Strategic Action towards Inclusive Development: Disability, Human Rights and Statistics

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**Strategic Action towards Inclusive Development: Disability, Human Rights and Statistics**

**Executive Summary**

The United Nations General Assembly requested that the Millennium Development Goals (MDGs) be more disability-inclusive\(^1\). This report reviews disability statistics useful for monitoring progress towards disability-inclusive development goals, such as the MDGs, in light of their impact on the situation of persons with disabilities. The report is intended for a general audience so that they may better understand the current status of disability statistics and consider the potential of these statistics for improved monitoring and evaluation of development goals, such as MDGs.

The purpose of the report is to provide the basis for a plan of action to use agreed international standards of official statistics and indicators and related data sets as immediate tools for improved disability-inclusion in development goals, including the MDGs. This is best served by a statistical system that focuses upon the assessment of human rights and equalization of opportunity, in line with the *Convention, the World Programme of Action concerning Disabled Persons*\(^2\) and the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*\(^3\) as well as international development goals, such as those that reside within the *Millennium Development Goals*\(^4\).

Strides in the last decade have been made in the inclusion of disability into development planning and statistics, focused on equalization of opportunity. In the United Nations *Principles and Recommendations for Population and Housing Censuses, Revision 2*, for example, it is stated that “The assessment of equalization of opportunity is the purpose that can be best achieved in a census”\(^5\). The *Principles and Recommendations* also state that the census is an important source of data on persons with and without disabilities. Census data help to monitor the social and living conditions of persons with and without disabilities in terms of school attendance, educational attainment, employment, marital status and living arrangements.\(^6\)

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\(^1\) GA resolution on MDGs here.
\(^2\) The World Programme of Action concerning Disabled Persons was adopted by the United Nations General Assembly at its thirty-seventh session on 3 December 1982 by its resolution 37/52. See *Official Records of the General Assembly, Thirty-seventh Session, Supplement No. 51 (A/37/51)*. Hereafter referred to as the World Programme.


\(^4\) Hereafter referred to as MDGs


\(^6\) *Principles and Recommendations*, Para. 3.78 Also see The *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, adopted by the United Nations General Assembly at its 48th
Census data thus provide an important basis for meeting the needs of statistics for

disability-inclusive development, including the MDGs. The United Nations Principles
and Recommendations describes how census data may be used to produce a number
of MDG indicators. However, it is recognized that all the sources of data, i.e., census,
sample surveys and administrative registers, are needed to fulfill the many data
requirements for disability-inclusive development goals, including the Millennium
Development Goals.

Strides have also occurred in the reporting to the United Nations of a standardized set of
disability statistics from Member States that is useful for assessment of equalization of
opportunity and usefully serves disability-inclusive development goals such as MDGs.
The United Nations Statistics Division’s Demographic Yearbook (DYB) Database houses
internationally agreed data sets provided by Member States to the United Nations from
the World Programme of Population and Housing Censuses. These data sets are
compiled and distributed world-wide and are used by United Nations agencies for
preparation of indicators on human development, population aging, gender differences,
status of children, educational attainment, school attendance, economic activity, housing
quality, disability status and the like.

At its 34th session in 2003, the United Nations Statistical Commission emphasized the
need to ensure the collection of internationally comparable statistics and approved the
collection of disability statistics from member states on a regular basis through the United
Nations DYB System. To facilitate this process the UNSD developed the Human
Functioning and Disability Questionnaire, sent by the United Nations Statistics Division
to Member States for the reporting of their metadata and national statistics on persons
with and without disability on selected topics.7

In 2005, as requested by the Statistical Commission, the Statistics Division initiated the
compilation of national disability statistics provided by member states. That year, 45
Member States reported their national disability statistics and related metadata to the
United Nations and these data are held in the Demographic Yearbook Database. Member
States report to the United Nations a common set of statistical tabulations and related
metadata from their national censuses, sample surveys and administrative registers
including statistics on an agreed set of demographic, economic and education
characteristics of persons with and without disabilities. These data sets provide an
important source of data for reporting on the comparative demographic and
socioeconomic situation of persons with and without disabilities. Annex 1 provides a
more detailed description of decisions reached by the United Nations Statistics
Commission concerning this matter.

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7 For a detailed look at the metadata reported by Member States using this mechanism, see
Central to these data sets are the need for common definitions, concepts, standards and methods for production of statistics that identify persons with and without disabilities in an internationally agreed and standardized way so that their situations regarding equalization of opportunity and development may be appropriately compared. Under the auspices of the Statistical Commission, the Washington Group has developed a short set of disability questions that can be included in censuses, and is also developing extended sets of disability questions for use in population surveys, using these internationally agreed definitions, concepts, standards and methods. See Section II. for details of the work of the Washington Group. This work, now in trial use, will set the stage for improved harmonization of disability measurement and reporting in upcoming censuses and surveys.

The collections and compilations of national statistics and metadata on persons with and without disability compiled by Member States through their official statistics programmes and reported to the World Programme of Population and Housing Censuses provide useful lessons on how to prepare statistics for disability-inclusive development goals. One key result is the understanding by all concerned that greater consideration must now also be given to the preparation of analytical reports for purposes of national and international planning that use these official statistics reported to the United Nations by Member States, aimed at improved public understanding and assessment of the implementation of the agreed goals. It is fully agreed that statistics must be used in order to be fully meaningful, including disability statistics.

Although there is considerable evidence that Member States have collected relevant data on persons with and without disabilities, in some cases over many decades, the use of these national datasets by planners and policymakers has been limited. For example, it is not well-known that in many countries around the world, data on persons with and without disability have been collected for at least 100 years by a number of national statistical offices. The data from these past efforts are not effectively utilized in the reports of ministries and also have been under-utilized in the analysis and reporting of information concerning development or human rights.

A stronger partnership is needed between data collection and reporting systems regarding disability and development goals. Currently, there is limited use of these national datasets by planners and policymakers for the analysis and preparation of in-depth reports on the situation of persons with and without disabilities in the assessment of MDGs and other development goals.

An ideal situation would consist of the following key components:

1. Member States would collect data on disability following international agreements already reviewed by the Statistical Commission and approved by the Third Committee for its work on standards for statistics and indicators in censuses, sample surveys and the administration of civil registration systems;
2. National data collected would be widely presented in national reports and would also be reported by Member States to the United Nations using internationally agreed formats that compare persons with and without disabilities;

3. A compilation of these national datasets would then be reviewed, evaluated, published and disseminated by the United Nations through an agreed statistical reporting system on a regular basis;

4. These statistical reports would then be the basis of analytical studies and development monitoring reports undertaken by United Nations agencies and bodies for mainstreaming of disability into human rights, equalization of opportunity and development goals including those of MDGs;

5. The United Nations would regularly report to the General Assembly through relevant bodies on achievement in the assessment of equalization of opportunity, in line with the Convention, the World Programme of Action concerning Disabled Persons\(^8\) and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities\(^9\) as well as international development goals, such as those that reside within the Millennium Development Goals\(^10\); and.

6. Recognizing the great need for access to these statistics in meaningful analytical formats, starting in 2015, the first United Nations Global Disability Report would be submitted to the General Assembly summarizing disability statistics provided by Member States and also presenting additional summary information derived from other reporting mechanisms provided by States Parties to the Convention addressing national policies devised, legislation implemented and other actions taken during the 5 year period from 2010-2014 to ensure human rights and equalization of opportunities of persons with and without disabilities.

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\(^8\) The World Programme of Action concerning Disabled Persons was adopted by the United Nations General Assembly at its 37th regular session on 3 December 1982, by its resolution 37/52 Hereafter referred to as the World Programme.


\(^10\) Hereafter referred to as MDGs.
I. DISABILITY, HUMAN RIGHTS AND STATISTICS: A FRAMEWORK

Statistics must be meaningfully linked with development goals in order to successfully evaluate how development programmes are faring. Much of the linking takes place through common definitions, concepts and frameworks. This section describes a development framework for disability agreed upon by Member States and then shows how policy, programmes and statistics are usefully linked using this framework.

The Convention on the Rights of Persons with Disabilities works to maintaining the human rights of persons with disabilities and ensure equal opportunities for their inclusion and participation in society, to “Promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities; and promote respect for their inherent dignity”. (Convention, Article 1) Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

The Convention represents an international milestone by acknowledging the shift in attitudes and approaches to persons with disabilities that have been evolving over the past few decades. It acknowledges that disability results from the interaction between persons with impairments and the barrier, both attitudinal and environmental, which hinder their full and effective participation in society on an equal basis with others. The Convention is intended as a human rights instrument with an explicit social development dimension. It recognizes the broad diversity among persons with disabilities and reaffirms that all persons with all types of disabilities should enjoy human rights and fundamental freedoms. More specifically, included among the Convention’s general principles are full and effective participation and inclusion in society, non-discrimination, accessibility and equality of opportunity for people with disabilities.

Assessing equalization of opportunities In order to monitor disability-inclusive development goals an agreed set of official statistics on persons with and without disabilities is needed and that can be used to compare how development goals are being met for persons with and without disability. This dataset would be potentially useful for preparation of reports by various parts of the United Nations to assess disability-inclusive human rights and equalization of opportunities. A report to the General Assembly could summarize and highlight these findings, such as that proposed in this report, a quinquennial Global Disability Report.

Under the auspices of the United Nations Statistical Commission, a city group called the Washington Group on Disability Statistics has begun to outline ways for countries to monitor disability-inclusive development and MDG goals in light of the principles provided in the United Nations Convention, the World Programme and the Standard Rules by setting target areas for measuring outcomes including socio-economic outcomes related to equalization of opportunities both in terms of economic development.

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and the human rights perspective of empowerment of persons with and without disabilities.\textsuperscript{12}

The Washington Group is charged by the United Nations Statistical Commission with the responsibility of improving upon the quality and international comparability of disability measurement in national censuses and surveys. The Washington Group works to develop a short set of questions to identify persons with disabilities for censuses and national sample surveys. It also works to prepare an extended set of questions for surveys that would address a specific aspect of the disablement process, namely, the issue of whether persons with disability participate to the same extent as persons without disabilities in activities such as education, employment or family and community life, in other words, the equalization of opportunities.

In order to address the equalization of opportunities for persons with disabilities it is necessary to identify persons who are at greater risk than the general population of experiencing limited participation in society. The recommended short set of questions of the Washington Group is intended to identify the majority of the population with difficulties in functioning in basic actions; difficulties that have the potential to limit independent living or social integration if appropriate accommodation is not made. This indicator, coupled with other information collected through the census or survey on complex activities, for example, education, employment, or family and social life, can then be used to compare the levels of participation in these complex activities between those with and without disability, as measured by difficulty in performing basic actions and would thereby assess equitable access to opportunities.

For example, data on difficulty in performing basic actions might be cross-classified with a measure of employment to identify the proportion of persons with and without disability who are employed. This is an assessment of the equality of employment opportunities. If policy interventions are initiated to enhance workplace accommodations, the effect on employment of persons with and without disability can be determined.

Earlier work was completed without international agreement on definitions, concepts, classifications and survey questions to be used to identify persons with and without disabilities and thus data were often not comparable. While there were internationally agreed standards for the measurement of employment, for example, the approaches to measuring disability remained ad hoc and largely without internationally agreed standards. This is no longer the case.

International agreement on the \textit{International Classification of Function, Disability and Health (ICF)}\textsuperscript{13} has stimulated work on common approaches to disability measurement. The Statistical Commission reviews the work of the Washington Group on Disability Statistics for its approaches to the measurement of disability with anticipation that


\textsuperscript{13} World Health Organization, \textit{International Classification of Functioning, Disability and Health} (Geneva, 2001).
common definitions and concepts based on the ICF will be used and the degree of comparability of the census results will be increased.

In addition to employment, it will be important to collect data on a variety of forms of participation, such as education, housing, transportation, social and health services, in addition to aspects of family, cultural and social life. As barriers are reduced to full participation, a trend analysis would also be expected to show improvements among those with disabilities over a period of time.

Further information is also needed on the mechanisms that facilitate or impede participation in complex activities, such as environmental and attitudinal barriers to equitable access. In a number of cases, environmental factors may be identified through comparing persons with and without disabilities for their housing arrangements, type of transportation used, and the like, using the agreed tabulations presented in the Principles and Recommendations for censuses.

The international agreements on statistics reached by the United Nations and already approved by the Third Committee support the goal of mainstreaming disability into the larger socioeconomic and development context. Broad agreement has been reached on ways to strengthen the partnership between policy, legislation, statistics and research through internationally agreed definitions and concepts.

Most notably, is the achievement by the World Health Organization of the International Classification of Functioning, Disability and Health (ICF) that has led to reform in the definitions, concepts and classification of disability for use in policy, legislation, statistics and research, world-wide. In the newly agreed ICF, comparisons of persons with and without disabilities are encompassed in the umbrella framework of human functioning, seen from a neutral perspective\(^{14}\). Three key domains of functioning are described below:

**Human Functioning and Disability**

**Human Functioning** is part of the umbrella framework of the ICF seen through a neutral lens.

1. Individual *body structure and function*;
2. Human *activities*;
3. Community *participation*.

**Disability** is also part of the umbrella framework of ICF, which looks at functioning through a problematic lens (WHO, ICF, p.3); i.e., it indicates a limitation in one of the three domains of functioning:

1. *Impairments* of *body structure and function*;
2. *Limitations* of *human activities*;

In the ICF framework provided by the World Health Organization, there are three important factors affecting human functioning: (a) contextual factors of the environment, having the capacity to both facilitate and debilitate human functioning; (b) characteristics

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of the person, such as age and sex; and (c) conditions of health. All three factors are briefly described below.

**Contextual Factors of the Environment:** the physical social and attitudinal environment in which people live and conduct their life that result in both barriers and facilitators for functioning. Environmental factors are organized in the ICF to focus on two different levels: (1) the individual level; and (2) the societal level. At the individual level the ICF describes the immediate environment of the individual at such locations as home, at work and at school. At the societal level, the ICF broadly describes a wide range of formal and informal social structures and services provided by organizations covering communications, transportation, and etc.  

**Personal factors:** the particular background of an individual’s life and living and comprise features of the individual that are not part of a health condition or health states, such as gender, race, age, education, profession, etc. ICF does not include a classification of personal factors.

**Health conditions:** disorders or disease: These conditions are classified in programmes and statistics using the World Health Organization’s *International Classification of Diseases (ICD)*. See [http://www.who.int/classifications/icd/en/](http://www.who.int/classifications/icd/en/).

Survey measures of environmental factors. Agreements are reached in the *Principles and Recommendations* for census and survey measures of certain environmental factors, for example of: the type and location of living quarters; availability of elevator in the building; tenure of housing; and also such topics as availability of information and communication technology devices in the home, number of cars, outdoor space availability, etc.

Survey measures of personal factors. Agreements are also reached in the *Principles and Recommendations* for census and survey measures of personal factors, for example: geographical and internal migration characteristics of persons; international migration characteristics of persons; household and family characteristics of persons; demographic and social characteristics of persons; fertility and mortality experiences of households; educational characteristics of persons; economic characteristics of persons; disability characteristics of persons; agricultural production characteristics of households.

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15 It is important to note that the Washington Group proposes to further subdivide environmental barriers or facilitators into three levels: (1) *Micro-environment:* defined in terms of personal and technical assistance. These are type of assistance that follows the person wherever they go, for example wheelchair, glasses, or personal attendant. In the ICF, they are discussed in Chapter 1 of Environmental Factors; (2) *Meso-environment:* refers to the environment beyond the person. These are issues of accessibility that are facilitated or hindered based on, for example, transportation infrastructure, service provision at the local level, or attitudes of others. In the ICF, they are discussed in Chapters 2-4 of Environmental Factors; and (3) *Macro-environment:* refers to factors that affect persons on a regional, societal or national scale, such as policies, legislation, or general societal attitudes and practices. In the ICF, they are discussed in Chapter 5 of Environmental Factors.

16 Principles and recommendations Section VII, C. Definitions and specifications of topics for: type of living quarters; location of living quarters; occupancy status; type of ownership; number of rooms; useful floor space; water supply system; main source of drinking water; type of toilet; sewage disposal; bathing facilities, etc. It also includes such pertinent topics as: availability of elevator; state of repair; number of cars; and availability of information and communication technology devices.
For a discussion of internationally agreed health topics, such as survey reports of causes of death, or survey measurement of disease conditions and the like, one would need to consult in the *International Classification of Diseases* and related work of the World Health Organization with respect to epidemiological and health interview survey implementation.

The question then becomes, how does one put all these various agreements together into a common framework for the development of disability statistics that are useful for inclusion in development goals, including MDGs? The United Nations Statistics Division (UNSD), in 1990, prepared a useful way to describe how internationally agreed frameworks and programme goals would be associated through the use of a development matrix (See Figure 1)\(^\text{17}\). The development matrix presents two broad dimensions. The first dimension describes what or who is targeted for services, i.e. persons with disabilities and/or environmental barriers. The second dimension describes the types of services or interventions that are proposed to reduce environmental barriers or to support activities and participation of persons with disabilities so that they may fully participate in community life.

The rows. The matrix rows incorporate the concepts laid out in the ICF. With respect to identifying persons with and without disabilities, human functioning may be described using concepts in the ICF related to body structure and function (impairments), activities (limitations) and participation (restrictions). The situation affecting human functioning and disability may also be described through description of environmental factors (barriers/facilitators)\(^\text{18}\).

The columns. Also included in this matrix are the broad development goals proposed by the World Programme of Action, and the Standard Rules, namely equalization of opportunity, rehabilitation and prevention. These three broad programme goals aim to address problems associated any of the three dimensions of functioning (impairment, activity limitation and participation restriction) and problems of the environment that are associated with barriers leading to disability and loss of opportunity.

![Figure 1. Matrix Framework: Disability Statistics for Development](image-url)
Description of Figure 1: This matrix highlights the fact that the field of human functioning and disability is a broad and complex part of development. It addresses principles relevant to MDGs and other development goals including those of prevention; rehabilitation and equalization of opportunity of people with and without disabilities to ensure their full participation in community activities,

Using such a matrix, targets may be set for a variety of programmes with a wide range of purposes depending upon national legislation and levels of development as well as upon other factors such as regional and national goals and priorities. Development programmes are disability-inclusive based upon the extent to which they serve the needs of persons with and without disability for equal opportunity, habilitation and rehabilitation, and also through the preventing of disease, loss of function and reduction environmental barriers. Official statistical measurement will then assess progress in the goals of policy and programmes for the degree to which they aid people with and without disabilities to participate more fully in community life.

Programmes may vary according to the type of interventions being tried. They may focus upon the environment, the person, or to specific body functions and structures. Different types of official statistics, training and research will then be designed to meet the needs of each set of priority targets and goals. Because human functioning and disability descriptions are the result of many different and complex interactions among individuals and environments, there is not one disability prevalence rate to describe this.

The three cells that form the shaded diagonal shown in Figure 1 reflect the concerns of most policies and programs and official statistics. However, not all principles of the Convention, or the World Programme and the Standard Rules fit neatly into these three broad categories shown on the diagonal in Figure 1.

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<tr>
<td>Activities and Participation</td>
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<td>Body Functions and Structures</td>
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Take prevention programmes, for example. Prevention programmes may aim to prevent
diseases that lead to impairments; to prevent barriers that result in reduced participating
in daily living activities; or to prevent discrimination that may result in loss of
participation at school or work. Each of these types of prevention is important for
assessment of disability and also for assessment of broad development goals, including
MDGs.

For example, a campaign for the prevention of infectious diseases, such as malaria by
providing more equal access to mosquito nets is an important disease prevention program
that might also result in increased functioning of the population, thus reducing disability.
Such activities may also be viewed as equal opportunity programmes aimed at increasing
access to preventive services for persons with and without disability. This suggests that
no program is necessarily perfectly placed in any one location and the matrix simply
offers a broader understanding of the way in which purpose of legislation, programmes,
policies and statistics of Member States might address particular aspects of functioning
and disability to further development goals including the MDGs.

Both programmes and statistics have strategies for identifying persons with and without
disabilities and in order to be useful for purposes of monitoring, they must be
comparable. In order to monitor and evaluate programme results over time, both
development programmes and official statistics programmes need to use similar
definitions, concepts and classifications for the identification of persons in need of
services and persons not in need of services so that they may be compared for their
resultant levels of activity and participation. Factors affecting the preparing of
government targets for programme services and also influencing the proportions of
persons identified in censuses and surveys as persons with and without disabilities, i.e.
prevalence rates, are briefly summarized below.

**Targeting the need for services and resultant prevalence rates** The goals set by
legislation and service programmes result in targets and subsequently, estimates of
persons in need of programme services. Prevalence rates of persons with disability may
vary according to the goals set for services. Below, is an illustrative example of how
prevalence rates and estimates of persons in need of services might differ depending upon
the type of services being proposed, based on the results of the Disability Statistics
Compendium.\(^\text{19}\)

Some programmes may try to provide services to persons with specific problems of
impairment or problems of body function, as shown in \(B_p\). In such a case, services may
be provided to persons who are deaf, or to persons who have one leg, for example, to
prevent poverty or job loss, or to prevent further reductions in body function owing to
lack of health services, or rehabilitation services. When the target for services is persons
with specific and more severe impairments or problems of body function, survey
screening approaches to identify persons in need of services usually result in disability

\(^{19}\) Especially see “Consequences of Screening Techniques” Disability Statistics Compendium (ST/ESA
SER.Y/4, p. 28 and also see Figure II.2.)
prevalence rates that range from 0.5 to 7 percent of the population (United Nations Statistical Office, 1990, p. 29).

Prevalence rates can also be attained to target services prepared for persons who report limitations of activity and reduced participation. Populations and members of households may be asked to describe the activities of daily living they perform, or to describe their reduced participation in instrumental activities of daily living. Such programs as shown in cell \textit{A}, may aim to support and strengthen personal dressing activities, feeding, toileting, moving about, climbing stairs, and the like. Such programs focus on the needs of a wider population than if they focused solely upon populations with very specific impairments of body function or structure. In population and household surveys, disability prevalence rates based on questions about reduced daily activity and participation in community life generally range from 10 to 20 percent of the total population.

Studies aimed at environmental factors such as restrictions of housing or public transport shown in the matrix as cell \textit{E} may come up with very different prevalence rates and target a different group in their programs. For example, one national survey of China found that whereas 5 percent of the total population was reported to have a disability, among this same population, a total of 18 percent of households reported a person with a disability (Chamie, 1989, p. 127). In this latter case, families, households and living arrangements would be assessed for their environmental barriers and levels of access to services.

Prevalence rates are also affected by the degree of trust that a population has of its government and its official statistical programmes. An important agreement in statistics is the United Nation’s internationally agreed \textit{Fundamental Principles of Official Statistics}.\footnote{United Nations, \textit{Fundamental Principles of Official Statistics}. See http://unstats.un.org/unsd/dnss/gp/fundprinciples.aspx} This agreement has implications for the collection and use of official statistics worldwide. This is because when statistical information is misused, or when data are collected but not properly disseminated for purposes of public education, or when people fear the purpose of data collection, population support for data collection and analysis may severely decline, resulting in a slow-down of information necessary for purposes of policy formulation, program planning, monitoring and public education. It may also result in fewer persons reporting that they have a disability.

According to the Fundamental Principles, scientific principles and professional ethics—not political influence or outside pressures—should guide selection of methods and procedures for the collection, processing, storage and presentation of statistical data. In addition, based on this agreement, statistical agencies are empowered to comment on erroneous interpretation and misuse of disability statistics. Individual data on all topics including disability are to be kept strictly confidential and used exclusively for statistical purposes. The laws, regulations and measures under which the statistical systems operate need to be made readily available to the public to ensure transparency, accountability and
general support. Both national and international coordination among statistical agencies are essential to achieve consistency and efficiency in the system.

Discrimination and exclusion affect services provided and resultant prevalence rates. Many factors impact upon the choice of the questions used to determine persons with and without disabilities for purposes of program services or in censuses and surveys. The word “disability” often carries with it negative connotations and it is not uncommon that people may feel stigma or shame at self-identifying as disabled. This may be true whether they are being identified for the provision of services or whether they are being identified in surveys for the purpose of the production of statistics.

For this reason, the question “Do you have a disability?” is considered inadequate for identifying, for example, mental or psychological impairments which tend to be particularly stigmatizing. This is a factor that affects both the identification of a person with disabilities for services, or for purposes of survey screening. Upon questioning, individuals may deny their disability or hide the fact that they have a disabled family member. Furthermore, “disability” often implies a very significant condition. Persons who can walk around their homes but are incapable of walking to the market may perceive their situation as not severe enough to be considered a disability even though their daily activities are limited.

Disability may also be interpreted relative to an unspoken cultural standard of what is considered as normal functioning. This may vary across cultures or age groups; for example, elderly people who have significant limitations may not self-identify as having a disability because in their minds they can function about as well as they expect someone their age to function. They may consider themselves as legitimately interested in gaining access to programmes for the elderly but see no need for disability services. However, at the same time they may have significant difficulties performing some basic actions.

Basing disability statistics on questions that ask about diagnosable medical conditions is also problematic in a census or at the program level. Many people may not know their medical diagnosis, particularly with respect to mental and psycho-social conditions; and knowledge about one’s diagnosis is not necessarily a good predictor of the degree of disability that a person might have. In addition, medical diagnosis is often correlated with education, socio-economic status, and access to health services, all of which may bias collected data.

Questions that focus on basic actions like those proposed by the Washington Group, serve as a basis for identifying a broad range of persons with disability. The question “Do you have difficulty walking or climbing steps?” identifies persons with mobility limitations without labelling them as disabled nor is any medical diagnosis required to describe such a situation. For purposes of social participation and the equalization of

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22 Washington Group, “Understanding and Interpreting Disability”, p. 6. (For details on all reports and working papers from the Washington Group, see http://www.cdc.gov/nchs/washington_group.htm)
opportunities, the functional status and how that impacts someone’s life, is of interest and not necessarily the cause, medical or otherwise.

Finally, other factors affecting disability, such as access to prevention programmes and medical care can vary widely. For example, untreated diabetes can lead to profound functional limitations such as blindness or mobility limitations due to the loss of limbs, while diabetes that is properly managed can have a relatively minor impact on someone’s life. Or in the case of the amputation of a leg, with proper medical treatment, rehabilitation services and a prosthetic, a person may have few limitations in terms of daily life activities. Poor treatment, on the other hand, can lead to complications and a series of painful and severe infections.\textsuperscript{23}

II. MEASURING DISABILITY INCLUSIVE DEVELOPMENT: HOW ARE WE DOING?

The 2010 round of censuses (2005-2014) is in the process of being implemented by Member States through the internationally agreed 2010 World Programme of Population and Housing Censuses, Rev.2. Owing to progress made in the setting of definitions, concepts, standards and methods for the study of disability and the inclusion of disability as a topic in the Principles and Recommendations, Rev. 2, the 2010 census round has a system in place for the collection and tabulation of statistics on persons with and without disability. However, these disability statistics need to be regularized, strengthened and fully supported by planners to ensure that they are available for use in the assessment of development goals focused on equalization of opportunity, such as those of the MDGs, while taking into consideration the decisions of the Convention on the Rights of Persons with disabilities, the World Programme of Action for Disabled Persons and the Standard Rules.

A set of actions are needed to resolve some of the problems and delays currently confronting the dissemination and use of these existing data sets on persons with and without disabilities, by development planners, policymakers and researchers. Even when some national data sets from censuses and survey rounds have already been collected and compiled, they are not readily available for purposes of analysis. The reasons for this include the following:

\textit{First}, some countries did not include a question on disability in their census;

\textit{Second}, numerous countries asked census questions concerning disability but have not yet produced their census tabulations, nor disseminated the results;

\textit{Third}, although a number of countries asked census and survey questions concerning disability and have prepared their tabulations and published them, they have not yet reported the results in a standardized way to the United Nations;
Fourth, the United Nations system of statistics on persons with and without disabilities is designed and prepared to compile national disability data produced from the 2010 round censuses and now needs the full support of Member States in the completion of these international activities;

Fifth, some disability data that are already reported to the United Nations are compiled but not necessarily fully disseminated for use in report-writing, and;

Sixth, these national statistics need to be mainstreamed into the regular reporting mechanisms of national planning ministries and of the United Nations so that they are readily available in the preparation of MDG and other development statistics and indicators.

From the above, it is evident that data collection and data dissemination concerning disability statistics at the national and international level are incomplete and in need of further strengthening, with special attention to their further use in the monitoring of development goals, such as the MDGs.

The current situation regarding international compilation of disability statistics from population and housing censuses, and related sample surveys and administrative records is summarized in Table 1, below.

| Table 1. World Programme of Population and Housing Censuses (1995-2010) |
|-----------------|-----------------|-----------------|
| Censuses Conducted | 203              | 87              |
| Questionnaires analyzed by UNSD | 175              | 70              |
| Disability included | 103              | 44              |
| Entered into DYB Database | 45               | 0               |


24 Information collected by UNSD as of April 2010. This census round will not be complete until the end of December 2014.
The 2010 census decade round is ongoing from 2005 until the end of 2014. As of April 2010, 87 censuses were conducted by Member States as part of the 2010 round. It is expected that many more censuses will be conducted before 2014. Among the 87 that were already conducted, 70 census questionnaires were received and reviewed by UNSD for their topical content. In all, 44 censuses are identified as having disability questions and all but one utilized the core set of questions recommended in the Principles and Recommendations. Information for 17 Censuses were not yet ascertained by UNSD, primarily owing to problems of translation and in addition, not all census questionnaires are yet submitted by Member States to UNSD for archiving.

In the UNSD review of topics covered in the 2000 census decade round (1995-2004), a total of 203 Censuses were conducted and 175 Census questionnaires were reviewed by UNSD for their topical content. Of those reviewed, 103 censuses had disability questions and also utilized core sets of questions recommended in the Principles and Recommendations. For the remaining 100 countries, it was not yet ascertained by UNSD whether Member States included disability in the census.

Of the 103 censuses found to have disability as a topic in their censuses, 45 countries or areas reported their national data on disability to the DYB System during a single year of DYB data collection in 2005 (See Table 2) 25.

| Table 2. | National tabulations provided to the United Nations through the Demographic Yearbook Questionnaires providing national disability statistics on core topics that may be used for comparison of persons with and without disabilities with respect to equalization of opportunities (1995-2006) 26 |

Among the 45 countries or areas that reported their national data on disability to the DYB System during a single year of DYB data collection (2005-06) 27:

- 42 reported the age and sex and urban/rural residence of persons with and without disabilities.
- 29 reported information concerning school attendance of children. These data are useful for assessing universal primary enrolment among children with and without disabilities.

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26 Data were collected during a one-year period of DYB data collection that took place 2005-2006.

27 The 45 countries or areas that reported disability data at that time include: Aruba, Australia, Austria, Azerbaijan, Bahrain, Belarus, Brazil, China, Hong Kong; China, Macao; Costa Rica, Croatia, Cyprus, Egypt, Guam, Honduras, Hungary, India, Ireland, Israel, Italy, Jamaica, Japan, Latvia, Lithuania, Malta, Mexico, New Zealand, Niger, Occupied Palestinian Territories, Oman, Philippines, Poland, Portugal, Rep. of Korea, Romania, Russia, Saudi Arabia, Slovakia, Solomon Islands, Spain, Switzerland, Trinidad and Tobago, Turkey, Turks and Caicos, and Ukraine.
34 reported information concerning economic activity.

**Source:** UN DYB Database System, Statistics Division, DESA 2010.

These national data are potentially useful in poverty comparisons and also for consideration of equalization of opportunities of persons with and without disabilities in major development goals, including the MDGs.  

National collection and reporting of disability data is improving owing to the agreements that have been reached by the United Nations on ways to proceed in harmonizing the definitions, concepts, standards and methods of statistics on persons with and without disabilities. Evidence that national data can be reported to the United Nations under these new agreements is reflected in the results of the 45 countries that first submitted their national disability statistics to the United Nations in 2005 using the DYB Human Functioning and Disability Questionnaire (See Table 2 and also Http://www.un.org/disabilities/default.asp?navid=13&pid=1515). The compilation of these metadata by the United Nations from Member States were possible because of a number of noteworthy international agreements that have been reached to improve the comparability, validity and reliability of disability statistics. They include:

1. The 2008 publication of the internationally agreed *Principles and Recommendations for Population and Housing Censuses, Revision 2* by the Statistics Division. This publication states clearly and unambiguously the recommendations for inclusion of disability characteristics as a census topic.


3. The 2002 agreement to push forward with the development of disability measurement in censuses and surveys through the newly formed Washington Group on Disability Statistics, a United Nations city group that focuses on proposing international measures of disability. The Washington Group has developed a short set of disability questions that can be included in censuses, and

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28 As of the date of this current report, these data had not yet been published by the United Nations for further information and use.
29 Series M. No. 67/Rev.2
30 *Principles and Recommendations for Population and Housing Censuses, Revision 2*, Paras. 2.350 - 2.380.
31 In the 2002 agreement of the Statistical Commission it was referred to as the Washington Group on Disability Measurement; however, its name was subsequently changed to Washington Group on Disability Statistics.
is also developing extended sets of disability questions for use in population surveys. These questions follow the core disability domains laid out in the Principles and Recommendations and use the ICF model as the basis for the development of these questions. See www.cdc.gov/nchs/city_group.htm for updates on the questions.

4. The 2001 publication of the internationally agreed *International Classification of Functioning, Disability and Health*[^32] by the World Health Organization that provides a unified standard for definitions, concepts and classifications of policy, legislation and statistics.

5. The 1994 United Nations agreement on the *Fundamental Principles of Official Statistics* that aims to protect privacy and ensure validity and reliability of data and its interpretation

For greater detail about each of these international agreements, see Annex 1.

Recent strides in the development of disability statistics, however, are not yet fully reflected in analytical reports. Disability statistics are not yet sufficiently integrated into the work programmes of the groups of analysts who would need to monitor and evaluate progress in achieving development goals, such as MDGs.

Although there is considerable evidence that Member States have collected disability data, in some cases over many decades, the use of these national datasets by planners and policymakers has been limited. For example, it is not well-known that in many countries around the world, data on disability have been collected for at least 100 years by a number of national statistical offices. The data from these past efforts are not effectively utilized in the reports of ministries and also have been under-utilized in the analysis and reporting of information concerning development or human rights. To make this point, for example, in Egypt, the United Nations has published disability statistics from Egypt’s 1907 population census. See Table 6 shown at this website: [http://unstats.un.org/unsd/pubs/gesgrid.asp?id=214](http://unstats.un.org/unsd/pubs/gesgrid.asp?id=214).

In numerous instances, existing data were not incorporated in general reports on disability nor were they published in in-depth ministerial reports aimed at monitoring and evaluating their population’s socioeconomic conditions. More often, these data were shunted aside, or ignored, as were many persons with disabilities. What is seriously lacking is the preparation of analytical reports that use these datasets for assessment of development goals, including disability-inclusive MDG indicators[^33]. Increased utilization of these data sets is needed for the preparation of analytical reports by policymakers and programme managers that mainstream disability concerns into general development goals and programmes.


[^33]: Earlier works published by the United Nations that report national census and survey data useful for assessing development goals are summarized in Annex 1. Actions Taken by the United Nations in support of Disability-Inclusive Development Goals.
However, in addition to using existing data, plans must be made to improve further work. There is now much greater potential for future development reports to provide data that are both comparable and valid, based on the work completed by the Washington Group. Increased attention to the work of the Washington Group by development planners including MDG planners, while taking into consideration the principles of the Convention, should be strongly encouraged.

Identifying persons with and without disabilities in censuses and sample surveys through a short set of questions now being tested by the Washington Group. The Washington Group has prepared a short set of questions for use in censuses and national sample surveys, that was developed according to the *Fundamental Principles of Official Statistics* and is consistent with the World Health Organization’s *International Classification of Functioning, Disability, and Health (ICF)*. These questions were developed for administration using census methodology and testing has shown that they produce internationally comparable data on persons with and without disabilities both in censuses and in sample surveys of living conditions, among others.

The questions cover six core functional domains or basic actions: seeing, hearing, walking, cognition, self care, and communication. The short question set reads as follows:

**Text Box 1. SHORT SET OF QUESTIONS**

“The next questions ask about difficulties you may have doing certain activities because of a health problem:

1. Do you have difficulty seeing, even if wearing glasses?¹
2. Do you have difficulty hearing, even if using a hearing aid?²
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?”

Each question has four response categories that result in a severity scale:

- (1) No, no difficulty,
- (2) Yes, some difficulty,
- (3) Yes, a lot of difficulty and
- (4) Cannot do it at all.

**Source:** Washington Group, 2009., [http://www.cdc.gov/nchs/citygroup/citygroup_questions.htm](http://www.cdc.gov/nchs/citygroup/citygroup_questions.htm)

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³⁴ See [www.cdc.gov/nchs/citygroup.htm](http://www.cdc.gov/nchs/citygroup.htm) for methodological updates on the short set of questions.
³⁶ *International Classification of Functioning, Disability and Health* (World Health Organization, Geneva, 2001)
³⁷ *Principles and Recommendations*, para. 2.358.
The Washington Group short set of questions are proving useful for addressing, through a set of planned census tabulations, the issue of whether persons with disability participate to the same extent as persons without disabilities in activities such as education, employment or family/civic life. This short set of questions can be used to prepare cross-tabulations in censuses and in specialized surveys covering education, labor, population, living conditions and the like, and can be used as a way of expanding ones understanding of people’s experience with disability across a number of topics and concerns. A major reason for this choice is the central importance of the issue of community development, social participation and equality of opportunity from a policy perspective as stated in the MDGs and in the Convention.

The Washington Group has found that, this short set of questions can provide valuable information on disability that is especially useful for local areas, and for programme planning. Additional data collection mechanisms such as specialized national surveys using an extended set of questions is proving useful for obtaining a more complete understanding of disability.

The United Nations Principles and Recommendations for Population and Housing Censuses, Rev. 2 incorporated the work thus far completed by the Washington Group.\(^38\) The newly revised Principles and Recommendations for censuses envisioned three major classes of purposes for measuring disability:

*First*, to provide services, including the development of specific programs and policies for service provision and the evaluation of these programs and services. The provision of services at the population level includes, but is not limited to, addressing needs for housing, transportation, assistive technology, vocational or educational rehabilitation and long-term care;

*Second*, to monitor the level of functioning in the population. Monitoring levels of functioning includes estimating rates of body function, activity and participation and analyzing trends. The level of functioning in the population is considered a primary health and social indicators, which characterizes the status of the population in a society; and

*Third*, to assess equalization of opportunities. The assessment of equalization of opportunity involves monitoring and evaluating outcomes of anti-discrimination laws and policies, and service and rehabilitation programmes designed to improve and equalize the participation of persons with disabilities in all aspects of life.\(^39\)

**Identifying persons with disability** When studies are undertaken and disability is to be included as a topic, relevant data on persons with and without disability are required for broad comparative purposes. More detailed questions can then be asked among the broad group of persons with disabilities, to further disaggregate their situation. This effort includes preparing a set of questions to be instituted into censuses, surveys and registries that identify persons with disabilities. By so doing, people with and without disabilities

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\(^38\) See: Principles and Recommendations, Section VI, Group 8: Disability Characteristics; and Tabulations on Disability Characteristics.

\(^39\) Para. 2.360.
may be compared regarding their disability experiences as well as for their demographic and geographic characteristics, levels of education and economic activity, and household and housing differences, etc. This is the approach now recommended in the *Principles and Recommendations* and used by the Washington Group.

The *Principles and Recommendations for Population and Housing Censuses* include a set of recommended tabulations on disability characteristics[^40]. They cover comparisons of persons with and without disabilities for (a) geographic division, age and sex; (b) educational attainment; (c) Current or usual activity status (economic activity and employment).

In addition to the recommended sets, four additional tabulations are also proposed in the *Principles and Recommendations* for disability characteristics. They include: (a) Total population by disability status according to whether they are living in a household or institution, by age and sex; (b) Households with one or more persons with disabilities, by type and size of household; (c) Total population 15 years of age and over by disability status, marital status, age and sex; and (d) Population 5-29 years of age by disability status, school attendance, age and sex.[^41]

The six domains proposed by the Washington Group in the short set of questions to identify persons with disability cover the areas of functioning related to vision, hearing, mobility, cognition, self-care and communication. Furthermore, the response categories also capture the degree or severity of the difficulty experienced. Multiple disability scenarios can be described depending on the domain(s) of interest and the choice of severity cut-off.

**Variations in prevalence rates of persons with disabilities: an illustrative example**  
It is important to note that there is more than one way to capture disability and that the way chosen impacts on the prevalence rates. In Zambia for example, the 1990 census asked the question “Are you disabled in any way? Yes/No”. If “Yes”, then “What is your disability?” A total of 4 impairment categories were included for the reply: blind; deaf/dumb; mentally retarded; and crippled. This resulted in a population prevalence rate of 0.9%

In the 2000 Census of Zambia[^42] a similar question was used and 7 impairment categories were included to choose from: blind; partially sighted; deaf/dumb; hard of hearing; mentally ill; ex-mental; mentally retarded; and physically handicapped. This impairment


approach yielded a disability prevalence rate in Zambia of 2.7% which, in fact, represented a trebling of the 1990 disability rate.\textsuperscript{3,43}

The short set of Washington Group questions was included in a 2006 Living Conditions Survey in Zambia\textsuperscript{44}. In the analysis, several possible cut-off points for measuring disability were assessed across the six domains of: (1) seeing; (2) hearing; (3) mobility (walking or climbing steps); (4) remembering, or concentrating; (5) self care e.g. washing all over or dressing; and (6) communicating using your usual language, do you have difficulty communicating, for example understanding or being understood by others.

This set of core questions also may result in not one but several possible prevalence estimates. The prevalence rates differ according to the selection of severity cut-off points. For example, In the Zambia Living Conditions survey: (a) some difficulty in carrying out at least one of the six domains results in a prevalence rate of 14.5% . (b) a lot of difficulty on at least one of the six domains results in a prevalence rate of 8.5%.

Both of these estimates represent a valid estimate of prevalence, and each has its own uses and limitations. These results speak to the flexibility of the instrument in allowing for a choice of definition based on the purpose of data collection.

To take into consideration the degree of difficulty experienced by persons with disability, a number of prevalence rates are proposed by the Washington Group and they are shown in the Text Box below.

**Text Box 2. Four prevalence measures proposed by the Washington Group\textsuperscript{45}**

1. **Broad Measure**: includes everyone with at least one disability domain coded according to any degree of difficulty reported, i.e. some difficulty (mild), a lot of difficulty (moderate), or unable to do it (severe).

2. **Second measure**: Includes everyone with at least one domain coded as a lot of difficulty, or unable to do it. It excludes “at least some difficulty”.

3. **Third measure**: Includes everyone with at least one disability domain coded as unable to do it at all. It excludes “at least some difficulty” and “a lot of difficulty”.

4. **Multiple basic action difficulties**: Includes everyone with two or more disability domains coded according to any degree of difficulty i.e., “some difficulty”, “a lot of difficulty”, or “unable to do it”. It excludes everyone with only one disability domain coded according to any degree of difficulty.


\textsuperscript{43} CSO, 1990 Census of Population, Housing and Agriculture, Available online at: \url{http://www.hist.umn.edu/~rmccaa/IPUMSI/index.htm}


\textsuperscript{45} Washington Group on Disability Statistics, “Understanding and Interpreting Disability as Measured using the WG Short Set of Questions” (04/20/09)
Table 3 below shows an illustrative example of variation in prevalence measures for one country.

Table 3: Illustrative example of variations in prevalence measures, Zambia, 2006

<table>
<thead>
<tr>
<th>Determination of Disability</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cut-off is:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Broad Measure:</strong> at least one domain is scored <em>some difficulty</em></td>
<td>4053</td>
<td>14.5</td>
</tr>
<tr>
<td><strong>Second Measure:</strong> at least one domain is scored <em>a lot of difficulty</em></td>
<td>2368</td>
<td>8.5</td>
</tr>
<tr>
<td><strong>Third Measure:</strong> at least one domain is scored <em>unable to do it at all</em></td>
<td>673</td>
<td>2.4</td>
</tr>
<tr>
<td><strong>Multiple Basic Action Disabilities:</strong> two or more disability domains coded according to any degree of difficulty i.e., some difficulty, a lot of difficulty, or unable to do it.</td>
<td>1718</td>
<td>6.1</td>
</tr>
</tbody>
</table>

| Total number surveyed (Grand Total) | 28,010 |


Again, in Table 3, higher prevalence rates are associated with the inclusion of any disability (14.5%). Lower prevalence rates are shown among those who reported moderate disability (8.5%); and lowest prevalence rates were shown among those who reported severe disability (2.4%).

Note that the severe disability prevalence rate of 2.4% for Zambia from the 2006 Survey of Living Conditions is similar to the national prevalence rate from the 2000 census of 2.7% which was based on an impairment-based definition that included the more severe forms of disability. It has been postulated by the Washington Group that the relatively low prevalence rates reported in many low-income countries, as in Zambia in 2000, may in fact correspond more closely to true rates of severe disability in these countries.

For each of the six core domains it was possible to calculate the proportion of those with disabilities according to severity or degree of difficulty. Three degrees of difficulty were proposed and the results for Zambia are shown below in Table 4.

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46 Washington Group, “Understanding and Interpreting Disability as Measured using the WG Short Set of Questions”, p.4.
Table 4: Percent of persons with disability (prevalence per 100) according to core disability domain and degree of difficulty, Zambia. (2006; N=28,010; 179 missing data)

<table>
<thead>
<tr>
<th>Type of Disability: Core Domains</th>
<th>Degree of Difficulty %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>At least some difficulty - Broad measure</td>
</tr>
<tr>
<td>Vision</td>
<td>4.7</td>
</tr>
<tr>
<td>Hearing</td>
<td>3.7</td>
</tr>
<tr>
<td>Mobility</td>
<td>5.1</td>
</tr>
<tr>
<td>Remembering</td>
<td>2.0</td>
</tr>
<tr>
<td>Self-Care</td>
<td>2.0</td>
</tr>
<tr>
<td>Communication</td>
<td>2.1</td>
</tr>
</tbody>
</table>


Results in Table 4 show that in Zambia, mobility problems had the highest prevalence rates across all three degrees of difficulty, 5.1%, 3.8% and 0.8%, respectively. This was followed by visual, then hearing difficulties. Problems relating to remembering, self-care and communicating all showed a lower prevalence. In general, prevalence rates for persons reporting mild disability are higher than prevalence rates for persons reporting severe disability. For example, in the Zambian survey highest prevalence rates were reported for people who say they have at least a mild disability or “at least some difficulty with vision”; lower prevalence rates were shown for people who have a moderate disability or “a lot of difficulty seeing”; and lowest prevalence rates were reported for people who say they have a severe disability and are “unable to see”: 4.7%; 2.6%; and 0.5%, respectively. The core domains presented in Table 4 are not mutually exclusive. It is possible for persons to report disability in more than one domain. For this reason, the sum of disabilities might be greater than the number of persons.

Socioeconomic and demographic comparisons of persons with and without disabilities There is a great need for further analysis of disability data that moves beyond prevalence to comparisons of persons with and without disability for their demographic and
socioeconomic characteristics. Disability data collected from censuses and surveys can be used, in combination with data on other variables, to measure development goals such as the MDGs for their compliance with the United Nations Convention on the Rights of Persons with Disability. Data derived from the short set of questions proposed by the Washington Group, coupled with information collected through the population and housing census or a sample survey on employment, education, housing, transportation, social and health services, in addition to aspects of family, cultural and social life can be used to compare the levels of participation between those with disability and those without, thereby assessing equitable access to opportunities as required by development goals, including the MDGs.

School  An illustrative example prepared by the Washington Group of how such national data may be presented to highlight comparisons of persons with and without disability to assess issues relevant to the Millennium Development Goal of universal primary school enrolment is shown in Table 5 below.
Table 5. Population aged 15 years or over who *never attended school* according to disability status in selected countries (percent)

<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>With disability</th>
<th>Without disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>Mozambique</td>
<td>38</td>
<td>27</td>
</tr>
<tr>
<td>2006</td>
<td>South Africa</td>
<td>23</td>
<td>6</td>
</tr>
<tr>
<td>2008</td>
<td>Tanzania</td>
<td>42</td>
<td>21</td>
</tr>
<tr>
<td>2006</td>
<td>Uganda</td>
<td>42</td>
<td>16</td>
</tr>
<tr>
<td>2006</td>
<td>Vietnam</td>
<td>30</td>
<td>6</td>
</tr>
<tr>
<td>2006</td>
<td>Zambia</td>
<td>23</td>
<td>10</td>
</tr>
</tbody>
</table>

*Source: Provided by the Washington Group on Disability Statistics, 2010*[^17]

**Employment** Data on persons with and without disabilities can be cross-classified with employment data to identify the proportion of persons with and without disability who are employed. This is an assessment of the equality of employment opportunities. If policy interventions are initiated to enhance workplace accommodations, their effect on the employment of persons with disability can be determined. From a theoretical perspective, if opportunities have been optimized then participation should be equal between persons with and without disability. For a national example of such a comparison, see Table 6 below.

[^17]: Original national data from:
- **Vietnam**: *Vietnam Household Living Standards Survey, 2006*;
Table 6: Access to education and employment by disability status
(Zambia, 2006)

<table>
<thead>
<tr>
<th>Determination of Disability</th>
<th>Never attended school (%)</th>
<th>Not working (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(age 6 years or older)</td>
<td>(age 15 – 65 years)</td>
</tr>
<tr>
<td>Cut-off is:</td>
<td>Not</td>
<td>Disabled</td>
</tr>
<tr>
<td>Broad Measure: at least one domain is some difficulty</td>
<td>8.2</td>
<td>22.8</td>
</tr>
<tr>
<td>Moderate Disability: at least one domain is a lot of difficulty</td>
<td>8.8</td>
<td>23.3</td>
</tr>
<tr>
<td>Severe Disability: at least one domain is unable to do it</td>
<td>9.8</td>
<td>37.2</td>
</tr>
<tr>
<td>Multiple Basic Action Disability: two or more disability domains coded according to any degree of difficulty i.e., some difficulty, a lot of difficulty, or unable to do it.</td>
<td>9.5</td>
<td>24.7</td>
</tr>
</tbody>
</table>


The data from Zambia used in table 6 illustrate that persons with disabilities are less likely to have attended school and also less likely to be employed than are persons without disabilities. These findings again show, the more severe the disability reported, the less access there is to education and employment.

Environmental factors The analysis would not need to stop here. Further analysis might be tried, through preparation of tabulations of environmental factors and their impact on persons with and without disabilities. Such as information about available transportation systems, housing conditions, gender attitudes, community poverty levels, nutritional and work status of children, etc., would be beneficial in helping to better understand the types of barriers that reduce participation in school and work, and to help consider ways to improve on the situation through the provision of more equal opportunities for school, work and community participation among persons with disabilities, thereby mainstreaming disability concerns into already existing development goals, such as the MDGs, as mandated by the United Nations.

Policy implications To conclude, determining disability prevalence on the basis of the presence or absence of some major impairment in a census can be both problematic and restrictive. This is because it may exclude a broader group of persons with disabilities
who also confront barriers and discrimination. An approach is suggested by the Washington Group that focuses on functional limitations rather than solely upon impairment and allows the reporting of several prevalence rates based on thresholds of difficulty in performing different basic actions.

Referring back to the UNSD matrix that provides a broad working framework of disability useful for planning statistics, we note that it included both the disability domains of the ICF and also three broad programme areas of prevention, rehabilitation and equalization of opportunity as stated in the World Programme of Action and the Standard Rules. Through such a matrix framework, and using the Washington Group short set of questions for identifying and comparing persons with and without disabilities results in improved comparisons of program targets and persons served.

Policy implications related to the flexibility in this survey approach to disability may be profound. If service provision is based on the prevalence of persons with disabilities then clearly this would impact on policy, particularly in low-income, developing countries where essential resources and capital are scarce. One might ask for example, “What are the implications of developing a policy that provides services for 2.7% of the population if 13.4% require some service?” However, one might also ask, “Would it not be more appropriate and efficient to provide services to the specific population that requires them?” In the case of Zambia, while 14.5% of the sample population (Table 8) may have some difficulty in performing one or more basic actions, 0.5% was unable to see and 4.7% had some visual impairment. Targeting specific sub-populations would be more cost-effective, and would provide for the equitable and efficient delivery of services.

Also, with the knowledge that many children with disabilities in low-income countries do not attend school because of vision problems correctable by glasses, policy could be directed to target this specific sub-population, to provide necessary services and to rectify inequalities. A relatively minor and easily correctable functional problem that would have significant debilitating personal consequences could be avoided.

Efforts are now underway by the Washington Group to expand upon the short set by incorporating additional domains of functioning both in terms of basic actions, i.e., upper body function, learning, and affect; and developing standardized complex activity domains i.e. getting along with others, major life activities like employment and education, and participation in society. In addition more detailed information is sought on the impact of environmental factors at all levels (micro, meso, and macro), as well as other allied information on age at onset, duration, impact and cause of basic action/complex activity limitations.

By standardizing these questions it will be possible to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources; comparable data that can be used to assess a country’s development goals in light of

compliance with the Convention and, over time, their improvement in meeting the requirements set out in their development goals, including those of the MDGs.

In sum, the Washington Group is proposing that the assessment of equalization of opportunity, employing general disability measures is a suitable and meaningful approach to monitoring development goals like the MDGs in light of the principles put forward in the United Nations Convention on the Rights of Persons with Disabilities. Equalization of opportunities was chosen as the guiding purpose in the development of the Washington Group approach to measuring disability and it meets the criteria of relevance and feasibility of implementation internationally.

It is important to recognize that the general disability measure developed by the Washington Group to assess equalization of opportunities may not suit other purposes, nor will it provide a fully comprehensive assessment of disability concerns. For example, disease-specific impairments would not be measured using this technique, nor would such impairment-specific issues such as that of one leg missing. Instead, the focus is upon functional domains of activity, using a broad definition of the ICF. If such specific type of information was required, then additional screening questions would need to be included.

However, by coupling responses to questions that focus on one’s ability to function in basic actions with information collected on activity limitations and participation restrictions, in particular restricted access to employment and education, family and cultural life, it will be possible to assess the degree to which people with disabilities are afforded the same rights and access as people without disabilities.

In sum, disability represents a complex process and is not a single, static state. It refers to the outcome of the interaction of a person and his/her environment, whether physical, social, cultural or legislative and represents a measure of the negative impact of environmental factors on one’s ability to function.

The complexity of the concept of disability has resulted in the proliferation of statistics on disability that are neither comparable nor easy to interpret. Furthermore, disability data are collected for different purposes such as to estimate the prevalence of physical impairments or to plan for the provision of services. Each purpose elicits a different statistic and even when the intention is to measure the same concept, the actual questions used differ in ways that severely limit comparability. The conclusion is not that some estimates are right and others are wrong, but that they are measuring different things.

The Washington Group chose to develop a set of questions that would help to identify persons with and without disability in such a way that more harmonized comparisons may be made regarding their activity and participation. This addresses the issue of whether persons with disability participate to the same extent as persons without disabilities in activities such as education, employment or family/civic life. A major reason for this choice is the pivotal importance of the issue of social participation and equal rights from a policy perspective as illustrated by the recently ratified UN Convention on the Rights of Persons with Disabilities and embedded in development
goals, including the MDGs. In addition, there was agreement that it would be possible to develop a question set to meet this objective, that could be administered using census methodology and that could produce internationally comparable data.

The Washington Group continues to work on the development and testing of extended question sets more useful for surveys and survey modules and the production of technical reports on methodological issues such as dealing with special populations, for example, children and institutionalized persons, and these activities will continue to be reviewed by the Statistical Commission and ultimately approved by the Third Committee for their applicability and usefulness worldwide.

If resources allow, the Washington Group also plans to continue to offer technical assistance to countries to build national capacity for disability measurement and analysis.

III ANALYSIS AND REPORT PREPARATION: HOW ARE WE DOING?

After it is agreed as to how persons with and without disabilities will be identified in censuses or surveys using a short set of agreed questions, the next step is to plan for the necessary comparisons of persons with and without disabilities across a number of topics in order to monitor development goals including the MDGs. Census tabulations proposed below are already internationally agreed upon, including tabulations necessary to monitor some of the MDGs. If all countries prepare similar census tabulations, then disability statistics become increasingly harmonized and comparable and development indicators can be more readily prepared that are disability-inclusive.

In the United Nations Principles and Recommendations, Rev. 2, it is stated that a census can provide valuable information on functioning and disability in a country. For countries that do not have regular special population based disability surveys or disability modules in ongoing surveys, the census can be the only source of information on the frequency and distribution of disability and functioning in the population at national, regional and local levels. Countries that have a registration system providing regular data on persons with the most severe types of impairments may use the census to complement these data with information related to selected aspects of the broader concept of disability. Census data can be utilized for general planning of programmes and services for prevention and rehabilitation, monitoring selected aspects of disability trends in the country, evaluation of national programmes and services concerning the equalization of opportunities, and for international comparison of selected aspects of disability prevalence in countries.

Disability status is a core topic for censuses and in the Principles and Recommendations, Rev. 2. In addition, as stated earlier, three census tabulations on disability characteristics are recommended, covering disability domain, age and sex, educational attainment and economic activity of persons with and without disabilities.


51 See para 2.350 in Principles and Recommendations.
In the Principles and Recommendations, it is recommended that the following four domains be considered essential in determining disability status in a way that can be reasonably measured using a census and that would be appropriate for international comparison: 

- (a) Walking;
- (b) Seeing;
- (c) Hearing;
- (d) Cognition. A comprehensive measure would include all domains\(^{52}\). Two other domains, self care and communication, have been identified for inclusion, if possible. Another domain that should be considered for inclusion is upper body functioning\(^{53}\). These recommendations are in line with the ideas and proposals put forward by the Washington Group.

Once the disability status of each person recorded in the census is known, it then follows that tabulations may be tried across hundreds, and perhaps even thousands of comparisons. This is why it is very important to set priorities. Crossing each and every topic by each and every other topic is exorbitantly expensive and very difficult to comprehend. The purpose of the analysis must be well planned and priorities set so that the tabulations may be meaningfully and selectively provided.

Once persons with and without disabilities are identified in censuses and surveys, cross-tabulations may be prepared covering a wide range of topics. Census tabulations for disability characteristics are proposed, both as recommended and additional tabulations that may be produced.

The three recommended tables include the comparison of persons with and without disabilities by:

- (a) Age and sex;
- (b) Educational attainment; and
- (c) Current (or usual) economic activity status.

With respect to the first recommended census tabulation on age and sex, there is widespread interest in the prevalence of disability by age and sex of the population. This recommended tabulation provides information for the calculation of prevalence rates distributed by geographical division, urban/rural residence and the living arrangements of persons with disabilities.

The second recommended census tabulation provides data for the comparison of the educational attainment of persons with and without disabilities. The percentage of people with and without disabilities who have no schooling can be compared. This provides information on the status of integration of persons with disabilities and on the opportunities that they have to participate in the economic, social and cultural development of the country.

The third recommended tabulation address access to paid work because it is crucial to achieving self-reliance and ensuring the well-being of the adult population, both of persons with disabilities as well as of those without disabilities. Tabulations by economic

\(^{52}\) Principles and Recommendations, Para. 2.367.
\(^{53}\) Principles and Recommendations, Para. 2.352.
activity status provide a basic measure of the social and economic integration of the population with disabilities as compared with those without disabilities. Economic activity tabulations by urban/rural residence, age and sex are essential to identifying groups of the population that may be most disadvantaged.

In all cases, estimates of the population with and without disability are a function of the exact methods and question wording used in the data collection. It is important to consult the metadata for information on the methods (include the specific questions) used to collect this information. Note that the minimum age adopted by the country for enumerating the economically active population will vary.

In the Principles and Recommendations, Rev. 2 additional tabulations are also suggested. They include comparisons of persons with and without disabilities according to:
(a) Whether living in household or institution;
(b) Households with one or more persons with disabilities, by type and size of Household;
(c) Marital status and
(d) School attendance.54

This first additional tabulation provides information for the calculation of prevalence rates distributed by geographical division, urban/rural residence and living arrangements of persons with and without disabilities.

The second additional tabulation offers information on the number, type and size of households in which persons with and without disabilities live. The size of households and the distinction among the one-person household, the nuclear family household and the extended family household are useful for determining the economic and social provisions that may be needed for persons with disabilities living alone or with relatives. The tabulation also provides data for calculating prevalence of disability per household (number of households with at least one person with disability per 1,000 households).

The third additional tabulation provides information on the marital status of persons with and without disabilities and is important for understanding social integration and also reflects on human rights. This tabulation provides data on the marital status of persons with disabilities which are the basis for the calculation of age-sex specific marriage rates and divorce rates for comparison with persons without disabilities.

Finally, the fourth additional tabulation is focused upon school attendance patterns for children with and without disability. This tabulation is used to compare the current pattern of participation and non-participation in education. The percentage of people with disability of the school-age population who attend school can also be compared among the different types of disability.

If one were to gain access to national data based on these three recommended and four additional tables shown in the Principles and Recommendations, a comparison could be

54 Principles and Recommendations, Annex I.
made of key socioeconomic outcomes related to equalization of opportunities both in terms of economic development and the human rights perspective, i.e., empowerment of persons with disabilities.

If such basic information of persons according to their disability status for these seven tabulations from population censuses were to become widely available, covering such topics as age and sex and geographic location, educational attainment, economic activity, marital status, family or household formation, institutional living arrangements, and school attendance, then analytic opportunities would abound. Based on these seven tables alone, the monitoring and evaluation of development goals, including MDGs, in light of the Convention could begin in earnest.

Development indicators, like those used to assess the MDGs, are reviewed in the Principles and Recommendations for their potential to be compiled from census data. All the sources of data i.e., census, sample surveys and administrative records are needed to fulfil the data requirements of development goals, including the MDGs. By their nature, most of the MDG indicators cannot be computed from data that are typically collected through population and housing censuses alone, but would also require data from either household sample surveys or vital statistics.

However, a fair number of countries have been collecting, in their censuses and surveys, data on education and employment of persons with disabilities useful for providing information on progress towards MDG target 1B (employment) and MDG target 2A (education). In addition, data on sex differences in education and employment of persons with disabilities can be used to assess progress towards eliminating gender disparities in education and employment (Goal 3). For other aspects of the Goals—such as access to water and sanitation, child and maternal health, and hunger-poverty—the census data on households having persons with disabilities could prove very useful in shedding some light on these topics. In cases where data are very scarce or non-existent; case-studies might be required to provide some additional insight into these issues.

Those MDG indicators, for which disability status is already recommended or suggested in the Principles and Recommendations, Rev. 2 are shown below.

**MDG Target Indicator**

<table>
<thead>
<tr>
<th>MDG Target</th>
<th>Indicator</th>
</tr>
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<tbody>
<tr>
<td>8</td>
<td>Literacy rate of 15-24 years old</td>
</tr>
<tr>
<td>10</td>
<td>Ratio of literate women to men, 15-24 years old</td>
</tr>
<tr>
<td>11</td>
<td>Share of women in wage employment in the non-agricultural sector</td>
</tr>
<tr>
<td>45</td>
<td>Unemployment rate of young people aged 15-24 years, each sex and total</td>
</tr>
</tbody>
</table>

In addition, the following MDG indicators are potentially produced using census data, but comparisons for persons with and without disabilities are not yet recommended in the Principles and Recommendations, Rev. 2

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55 Principles and Recommendations, Paras. 3.120-3.124
**MDG Target Indicator**

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td>13</td>
<td>Under five mortality rate (potential)</td>
</tr>
<tr>
<td>14</td>
<td>Infant mortality rate (potential)</td>
</tr>
<tr>
<td>16</td>
<td>Maternal mortality ratio (potential)</td>
</tr>
<tr>
<td>21</td>
<td>Death rates associated with malaria (potential)</td>
</tr>
<tr>
<td>23</td>
<td>Death rates associated with tuberculosis (potential)</td>
</tr>
<tr>
<td>29</td>
<td>Proportion of the population using solid fuels</td>
</tr>
<tr>
<td>30</td>
<td>Proportion of population with sustainable access to an improved water source, urban and rural</td>
</tr>
<tr>
<td>31</td>
<td>Proportion of population with access to improved sanitation, urban and rural</td>
</tr>
<tr>
<td>32</td>
<td>Proportion of households with access to secure tenure</td>
</tr>
<tr>
<td>47</td>
<td>Telephone lines and cellular subscribers per 100 population (potential)</td>
</tr>
<tr>
<td>48</td>
<td>Personal computer in use in 100 population and Internet use per 100 population (potential)</td>
</tr>
</tbody>
</table>

**Source:** United Nations. *Principles and Recommendations for Population and Housing Censuses, Revision 2*, Chapter IX, Census Data Utilization, D. Development Indicators, Table 4 and paras. 3.120-3.124.

It is possible that even though the tabulations are not yet recommended for persons with and without disabilities on the above topics, that they could still be produced, on a trial basis. For example, once persons with and without disabilities are identified as members of a household in a census, it would then be possible analytically to divide the analysis into two groups: households having persons with disabilities and households without persons having disabilities so that their household or housing characteristics may be compared. This would be a major first step to assessing environmental factors. Although such analysis is not yet readily available, it could potentially be developed in future tabulations.

In addition, it should be remembered that even if a short set of disability questions are not included in censuses that statistics from censuses are still needed for producing MDG and other development indicators including disability indicators. Such development indicators are dependent on the censuses in quite a few ways. In addition to the indicators summarized above, the population census also provides the total population figure, which is a denominator for most indicators, including disability indicators. Also, the population and housing census provides the sample frame without which the design of necessary and accurate household surveys would be adversely affected.

It is not enough to simply produce a set of recommended tabulations. A programme needs to be put in place to support the use of these national disability statistics for analysis and reporting purposes with emphasis upon specific MDG targets related to equalization of opportunities at home, school and work.

To meet the need for further analysis, this report recommends that starting in 2015, the first quinquennial United Nations *Global Disability Report* should be prepared and
submitted to the General Assembly based on the statistics on persons with and without disabilities provided by Member States to the United Nations and also using other official reports provided by States Parties to the Convention on legislation and other actions taken to ensure the rights and opportunities of persons with disabilities are included in development planning, including the MDGs.

Further steps are needed to fully report and analyze the situation regarding the rights of persons with and without disabilities and to agree on a set of indicators for purposes of monitoring and evaluation: most notably is the need for a Global Disability Report aimed at assessing equalization of opportunities of persons with disabilities and also assessing progress made in national policy and legislation on human rights of persons with and without disabilities.

One recent illustrative example of a regional report that would feed into a Global Disability Report is that of the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP), namely Disability at a Glance 2009: a Profile of 36 Countries and Areas in Asia and the Pacific. This report, in accordance with the Convention, the Biwako Millennium Framework for Action and Biwako Plus Five, addresses the need for governments to: (a) develop rights-based policies and legislation; (b) mainstream disability perspectives in sectoral laws and policies; (c) strengthen national coordination mechanisms; and (d) enhance national capacities in data collection and analysis of disability statistics.

This report recognizes problems related to disability data collection in the region, as the definitions of disability, methods and institutional capacity regarding the data collection vary. It notes that although there are problems of comparability, that the ESCAP secretariat is of the view that the compilation of currently available data and information itself can reveal regional trends in the development of disability data, policy and institutional mechanisms. The compilations in this report are provided by the Secretariat as a reference whereby Governments, researchers, organizations of persons with disabilities, and other stakeholders are encouraged to take further action to enhance their data collection efforts and create an inclusive, barrier-free and rights-based society.

This regional report that already presents existing data, has set a baseline for comparison over time on progress made in the region regarding the equalization of opportunities of persons with and without disabilities and progress in legislation, institutional development and human rights.

A similar but global report is needed that incorporates basic indicators of progress at the global level that respects the request by Member States that official national statistics be reported to the United Nations and then widely and efficiently distributed as needed for preparation of reports and further analysis, and to reduce the likelihood that Member States will be receiving repeated requests by various parts of the United Nations and other interested organizations for these same national data. The demand for national disability statistics for national, regional and global reports is likely to increase significantly, now that disability-inclusive development in the monitoring and evaluation of internationally agreed goals including those of the MDGs, is a reality.
III. CONCLUSIONS

This report shows that disability-inclusive development statistics to monitor development goals, including the MDGs can be produced using data collected by member states in their population and housing census programmes. It also illustrates, using national examples, how disability measurement would potentially be further improved through the use of a common set of concepts, definitions, standards, and methods, such as those being developed and tested by the Washington Group under the auspices of the Statistical Commission and with large parts of it already approved by the Third Committee and published in the revised Population and Housing Census Recommendations, Revision 2.

This report suggests that disability-inclusive development goals are best served by a statistical system that focuses upon the assessment of equalization of opportunity, a major goal of the Convention and a major objective the World Programme of Action concerning Disabled Persons and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities as well as a majority of Development Indicator goals, such as those that reside within the Millennium Development Goals.

Also, recognizing that The Demographic Yearbook (DYB) database houses the 2010 round of internationally agreed data from the World Programme of Population and Housing Censuses, and recognizing that at its 34th session the United Nations Statistical Commission emphasized the need to ensure the collection of internationally comparable statistics and approved the collection of disability statistics on a regular basis;

Welcoming the work of the Washington Group on Disability Statistics as a United Nations city group which focuses on proposing international measures of disability that has developed a short set of disability questions, which can be included in censuses and surveys and extended sets to be recommended for use in sample surveys;

Seeing the need for improved use of these disability statistics for policy, legislation, and monitoring, notes the recent strides in disability statistics.

In light of these accomplishments and new initiatives in disability statistics, while also recognizing that the development of disability statistics are not yet sufficiently integrated into the work programmes of the groups of analysts that monitor and evaluate progress in achieving development goals, including those of the MDGs in light of the goals of the Convention. The General Assembly may wish to:

1. Encourage Member States to continue to report national disability data to the United Nations and ensure that the national datasets reported to the United

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57 Hereafter referred to as the World Programme.
58 Hereafter referred to as the Standard Rules.
59 Hereafter referred to as MDGs.
Nations be reviewed, evaluated, published and disseminated on a regular basis;

2. Asks that a series of reports be submitted through appropriate reporting mechanisms within the United Nations to promote the use of existing disability statistics, such as in a series of analytical briefs, with a view to contributing to the common goals of the Convention, the World Programme, the Standard Rules as well as the internationally agreed development goals, including MDGs; and

3. Starting in 2015, consideration should be given to preparation of the first United Nations Global Disability Report by the Secretary General for submission to the General Assembly summarizing disability statistics provided by Member States and presenting information provided by States Parties to the Convention addressing new legislation and other actions taken during the 5 year period from 2010-2014 to ensure human rights and equalization of opportunities of persons with and without disabilities.

In many areas of governmental activity, e.g. education, employment, health, housing, welfare, immigration and environment, it is the case that policies, legislation, and programmes exist. However, a primary difficulty is they may not always be effectively implemented. When human rights and equalization of opportunity are legislated, they too, must be followed up with monitoring and evaluation to ensure effective implementation.

No statistical system is ever perfect. There will always be room for improvement. Because of this, producers and users of statistics including representatives of persons with disabilities should meet on a regular basis to monitor and evaluate the outcome of statistical activities in support of disability-inclusive development goals including the MDGs, as well as those of the Convention, in collaboration with the Statistics Division and interested others to conduct such regular reviews. These reviews are periodically necessary to ensure the appropriateness and effectiveness of the statistical system in meeting the needs of and addressing these disability-inclusive development goals. The regular participation of producers and users in this review process will help to ensure that there is effective feedback to the statistical system on ways to improve further work. At the same time, it should also help to inform users of disability statistics on ways to more effectively utilise statistics for addressing these same goals.
Annex 1. Actions Taken by the United Nations in support of Disability-Inclusive Development Goals

A. Actions taken by the UN Statistical Commission in support of disability statistics

The United Nations Statistical Commission, in its Special Session of 11-15 April 1994, adopted the **Fundamental Principles of Official Statistics**. The Principles addressed ways to increase the public trust in official statistics. Principle 6 states that *Individual data collected by statistical agencies for statistical compilation, whether they refer to natural or legal persons, are to be strictly confidential and used exclusively for statistical purposes*.

References to the Fundamental Principles are noted by the Convention with respect to disability statistics, for example in its discussion of the proper safeguards for statistics.

In 2002, the Statistical Commission, at its 33rd session, welcomed the formation of the Washington Group on Disability Statistics as a city group and endorsed its programme, noting: (i) The need for standard instruments and comparable indicators on disability; (ii) The relevance of its work to the wider area of social integration and exclusion; (iii) The importance of validating and reconciling data collected by different organizations. In addition, at this same session, it took note of the newly approved World Health Organization *International Classification of Functioning, Disability and Health* and welcomed the initiative of the Washington Group to use the *Classification* as a framework for the development of statistics on disability.

In 2003, at its 34th session the Statistical Commission: (i) Supported the collection of disability statistics through the *Demographic Yearbook* system and approved the collection of disability statistics on a regular basis; (ii) Emphasized the need to ensure the collection of internationally comparable disability statistics; (iii) Encouraged the United Nations Statistics Division to work with the Washington Group on Disability Statistics to identify items for which statistical information on disability was comparable; (iv) Advised the judicious and complementary use of the sources of disability statistics and information, namely, censuses, surveys and administrative records.

In 2004, at its 35th session, the Statistical Commission recognized that the United Nations Statistics Division decennial census programme could not cover all emerging topics and asked the expert group on censuses address newly emerging concerns and seek ways to harmonize census results and prepare an updated version of guidelines that would take into consideration the varying needs of both more developed and less developed national statistical offices, as well as regional differences. Attention must be paid to… the need for improved statistics on…disability. The goal was to anticipate the need for a common approach for countries choosing to cover newly emerging topics, rather than to make this a requirement for all. The Commission also approved two new workshops on *Collection and dissemination of disability statistics into the United Nations Demographic*

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Yearbook system and took note of the presentation made by the Washington Group on Disability Statistics and noted the progress being made;

In 2007, at its 38th session the Statistical Commission adopted Principles and Recommendations for Population and Housing Censuses, Revision 2 which included recommendations on disability characteristics as a newly emerging census topic. The Commission also at this same session asked that the work of the Washington Group on Disability Statistics continue.

**B. Actions taken by the General Assembly in support of disability statistics**

What follows here is a summary of General Assembly decisions on disability related to the development and use of disability statistics.

Disability-inclusive development in the monitoring and evaluation of internationally agreed goals including the MDGs and its Optional Protocol was adopted on 13 December 2006 and entered into force on 3 May 2008. Article 31 of the Convention clearly articulated that State Parties shall assume responsibility for collecting and disseminating information including statistics and data to improve policy-making and thereby giving effect to the Convention.

Article 31 of the Convention addresses statistics and data collection by governments that need to be undertaken in order to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention. It states in its first paragraph that the process of collecting and maintaining statistical information shall (a) comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect of the privacy of persons with disabilities; that it shall (b) comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics (Convention, para.1).

The purpose for which the data are collected are to help assess the implementation of States Parties’ obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

The Convention is built upon earlier decisions reached in 1982 under the World Programme of Action concerning Disabled Persons (A/RES/37/52) and a decade later in 1993 under the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (A/RES/48/96). These two actions both stressed the importance of statistics and indicators for purposes of monitoring and evaluation and emphasized that the major purpose of the development and indicators of statistics was to assess the full participation and equality of persons with disability.

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62 Principles and Recommendations for Population and Housing Censuses, Revision 2, Paras. 2.350 - 2.380.
In 1982, *The World Programme of Action concerning Disabled Persons* stated the need for monitoring and evaluation (Para. 194). It asked that assessment be carried out periodically, of the situation relating to disabled persons, at the international and regional levels, as well as at the national level and that a baseline be established to measure developments (A/RES/37/52). The most important criteria for evaluating the World Programme of Action were stated as those of “Full participation and equality”.

With respect to development of statistics, the Statistical Office was urged, together with other units of the 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. In particular, a need was identified for technical manuals/documents on how to use household surveys for the collection of such statistics. These manuals would be used as essential tools and frames of reference for launching action programmes in the post-IYDP years to ameliorate the condition of disabled persons. (Para. 198). In this extensive exercise the United Nations Centre for Social Development and Humanitarian Affairs should play a major role, supported by the United Nations Statistical Office (Para. 199).

In 1993 the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* were agreed to (A/RES/48/96). Rule 13 on information and research asked for greater research attention to the programs and services offered persons with disabilities. It asked that participation of persons with disabilities be included in the production and dissemination of statistics. It says that States would assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities as well as on programmes and services and their use. Specific references are made in the text to the use of national censuses and household surveys and the need for databanks housing disability statistics produced.

The Standard Rules also referenced the need for protection of individual privacy and personal integrity. In addition, it asked States to develop and adopt terminology and criteria for the conduct of national surveys, in cooperation with organizations of persons with disabilities. The exchange of research findings and experiences were also emphasized including taking measures to disseminate information and knowledge on disability to all political and administration levels within national, regional and local spheres.

The Standard Rules, like the World Programme, requested that States should initiate and support programmes of research on social, economic and participation issues that affect the lives of persons with disabilities and their families. The Standard Rules specifically requested that such research should consider the need for development and evaluation of services and support measures ((Rule 13). (Refer to the addendum associated with it also, here, in a footnote.)

Recent actions taken by the General Assembly (A/C.3/64/L5/Rev.1) encourage Member States to make use of statistics, to the extent possible, to integrate a disability perspective in reviewing their progress towards realizing the Millennium Development Goals for all.
In order to do this effectively with statistics, comparisons, at a minimum, must be made between persons with disabilities and persons without disabilities across numerous socioeconomic and development indicators. Statistics on characteristics of persons experiencing specific diseases and medical conditions necessary for monitoring the MDGs would go beyond the reach of recommendations for population and housing censuses. Consultations with the World Health Organization and other interested parties would be necessary for further development of statistics for these disease-specific MDG goals.

C. Compilation of national disability statistics through the Statistical Commission

Essential to monitoring and evaluation of national programmes are data collected from national population and housing censuses, related sample surveys and administrative record programs. Since 1981, using such sources and under the guidance of the Statistical Commission, several compilations of disability statistics were tried. It became clear during these trials that once tabulated, national disability statistics have often languished, owing to lack of training in analysis of disability statistics among interested users, lack of comparability of datasets owing to a lack of agreed standards and methods; and lack of funding and support for the analysis of disability statistics and subsequent lack of production of disability reports by interested ministries and offices using official statistics as their source.

These problems are compounded when statistics are collected for population subgroups encountering problems of human rights, like those of persons with disabilities, among others. The *Fundamental Principles of Official Statistics* were agreed upon by the Statistical Commission as one important way to help to ensure the protection of privacy of persons and validity of statistics required for satisfactory data collection and analysis and to ensure their protection from misuse.63

The first trial compilation of disability statistics by the United Nations was conducted in the early 1980’s and resulted in a United Nations publication, *Development of Statistics of Disabled Persons: Case Studies* (ST/ESA/STAT/SER.Y/2). The Case Studies were prepared by the United Nations Statistical Office in collaboration with the Centre for Social Development and Humanitarian Affairs of the United Nations Secretariat. Financial support for this work was provided by the International Year of Disabled Persons Trust Fund. This trial analysis reviewed data from five countries collected by national statistical programmes during the period from 1947-1981. Based on the results, the advantages and disadvantages of selected data collection methods for the study of disability were outlined and a trial data presentation and analysis was conducted to show the extent to which the data were potentially useful for purposes of policy formulation and programme planning.

For example, levels of illiteracy were compared among countries that reported illiteracy levels for persons with and without disability. In addition, a review of educational attainment, economic activity and occupational attainment of persons with and without disabilities was tried using these same national data sets. The data showed substantially

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63 Reference for Fundamental Principles here.
different results for persons with disabilities and for the total population; persons with
disability generally showed lower rates of participation in education and employment.
Persons with and without disability also had substantially different age and sex
distributions than did the total population. This case study concluded that there is a
need for increased attention to the analysis of existing data as a method of improved
understanding and knowledge about disability.

The results of the case study were reviewed by an expert group and then published as a
United Nations document. This early international statistical activity demonstrated the
need for compiling, evaluating and disseminating existing disability data from key
national data sources as a way of encouraging further improvement and development of
disability statistics, while at the same time such activities offered opportunities for
learning a great deal about the demographic, social and economic situation of persons
with disabilities.

This earlier work acknowledged the many problems associated with existing national
data sets including lack of internationally agreed classifications, definitions, concepts and
methods for data collection and analysis. Without agreed standards and methods,
disability data were not readily comparable.

In its conclusions, the Case Studies noted, for example, that the following materials were
needed for more effective use and dissemination of existing data: (a) studies on the
application of an internationally agreed classification of disability for various statistical
purposes and suggested tabulations; (b) a review of the social and economic
characteristics of persons with disability on which data were collected and the tabulations
and basic indicators that might be derived from those data; and (c) a methodological
study suggesting ways to integrate statistics on persons with disability from numerous
data sources into a reasonably cohesive description of prevalence rates, geographical
distribution and the social and economic circumstances of persons with disability.

The second disability statistics compilation activity of the Statistics Division was
completed in the 1990, in co-operation with the United Nations Centre for Social
Development and Humanitarian Affairs of the United Nations Office at Vienna and the
World Health Organization who collaborated on the development of the conceptual
framework for the first Disability Statistics Compendium (ST/ESA/STAT/SER.Y/4). This
Compendium reviewed three types of data collection activities: population and
housing censuses; sample surveys; and administrative reporting systems of 55 countries
or areas. This Compendium of national disability statistics reviewed data available for

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64 For example, see section IV in the Development of Statistics of Disabled Persons: Case Studies
(ST/ESA/STAT/SER.Y/2) that provides illustrative tables of census and survey data on persons with
disabilities, pp. 144.-199.

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66 Previously referred to as the International Classification of Impairments, Disabilities and Handicaps
(ICIDH) and now referred to as the International Classification of Functioning, Disability and Health
(ICF).
monitoring the implementation of the World Programme of Action Concerning Disabled Persons, pursuant to paragraphs 194-195 and 198 of that Programme.<sup>67</sup>

Although it was recognized that there was room for improvement, censuses, surveys and registration systems at that time were already addressing a number of issues relevant to monitoring the implementation of the World Programme of Action. Table 4 show topics covered in the Disability Statistics Compendium for 63 national censuses, surveys and registration systems of 55 countries that collected data on topics pertinent to the monitoring of the World Programme of Action.<sup>68</sup>

The Compendium assessed how disability concepts and definitions were used in countries to identify persons with and without disability and also demonstrated how this affected statistical findings. Statistics presented in the Compendium indicated that the percentage of persons with disability ranged from a low of 0.2 to a high of 20.9 percent for the 63 surveys of the 55 countries, when including data from all types of definitions, age ranges and data collection systems and recognizing their lack of comparability.

The Compendium also found that the prevalence rates were consistently different when stratified by their screening questions. Impairment questions resulted in lower prevalence rates and fewer women reporting a disability than men. In contrast, when disability screens focused on activity limitations, it resulted in higher prevalence rates of disability and more equal distributions of women and men reporting that they have an activity limitation.

The Compendium also noted that when comparing persons with and without disabilities the relationships to socioeconomic status were reasonably consistent: the results of these censuses and surveys indicated that persons with disabilities are on the average older, less educated and have lower socio-economic status and reside in rural or poor areas than do persons without disabilities.<sup>69</sup>

[Table 4 about here]

Also in the 1991, a third statistical compilation tried by the United Nations Statistics Division mainstreamed the collection of disability statistics into the United Nations Demographic Yearbook System for the reporting by Member States of their population of persons with disability by age and sex and urban/rural residence: latest available year.

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<sup>68</sup> Countries or areas included in the <em>Disability Statistics Compendium</em> include the following: AFRICA, Cape Verde, Central African Republic, Comoros, Egypt, Ethiopia, Kenya, Mali, St. Helena, Swaziland, Tunisia, Zimbabwe; ASIA, Bahrain, Burma (now Myanmar), China, Hong Kong, India, Indonesia, Japan, Jordan, Kuwait, Lebanon, Nepal, Pakistan, Philippines, Singapore, Sri Lanka, Thailand, Turkey; EUROPE, Austria, Denmark, Finland, Federal Republic of Germany, Ireland, Norway, Northern Ireland, Poland, Spain, Sweden; NORTH AMERICA, Belize, Canada, Republica de Cuba, Jamaica, Mexico, Netherlands Antilles, Panama, Trinidad and Tobago, United States of America; OCEANIA, Australia, Fiji, Kiribati, New Zealand; SOUTH AMERICA, Guyana, Peru, Uruguay, and Venezuela.

The results of this first effort to mainstream disability statistics into the international statistical demographic data collection system resulted in reporting of census, survey and registry data from 57 countries or areas. The results of this endeavor were published in the 1993 special topic on population aging and the situation of elderly persons by the Statistics Division and are also available at the following website http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp.

From these works, several things were clear. There was a substantial amount of data produced by countries as part of their official statistics programme, but it was not well known by potential users that nations were already collecting and compiling disability statistics on a regular basis and that these data were available for further analysis and dissemination. In addition, many countries were comparing their populations of persons with and without disability for their sociodemographic characteristics and programme needs. These reports concluded that disability is a cross-cutting issue related to socioeconomic concerns, population aging, status of women, rights of children, poverty eradication and equalization of opportunity, among others.

These reports also noted that there is a great need for international testing and agreement of standards for data collection and compilation of disability statistics to improve on their comparability, validity and reliability. Owing to the limited data analysis and dissemination of the existing results, progress was viewed as slow. There was a general lack of training in universities on how to compile and use disability statistics. These limitations slowed down the process of the incorporation of disability statistics into statistics produced for development planning.

However, progress throughout the next decade from 2000-2010 has continued.

<table>
<thead>
<tr>
<th>Disability Topics</th>
<th>National Studies (Number)</th>
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</thead>
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<td><strong>Demographic</strong></td>
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<td>Age group/sex</td>
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<td>Urban/rural status</td>
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<tr>
<td><strong>Socio-economic</strong></td>
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<td>Educational attainment</td>
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<tr>
<td><strong>Household and family formation</strong></td>
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<td>Marital status</td>
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<tr>
<td>Household characteristics</td>
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<td>Family information</td>
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</tbody>
</table>

Household and personal income 5
Disability Experience
Presence of an additional impairment 3
Age of onset 7
Cause of impairment 15
Disability status 4
Severity of impairment/degree of disability 7
Aids used for reducing disability 4
Services/treatment received 7

Other
Special disability issues 13

Total number of national studies 63
Total number of countries or areas 55

Source: United Nations Disability Statistics Compendium (ST/ESA/STAT/SER.Y/4), Table I.1