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Institution Name Agenzia Regionale della Sanità

Name of Department, unit, section or area of the institution designated as WHO.CC

Health Information Systems, Standards and Coding Systems and Epidemiological Department

City Udine

Country ITALY

Country ID

Title WHO Collaborating Centre for Family of International Classifications

Report Year 07/2008 to 07/2009

1. Implementation of the work plan. For each main activity briefly explain how the activity was implemented, the outcome and impact and, if available, the results of the evaluation (e.g. evaluation of a course by the participants). Also explain difficulties (if any). Do not provide technical results in this form (technical results, if applicable, are to be sent directly to the WHO Department you work with).

Activity 1 Promote development and use of WHO-FIC

Explanation

At the end of June 2009 the Italian Portal of Classifications (www.reteclassificazioni.it) has been officially released. The portal has been developed by the Italian Collaborating Centre, the CC branches Regional Agency of Health (ARS) and University of Udine Dep. of Medical Informatics, Telemedicine and E-health (UNIUD), in agreement with the Ministry of Labour, Health and Social Policies. This project is part of a wider plan of collaboration between the Ministry and the Italian CC for the development and implementation of classifications at national level.

The main aims of the portal are:

- to create the Italian community of users and coders of WHO-FIC;
- to facilitate the dissemination of the electronic versions of WHO-FIC;
- to support the collaboration of Italian experts to the international development of WHO-FIC

The portal implements the same wiki technology proposed by the WHO for the review process of ICD11.

ICF, ICF-CY and ICD10 are currently available on the portal. As part of the development of a classification for Pathology, ICDO-3 will be available soon.

An informal network of software developers interested to the implementation of ICF in their platforms has been established under the coordination of the CC. Basically the idea is to share general rules and guide lines for the use of ICF in health and social information systems.

The network is discussing the possibility to develop open-source components based on ICF and to define a procedure for the certification of the correct implementation of ICF in Health Information systems. The certification procedure could be managed by the CC.

The Italian CC is actively involved in the project of ontological development of ICF. Italian CC, the CC branch UNIUD experts, participated to the seminar, organized by WHO in Nottwil (December 2008) and a first draft of the analysis and research work carried out in Italy has been sent to WHO in July 2009, regarding the connection between ICF concepts and basic upper ontologies like SUMO, BFO and DOLCE.

Activity 2 Contribution in development of methodology for the use of WHO-FIC

Explanation

The Italian CC is continuing the project of ICF implementation to support the process of disability certification reform in Italy. The project, financed by the Ministry of Labour, Health and Social Policies, involve all the CC branches (ARS, ISTAT, BESTA and MEDEA research institutes). The research agenda identified 6 phases as follows:

1. adopting a definition of disability in line with the United Nation Convention on the rights of the persons with disabilities (UNC), capable of making it explicit how the different definitions in use in the welfare system can converge in a general framework;
2. propose an analytical breakdown of the contents of the definition, based on ICF structure, so as to indicate, as clearly as possible, the core information essential to substantiate the evaluation process;
3. defining a data collection protocol;
4. planning a survey at national level in different welfare settings and gathering data useful for defining functioning/disability profiles (approx 1000 cases);
5. propose a methodology to process the information with particular attention to supporting decision making;
6. compare the proposal with the empirical data

The data collection will be completed at the end of 2009. A detailed proposal of ICF data processing and a person-environment interaction classification tree has been defined and could be presented at the 2010 annual meeting of WHO-FIC Network

Activity 3 Support**Explanation**

The network of institutional subject that support the activities of Italian Collaborating Centre, continues and strengthen its collaboration with WHO-FIC.

The Italian delegation at the WHO FIC Annual Meeting was involved in the activity of:

- EC (Andrea Martinuzzi, Matilde Leonardi)
- ETC (Vincenzo della Mea)
- FDRG (Matilde Leonardi, Andrea Martinuzzi)
- IC (Matilde Leonardi)
- MRG (Monica Pace)
- MbRG (Giulio Borgnolo)
- URC (Carlo Francescutti)
- TRG (Vincenzo Della Mea)

During the WHO FIC Annual Meeting in India, the Head of the Italian CC, Carlo Francescutti was elected as Co-chair of URC and Matilde Leonardi as Co-chair of IC. The Centre also provides the secretariat Raffaella Troiano for the URC. In particular, the Italian Centre, the CC Research branch Besta, provided support (collaboration with a statistician) working in Geneva and in Milan for the development of the "WHO-FIC Implementation Data Base". ARS, provides a medical doctor Francesco Gongolo, to help ICD11 revision process

The members of the Italian CC have participated also to the mid year activities of different groups and committee of the WHO FIC Network:

- MbRG (Giulio Borgnolo in Australia)
- FDRG (Matilde Leonardi in Brasil)
- IC (Matilde Leonardi in Geneva)
- URC (Carlo Francescutti and Raffaella Troiano in Geneva)
- ETC (Vincenzo Della Mea in Köln)
- COUNCIL (Carlo Francescutti in Geneva)

Andrea Martinuzzi (MEDEA) was also involved in the "ICF Workshop in Turkey" 26-30 November 2008 and in Iran 24-30 January 2009 and Vincenzo Della Mea and Andrea Simoncello (UNIUD) took part to the workshop "WHO ICF Ontology Protège" in Nottwil from 1-5 December 2008

Activity 4 Develop education and training material.**Explanation**

The educational and training work on ICF continued in 2009:

a) to support the project of ICF use in the process of disability certification reform in Italy (in collaboration with Ministry of Labour, Health and Social Policies) more than 500 professional have been trained;

b) to respond at specific health and social institution requests related to the implementation of ICF in the professional activity and information systems.

c) Andrea Martinuzzi, Alberto Raggi together with other Italian experts, members of the Disability Italian Network, participated to the development of the ICF e-learning tool, commenting on its limited feasibility and adequacy for an advanced learning.

d) Matilde Leonardi, with the other ICF and Ethics co-chair Jerome Bickenbach, contributed to the writing of educational material "ICF overview" in preparation for updating WHO classifications' website. In 2008 we have published two introductory books on ICF in Italian and Portuguese (this one related to the cooperation project in Mozambique), and developed in close collaboration with the Ministry of Health of Mozambique and an Italian NGO operating locally (CESTAS).

With ISTAT (National Institute of Statistics) two initiatives for the training of mortality coders has been done: the first in October from 6 to 10, the second one in February from 23 to 27. During the first session there has been a statement by Robert Jakob (WHO) on the ongoing developments of classification, the international mechanisms to review and the use of classifications at international level.

With SIAPEC (National Institute of Italian pathologists) and our Italian Ministry of Labour, Health and Social Policies, a workshop has been organized about "New strategies for the standardization of information for the clinical research, epidemiology and public health". The event was held in Bologna, November 29th 2008. Dr. Jakob gave a presentation on "Sharing knowledge: the role of the terminology and classification. The strategy and the plans of the WHO"

The large Italian rehabilitation network "MEDEA La Nostra Famiglia" decided to adopt ICF for the functional description of the over 12,000 children cared for within its 35 locations in 7 Italian Regions. For this reason a massive systematic education and training on ICF and ICF-CY was launched by the Institution, and carried out by the team of the WHO-FIC CC in Conegliano. Multiple editions of basic and advanced ICF courses, with special emphasis on ICF-CY were held in S.Vito al Tagliamento (Friuli), Bosiso Parini (Lombardia), Ostuni (Puglia), Cava dei Tirreni (Campania), and Conegliano (Veneto). Professionals of all areas involved in rehabilitation team work (MDs, Psychologists, Physical Therapists, Speech therapists, Occupational therapists, nurses, Pedagogists, social workers attended the courses. Andrea Martinuzzi (MEDEA) participated to workshop "Work and Rehabilitation" that was held in Harkany in Hungary 15 October 2008. Together with Giulio Borgnolo and Alberto Raggi, he also participate to the multilateral conference "Development of a common language on health and disability in the alps Adriatic regions: promoting application of the International Classification of Functioning, Disability and Health (ICF)", that was held in Szombathely (Hungary) on December 15th 2009, as part of the last event organized of the Alpe Adria Network Project (in collaboration with Friuli Venezia Giulia Region and Veneto Region/Italy, Slovenia, Hungary, Croatia). Together with Giulio Borgnolo (ARS), Andrea Martinuzzi (Italian CC research branch MEDEA) in March, and two collaborators of the CC research Branch Besta, Paolo Meucci and Rui Quintas, in July, did a training course for PHC workers on ICF CY in Mozambique (see below)

Andrea Martinuzzi was involved through WHO with a ICF Training workshop in Antalya on November 26-30 2008 sponsored by the Turkish administration for persons with disabilities, Office of the Prime Minister, a three day long training workshop (ICF basic and advanced course) in Tehran, Iran between the 24th and the 30th of January 2009, and a week long training mission for the WHO EMRO in Damascus Syria, April 8-14th 2009, with the aim of putting the basis for implementation of ICF in rehabilitation and CBR in that country.

Activity 5 Develop reasearch

Explanation

The main research projects related to the use of ICF that has been developed and continued in 2008 regarded:

1. the use of ICF in disability certification (project financed by the Italian Ministry of Labour, Health and Social Policies);
2. the use of ICF in evaluating functioning of adults and young people with disability in residential settings (joint project of Friuli Venezia Giulia and Tuscany Region);
3. the use of ICF in evaluating health and disability in children with AIDS in Mozambique
4. the use of ICF in describing functioning profile of adults and young people with disability involved in projects of employment access
5. the use of ICF in describing functioning profile of children in Ankara "WE ARE IN: We are in for an unhindered accession to the European union" in the project Promotion Of The Civil Society Dialogues Between European Union and Turkey: Youth Initiatives For Dialogue
6. the participation to the EU COURAGE project (Collaborative Research on Aging in Europe) that aims to conduct a comparative study on health and health related outcomes for an aging population in three different European countries (Spain, Finland and Poland) with high rates of aged people. The role of welfare organizations, social and health policies and other environmental factors in the quality of aging, will be evaluated using assessment tools based on ICF
7. the involvement in the EU-MURINET project (Multidisciplinary Research Network on Health and Disability in Europe), Financed by the EU the project aims to create an European group of experts in research and management of health and disability who can integrate different skills in the light of the ICF classification;
8. participation in the public notice for the submission of strategic projects relating to the Program for the CBC Italy – Slovenia that have to be pursued through four specific objectives:
 - ensure the territorial development;
 - increased competitiveness and development of a knowledge-based society;
 - improve communication social and cultural cooperation, in order to remove the persistent barriers;
 - improve the efficiency and effectiveness of the Program;

Activity 6 Maintain Italian language edition of ICF.

Explanation

As already mentioned, as part of a general agreement between the Ministry and the Italian CC we received the specific assignment to provide, within the end of Spring 2010, the update of the Italian version of ICD10. The Italian translation available today is based on the first edition.

The translation work will begin in August 2009 and will use the resources of the Italian Portal of Classification to support the work of the different experts involved.

Activity 7 To promote and support

Explanation

At national level the CC has been included in the institutional work-group on Health and Disability promoted by the Ministry of Labour, Health and Social Policies. The work-group agenda includes the adoption of the UN Convention on the rights of the persons with disability in Italian legislation and the use of ICF as the official classification for functioning and disability.

The Ministry is also considering the possibility to introduce ICD10 for coding hospital discharge data. The Italian CC is actively evaluating the complex process of replacing ICD9-CM both in terms of education and training and alignment with the DRG system.

The international cooperation project between the Italian CC, the government of Mozambique and the CESTAS (NGO operating locally) for the evaluation of disability of children has been refinanced and will continue throughout 2010. In July 2009, Paolo Meucci and Rui Quintas joined Giulio Borgnolo in Maputo for implementing this project and holding training course for health professionals and social workers.

In December 2008 the Italian WHO CC presented a cooperation proposal within the framework of the UNDP program of decentralised cooperation. In the proposal a major part is represented by the implementation of ICF as a tool to evaluate functioning and disability in developing countries. Two regions, one in Lebanon and one in Ecuador, have positively evaluated the proposal and the first site visits have been planned for the Autumn 2009.

In June 2009 in collaboration with the Bioethic Centre of Italian Catholic University, under the auspices of the FDRG ICF and Ethics workgroup and supported by EU MURINET project, it has been organized by Matilde Leonardi, ICF and Ethics co-chair, the international conference "Ethics, Disability and Justice" to discuss about these issues also in light of the ICF and UN Convention. Several participants from WHO-FIC Collaborating centres came, together with national and international experts. Results and suggestions that emerged have been presented to the FDRG mid term meeting in Brazil and will be reported to the annual WHO FIC meeting.

A special mission in Iran, under request by EMRO WHO offices and the competent authority in Iran, was held in January by Dr Martinuzzi with the aim of devising the best way to use ICF in the assessment and evaluation of CBR in rural Iran. A work plan has been drafted and follow-up visits are scheduled.

Activity 8 To collaborate with national authorities

Explanation

At national level the CC:

- has been included in the institutional work-group on Health and Disability coordinated by the Ministry of Labour, Health and Social Policies;
- is part of the national commission for the disability information system;
- is involved in the national work force for the monitoring UN Convention on the rights of persons with disability application.

Activity 9 To present periodic reports on the Centre s activities

Explanation

This is the second annual report.

2. Other information related to the Collaboration between the centre and WHO. Briefly describe visits by WHO staff to the centre, visits by the centre staff to WHO (HQ and/or Regional Office), use of the centre staff by WHO, support provided by centre staff for courses cosponsored or organized by WHO (HQ and/or Regional Office), WHO financial support to the centre through contractual or Technical Services Agreement or other type of support provided by WHO, any other collaborative activities. Please mention any difficulties encountered in the collaboration and suggestions for increased and improved collaboration with WHO.

As already mentioned a close and intensive collaboration with the WHO staff has been continued, and in particular:

1. as request during the last Mid year meeting, in Geneva, Italian CC, the branch ARS, provides a medical doctor Francesco Gongolo, to help ICD11 revision process ;
2. the Italian Centre, the research branch BESTA, provides a Statistician, Rosalba Lembo, working in Geneva and in Milan for the development of the "WHO-FIC Implementation Data Base".
3. Matilde Leonardi and Rosalba Lembo (Italia CC research branch BESTA), are collaborating with Nenad Kostanjsek to the development of a questionnaire to be distributed to all WHO's countries to obtain common information on disability prevalence for the World Disability and Rehabilitation Report.
4. Andrea Martinuzzi (Italian CC research branch MEDEA) has done training in Iran and Turkey on behalf of WHO on ICF

3. Collaboration with other WHO Collaborating Centres: Briefly describe the nature and outcome of the collaboration and the name(s) of the other WHO collaborating centre(s) with which the centre has collaborated. If applicable, please mention the name of the network of WHO CCs to which the centre belongs. Also include suggestions for increased and improved collaboration with other WHO CC

THL expert Dr. Matti Ojala, in order to prepare and define a strategy of collaboration between Italian and Finnish experts at national and local level, held a two days seminar in Italy about "Person with disability and Accessibility" with a special focus on the "Finnish Accessibility Classification" (presented at the New Delhi meeting in 2008) and related accessibility assessment tools. The event was organized by the Italian CC members (ARS) and supported by expert from different centres of the Italian network.