic of indicators is discussed in a separate section later in this chapter. Another example of a special report would be an in-depth discussion of disability among children.

      The following special topic reports were produced from the 1986 Canadian Health and Activity Limitation Survey:

      (i)   *Barriers confronting seniors with disabilities in Canada;*[8]
      (ii)   *Selected socio-economic consequences of disability for women in Canada;*[9]
      (iii)   *Blindness and visual impairment in Canada;*[10]
      (iv)   *Leisure and lifestyles of persons with disabilities in Canada;*[11]
      (v)   *Canadians with impaired hearing.*[12]

      (d)   Policy-oriented analytical reports: since one of the main purposes of statistics on disability is to guide policy decisions and their implementation, it is important for this type of analysis to be performed. For instance, the data might show that there is a difference in school attendance between children with disabilities and those without. Uncovering the reasons for the situation reported as well as its programme and policy implications are matters that may require further analysis, interpretation and judgement beyond the competence or authority of the data collection agency. Also, in

policy-oriented analytical reports, multivariate analysis of the data is required so that some of the relationships among the types of disabilities can be more readily recognized, including further study of the extent to which multiple disabilities have an impact upon the situation of persons with disabilities.

C. OTHER FORMS OF DISSEMINATION AND USE

To meet a variety of user needs, formats other than reports and publications should be considered to ensure strategic dissemination and use of the data, including:

a.   Making unpublished data available;
b.   Preparing of special tabulations on request;
c.   Disseminating of microdata files on computer media;
d.   Providing on-line dissemination and computer access to the data.

These four formats are described in detail below.

1. Making unpublished data available

Usually, not all tabulated results are published because of the cost and space involved or because of reduced public interest in some aspects of the data being presented. Some of the unpublished results, however, may be of considerable interest and value to specific users. One way of meeting these needs is to provide such users with unpublished data in some informal format, such as work sheets, copies of tabulation sheets or photocopies of computer print-outs.

Information disseminated in this manner should be limited to data that meet at least minimum reliability standards, and the data collection agency should specify certain restrictions regarding publication by the user. Alternatively, or additionally, the data collection agency may ask to review any proposed publication by a user prior to actual issuance.

2. Preparing special tabulations on request

The tabulations prepared by a statistical agency will not necessarily meet the needs of all users in terms of level of detail, cross-classification of subjects or otherwise. Users must always be consulted in planning the tabulations; however, some of the expressed needs may be too costly or time-consuming to be feasible. Furthermore, additional needs may emerge after the planning date, and some potential users may have initially been overlooked.

While statistical agencies are encouraged to respond to requests for ad hoc tabulations, consideration should be given to the resources required. The efficiency with which this service is provided as well as the period of time during which it is offered following data collection would depend on the availability of resources.

Special tabulations on persons with disabilities should be provided subject to the constraints of confidentiality and sampling variability. The data collection agency should ensure that there is no breach of individual confidentiality and that data reliability is not compromised, as would occur when the data pertain to a very small geographical area or a small and quite specific segment of the population.

Guidelines should be given to the requesting party so that the required detailed specifications for the tabulations are made. This eliminates misunderstandings and ensures that the tables provided meet the needs of the user. The data provider, on the other hand, should make available a list of data items from the study. For each item on the list there should be a data item name, the number of categories the item contains and a description of the categories. The data collection agency should compile this list as soon as possible after the data have been collected.

The following examples of guidelines for users on the requirements for table requests are from the Canadian HALS.[13]

A table request should consist of two parts:

(a)   A description of all variables or data items to be used in the table;
(b)   The actual specifications for the tables.

In the description of the variables, all of the variables to be used in the set of tables must be listed. A number in brackets should follow the name of the variable, which indicates the number of categories into which the variable is broken down, including totals and subtotals. Then the variable Astub≅ should be listed. Stubs are the labels or descriptions of the various categories, which will appear in the tables. A request for data tables must contain the following information for each table:

(a)   Table title;
(b)   Unit of count (universe);
(c)   Geographical area from which the data are to be taken.

Any plans involving the preparation of such special tabulations as a form of data dissemination should recognize that many grassroots interest groups, especially in developing countries, might not have the expertise to provide the needed detailed specifications for the tabulations. Therefore, to the greatest extent possible, depending on the local situation, other means of disseminating the data should be explored.

3. *Disseminating microdata on computer media*

Still another, increasingly common form of data dissemination is the release to users of computer data files containing the individual data results, or microdata, on diskette, tape or CD-ROM. These may be either complete data sets or various sub-samples. This approach reduces pressure on the data collection agency to prepare special

tabulations while enhancing maximum utilization of the data. This form of data dissemination is quite popular with researchers, who mainly utilize these data to write articles for publication in academic and professional journals.

However, since the data collection agency has no control over how the data will be used, all personal identifiers must be removed from the data before dissemination in order to avoid unintentional disclosure. For example, for users who want to produce their own tabulations and analyses, the Australian Bureau of Statistics makes available files containing unidentified records from the 1993 Disability, Ageing and Carers Survey. [14] To protect the confidentiality of individual persons and families, some data may not be released if few items are contributing to data cells.

4. *Providing on-line dissemination and computer access to the data*

Sometimes analysts gain direct access to data stored in computers via remote access terminals. Permission is required to access the data, and passwords or other similar security measures are needed to exclude unauthorized users from gaining access to the data. On-line dissemination generally requires the existence of a carefully developed and fully documented database, whereby the location and identity of each piece of information in the system is ascertainable.

An emerging development is the use of the Internet and the World Wide Web for on-line dissemination of information, including statistical information.[15] Given the wide range of users, the Internet is ideal for publicizing highlights of studies, including percentages and charts, as well as abstracts of publications with data on disability. The Internet offers great potential for the presentation of information on disability in accessible formats for persons with disabilities. When data are disseminated on the Internet, information on methods used, such as questions, definitions and population coverage, must be made available in order to aid interpretation of the data provided. It is also important for the Internet site to provide the name of the person(s) to be contacted for further information.

In addition to the dissemination of data, the Internet may also be used for other forms of communication with users, including on-line orders for publications and requests for any additional data not posted on the site.

The United Nations Statistics Division maintains an Internet web site that contains global statistics and indicators on various topics as well as information on the major publications of the Division. It also includes a specific site on disability. This web site, Disability Statistics, is a statistical reference and guide to sources of national disability data.[16] It also contains basic disability prevalence rates and the guidelines used to identify persons with disability.

D. INDICATORS

Statistical indicators are an important tool for countries in their policy-making process because they permit an assessment of the prevailing situation, as well as the

quantification of specific policy objectives.[17] Many types of indicators can be produced from data on persons with disabilities. These can be clustered in three main categories ranging from the simple to the more complex, including (a) those that measure the presence of disability in the population; (b) those that measure the extent to which persons with disabilities experience equal opportunities within a society; and (c) those that measure health expectancy and quality of life by integrating mortality and disability information. For additional information on disability indicators see *Manual for the Development of Statistical Information for Disability Programmes and Policies*. [18]

Again, when interpreting statistical indicators on disability, the issue of how disability was defined and measured during data collection is an important consideration. It is important to describe in detail in published material the measurement instrument used, including the wording of questions . In addition, instruction should be provided on the survey that yielded the data-sample frame used (especially concerning the inclusion of the population in health-related institutions) as well as the type of survey and response rate. Furthermore, it is important for all indicators to be presented in as non-judgemental a manner as possible and for the wording to be carefully considered to avoid the erroneous implication that persons with disabilities are of lesser worth.[19]

1. Indicators that measure the presence of disability

Indicators on the presence of disability are generally derived from data on the distribution of the population by disability status and also by type of disability for various demographic characteristics. This information is important not only to show the prevalence of disability in the population, but also for planning community-based rehabilitation (CBR) programmes. From this information indicators can be prepared on the following:

(a)   The number of persons with disabilities by type of disability, according to age and sex, and area of residence (urban and rural areas);

(b)   The prevalence of disability per 100 or 1,000 population (males, females and total population, as well as for urban and rural areas);

(c)   The age-sex pyramid of disability, based upon the number of males and females in each age group, by area of residence (urban and rural areas);

(d)   The sex ratio of persons with disabilities, or the ratio of males with disabilities to females with disabilities, by age and area of residence (urban and rural areas).

For the third monitoring of progress towards Health for All issued at the global level, the World Health Organization, in collaboration with the United Nations Statistics Division, recommended that the following types of disabilities should be identified for inclusion:[20]

(a)   Seeing

    (b)   Hearing
    (c)   Speaking
    (d)   Moving
    (e)   Learning/comprehending
    (f)   Other (to be specified)

For the assessment of progress towards the aims of the World Summit for Children, the United Nations Children's Fund (UNICEF) has developed the following indicator:[21]

The total child disability rate is represented by the proportion of children aged less than 15 years with some reported physical or mental disability.

2. Indicators that measure the equalization of opportunities

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities provide a framework for producing indicators to measure the extent to which persons with disability experience equal opportunities within their society. All aspects of daily living within a society, including education, employment, and income maintenance and social security, are target areas for equal participation.[22] Similarly, the ICF-2 includes in the participation dimension categories of life situations to be used to assess whether an individual is being engaged in an area of life, being accepted, or having access to needed resources. The following areas of life are included:

    (a)   Learning and applying knowledge;
    (b)   General tasks and demands;
    (c)   Communication;
    (d)   Mobility;
    (e)   Self-care;
    (f)   Domestic life;
    (g)   Interpersonal interactions and relationships;
    (h)   Major life areas;
    (i)   Community, social and civic life.

In most studies, comparisons between persons with and without disabilities have been based on traditional socio-economic characteristics such as education and employment. An indicator to measure the equalization of educational opportunity, for example, could be produced from the "level of education" variable. Similarly, an indicator of employment equalization could be produced from the "employment status" variable. In more specific terms, the level of education and the employment status variables should be tabulated by disability status (persons with disabilities and persons without disabilities) and, within disability status, by age group, gender and geographical location. The resulting tabulation would then be reviewed to determine if there are any significant differences in education level or employment status between the population with disabilities and persons without disabilities within each age group, gender and geographical location.

Similar calculations could be done using other socio-economic variables for which data were collected, and the results assessed to see the extent to which persons with disabilities have the same opportunities as those without.

3. Disability-free life expectancy

The summary measures of population health represent another group of indicators that have gained prominence during the last three decades. These aim at measuring years of healthy life. Interest in indicators to measure health expectancy and quality of life relates to the impact of improvements in life expectancy on the quality of (healthy) life. For example, has the increase in average life expectancy been accompanied by an increase in the time lived without disability and time lived without chronic disease? To answer this and other similar questions, disability-free life expectancy (DFLE) and other indicators on health expectancy were developed. In this section only disability-free life expectancy is considered because it is the most common of health expectancy indicators and is perhaps the most easily compiled indicator, given the data available in most countries.

(a) General information on DFLE

Disability-free life expectancy (DFLE) is a summary measure of the average number of years lived without disability by a population. This indicator is derived form mortality and disability information using life table techniques.[23] As a health indicator, DFLE presents the average number of years lived without disability by a population if current conditions of mortality and disability remain unchanged.[24] In 1985, it was proposed as an optional regional indicator that could be used to monitor progress towards targets for Health for All by the Year 2000 in Europe.[25]

Disability-free life expectancy can be calculated either by the Sullivan method from disability prevalence rates by age, derived from cross-sectional surveys, or with more advanced calculation methods, such as the double decrement life table method or the multistate life table method. The latter two methods use information on transition rates between different disability states, derived from longitudinal studies. As data from longitudinal studies are often not available, the Sullivan method is the method most commonly used.

(b) Calculation procedure

The Sullivan method involves taking the number of survivors *(b)* in a life table and then calculating the number of years of life between each age *(c)*. The number of years lived with a disability *(e)* is calculated by multiplying *(c)* and *(d)*. By deducting the years lived with a disability from the number of years lived between each age *(c)*, the number of active years (without a disability) is obtained *(f)*. The cumulative total of these years is then computed from any given age *x (a)* and divided by the total number of survivors at that age *(b)* to obtain active life expectancy at age *x (g)*. In the illustration

provided, the total number of years without a disability from age 65 upwards is 1,087,653. This total is divided by the number of survivors aged 65 to estimate DFLE at age 65; 1,087,653 divided by 100,000 (*b*) gives 10.9 years *(g)*.

TABLE 7. ILLUSTRATION OF THE CALCULATION OF DISABILITY-FREE LIFE EXPECTANCY D (DFLE) BY THE SULLIVAN METHOD

Age x	Survivors Sx	Years of life between x and x+a	Prevalence of disability between x and x+a [a]	Years of disability between x and x+a	Years without disability between x and x+a	DFLE from x
(a)	*(b)*	*(c)*	*(d)*	*(e)*	*(f)*	*(g)*
65	100 000	463 715	0.078	36 170	427 545	10.9
70	85 486	376 533	0.137	51 585	324 948	7.7
75	65 127	266 085	0.243	64 659	201 426	5.1
80	41 307	147 690	0.310	45 784	101 906	3.2
85	17 769	59 025	0.615	36 300	22 725	1.8
90	5 841	19 043	0.522	9 940	9 103	1.6

Source: Prepared by Lawrence Haber for the United Nations Statistics Division, based on a paper by L. D. Haber and J. E. Dowd "A human development agenda for disability: Statistical Considerations" (1964).

[a] N. Brouard and J. M. Robine, "A method for calculation of health expectancy applied to longitudinal surveys of the elderly in France" in Jealth Expectancy, J. M. robine and others, eds., OPCS, London, 1992.

Table 8 gives an overview of disability-free life expectancies for 36 countries calculated by using the Sullivan method. In addition to information on DFLE, this table also includes an indicator of relative longevity, the ratio of disability-free life expectancy to total life expectancy (DFLE/LE). This ratio allows comparisons across countries where life expectancies differ substantially and over ages within a country. The increase, decrease or stability of this ratio across ages and between males and females gives a picture of the differential development and maintenance of disability between sexes at different ages. When tracked over time, this ratio provides an answer to the question, "Are we living longer but living more disabled?" in those countries where life expectancy is increasing. This means that disability studies must be carried out over time using the same questionnaires and protocols. However, it should be noted that cross-national comparisons of DFLEs should be interpreted with the same degree of caution as the comparisons of disability prevalence rates. The user must remember that there are great differences across countries in the instruments used to measure disability and that this significantly affects the measured prevalence rates.

TABLE 8: LIFE EXPECTANCY (LE), DISABILITY-FREE LIFE EXPECTANCY (DFLE)
AND RATIO OF DFLE/LE

	Year of survey	Age	Gender	Life Expectancy (years)	Disability Free life Expectancy (years)	Expected Years disability	Ratio DFLE/LE
Australia	All Disabilities 1988	Birth	Male	73.1	58.4	14.7	84
			Female	79.5	63.4	16.1	80
	Severe Impairments 1981	Birth	Male	73.1	69.9	3.2	96
			Female	79.5	73.4	6.1	92
Austria	1986	Birth	Both sexes	74.6	62.8	11.8	84
Bahrain[a/]	1981	Birth	Male	64.7	62.9	1.8	97
			Female	67.8	66	1.8	97
Botswana	1991	Birth	Both sexes	59.8	56.4	3.4	94
Brazil	1986	15 years	Both sexes	52.9	51	1.9	96
Bulgaria[a/]	1990	Birth	Both Sexes	58.2	36.3	21.4	63
			Male	54.7	35.4	19.3	65
			Female	61.3	38.1	23.2	62
Canada	1986	Birth	Both Sexes	76.4	63.7	12.7	83
			Male	73	61.3	11.7	84
			Female	79.8	64.9	14.9	81
China	1987	Birth	Male	66.4	61.6	4.8	93
			Female	70	61.4	8.6	92
Cuba	1981	20 years	Both Sexes	60.3	59.2	1.1	98
			Male	59	52.3	6.7	89
			Female	61.9	61.3	0.6	99
Egypt[a/]	1976	Birth	Male	53.1	52.8	0.3	99
			Female	55.9	55.8	0.1	100
Finland	1986	15 years	Both sexes	60.4	48	12.4	79
			Male	56.3	47.1	9.2	84

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			Female	64.4	48.8	15.6	76
TABLE 8 (*CONTINUED*)							
France	1982	Birth	Male	70.7	61.9	8.8	88
			Female	78.9	67.1	11.8	85
Germany	1991	Birth	Both sexes	75.7	68.9	6.8	91
			Male	72.2	64.5	7.7	89
			Female	78.9	72.9	6.0	92
Hungary	1988	15 years	Both sexes	56.5	54.4	2.1	96
Indonesia[a/]	1977	Birth	Male	51.8	47.5	4.3	92
			Female	54.8	50.3	4.5	92
Ireland	1981	15 years	Both Sexes	58.9	56.5	2.4	96
			Male	56.3	53.5	2.8	95
			Female	61.7	59.9	1.8	97
Japan	1987	Birth	Both sexes	79.1	76.9	2.2	97
Kuwait	1980	Birth	Both Sexes	69.5	68.9	0.6	99
			Male	67.8	67	0.8	99
			Female	72	71.4	0.6	99
Mali[a/]	1976	Birth	Male	48.6	45.7	2.9	94
			Female	52.2	48.9	3.3	94
Mauritius	1990	Birth	Male	65.5	62.0	3.5	95
			Female	73.3	67.9	5.4	95
Netherlands	1986	15 years	Both sexes	62.3	51.8	10.5	83
			Male	59	51.2	7.8	87
			Female	65.6	52.3	13.3	80
Netherlands[a/]	1990	Birth	Male	73.9	60.4	13.5	82
			Female	80.1	59.9	20.2	75
New Zealand	1980	15 years	Both sexes	59	49.8	9.2	84
Norway	1991	15 years	Both sexes	62.9	49.2	13.7	78
			Male	59.8	50	9.8	84
			Female	66	48.4	17.6	73
Pakistan[a/]	1981	Birth	Male	60.2	59.8	0.4	99
			Female	59.9	59.3	0.6	99

Chapter IV. Dissemination and use of disability data

				TABLE 8 (*CONTINUED*)			
Poland	1988	Birth	Both sexes	71.4	62.6	8.8	88
			Male	67.1	59.8	7.3	89
			Female	75.7	62.6	13.1	83
Portugal	1981	15 years	Both sexes	58.9	55.4	3.5	95
			Male	55.5	52.5	3.0	95
			Female	62.3	58.6	3.7	95
Singapore	1985	Birth	Both sexes	72.8	72.5	0.3	99
Spain	1986	Birth	Both sexes	76.7	62.7	14.0	82
			Male	73.2	61.6	11.6	84
			Female	79.6	63.6	16.0	80
Sweden[a]	1987	16 years	Male	57.9	45.1	12.8	78
			Female	62.1	45.1	17.0	73
Switzerland[a]	1988-89	Birth	Male	74	67.1	6.9	91
			Female	80.9	72.9	8.0	90
Taiwan[a] Province of China	1989	Birth	Male	57.6	44.4	13.2	77
			Female	62.9	52	10.9	83
Thailand[a]	1981	Birth	Male	64.3	63.5	0.8	10
			Female	71.3	70.6	0.7	99
Trinidad & Tobago[a]	1980	15 years	Both sexes	55.1	55	0.1	99
			Male	54.1	53.2	0.9	98
			Female	57.5	56.8	0.7	99
United Kingdom of Great & Northern Ireland	1986	Birth	Both sexes	74.9	65.2	9.7	87
			Male	71.9	63.9	8.0	89
			Female	77.8	66.1	11.7	85
United Kingdom[a]	1988	Birth	Male	72.4	58.5	13.9	81
			Female	78.1	61.2	16.9	78
United States of America	1985	Birth	Male	71.2	51.9	19.3	73
			Female	78.2	57.9	20.3	74
United States of	1990	15 years	Both sexes	61.5	42.8	18.7	70

Chapter IV. Dissemination and use of disability data

America						
		TABLE 8 (*CONTINUED*)				
Venezuela	1981	Both sexes	58.2	53.8	4.4	92
		Male	55.9	44.6	15.5	72
		Female	60.7	58.1	2.6	96

Sources: Life tables mortality data-bank file, <u>World Health Statistics Annual</u> (World Health Organization, 1993). Disability prevalence rates are from the United Nations Disability Statistics Database (DISTAT).
[a/] Values of LE, DFLE and Radio of DFLE/LE are from REVES 1993.

The Sullivan method shows prevalence and not incidence of disability. Use of this method does not tell us anything about the probabilities of entrance into disability at each age in a given year or for the population without disabilities at the outset. This information is especially useful in countries where the number of aged and very aged persons is rising. Precise evaluation of entrance into disability probabilities (disability-free survival probabilities) will be indispensable for the future needs of health services. [26] Such information can be obtained through a longitudinal study lasting at least one year.

By employing period (current) prevalence rates to calculate health expectancy, this method assumes that these disability rates remain unchanged over the entire life of the hypothetical cohorts. This method also assumes that persons who become disabled remain disabled for life. In reality, however, this is not the case, since not all disabilities are permanent. Also, the prevalence rates used in the Sullivan method reflect, in part, the past health experience of each age cohort, and not just the current incidence rates. For example, in certain countries some of the disabilities among the elderly today might be the result of events that occurred during the distant past, such as during World War II. The rates of disability for these elderly persons would be included in the rates used for the calculation of disability-free life expectancy at birth for the current year. Clearly, there is no reason to expect that a baby born today will have similar war-related disabilities during old age. Consequently, it has been argued that this method is not suitable for projections into the future and for comparisons over time. [27] However, simulation studies have shown that the Sullivan method provides a good estimate of the "true" period value if the disability incidence rate is changing relatively slowly over time, as is usually the case, except during time of war or other major catastrophes.[28]

Sometimes disability rates are available only from surveys that exclude people living in institutions, such as nursing homes. Because a substantial part of the institutionalized population may be impaired, disabled or have a handicap, disability prevalence rates will be underestimated if they are based only on data from household surveys. Therefore, it is necessary to adjust these rates for the proportion of the population that lives in institutions. It is usual to assume that persons living in health-related institutions are all disabled, impaired or have a handicap.

Lastly, it should be mentioned that use of the term "Disability-Free Life Expectancy" has been criticized as being insensitive because the term suggests that disability is a bad thing, and that health and disability are mutually exclusive.

NOTES

1 *Manual for the Development of Statistical Information for Disability Programmes and Policies* (United Nations publication, Sales No. E.96.XVII.4).

2. F. McGlone F. and L. Clarke "Disability and carers: the information needs of non-specialist policy users and service providers, in *Disability and Care: Questions and Needs Considered* (London, Office for National Statistics).

3. *Report of the International Workshop on the Development and Dissemination of Statistics on Persons with Disabilities,* 13-16, October, 1992 (Ottawa, Statistics Canada; United Nations Statistical Division).

[4] *Official Records of the General Assembly, Forty-eighth Session, Supplement No. 49 (A/48/49)*, General Assembly, General Assembly Resolution 48/96 of 20 December 1993.

[5] *Development of Statistical Concepts and Methods on Disability for Household Surveys* (United Nations publication, Sales No. E.88.XVII.4).

[6] *Principles and recommendations for Population and Housing Censuses, Revision 1 (*United Nations publication, Sales No. E.98.XVII.8).

[7] *Handbook of Household Surveys, Revised Edition*, Statistical papers, series F, Studies in methods No. 31 (United Nations publication, Sales No. E.83.XVII.13).

[8] *Health and Activity Limitation Survey*, Special Topic Series, vol. 1, Barriers confronting seniors with disabilities in Canada (Ottawa, Statistics Canada, Catalogue No. 82-615, 1990).

[9] Ibid, vol. 2, Selected socioeconomic consequences of disability for women in Canada.

[10] Ibid., vol. 3, Blindness and visual impairment in Canada.

[11] Ibid., vol. 4, Leisure and lifestyles of persons with disabilities in Canada (1991).

[12] Ibid., vol.5, Canadians with impaired hearing (1992).

[13] *Health and Activity Limitation Survey—1991 User=s Guide* (Ottawa, Statistics Canada, 1991), p. 48.

[14] *Survey of Disability, Ageing and Carers, 1993* (Canberra, Australian Bureau of Statistics, data reference package, Catalogue No. 4432.0).

[15] *Principles and Recommendations for Population and Housing Censuses, Revision 1* (United Nations publication, Sales No. E.98.XVII.8).

[16] The United Nations Statistics Division web site on disability statistics is at **http://esa.un.org/unsd/disability**.

[17] Report of the Secretary-General on integrated and coordinated implementation and follow-up of major United Nations conferences and summits: a critical review of the development of indicators in the context of conference follow-up (E/1999/11).

[18] *Manual for the Development of Statistical Information for disability Programmes and Policies* (United Nations publication, Sales No. E.96.XVII.4).

[19] Ibid.

[20] Implementation of Strategies for Health for All by the Year 2000, Third monitoring of Progress: Common Framework (CFM3) (Geneva, World Health Organization, 1993, WHO/HST/GSP/93.3).

[21] United Nations Children's Fund, End-decade assessment – indicators for assessing progress globally, executive directive (CF/EXD/1999-03).

[22] For a complete description of the target areas within the Standard Rules, the reader should consult The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations publication, Sales No. E.DPI/1454).

[23] Jean-Marie Robine and Isabelle Romieu "Healthy active ageing: health expectancies at age 65 in the different parts of the world" (REVES, paper No. 318, 1998).

[24] A subcommittee on conceptual harmonization for the international network on health expectancy, REVES (Reseau Esperance de Vie en Santé), recommended that health expectancies should, when appropriate, be differentiated according to the ICDH into impairment-free, disability-free and handicap-free. They also recommended that DFLE should be differentiated into functional limitation-free and activity restriction-free life expectancies. (Functional limitations are the specific reductions in body functions, such as seeing, hearing or climbing stairs, while activity restrictions are specific reductions in daily activities, such as dressing, bathing or using the phone. Both are described at the level of the person, in contrast to impairments, which are described at the level of an organ or organ system).

[25] Targets for Health for All: Targets in Support of the European Regional Strategy for Health for All by the Year 2000, European Health for All, WHO Regional Office for Europe Series, No. 4 (Geneva, World Health Organization, 1985).

[26] A. Colvez, "Minimum set of indicators for monitoring progress towards health: the area of disability in health interview surveys". Institut National de la Santé et de la Recherche Médicale (INSERM), U.164.

[27] N. Brouard and J. M. Robine "A method for calculation of health expectancy applied to longitudinal surveys of the elderly in France", in *Health Expectancy,* J. M. Robine and others, eds.(OPCS London, 1992).

[28] Mathers C. and Robine J.M. (1993*)* Measuring compression or expansion of morbidity through changes in health expectancy, in Calculation of Health Expectancies: Harmonization, Consensus Achieved and Future Perspectives, J. M. Robine and others, eds., (Paris, INSERM, and London, John Libbey Eurotext Ltd., 1993).

ANNEX I

ICF QUALIFIERS

All the codes in the ICF are written in neutral language and are only complete with the presence of a "qualifier" that denotes the magnitude or extent of the functioning or disability in that category. Without the qualifiers the codes are meaningless. Qualifiers are coded as one, two or more numbers after a decimal point that follows the letter denoting component and the numbers referring to domain. There are two types of qualifiers: (a) the first qualifier, also known as the "generic qualifier", which can be used for the ICF components, and (b) the second qualifier which can be used to obtain additional information for some of the components. For example, "capacity" can be used as a second qualifier in conjunction with the Activity and Participation component.

According to the generic qualifier, the ICF components, Body Functions and Structures, Activity and Participation, and Environmental Factors, are coded in the same manner. Appropriate quantifying words as shown in brackets below should be chosen according to the relevant classification component. Having a problem may mean an impairment, limitation, restriction or barrier depending on the component.

xxx.0	NO problem	(none, absent, negligible...)	0 - 4 %
xxx.1	MILD problem	(slight, low...)	5 - 24 %
xxx.2	MODERATE problem	(medium, fair...)	25 - 49 %
xxx.3	SEVERE problem	(high, extreme...)	50 - 95 %
xxx.4	COMPLETE problem	(total...)	96 -100 %
xxx.8	not specified		
xxx.9	not applicable		

In the case of Environmental Factors, the first qualifier indicates the extent to which a factor is a facilitator or a barrier. The decimal point indicates a barrier; for facilitators, a plus sign is used instead of the decimal point. For example, a code of *e125.2* denotes moderate unavailability of products for communication, while *e125+2* means moderate availability of these products.

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ANNEX TABLE I.1. ICF COMPONENTS, QUALIFIERS AND SELECTED EXAMPLES FOR FIRST AND SECOND QUALIFIERS [a/]

Component	First qualifier	Second qualifier
Body Functions (b)	Generic qualifier with the negative scale used to indicate the extent or magnitude of an impairment Example: b168.3 to indicate a severe impairment in specific mental functions of language	None
Body Structure (s)	Generic qualifier with the negative scale used to indicate the extent or magnitude of an impairment Example: s730.3 to indicate a severe impairment of the upper extremity	Used to indicate the nature of the change in the respective body structure 0 no change in structure 1 total absence 2 partial absence 3 additional part 4 aberrant dimensions 5 discontinuity 6 deviating position 7 qualitative changes in structure, including accumulation of fluid 8 not specified 9 not applicable Example: s7300.32 to indicate the partial absence of the upper extremity.

ANNEX TABLE I.1. (*Continued*)

Component	*First qualifier*	*Second qualifier*
Activity and Participation (d)	PERFORMANCE	CAPACITY
	Generic qualifier	Generic qualifier
	Problem **in the person's current environment**	Limitation **without assistance**
	Example: d5101.1 to indicate mild difficulty with bathing the whole body with the use of assistive devices that are available to the person in his or her current environment.	Example: d5101.2 to indicate moderate difficulty with bathing the whole body and implies that there is moderate difficulty without the use of assistive devices or personal help.
Environmental Factors (e)	Generic qualifier, with negative and positive scale to denote extent of barriers and facilitators respectively	None
	Example: e130.2 to indicate that products for education are a moderate barrier. Conversely, e130+2 would indicate that products for education are a moderate facilitator.	

Source: *International Classification of Functioning, Disability and Health–ICF*, Final Draft, Full Version (Geneva, World Health Organization, 2001).

a/ Code in example refers to component (letter), domain (numbers before decimal point), and qualifier (digit[s] after decimal point).

ANNEX II

**QUESTIONS FOR IDENTIFYING DISABILITY AMONG CHILDREN:
EXAMPLES FROM NATIONAL SURVEYS**

A. STATISTICS NEW ZEALAND 1996 HOUSEHOLD DISABILITY SURVEY

1. Is .... blind or does .... have trouble with her/his eyesight, which is not corrected by glasses or contact lenses?

2. Is .... deaf or does .... have trouble hearing, which is not currently corrected?

3. Because of a long-term condition or health problem, does .... have any trouble speaking and being understood?

4. Does .... use any of the following equipment:

(a) A special buggy or a trolley?

(b) A standing frame?

(c) Any kind of braces, other than braces for teeth?

(d) A wheelchair?

(e) Crutches, walking sticks, a walking frame or any other kind of walking aid?

(f) An artificial leg, arm, hand or foot?

5. Does .... use any other kind of equipment because of a condition or a health problem that has lasted or is expected to last for 6 months or more? Don't count asthma inhalers, braces for teeth or grommets.

6. Does .... have any long-term emotional, behavioural, psychological, nervous or mental health condition, which limits the kind or amount of activity that she/he can do at home, at school or at play?

7. Does .... have a long-term lung condition or disease that limits his/her activities?

8. Does .... have a long-term heart condition or disease that limits his/her activities?

9.   A kidney condition or disease that limits his/her activities?

10. Cancer?

11.   Epilepsy?

12.   Cerebral palsy?

13.   A chronic gastrointestinal condition which is long-term?

14.   Growth-failure or failure to thrive?

15.   An intellectual disability or handicap, or an intellectual development delay?

16.   A learning disability?

17.   Does .... have any other condition or health problem that you haven't already told me about, which limits what she/he can do at school, at play or in any other activity that children her/his age can usually do?

18.   Does .... attend a special school or a special unit or class at a regular school?

19.   Because of learning or developmental difficulties, does .... have any Individual Education Plan (IEP), Individual Development Plan (IDP) or an individualized programme?

B. UNITED KINGDOM OF GREAT BRITAIN AND NORTHERN IRELAND 1985-1988 OFFICE OF POPULATION CENSUSES AND SURVEYS (OPCS) SURVEYS OF DISABILITY IN GREAT BRITAIN

Is there any child in your household …

(a)   who is unable to do things, which most children of the same age can do, because of a health, development or behaviour problem?

(b)   who needs more help than usual for children of the same age with feeding, dressing, toileting, walking, going up and down stairs or other daily activities?

(c)   who attends a special school, or special or remedial unit of an ordinary school, because of health or behaviour problems, disabilities or learning difficulties?

(d)   who attends an ordinary school but is limited in taking part in school activities because of health or behaviour problems or disabilities?

(e)   whose health, behaviour or development causes worry that he or she may have a long-term health problem, physical or mental disability or handicap?

C. UNITED STATES OF AMERICA , NATIONAL CENTER FOR HEALTH STATISTICS, 1994 NATIONAL HEALTH INTERVIEW SURVEY

1.   Do you think that *{names of persons under 18}* have any significant problems or delays in physical development?

2.   Do *{names of persons under 18}* NOW have a physical, mental, or emotional problem for which they regularly take prescription medication?

3.   Has *{names of persons under 18}* ever been a patient in a hospital overnight for a physical, mental, or emotional condition that they STILL HAVE or GET FROM TIME TO TIME?

4.   Do you think that *{names of persons 1-17 years old}* NOW have any problems or delays in understanding things, that is, delays in cognitive or mental development?

5.   Do you think that *{names of persons 1-17 years old}* NOW have any problems or delays in speech or language development?

6.   Do you think that *{names of children 1 - 17 years old}* have any problems or delays in emotional or behavioral development?

7.   Because of a physical, mental, or emotional problem, do *{names of children 2-17 years old}* NOW have any difficulty participating in strenuous activity (such as running or swimming) compared to other children their age?

8.   Because of a physical, mental, or emotional problem, do *{names of children 2-17 years old}* NOW have any difficulty playing or getting along with others their age?

9.   Do *{names of persons under age 5}* NOW have any (physical, mental, or emotional) problem, which makes it difficult to chew, swallow, or digest?

10.   Do *{names of persons under age 5}* NOW need special medical equipment to assist with eating or toileting?

D. TEN QUESTIONS FOR SCREENING SERIOUS CHILDHOOD DISABILITY

1. Compared with other children, did the child have 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)?
9. 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)?"
9a. 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?

M. S. Durkin, and others The Validity of the ten questions screen for childhood disability: results from population-based studies in Bangladesh, Jamaica and Pakistan. *Epidemiology*, Vol. 5, No. 3 (1994).

ANNEX III
INSTRUMENTS FOR MEASURING COGNITIVE AND PSYCHOLOGICAL FUNCTIONING

The instruments contained in this annex were compiled as part of an effort by Statistics Netherlands and the World Health Organization Regional Office for Europe to organize a series of international consultations to develop common methods and instruments for health interview surveys. Instruments are presented for the following major chronic cognitive and psychological: dementia, mental retardation, and mental disorders. An additional instrument is included to identify mental health problems among children.

A. ASSESSMENT OF DEMENTIA[1]

The test is introduced as follows:

We would like to know the opinion of older people on a number of questions and investigate the performance of a few simple tasks. From time to time, everyone has trouble remembering the name of a familiar person, or learning something new, or they experience moments of confusion. However, do you have any ongoing problems with your ability to remember or learn? (Yes/No) I should like to ask you some questions on this subject.

1. The measurement of Temporal Orientation

The interviewer then asks the following three questions and scores the responses as indicated below.

1. Can you tell me today's date? (The subject is required to give day, month and year)

2. Can you tell me what day of the week it is?

3. Please, do not look at your watch. Can you tell me what time it is now? (Interviewer makes sure that subject cannot look at watch or clock)

    Scoring

  Day of week: 1 point for each day removed from correct day, to a maximum of 3 points.
Day of month: 1 point for each day removed from correct day, to a maximum of 15 points.
      Month: 5 points for each month removed from correct month, to a maximum of 30 points (with qualification that if stated date is within 15 days of correct date, no points are added for incorrect month, e.g., 29 May for 2 June is four points).

Year: 10 points for each year removed from correct year to a maximum of 60 points (with qualification that if stated date is within 15 days of correct date, no points are added for incorrect year, e.g. 26 December 1992 for 2 January 1993 is seven points).

Time of day: 1 point for each 30 minutes removed from correct time to a maximum of 5 points.

Score 0:   perfect temporal orientation
Score 1-3:   normal orientation
Score ∃ 4:   inferior orientation

2. *The controlled Oral Word Association test*

This test is introduced as follows:

I want to see how many words you can say beginning with a certain letter in one minute. Don't say proper names or numbers or the same word with a different ending. The letter is F; you can begin.

If subjects have difficulty in understanding the task, it can be explained with examples, using a non-designated letter. After the first (F) trial has been completed, the A and S trials are administered. The interviewer keeps record of the subject's verbal responses.

Scoring

The total number of correct words during the three one-minute trials is recorded, constituting a raw score, which is adjusted for educational level, sex and age. A corrected score of 22 or less is classified as defective (this performance level is exceeded by 97% of normal subjects). When this test is administered in a language other than English, the adjustment formula and cut-off point should be used with caution. Ideally, comparable normative data should be developed for other (non-English) languages.

TABLE A.III.1. ADJUSTMENT FORMULA FOR EDUCATION, SEX AND AGE, CONTROLLED ORAL WORLD ASSOCIATION TEST

Years of schooling	Males		Females	
	55-59 years	60-64 years	55-59 years	60-64 years
9 or less	+15	+17	+10	+12
9-11	+7	+9	+7	+9
12-15	+5	+7	+5	+7
16+	+1	+3	+1	+3

Source: A. de Bruin, H. S. V. Picavet and A. Nossikov, *Health Interview and Surveys: Towards International Harmonization of Methods and Instruments,* WHO Regional Publications, European Series, No. 58 (Copenhagen, World Health Organization Publication, regional Office for Europe, 1996),

3. The Benton Visual Retention Test

This test is recommended as a measure of visual perception and short-term visual memory for design. The test consists of 15 designs. Each is shown for 10 seconds and immediately afterwards the subject has to select it from a group of four. Scores (number correct) range from 0 to 15. For all different forms, norm tables exist. Abnormal scores range from lower than 6 (for children 7 years of age) to lower than ten (for adults).

For official manual and copyright information, please contact: The Psychological Corporation, 555 Academic Court, San Antonio, Texas, 78204, Attn: Customer Care; or visit their web site at http://www.psychcorp.com.

To screen for dementia from a proxy informant the following questions should be asked:

1. Does the subject usually know today's date? (Yes/No)
2. Does the subject usually know what day of the week it is? (Yes/No)
3. Does the subject have problems with his or her memory? (Yes/No)

If yes, does the subject forget after a few minutes things that should have been remembered? (Yes/No)

4. Is the subject capable of taking care of himself or herself completely? (Yes/No)

If any of the answers to questions 1, 2 or 4 is ANo≅ or if the answer to question 3 is AYes≅ the following question should be asked:

5.   Has a health professional ever given a diagnosis of dementia or Alzheimer's disease? (Yes/No)

If the answer to question 5 is AYes≅ a diagnosis of dementia can be established. If the answer is "No" it is only possible to give a diagnosis of probable dementia.

B. MENTAL RETARDATION

Mental retardation should be assessed only in persons with lower education levels (at or below primary school level) and younger than 55 years of ages. Persons with higher education are not supposed to be mentally retarded, and those 55 and older are not questioned to avoid confusion with a diagnosis for dementia.

1. Screening

The following screening question may be asked prior to formal assessment for mental retardation:

1.   Did you finish school? (Yes/No)
2.   How are (were) your grades in school? (Good/Poor)
3.   Have you had to repeat a term or year (i.e., remain in the same class) more than once at school? (Yes/No)
4.   Has a school or health professional ever told you that you have (had) a learning disability? (Yes/No)

If the answer to question 1 is ANo≅, or the answer to question 2 is APoor≅, or the answer to question 3 is AYes≅, or the answer to question 4 is AYes≅, then the person should be given the detailed mental retardation test.

2. Instrument: Mini-Mental State Examination

The Mini-Mental State Examination is recommended for the assessment of mental retardation for persons aged 14-55 years.

Scoring

The interviewer scores each item as correct or incorrect. Refusals to answer specific items or "don't knows" are scored as incorrect. The number of correct answers is summed. There

is a range of 0-30 points. Subjects with a score of 17 or less are considered to be mentally retarded.

The Mini-mental State Examination

Orientation		(Points)
1. What is the	Year?	(1)
	Season?	(1)
	Date?	(1)
	Day?	(1)
	Month?	(1)
2. Where are we?	State?	(1)
	Country?	(1)
	Town or city?	(1)
	Hospital?/This address?	(1)
	Floor?	(1)

Registration
3. Name three objects (apple, table, coin), taking one second to say each.
Then ask the subject all three after you have said them. Give one point for
each correct answer. Repeat the answers until the patient learns all three.   (3)

Attention and calculation
4. Serial events. Give one point for each correct answer.
    Stop after five answers.
    Alternative: spell WORLD backwards.   (5)

Recall
5. Ask for names of three objects learned in Question 3.
    Give one point for each correct answer   (3)

Language
6. Point to a pencil and a watch.
    Ask the subject to name them as you point.   (2)

7. Ask the subject to repeat "Not ifs, and or buts"   (1)

8. Ask the subject to follow a three-stage command:
    "Take a paper in your right hand.
    Fold the paper in half. Put the paper on the floor."   (3)

9. Ask the subject to read and obey the following:
    "'Close your eyes". (Write it in large letters).   (1)

10. Ask the subject to write a sentence of his or her choice.   (1)

11. Enlarge the design printed below to 3 cm per side,
      and have the patient copy it.   (1)

                    (Total = 30)

3. Proxy-informant questions

1.   What do you think about the intellectual faculties of the subject? (Good/Poor)
2.   Does he or she seem to understand everything? (Yes/No)
3.   Can he or she read, write and calculate?(Yes/No)

If the answer to question 1 is "Poor", or the answer to question 2 or question 3 is ANo≅, the following question should be asked.

4.   Has the subject ever been diagnosed as being mentally retarded? (Yes/No)

If the answer to question 4 is "Yes", a diagnosis of mental retardation can be made.

3.   MENTAL IMPAIRMENTS

Mental impairments include anxiety disorders, schizophrenia and affective (mood) disorders.

To screen for mental impairments the 12-item version of the General Health Questionnaire (GHQ) is recommended, followed by two additional screening questions to detect chronic mental conditions.[2] The GHQ is especially suited to detect affective (mood) disorders in population surveys. A concern about the GHQ is its suitability for surveys with chronic patients since the questions only deal with changes in the last few weeks. It is argued that subjects are likely to respond "no more than usual" to a number of negatively worded items. To compensate for this, the two additional questions should be asked as part of the screening.

Because the GHQ deals with thoughts and feelings, which in most cases are not known to anyone other than the subject, it has no proxy-informant version.

Guidelines and Principles for the Development of Disability Statistics

Annex III. Instruments for identifying chronic cognitive and psychological impairments

General Health Questionnaire - 12-item version				
Introduction: AWe would like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer ALL the questions simply by underlining the answer that you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you have had in the past.≅				
Have you recently:	Score 0	Score 0	Score 1	Score 1
1. Lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
2. Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Been able to concentrate on whatever you are doing?	Better than usual	Same as usual	Less than usual	Much less than usual
4. Felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
5. Been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able
6. Felt capable of making decisions about things?	More so than usual	Same as usual	Less capable than usual	Much less capable
7. Felt you couldn=t overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
8. Been feeling reasonably happy, all things considered?	More so than usual	About the same as usual	Less so than usual	Much less than usual
9. Been able to enjoy your normal day-to-day activities?	More so than usual	About the same as usual	Less so than usual	Much less than usual
10. Been feeling unhappy and depressed?	Not at all	Not more than usual	Rather more than usual	Much more than usual
11. Been losing confidence in yourself?	Not at all	Not more than usual	Rather more than usual	Much more than usual
12. Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual

Guidelines and Principles for the Development of Disability Statistics

Annex III. Instruments for identifying chronic cognitive and psychological impairments

Source: A. de Bruin, H. S. V. Picavet and A. Nossikov, *Health Interview and Surveys: Towards International Harmonization of Methods and Instruments,* WHO Regional Publications, European Series, No. 58 (Copenhagen, World Health Organization Publication, regional Office for Europe, 1996.

      Respondents with a GHQ-12 score of three or more are considered possible cases, and for those with a score of two or less the following additional questions should be asked:

    1.   Do you take any tablets or medicines for your nerves? (Yes/No)
    2.   Do you consider that you suffer from a nervous illness? (Yes/No)

      Psychosis screening questions need to cover symptoms, self-report, report of doctor's diagnosis, oral medication(s) taken and injections received. It is necessary to ask about all of these because there is a tendency towards denial. The following questions are recommended and should be answered "Yes", "Unsure" or "No". Any "Yes" answer at the last part of each question screens positive.

1.   Over the past year, have there been times when you felt very happy indeed without a break for days on end?
     (a) Was there an obvious reason for this?
     (b) Did your relatives or friends think it was strange or complain about it?

2.   Over the past year, have you ever felt that your thoughts were interfered with or controlled by some outside force or person?
     (a) Did this come about in a way that many people would find hard to believe, for instance, through telepathy?

3.   Over the past year, have there been times when you felt that people were against you?
     (a) Have there been times when you felt people were deliberately acting to harm you or your interests?
     (b) Have there been times when you felt that a group of people was plotting to cause you serious harm or injury?

4.   Over the past year, have there been times when you felt that something strange was going on?
     (a) Did you feel it was so strange that other people would find it very hard to believe?

5.   Over the past year, have there been times when you heard or saw things that other people couldn't?
     (a) Did you at any time hear voices saying quite a few words or sentences when there was no one around that might account for it?

D. MENTAL HEALTH AND SOCIAL DISABILITY

Research on the assessment of social disability associated with mental impairments is less evolved than that on either general impairments or mental impairments. This mainly results from a lack of appropriate guidelines for data collection and analysis and of a meaningful conceptual framework.[3] Consequently, many different techniques of data collection have been used, including statistics about the use of health services (usually a by-product of administrative or payment procedures) and administrative records of institutions (long-term care). Institutions can provide information on social disabilities, especially on the level of dependency.

A variety of instruments have been developed to asses social disabilities. The following, which is adapted from the 1991 Canadian Health and Activity Limitations Survey, (HALS), is an example of a screening question for social disabilities:

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...

(i) in the residence or institution?
(ii) in other activities outside the residence or institution such as travel, recreation or leisure?

An instrument for the assessment of long-term social disabilities, which was designed within the conceptual framework of the ICIDH, is the Groningen Social Disabilities Schedule (GSDS). The objective of the GSDS is to obtain information about a person's social functioning and subsequently to assess his or her disabilities in this context.[4] The GSDS was developed in the Department of Social Psychiatry of the University of Groningen, of the Netherlands in order to improve measurement of basic concepts of the ICIDH in psychiatric epidemiological research. From the literature on social role functioning, and from the results of psychometric analyses, eight social role areas appeared to be relevant for studying the social consequences of mental illness. These eight social fields provided a useful and reliable rating scale, and for every role a number of relevant behaviours (dimensions) were categorized. The relevant areas include the following:

The role of self-care (bodily care and hygiene, management of personal possessions);
The role in household (taking part in household activities);
Family role (relationships with the family of origin);
Role of partner (emotional ties, sexual role or relationship to partner);
Role of parent (contact with and interest in well-being of children);
Role of citizen (interest and participation in society or community);

Social role (social contacts and activities in leisure time);

Occupational role (role in profession or trade or regular daily activities).

Each of these areas is evaluated separately in the GSDS. Psychopathology is not taken into consideration since the instrument only intends to chart the consequences of mental impairments. For each role, disabilities are rated on a four-point scale, as follows: 0 for no disability; 1 for slight disability; 2 for clear disability; and 3 for severe or maximum disabilities.

The design of the instrument is such that information might be obtained from the person in question (subject) or from an informant since the GSDS deals with observable behaviour that can be noticed by a partner or other informant.

The GSDS is a rather complex instrument and training in interviewing is essential. The reference period is the four weeks prior to the interview, and the total time of interviewing is approximately 20 minutes (when all sections are covered). The GSDS is recommended for administration to persons aged 16 years or more because the assessment of social disabilities in children almost invariably means measuring psychopathology, i.e., personality and behavioural problems.

1. Measuring functioning as a result of mental impairments and disabilities

Apart from social disability, which is a critical consequence of mental impairments, other types of functional disabilities that may be a result of psychiatric disorders and need to be taken into account. These include unemployment (inability to work full time or not at all because of a psychiatric impairment), inability to manage household activities, and inability to manage financial affairs (financial dependency, receiving welfare assistance).

The following questions on some of these topics come from the OPCS Survey of Psychiatric Morbidity in Great Britain (1993):

Did a mental, nervous or emotional problem have anything to do with your leaving your last job?

If "Yes": Did your employer ask you to leave or did you leave on your own accord?

"Is the reason you are not working at present that....

The way you are feeling makes it impossible for you to do any kind of paid work?

 A physical problem makes it impossible for you to do any kind of paid work?

 You have not found a suitable paid job?

 Or because you do not want or need a paid job?"

Another way to investigate functional status resulting form people's mental impairments is to assess how they perceive themselves. The following five simple questions can be used to measure degree of stigma. In the OPCS Surveys of Disability in Great Britain (1985) these five questions were embedded in the Leeds scales for the self-assessment of anxiety and depression. The following questions, which focus on stigma, are rated in terms of "Yes, definitely", "Yes, sometimes", "No, not much" and "No, not at all".

1. I avoid other people these days;
2. I feel odd and different from other people;
3. I feel self-conscious and embarrassed;
4. I feel less attractive than I used to;
5. I feel that people are avoiding me these days;

E. AN INSTRUMENT FOR IDENTIFYING BEHAVIOURAL PROBLEMS AMONG CHILDREN[5]

The *Strengths and Difficulties Questionnaire* is used to screen for children's emotional and behavioural problems. It includes 25 items referring to different emotions or behaviours as well as a set of follow-up questions for children identified as having difficulties with their emotions, concentration, behaviour or relations with others. The questionnair eincludes several different formats. The following questions are taken from the questionnaire for children 4-16 years of age.

THE STRENGTHS AND DIFFICULTIES QUESTIONNAIRES

Please give your answers on the basis of your child's behaviour over the last six months.

		Not true	Somewhat true	Certainly true
a1	Considerate of other people's feelings			
a2	Restless, overactive, cannot stay still for long			
a3	Often complains of headaches, stomach aches or sickness			
a4	Shares readily with other children (treats, toys, pencils, etc.)			
a5	Often has temper tantrums or hot tempers			
a6	Rather solitary, tends to play alone			
a7	Generally obedient, usually does what adults request			
a8	Many worries, often seems worried			
a9	Helpful if someone is hurt, upset or feeling ill			
a10	Constantly fidgeting or squirming			
a11	Has at least one good friend			
a12	Often fights with other children or bullies them			
a13	Often unhappy, down-hearted or tearful			
a14	Generally liked by other children			
a15	Easily distracted, concentration wanders			
a16	Nervous or clingy in new situations, easily loses confidence			
a17	Kind to younger children			
a18	Often lies or cheats			
a19	Picked on or bullied by other children			
a20	Often volunteers to help others (parents, teachers, other children)			
a21	Thinks things out before acting			
a22	Steals from home, school or elsewhere			
a23	Gets on better with adults than with other children			
a24	Many fears, easily scared			
a25	Sees tasks through to the end, good attention span			

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

	No	Yes minor difficulties	Yes definite difficulties	Yes severe difficulties

If you answered "Yes" to this question, please continue with questions 2-5.

2. How long have these difficulties been present?	Less than a month	1-5 months	6-11 months	A year or more

3.Do the difficulties upset or distress your child?	Not at all	Only a little	Quite a lot	A great deal

4. Do the difficulties interfere with your child's everyday life in the following areas?	Not at all	Only a little	Quite a lot	A great deal
Home life				
Friendships				
Classroom learning				
Leisure activities				

5. Do the difficulties put a burden on you or the family?	Not at all	Only a little	Quite a lot	A great deal

NOTES

[1] A. de Bruin, H. S. V. Picavet and A. Nossikov, *Health Interview Surveys*: *Towards International Harmonization of Methods and Instruments,* Regional Publications, European Series, No. 58, (Copenhagen, World Health Organization Regional Office for Europe, 1996) Annex 3.

[2] For official manual and copyright information contact NFER-Nelson Publishing Company Ltd., Darville House, 2 Oxford Road East, Windsor, Berkshire, SL4 IDF, United Kingdom.

[3] Chamie M., Survey design strategies for the study of disability, World Health Statistical Quarterly, 1989, Vol. 42, p. 122-140.

[4] Wiersma D., A. De Jong, and J. Ormel, "The Groningen Social Disabilities Schedule: development, relationship with ICIDH, and psychometric properties", *International Journal of Rehabilitation Research*, 1988, Vol. 11, p. 213-224.

[5] This instrument was used in the 1997 Health Survey for England conducted by the Joint Health Surveys Unit of Social and Community Planning Research (SCPR) and the Department of Epidemiology and Public Health at University College, London (UCL), and in the United States National Center for Health Statistics 1999 National Health Interview Survey on Disability (NHIS-D).

ANNEX IV
NATIONAL EXAMPLES OF SURVEY QUESTIONS RELATING
TO USE OF SERVICES SUPPORT

A. AUSTRALIA

The 1993 Australian Bureau of Statistics survey of disabled and aged persons questionnaire was divided into two broad sections:

(a) Disability and aging;
(b) Caring for people with a disability and older people.

In addition to collecting information on long-term health conditions and functional limitations, the survey collected information on the respondent=s need for assistance and the extent to which that need was met. The survey investigated both formal and informal care; "personal assistance received" included a description of the person providing the care, the type of care provided and the time spent providing the care. Information was also gathered on the older population without functional limitations, on their need for assistance with household tasks and transport, their participation in community activities and any emergency arrangements they might have.

Among the population of interest, the survey asked questions about the need for help with "personal care activities" (i.e. showering/bathing, dressing, eating/feeding, toileting, and bladder/bowel control), "mobility" (i.e., going places away from home, moving about the house, transferring to and from bed or chair), "verbal communication", "health care" (i.e., taking medication/dressing wounds, foot care), "home help and home maintenance/gardening", "meal preparation", "financial management/writing letters", "transport", and "emergency arrangements". The following question repeated for each activity:

Do you ever need help or supervision to ... ? (Yes/No)

If "yes" to the above question, ask, "You have just told me that you need help or supervision with ... Do you always need help?" (Yes/No)

Does anyone usually provide this help? (Yes/No)
If "Yes", ask, "Who usually provides this help?"

Informal carers included a spouse/partner, mother, father, daughter, son, daughter-in-law, son-in-law, other relative, friend/neighbour). Formal carers included a home care/home help/council handyperson, privately arranged help/commercially provided service, Meals on Wheels, voluntary community assistance scheme, physiotherapist, chiropodist/podiatrist, speech therapist and other. If the person received care from more than one person, the main provider had to be identified. If the main provider was a formal carer the next question was asked:

How did you find out about (this carer/service)?

Do you feel a need for (more) help with (this/these) task(s)?
If "Yes", ask,
        (a) Which task do you need (more) help with most?
        (b) What is the main reason you are not receiving (more) help with this from organized
        services, such as the home and community care program?
        (c) What is the main reason you are not receiving (more) help with this from family or
        friends?

B. CANADA

The Statistics Canada Health and Activity Limitation Surveys (HALS) of 1986 and 1991 included questions related to the use of services and help from others (section C of the questionnaire: " every day activities"). Some examples of those questions follow:

    C1.   Who usually prepares your meals?
                  Yourself alone
                  Yourself and someone else
                  Someone else

    C2.   Is this because of your condition or health problem?
                  Yes
                  No

    C3.   Who helps prepare your meals?
                  Husband, wife or partner
                  Son
                  Daughter
                  Parent
                  Brother or sister
        Other relative
        Friend or neighbour
        Voluntary organization or agency
        Private organization or agency

    C4.   Do you have to pay for these services out-of-pocket; that is, you are not
           reimbursed by any sources?
                  Yes

No

C5.   Because of your condition, do you need help or additional help in preparing your meals?

        Yes
        No

Similar questions were asked about the following activities:

(a) Shopping for groceries
(b) Every day housework
(c) Heavy household chores
(d) Looking after personal finances
(e) Personal care
(f) Moving about in own residence

Section C ended with the following questions:

C35.   During the past 3 months, including regular treatment, counseling or therapy, how many times did you see or talk to a _____

        Dentist
        Nurse
        Chiropractor
        Psychologist
        Physiotherapist
        Family doctor or general practitioner
        Medical specialist
        Any other health care professional: please specify _____

C36.   Did you have any difficulties getting these services?
        Yes
        No

C37.   What kind of difficulties did you have getting these services? I will read a list. Please answer "Yes" or "No" to each.
        Too costly
        Needed someone's assistance to make arrangements or to go and stay with you
        Inadequate transportation
        Location too far away

Facilities or services not accessible
Physically unable to go
Other: please specify _____

C38.   Did you spend any nights as a patient in a hospital, nursing home or convalescent home during the last 12 months?
Yes
No

C. KENYA

The following questions were asked in a 1981 survey of disabled persons in Kenya. The questions were asked of persons who had been identified as having a disability.

Does your disability require medical care? (Yes/No)

IF YES:
(a) How often do you require medical care? (probe number of visits per week, month, or year)

(b) Where do you usually obtain the medical care? (a) a Government hospital; (b) a mission hospital; (c) a mobile clinic; (d) a dispensary; (e) other(s): specify _____

(c) How far do you have to go to get medical care?

(d) By what means do you travel to the medical centre?

(e) If you travel by public transportation: how much does it cost you per visit?

D. THE NETHERLANDS

In the 1986/1988 Statistics Netherlands health interview survey, the questions on the Ause of services and support≅ were not specifically focused on the population with disabilities, but were asked of everybody in the sample population. The following services were covered in the survey: consultation with general practitioner, specialist and dentist; use of prescribed and non-prescribed medicines; hospital admissions; and a global checklist of the respondent's use of other health care facilities.

1.   General practitioner (GP) consultations: Including consultations at the GP's practice, visits by the GP, but also contacts by telephone, except to make an appointment.

How often have you visited or talked to your GP during the past 2 months, since......? (also include consultations of a locum)

If never: can you tell when you consulted your GP for the last time?

> For consultations in the past 2 months:

During those 2 months, when did you consult your GP for the first/second/ etc. time?

Why did you consult your GP? (mention illness or complaints)

Where or how did the consultation take place: at the GP's practice, at home, by telephone, other?

Were you referred to a specialist, a hospital or some other institution giving assistance? If yes, to whom?

Did you consult your GP on your own initiative?

2.   Specialist consultations: Don't count visits to in-patient clinics, but do count outpatient treatment, and also first aid and X-rays.

How often have you consulted a specialist during the past 2 months, since....?

If never: can you tell when you consulted a specialist for the last time?

> For consultations in the past 2 months:

During those 2 months, when did you consult a specialist for the first/second/ etc. time?

What kind of specialist did you consult?

For what complaints, illness or treatment did you go to a specialist?

Did the visit take place at a hospital, at an outpatient clinic of a hospital or somewhere else?

Was it your first visit to the specialist for this illness/complaint treatment, or was it a follow-up visit?

If it was the first visit, how was the visit arranged? (on own initiative, referred on GP's initiative, summoned by the specialist, other)

How much time passed between the referral/call/request and this visit?

3.   Medicines: Don't count medicines during hospitalization, or the [contraceptive] Pill.

Have you been prescribed any medicines during the last fortnight? (Here, the writing of a prescription is meant, NOT the use of the medicines).

Have you used any prescribed medicines during the last fortnight?
*   If "No": when did you use any prescribed medicines for the last time?*
*   If "Yes": what kind of medicines and prescribed by whom: GP, specialist or someone else? (list with 16 kinds of medicines).*

Have you used any non-prescribed medicines during the last fortnight? (Here medicines bought without a prescription from a pharmacy or chemist are meant).
*   If "No": when did you use non-prescribed medicines for the last time?*
*   If "Yes": what kind of medicines did you use? (list with 11 kind of medicines)*

Are you on the Pill? (Only for women 16-49 years).

4.   Hospital admissions: Don't include admissions for childbirth.

Have you been admitted to a hospital or clinic during the past year, since ..?
*   If "Yes": how often?*
*   If "No": can you tell me when you were admitted for the last time?*

        For admissions during the last year:

When were you admitted?

To which hospital? (Note the name of the hospital and place)

How many nights did you spend in hospital?

For what condition did you go to hospital?

Did you undergo surgery during this stay?

5.   Dentist consultations

How often have you visited the dentist during the past 2 months, since....?
        If never: could you tell when you visited the dentist for the last time?

        For consultations in the past two months:

During the past 2 months, when did you go to the dentist for the first/second/etc. time?

Did you go to the dentist because of pain, for a regular check-up or due to prolonged treatment?

What was done to your teeth? (only a check-up, extraction of a (molar) tooth, filling in a (molar) tooth, a crown or a bridge, teeth regulation, fluoride treatment, tartar removal, other treatments)
        If extraction or filling: how many teeth were extracted/filled?

6.   Checklist for other health care services

Have you used any of the following health care services during the past year, since.....?
        Physiotherapy (without hospital admission);
        Alternative practitioners, not your own GP, such as homeopaths, acupuncturists, naturo-
        paths, mesmerists or paranormal practitioners or other alternative practitioner;
        RIAGG (Regional Institute for Community Mental Health Care), CAD (centre for alcohol
        and drug addicts), or other similar institutions;
        Assistance by a 'cross association' (district nurse, special aids);
        Family boarding out, care for the elderly;
        General social work

E. UNITED KINGDOM OF GREAT BRITAIN AND NORTHERN IRELAND

Reproduced below are selected questions from the health and social services section of the 1985-1988 survey of disability among adults conducted by the Office of Population Censuses and Surveys. The numbers before each question refer to the item in the questionnaire.

S   *HEALTH AND SOCIAL SERVICES*

S1.   *How often have you seen your family doctor or GP in the past year in connection with your health problem/disability?*

     INCLUDE SEEING A PARTNER
     OR LOCUM

                        NUMBER OF TIMES   (a)

     EXCLUDE VISITS WHEN DOCTOR NOT SEEN   0
     E.G., JUST TO COLLECT PRESCRIPTION   *Never*   S2

     *(a) Do you generally visit the surgery or does the
        doctor come and see you at home?*

                    Visits surgery   1
                    Doctor visits home   2

S2.   *During the past twelve months, have you been in hospital as an in-patient for treatment or tests in connection with your health problem/disability?*

                         Yes   1   (a)-(c)
                         No   2   S3

     *(a) How many separate stays have you had in hospital
        in the past twelve months?*

                  NUMBER OF STAYS ....

     (b) How long were you in hospital (all together)
              (IF LESS THAN A MONTH) DAYS ....

              (IF MORE THAN 1 MONTH) WEEKS ......

(c) When you were in hospital, which of the people listed on this card did you see?

SHOW CARD S2/S4

	Yes	No
Consultant ………………………….	1	2
Other doctor ……………………..	1	2
Radiographer ………………………	1	2
Physiotherapist ……………………	1	2
Occupational therapist (OT) ……	1	2
Speech therapist ……………………	1	2
Hearing therapist or technician ...	1	2
CODE *Optician or oculist ………………..*	1	2
ALL *Chiropodist ………………………….*	1	2
THAT *Dietician …………………………….*	1	2
APPLY *Psychologist ………………………*	1	2
Psychotherapist ………………..	1	2
Artificial limb/appliance fitter ...	1	2
Health visitor …………………….	1	2
Hospital social worker …………	1	2
Nurse ……………………………….	1	2
Other (SPECIFY) ………………….		

S3.   *(Apart from occasions you just told me about when you saw your own doctor/when you stayed in hospital) have you been to a hospital or clinic or anywhere else in the past year for treatment or checkups for your health problem/disability?*

Yes ………   1 → (a)

No ………   2 → S8

INCLUDE VISITS TO HOSPITALS, DAY HOPITALS, CLINICS, PRIVATE CONSULTING ROOMS

EXCLUDE ATTENDANCE AT DAYCENTRE OR SHELTERED WORKSHOP

(a) *How many different places have you been for treatment or checkups in the past year?*

NUMBER → S4

	1	2	3	4

S4.   *FOR EACH PLACE ATTENDED RING NUMBER*
   DESCRIBE AND ASK (a) - (d)
   RING NO

   Description of place attended (eg HOSPITAL/CLINIC etc)

   (a)How may times have you been to this
      HOSPITAL/CLINIC in the past year?
                        NUMBER OF TIMES

   (b)When you go there are you normally there ....
                        for an hour or two ....
      RUNNING   for half a day ....
      PROMPT   or the whole day? ....

	1	1	1	1
	2	2	2	2
	3	3	3	3

   (c)Which of these people do you usually see at this
      HOSPITAL/CLINIC?

SHOW CARD S2/S4

	Y N	Y N	Y N	Y N
Consultant	1 2	1 2	1 2	1 2
Other doctor	1 2	1 2	1 2	1 2
Radiographer	1 2	1 2	1 2	1 2
Physiotherapist	1 2	1 2	1 2	1 2
Occupational therapist (OT)	1 2	1 2	1 2	1 2
Speech therapist	1 2	1 2	1 2	1 2
Hearing therapist or technician ...	1 2	1 2	1 2	1 2
CODE *Optician or oculist ....*	1 2	1 2	1 2	1 2
ALL *Chiropodist ....*	1 2	1 2	1 2	1 2
THAT *Dietician ....*	1 2	1 2	1 2	1 2
APPLY *Psychologist ....*	1 2	1 2	1 2	1 2
Psychotherapist	1 2	1 2	1 2	1 2
Artificial limb/appliance fitter ...	1 2	1 2	1 2	1 2
Health visitor	1 2	1 2	1 2	1 2
Hospital social worker	1 2	1 2	1 2	1 2
Nurse	1 2	1 2	1 2	1 2
Other (SPECIFY)	1 2	1 2	1 2	1 2

CONTINUE SHOWING CARD S2/S4

*(d) Which specialist on the card do you
      see most often?*

                                    ENTER CODE

*(i)Do you usually see the same person
    (individual) each time?*

                                    Yes ……………   1
                                    No ……………   2

*(ii)Do you/would you like to see the
     same person (individual) each time?*

                                    Yes ……………   1
                                    No ……………   2
                                    Don't mind …   3

(Questions S5 to S7 are not included)

S8.   *Here is a list of some of the people who come to the home
        To treat people with health problems or disabilities. Have
        Any of those people visited you in the past year?*

                        Yes ……   1   (a)-(e)
                        No ……   2   (e)

CARD S8

District nurse	*1*
Nursing auxiliary (e.g., bath attendant	*2*
Community psychiatric nurse	*3*
Community mental handicap nurse	*5*
Health visitor	*6*
Other community nurse (what does she do?)	*4*
Physiotherapist	*7*
Occupational therapist	*8*
Chiropodist	*9*
Speech therapist	*10*
Don't know who they are	*11*

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IF "YES" TO ANY, PUT NUMBER AT TOP OF COLUMN AND COMPLETE (a)—(d) FOR EACH PERSON WHO COMES

	1	2	3	4	5
(a) CODE NO. OF PERSON (FROM CARD)					
(b) NAME OF PERSON IF CODE 4 OR 11; DESCRIBE WHAT THE NURSE DOES					

(c)   How often does the ……………come?

	1	2	3	4	5
Every day or nearly ……….	1	1	1	1	1
2 or 3 times a week ……….	2	2	2	2	2
Once a week ………..……	3	3	3	3	3
Less than once a week ……	4	4	4	4	4

IF CODED 7-9 AT (a)

(d)   Do you pay anything for the …………?

	1	2	3	4	5
Yes	1-(i)	1-(i)	1-(i)	1-(i)	1-(i)
No	2	2	2	2	2

IF YES

(i)   How much do you pay per week?

	1	2	3	4	5
	£ p	£…..p	£ p	£ p	£ p
AMOUNT					
DK	9	9	9	9	9

(e)   Can I just check:

Is there anyone who visits you about your health but you are not sure who they are?

Yes   1

No   2   S9

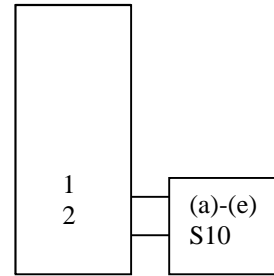*IF "YES", PLEASE CODE (11) AT (a) ABOVE AND COMPLETE (b) THROUGH TO (d).*

S9.   *Here is a list of services which can help people with health problems and disabilities and their families. Have you had any of these services in the past year?*

Yes ……   1
No ……   2   (a)-(e) S10

SHOW CARD S9

CARD S9	
Social service home help	*12*
Meals on Wheels	*13*
Laundry service	*14*
Incontinence service	*15*
Night sitting service	*16*
Mobility/technical officer for the blind	*17*
Social worker	*18*
Voluntary worker	*19*
Visiting service	*20*
Private domestic help	*21*
Private nursing help	*22*
Access/safety officer	*23*
Other (please describe)	*24*

IF YES TO ANY RING NUMBER AT TOP OF COLUMN AND COMPLETE (a)—(e) FOR EACH SERVICE

	1	2	3	4	5
(a) RING NO. OF SERVICE (FROM CARD)					
(b) NAME/DESCRIPTION OF SERVICE					
(c) How often does the ………………come?					
Every day or nearly…………	1	1	1	1	1
2 or 3 times a week …………	2	2	2	2	2
Once a week……………………	3	3	3	3	3
Less than once a week ………	4	4	4	4	4
(d) Do you pay anything for the …………?					
Yes	1-(i)	1-(i)	1-(i)	1-(i)	1-(i)
No	2	2	2	2	2
IF YES					
(i) How much do you pay per week?	£ p	£ p	£ p	£ p	£ p
AMOUNT					
DK	9	9	9	9	9
IF HAS A SOCIAL SERVICES HOME HELP (CODE 12)					
(e) How may hours a week do you have a home help for?					
HOURS					
IF VARIES GIVE AVERAGE					

F. UNITED STATES OF AMERICA

The 1994 supplement of the yearly National Health Interview Survey conducted by the National Center for Health Statistics included questions on help received. Separate questions examined the use of services, the benefits of special programs for people with disabilities and the special health needs of children. Most of the questions were asked of all members of the household.

1.   Questions with respect to help received

One part of the questionnaire concerned the help received and/or needed by persons to perform the (instrumental) activities of daily living. These questions were asked of persons 5 years of age and over. The questionnaire made use of a two-stage procedure. In the first stage persons were screened with the following questions:

Because of a physical, mental or emotional problem, do ... get help from another person in:

> *(1) Bathing or showering (Yes/No)*
> *(2) Dressing (Yes/No)*
> *(3) Eating (Yes/No)*
> *(4) Getting in and out bed of bed or chairs (Yes/No)*
> *(5) Using the toilet, including getting to the toilet (Yes/No)*
> *(6) Getting around inside the home (Yes/No).*

Because of a physical, mental or emotional problem, do ... need to be reminded to do [any of these/any of the following] activities, or need to have someone close by when they do them?

For which activities (listed above) does ... need to be reminded or to have someone close by?

If the answer was "Yes" to any of the above questions, additional questions were asked about the use of special equipment to perform the activity and the nature of the problems the person had in performing the activity. With respect to the help received, the following questions were asked:

You said that ... gets help, needs to be reminded, or needs someone close by when (refer to activities 1-6 above).

Who gives this help?
> *(1)   Household members*
> *   Relative(s)*
> *   Non-relative(s)*
> *(2)   Non-household members*

Relative(s)
Non-relative(s)
(3)   Anyone else?

Is any of this help paid for? (Yes/No). If the answer is ANo≅ ask if only help from spouse/child(ren)/parent.

Which helpers are paid for?
(1)   Household members
Relative(s)
Non-relative(s)
(2)   Non-household members
Relative(s)
Non-relative(s).

For each activity for which the person needs help, needs to be reminded or uses special equipment, it was asked how much difficulty ... would have in performing the activity if ... did not receive help from another person and/or use special equipment. The same set of questions were asked about performing the instrumental activities of daily living, including preparing one's own meals, shopping for personal items (such as toilet items or medicine), managing money (such as keeping track of expenses or paying bills), using the telephone, doing heavy work around the house (scrubbing floors, washing windows and doing heavy yard work) and light work around the house (doing dishes, straightening up, light cleaning or taking out the trash).

2.   Questions concerning the use of special services

Another part of the questionnaire focused on the use of special services for persons with disabilities.

(a)   Adults aged 18 years and over

i.   Paid work facilities

Some programmes help people with disabilities to develop skills and opportunities for paid employment. During the past 12 months, did ... participate in a sheltered workshop, transitional work training, or supported employment? (Yes/No)

> *If "Yes", in which programme did ... participate during the past 12 months?*

Are ... now on a waiting list for any of these programs? (Yes/No)

ii.   Social activities during working hours

During the past 12 months, did ... go to a day activity centre for persons with disabilities which provides social, recreational and developmental activities during working hours? (Yes/No)

Are ... now on a waiting list for a day activity centre? (Yes/No)

iii.   *Physical therapy*

During the past 12 month, have ... received any physical therapy? (Yes/No)

Has the condition for which ... get physical therapy been going on or is it expected to go on for at least 12 month? (Yes/No)

What is the main condition for which ... get physical therapy? List of conditions.

iv.   *Occupational therapy*

During the past 12 month, have ... received any occupational therapy? (Yes/No)

Has the condition for which ... get occupational therapy been going on or is it expected to go on for at least 12 month? (Yes/No)

What is the main condition for which ... get occupational therapy? List of conditions.

v.   *Vocational rehabilitation*

Vocational rehabilitation provides equipment and services to people with disabilities to improve their ability to work or to live independently.

Have ... ever received any equipment or services through vocational rehabilitation? (Yes/No)

During the past 12 months, did ... have a case manager? (Yes/No) (A case manager coordinates personal care, and social or medical services for persons with special needs).

If "Yes", during the past 12 months, did ... need a case manager to coordinate personal care or social or medical services? (Yes/No)

Did ... have a court-appointed legal guardian? (Yes/No)

(b)   Children (persons under 18 years old)

Does ... NOW go to a medical doctor or specialist on a regular basis for anything other than routine physical exams?

Do .... NOW go to a counseler, psychiatrist, psychologist, or social worker on a regular basis?

During the past 12 months, have .... received any physical therapy?

During the past 12 months, have .... received any occupational therapy?

Does .... NOW receive any physical or occupational therapy AT HOME? THIS INCLUDES THERAPY GIVEN BY YOU, OTHER FAMILY MEMBERS, FRIENDS, VOLUNTEERS OR PAID PROFESSIONALS

> *Who pays for this therapy?*

Does .... receive any physical or occupational therapy at any other place, that is, OTHER THAN AT HOME?

> *Does .... receive this therapy at school, at a location other than school or both places?*

Besides physical or occupational therapy do .... NOW have any (other) medical or health procedures done AT HOME?