

**Briefing note on the collection and dissemination of
disability statistics**

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Introduction

1. Countries and NGOs recognize that statistical information is an essential basis for the development of adequate policies and programmes for promoting the rights of persons with disabilities. There is, however, legitimate demand, by persons with disability, that such information about individuals should be strictly used for statistical purposes paying due regard to privacy and confidentiality of the data collected.
2. The Working Group of the Ad Hoc Committee has addressed this issue by including such concerns in the draft of an article on statistics and data collection presented in the Third Session of the Ad Hoc Committee.
3. Several individuals requested an expert opinion of the United Nations Statistics Division on the collection and dissemination of disability statistics. This briefing note aims at responding to this request by presenting an overview of the international agreements in place on the collection and dissemination of disability statistics.
4. In particular, this note highlights the need to consider the *Fundamental Principles of Official Statistics*¹ in the collection and dissemination of statistics on disability. These fundamental principles were adopted by the United Nations Statistical Commissionⁱ in 1994² as the guideline for any official body or agency responsible for data collection, processing and dissemination. It consists of ten fundamental principles on reliability of statistics, protection of individual rights and prevention of misuse of information.
5. A considerable number of countries already collect official national data on disability. According to the disability database of the United Nations Statistics Divisionⁱⁱ, this number was at least 80 in the 1990s. The inclusion of a reference to the *Fundamental Principles of Official Statistics* in international recommendations, agreements or conventions on the collection, analysis, dissemination and use of disability statistics

¹ See annex 1 of this note.

² See *Statistical Commission, Report on the Special Session (11-15 April 1994)*, Economic and Social Council, Official Records, 1994, Supplement No.9, Series No. E/CN.3/1994/18, United Nations, New York, 1994. Available at <http://unstats.un.org/unsd/goodprac/bpabout.asp>

would ensure that the rights of persons with disabilities are recognized both in countries where the collection and analysis of disability data is already in place and in countries that will start this collection and analysis in the future.

6. Over the last decades, there has been an increased national and international interest in the situation of persons with disabilities. As a result, national efforts to collect data on disability in both developed and developing countries have increased. At the international level, the World Programme of Action concerning Disabled Persons³ called upon the United Nations to develop, on a continuing basis, suitable systems for the collection and dissemination of information on disability necessary for programme evaluation at all levels.⁴ The United Nations Statistical Commission, at its 34th Session, emphasized the need to ensure the collection of internationally comparable disability statistics and approved the collection of disability statistics on a regular basis through the United Nations *Demographic Yearbook*ⁱⁱⁱ system.⁵

7. The first two sections of this briefing note explain the importance of the collection of data on disability and describe the *Fundamental Principles of Official Statistics*, pointing out the crucial issues on the collection and dissemination of disability data.

8. The third section of this note presents some international recommendations and a framework for the collection and dissemination of disability data and ongoing developmental work on the measurement of disability.

9. The last section presents some of the past and current training workshops on the methodology, collection and analysis of data on disability, organized by the United Nations Statistics Division. These workshops aim at improving the national capacity of countries to collect internationally comparable data on disability.

³ 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. 52 (A/RES/37/52)*.

⁴ *Ibid.* para. 195.

⁵ See report on the thirty-fourth session of the Statistical Commission, 4-7 March 2003. E/2003/24 and E/CN.3/2003/34.

A. The need to collect official data on disability

10. Official statistics on disability play an essential role in the monitoring of equality of opportunity and achievements at the economic, social, political and cultural levels. In particular, disability statistics are useful tools in the planning, implementation and monitoring of policies and programmes for the promotion and protection of rights of persons with disabilities. In the planning and implementation of programmes, disability statistics identify areas that need intervention. As monitoring mechanisms, disability statistics allow countries to monitor and evaluate the outcome of policies and programmes.

11. Another important use of statistics on disability is their use as surrogates for other variables. For example, they may be used to detect areas where landmines are spread.

12. Finally, statistics on disability can help to monitor several aspects of the population with disabilities, in particular, aspects treated in the articles of the draft of the international convention on the protection and promotion of the rights and dignity of persons with disabilities⁶, such as access to education and employment.

13. Several international events and policy documents called for the production of statistics on a broad spectrum of topics necessary for the evaluation and monitoring of the situation of persons with disabilities. Both the World Programme of Action concerning Disabled Persons and the *The Standard Rules on the Equalizations of Opportunities for Persons with Disabilities*⁷ in 1993 made reference to the need for relevant disability statistics and indicators to be used in the development and implementation of appropriate policy and programmes and their monitoring and evaluation. However, it is crucial that the collection, analysis, dissemination and use of disability statistics is supported by appropriate principles and regulations to prevent misuse.

⁶ See report of the working group to the Ad Hoc Committee, 27 January 2004. A/AC.265/2004/WG.1.

⁷ Adopted by the United Nations General Assembly, forty-eighth session, resolution 48/96, annex, of 20 December 1993. In Rule 13 of *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, States are urged to collect information on the living conditions of persons with disabilities.

B. Fundamental Principles of Official Statistics

14. The United Nations Statistical Commission, in its Special Session of 11-15 April 1994, adopted the *Fundamental Principles of Official Statistics*. These *Fundamental Principles* have been developed to ensure that the rights of the individuals are respected in the collection and dissemination of official statistics while ensuring reliability of the statistical information. In particular, the *Fundamental Principles* lay out objective guidelines in the collection, dissemination and use of statistics, such as disability statistics, taking into account the privacy concerns and confidentiality of data pertaining to individuals. The full text of the *Fundamental Principles of Official Statistics* is provided in Annex 1. These principles include, among others, the principle of **confidentiality** (cf. annex 1, principle 6) “*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.*”

15. With regard to **prevention of misuse** of statistical information (cf. annex 1, principle 4) “*statistical agencies are entitled to comment on erroneous interpretation and misuse of statistics.*” Principle 7 states that “*The laws, regulations and measures under which the statistical systems operate are to be made public.*” (cf. annex 1). This ensures that persons with disabilities, and the population in general, are informed about the rules guiding the collection and dissemination of data on disability, particularly in terms of confidentiality and prevention of misuse. The transparency of a statistical system is essential for obtaining the trust of the respondents and the public.

16. **National coordination** (cf. annex 1, principle 8) and **international standards** (cf. annex 1, principle 9) are important to achieve efficiency and consistency of statistical systems. These internationally adopted *Fundamental Principles of Official Statistics* go a long way to support the collection and dissemination of data on disability. In addition, they lay a very useful and pragmatic foundation for collecting and disseminating valid and reliable statistics on disability while maintaining the right to privacy and ensuring confidentiality of individual respondents.

C. Collection and dissemination of data on disability

Measurement of disability

17. The primary goal of the collection of disability statistics is to satisfy the need for reliable data for specific purposes. These purposes may change with time and therefore international recommendations on data collection and dissemination are regularly revised to adapt to new demands. More important than specifying the attributes for collection of data on disability, is to encourage countries to follow the international agreements and use the international standards. Countries can further adapt their questions to meet the data demands required by their national programmes for the promotion of the rights of persons with disabilities.

18. The design of questions to identify persons in the population with disabilities presents particularly complex problems. From the conceptual standpoint, there is no universal definition of what constitutes a disability nor of who should be considered to have a disability. Recognizing the complexity of this issue, the WHO *International Classification of Functioning, Disability and Health*⁸ (ICF) provides a multidimensional framework within which to define the population with disabilities, rather than a single clear definition. The ICF provides standardized concepts and terminology for use in disability measurement, in order to avoid the unstandardized and often pejorative terms used in some studies on disability.

19. The United Nations Statistics Division published the *Guidelines and Principles for the Development of Disability Statistics*⁹ for assisting national statistical offices and other producers of disability statistics in improving the collection, compilation and dissemination of disability data. The *Guidelines and Principles* recommends the designing of questions for the measurement of disability to be done within the conceptual

⁸ *International Classification of Functioning, Disability and Health* (World Health Organization, Geneva, 2001).

⁹ *Guidelines and Principles for the Development of Disability Statistics* (United Nations publication, Sales No. E.01.XVII.15).

framework of the ICF. It is generally recognized that the question wording and the range of activities covered affect the number of persons that will be identified as having a disability. The *Guidelines and Principles* provide assistance in the design of questions to meet specific data demands. The document also addresses other methodological issues by providing guidelines and principles on data collection, through surveys and censuses, and also on the compilation, dissemination and usage of data on disability.

20. Some countries are already collecting data on disability, but due to differences in the concepts and methods used in the questions to identify persons with disabilities, prevalence rates are not comparable across countries. The use of the ICF for the measurement of disability contributes to greater comparability of data at the national and international levels, as recommended by principle 9 of the *Fundamental Principles of Official Statistics*, thereby increasing the relevance of the data to a wide set of users. It is primarily for these reasons that the United Nations, in its methodological guidelines, recommend the use of the ICF in disability measurement as a basis for the definition of the population with disabilities, in the formulation of questions, and also in the classifications of data.

21. The measurement of disability for statistical reporting was the focus of the *International Seminar on the Measurement of Disability* held in New York 4-6 June 2001 and sponsored by the UNSD, UNICEF, Eurostat and the Centers for Disease Control and Prevention (CDC) of the United States. The Seminar, which brought together developed and developing country experts in disability measurement, reviewed and assessed the current status of methods used in population-based data collection activities to measure disability in national statistical systems, and established the Washington Group on Disability Statistics^{iv} to implement the Seminar's recommendations for further work to improve the measurement of disability.

22. The main purpose of the Washington Group is the promotion and co-ordination of international co-operation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys that will provide basic necessary information on disability throughout the world. All disability measures recommended by the Group, will be accompanied by descriptions of their technical properties, and

methodological guidance will be given on their implementation and their applicability to all sections of the population.

23. The Washington Group is comprised of representatives of national statistical offices from over 44 countries and areas; and interested international organizations and non-government organizations. Information on the activities of the Washington Group are detailed in the paragraphs that follow.

24. The first meeting of the Washington Group, initiated by United Nations Statistics Division and hosted by the National Center for Health Statistics of the CDC, was held in Washington, D.C., on 18-20 February 2002. The meeting refined the objectives of the Washington Group to be:

(1) To guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world;

(2) To recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population surveys or as supplements to specialty surveys; and

(3) To address the methodological issues associated with the measurement of disability considered most pressing by the Washington Group participants.

25. In addition to setting the objectives of the Washington Group, the first meeting discussed various methodological issues in disability measurement, including purposes of measurement, an examination of the ICF model, the United Nations disability tables, global measures of disability, the relationship of global measures to the ICF, the confounding function of assistive device use, cultural practices that influence the nature of the environment or proscribe participation, cultural issues that act as barriers to collecting data and cross-national comparability of information. Despite the complexity of measuring disability, the Washington Group has endorsed, at this meeting, the

following statement: “It is important and possible to craft internationally comparable general disability measures.”¹⁰

26. The second meeting of the Washington Group was held in Ottawa, Canada on 9-10 January 2003, and covered the following topics: development of a measurement matrix that linked purpose of measurement with question characteristics; review of general disability measures currently in use; identification of measurement gaps; general health measures used in censuses and surveys; implementation of the Minimum European Health Module; reports from selected countries using general disability measures; measurement of environment and participation in existing surveys.

27. The third meeting of the Washington Group was held in Brussels, Belgium in February 2004. The meeting covered the priority purposes of disability measurement and confirmed the links between these purposes, measurement concepts, and characteristics of census and survey questions needed to reflect the concepts.¹¹

28. A fourth meeting is planned for September, 2004 (Bangkok). This meeting will consider and finalize a set of questions on disability for inclusion in census and national sample survey questionnaires. This set of questions will be reviewed and considered for inclusion in the next revision of the *Principles and Recommendations for Population and Housing Census*.

Important variables

29. The collection of data on disabilities is usually carried out in census and surveys. The Statistical Commission of the United Nations decided in 1997 to include disability as a census topic in the *Principles and Recommendations for Population and Housing*

¹⁰ See report on the thirty-fourth session of the Statistical Commission, 4-7 March 2003. E/CN.3/2003/8.

¹¹ The summary report of the Washington Group’s third meeting, prepared for the thirty-fifth session of the Statistical Commission, New York 2004, can be accessed at the Washington Group website, <http://www.cdc.gov/nchs/citygroup.htm>. This website also contains the agenda and products of the first and second meetings of the Washington Group, including the final reports.

Censuses.¹² The inclusion of data collection on disability in national censuses provides a valuable source of information on the prevalence and distribution of disability in the population, at national, regional, and local levels and gives possibilities for its correlation with data on employment, level of education and other relevant variables collected in the census. The *Principles and Recommendations* state that

“For the purpose of developing statistics on the situation of people with disability the principal topics in census recommendations include, *inter alia* (a) sex, (b) age, (c) place of residence, (d) type of household, (e) marital status, (f) type of disability (including multiple disabilities), (g) cause of disability, (h) educational attainment and attendance, (i) activity status, (j) status of employment, (k) industry and (l) occupation.”¹³

30. Surveys tend to collect more detailed information on disability due to their flexibility in implementation.

31. Data on disability collected in censuses and surveys can be a precious source of information for policy makers and organizations. For example, information on age is essential to distinguish child disability from adult disability and the collection of data by sex permits the identification of gender discrepancies regarding disability. Information on type of disability helps countries to identify subpopulations with different needs.

32. Statistics on disability also permit the identification of subgroups within the disabled population that are vulnerable to social disadvantage. For example, in some countries, rural and urban populations do not have equal access to health care and support. Information in census and surveys regarding place of residence (rural/urban) would permit to follow up to these situations, among persons with disability.

33. Regarding the dissemination of data on disability, the *Principles and Recommendations for Population and Housing Censuses, Rev. 1*, indicate that the data on

¹² Report on the twenty-ninth session of the Statistical Commission, 11-14 February 1997. E/CN.3/1997/29-E/1997/24.

¹³ *Ibid.*

disability should be presented in a way that facilitates comparisons of persons with and without disability on key social and economic characteristics.

International collection and dissemination of information on disability

34. The World Programme of Action Concerning Disabled Persons specifically requested the United Nations to develop systems for the regular collection and dissemination of information on disability. As a step in implementing this mandate, the United Nations Statistics Division disability website

<http://unstats.un.org/unsd/demographic/sconcerns/disability/default.htm>

provides a convenient source for statistical reference and guide to the available data, specifically, national sources of data, basic disability prevalence rates and questions used to identify the population with disability. More broadly, the materials in the web site facilitate and promote a dialogue on the needed improvements in the collection and compilation of comparable disability statistics.

35. In 2005, the United Nations Statistics Division will initiate the systematic and regular collection of basic disability statistics by introducing a disability statistics module into the existing *Demographic Yearbook*ⁱⁱⁱ data collection system, which compiles population and demographic statistics annually from national statistics offices. The United Nations Statistics Division is in the process of developing the disability module and determining the data collection and dissemination content, schedule and format.

D. Training workshops on disability statistics

36. Since the publication of the *Guidelines and Principles for the Development of Disability Statistics*, the United Nations Statistics Division has organized and conducted two regional training workshops on disability statistics. The overall objective of these workshops was to strengthen national capabilities to produce, disseminate and use data on disability for policy development and implementation. A specific objective of the workshops was to discuss the use of the ICF as the conceptual framework for collecting and classifying data on disability. At the workshops, participants from national statistical offices and data users from relevant government ministries were trained in how to

identify disability data needs, and the use of the ICF concepts and definitions in the design of questions on disability and classification of the data.

37. The first regional training workshop on disability statistics was the *United Nations Workshop on Disability Statistics for Africa*, which was held in Kampala, Uganda, from 10-14 September 2001. The second workshop, the *Meeting on Disability Measurement for ESCWA Countries*, was held in Cairo, Egypt from 1-5 June 2002 in collaboration with the Economic and Social Commission of West Asia (ESCWA).

38. The United Nations Statistics Division organized recently the *United Nations Workshop on Improving Statistics on Fertility, Mortality and Disability for English-speaking countries in Africa*, Accra, Ghana 14-18 June 2004. The workshop reviewed national approaches to the collection of disability statistics, and assessed ways to strengthen national capabilities to produce, disseminate and use the data on disability for policy development and implementation. In addition, the collection and dissemination of disability statistics at the international level were addressed.

Annex 1. Fundamental Principles of Official Statistics¹⁴

Preamble

The Statistical Commission,

- Bearing in mind that official statistical information is an essential basis for development in the economic, demographic, social and environmental fields and for mutual knowledge and trade among the States and peoples of the world.

- Bearing in mind that the essential trust of the public in official statistical information depends to a large extent on respect for the fundamental values and principles which are the basis of any society which seeks to understand itself and to respect the rights of its

¹⁴ *Statistical Commission, Report on the Special Session (11-15 April 1994)*, Economic and Social Council, Official Records, 1994, Supplement No.9, Series No. E/CN.3/1994/18, United Nations, New York, 1994. Available at <http://unstats.un.org/unsd/goodprac/bpabout.asp>

members.

- Bearing in mind that the quality of official statistics, and thus the quality of the information available to the Government, the economy and the public depends largely on the cooperation of citizens, enterprises, and other respondents in providing appropriate and reliable data needed for necessary statistical compilations and on the cooperation between users and producers of statistics in order to meet users' needs.

- Recalling the efforts of governmental and non-governmental organizations active in statistics to establish standards and concepts to allow comparisons among countries,

- Recalling also the International Statistical Institute Declaration of Professional Ethics,

- Having expressed the opinion that resolution C (47), adopted by the Economic Commission for Europe on 15 April 1992, is of universal significance,

- Noting that, at its eighth session, held in Bangkok in November 1993, the Working Group of Statistical Experts, assigned by the Committee on Statistics of the Economic and Social Commission for Asia and the Pacific to examine the Fundamental Principles, had agreed in principle to the ECE version and had emphasized that those principles were applicable to all nations,

- Noting also that, at its eighth session, held at Addis Ababa in March 1994, the Joint Conference of African Planners, Statisticians and Demographers, considered that the Fundamental Principles of Official Statistics are of universal significance,

Adopts the present principles of official statistics:

Principle 1. Official statistics provide an indispensable element in the information system of a democratic society, serving the Government, the economy and the public with data about the economic, demographic, social and environmental situation. To this end, official statistics that meet the test of practical utility are to be compiled and made available on an impartial basis by official statistical agencies to honor citizens' entitlement to public information.

Principle 2. To retain trust in official statistics, the statistical agencies need to decide according to strictly professional considerations, including scientific principles and professional ethics, on the methods and procedures for the collection, processing, storage and presentation of statistical data.

Principle 3. *To facilitate a correct interpretation of the data, the statistical agencies are to present information according to scientific standards on the sources, methods and procedures of the statistics.*

Principle 4. *The statistical agencies are entitled to comment on erroneous interpretation and misuse of statistics.*

Principle 5. *Data for statistical purposes may be drawn from all types of sources, be they statistical surveys or administrative records. Statistical agencies are to choose the source with regard to quality, timeliness, costs and the burden on respondents.*

Principle 6. *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.*

Principle 7. *The laws, regulations and measures under which the statistical systems operate are to be made public.*

Principle 8. *Coordination among statistical agencies within countries is essential to achieve consistency and efficiency in the statistical system.*

Principle 9. *The use by statistical agencies in each country of international concepts, classifications and methods promotes the consistency and efficiency of statistical systems at all official levels.*

Principle 10. *Bilateral and multilateral cooperation in statistics contributes to the improvement of systems of official statistics in all countries.*

ⁱ The United Nations Statistical Commission is an official body established in 1946 with the following terms of reference: To assist the United Nations Economic and Social Council (a) in promoting the development of national statistics and the improvement of their comparability; (b) in the coordination of the statistical work of specialized agencies; (c) in the development of the central statistical services of the Secretariat; (d) in advising the organs of the United Nations on general questions relating to the collection, analysis and dissemination of statistical information; and (e) in promoting the improvement of statistics and statistical methods generally.

The Statistical Commission meets annually. Its sessions are substantively serviced by the United Nations Statistics Division (see endnote ii below) and attended by member countries, the United Nations regional commissions, other United Nations organizations, specialized agencies and related organizations, non-United Nations international organizations active in international statistical work, and non-governmental organizations. The Commission reports to the Economic and Social Council.

ⁱⁱ The United Nations Statistics Division is part of the United Nations Secretariat's Department of Economic and Social Affairs. The Statistics Division's main functions are:

- a. the collection, processing and dissemination of international statistical information;
- b. the standardization of statistical methods, classifications and definitions;
- c. the technical cooperation program; and
- d. the coordination of international statistical programs and activities.

To carry out these functions, it:

- a. provides a global center for data on international trade, national accounts, energy, industry, environment, transport and demographic and social statistics gathered from many national and international sources;
- b. promotes international standards of methods, classifications and definitions used by national agencies;
- c. assists Member States, at their request, to improve their statistical services by giving advice and training;
- d. coordinates international statistical programs and activities entrusted to the Division by the United Nations Statistical Commission and the Committee for the Coordination of Statistical Activities
- e. provides input and secretarial support to the United Nations Statistical Commission (see endnote i above).

ⁱⁱⁱ The United Nations *Demographic Yearbook* is a unique source of national population and vital statistics, provided by national statistical authorities to the United Nations, and published annually, for over 233 countries or areas in the world. It provides statistics on population size and composition, fertility, mortality, infant and fetal mortality, marriages and divorces. The *Yearbook* also includes a detailed set of technical notes and footnotes explaining the sources, availability, timeliness, quality, reliability and coverage of the data presented. The primary sources of the data reported in the *Demographic Yearbook* are national population and housing censuses, population-related statistics from national administrative recording systems, and population and household surveys reported by national statistical authorities. The current *Demographic Yearbook* and all the other previous issues contain data on a wide range of topics that make it possible to conduct various in-depth analyses and international comparisons.

^{iv} The Washington Group is an informal consortium of national statistical offices, non-government organizations on disability, and international and regional organizations concerned with disability statistics.

The Washington Group reports to the United Nations Statistical Commission. The Washington Group is a textbook case of coordinated, parallel activity. It does not have a legal existence; it does not have its own staff; and it does not control pooled funds or make expenditures on its own behalf or as the agent of any member. The objectives of the Washington Group are to:

- (a) develop a set of general disability measures for censuses and surveys, which will provide basic, necessary information on disability throughout the world;
- (b) recommend extended sets of survey items, related to the general measures, to be used as components of population surveys or as supplements to specialty surveys; and
- (c) address other important methodological issues associated with disability measurement.

Participants in the Washington Group on Disability Statistics include representatives of national statistical offices or non-government organizations on disability from: the African Rehabilitation Institute, Australia, Belgium, Brazil, Canada, Côte-d'Ivoire, the Council for Disabled People of Mexico, Denmark, Egypt, the European Disability Forum, Eurostat, Finland, France, Hong Kong/China, Hungary, Israel, Italy, Japan, Kenya, Mexico, the National Institute on Disability and Rehabilitation Research, Netherlands, Organization for Economic Cooperation and Development (OECD) Health Policy Unit, Peru, Philippines, Poland, Puerto Rico, Sierra Leone, South Africa, Spain, St. Lucia, Sweden, Tanzania, the United Nations, Uganda, the United Kingdom, the United States, Vietnam, the World Health Organization, Zambia and Zimbabwe.