

## Disability: concepts and statistical information

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### Abstract

**Background:** The measurement and definition of disability is difficult due to its objective and subjective characteristics. In Italy, three different perspectives have been developed during the last 40 years. These various perspectives have had an effect, not only on how to measure disability, but also on policies to improve the social integration of people with disabilities.

**Methods:** This paper examines the various conceptual models behind the definition of disability and the differences in the estimated number of persons with disabilities. In addition, it analyses in accordance with the International Classification of Functioning, disability and health, the European and international initiatives undertaken to harmonize the definitions of disability.

**Discussion:** There are various bodies and central government agencies that either have management data or carry out statistical systematic surveys and disability surveys. Statistically speaking, the worst aspect of this scenario is that it creates confusion and uncertainty among the end users of this data, namely the policy makers. At international level the statistical data on disability is scarcely comparable among countries, despite huge efforts on behalf of international organisations to harmonize classifications and definitions of disability.

**Conclusions:** Statistical and administrative surveys provide information flows using a different definition and label based on a conceptual model that reflects the time period in which they were implemented. The use of different prescriptive definitions of disability produces different counts of persons with disabilities in Italy. For this reason it is important to interpret the data correctly and choose the appropriate cross section that best represents the population on which to focus attention.

*Key words: definition of disability, statistical surveys, administrative sources*

### Introduction

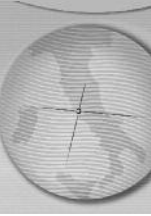
Disability is difficult to measure and define because it is a multidimensional concept with objective and subjective characteristics. In Italy, three different perspectives were developed during the last 40 years. The various perspectives have had an effect not only on how to measure disability but also on the performances planned to improve the social integration of people with disabilities.

In the past, the *impairment perspective* has considered disability a health problem or an abnormality that is situated in an individual's body or mind. This perspective is best expressed by the medical model that assumes disability as a strictly personal condition.

In the 80's another perspective came out, based on the International Classification of Impairments, Disability and Handicap (ICIDH), the *functional limitations perspective*. The aim of this new

perspective is to expand the medical model including non medical criteria of disability. The ICIDH framework presents disability as a linear process that begins with an underlying cause, which brings about impairment, which in turn causes a disability that may result in a handicap. Despite the inclusion of non medical criteria, disability is measured in quantitative terms as functional restrictions against a standard.

The third model is the *ecological perspective* where disability is seen as resulting from the interaction of impairment, activity limitations and participation restrictions in a specific social or physical environment such as work, home, or school. In this perspective, if the environment is adapted to the person, the disability can change or even disappear. According with this model, even though impairment has an objective reality that is attached to the body or mind, disability has more to do with society's failure to account for the



needs of persons with disabilities. The latest International Classification of Functioning, Disability and Health (ICF) represents the implementation of these concepts.

Of course, those three different perspectives have an influence on disability measurement and on data collection.

The objective of this paper is to examine the various conceptual models behind the definition of disability and the differences in the estimated number of persons with disabilities, as drawn from the various existing national informative flows. It also analyses the European and international initiatives undertaken to compare the definitions of disability and the survey methods.

### 1. Italian informative flows and conceptual model of disability

There are various bodies and central government agencies that either have management data or carry out statistical systematic surveys and disability surveys. Each one of these informative flows uses a different definition and label (disability, invalidity, inability, handicap), based on a conceptual model that reflects the time period in which they were implemented. The use of different prescriptive definitions of disability and/or to the different value of these definitions produces a different number of people with disabilities in Italy.

If we want to quantify, for example, all the minors aged (under 19) with disabilities, different estimates will be obtained based on the data source used. It amounts, in 2005, to 143,163 units according to the INPS (National Institute of Social Welfare) data relative to pension funds and, especially when we consider the persons who receive a civil disability pension and similar allowances. According to ISTAT's survey on "Health conditions and use of health services", in the same year, children aged between 6 and 19 who live with their family amount to 93 thousand units, because of the age and residence limits. The data from the Informative System of the Ministry of Education, which considers students with disabilities present in state schools from all orders and levels, allow estimating 168 thousand units in the school-year 2004-2005.

The differences between these three estimates derive from the fact that the different groups considered, although they do intersect, are never fully superimposed. Non-homogeneous survey instruments are indeed used according to the administrative or research needs, each one with different objectives and especially different definitions based on different conceptual models.

Thus, while the INPS data are based on what was previously called *impairment perspective*, the ISTAT survey data refer to the *functional limitation perspective*.

The problem of the different estimated numbers cannot be solved simply by using the same data source or the same measurement instrument. For example, if one uses the same survey instrument, namely the scale of essential daily life functions, to arrive at an estimate, then considers both "those who are not able" and those who have "a lot of difficulties" to carry out one of these functions to arrive at an estimate, the estimates obtained still differ. With regards to number of "those who are not able" to carry out one of these functions, in Italy, they amount to 2 615 000, or 5% of the population aged 6 and over who live with their family. Those who have "a lot of difficulties" in doing so amount to 6 980 000 persons, i.e. 13% of the population aged 6 and over who live with their family.

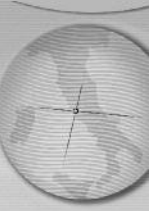
However, the variability in numbers can lead to some confusion in reality, depending on the definition used. It is important to explain such a definition to correctly interpret the data and choose the appropriate cross section of people that best represents the population on which to focus attention.

On this premise it was decided to analyse separately the national statistical surveys' informative flows from the administrative databanks flows to illustrate as clearly as possible the differences.

#### 1.1 Statistical surveys flows

Statistical surveys that provide information on disabilities can be divided in two well identifiable groups. The first group includes surveys such as: patients in socio-welfare residential homes, the municipalities' expenditure for social interventions and services, and the activities' of the no-profit sector for persons with disabilities. These surveys do not point out information on disability at individual level but examine the activities and services provided to these persons. For these reasons these data sources do not provide any definition of disability, leaving it up to the Institution being interviewed the "freedom" to attribute an activity or a service to a specific target population.

The second group includes information deriving from the population surveys, such as the ISTAT System of multi-purpose surveys ("Health conditions and use of health services", "Aspects of daily life", "Family and social subjects") or the ad



hoc module included in the July 2002 Labour Force survey. These surveys have the purpose to identify all persons with disabilities and analyse the socio-economic context in which they live. Here we will focus on the second type of data and highlight the different definitions of disability that characterise such a group. Despite being different one from the other, the various definitions all rely on the *functional limitations model*, since they consider the impact that a health problem has on the function/activities daily carried out. In the "Aspects of daily life", "Family and social subjects" and "Labour Force" surveys, the interviewee is asked whether they have a health problem (chronic illness, invalidity...) that reduces their personal autonomy to the extent that it requires the help of other persons for daily life needs at home and outside the house. As suggested at a European level, the Labour Force survey's ad hoc module also includes the time reference "that can last more than 6 months". The "Health Conditions and Use of Health Services" survey presents a set of questions that include a series of functions. These questions regard level of difficulty and autonomy in daily life activities (such as walking, walking up and down stairs, bending and kneeling down, getting in and out of bed or chair, dressing yourself, washing and bathing yourself, feeding yourself), bed confinement and chair confinement (except for wheelchairs) at home, and sensory difficulties (hearing, seeing and speaking). Hence, according to this survey, persons with disabilities are those who declare not to be able to carry out their usual daily functions, while taking into account all types of health equipment aid (prosthesis, canes, eyeglasses, etc). It does not consider however, conditions recognised as temporary. Compared to the previously seen question, this set analyses more in detail the compromised abilities. These abilities are not surveyed among the population aged under 6 as it is difficult to distinguish the age-related difficulties from those that arise from a specific pathology. Thus, the functional limitation model in this informative flow appears more evident, as the abilities selected represent the standard through which the functional restrictions can be determined.

### 1.2 Administrative data sources

The integration of statistical sources with those that are administrative enables one to describe, more exhaustively, disability phenomenon and to provide different approaches to its concept [1]. The information that can be drawn from the administrative sources is based on considerable production of laws on disability.

Disability often involves recognising rights

guaranteed and protected by the Italian laws. We obtain different definitions when examining the rights of persons with disabilities. Let us start from what can be considered a basic right: the right to a minimum economic level for persons with disabilities.

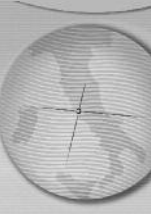
The definition of disability used in legislation that gives access to an economic allowance, Law nr. 382/1970, nr 118/1971, nr 18/1980, nr 508/1988 and nr 289/1990, regards civil disabilities and is articulated in four levels. In the case of minors, these laws consider the persistent difficulties they have in carrying out tasks and functions relative to their age. With regard to an invalidity that involves reduced working capacity, the definition of disability considers both the invalidity and the partial or total limitation in the working capacity. In the most serious cases, it considers not only the invalidity with total or permanent inability to work, but also the difficulties encountered in carrying out daily life functions, such as walking without help or the need for a continuous assistance.

With regard to elderly persons aged over 65, Italian law take into account their capacity to move and to carry out the daily life functions: the possibility to walk without help or the need for a continuous assistance to carry out the daily life activities.

The definitions of civil disability are based on a compensation principle typical of money transfers. In addition, they also take the incapacity to carry out daily life activities as a further element for the lawmaker to qualify the seriousness of the disability.

Italian law identifies two important priorities for social inclusion: the right to study, Law nr 104/1992, and the right to work, Law nr 68/1999. Law nr 104/1992 defines as handicapped a person with a physical, psychic or sensorial disability that leads to difficulties in learning, in social relations and in work integration, and which thus determines a process of social disadvantage or marginalization.

With regard to the right to study, the law not only focuses on the aspects relative to the disabilities and to the difficulties encountered in the school context, but also on the evaluation of the "residual capacity" of the student. While it examines the limitations in the functional diagnosis, it also lays down a functional-dynamic profile for formulating an individualised education plan. Hence, it considers learning difficulties consequent to the handicap as well as the possibility of recovery and the capacity that must be sustained, stimulated and progressively strengthened and developed, while at the same time, respecting the cultural choices of the person



with disabilities. The individualised education plan, which identifies the instruments that help to improve the student's learning performances, rests on a functional dynamic profile that lays down the student's residual capacities and abilities according to the functional diagnosis analysis. Thus, in the laws that establish the right to study, both aspects relative to the person and to the life context of the person are considered.

Besides defining a handicap, Law nr 104/1992 also defines and qualifies its level of seriousness. In case of a serious handicap, the disability involves reduced personal autonomy. According to the law, if a disability reduces the age-related personal autonomy to the extent that a permanent continuous and global assistance is required in the individual or relational context, it is considered as severe. Hence, here too, just as for the definition of civil disability, the personal autonomy dimension is also evaluated when having to label it as severe.

A further interesting aspect of the law, D.P.C.M. nr 185/2006, relative to the right to study is the sensitivity the lawmaker demonstrates by referring to the international classifications of the World Health Organisation in the report, which indicates the confirmed stabilised or progressive pathology. This promotes a process that makes homogeneous all information gathered on students with disabilities that, when fully operational, will provide detailed and comparable data.

With regards to employment, Italian Law nr 68/1999 guarantees and protects the right to work for persons with disabilities. The definition of disability used by the lawmaker helps persons with disabilities enter and be integrated in the world of employment through specific sustained and placement services. The definition of disability is articulated around three categories. The first category covers reduced working capacities following a disability, in particular of persons in working age affected by physical, psychical or sensorial disabilities and intellectual handicapped persons with a 45% reduction of the working capacity. The second category covers work invalidities due to a damaging event on the place of work. It thus includes all persons unable to work with a degree of invalidity over 33% following an accident at work or an occupational disease. Finally, the third category covers sensorial difficulties, in particular, people partially or totally blind and deaf.

Besides defining disability, which is necessary for identifying the persons entitled to the right to work following a disability, the aforementioned law also identifies technical and support

instruments to help evaluate the working capacity of persons with disabilities. This is important as it assists them in finding suitable work, by analysing the forms of support, positive actions and solutions of problems linked with the environments, instruments and inter-personal relations on daily relation and workplaces.

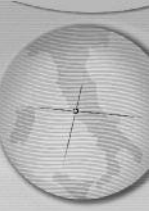
The analysis of the law clearly highlights two elements. Firstly it gathers the aspects relative to the functional limitations linked with illness or accident of the disability concept. Secondly, it considers the capacities of a person to participate in society. These two elements are coherent with the concepts expressed by the ICF classification that deals separately with the activities functions and the social participation.

## 2. Harmonisation of the definition of disability in the European context

One of the first attempts to standardize disability measures across countries was undertaken by the OECD in the late 1970s, as part of a broad programme to develop social indicators. This effort led to the so-called "OECD long-term disability list" [2]. The proposed instrument focused on the measurement of long-term disability, based on an ADL (Activity of Daily Living) scale covering mobility, self-care and communication items.

An attempt to standardize disability measures was also undertaken by WHO-Europe, in collaboration with Statistics Netherlands, as part of an on-going effort to standardize methods and instruments in health interview surveys [3]. WHO-Europe made recommendations for standardized instruments to measure both short-term disability and long-term disability. The WHO-Europe "long-term disability list" is designed to measure disability through ADL-type limitations, covering the same key basic activities related to mobility, self-care and communication.

Following on, the Euro-REVES Network (Réseau espérance de vie en santé), with support from the European Commission, released a set of recommendations for survey instruments in five areas (i.e., physical and sensory functional limitations, ADL limitations, limitations in usual activities, self-rated general health and mental health), as part of an effort to develop a consistent set of health indicators across European countries [4]. In the area of disability, Euro-REVES proposed to break down the WHO-Europe "long-term disability list" into two components: some of the questions measure "physical and sensory functional limitations", while the other questions measure "ADL restrictions". This distinction has been



justified on the grounds that “functional limitation and activity restriction refer to different levels of disability leading to different types of consequences on daily life, and towards which different public health actions can be addressed” [5]. Euro-REVES recognizes however that “the distinction [between functional limitation and activity restriction] is not straightforward, especially as existing measurement instruments are most of the time combining these two levels and are relying on apparently similar questions” [5].

More recently the European Disability Measurement (EDM) project, carried out by TNO, adopted as general disability measurement the first version of the Minimum European Health Module (MEHM) which is the basis of questions on disability (self-perceived health, presence of illness/disability, hampering in ADL) included in the three fully harmonized EU-wide surveys (European Community Household Panel - ECHP, European Labour Force Survey -LFS, Survey on Income and Living Conditions -SILC).

Namely, in the ECHP (1994-2001), a general measure made up of two questions is used. The first one investigates the health/disability condition while the second one surveys the limitations of the activities. In the SILC (2004), the activity limitations are investigated by referring to health condition and without using reference norms (“in your daily activities”) or to work context/job activities. The answer categories are dichotomous (in the first one) and multiple (in the second one). Finally in the European LFS (2002), only one question is used as general measure for screening the respondents for the module on “employment of disabled people”. The question investigates the presence of any longstanding health problem or disability [6].

Several conceptual definitions of disability exist. If this is a problem - with consequences for data comparability- depends upon whether the different definitions have been logically converted/translated to concrete measurement instruments.

The problem of language and cultural bias in the European harmonised surveys has to be dealt with both at the data production (the input-side) and at the data manipulation (the output-side) as they are complementary. It is thus necessary to search practical solutions. Tools such as the “Response Conversion” [7], for example, were developed to take into account and to do a final adjustment to possible left-over language and cultural confounding [8]. The ICF represents another 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 [9].

### Conclusions

One of the most important roles that the statistics must carry out as regards disability is to produce information, and participate in the process to extend the knowledge of the aspects characterising the main dimensions of social inclusion of persons with disabilities.

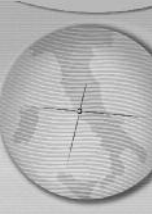
In order to do so, it is necessary first to resolve many issues, especially the definition of persons with disability. A statistician measures what has been previously defined: there is no phenomenon but only what is defined as such.

Disability is a term that indicates the negative aspects of the interaction between a person (with a specific health condition) and the environmental and personal factors of that person. Despite such complex but strict definition of disability, a huge confusion still persists in Italy, in common language and in legal texts, as reported in this work. Legal analysis and statistical production clearly identify two very different points of view: one that considers the aspects relative to the integration and social participation of persons with disabilities and the other refers only to the physical or mental impairment.

The worst aspect, statistically speaking, is that of creating confusion and uncertainties among the privileged users of the data, namely, the policy makers. Hence, it is important to provide them with data so they can identify and plan efficient actions for persons with disabilities.

Internationally too, the statistical data cannot be compared among countries, despite the huge effort of the international organisations to promote and implement classifications and definitions that would help reach such an aim.

In Italy, and in many other countries, the hope is to see, as soon as possible, results of the sensitisation actions undertaken to deal with the topic of disability from a wider point of view, that is, the one proposed in the ICF classification. Such classification employs concepts and cognitive instruments that allow the best results to be obtained for the social inclusion of persons with disabilities. In Italy, for example, many initiatives are currently being undertaken to identify the protocols that would evaluate disability, based on the ICF framework, in selected contexts such as school and work integration.



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