

EDITORIAL

## Eight years of ICF in Italy: Principles, results and future perspectives

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### Abstract

**Purpose.** To report on the process of implementation and dissemination of the International Classification of Functioning, Disability and Health (ICF) [1] in Italy.

**Methods.** The Agenzia Regionale della Sanità of Friuli Venezia Giulia Region (ARSFVG) is a WHO Collaborating Centre for the Family of International Classifications. It collaborated with Italian research institutions such as the C. Besta Neurological Institute IRCCS Foundation, the Medea Institute, and the National Institute of Statistics in revising, field testing and validating the ICF in Italy and in the preparation of ICF-CY (Children and Youth Version).

**Results.** The value of ICF profiles in defining personalised programmes of interventions was explored by evaluating the link between ICF items and the UN Convention, which was taken as a criterion of clear ethical and political orientation in the evaluation of the disability condition. The first and main effort of ICF implementation was directed in the field of public health and welfare policies. Two main nationwide projects were launched: *ICF and the labour policies* in 2003 and *ICF and the disability certification reforms* in 2006. ICF also received a strong attention by the professional working in the school system, and was used to define the functioning profile of children and to establish personalised educational programmes.

**Conclusions.** The implementation of ICF in Italy was strongly facilitated by a favourable cultural and scientific context.

**Keywords:** ICF, ICF-CY, functioning, disability, environment

### ICF in Italy a successful story

The process of implementation and dissemination of the International Classification of Functioning, Disability and Health (ICF) [1] in Italy has been particularly successful. It was strongly supported by public and private institutions and it was developed in a continuous and close collaboration with WHO. Some specific and original characteristics of this process are herein highlighted.

#### *A joint, extended and continuous effort for implementation*

In 1998, the Agenzia Regionale della Sanità of Friuli Venezia Giulia Region (ARSFVG) took the lead in revising, field testing and validating the ICF in Italy.

As the beginning, the process became a joint effort that brought together professionals from different backgrounds (medical, social and educational), as well as associations of persons with disabilities. In fact, ICF was never conceived as a tool designed for health professionals or for the health sector only, but as a tool for a common approach to functioning and disability.

The first Italian ICIDH-2 Consensus Conference took place in 1998. In the same year, ARSFVG activated the procedures to become a WHO Collaborating Centre, and a large group of people from all over Italy founded the Disability Italian Network (DIN), which worked according to WHO's instructions for the development of the new classification system. The ICF was formally approved in 2001. The Italian translation of ICF was published in spring 2002, and in April 2002 the "WHO- ICF Health and Disability Conference" in Trieste was the

occasion to present the Classification to more than 70 Member States.

Italian research institutions had a first-line role in WHO's international task force for the preparation of ICF-CY (Children and Youth Version) [2]. In 2007, the ARSFVG was recognised as a WHO Collaborating Centre for the Family of International Classifications, jointly with three research branches: the C. Besta Neurological Institute IRCCS Foundation of Milan, the Medea Institute in Conegliano Veneto, and the National Institute of Statistics (ISTAT) in Rome. In autumn 2007, Italy hosted two WHO events: a conference in Venice for the presentation of ICF-CY and the annual meeting of the WHO-FIC network in Trieste.

### *The emphasis on functioning as a new anthropological paradigm*

ICF in Italy has been generally evaluated as a worthy tool to present the disablement process as the interaction between a health condition and environmental factors, to facilitate the description of human functioning, and to overcome the stigmatization of persons with disabilities.

The focus of the classification has shifted from the 'sick' or 'impaired' body to the person-context interaction. In all implementation and training experiences, the 'systemic' approach to health and disability introduced by ICF has been strongly supported and presented as a key to understand correctly the revolutionary concepts of 'performance' and 'capacity' that qualify the domains of activity and participation [3]. The ICF perspective on functioning and disability was in line with the dominant culture in the scientific Italian community (institutions, political forces and associations of persons with disabilities), which was oriented to consider disability as a universal condition, and to consider social inclusion and empowerment as a central value to policy support.

During the implementation work, the complementarity between ICF and the UN Convention for the Rights of Persons with Disabilities [4] became more and more clear. ICF has been considered and used as the natural conceptual framework and language to describe and evaluate the effective exercise of human rights and to monitor the UN Convention's application in Italy.

### *Establishing ICF as general assessment framework against the 'plethora' of disability assessment instruments*

ICF is strongly appreciated for its conceptual structure, semantics and qualifiers system. ICF places the assessment of disability in a new perspective and opens

the way to a critical revision of assessment instruments by focusing on the ambiguities and limitations of most 'disability scales' that underestimate the effect of the environment on human functioning.

In the Italian experience, ICF has never been considered simply as a 'change in language', forcing the use of new and more 'politically correct' words, but as a real new perspective in understanding, describing and measuring disability. The priority was placed on reaching an agreement between users of the methodology and contents of the functioning evaluation, leaving in the background the choice of the assessment instruments. Mapping assessments against ICF items has been considered a fundamental contribute to understanding the validity and dimensions of the measurement process.

### *A cultural and scientific favourable context*

The implementation of ICF in Italy has been strongly facilitated by a favourable cultural and scientific context. In fact, many themes related to the rights of persons with disabilities and the role of environment in promoting and maintaining the health of people have been extensively debated. Many Italian laws have focused on these themes, sometimes courageously, like in the case of the The Law n. 180 approved in 1978 [5] that stopped the admission of new patients to mental hospitals, determining their gradual closure. Earlier, the Law n. 517 approved in 1977 [6] fixed rules and norms for the integration of the so called 'handicapped' children in 'ordinary' schools determining the end of the 'schools for children with special educational needs' and the segregation of children with disability. The principle of inclusion of the persons with disabilities in the labour market was stated repeatedly till to the approval of the Law n. 68 in 1999 [7] that reformed completely the rules and organizations devoted to the support of disabled persons looking for a job.

### **Main directions of ICF implementation and dissemination**

On the basis of these premises, we can depict some specific characteristics of ICF implementation and dissemination in Italy that are clearly reflected in the contents of the articles proposed in this issue of D&R.

### *ICF implementation in public health, school system, welfare policies and the national statistical system*

The first and main effort of ICF implementation was directed in the field of public health and

welfare policies. Two main nationwide projects were launched: *ICF and the labour policies* in 2003 and *ICF and the disability certification reforms* in 2006. The first project has been recently refinanced by the Ministry of Labour, Health and Social Policy in order to complete the dissemination at national level of an ICF-based checklist for the evaluation of the functioning profile of persons with disabilities who are seeking employment (Conclave et al. [8]). The second project will end in May 2010 and proposes a methodological approach and a disability evaluation protocol as a reference framework for all the processes of disability certification (Francescutti et al. [9]; Leonardi et al. [10]).

The value of ICF profiles in defining personalised programmes of interventions has been deeply explored (Martinuzzi et al. Use of ICF and ICF CY in rehabilitation) [11]. In particular, the link between ICF items and the UN Convention contents was tested as a criterion capable to give a clear ethical and political orientation to the evaluation of the disability condition, at least with the same value of the statistical-oriented item selection procedures that often guide the researcher in defining 'core sets' or in testing assessment instruments [12]. The process of revision of the Italian statistical information system on disability in the light of the ICF semantic structure is described in the contribution of the researchers of the National Institute of Statistics (ISTAT) [13].

ICF has also received a strong attention by the professional working in the school system, and has been used to define the functioning profile of children and to establish personalised educational programmes. Teachers, and health and social professional have been directly and jointly involved in education and implementation programmes in many projects in several parts of Italy, at regional levels. The results of these applications are explored in two contributions [14,15].

#### *Dissemination and training on a large scale*

As the publication of the ICF Italian translation in 2002, DIN firstly and the Italian WHO Collaborating Centre (CC) secondly received a strong request for training courses on ICF from different parts of Italy, supported by educational, health and social services institutions. The request was often followed by the proposal of practical implementation of the classification. The training proposal extended over several months and getting more complex with time, included: the definition of protocols of disability evaluation including ICF as the descriptive language; the application of ICF on real cases; a period of 'on

site' application supported by a web training platform; a direct tutorship by experts; and a final evaluation followed by a formal acknowledgement of the training results.

As reported by Francescutti et al. [16] in 'Describing and promoting human functioning and research through training programs based on ICF framework', several thousands of persons attended DIN training courses. In some cases, the training programme involved professional representatives of the entire network of the regional health or social services, such as in the case of the Piedmont Region in 2004/2005 and the Veneto Region in 2006. Extensive training programs were carried out under specific implementation projects like that described by the aforementioned contribution of Conclave et al. [8], with training sessions organized in each of the 94 provincial county towns.

#### **Future perspectives**

Eight years after its release, ICF implementation in Italy is at a turning point: the passage from the experimental projects to the routine use, from research to a consolidated institutional commitment. Considering the experiences and results achieved we expect that in a short-term:

- ICF will be recognised more clearly and widely, in national and regional laws, as the general conceptual framework for all welfare services and organizations dealing with disability and persons with disabilities;
- ICF and ICF-based evaluation protocols will become the reference language for disability evaluation and certification and in the professional communication;
- health and social information systems dealing with ICF codes and contents will be developed, showing the potential use of ICF as a basic semantic structure to represent heterogeneous sources of information on health, functioning and disability;
- ICF will be stably included in academic curricula of different professional profiles (medical doctors, social workers, psychologists and other);
- ICF will be widely included in clinical information systems and data collection, at least in the rehabilitation sector.

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