

**Expert Group Meeting on
Setting the Scope of Social Statistics**
United Nations Statistics Division
in collaboration with the Siena Group on Social Statistics
New York, 6-9 May 2003

Promoting a Better Use of Statistical Information:
An Integrated Information System on Disability*

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* This document is being issued without formal editing.

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1. Statistical information system

The contemporary reality has become more and more complex and the rapidity with which behaviours and conditions of life are changing impose a higher awareness and a greater timeliness to the government's actions.

The effective management of information resources, that has always been a point of crucial importance in the decision-making and political action process, has become an essential element in the actual phase of resource use rationalisation. Policy makers, social and economic operators and citizens have a continuous need for information in order to guide their choices, establish priority scales, estimate costs and benefits, effects and results of the accomplished actions. At the same time, information management plays a fundamental role as regards the need to the public opinion to be informed and to control the political choices and the government activity, so that to each of us is granted the expression of his/her own rights as a citizen.

However, especially in the modern society, largely based on information, due to the messy proliferation of information of various nature and of unequal quality, often in apparent or real contradiction, the information tool runs the risk of losing effectiveness just when it is needed most, causing disorientation in the public opinion and depriving decision makers of an essential tool. The extraordinary technological progress of the last years has evidenced this risk, leading many people to the misbelief that the amelioration of information and its better fruition by the users, such as governmental bodies, institutions or simple citizens, could be obtained simply by an increasingly massive use of sophisticated technological tools. The number of information sources and the large administrative databases built in the last years show that many people still believe in the healing power of those information tools that allow us to access to data of different nature more and more rapidly and at lesser costs.

However the passage from quantitative or qualitative basic data to actual information implies the notion of selection that cannot be set apart from the conceptual background in which data acquire meaning and informational power. The lack of interpreting assumptions in no way can be replaced by any database or even by the fastest and more technologically advanced processing procedures. In fact interpreting assumptions determine the quality and

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the explanatory power of information, from basic data collection along the whole chain leading to useful information and indicators.

This is even more true when the potential users operate in the social field: the natural complexity of social phenomena and dynamics requires, in fact, not only a mere collection of indicators but a real "system" of indicators that may allow to represent the various dimensions of the phenomenon adequately but also, whenever an operational aim is pursued, that may ensure the possibility to perform a comparative evaluation of alternative intervention strategies, cost/benefit analyses of the different policies, a monitoring of the effects caused on a given phenomenon or on a given situation by the accomplished interventions.

In general, the construction of an information system capable of guiding and supporting the decision making process would therefore consider at least four fundamental stages:

- the clear identification of the objectives to be pursued by means of the system of indicators;
- the explicit presentation of a conceptual framework laying out the dimensions of the phenomenon that needs to be known and monitored, or which the intervention refers to, as well as the possible relationships between the elements in play;
- the designing of the contents of the information system and the identification of the sources chosen for it;
- the designing of system architecture and the identification of the most adequate formats and practices by which the information contained in the system may be made available to users.

In recent years many of the world's main countries have had to face the problems created by the growing constraints on resources for social policy and, at the same time, the growing need for care arising from the ageing of the population. In this general context of rationalisation the role played by statistics has become fundamental. Just as fundamental is the link that must be created between systems of indicators and decision-making systems. In this context both systems of 'scenario indicators' and systems of 'specific problem oriented indicators' are needed. The former, as is the case of the system that Eurostat is attempting to construct with the co-operation of all European countries (General framework for health statistics in the European Union), and as with other national systems (for example the Italian, German, British and Dutch systems), must feed an information framework that represents the 'background' from which institutions and administrations must move, fostering considerations, proposals and awareness of problems. In certain moments of activity and planning, reasoning by watertight compartments is impossible; a global vision is necessary. The availability of systems of this type must serve to fight the tendency to promote actions in the absence of a wider outlook and prospects. In addition, these systems are also a channel of 'democratic' information available to all. They allow the community as well as experts to grasp a sense of the basic dynamics and issues and to support public and private decision-makers as well as private citizens.

The second type of system is aimed at an area of objectives that supports operators and decision-makers at the moment of decision or commitment. It is no longer enough to have only a few general indicators for these ends. Information on the scale of needs is required. The growing complexity of problems brings with it an equivalent complexity of information needs that must be met with diversified, as it were, personalised, choices.

In synthesis we can state that today statistical information systems must become an ordinary instrument in the processes of planning and evaluation as well as in the understanding of population problems. However, these measures should be included in a conceptual reference model that presents the interpretative framework of the phenomena and of the processes involved. A model that must originate from debate involving not only decision-makers but also the world of researchers and area experts, since information alone is never neutral and needs to be explicitly placed in its conceptual background.

In the Italian context an emblematic interesting example is the “Disability Information System” in the field of linking data coming from different sources, different definitions and different areas.

2. “Disability Information System”: a project linking different data sources on disability

2.1 From source-oriented data to an integrated system

The “Disability Information System” project, recently built up by the Italian National Statistical Institute, could be an example of activities carried out and problems faced in setting up a multi data sources statistical system.

Changes coming from the new framework of ICF in the field of disability mean that greater efforts of conceptualization, study and measurement are now required. The complexity of the inter-dependence between demographic and social phenomena underlines the necessity to aim for integration of information, analyses and interpretations as a basis for policy integration. To have a complete picture of disability (as phenomena) and of living condition and needs of people with disabilities requires the use of all data available which cover several aspects such as: health, scholastic and work integration, use of services, architecture barriers and so on. These data belong to different information systems or registers or surveys, which have to be integrated for an effective implementation of the policies and for assignment of adequate resources.

Without a complete and currently updated database on the various aspects of disability it is not possible to accurately state how many disabled persons there are in Italy, what disabilities they have, their level of social integration and what needs (fulfilled or unfulfilled) they and their families have. A national law (162/98) firmly underlines the need for policy makers to have a broad, detailed and up-to-date picture of the situation of disabled persons in Italy to enable innovation of social policies, in consequence the Ministry of Welfare has entrusted ISTAT with the task of implementing the “Disability Information System” project.

It must be pointed out that until the last decade, statistical information on disability was largely fragmented, with coverage of only specific target populations. The information collected was often inconsistently defined, not standardized, and in most cases difficult to access.

The administrative sources were the pillars of information on persons with disabilities until the '80s. This information was usually collected for non-statistical reasons, mainly related to administrative activities, as required for a particular program or service for disabled persons meeting specific inclusion criteria. Various administrative records and registers have been used to generate information on disability at national level.¹

In 1980, ISTAT carried out the first Health Interview Survey investigating in-depth the topic of permanent disability and invalidity, providing a new opportunity to analyse the social and demographic profile of people with permanent invalidity.² Since then, ISTAT has developed a new social survey system on household and in 1997-98 the Multi-Purpose Family Survey System was launched. This provides a picture of the social conditions of Italian families and includes the issue of personal autonomy in a context of continuous (annual) study.

Many data are now available coming from different information sources. The problem is that they are not comparable, as different definitions of disability and different collection methods are employed, on the basis of the specific aims of each source.

2.2 Actions and products of “Disability Information System” project

The project was carried out after a thorough understanding was reached of information needs of policy makers, of all data sources available, of the gaps in available information and of lack of comparability.

To create an integrated statistical system capable of fulfilling the information needs of potential users a process of consultation was carried out with policy makers, representatives from various types of data users and institutions gathering or producing data on disability. This process allowed the exploitation of the experience accumulated in the creation and management of other social and health information systems. This also

¹ These include: Persons drawing invalidity pensions and allowances awarded by the National Social Security Institute (INPS); Workers with a disability due to an occupational accident or an industrial disease (National Institute for occupational accident insurance (INAIL); Disabled persons drawing an assistance pension or an allowance for assistance from a third party. (Civilian disabled, civilian blind, deaf-mutes) (Ministry of Interior). The assistance pension comes under the social assistance scheme category, although its award is dependent on the level of private income; Pupils with visual, aural or psychophysical impairments in ordinary education (Ministry of Education); Children with a mental, physical or sensory impairment in special education (Ministry of Education); Unemployed disabled persons (Ministry of Labor).

² The survey took into account only some of the disabilities contained in the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) (persons with visual impairments and a mixture of hearing and speech impairments and movement disability), and therefore underestimated the number of persons with permanent disabilities.

enabled identification of other information sources, creation of a more coherent picture of statistical information on disability in Italy and creation of a collaboration network.

Following the various meetings, two principal work lines were established: a brief period activity oriented to analyse and evaluate existing data, and a long period one mainly oriented to organise a quality Information System with the objective of improving existing statistical sources and setting up new ones where necessary.

Various products were planned around these two strategies. In the first period were planned:

- Disability indicators system
- Data warehouse
- Web Site www.handicapincifre.it

And in the long period:

- The integration of register data sources on disability, available at local level
- The implementation on handicap certification systems
- Survey on persons with disabilities

The disability indicators system

To define an efficient statistical indicators system it is first necessary to have a correct conceptual framework. Its construction is a complex and delicate task, as disability is a multi-dimensional, dynamic phenomenon in which conditions of health and life evolve in time and during life cycle. Several analytical viewpoints must therefore be taken into account: target areas of intervention of legislation³, target population groups and causes disability. The main concepts and dimensions to be monitored by indicators were identified for each viewpoint and then all data available were used, taking into account the problem of their comparability and using the ex-post harmonization approach.

It required building a metadata system for supporting the integration and harmonization of statistical information production. Meta-information on the survey's content, definition, classification and methodology allows the correct data reading analysis, comparisons and reconciliation techniques. The metadata consists of a description of indicators, data sources, and glossary.

Data warehouse

The "disability indicators system" provides all data available for specific thematic area; the data warehouse is useful for more expert users and those with a precise objective or in search of specific data. It consists of a query system allowing data extraction from the various information sources and construction of personalized tables in accordance with available data (criteria are defined to ensure respect of laws on privacy).

³ The system's thematic areas are: Households, Social Life, Education and scholastic integration, Transport, Health and Assistance, Work and Employment, Accidents and Social Protection, which comprises Recipients of monetary benefits, and Spending on monetary benefits.

The web site

The web site www.handicapincifre.it has been planned as a tool for diffusion of statistical information, facilitating data accessibility and reinforcing the relationship between data producers and users, in accordance with ISTAT policy to produce more user-friendly statistical information. It is accessible to disabled persons respecting the CAST (Center for Applied Special Technology) rules on accessibility. The English version is currently under construction.

The site offers not only constantly updated data, but also context information that may be of interest to a wide public.

In addition to the products already described, others were made following the long period work line to organise quality information system with the objective of improving existing statistical sources and setting up new ones where necessary. In the starting phase of the project it was very clear that several data sources were not fully utilised, particularly at local level, where there are many archives and databases on handicap and disability mainly based on certification of disability, useful to complete the picture of disability in Italy. Furthermore, data on several aspects of every daily life of people with disabilities are missed in data sources.

To overcome this situation several activities were carried out:

Registers available at local level containing information on disability

A survey of local data sources and information was conducted, whose results are extremely important to initiate information exchange among data sources currently isolated from one another. Several bodies were contacted (Regions, Local Health Authorities, Provinces, Prefectures and Education Offices) and a notable difference was found in the classifications used, making data comparison from these sources difficult. A great deal of information was also available but in a non-electronic form, which is a major obstacle in the aim of reorganizing data exchange. The information gathered from this survey was organized and standardized to create the Register previously mentioned.

Implementation of handicap certification systems

The importance, from the statistical point of view, of certificate data lies in the fact that it is the only source that would allow calculation of the number of disabled persons in Italy, who they are and what disabilities they have. There are in fact currently several obstacles to its use: the certificates themselves are issued by specific commissions and each commission uses different forms even within the same geographical region; definition and classification utilized are different, most certification is registered on paper only, making detailed analysis of the data impossible. To overcome these obstacles, a new model to survey certification has been planned and tested together with the method of data transmission, elaboration and use in a pilot study. The nationwide implementation of this model following the experimental phase will finally allow the use of certification as a source of information.

Survey on persons with disabilities

The current information is lacking especially in the area of the needs of disabled persons and their families, satisfaction with services offered, but also relating to various activities in their lives, their level of social integration, formal and informal help networks and so on. Also missing is information that would allow monitoring of changes in life and health conditions with time. To respond to these needs an ad hoc survey is in progress.

The results of this research will add significant new information for planning of social policies that promote full participation of citizens with disabilities in various social contexts⁴, and push for an improvement in the quality and characteristics of services for their benefit.

It is based on a sample composed of those who declared a reduced autonomy in the activities of daily life, or invalidity, in the 1999-2000 ISTAT survey “Conditions of Health and Recourse to Health Services”.

3. Concluding Remarks

In implementing the “Disability Information System” and particularly the Integrated Indicators System, various difficulties have been encountered due to the current situation of information on disability in Italy:

- *Lack of data sources covering all aspects of disability and living conditions of people with disabilities.* Various information gaps were discovered, especially regarding disabled children, the mentally disabled, causes of disability and regarding issues related to the role of environmental factors in the limitation in activity of disabled people in different contexts (school, work, social life, mobility). These aspects must be covered in future specific surveys. Longitudinal studies and data were also absent. Disability is a continuous, dynamic and interactive process and it is, therefore, extremely important to understand the evolution of health and life conditions with time and their impact on the social participation of disabled persons.

- *Lack of communication among information sources.* There are several institutional data sources, at both national and local level, but few have been planned as part of a single, integrated information system. An effort in promoting collaboration among data producer bodies should be done.

⁴ The survey investigates several aspects such as: typology of the reduction in autonomy / invalidity, its cause and onset; diagnostic process to reach diagnosis of the problem of health at the basis of this reduction of invalidity; social and health services and interventions utilized, those which the individual would have liked to use but was unable to and the reasons for this inability; scholastic and employment experiences, difficulties encountered, needs and responses obtained; mobility in cities and the countryside and social participation; presence or absence of architectural barriers of the building and inside the apartment where the person interviewed lives.

- *Lack of reliable and comparable data.* As we have seen, the diverse information sources (both administrative and non) utilize different conceptual paradigms and instruments to identify and collect information about disability. This leads to great obstacles in data comparability, for which it was necessary to adopt the ex-post harmonization approach.

The “Disability Information System” underlines the importance of enhancing data and data sources already available by linking statistical surveys with administrative data, reconciling different source figures and indicators as well as to establish regular and systematic collections.

The collection of information on disabled people is a complex task that still requires great effort. Using and adjusting already existing data is important but not sufficient: adoption of identical conceptual paradigms and common language as well as identifying statistical reference instruments is also necessary.

The ICF represents an important resource in this area as it offers a multi-perspective approach and proposes a common language applied in several fields. This will give a great support in the integration and harmonization process of data related to information system, registers, population surveys covering different aspects of disability.