

The Italian information system on disability

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Abstract

Background: The Disability Information System Project started in 2000 following an agreement between the current Ministry of Social Solidarity and Istat in implementation of article 41-bis of Law 162/98, that highlighted the need to promote statistical and cognitive surveys on disability.

Methods: The System was created to meet the increasing attention of policy makers and society in general to people with disabilities and their participation in society. The system provides statistical information on disability by integrating and coordinating data sources available relating to this issue in Italy and to establish new sources that are suitable for addressing the current information gaps.

Discussion: Activities of Istat in recent years have reached the ambitious goal of transforming the extensive data and numerous documents of an administrative nature on disability into statistical information. It means to create an organised body of information, documented and processed using statistical tools that can be understood and used by policy-makers, experts, and citizens.

Conclusions: The phenomena analysed are very often characterised by various dimensions that are unlikely to be independent of one another. It is precisely in studying these phenomena that the information system provides significant added value since it makes it possible to have quicker and a guided access to the multiplicity of data sources that describe different aspects of a topic. This makes possible for the user to integrate information and to create an overall or sufficiently comprehensive picture.

Key words: information system, disability, social integration, indicators, data sources

Introduction

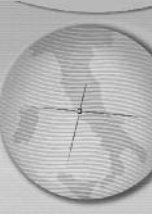
In the last ten years people with disabilities and their participation in society have increasingly drawn the attention of policy makers. This is shown, for example, by the objectives included in the Council of Europe declaration that proclaimed 2003 as the "European Year of Disabled People" as well as in various documents produced by the European Commission and some International Bodies. Attention was also drawn to this matter by the International Classification of Functioning, Disability, and Health (ICF) [1], drawn up by the World Health Organisation in 2001, which puts forward a new vision of the condition of disability, no longer associated only with pathological states or functional limitations but with the results of a host of interactions between physical/mental conditions and the social and environmental context in which the person lives. The new approach suggested by the ICF provides the starting points required to guide policies and actions in favour of people with a disability. One

thinks, for example, about customised programmes that deal with the problems of disability should be based on close integration of social and health assistance and the implementation of active policies in the various social and economic environments (school, work, social participation, etc.) in order to remove any physical or cultural barrier that gets in the way of striving for complete social inclusion of these people.

This new vision, which adds additional areas for the debate on social policies, also calls for planning and construction of a body of information that is increasingly detailed in order to provide adequate responses to the numerous aspects that characterise the actual condition of disability in our country.

The current Information System

The Disability Information System Project started in 2000 following a convention between the current Ministry of Social Solidarity and Istat in implementation of article 41-bis of Law 162/98,



that highlighted the need to promote statistical surveys on disability. The system provides statistical information on disability by integrating and coordinating data sources available on this matter in Italy and to establish new sources that are suitable for making up for the current information gaps. In order to facilitate maximum distribution of data on disability and the various products carried out within the information system, the www.disabilitaincifre.it website has been set up. Easy access to statistical information meets the needs strongly felt by various subjects, such as, to name but a few, policy makers, organisations in the sector, experts, researchers, as well as citizens.

The backbone of the whole information system is made up of the indicators system that contains about 2,600 tables with more than 600 indicators broken down by sex, age group, and region. The tables are provided by *subject areas* that relate to health, major dimensions of social integration, policy actions and financial resources used by the welfare system for people with disabilities. Specifically, the *subject areas* are: Health and Social Assistance, Families, Incidents, Non-profit Organisations, Education and School Integration, Work and Employment, Social Protection, Health, Transport, and Social Life. The indicators system is based on various data sources that gather the information for their own purposes using their own methods, and adopt different definitions of disability. A meta-data system was set up in order to support the correct interpretation of data. It comprises of three elements: a) the data source schedules that show the main characteristics of various sources used, b) the indicators schedules that appear before each table explaining: purpose of the indicator, type of data source, a definition of the disability, years to which the data refers and any other useful information, c) a glossary containing the meaning of technical terms.

The website also has other areas, for example, "Document" that contains researches and study materials produced by Istat or other bodies that is relevant for scientific information and debate, or "Europe for the Disabled" that contains international documents and guidelines on disability policy, materials produced during the "European Year of People with Disability", international research reports, and major data available on some countries in the European Union.

The information system activity not only valorises the existing flow of information, but it also seeks to implement new flows and to look at aspects that qualify the life of people with disabilities in greater detail. As far as new flows

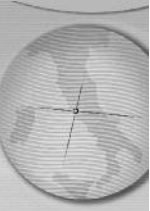
are concerned, a survey on disability certification was planned and tested. It was issued by the legal medical commissions working in the Local State Health Centres. The survey valorises the vast body of information available via these Health Centres that, due to a great lack of uniformity of information, makes it difficult - if not impossible - to make correct statistical use of it on a national level. Thus, a flow of information has been designed that is suitable for gathering the certifications issued by the Local State Health Commissions, using a model that includes a core of minimum information common to the various certificates issued by these bodies. Once it is running properly, the survey will create a database of disability certificates that will make it possible on the one hand to run specific processing by type and seriousness of the disability and socio-demographic characteristics, and on the other hand to eventually have a reference population for more in-depth surveys.

In 2004 a survey on "Social integration of people with disabilities" was carried out to draw up a wide-ranging, detailed picture of the characteristics of disability and their quality of life. The survey gathered data health status, occurrence of the disability, diagnostic process, health and social intervention, education, work, mobility, social participation, and architectural barriers. Attention was therefore also given to the major dimensions of social integration needs and difficulties that people with disabilities encounter in social relations, school and work contexts, dealings with the institutions they refer to, the services used and required. For the first time in Italy, a start was made on surveying aspects that act as a barrier/facilitator for the process of social inclusion of people with disabilities.

Other studies have been developed and their results are presented on the web site. These studies deal with issues that are very relevant and current such as: "People not self-sufficient", "Employment placing of people with disabilities", and the problem known in Italy as "After us".

One of the main priority topics in terms of disability policy is the problems connected with care and treatment of people who are not self-sufficient and the definition of new organisational services models. In this sense, it seemed necessary to estimate these people and to measure, in terms of quality and quantity, the needs satisfied and those not met. This information is essential for defining adequate policies and plans of action.

Employment placing is a decisive element for facilitating the social participation of people with



disabilities, and the Italian legislation is ahead of those in other European countries, even though delays are experienced in terms of implementation and reorganisation of the services tasked with these activities. The study set itself the goal of providing a fact-finding reference framework that is up-to-date and complete, analysing both the different paths to employment placing used by people with disabilities and the characteristics of the Employment Services activities and information on users that turn to them. The analysis made it possible on the one hand to highlight any obstacles encountered by people with disabilities along the way to finding a place in the employment world, and on the other hand to analyse the extent of use of recent instruments for employment placing provided for in legislation.

Finally, there was an in-depth study on "After us", a very important topic for people with disabilities especially for those at risk of suffering solitude and abandonment once they lose their parents. In particular, attention was given to estimating the number of people who are or risk of being in this situation. In addition to the major socio-economic characteristics of these people, the estimate can provide a useful tool for planning ad-hoc policies.

Added value of the information system

The phenomena analysed are very often characterised by various dimensions that are unlikely to be independent of one another. It is precisely in studying these phenomena that the information system provides significant added value, since it makes it possible to have quicker, guided access to the multiplicity of data sources that describe different aspects of a topic. This makes possible for the user to integrate information and to draw up an overall or sufficiently exhaustive picture.

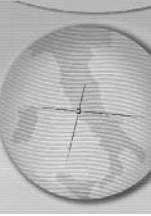
To give an example: in order to understand of the employment integration of people with disabilities phenomenon in overall terms, various elements must be considered such employment levels of people with disabilities, type and use of the tools made available by recent laws, diffusion of these tools around the country, and the activity of the services sector in terms of employment placing. Using the Disability Information System it is possible to simultaneously gain access to all of this information, which avoids wasting time and energy on researching individual data sources that also often belong to different producers. In the case of the phenomenon used as an example, there are only two bodies involved Istat and Isfol (Institute for the development of professional

training for workers). In fact, with its ad-hoc form in 2002 for the Labour Force survey, Istat makes it possible to determine the employment levels of the population covered by the study and to compare it with the rest of the Italian population as well as at international level by using definitions agreed at an European level. Furthermore Istat provides the sole information on the obstacles encountered by people with disabilities along the path to employment placing, thanks to the survey on "Social integration of people with disabilities" carried out in 2004, as part of the Disability Information System Project.

Isfol, on the other hand, with its "Monitoring of Employment Services" provides information about the territorial distribution and the related use of the structures and services provided for by the numerous standards relating to employment placing. Finally, as far as the role of the services sector in facilitating employment placing of people with disabilities is concerned, Istat also provides information in this regard by means of its "Survey of Social Cooperatives".

Another example is the analysis of Health and Social Assistance. The overall picture of assistance for people with disabilities is comprised of various types of assistance (hospital and ambulatory care) and the various types of services, such as diagnostic checks, medical check-ups, home care and rehabilitation. The picture is complex and there are multiple data sources, both from Istat and the Health Ministry, that cover all aspects of the demand, activity, and offer, even though in the latter case it is often not possible to clearly distinguish which are specifically dedicated to people with disabilities.

The Ministry of Health provides information of a structural type such as, for example, public and private structures to assist people with disabilities, and hospital beds for long-term hospitalisation and rehabilitation. This data is added to by information on hospital beds in residential socio-assistance centres and health assistance centres (Istat survey of socio-assistance residential centres) and those related to action and services of a social type provided by the Municipalities (Istat survey on Municipal social actions and services). Ministry data also provides information on activities in terms of hospital discharges, rehabilitation services, cases handled by means of domestic assistance. Information on socio-health activities can be obtained from surveys on the non-profit sector (Istat surveys on Social Cooperatives) focusing on type A Social Cooperatives (Social cooperatives that provide socio-health and educational services). Moreover



the Istat survey on "Health conditions and recourse to health services" provides information on recourse to diagnostic checks, medical check-ups, and hospitalisation of people with disabilities. The only source of data that provides information on the levels of satisfaction and the ease of access to socio-health services is the Istat survey on "Social integration of people with disabilities", mentioned above.

For both the phenomena, merely referred to here, the possibility of having all the information available within the information system itself is a significant added value, especially when evaluated in terms of ease of access to statistical information in overall terms (data and metadata).

The Information System in the future

The growing sensitivity to promoting initiatives aimed at improving statistical information and the monitoring of disability policies shows through in the text of the 2007 ONU Convention on the rights of people with disabilities [2], which draws the attention of the Countries to the gathering of statistical information and ad-hoc surveys able to support the policies (art 31).

Istat's activities in recent years have, as indicated in the previous paragraphs, attained the ambitious goal of transforming the extensive data and numerous documents of an administrative nature on disability into statistical information. It means to create an organised body of information, documented and processed using statistical tools that can be understood and used by policy-makers, experts, and citizens.

The future challenge in coming the years will be to provide statistical information on disabilities in a manner that is coherent with the concepts introduced by the new ICF classification, thereby overcoming a mere consideration of functional limitations and valorising interaction between the health status and environmental factors as a tool for analysing living contexts and social integration of people with disabilities. Of no lesser relevance will be the commitment to extend statistical coverage to the portion of the population not yet completely surveyed such as, for example, children with disabilities, or to improve the survey instruments for some types of disability, such as mental disabilities.

In order to satisfy the new information needs for the immediate future, a decision has been taken to invest resources in three new working directions.

The first direction focuses on quantifying the phenomenon of disability in early infancy (0-5 years), exploring information coming from

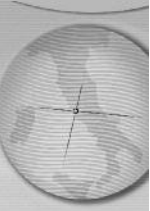
existing data flows, such as for example, registers for congenital malformation and hospital discharge forms. This subject is particularly problematic to survey since for this age diagnoses are often not definitive and some consequences of pathologies or congenital malformations may have not yet manifested themselves. Current instruments such as population surveys cannot be used as a support because no instruments of measurement have yet been set up that are fully adequate and coherent with the ICF.

The second aim seeks to analyse the level of school integration, especially for students with disabilities in primary or junior high schools. The survey will make use of the resources, activities, and instruments that the school institutions have as well as the socio-demographic and epidemiological characteristics of the students in order to obtain a more detailed description, compared to existing data, of the complexity of the needs of students with disabilities.

The third aim retraces a line already taken in the past with the survey of social integration of people with disabilities, by re-interviewing, three years later, people with disabilities contacted for the multi-purpose survey of "Health status and recourse to health services". The aim of the survey will be to analyse in depth the life conditions of people with disabilities and their families, from an ICF point of view, with particular attention being given to the subject of social integration and participation.

Conclusions

From a measurement point of view, gathering information on people with disabilities is a very complex topic, due to the characteristics of the phenomenon itself, the variety of existing conceptual paradigms, and the diversification of the survey or gathering instruments used. Although some steps forward have been made to promote greater integration of the sources, further efforts must be made in terms of the quality of the data gathered, and on the reorganisation and integration of currently available informative flows. The Disability Information System project, implemented by Istat, constitutes an initial significant step in this direction seeking, among other things, to reinforce dialogue between producers and data users in order to get an accurate knowledge of the information needs and to create effective systems of indicators able to meet these needs, but also to represent the multi-dimensional nature of the phenomena offering new information horizons for policies in favour of people with disabilities.



Also, statistical information must not be seen only in terms of data available, but also its accessibility. From this point of view, running the project represents a significant step forward because gathering the various information sources on disabilities countrywide in a single "container" and the wide range of data produced makes it possible to facilitate access to data by institutions and citizens.

In a society characterised by quick, significant transformations that affect the health and living conditions of the people, statistical information as a tool to support policies becomes even more essential. Despite the processes of rationalising resources, the policies must be able to effectively meet the current needs as well as anticipate those of the future. What is needed, therefore is investment in statistical information and the processes for its production, as well as constant updating of data, the quality of the data, and extending the content of the surveys. Investing in statistical information means investing in new, appropriate social policies on people with disabilities and their families.

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