



HEADNET

Public Health and Disability Network

Gruppo di Ricerca Salute Pubblica, Disabilita' e ICF

ISTITUTO NAZIONALE NEUROLOGICO "Carlo Besta" IRCCS

HEADNET Research Group



Italian National Neurological Institute "Carlo Besta"

12th Annual North American Collaborating Center Conference on ICF

LIVING ON ENVIRONMENT: THE PROMISE OF ICF

Dr. Matilde Leonardi

June the 7 th 2006





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Our research and training activities on 2006

- MHADIE, Measuring Health and Disability in Europe: Supporting Policy development;
- Population Survey on Invalidity pension in Italy: defining needs of PwD with ICF model;
- Education and Training on ICF in Italy and internationally;
- “ICF in Neurology” project: the Italian National Neurological Institute C. Besta database on functioning and disability in Neurology;
- ICF and Mental Health: inclusion in the labour sectors of people with psychiatric disorders;
- Functioning and Disability in Children with Neuro-Oncological Disease: The ICF framework to define cure and care and the use of ICF-CY and ICFCY questionnaires;
- Accessibile Tourism and ICF;
- Mental Retardation, competitive sports activities and ICF

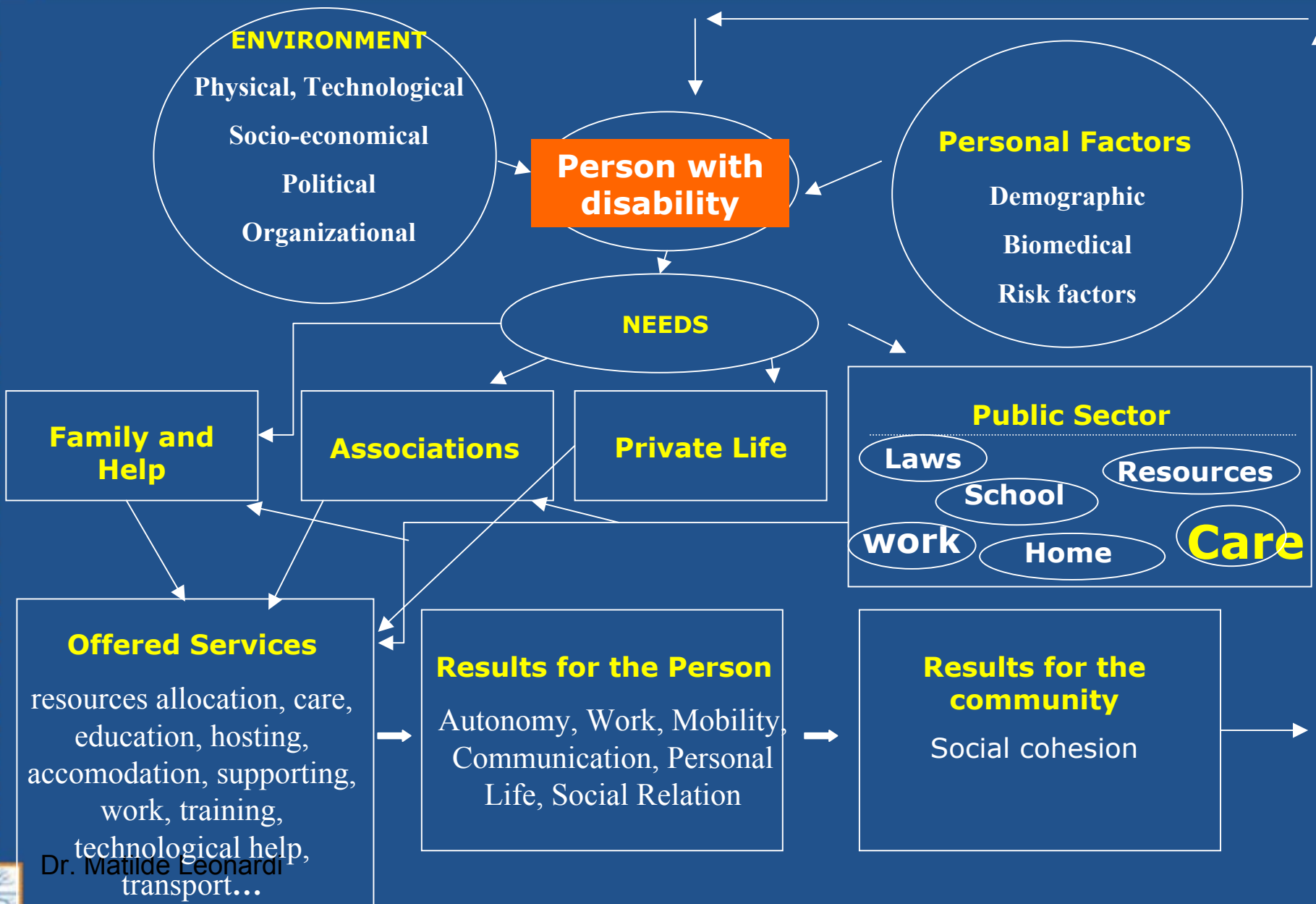




Headnet Research Group projects presentation 7 June 2006

- “ICF in Neurology” project;
- ICF and Mental Health;
- Functioning and Disability in Children with Neuro - Oncological Disease;
- Accessible Tourism and ICF;
- Mental retardation, competitive sports activities and ICF







Cultural changes: the ICF's revolution

DEFINITION:

**any person in any moment of
life can have a health
condition that in a negative
environment becomes
disability**



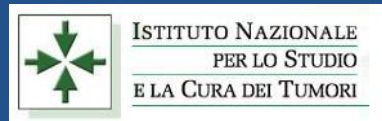


Grant from Italian Ministry of Health

Functioning and Disability in Children with Neuro - Oncological Disease: The ICF framework to define cure and care

Leonardi M, Ajovalasit D, Cattoni G, Pisoni C, Raggi A

In collaboration with



Dr. M. Leonardi





Partners Project

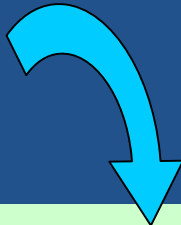
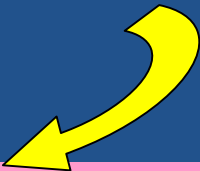
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Italian National Neurological Institute
C. Besta, Milan

Child Neuro-oncological unit
Italian National Institute for Cancer, Milan

Headnet Research Group
Project Scientific Coordinator

Pediatric Oncological unit
Paediatrics Hospital "Bambin Gesù"
Rome

Children in Hospital Association, Milan





Research background

For two years these three Italian research institutions will cooperate with associations of volunteers to develop a network between the health institutions and the whole environment where children with brain cancer live.

Given ICF's multidimensional application all of them will work to identify a multidisciplinary cure and care pathway using ICF as a common language





First step

All the operators involved will undergo
intensive training on ICF

A day of **basic course**

Two days of **advanced course**

A day on **ICF - CY**





- Institute Besta is one of the centres that developed and validated the ICF children and youth version and the ICF CY checklists and questionnaires.
- Dr. Leonardi is co-chair of the WHO ICF CY working group



ICF – CY related instruments

ICF CY Questionnaires

0 – 3 yrs. version 1A

3 – 6 yrs. version 1B

7 – 12 yrs. version 1 C

13 – 18 yrs. version 1 D

WHO DAS II

World Health Organization
Disability Assessment
schedule, second version

WHO DAS II proxy

World Health Organization
Disability Assessment
schedule, version for
proxy

ICF-CY Questionnaire



“Centre Suisse de Pédagogie spécialisée” has tested an original way to administer ICF – CY checklist to children with MR: when the interview begins, children know that the red puppet means “NO” and the blue one means “YES”. So, for each question they can indicate one of the two puppets to answer.

Applying this original methodology seems easier than a normal one.

It promote the interaction and the relationship between children and interviewer through playing activities



To assess adaptive behavioural

Vineland Adaptive Behavioural Scales

S. Sparrow, D. Balla and D. Cicchetti

Adaptive behavioural concept express interaction between a person and his environmental context

Vineland scales allow a survey of the most important areas on adaptive behavioural.

**Communication, daily skills,
socialization and motor skills**



Main purpose

with this project



the first Italian **database of
functioning and disability in
children with neuro-
oncological diseases**



Main purpose

using ICF will establish

a common background and language

between all professionals involved, thus providing a conceptual order for the information gathered with the assessment tools used in the children neuro-oncology



Main purpose

Through ICF classification
and its correlated instruments

It will possible to analyze

the needs of Children

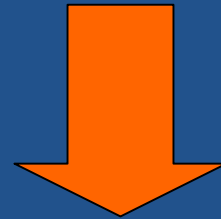
with neuro – oncological disease



Identify a **Cure and care pathway**
starting from needs

Main purpose

from data and context analysis



a **multidisciplinary team**

which is to answer

the needs of children and their families and
to design a pathway leading from cure to
care within the family social network



Outcome

The main expected outcome of the project will be a **support-oriented operational model** based on a wide knowledge of the needs of children with neuro-oncological diseases and their families. Such a model will be transferable to other operational units of paediatric oncology.





Credits

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Accessible Tourism and ICF

Leonardi M., Cornelio P.,
Ajovalasit D., Cattoni G., Pisoni C., Raggi A.





Accessible Tourism and ICF

Headnet Group is performing a research project with the purpose to evaluate which are the **incoming and general tourist policies in several countries** and which are the parameters used to fulfill persons with different functional levels.





Accessible Tourism and ICF

Our meta analysis of different policies and national and international studies shows that the disabled client's supply to the tourism area has a relevant economic weight not yet fully estimated.



Accessible Tourism and ICF

It is a significant market that is growing

Research has shown that PwD like to take a holiday in a mainstream environment. Many also have the financial means to do so – given the right facilities.

PwD usually travel with friends, family or carers, which brings in additional revenue.

Accessible Tourism and ICF

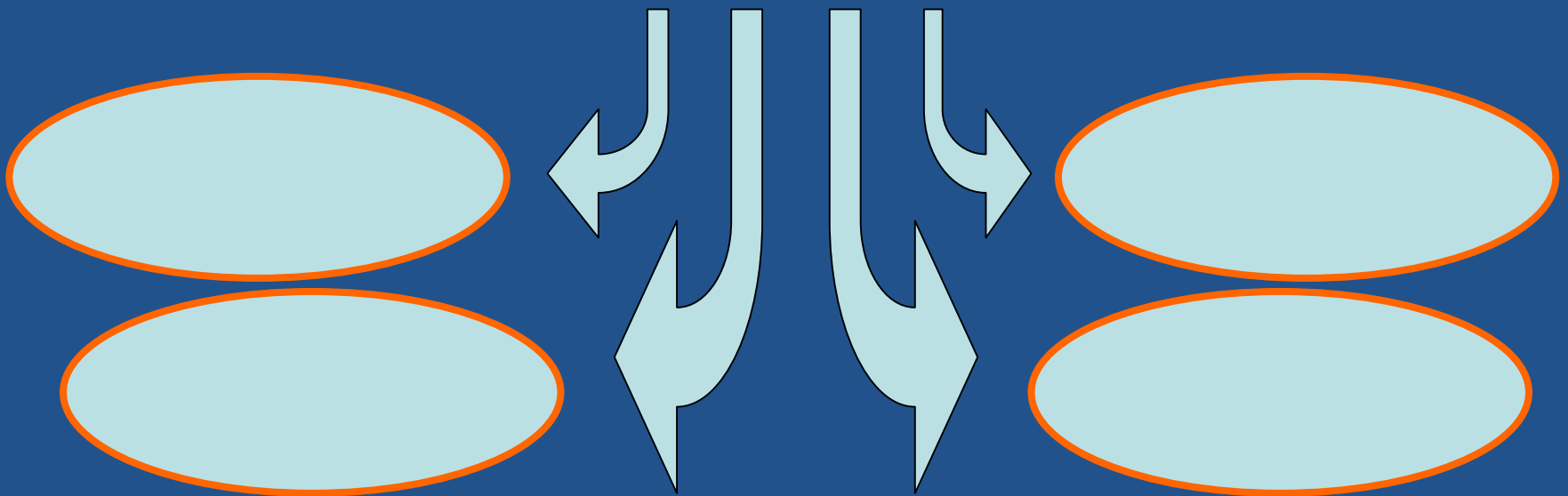
PwD tend to book in advance and often return on a regular basis once they find the right facilities.

The tourism market is changing – over 55s take more holidays and often travel out of season – which reduces peak season pressures, spreads demand more evenly and lengthens operating seasons

Accessible Tourism and ICF

Statistical reports show how just in Italy 3,5 million persons could belong to this category of potential clients.

Around 10% of Global Tourism Market

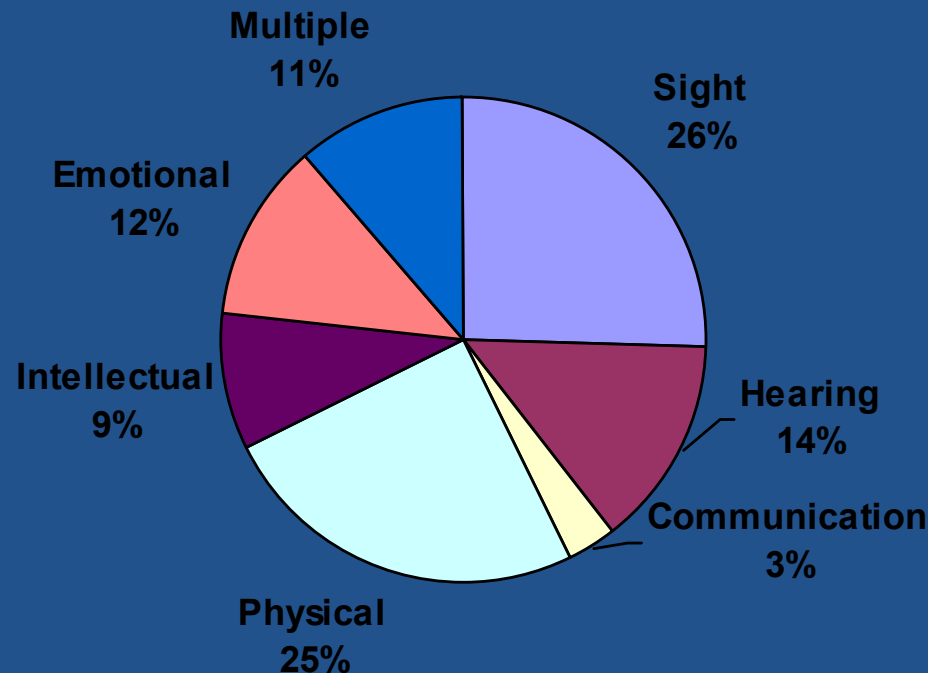


Accessible Tourism and ICF

ICF brings a crucial contribution on **standardizing evaluations on environmental factors**, as advised by EU and European Disability Forum, as a key element to understand and develop comprehensive tourism politics.

Accessible Tourism and ICF

Persons with disabilities even in the same diagnostic group, don't represent a standard category but persons with different functioning levels and needs.



Accessible Tourism and ICF

According to the ICF guidelines, the Italian and international tourism sector must learn to be a **facilitator** for every person with disability in taking care of them independently from what kind of need is, with a special respect to the person

Dedicate the client with disability the necessary time and an appropriate behaviour means to be a **facilitator** to overlap a barrier for the persons with disability

From: "Rules for tourism operators"

Treat with respect

Offer assistance to a disabled person, but wait until the offer has been accepted.

Speak directly to a disabled person and not through a companion.

Never ask a person what their impairment is. If a person wants you to know they will tell you.

People with what might seem similar impairments often cope differently.

Staff should not expect uniformity, as PwD are all individuals.

Should be treated as any other person, with consideration and without condescension.

Dr. Matilde Leonardi

Accessible Tourism and ICF

With ICF is possible to classify needs in comparison with the logistics and organization of the tourism offer, the first step to settle a workable tourist package for persons with special needs.

“ICF environmental factor based unified system “ to standardize evaluation of **barriers and facilitator**

Accessible Tourism and ICF

ICF allows a better understanding of these phenomena, making tourism one of the most important and innovating aspects of PwD's social integration, participation and mainstreaming processes.

Dr. Matilde Leonardi



Accessible Tourism and ICF

Our research project uses ICF to build a knowledge, to improve and share the existing information, organize the barrier's elimination process, build good practices that should be positive towards persons with different functioning levels





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**Italian National Neurological Institute
Carlo Besta (INNCB)
Milan, Italy**

MENTAL RETARDATION, COMPETITIVE SPORTS ACTIVITIES AND ICF

Leonardi M, Ajovalasit D, Cattoni G, Pisoni C, Raggi A





Introduction

Research supported by an unrestricted grant by CIP (Comitato Italiano Paralimpico)

CIP requested to **Headnet Research Group** a research to find and then apply an **ICF universal model of disability** that could help to bypass the gap created by the exclusion of athletes with MR from Paralympics games.





Methodology

Headnet coordinated a group of several Italian and international experts which identified the need of a different perspective to evaluate functioning and disability in MR

The present criteria and **protocols for sports eligibility** (SIC Q) in individuals with MR seem to be inadequate in comparison with the AAMR's diagnostic criteria.



Methodology

New AAMR's criteria

ICF's Biopsychosocial model

Identifying supports, needed to perform daily activities and to be involved in life situations

is essential to determine the burden of MR as well as to assess the functioning of individuals with MR



HEADNET Group developed a dedicated
“ICF checklist for athletes with MR”,
useful to measure persons with MR's
sports abilities

This dedicated checklist takes into account
an **athlete's functioning profile rather
than MR diagnosis only**





ICF checklist for athletes with MR

This ICF-MR dedicated checklist was developed keeping in mind not only the characteristics of individuals with MR, but also the specific features of sports activities in which athletes with MR can be involved





ICF checklist for athletes with MR

1. Headnet Group researchers and colleagues identified a series of **ICF codes** which can be **associated to MR condition and competitive activities**;
2. A matching analysis was made between the contents of ICF codes and some assessment instruments taken into consideration: the **WAIS** (Weschler Adult Intelligence Scale), the **Vineland** and the **Supports Intensity Scale (SIS)**, in order to identify their correspondence.



ICF – dedicate checklist for athlete with MR

ICF - dedicate checklist for athletes with Mental Retardation

Made up **215** codes
87 add codes more than 2003 WHO standard checklist

BODY FUNCTIONS

17 codes at the 2nd level
28 codes at the 3rd level

Total add codes **45**

BODY STRUCTURES

No one add codes

ACTIVITY AND PARTICIPATION

17 codes at the 2nd level
20 codes at the 3rd level

Total add codes **37**

ENVIRONMENTAL FACTORS

5 codes at the 2nd level

Research results

- The “**ICF checklist for athletes with MR**”, to be used with athletes with MR, in order to facilitate their inclusion in competitive sports activities;
- A research protocol to be implemented by the Italian Paralympics Committee (CIP) to test the ICF MR checklist so as to define competitive sport activities eligibility in **athletes with MR**;

Research results

- Promotion within CIP of the ICF Biopsychosocial model, as a common background to map out accessibility pathways to competitive sports activities for athletes with MR;
- The implementation of a common language among different operators working in national and International Paralympics Committees;

Research results

- The methodology to revise the SICQ so as to allow athletes with MR to compete on equal dignity and rights with other athletes with disability;
- The production of a scientific ground that allows CIP to enhance the integration of persons with MR in competitive sports activities;

Conclusions

If a person is able to play competitive sports activities,
how is important IQ or adaptive behaviour ?

What is crucial is whether sport performances of a person with MR meet the required standards?

If so, then, such a person is eligible for participation in competitive sports, Paralympics or even Olympics Games.



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ICF and Mental Health: inclusion in the labour sectors of people with psychiatric disorders

Leonardi M., Raggi A., Ajovalasit D., Cattoni G., Pisoni C



Background

- Severe psychiatric disease have never been faced in researches on functional profiles, given to the lack of interest and the difficulty of obtaining relevant information.
- Up to now, the only relevant application of ICF in psychiatry is in the field of depressive disorders (ICF core-sets for Depression).
- The role of environmental factors is under-represented in the researches, that focus on them not in the perspective of ICF.
- Headnet group's research in the field of psychotic disorders, in collaboration with Mental Health Distric of Iseo (Brescia, Italy) represents the first application of ICF in severe psychiatric diseases.

Research Topics

Identify the needs of persons with disabilities in three areas:

- Work
- Housing
- Socialization



**ICF domain of
Environmental
Factors**

Measure and compare the outcome in term of social inclusion, working situation, global well-being and quality of life.

Crosswalk of ICF relevant categories to clinical and social indicators.

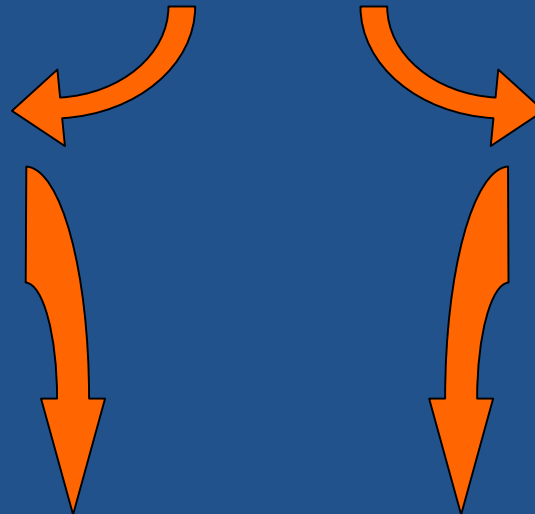
Research Topics

Draw complex profile of functioning to assess and point the areas in which these persons meets most of their difficulties.

Use these information to design interventions, with special attention to the area of **labour**

Social services in charge of employment inclusion

Psychiatric condition double diagnosis

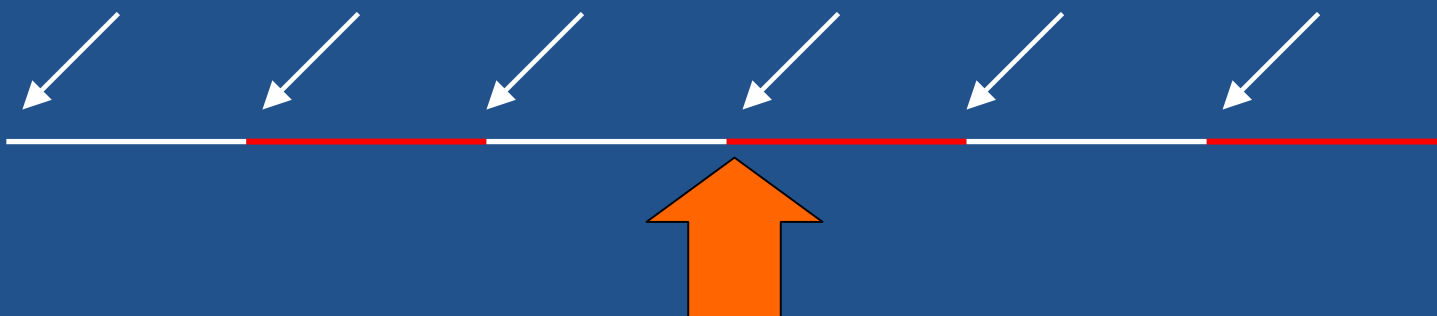


Finding a job that fits the person's capacities

Sample and Methodology

A sample of 35 persons with severe psychiatric diseases (psychosis, schizophrenia and persons with a comorbidity of substance addiction) will be followed for three years by a multidisciplinary team (psychiatrist, psychologist and social workers).

Protocol administration (every six months)



HEADNET's Supervision (every three months)

Expected Results

- Qualitative and quantitative analysis will be performed to point common elements, determine the presence of barriers and facilitators, describe difficulties and strong points
- Demonstrate the feasibility of ICF model to severe psychiatric conditions
- Operationalize a good practice in the care process of persons with psychiatric diseases, adequate to address their difficulties and to create a relational environment suitable to meet their personal features



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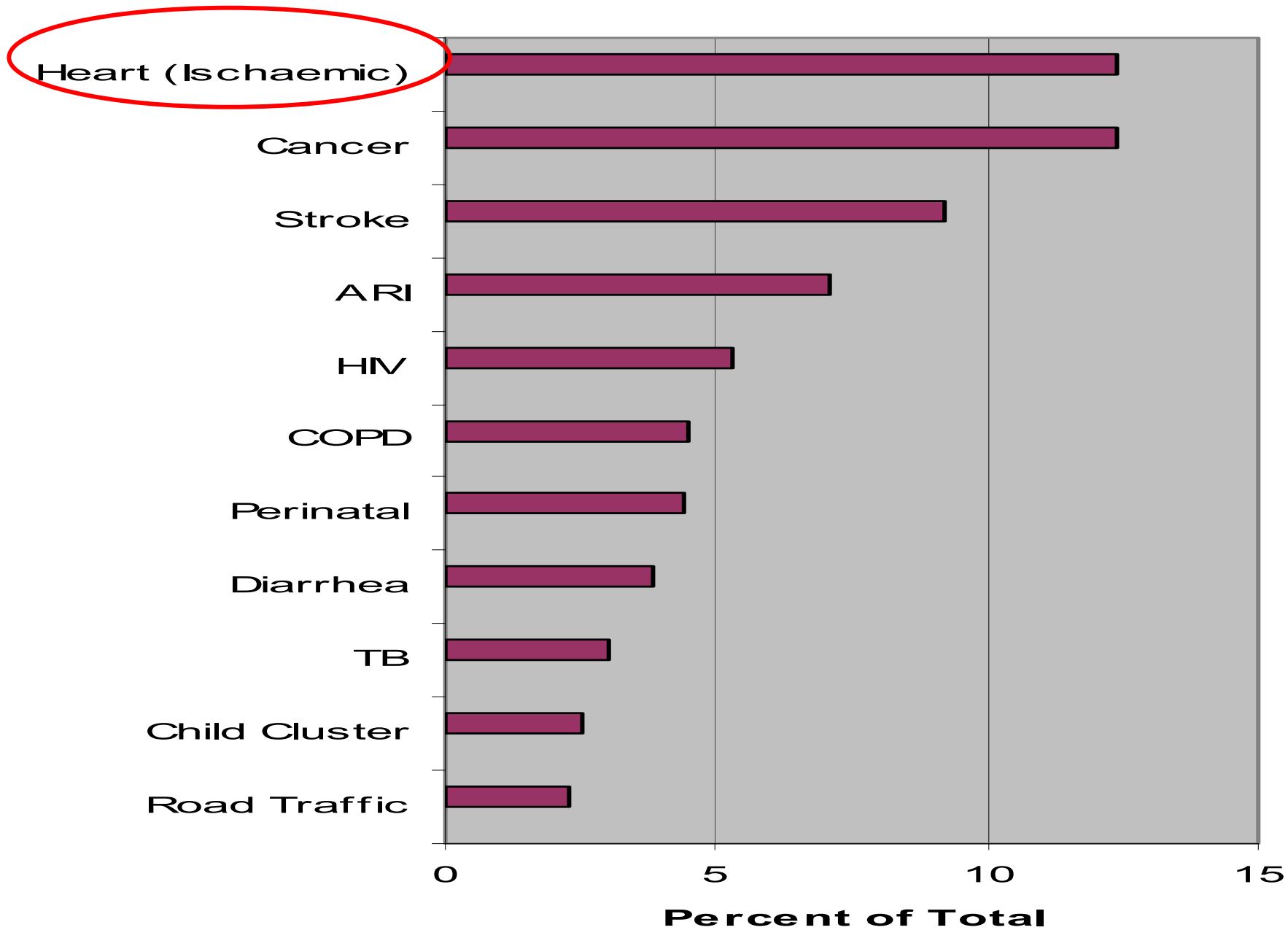
“ICF in Neurology” project: the Italian National Neurological Institute C. Besta database on functioning and disability in Neurology

Leonardi M., Raggi A., Ajovalasit D., Cattoni G., Pisoni C.



2000

World - Deaths



Global Burden of Disease Studies

(World Bank, Harvard University, and World Health Organization)

METHODS



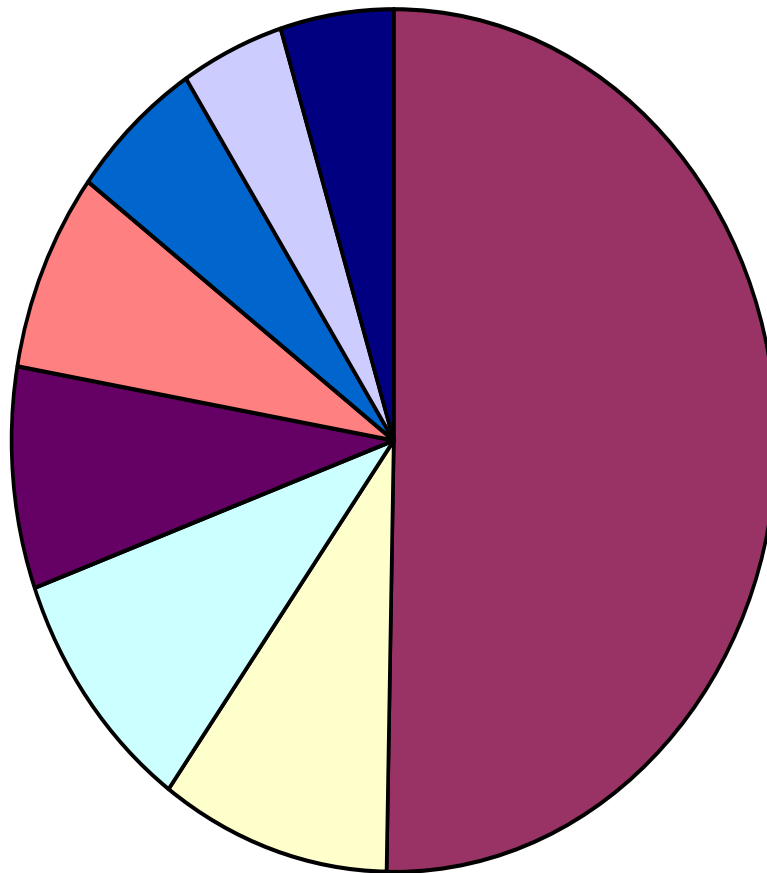
- **Years of Life Lost (YLL):** number of years of healthy life lost because a disease.
- **Years Lived with Disability (YLD):** years lost because of disability
- **Disability Adjusted Life Years (DALY):** $YLL + YLD$

EURO: Top Ten DALYs 2000

| | | |
|-----|-------------------------------|-------|
| 1. | Ischaemic heart disease | 10.5% |
| 2. | Cerebrovascular disease | 6.8% |
| 3. | Unipolar depressive disorders | 6.1% |
| 4. | Alzheimer and other dementias | 3.0% |
| 5. | Alcohol use disorders | 2.9% |
| 6. | Hearing loss, adult onset | 2.6% |
| 7. | COPD | 2.4% |
| 8. | Road traffic accidents | 2.4% |
| 9. | Osteoarthritis | 2.4% |
| 10. | Self-inflicted injuries | 2.3% |

EURO A: Top Ten YLDs 2000

Very low child, very low adult mortality



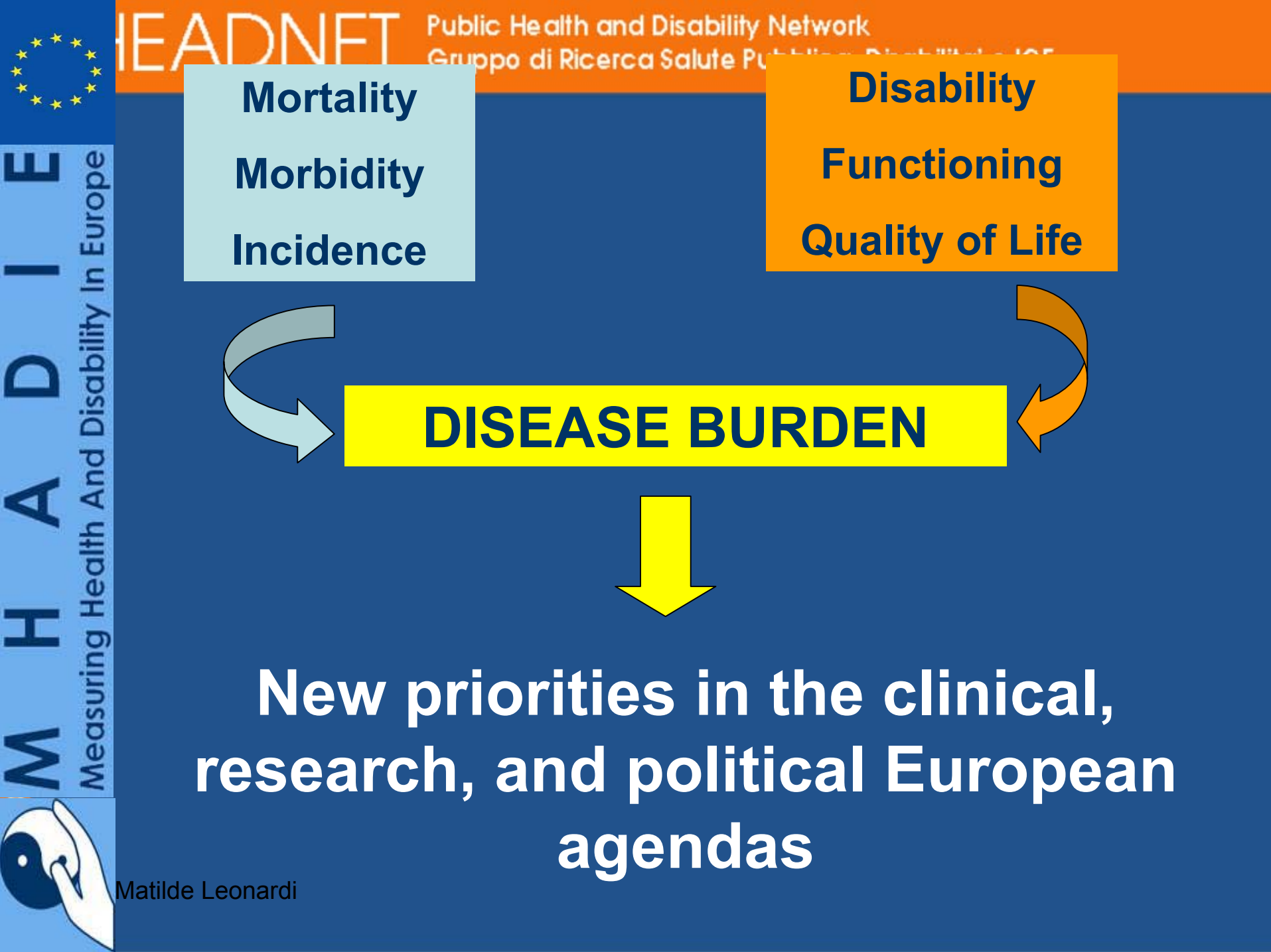
- Others
- Neuropsychiatric disorders
- Respiratory diseases
- Sense organ disorders
- Musculoskeletal diseases
- Cardiovascular diseases
- Injuries
- Osteoarthritis



YLD Top Ten 2000 15-44 years old

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| Rank | Cause | % total |
|------|---------------------------------------|---------|
| 1 | Unipolar depressive disorders | 15.8 |
| 2 | Alcohol use disorders | 5.6 |
| 3 | Schizophrenia | 4.9 |
| 4 | Anaemia | 4.9 |
| 5 | Bipolar disorder | 4.7 |
| 6 | Hearing loss, adult onset | 3.8 |
| 7 | HIV/AIDS | 2.9 |
| 8 | Osteoarthritis | 2.6 |
| 9 | Chronic obstructive pulmonary disease | 2.4 |
| 10 | Road traffic accidents | 2.3 |



Mortality
Morbidity
Incidence

Disability
Functioning
Quality of Life

DISEASE BURDEN

**New priorities in the clinical,
research, and political European
agendas**



“ICF in Neurology” project

Why collect functional data in Neurology?

- Neurological Diseases, often chronic and degenerative, represent a high burden for populations and cause high costs to societies.
- Diagnosis alone provide poor information, because lifelong changes regard only the level of personal independence and the capacity of performing actions.
- In the most situations, diagnosis will not change through the years, so what is needed to plan intervention must not be strictly based on diagnosis alone

“ICF in Neurology” project

The cost of a Disease is based on different parameters:

- Medical costs
- Services' utilization
- Levels of assistance

Facing these issues is a direct duty of a health system, but they are not exhaustive of the whole outlook. A disease has a more general cost for societies, also including

- Aids
- Invalidity pensions
- Working ability and loss of productivity
- Social integration



“ICF in Neurology” project

Psychosocial interventions are particularly important because the burden of Neurological Diseases, given the low efficacy of strictly medical therapies, must also be read through the lens of environmental interventions.

Information about environmental features are essential to design a care, education or employment pathway.




The ICF classification is the primary tool to gather these information.



“ICF in Neurology” project

In the “ICF in Neurology” project Headnet group’s activity is to collect data on functioning and disability in neurological diseases.

This information will be collected using a common protocol, given the fact that at INN CB, patients are diagnosed by the different neurological Units.

- **ICF checklist**  data on functioning at the level of body, person and environment
- **WHO-DAS II**  data on the difficulties the persons experience in performing actions
- **SF-36**  data on the experience of quality of life



“ICF in Neurology” project

Up to now data have been collected for patients with Myasthenia Gravis – 102 cases

Migraine – 52 cases

Parkinson Disease – 13 cases

Data collection will start soon also for children with brain tumors,

Stroke and

Epilepsy.





“ICF in Neurology” project

The final objective is to have around 100 cases for each condition, in order to built a database of functional profiles in neurological disease.

This will enable to highlight differences and similarities and to compare common health pathways in similar situations.



“ICF in Neurology” project

Persons with Myasthenia share with those affected by Migraine a peculiar feature: the invisibility of their disease and the important relevance of drug treatment as a facilitator.

Having these diseases determines several problems in the relational area, and the difficulties are often experienced in the workplace, where colleagues and supervisors often can't recognize these disease and understand the difficulties of these persons.



“ICF in Neurology” project

Most of the barriers are related to **e3** and **e4 ICF** Chapter. However, in the same chapters, we have evidenced many facilitators, highlighting the central role of some these factors, in particular **family**.



Myasthenia

- Together with Italian Association of Myasthenia patients, the information collected with ICF allowed to prepare a specific information package for employers so as to explain the causes of fatigue of Myasthenia patients to them.



“ICF in Neurology” project

Crosswalks from existing disease assessment to ICF categories will be performed throughout the project, to link functional information to scientific basis.

Having a scientific base to define the extent of an impairment and the measure in which the environment is a barrier or a facilitator is the prerequisite to develop a real common language through different sectors and professionals.





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