



#### I CONTRIBUTI

#### del Centro Collaboratore italiano dell'Organizzazione Mondiale della Sanità per la Famiglia delle Classificazioni Internazionali



#### WHO-FIC Network Annual Meeting | 2011 Health Information is Vital

29 October - A November | Cape Town, South Africa





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In reply please refer to: I3-MTG-0004/WHO-FIC 2011

Your reference:

09 June 201

Dear,

#### WHO Family of International Classifications (WHO-FIC) Network Meeting Cape Town, South Africa 29 October-04 November 2010

I take great pleasure in inviting you and your centre's delegation to the next annual meeting of World Health Organization Family of International Classifications Network, which will take place in Cape Town, South Africa, from Saturday 29 October to Friday 04 November 2011.

The meeting will be hosted by the members of the upcoming South African Collaborating Centre. The Secretariat function will be carried out by WHO's unit of Classifications, Terminologies and Standards.

This invitation is sent to you by e-mail. Should you require a regular copy, please inform us and we will send one for you and your team members accordingly.

Please find attached the draft provisional timetable and a tentative list of participants. These will be updated in line with comments from the Small Executive Group (SEG) and yourselves after review by the Secretariat. Updates will be posted on the WHO web site.

The meeting venue is the Cape Town city Southern Sun Cape Sun Hotel.

The website for coordination of meeting registrations and accommodation reservations developed by our hosts has been activated. It provides all details regarding general orientation and meeting facilities, as well as accommodation and social program reservations forms and procedures. Please copy the following URL in your browser14: www.whofic.org.za/ The website can also be accessed via hyperlink from our WHO FIC website: www.who.int/classifications/network/meeting2011/.

Registrations to the meeting are <u>mandatory</u> and should be made through the meeting web site

Each WHO Collaborating Centre is to be represented by <u>two main delegates</u> and as many alternates as you deem appropriate. However, we would like you to restrict the size of each team to no more than 5 members, unless responsibilities for the work program warrant a higher number. Please send an updated list of your delegation with full individual details (including email address) to Anne-Laure

#### ・世界卫生组织 • منظمة الصحة العالمية

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Lameyre (lameyrea@who.int) by 3 August, and complete their registration through the web site by 14 October 2011 at the latest.

As per established practice, we understand that all costs of your and your team's participation will have to be borne by yourself or your organization.

If you plan to submit a poster for the poster session or you are interested to present a paper to the committees or reference groups please follow the instructions at the WHO web site at: http://www.who.int/classifications/network/meeting2011/ or the meeting website : www.whofic.org.za

The deadline for submitting titles, abstracts and profile of posters and papers is <u>30 June 2011</u>. If you plan to present a paper to the committees or reference groups you need to get in touch with the respective Chairs. The paper proposals should be referenced to a specific item of the strategic workplan of the WHO FIC network. The Chairs of Committees and Reference Groups will - in consultation with the WHO secretariat - will review and select the paper proposals. The deadline for submission of final papers is 20 August 2011.

"Health information is vital" has been identified as the main theme for the meeting and poster sessions by the WHO-FIC Council. This theme comprises the subtopics ICD-11, vital registration-MoVE-IT, low resource settings requirements and solutions- (SADC countries report on their work), traditional medicine (including traditional African medicine), and improving health systems Posters relating to these topics will have priority for presentation. The deadline for poster submissions is 20 August 2011. The SEG will select posters relevant to sessions (see agenda) that will be given a short presentation time of 3-5 minutes and a maximum of 6 electronic PowerPoint slides to deliver the key messages. In addition, we will arrange for printing of the posters. All papers and posters will have to use the templates provided on the sites.

If you require any further information regarding the meeting please do not hesitate to contact me and the members of the WHO-FIC Team. I am looking forward to meeting you in Cape Town.

Yours sincerely,

Mi hangin

Dr T. Bedirhan Üstün Coordinator Classifications, Terminologies and Standards Department of Health Statistics and Informatics

ENCLS.







#### **Composizione della delegazione 2011**

#### Lucilla Frattura

Italian WHO-FIC Collaborating Centre Head, Council (voting member), Update and Revision Committee (ICF voting member), Education and Implementation Committee (voting member), Family Development Committee (member) *Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine* 

#### Francesco Gongolo

Update and Revision Committee (co-chair and ICD voting member), Council (voting member), Functioning Topic Advisory Group (voting member) Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine

#### Vincenzo Della Mea

Informatics and Terminology Committee (secretariat) University of Udine, Dept Mathematics and Informatics

#### Andrea Martinuzzi

Functioning and Disability Reference Group (voting member) "E. Medea" Scientific Institute, Conegliano Research Centre

#### Andrea Simoncello

Informatics and Terminology Committee (member) Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine

I contributi sono scaricabili

- dal sito dell'Organizzazione Mondiale della Sanità (<u>http://www.who.int/classifications/network/meeting2011/en/index.html</u>)
- dal Portale Italiano delle Classificazioni previa registrazione (<u>http://www.reteclassificazioni.it</u>)





#### Lista dei Contributi

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- WHOFIC2011\_D018 Functioning interventions in ICHI: populating a crowded desert
- WHOFIC2011\_D020
   Tools for collaborative development and update of ICHI
- WHOFIC2011\_D030p
   ICF implementation in regional policies: the case of the Friuli Venezia Giulia Region, Italy
- WHOFIC2011\_D039p
   Health information systems learn to speak ICF: Toward electronic ICF-based individual records
- WHOFIC2011\_D031p ICF implementation in targeted employment of persons with disabilities: the Italian work in progress
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   Understanding ageing and determinants of health and disability in ageing to guide public health policies: the COURAGE in EUROPE Project
- WHOFIC2011\_D005p ICF-based project/programme in a paediatric neurorehabiltation hospital: appraisal of 3 years of implementation
- WHOFIC2011\_D009p Preliminary Mapping of ICF-CY Body Structures to SNOMED-CT



#### Updating Annex 5: ICF, people with disabilities and UN CRPD: implications for statistics and policies monitoring.

Lucilla Frattura (1), Giampiero Griffo (2)

(1) Italian WHO-FIC CC, Italy; (2) Disabled Peoples' International

#### Abstract

The definition of "persons with disabilities" given by the UN Convention on the Rights of Persons with Disabilities (CRPD) poses a challenge. Without questioning bodily impairment (seen as a precondition), the UN definition focuses on "disabilities" as negative outcomes and describes the restriction to participation and inclusion in society as the result of the presence of barriers and discrimination. ICF also provides a conceptual framework for understanding disability. According to the ICF model, disability and functioning are the negative and positive outcomes of the interactions between an individual with a health condition and contextual factors. Since ICF and UN CRPD are the two pillars of a modern way to approach disability, the practical and political implications of the new definitions are various, first of all for people who "remain" with disabilities.

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Functioning interventions in ICHI: populating a crowded desert

Andrea Martinuzzi, Thorsten Meyer

Medea Scientific Institute, Italian WHO-FIC CC, Hannover Medical School, Germany

#### Abstract

Population of ICHI alpha version with interventions linked to rehabilitation and functional assessment started from initial mapping of ICD-9-CM vol. 3 chapter 16, but comparing it with the wealth of different interventions delivered in rehabilitation services highlights the low granularity and lack of specificity of the existing categories. A two steps procedure was devised to enrich the initial list: 1) incorporate in the alpha draft items from other existing lists; 2) further enrich the resulting draft with appropriate description of relevant activities in functional assessment and rehabilitation as emerging from everyday practice. The process will keep an open dialogue with the ICHI structure definition list, calling when needed for enrichment (similarly to the 2011 dialogue for interventions targeted to the environment). While the first step can be completed in a defined time and preliminary results will be presented, the second will proceed during ICHI refinement, gathering evidence from tests in different locations.

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The views expressed in documents by named authors are solely the responsibility of those authors.

#### Tools for collaborative development and update of ICHI

Gongolo F., Simoncello A., Della Mea V.

WHO-FIC Italian Collaborating Centre, Udine, Italy

Abstract

For the preparation of the ICD11 Alpha draft, a collaborative authoring tool, iCAT, was developed in order to facilitate remote collaboration practices and to allow a broad involvement of a large number of experts. iCAT provides means for exchanging views and comments between people working remotely who can effectively contribute to the draft, revision and maintenance of the classification.

ICHI is the WHO Classification of Health Interventions. In recent years, extensive work has been done to design this object by defining axes of characteristics and by tailoring a content model in which, as it has already been done for ICD11, all the relevant characteristics of health interventions can be fully represented. However, to finalize the development of ICHI, it is fundamental to adopt a tool that enables bringing together the efforts of several working groups in different countries around the world, interested in developing a classification of health interventions.

The authors, starting from the positive experience with the use of iCAT for the revision of ICD11, analyzed the possibility of using such a tool for the management of the content model of ICHI. Depending on the uses of the content model, different hierarchies can be designed to better meet the needs of various users. Even more, iCAT allows great flexibility in defining links to other classifications by serving as a tool for alignment of terminology and by allowing direct mapping of specific objects in the classification. Therefore, iCAT aims to be the most suitable option for the drafting of a WHO Classification of Health Interventions.

## ICF implementation in regional policies: 29 Oct – 4 Nov 2011 the case of the Friuli Venezia Giulia Region, Italy

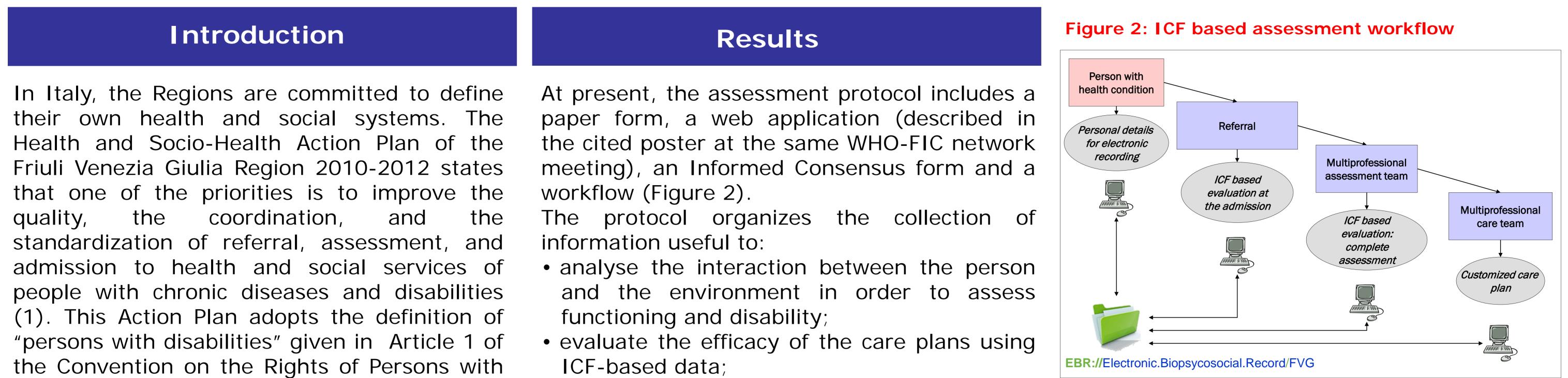
Lucilla Frattura<sup>1</sup>, Giovanni Bassi<sup>1</sup>, Andrea Simoncello<sup>1</sup>, Giuseppe Bazzo<sup>2</sup>

**D030p** 

<sup>1</sup> Regional Central Health Directorate, Classification Area, WHO-FIC CC, Regione Friuli Venezia Giulia, Udine, Italy

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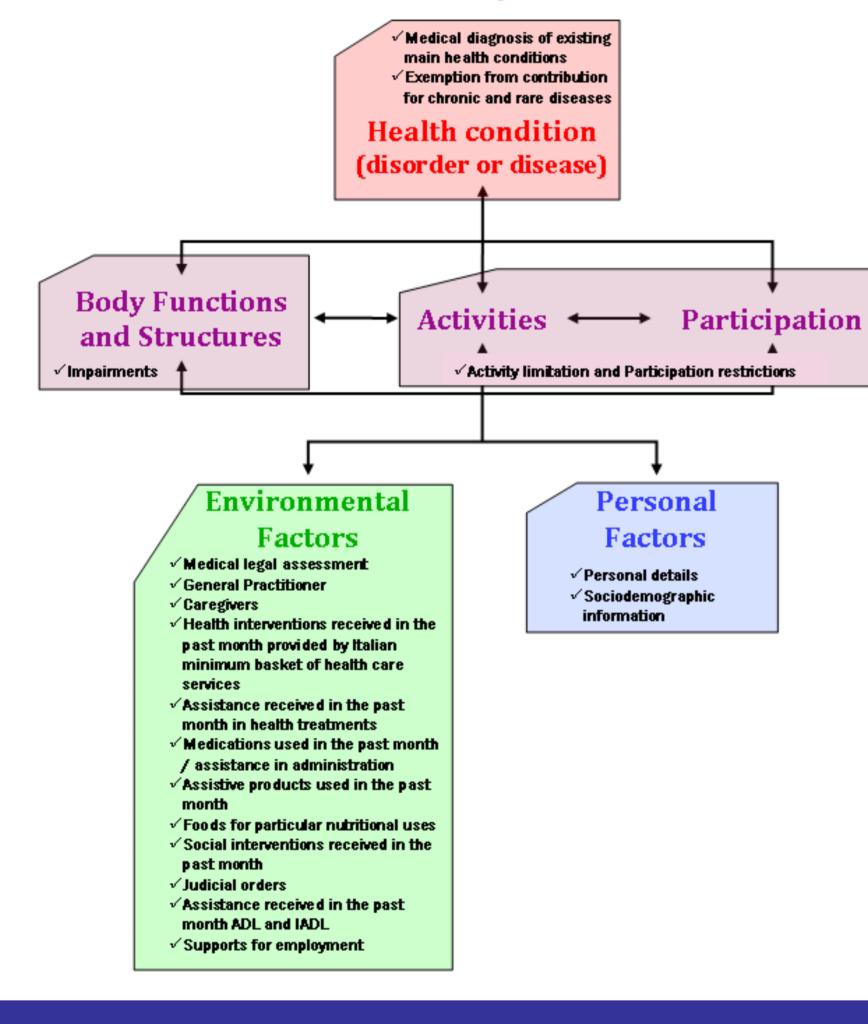
Abstract The Health and Socio-Health Action Plan of the Friuli Venezia Giulia Region 2010-2012 states that one of the priorities is to improve the quality and standardization of referral, assessment, and admission to health and social services of people with chronic diseases and disabilities using a common assessment protocol based on ICF. A field trial is ongoing, using a new web application named "electronic ICF-based individual record".



Disabilities as the pillar of the Action Plan and of future legislation.

The Action Plan states that disability evaluation and customized care plans are the tools for a more modern way of operating between the public system and the citizens, which together contribute to the improvement of a certain life condition. Moreover, the Plan clarifies that disability evaluation has to be made by multi-professional assessment teams and to be carried out by means of ad hoc protocols based on the language of ICF. By using its own ICF-based assessment protocol, the Region intends to collect data for evidence-based health and social planning.

#### Figure 1. The framework of the ICF based assessment protocol



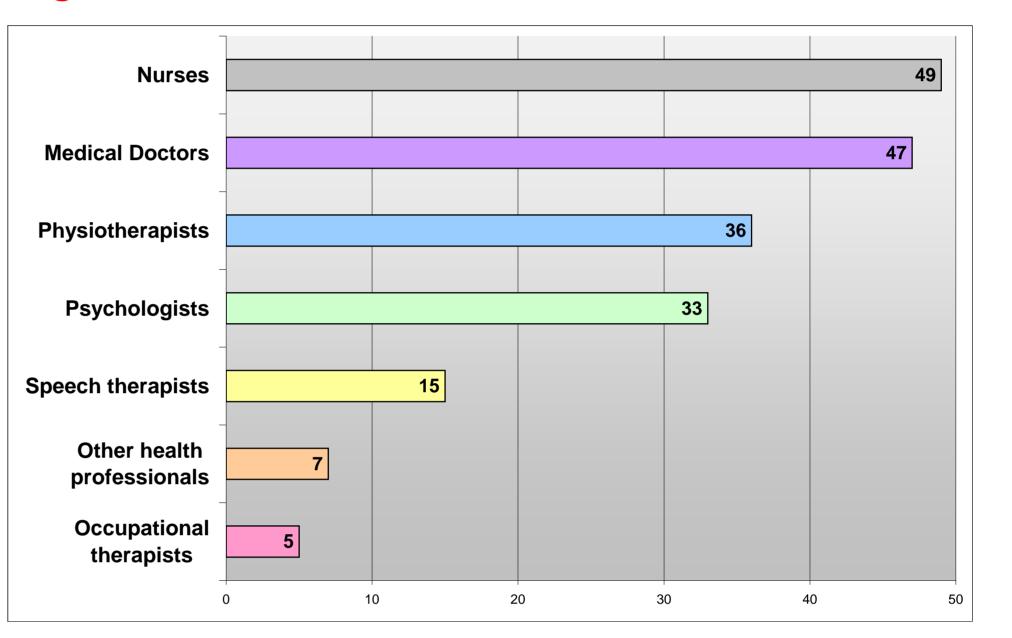
- make the tailored care planning more efficacious, thus overcoming the idea that care plan is based on the diagnosis. the

The protocol uses the ICF and its version for children and youth (ICF-CY) both as a model of functioning/disability and as a descriptive language.

For the collection of the information needed at the referral, no full knowledge of ICF language is required of the operators. In fact, the information system has been developed to translate into ICF all the information that can be translated. For the collection of the information needed to assess functioning and disability, full knowledge of ICF language is required of operators.

All the six local health authorities of the Region are involved in the first field trial in order to evaluate a defined number of patients. The

#### Figure 5: Professionals involved in the field trial



#### Conclusions

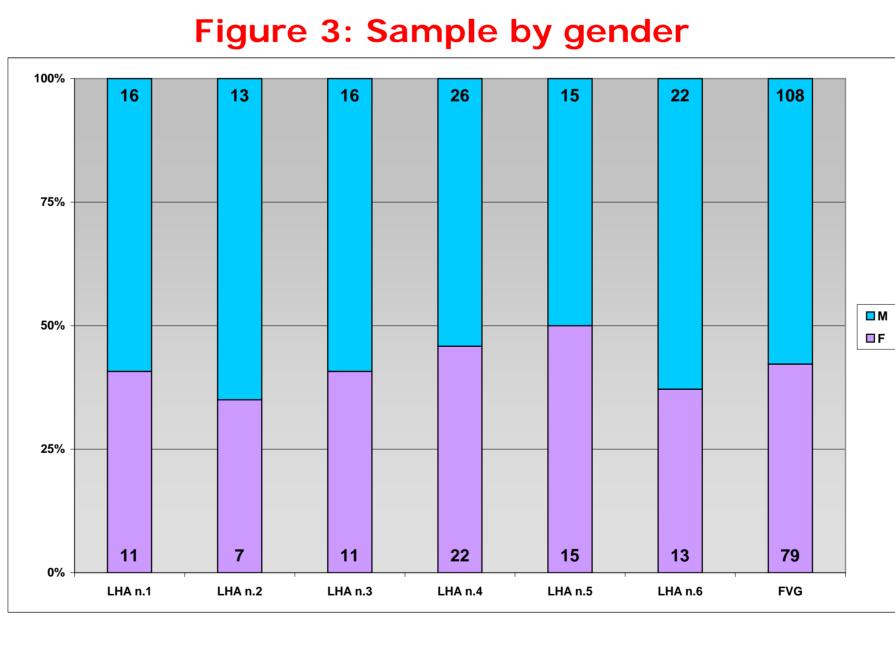
In accordance with MHADIE recommendations

## Methods & Materials

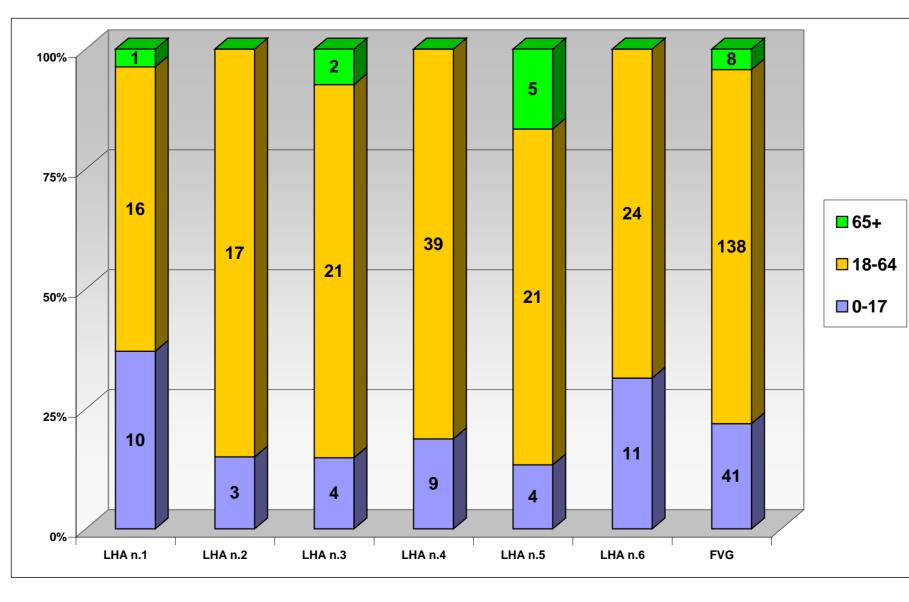
The Regional Central Health Directorate at the end of 2010 launched a specific programme "Development ICF-based and of use

main characteristics of the recruited sample are shown in Figures 3 and 4. It includes children aged 0-6 and a comparable numbers of females and males.

282 operators were trained in 2011 by the Italian WHO-FIC CC. One third of them were social workers (Figures 4 and 5).



#### Figure 4: Sample by age



(6), the ICF model of functioning and its related assessment protocol developed by the Friuli Venezia Giulia region are used to (a) define a person's level of functioning, (b) identify the patient's needs and planning interventions, (C) evaluate clinical and outcomes. The protocol under study has been developed for routine clinical use by different The assessment professionals. the Of environmental factors has been taken into account in an original way.

At present, no Italian or regional health information system is based on ICF or uses its potentialities linguistic information and standard.

The Italian WHO-FICCC has the institutional role of acting as a link between WHO and Italy the implementation of international in classifications, and aims to facilitate and make operatively and scientifically consistent the effort of the regions and public organizations in relation to the topic of fighting disability. The moment could not be better.

assessment tools" within the action plan for the management of the regional health system 2011 – line n. 3.4.4.7. (2). An assessment protocol was developed and is now under trial. The assessment protocol improves previous adopts, revises and versions experimented at national and regional level (3, 4). Moreover, it considers the analysis of the interaction between a person and the environment and the evaluation of the efficacy of the interventions as the basis for assessment and care planning. Figure 1 show the content model of the assessment protocol, which is also the model or the Web application named "electronic ICF based individual record" (see poster by Frattura et al at the same meeting (5), which describes this tool).

The training programme combines three types of training sessions: plenary sessions, small groups in the computer room, focus groups to analyze and discuss some cases under the supervision of experts from the Italian WHO-FIC CC. The majority of the operators (98%) were very satisfied with the training.

#### References

- (1) DGR n. 465, 11.03.2010, Regione Autonoma Friuli Venezia Giulia
- (2) DGR n. 2384, 25.11.2010, Regione Autonoma Friuli Venezia Giulia
- (3) Francescutti C, Frattura L, Troiano R, et al. Towards a common disability assessment framework : theoretical and methodological issues for providing public services and benefits using ICF. Disability and Rehabilitation 2009; 31 (S1): S8-S15
- Francescutti C, Gongolo F, Simoncello A, Frattura L. Description of the person-environment interaction: methodological issues and empirical results of an Italian large-scale disability assessment study using

an ICF-based protocol. BMC, 2011

(5) Frattura L. et al. Health information systems learn to speak ICF, WHO-FIC network annual meeting 2011 (6) Leonardi M, et al. Integrating research into policy planning: MHADIE policy recommendations, Disability and Rehabilitation, 2010 32 (S1): S139-S147

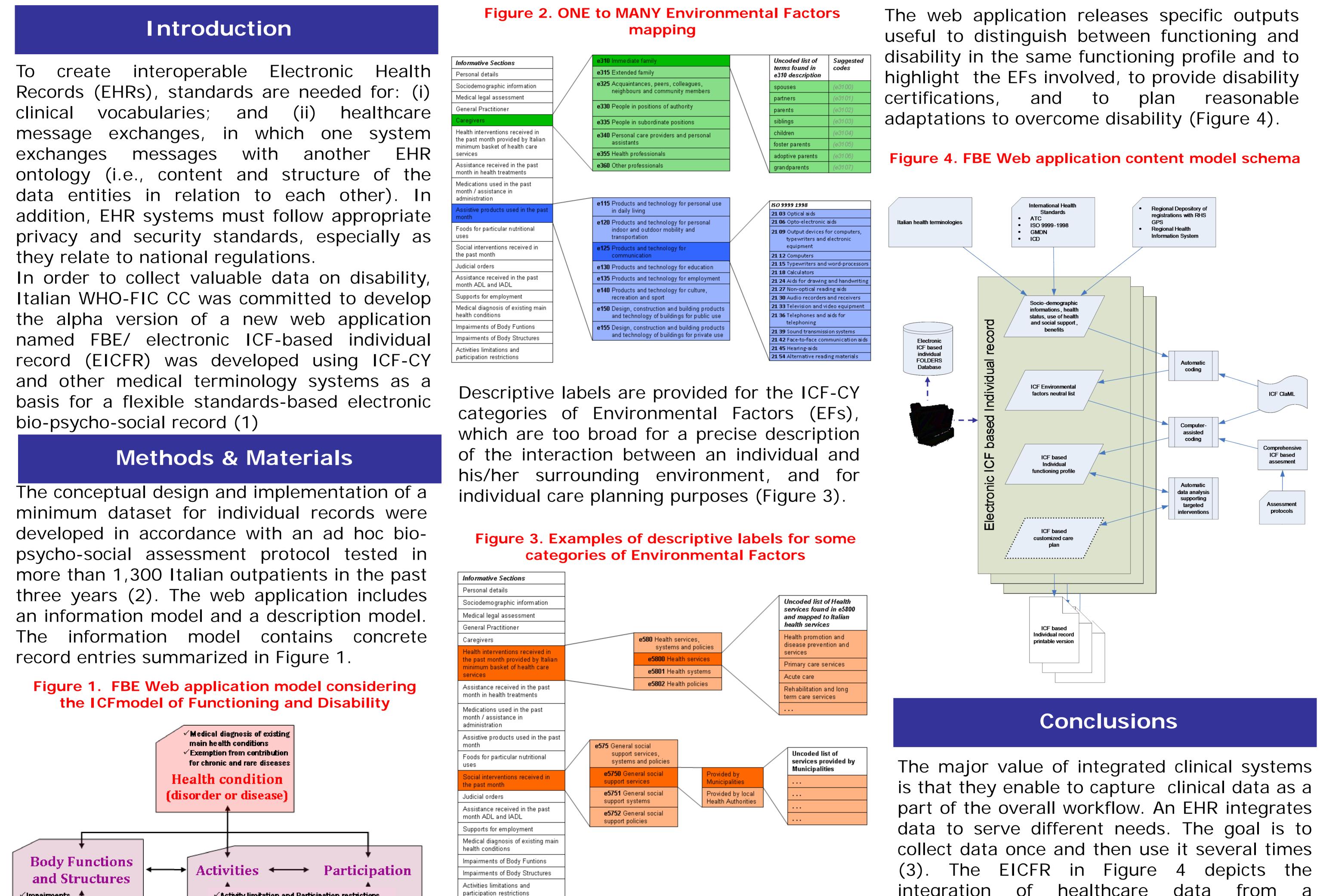
## Health information systems learn to speak ICF: 29 Oct – 4 Nov 2011 **Toward electronic ICF-based individual records**

Cape Town, South Africa

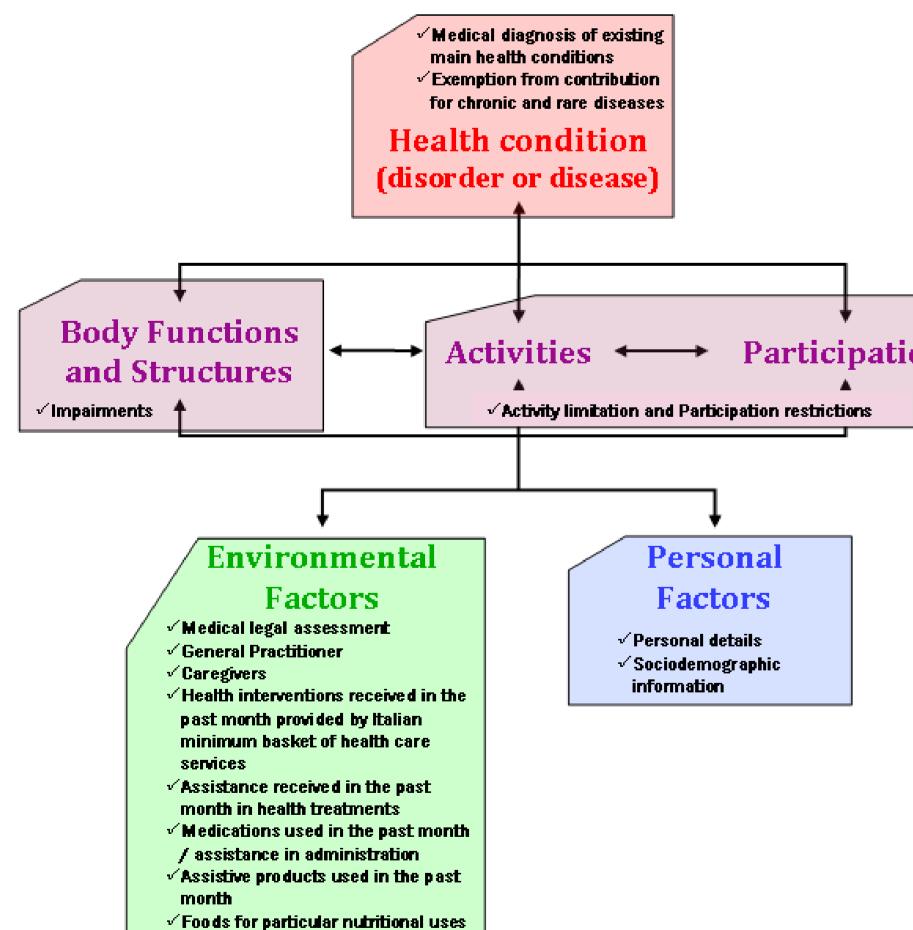
D039p

Lucilla Frattura<sup>1</sup>, Andrea Simoncello<sup>1</sup>, Giovanni Bassi<sup>1</sup>, Andrea Soranzio<sup>2</sup>, Stefano Terreni<sup>2</sup>, Fulvio Sbroiavacca<sup>2</sup> <sup>1</sup> Regional Central Health Directorate, Classification Area, WHO-FIC CC, Udine, Italy <sup>2</sup> Insiel SpA, Italy

Abstract The alpha version of a new web application was developed using ICF-CY and other medical terminology systems as a basis for a flexible electronic standards-based bio-psycho-social record. The web application translates information into ICF-CY EFs and releases a neutral list of EFs as first output. The functioning/disability ICF-CY based assessment is carried out by multi-professional teams, who input information to be coded, being facilitated by the web application in matching EFs to each B, S and A&P categories. The web application releases specific outputs useful to distinguish between functioning and disability in the same functioning profile and to highlight the EFs involved, to provide disability certifications, and to plan reasonable adaptations to overcome disability. The first field trial is ongoing in the Friuli Venezia Giulia Region, implementing the regional Health and Social Action Plan 2010-2012.



nformative Sections
'ersonal details
ociodemographic information



To create a suitable bio-psycho-social lexicon, information is aligned with a terminology collection containing ICF-CY, ISO9999 (1998), national nomenclatures of medical products, and social and health intervention vocabulary. A proposal of an HL7 CDA2 specification of representation of the records will be defined following the model of specification proposals for health records approved by national bodies.

of healthcare integration from a data participating collection of systems for a single patient encounter.

By using the electronic ICF-based assessment tool box it is possible to standardize data collection for evidence-based health and social planning and care and for statistical purposes. Some proposals may be submitted to update components of ICF EF and ICF-CY. the Recommendations are given to operationalize the concepts of "disability" and "functioning" respectively as a "negative interaction" and a

past month ✓ Judicial orders Assistance received in the past. month ADL and IADL Supports for employment.

Social interventions received in the

The description model provides templates for the bio-psycho-social record. The templates describe information that can be entered, all referred to the ICF conceptual model.

Particular emphasis was placed on collecting information useful to describe the interaction individual his/her between an and environment.

The information were automatically mapped to ICF-CY concepts, and specify how the concepts can be combined with natural language sentences and which concepts are mandatory or not (Figure 2).

The EICFR is filled in different steps and by Information different professionals. on environmental factors and personal İS collected using natural language (no skill in ICF language is needed) by health or social professionals at patient admission.

Results

The web application translates information into ICF-CY EFs and releases a neutral list of EFs as first output.

The functioning/disability ICF-CY based assessment is carried multiout by professional teams, who input information to be coded, being facilitated by the web application in matching EFs to each category.

"positive interaction" between an individual and his/her environment.

#### References

- (1) Frattura L et al, ICF implementation in regional policies: the case of the Friuli Venezia Giulia Region, Italy WHO-FIC Network annual meeting 2011 Francescutti C, Frattura L, Troiano R, et al. (2)Towards a common disability assessment framework : theoretical and methodological issues for providing public services and benefits using ICF. Disability and Rehabilitation 2009; 31 (S1): S8-S15
- (3) National Institutes of Health National Center for Research Resources. Electronic Health Records Overview, 2006

# ICF implementation in targeted employment of persons with disabilities: the Italian work in progress.

29 Oct – 4 Nov 2011 Cape Town, South Africa

D031p

Lucilla Frattura<sup>1</sup>, Mario Conclave<sup>2</sup>, Giovanna Gorini<sup>2</sup>

<sup>1</sup> Regional Central Health Directorate, Classification Area, WHO-FIC CC, Udine, Italy

<sup>2</sup> Italia Lavoro, Rome, Italy

Abstract. In 2010, a new national programme was launched on the evaluation of functioning/disability of disabled persons in order to study the conditions necessary for their inclusion in a work setting and to include a study sample. Matching a person's features with company's requirements is the key factor for a successful work placement. The common language provided by the ICF is tested to verify how the ICF model of disability may be useful to facilitate such a matching process.

#### Introduction

Action on the employment situation of disabled people in European countries should be considered in the context of the United Nations Convention on the Rights of People with Disabilities, the Lisbon Agenda and European Employment Strategy, Employment the Directive 2000/78/EC, and the European Disability Action Plan. The current economic downturn raises substantial challenges to the goals and actions proposed in recent periods of policy development. There is a substantial lack of detailed, up-to-date and comparative information about the employment situation of disabled people in European countries (1). National background - The Law no. 68 12 March 1999 ("The right to work of persons with disabilities") regulates the access in the labour market of disabled peoples in Italy, through local support and targeted employment services. The key points of this law are: the global evaluation of the individual, highlighting above all the personal skills and the acquired competences rather than disability; the role attributed to training and retraining disabled people targeted to the demands of the labour market; and the presence of incentives and tax relief for the companies that hire disabled persons. This scheme is known as "targeted employment" because it aims to allow disabled people to compete on the labour market.

### The workflow is showed in Fig.1

Assessment tools - Two ICF-based assessment tools (Employee Assessment Protocol, Company Assessment Protocol) were developed. The first was developed on the basis of the ministerial schedule for the evaluation of persons with disability and was set up starting from the protocol defined by

#### Table 1 . Professionals involved in ICF4 Programme

HEALTH operators (C.M. L.104/92 and L.68/99: doctors, social workers, administrative workers)	107	42%
WORK operators – (CPI operators, CPI trainers, provincial coordinators L. 68/99)	86	34%
SOCIAL POLICIES operators - (social workers, social services contact persons)	9	4%
INPS operators - (medico legal doctors, adminstrative workers of Medical Commissions)	8	3%
UNIVERSITY/SCHOOL operators - (disability offices contact persons)	7	3%
THIRD SECTOR operators - (social cooperators)	2	1%
DISABLED PERSONS ASSOCIATIONS - (FISH, FAND)	4	2%
Operators of the territorial multidisciplinary groups:		
Doctors	8	3%
Social workers	9	4%
Nurses	7	3%
Administrative professionals	9	4%
Total	256	100%

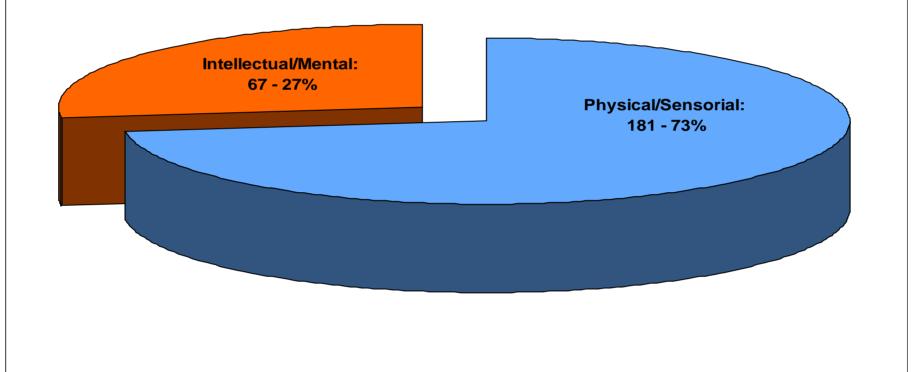
The implementation of ICF-based assessment

the WHO-FIC Italian CC and tested in more than 1,000 persons in Italy under a previous national programme (2).

The second represents a new way to analyze a work setting having in mind the principle that a successful placement depends on how a work place may be adapted to the need of a disabled employee.

Figure 2 . ICF4 Programme - Types of impairments of the 248 people that voluntarily accepted to be involved in the programme

Type of impairments of the sample (N=248)

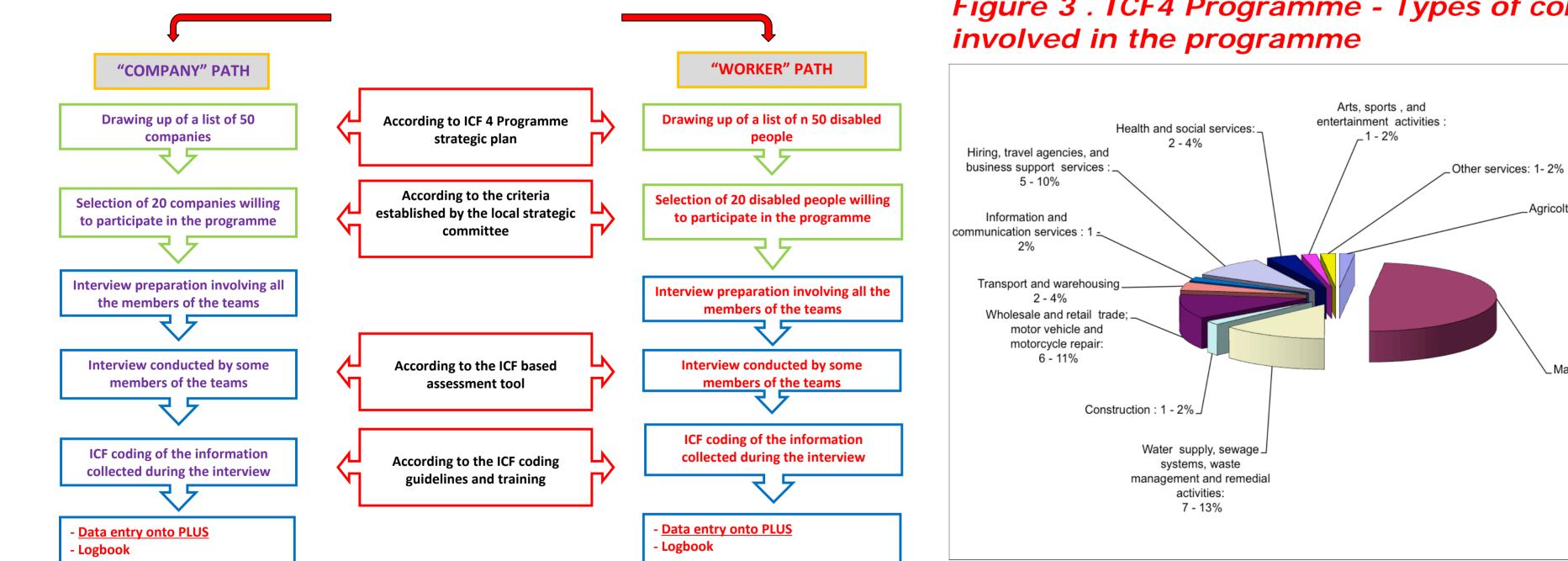


#### Conclusions

A well-known problem is that disability is not a single and clear policy concept, varying considerably definition in between administrative jurisdictions or relying upon individuals' perceptions about their disability status. The EU social model approach acknowledges disability as a social construct and focuses on the environmental barriers that restrict participation, while national policies are often dependent upon medical or functional assessments of individual impairment and capacity. WHO conveys some of this complexity by representing disability as an umbrella term impairments, activity limitations for and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors. The issue is further complicated when trying to disentangle the relationship between definition of disability and systems of disability benefit. Matching a person's features with company's requirements key factor for a successful work the İS placement. The ICF 4 Programme represents the first attempt in Europe to study this matching using the ICF model of disability. The common language provided by the ICF is tested to verify how the ICF model of disability may be useful to facilitate such a matching process. A that the ICF-based first analysis shows approach to assessment of both workers and companies is able to detect the aspects crucial for target employment. Nevertheless, the data on services and systems that support disabled people employment are difficult to map to ICF Environmental factors and adaptations are under study. The description of the job placement using ICF is challenging and a first mapping of job activities to ICF A&P is in progress.

tools to realize the targeted employment of people with disabilities started in Italy in 2004 and it represents a work in progress (2). In 2010, a new national programme was launched on the evaluation of functioning/disability of persons in order disabled to the study conditions necessary for their inclusion in a work setting (ICF 4 Programme).

#### Figure 1 . ICF 4 Programme flowchart



**Database** - A specific individual database (named PLUS) was realized and it was incorporated in a more general national labour information system.

**Training** - CoTraining was provided, on how to carry out interviews and to input data onto PLUS starting from September 2010 to Jjuly 2011.

# Figure 3 . ICF4 Programme - Types of companies

Agricolture, silvicolture

fishing:

1 - 2%

Manufacturing activities

25 - 48%

Italia Lavoro is the governmental body responsible for the programme on behalf of the Ministry of Labour. On the basis of a specific agreement, the WHOFIC Italian CC supports Italia Lavoro to train professionals, to develop the ICF based assessment protocols, to decide how the information system may use ICF as a standard, to analyse data, and to monitor the programme.

## Methods & Materials

4 Programme Organization - A steering ICF national committee and 11 local committees were established with the aim to monitor the implementation and to gather outputs and results.

## Results

More than 700 professionals from 11 Italian Regions were trained in the period September 2010-July 2011. 256 of them were grouped in 49 muldisciplinary teams and directly involved in the assessment, (Table 1).

A sample of 248 disabled persons from 11 Regions will be recruited and assessed (Fig.2). More than 200 companies that must hire persons with disabilities were selected and their assessment is ongoing (Fig. 3).

11 focus groups were realized in order to monitor the state of the art, to analize and solve problems in coding information using ICF, and to uptade the teams on the general programme.

## References

(1) Academic Network of European Disability experts (ANED). The labour market situation of disabled people in European countries and implementation of employment policies: a summary of evidence from country reports and research studies, 2009 (2) Conclave M, et al. The ICF and Labour Policies Project: the first Italian nationwide experience of ICF implementation in the labour sector, D&R, 2009; 31 (S1): S16-S21 (3) Francescutti C, Frattura L, Troiano R, et al . Towards a common disability assessment framework : theoretical and methodological issues for providing public services and benefits using ICF. Disability and Rehabilitation 2009; 31 (S1): S8-S15

# ICF for the analysis of persons with chronic spinal cord injury D. Marin, C. Pinzini, S. Lombardi, F. Schwoopes, V. Della Mea\*, L. Frattura\*, A. Zampa

29 Oct – 4 Nov 2011 Cape Town, South Africa

D027p

Spinal Unit - Physical Medicine and Rehabilitation Institute - Udine, Italy

\*Regional Central Health Directorate, Classification Area, WHO-FIC CC, Udine, Italy

**Abstract** Life expectancy for persons with chronic spinal cord injury (SCI) has increased in the last three decades, driving toward an increase in the years lived after injury. The ICF provides a comprehensive and accepted framework to classify and describe functioning, disability and health in people with any condition, including SCI. Aim of the present study is to assess a sample of 49 subjects with chronic SCI using ICF.

#### Introduction

Life expectancy for persons with chronic spinal cord injury (SCI) has increased in the last three decades, driving toward an increase in the years lived after injury. SCI has long-term consequences on:

## Evaluation

The patients were evaluated with the ASIA impairment scale, a clinical and demographic questionnaire, and the Brief ICF Core Set for SCI. The Brief ICF Core Set includes a total of 33 second-level categories, which represents 28.4% of all second-level categories selected for the Comprehensive Core Set. The data collected were analyzed for each of the ICF categories using descriptive statistics.

# Table 1: Environmental Factors identified asfacilitators or barriers

	e310	Immediate family
S	e155	Design, construction and building products and technology of buildings for private use
<b>ATORS</b>	e580	Health services, systems and policies
ACILIT/	e340	Personal care providers and personal assistants
FA	e110	Products or substances for personal consumption
	e115	Products and technology for personal use in daily living
<b>ARRIERS</b>	e150	Design, construction and building products and tecnology of buildings for public use
BA	e310	Immediate family

- community reintegration:
  - person's physical functioning
  - interrelated facilitators and barriers in the social and physical environment
- range of functional problems, which changes with increasing duration of injury.

Long-term care of people with chronic SCI requires an in-depth understanding of the broad range of functional problems. However, health status of persons with chronic SCI is not yet well studied.

The ICF provides a comprehensive and accepted framework to classify and describe functioning, disability and health in people with any condition, including SCI. ICF Core Sets (in the two versions: Brief and Comprehensive) represent a condition-specific selection of domains or categories from the whole ICF classification, which can be used as a minimal standard for reporting functioning and health status. A Core Set exists also for chronic SCI.(1) Aim of the present study is to investigate a sample of 49 subjects with chronic SCI using the Brief ICF Core Set for SCI.

## Software

Patient data collection was carried out with a computer program specifically developed to embed the Brief ICF core set for SCI, the ASIA impairment scale, and the clinical and demographic questionnaire. After

internationalisation, the software will be released to the public.

The patients required a substantial medical support and often found answers within the immediate family; 12 subjects had to rely on other facilitators. A peculiar finding is related to the category e310 (Immediate family): it is reported as a facilitator and as a barrier at the same time. In addition, we also found that 28 subjects, mainly tetraplegics, had to rely on people outside the family and health services. 81.6% of the sample was also satisfied policies for the private with construction, but 91.8% of subjects still had serious limitations when they had to access facilities for public.

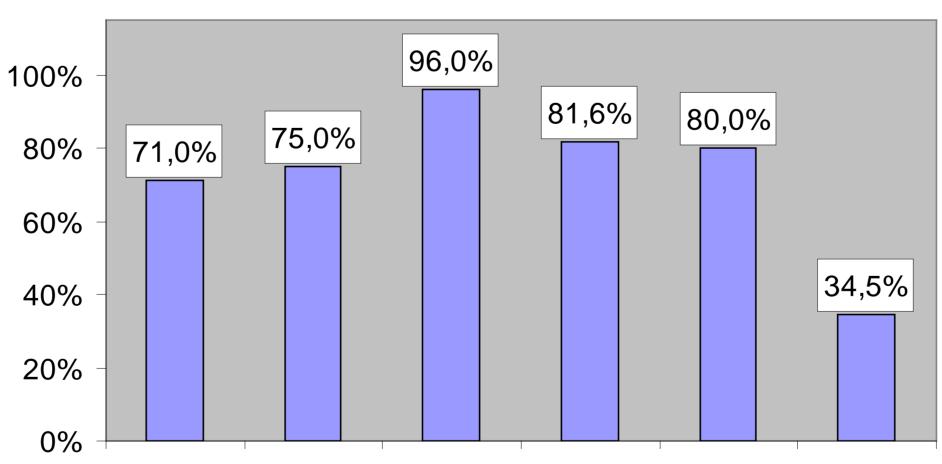
Methods & Materials

**Subjects** A group of 49 consecutive chronic SCI patients who regularly received care and rehabilitation therapy at an extensive rehabilitation centre of the regional Spinal Unit Department in Friuli Venezia Giulia was examined. Of the 49 subjects recruited, 38 were males and 11 females, with an average age of 54.45 years and an average time from injury of 17 years. SCI etiology was traumatic for 38 of them and non-traumatic for 11; there were 26 paraplegics and 23 tetraplegics. Thirty-one of them had an ASIA Impairment Scale grade A, 4 a grade B and 13 a grade C.

#### Results

A positive correlation was found between ASIA grade, neurological level of spinal cord lesion and problems in Body Functions and Activities and Participation. Figure 1 shows the distribution of specific problems in some Body Functions.

# Figure 1: Distribution of the sample by percentage of problems in some Body Functions



#### Conclusions

In the studied population, a nearly optimal performance was observed in a lot of Activity Participation and is indicative of categories. This technologies, caregivers, environmental infrastructures and social-welfare that resources can bridge any gap between reduced ability of an individual performing a task and what the individual actually does in his/her living environment.

b280 b640 b735 b620 b152 b525 Urinary Sensation Defecation Sexual Muscle tone Emotional Functions of pain Functions functions Functions Functions

In Activities and Participation, the data showed a good Performance for all patients, whereas Capacity was highly correlated with neurological level: paraplegics better than were tetraplegics in activities such as taking care of themselves (d520, d530, d550) and mobility (d410, d420, d465, 1 d470). Table shows the environmental factors identified in the sample.

## Acknowledgements

We wish to thank Massimo Linossi for the implementation of the software used in the study.

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# The use of ICF to describe the needs profile of student in primary and lower secondary schools

29 Oct – 6 Nov 2011 Cape Town, South Africa

D028p

A. Battisti, A. Solipaca, R. Crialesi Italian National Institute of Statistics

Abstract Italian National Institute of Statistics has released the first results of the survey on students with learning-support teacher in primary and lower secondary schools (public and private) for the school year 2009-2010. The survey response rate was 89%, for a total of 23,451 schools participating in the study. The survey collected also information on 5,600 students with learning-support teacher. The questionnaire was filled in by the learning-support teacher.

For the first time the ICF classification was introduced in a statistical survey carried out at national level. The ICF was used to describe the specific needs of students with learning-support teacher, completed by a description of the environment in terms of buildings accessibilities, staff and technologies available for students.



Sen to human well-being emphasizes the importance of freedom of choice, individual heterogeneity and the multidimensional nature of welfare. For Sen capabilities denote a person's opportunity and ability to generate valuable outcomes, taking into account relevant personal characteristics and external factors.



The approach of ICF takes into account the social model of disability which regards disability as a socially created problem and not as an attribute of an individual. For example, an adolescent boy using a self-propelling wheelchair in a well-adapted house might have full independence within the home but encounter serious difficulties in using public transport and local amenities. He can be excluded from school field trips because of insurance issues, thus affecting his independent participation in his community.

Taking into consideration this two main pillars the Italian National Institute of Statistics focuses the attention on the student with the learning-support teacher in the compulsory school, in the belief that in this age, a person should be able to acquire the capabilities necessary to be able to enjoy an adequate quality of life.

disabled students were enrolled in compulsory education: about 73 thousand in primary school and 59 thousand in lower secondary school.

The difficulties that characterized disabled students in primary and in lower secondary school were similar. Geographical differences were found with respect to learning and attention-deficit difficulties (Table 1).

Table 1. Students by type of problem, geographical area and scholastic order. School Year 2009-2010 (percentage values)

Problem type	North	Center	South	Italy
	Primary schoo			
Blindness	0.2	1.2	1.0	0.7
Partial blindness	5.1	3.8	4.5	4.6
Acute deafness	2.0	1.3	1.9	1.8
Partial deafness	4.3	4.2	4.3	4.3
Problems related to mobility	13.9	11.6	16.4	14.3
Learning-specific disorder	18.3	29.1	34.7	26.4
Language-specific disorder	25.0	22.4	28.6	25.8
Generalized developmental disturbance	17.8	14.2	19.3	17.6
Mental retardation	43.1	33.0	40.3	40.1
Attention deficit disorder	19.8	24.0	34.6	26.0
Emotional-relational disturbances	17.5	22.8	32.1	23.9
Behavioral disorders	15.8	14.4	21.3	17.5
Early psychiatric disorder	1.0	0.2	0.4	0.6
Other	14.0	16.5	14.0	14.2
	Lower secondary s	chool		
Blindness	0.5	0.5	1.3	0.8
Partial blindness	3.8	4.6	2.8	3.6
Acute deafness	1.6	1.4	0.9	1.3
Partial deafness	3.4	2.7	4.5	3.7
Problems related to mobility	9.5	9.6	14.2	11.2
Learning-specific disorder	26.4	40.1	40.9	34.3
Language-specific disorder	15.0	16.3	22.3	17.9
Generalized developmental disturbance	10.2	12.5	13.8	12.0
Mental retardation	44.8	34.1	45.3	43.0
Attention deficit disorder	17.5	22.8	32.1	23.9
Emotional-relational disturbances	18.1	15.8	24.6	20.0
Behavioral disorders	13.7	14.3	23.4	17.4
Early psychiatric disorder	1.5	0.5	1.3	1.3
Other	16.4	15.4	14.3	15.4

Figure 1. Students by type and level of **difficulties** (for 100 schools in the same region)

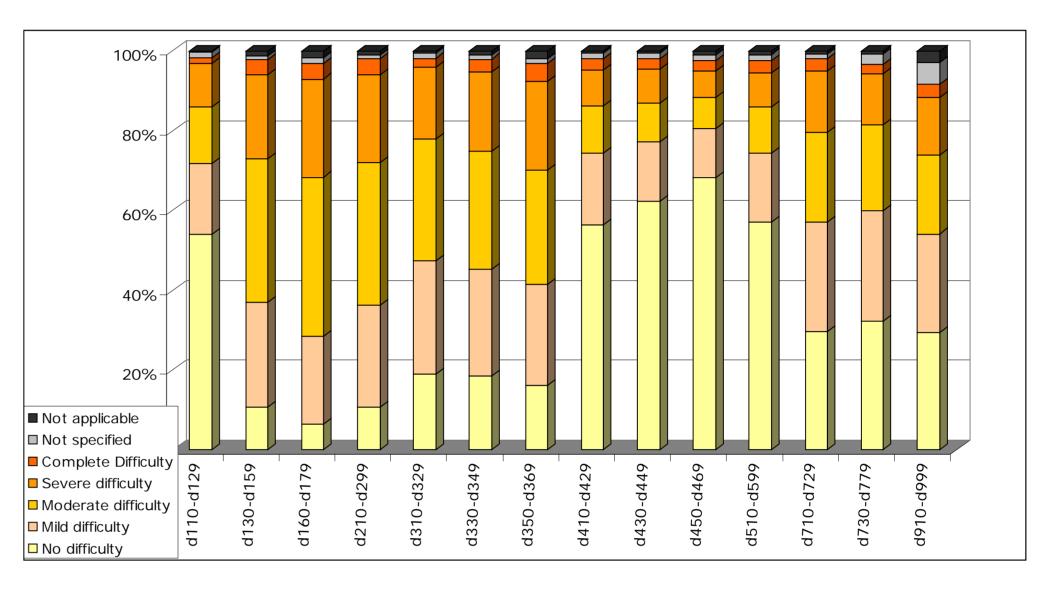
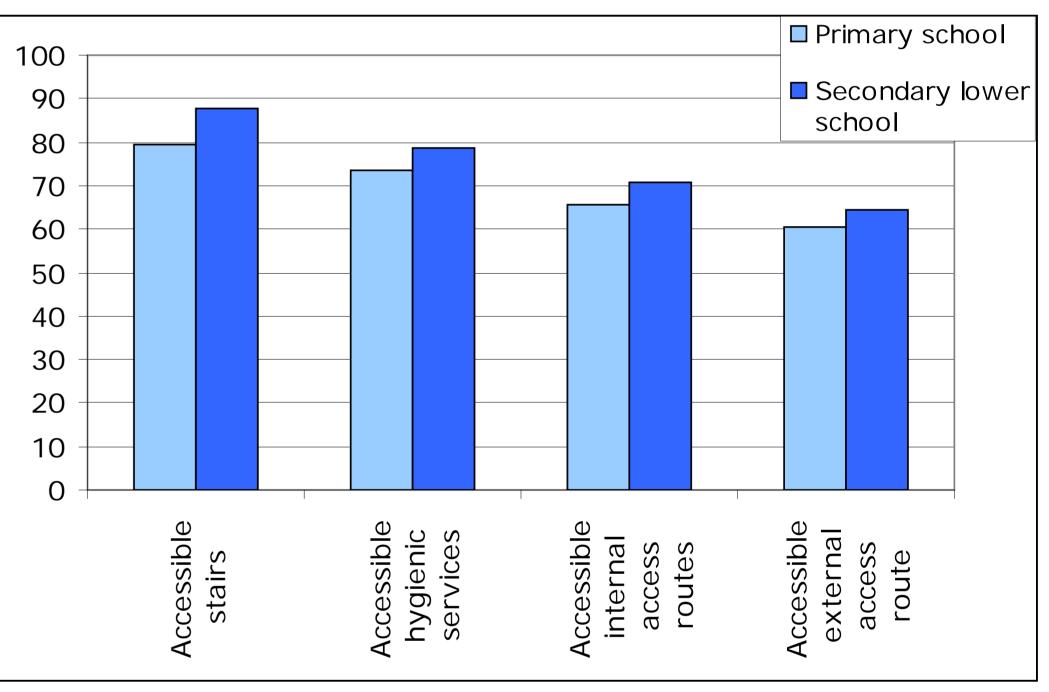
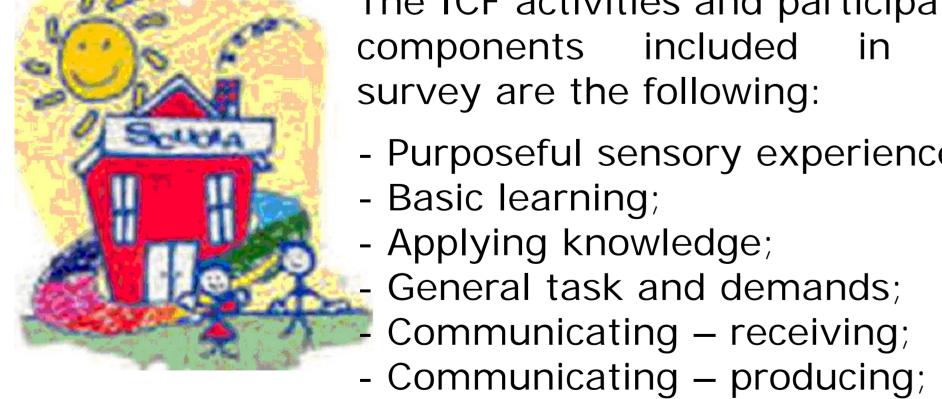


Figure 2. Schools with regulation architectural features by architectural feature and scholastic **order** (for 100 schools in the same region)



## Methods & Materials

A survey was done for the school year 2009-2010, and for the first time the ICF classification was introduced in a statistical survey carried out at national level. The ICF was used to describe the specific needs of students with the learningsupport teacher, completed by a description of the environment in terms of buildings accessibilities, staff and technologies. The survey response rate was 89%, representing a total of 23,451 schools participating in the study. The survey collected also information on 5,600 students with the learning-support teacher. The questionnaire was filled in by the learning-support teacher.



The ICF activities and participation in the

- Purposeful sensory experiences;

#### Consistent with the problems described in table

1, students with the learning-support teacher seems to have a high level of difficulties in the two of the following ICF domains: Learning and applying Knowledge and Communication (Figure 1). In these domains the percentage of students with severe or complete difficulty are between 20% and 30% of all the students with the learning-support teacher.

The analysis of the use of technologies as a teaching aids, points out that about the 40% of the students uses specific software for learning, the 15% of students with the learning-support teacher uses Systems for the facilitation of the texts, the 10% of students uses a recorder.

If we analyze all the students that use at least one of these learning aids by the type of students' problem, we will find, on one hand that the 70% of these students have learning difficulties or attention deficit or mental retardation, but also that there are more then 60% of students with these type of difficulties without any learning aids.

The scholastic environment remained fairly inaccessible and the number of schools equipped to overcome architectural barriers appears to be too low, although this area shows some improvement (Figure 2).

#### Conclusions

- Conversation and use of communication devices and techniques;

- Changing and maintaining body positions;
- Carrying, moving and handling objects;
- Walking and moving;
- Self care;
- General interpersonal interactions;
- Particular interpersonal relationships;
- Community, social and civic life;

The results presented above are the first of the survey and they give just an idea of the potentiality of all the information collected. The analysis presented here is not at individual level but the survey collects enough information to determine at individual level the appropriateness of the measures used by the school to develop the inclusion of all the students, independently by their health status.

It represents a significant step forward in the description of the specific needs of a single students and in the process to develop individual paths with specific facilitators. The authors are aware that the survey can be improved and that further analysis needs but they are also aware of the importance of this first step.

# ICF training in Albania and **Bosnia and Herzegovina** M.Leonardi, P.Meucci, M.Cerniauskaite, R.Quintas

29 Oct – 6 Nov 2011 Cape Town, South Africa

D029p

Abstract National Neurological Institute Besta in Milan, Italian WHO CC Research Branch, has been involved in two cooperation projects with Albania and Bosnia and Herzegovina (BeH) for ICF implementation through training and support to policy development. Both initiatives were born in a context where health and disability policies are changing, and where disability eligibility criteria needs be changed to better respond to a more accurate functioning evaluation. Professionals in clinical and social field feel the need for new perspectives and new instruments for disability evaluation as well as to respond better to persons' with disability needs.

	both countries professionals in clinical nd social settings feel the need of a	Results
The Italian WHO Collaborating Centre new Research Branch Besta is involved in for	ew perspective and a new instrument r assessment of persons with disability.	Different health professionals coming from Sarajevo and Banja Luka and

several International both authorities, health and professionals and NGOs. BOSNIA AND HERZEGOVINA (BeH) Disability prevalence in BeH estimated to be 14.6% and World Bank people with disability). study reveals that although expenditure for people with disability in BeH is among the highest in Europe however, the money is not directed towards real needs, nor to the persons for whom the support is the most important and needed (ref.1, 2). The key for this inadequate support is training course

ICF ICF Classification has been identified as implementation activities concerning the instrument for such national ICF training and policy development. NGOs working in both development, particularly in the field of countries were supported by Besta disability evaluation and data collection. Institute through ICF training. The aim of In 2010-2011 two new activities started the courses was to introduce ICF and in Bosnia and Herzegovina and in give basic knowledge and understanding Albania in collaboration with local about the classification and its possible social uses, that could be useful to a specific country context (with regard to disability eligibility system, securing and providing is support to the most vulnerable groups of

## Methods & Materials

In collaboration with Sumero (the Union of organizations supporting people with intellectual disability in Federation of BeH) ICF basic and advanced three days organized was in Sarajevo. is are Project Albania in involved the Government of Albania and Dokita -Italian NGO operating locally. Two ICF courses were held for social and health professionals in Tirana. There is a lack of common language The courses in both countries followed similar and validated modality (ref.3) and included the historical background of the ICF, ICF-CY and disability legislation in Europe, the development of ICF, its structure, codes and use of qualifiers, possible applications of ICF in different settings, ICF-based tools, ICF and the UN Convention for the Rights of people with Disability and some practical exercises and discussions.

representing clinical, academic and legal settings participated in the basic and advanced course in BeH.

In Albania ICF basic course, held in Tirana, involved around 80 participants from National statistical Office, Ministry of Welfare and of Health, and Medical University. Fourty people also underwent the ICF advanced course after 6 months, and they were mostly from rehabilitation sector (many of them are going to use ICF and its derived instruments in disability evaluation).

Participants got familiar with the ICF classification and biopsychosocial model and possible applications of ICF in different settings.

Trainers got a better understanding about the situation in two countries and tried to share their expertise in the field of disability and application of ICF.

how the assessment of disability actually done in BeH. There different assessment systems for war veterans with disability, working people with disability, children with disability and then other people with disability. governmental different between sectors, the health, social and education systems have different languages and structures and disability assessment is done in different ways using different instruments. This leads to unsustainable social welfare system.

Currently in all aspects of assessment the prevailing approach is the so called "medical approach", that is based not on the needs of a person nor on the environment evaluation but mainly on impairments one has.



## Conclusions

Basic and advanced courses of ICF were part of a collaboration between National Neurological Institute in Milan, Italian WHO CC Research Branch, and Albania and Bosnia and Herzegovina. They provided a needed knowledge about the ICF model and classification, improved participants' knowledge on international standards and assessment of disability, that will be helpful in choosing and creating an adequate model for disability eligibility, harmonization of the system, that will help to direct resources towards the real needs of people with disability. The training does not conclude the collaboration and further collaborative

#### ALBANIA

Although undergoing positive changes, situation in Albania leaves persons with disability among the most vulnerable in the society. No official statistics about the number of persons with disability exist. Albania has a set of laws that officially entitle people with disability to all human rights and other freedoms, but the implementation of these laws is quite complicated. Albanian law groups persons with disability in five categories and assessment of disability varies widely among these groups.

efforts and activities as well as support are being planned between Italy and Albania and BeH.

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#### 29 Oct – 4 Nov 2011 ICF in framing the National Action Plan Cape Town, South Africa for People with Disabilities in Kosovo D010p

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<sup>4</sup> Main Family Medicine Clinic Center of Gjilan/Gnjlane

<sup>5</sup> Ministry of Labour and Social Welfare of the Republic of Kosova

Abstract The implementation of the National Action Plan for People with Disabilities in Kosovo, for the years 2009 – 2011, supported by the Italian Ministry of Foreign Affairs and the Italian Cooperation (MAE-DGCS) has been a great opportunity for professionals of the Italian WHO-FIC Collaborating Centre in the use of ICF as operational language to implement, without historical constraints, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

## Introduction

**General training on ICF in Kosovo** 



In 2008 the Government of Kosovo approved with Decision 10/20 the draft of the National Action Plan for People with Disabilities, a strategic document resulting from the coordination and cooperation among the the Office on Good Governance of Kosovo/Office of the Prime Minister, representatives of different Ministries, representatives of associations of persons with Disabilities and the Italian Ministry of Foreign Affairs and the Italian Cooperation (MAE-DGCS). MAE-DGCS has supported the drafting process of the National Action Plan and has sustained its implementation relying on the expertise of professionals of the Italian WHO-FIC Collaborating Centre in the use of ICF as operational language to implement the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The goal of the activity was to frame the Disability Action Plan of the young nation, consistently with the UNCRPD and using the International Classification of Functioning Disability and Health (ICF) as the taxonomy by which the UNCRPD conceptual framework is applied in the making of policies and in their implementation.

This activity is consistent with the scope of the Friuli Venezia Giulia Region of enhancing and strengthening forms of international cooperation with Kosovo as stated in the Operational Plan 2010-2013 "The international dimensions of FVG Regional Health Policy".

#### Training at central level (Pristina)

2 days session

Commissions for invalidity pensions	6
Commissions for pensions of family with children with special	
needs	6
Ministry of Labor and Social Welfare	2
Ministry of Education Science and Technology (MEST)	2
Ministry of Health (MoH)	2
Statistical Office of Kosovo (SOK)	1

Training at municipality level (Gjilan/Gnjlane) 2 sessions of 2 days with a three/four months interval between them. **Community Based Services** 2 Community Based Medical Centres 6 Pediatricians from the local hospital 2 Local commission for school inclusion 4 Regional Employement Centre 2 Social Centre 2 Faculty of Education 1 Regional Hospital, Phisiotherapy 1 Regional Pedagogical Centre 1 40 Total trained professionals

The same general training was carried out at local level in the city of Gjilan/Gnjlane, a 100,000 inhabitant township in central Kosovo, with the aim of improving competence on disability at municipal level with particular regard to inclusive education. This focus was chosen because at the moment there are 7 special schools in operation in Kosovo and several so called "attached special classes" reserved to pupils with special needs and located inside regular schools. The training was carried out in English with synchronized translation into Albanian and sign language interpretation. The Head of the Office of Commissions from the Ministry of Labour and Social Welfare and the representative from the Special Education Unit of the Ministry of Education, Science and Technology have participated also in the second session held in the Municipality of Gjilan/Gnjlane.

The information gathered during the activity in in meetings with stakeholders, Kosovo, institutional and non institutional, both at ministerial and local level, has allowed to outline a very diverse scenario, both in terms of the level of knowledge on disability, and in terms of the effective interest in acquiring new methods to understand functioning and disability.

With regards to the interest in the acquisition of knowledge and the consequent implementation of new tools, this has manifested itself in a very concrete way in the area of education, both at the central level, where ministry officers have

shown to know very well the relevant aspects of National Action Plan for People with the Disabilities, and at local level. At the level of the municipality of Gjilan/Gnjlane however, knowledge on disability, even with regards to specific aspects of competence, is limited and in any case strongly relies on a medical model that does not allow the comprehension of the role played by the school to contribute concretely to improve the conditions of people with disabilities.

The lack of a full ICF in Albanian language (translation under approval at the moment in which the activities started), represents a limit to the further diffusion of the adoption of ICF as universally shared model and taxonomy to describe the condition of people with disabilities in Kosovo.

#### Methods & Materials

The Italian WHO-FIC involvement has two main branches of activity: a higher level consultation to promote the knowledge and the use of the ICF in the reshaping of eligibility and access criteria to disability associated benefits, and a field to test ICF-CY use for education inclusion in primary schools.

The activity on increasing awareness and knowledge has been designed after a broad consultation of the stake-holders and carried out through seminars held with representatives of the relevant Ministries, the College of Physicians, local and international NGOs working with persons with disabilities, and the Organizations representing Persons with Disabilities in Kosovo such as Handikos, Kosovo Association of the Deafs, Down Syndrome Kosova and Kosova Association of the Blind and Partially Sighted.

Increasing awareness and knowledge activities were planned through Education and training on ICF for the members of the commissions acting under Law on Disability Pensions 2003/40 and Law on Material Support for Families of Children with Permanent Disabilities SRSG 2008/33. The goal was contributing to increase the general awareness on the classification and to educate to a behavioral change in the current debate about the reform of the law on pensions and the adoption of new criteria for the evaluation of children with disabilities.

At the moment there's not an Albanian version of ICF and therefore education material was provided in form of slide sets and reports.

In the municipality of Gjilan/Gnjlane a specific ICF-CY training was completed in April 2011. 33 people were involved including physicians, allied health professionals, teachers, social workers who were engaged in practical coding exercises and discussions of implementation strategies at the Municipal school level of disability profiling using ICF-CY.



#### Conclusions

The implementation of the National Action Plan for People with Disabilities in Kosovo, for the years 2009 – 2011, is an important step in establishing and implementing anti-discrimination policies to ensure the rights and equal opportunities for all the citizens.

Framing the entire disability plan at national level in Kosovo presents many challenges but also offers the opportunity to design an approach free of historical constraints and open to the latest view on disability and functioning, fully consistent with the United Nations Convention for the Rights of Persons with Disability. In this context ICF becomes the taxonomy by which the UNCRPD conceptual framework is applied in the making of policies and in their implementation.

The activity of experts from the Italian WHO-FIC Collaborating Centre has achieved a first goal of increasing awareness and knowledge on ICF but the publication of an official ICF in Albanian language is a required step for the further diffusion of this classification in Kosovo.

The training, held at central level interested different officials as depicted in Table 1 and was carried out in a session of 2 days

## References

- 1. National Disability Action Plan for the Republic of Kosovo 2009-2011
- 2. Technical assistance project for the National Disability Action Plan in kosovo
- 3. The Operational Plan 2010-2013 "The international dimensions of Friuli Venezia Giulia Regional Health Policy" (All the reference are web available)

# Preliminary analysis for a process of implementation of ICD-10 in Albania

29 Oct – 4 Nov 2011 Cape Town, South Africa

D042p

Gongolo F.<sup>1</sup>, Loyola Elizondo E.G.<sup>2</sup>, Miho V.<sup>3</sup>, Jakob R.<sup>4</sup> <sup>1</sup>Regional Central Health Directorate, Classification Area, WHO-FIC CC, Udine, Italy; <sup>2</sup>WHO Regional Office for Europe; <sup>3</sup>WHO Country Office for Albania; <sup>4</sup>WHO Geneva

**Abstract** Albania is undergoing a wide process to realize an information and communication technology environment in order to enhance the quality of health care and ensure the availability of data in an integrated system. With the coordination of WHO-HQ, the WHO Regional Office for Europe asked the Italian WHO-FIC Collaborating Centre to render available expertise to the Albania WHO-Country Office in order to carry out strategic evaluation, planning and training activities for the implementation of ICD-10 at national level. this activity represents an example of cooperative model in which common goals for work in ICD matters can be catalysed by the joint effort of several countries, WHO and its Collaborating Centres. The present work presents the first results of these activities and draft the future steps of the process.

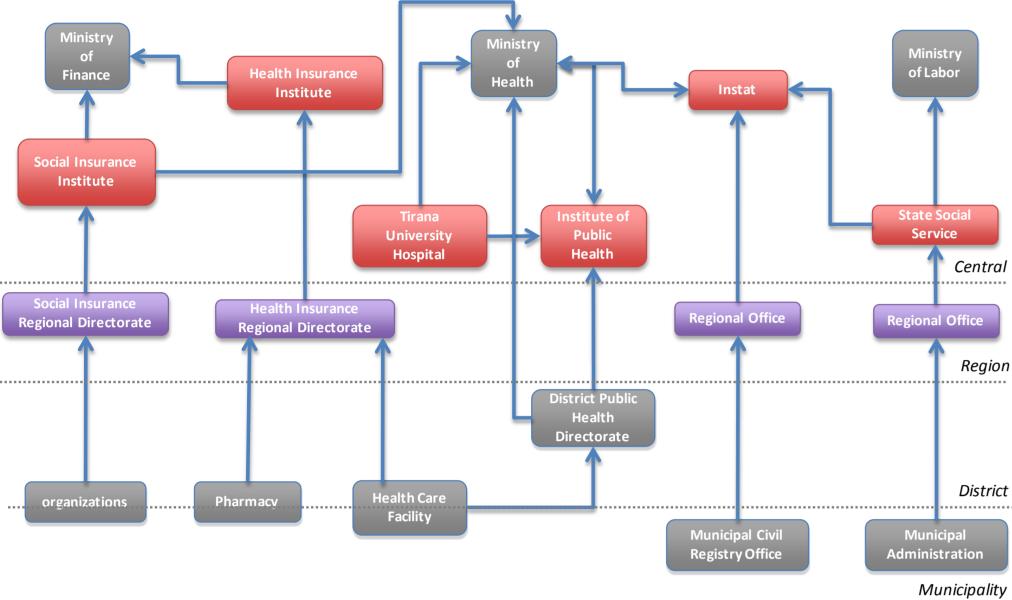
#### Introduction

The Albanian Government is undergoing a wide process to realize an information and communication technology environment, enhance the health care quality and ensure the availability of data in an integrated system (Fig. 1).

#### Methods & Materials

With the help of the Albania Country Office a series of meetings were performed with the stakeholders involved in the introduction of ICD-10 in Albania, aimed at the assessment of the implementation status of ICD in the Country. The collected information regards the different data flows in the health system, the classifications in use at the moment, the proneness to change to ICD-10 and the parts of the process that could be carried out by the different institutions in the Country. This activity is framed with a **cooperative model**, coordinated by WHO and based on a network between current and potential users of the WHO-FIC, that takes advantage of reference centres such as the WHO-FIC Collaborating Centres and brings together the efforts of several countries.

In this fragmented scenario the enforcement of ICD-10 would need law or strong regulation. At the moment there's a law on statistics that can give the general framework (information gathered for Eurostat Compendium) but there's no specific law enforcing data collection in the health system. This preliminary analysis shows the opportunity of a **Memorandum of Understanding** with identification of the coordinating working group The lead of the MoH seems to be the most appropriate solution with the involvement of other interested parties such as the National Institute of Statistics (INSTATS), the National Institute of Public Health, The Ministry of Innovation and Integration, the Office of the Prime Minister, the Commission on Data Protection and the Department of Epidemiology and Statistics of the Faculty of Medicine. The process would very much benefit of the involvement of other interested Countries such as Kosovo, Montenegro, Georgia and Poland that show similar interest for the introduction of ICD-10 as a tool to exchange patient information between the different service delivery facilities. The training at national level should be planned starting from strategic focus areas such as mortality coding and should include training of the trainers, tools for remote training (including submission of queries), feedback session and ongoing training.



#### Fig. 1 Albanian Health Information System Organizational Structure

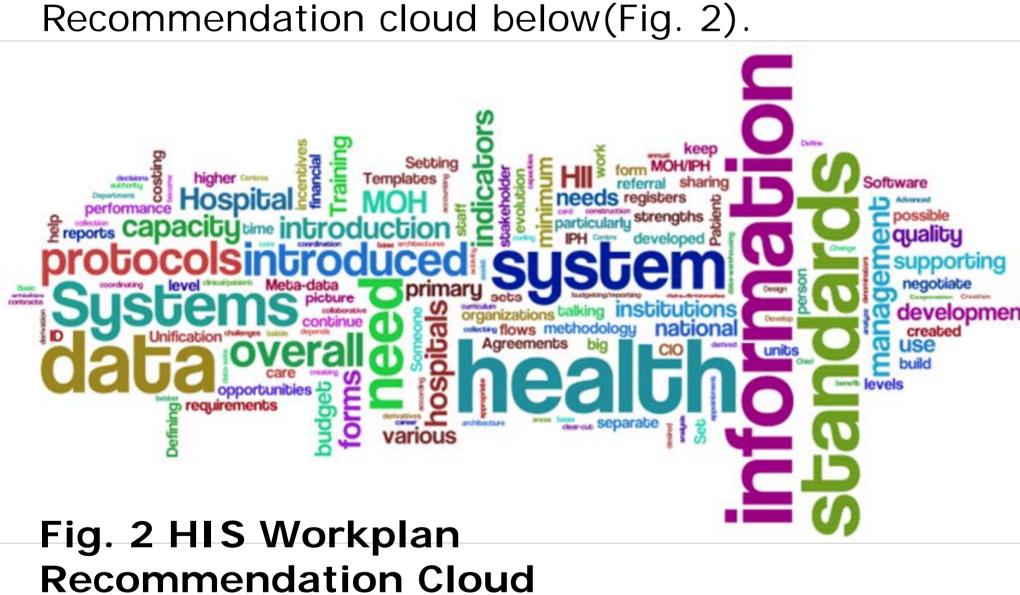
In 2009 the Ministry of Health (MoH) together with WHO Country Office and Health Metrics Network (HMN) drafted the **Albania HIS Work Plan**, with the aim of assessing the state of Albanian Health Information System (HIS) and planning a series of actions to help strengthen it, taking into account a series of priorities which are depicted in the Percommendation cloud below(Fig. 2)

## Results

The **Ministry of Health**, during this preliminary assessment confirms the interest in adopting interoperability standards such as ICD-10, but the analysis of the status of ICD implementation shows a fragmented scenario.

The Albanian translation of ICD-10 was made in 2001 from the 1998 English version. An updated version, (translation of the 1998-2010 updates), needs to be published. For this purpose an agreement is needed with the MoH in order to establish a group of Albanian speaking experts that could review the product. This process could profit of the Italian experience of translating the classification using the web-based translating **tool** of the Italian Portal of Classifications. The data flow in Death Certification needs to be refined, enhancing quality control on coding that at the moment shows misalignment between Civil Registration and Death Certificates with a relevant gap in infant mortality. The situation is particularly difficult in the over 3000 villages of the Country where a pilot study to implement the WHO Verbal Autopsy (to be translated as a preliminary step) would be appropriate. At the moment the Health Centres (419 Primary Health care facilities of the Country) use a small set of ICD-9 codes plus a list of nursing procedures prepared at national level. In the 41 Albanian **hospitals** the department budgets are determined mainly on historical basis with some bonuses on doctor salaries determined with output measures that do not involve the use of ICD. No data collection on interventions is performed. The implementation of ICD-10 as national standard will greatly improve the ability to exchange information between the hospitals. between the structures: the guarantor role of the Ministry of Health would be better performed with the adoption of a standard such as ICD-10 to increase quality and accessibility of data to control. Renovation of license can be a way to enforce an obligation to provide data using ICD-10. The Health Insurance Institute (HII) covers all the primary care services and the pharmaceutical reimbursement for outpatients: in this sector ICD-9 is in use and therefore a higher level political decision is needed to enforce, with a law or strong regulation, the change to ICD-10 against the usual inertia of the currently adopted standard.

The **cooperative model** can be further exploited in the WHO European region (53 Member States) to improve the collection, quality and use of health information required to provide evidence for policy makers.



**Training and education** on ICD coding is one of the recommendations made in the document, as part of the goal of increasing the basic knowledge of health workers on health information systems, including standards, data flows in the health system, minimum patient data set.

With the coordination of **WHO** Head Quarters, the WHO Regional Office for **Europe** asked the Classification Area of the Friuli Venezia Giulia Regional Health Directorate, Italian WHO-FIC Collaborating Centre, to render available expertise in order to carry out strategic evaluation, planning and training activities for the implementation of In the Private Health Sector there are differences ICD-10 at national level in Albania. This activity is consistent with the scope of the Friuli Venezia Giulia Region of enhancing and strengthening forms of international cooperation with Albania aimed at promoting human development, innovation in the health care system and the integration of health and social policies as stated in the Operational Plan 2010-2013 "The international dimensions of FVG Regional Health Policy". The present work describes the analysis of the implementation process and the future steps to take in order to implement ICD-10 in Albania.

#### Conclusions

Albanian relevant institutions, in the frame of a general process of reform of the Health Information System, are positively disposed toward the introduction of ICD-10 as information standard. The preparation of a memorandum of understanding of the stakeholders is the preliminary step to prepare an updated Albanian ICD-10 adaptation, to plan introduction of the classification, starting from strategic areas such as mortality coding, and to plan a wider national training to implement the classification.

Although the work ahead is challenging, this activity also represents an opportunity to show that the possibilities and common goals for work in ICD matters that may be catalysed by the joint effort of several countries, WHO and its Collaborating Centres.

#### ICD-10 in Albania : Recommendations and Priorities

- 1. Establishment of a coordinating working group
- 2. ICD and its updates translated into Albanian
- 3. Review training tool
- 4. Training materials translated
- 5. Select and train cadre of trainers
- 6. Revised data collection forms (e.g. death certificate)
- 7. Rapid assessment of required infrastructure for training
- 8. Selection of pilot areas
- 9. Training process

10.Evaluation of training

**References** 1. Albania HIS Work Plan 2010-15; 2. An overview of the Health care system in Albania, 2009; 3. Albania Demographic and Health Survey 2008-2009; 4. Assessment of the Health Information System in Albania, 2008; 5. WHO Verbal autopsy, 2007; 6. The Operational Plan 2010-2013 "The international dimensions of Friuli Venezia Giulia Regional Health Policy".

29 Oct – 6 Nov 2011

#### Understanding ageing and determinants of health and disability in Cape Town, South Africa ageing to guide public health policies: the COURAGE in EUROPE D006p Project

## Leonardi, M; Raggi, A; Koutsogeorgou, E; Cerniauskaite, M; Quintas, R. Neurological Institute Carlo Besta, Milan, Italy

Abstract There is a need to measure health, environment and social networks and their impact on quality of life and wellbeing of ageing population to produce comparable data in European ageing population. COURAGE in EUROPE Project propose the background of the ICF and based on a theoretical framework that defines disability as the interaction of a health condition with contextual factors, will try to produce these comparable data on determinants of health and disability in ageing.

Introduction	Methods & Materials	Results
Ageing is a phenomenon which is	The survey is administered to	A training process took place so as

of Europe and of the European Commission. There is a need to measure health, environment and social networks and their impact on quality of life and well-being of ageing population to produce comparable data implement COURAGE in Europe in European ageing population. in Collaborative Research on Ageing in Europe Project (COURAGE several parts, containing multiple in EUROPE Project) based on the sections and ICF-based instruments WHO's International Classification of addressing different aspects of health, Functioning, Disability and Health – ICF framework that defines disability as the interaction of a health condition with These two last sections ask questions contextual factors, will try to produce these comparable data on determinants of health and disability on ageing (WHO, 2001; Leonardi et al., 2006).

COURAGE in Europe is a three-year project involving 12 partners from four

becoming one of the leading priorities around 3000 persons aged 50+ years, and 1000 persons aged 18-49 years in Finland, Poland and Spain.

> The COURAGE in EUROPE Survey Protocol was created with the respective Manual. This tool helps to the interview's process. It is divided in quality of life, built environment and social networks in adult populations. about areas of the respondents' life that may impact on their well-being and overall situation. Built environment and Social Networks sections focus on interviewee's relationship with a number of features related to indoor and the World Health as on social network, social support, and of the social network of the person can become problematic during a normal ageing process, which is characterised by more or less severe

standardize data collection to methodology in three countries. Pilot study has been concluded and 100 cases per country collected. Quality assurance are taking place by WHO team to monitor the quality of data collection.

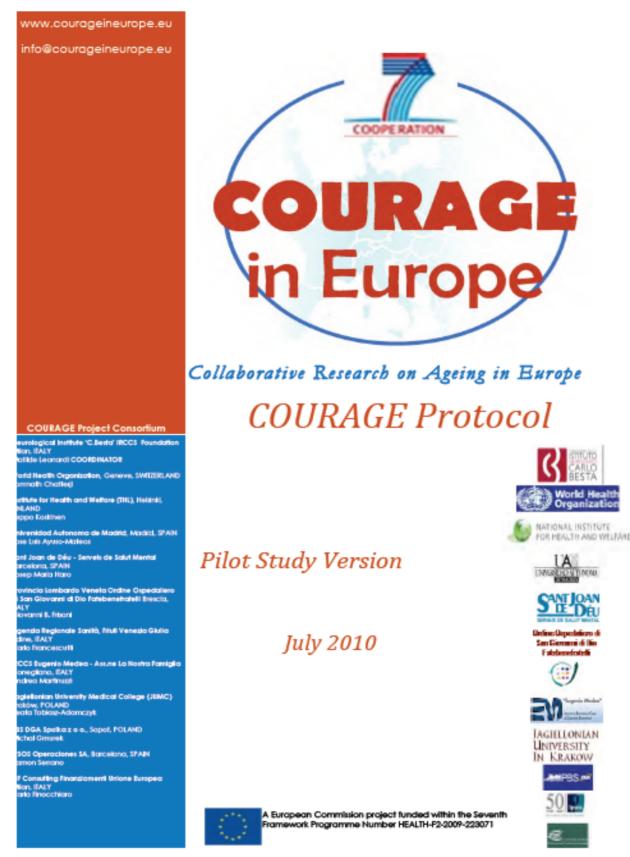
countries and to improve the quality of COURAGE in EUROPE methodology is producing comparable data on nonfatal physical and mental health outcomes, disability, quality of life and well-being, social cohesion and role of built environment in ageing population lay the foundation for It will longitudinal study on ageing in Europe by providing a methodology and an ICF based protocol.

#### Conclusions

Understanding ageing the and determinants of health and disability in ageing, by helping to identify intervention strategies, will have a considerable impact on public health policies. COURAGE in Europe protocol introduces a substantial innovation in ageing disability and survey methodology including these innovative elements that might have substantial bearing on ageing: the Built Environment and Social Networks. The assessment of disability, through activity limitations and participation restriction, and its relationship with environmental factors' effect are fundamental in determining people's health, quality of life and well-being.

countries (Italy, Spain, Poland and and outdoor built environment, as well Finland) Organization. It has been funded to social ties, social participation and answer the pressing need of the social integration. All these aspects European Commission to have valid and play a vital role in determining whether reliable measures to describe health an element of the built environment and disability in ageing population.

COURAGE in Europe Project developed and is validating ICF-based tools to measure health outcomes (both physical and mental), quality of life, limitations in functioning. and well-being in ageing populations and, thereby, to find and empirically substantiate determinants of ageing across populations, looking also at the role of the built environment and social networks as health and disability determinants.











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Please visit the COURAGE website: www.courageineurope.eu

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## 29 Oct – 6 Nov 2011 ICF-based project/programme in a paediatric **Cape Town, South Africa** neurorehabiltation hospital: appraisal of 3 years of implementation

D005p Andrea Martinuzzi, Elena Carraro, Elisa Petacchi, Sabrina Pasqualotti, Silvana Betto. "E. Medea" Scientific Institute, Conegliano Research Centre. Research Branch of the Italian WHO-FIC CC

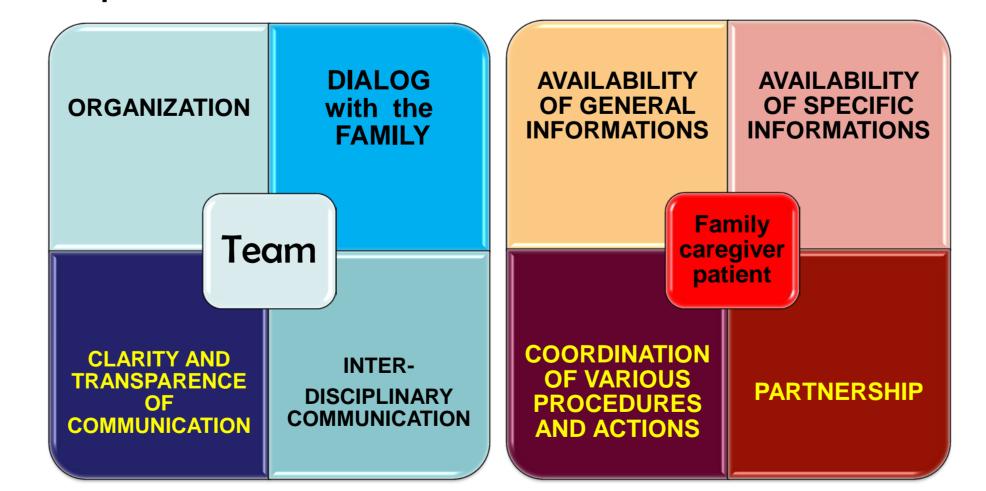
Abstract The introduction 3 years ago in the tertiary care pediatric neurorehabilitation hospital in Northern Italy has been reported previously. Here we follow-up on that experience by probing the implementation of the ICF based tool had on team members and families. More than 200 rehabilitation projects/programs have been completed in 36 months, for children with various health conditions accessing our Unit for intensive rehabilitation. Assessment of impact was on two stages: an evaluation of compliance with the new process design with an evaluation of resource consumption, and an appraisal of the perceived added quality by all the stakeholders. A structured questionnaire exploring the reactions of involved team members and familial caregivers was built by clustering opinions about added quality determinants in the rehabilitation process expressed by team members and family/caregivers. The clustering resulted in 4 areas deemed relevant by team members (organization of interventions, dialog with the family, intra-team dialog, unambiguity of communication), and 4 by family/caregivers (availability of general and of specific information, coordination of actions, partnership), and these areas were explored with 0-5 Likert scale. Results showed wide general appraisal for the introduced model, with scores always above 3 for team members and above 4 for family and caregivers. The results confirm the feasibility of the ICF-CY use in the hospital clinical setting, and showed clear appreciation by both team members and caregivers in spite of initial difficulties especially reported by the first. These results further encourage the diffuse use of ICF based tools in the clinical sector.

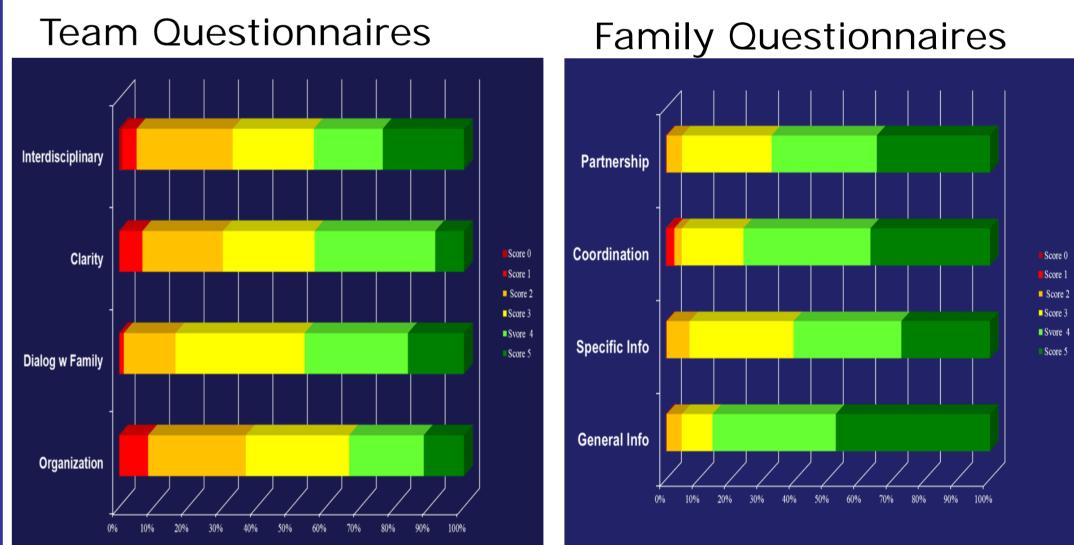
Introduction	Me	thods & Materi	als	Results		
Use cases for ICF have been since its approval reported in epidemiology, health statistics, education, policy making and clinical activities, exploring strengths and challenges associated with the use of such powerful, versatile but very complex tool. In 2010 (Martinuzzi et. al 2010) we reported our pilot experience of using the ICF (in its ICF-CY adaptation) as an ordering framework to build the	consecutively admitted, completed from 2007 to end of 2010, were revised for completeness, for adherence with the ICF coding rules and for consistency between indicated categories and programmed targets, actions and means of the rehabilitation process. The time dedicated by team			<ul> <li>171 of the form were fully completed (85%) with the majority of missing entries regarding the initial part (project) and the first verification.</li> <li>Adherence to ICF coding rules improved during the three years of observation, becoming after 2 years virtually complete.</li> <li>Consistency of the ICF-based functional profile with the activities programmed</li> </ul>		
rehabilitation project and to detail the	Diagnosis	N° of project-programs	SEX (M/F)	was excellent.		
rehabilitation program for children with disabilities admitted to our tertiary care neuro-rehabilitation hospital in Northeastern Italy.	Cerebral palsy Acquired Brain Injury Brain Tumors Rheumatic diseases	77 60 6 29	51/26 27/33 2/4 8/21	Indirect time dedicated by team members was dilated by 15% during the first semester, but returned to baseline afterwards		
36 months after the introduction of the	Neuromuscular disease	s 16	8/8	Team Questionnaires Family Questionnaires		
ICF based project/program we felt it was time to check for the results of the	Others Total	14 <b>202</b>	7/7 <b>103/99</b>	Interdisciplinary		
introduced changes in terms of						

introduced changes in terms of efficiency and in term of added quality to the rehabilitation process.

Patients mean age of 9.3 ± 3.2 years (range 1.4 – 18.4) Lenght of stay: 43 ± 24 days (range 2 weeks - 6 months)

A structured questionnaire focusing on quality determinants of rehabilitation was delivered to team members and families to assess the perceived impact of the ICF based format. The probed areas for the two groups of respondents are indicated:





Conclusions

ICF can be incorporated in the clinical process of in-hospital post-acute intensive rehabilitation functioning as an effective roadmap for intervention.

Summarizes the whole rehabilitation process, thanks to contribution of all professionals.

Bibliography: Martinuzzi et al. J Rehab Med 2010 42(1): 49-55

Responses from 20 team members and 25 families were recorded on a Likert 0-5 scale

Allows the precise tracking of data and the objective representation of them.

Provides a common language shared by health professionals and understood by families.

The therapeutic alliance between families and rehabilitation team is reinforced and the simultaneous sharing of needs and objectives effectively translates in increased empowerment of stakeholders

# Preliminary Mapping of ICF-CY **Body Structures to SNOMED-CT**

29 Oct – 4 Nov 2011 Cape Town, South Africa

D009p

Andrea Simoncello, Vincenzo Della Mea\* Italian WHO-FIC Collaborating Centre \*and University of Udine, Italy

Abstract In 2010 WHO-FIC and IHTSDO signed a cooperation agreement for the harmonization between WHO classifications and SNOMED-CT terminology. Among WHO classifications, we focused on the harmonization between ICF (in its ICF-CY variant) and SNOMED-CT. The present poster describes a preliminary mapping attempt between ICF-CY and SNOMED-CT, done on the Body Structure component.

Introduction	Methods & Materials	Results	
	Among its contents, ICF provides a classification of body structures, which	-	
	are anatomical parts of the body.	Body Structures could be mapped to	
cooperation agreement for the	As a first step, we identified the	SNOMED-CT terms. Similarly, it can be	

harmonization between classifications and the SNOMED-CT (Systematized of Nomenclature Medicine-Clinical Terms) terminology. The main reason behind this is that the tools provided by both organizations will complement each other in order to make it easier to summarise information and aggregate results from patients' health records.

WHO classifications are already used to information on diseases, gather disability and interventions about the population's health, often starting from electronic health records.

SNOMED CT is considered to be the comprehensive, multilingual most clinical healthcare terminology in the world.

SNOMED concepts are subdivided into a number of root concepts as follows:

WHO SNOMED root concepts more adequate for a mapping to ICF body structures. SNOMED-CT provides a number of terms related to anatomy, and in particular, with regard to the ICF structures, the most interesting subtree is constituted by the *Body* system structure concept.

> mapping of ICF-CY Body Structures to equivalent or with the aim of understanding the of intersection both overall terminologies, starting from exact correspondences between terms.

Mapping was done starting from ICF-CY concepts and looking for similar concepts into SNOMED-CT by using an online SNOMED browser.

When more than one partial candidate concept was found, all of them were registered. This helped to recognize situations where ICF structure an SNOMED includes more than one structure.

supposed that also Body Functions may be easily mapped to SNOMED-CT, whereas Activities and Participation and Environmental Factors will pose some more problems, in particular because the focus of ICF is not strictly healthcare-related, as in SNOMED-CT.

A total of 222 ICF-CY concepts were Thus, we attempted an exploratory taken into consideration and mapped to similar SNOMED SNOMED-CT Body system structures, concepts. Residual classes (unspecified, other specified) were not included in the mapping.

> Only 13 ICF structures (5.8%) were not found among SNOMED structures (see Table), plus 5 out of 8 chapters. Thus, 8% of ICF-CY structures did not find a proper mapping to SNOMED-CT. Regarding partial mappings, 11 ICF structures were mapped to 2 different SNOMED-CT structures; ICF 3 structures were mapped to 3 SNOMED-CT structures. Thus, 6.3% of ICF structures needed multiple SNOMED-CT codes to be represented.

•*Clinical findings* 

•Disorder

•*Procedure* 

•Body structure

•Anatomical concepts (Body Structure) •*Morphologies (Body Structure)* 

•Organism

•Physical Force

•Substance

•Specimen

•Social Context

•Attributes

•Context Dependent categories •Physical object

•Events

geographical •Environments and location

•Observable entity

•*Qualifier value* 

THE EYE, EAR AND RELATED s2 STRUCTURES s210 Structure of eye socket STRUCTURES INVOLVED IN VOICE s3 AND SPEECH STRUCTURES OF THE CARDIOVASCULAR, IMMUNOLOGICAL s4 AND RESPIRATORY SYSTEMS Muscles of respiration s4303 Structure of vagina and external s6303 genitalia STRUCTURES RELATED TO s7 MOVEMENT Ligaments and fasciae of shoulder s7203 region s730 Structure of upper extremity

## Conclusions

The present preliminary mapping aims at harmonizing ICF-CY with SNOMED-CT. We started from the easiest ICF component, that is, Body Structures. The work done proved that, at least on this component, mapping İS straightforward, although there are structures in ICF that correspond to more than one structure in SNOMED-CT, evidently more finely defined. high-granularity those Among structures, most ICF chapters (firstlevel codes) are also included. The main limitation of the present

study is that no validation has been carried out yet on mappings. Further work will include mapping of other components, starting from Body Functions. We expect that Activities and Participation and Environmental Factors will pose some more problems, in particular because the focus of ICF is not strictly healthcare-related as in SNOMED-CT. However, this means that they might be the unique contribution of ICF to the global terminology effort of SNOMED-CT.

•Staging and Scales •Special concept •*Pharmaceutical / biologic product* •*Record artifact* 

Among WHO classifications, we focused on the harmonization between ICF, in its ICF-CY variant, and SNOMED-CT.

present poster describes a The preliminary mapping attempt between ICF-CY and SNOMED-CT, done on the Body Structure component.

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