Functioning and disability in Europe

MHADIE project results: ICF functional profiles in 12 selected health conditions in Europe

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HEADNET
Health And Disability Network
Istituto Nazionale Neurologico "Carlo Besta"

Sixth Framework Programme

M H A D I E
Measuring Health And Disability In Europe

www.mhadie.it

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EU MHADIE PROJECT
Measuring Health and Disability in Europe: Supporting policy development

www.mhadie.it

MHADIE is a three-year Coordination Action financed by the EU Commission, within the Sixth Framework Programme – coordinated by Dr. Leonardi

Involves 16 European Centres and 10 different countries

Aims to demonstrate the utility and feasibility of ICF model in measuring different types and prevalence of impairments and limitations.

ISTITUTO NAZIONALE NEUROLOGICO "C.Besta"

MHADIE Partners

1. Istituto Nazionale Neurologico "Carlo Besta" (I)
2. World Health Organisation (CH)
3. European Federation of Neurological Associations (B)
4. Mälardalen University (S)
5. Zurich University of Applied Sciences, School of Education (CH)
6. Regione Autonoma Friuli Venezia Giulia–Agenzia Reg. Sanità (I)
7. Institut Municipal d'Investigacio Medica (E)
8. Regione Lombardia (I)
9. National Authority for the Persons with Handicap (RO)
10. National Disability Authority (IRL)
11. Universidad Autonoma de Madrid (E)
12. Ludwig-Maximilians-University Munich (D)
13. Charles University (CZ)
14. University Hospital of Hamburg (D)
15. Institute for Rehabilitation, Republic of Slovenia (SI)
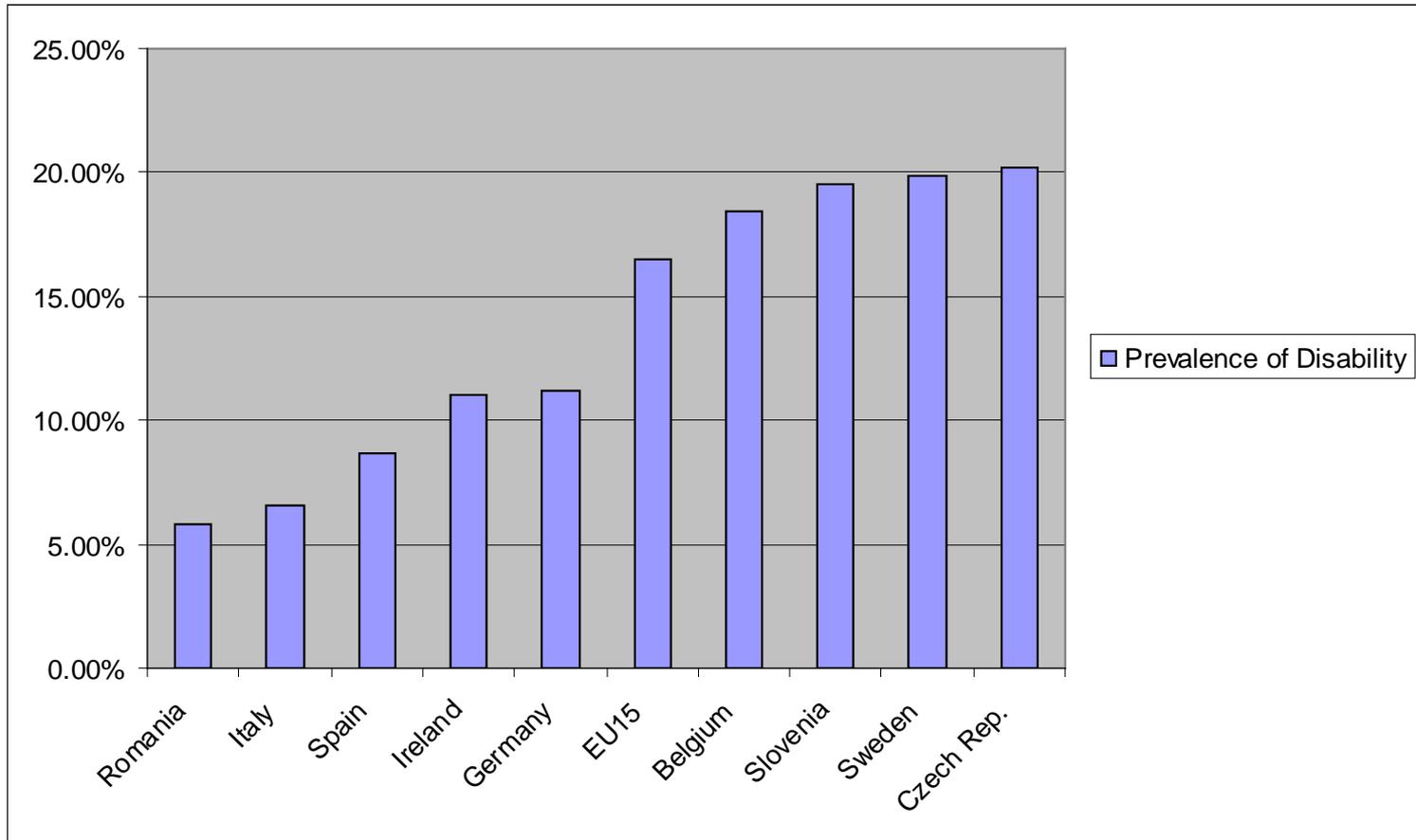16. CF consulting Finanziamenti Unione europea s.r.l. (I)

MHADIE primary objectives

1. To use the ICF model to evaluate existing sources of EU disability data, general population health surveys and education statistics data

2. To demonstrate that such a model is adequate to describe patterns of disability in clinical samples, and is useful to collect and analize data in clinical and educational sectors

3. To develop predictors of disability and environmental barriers to access in health care and full participation in society

4. To produce policy recommendation and guidelines concerning the use of ICF for effective and coherent health and social policies
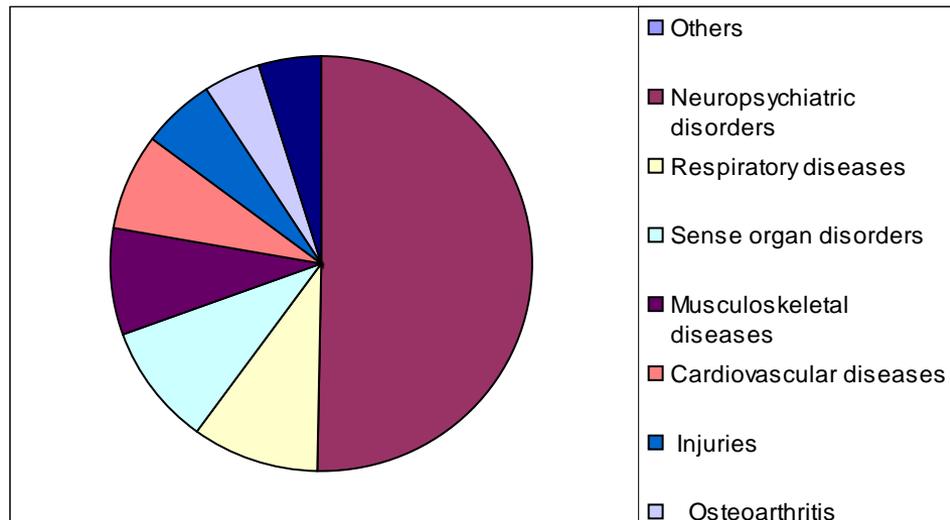
MHADIE project Overview

- MHADIE researchers will give evidence that data currently being collected, nationally and internationally, embody **conceptual confusions, inconsistencies and ambiguities about disability and the relationship between health conditions, impairments and other environmental factors.**

- The methodology used is leading to an **integration of existing statistical information systems,** across nations, sectors and life span of present and future members of EU.

Prevalence of disability in MHADIE countries

BURDEN OF DISEASES EURO A: Top Ten YLDs 2000

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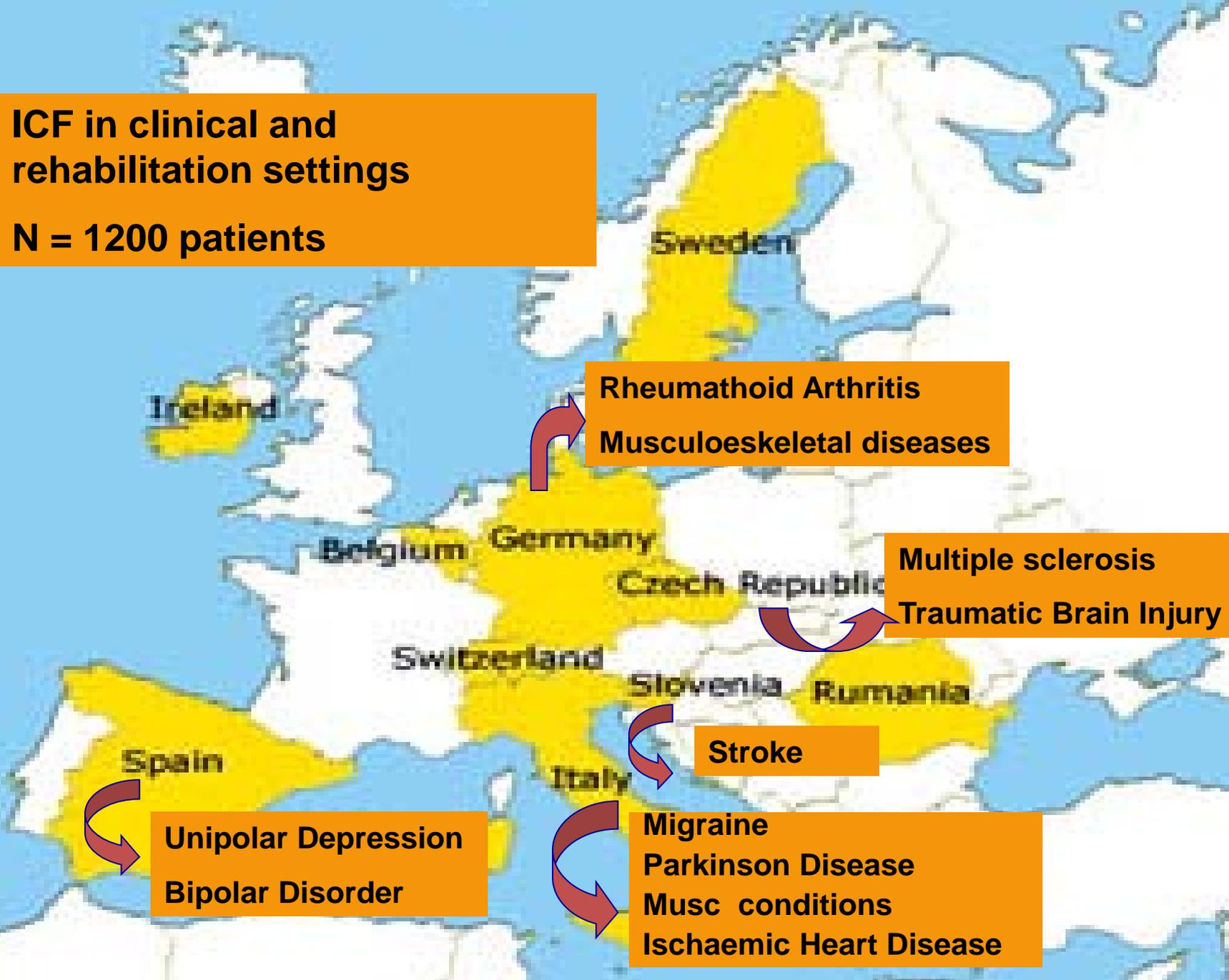- Cardiovascular diseases
- Injuries
- Osteoarthritis

MHADIE Survey: Materials & Methods

- Naturalistic cross sectional longitudinal study. A total of 1200 patients to be enrolled.

- Common Inclusion Criteria are:
  - Main diagnosis based on the International Classification of Diseases-10 edition criteria (ICD-10; WHO, 1996)
  - Age > 18 years old.
  - Informed consent form read and signed

- Specific Inclusion and Exclusion criteria were defined at each site for each health condition

- Patients were evaluated in individual sessions at <u>baseline, at six weeks and at three months after baseline.</u>

ICF in clinical and rehabilitation settings

N = 1200 patients

Rheumathoid Arthritis

Musculoeskeletal diseases

Multiple sclerosis

Traumatic Brain Injury

Stroke

Unipolar Depression

Bipolar Disorder

Migraine
Parkinson Disease
Musc conditions
Ischaemic Heart Disease

MHADIE Survey: Materials & Methods

- MHADIE project's clinical centres undertook a large data collection on the following selected health condition:
  - **Bipolar Disorder**
  - **Depression**
  - **Ischemic Heart Disease**
  - **Migraine**
  - **Multiple Sclerosis**
  - **Musculoskeletal Conditions (Osteoporosis, Osteoarthritis, Rheumatoid Arthritis, Chronic Widespread Pain, Low Back Pain)**
  - **Parkinson Disease**
  - **Stroke**
  - **Traumatic Brain Injury**

MHADIE Survey: Materials & Methods

- Common and specific research tools and indicators were used in the survey. The **common MHADIE protocol** is composed of:
  - Demographic information
    - nationality, gender, age, marital status, educational level, current job…
    - risk factors (smoke and alcohol consumption)
  - Functional outcomes and profiles
    - The ICF Checklist
    - The WHO Disability Assessment Schedule (WHODAS II)
    - The Health System Responsiveness and Satisfaction with Health Care (HSR&S) scale
    - Short Form 36 (SF-36)
    - The WHO Quality of Life Questionnaire (WHOQoL)

MHADIE Survey: data analysis

1. Baseline samples description

2. Cross-sectional analysis

   • Evaluation of the applicability of the ICF-based instruments

   • Evaluation of the cross-sectional reliability and validity of the ICF-based instruments (structural and construct validity)

   • Testing validity of known groups

   • Testing validity of the WHODAS II regarding WHOQoL-8 items

   • Validity of the ICF model

   • Reliability

3. Longitudinal analysis

MHADIE Survey: data analysis

4. ICF as a descriptive tool in clinical settings

- Analysis of quality of data
- Analysis on the descriptive power of ICF items
- Analysis of metric properties of ICF counts

5. Analysis on the utility of the ICF in health information systems

- Profiling cases using counts of functions, A&P and environmental codes counts

MHADIE Survey: results

1119 patients (mean age 52.8) have been included in the study:

    – 294 with different musculoskeletal conditions **MUSK**

    – 200 with stroke **STR**

    – 102 with migraine **MIG**

    – 100 of with ischemic heart disease **IHD**

    – 100 with multiple sclerosis **MS**

    – 100 with traumatic brain injury **TBI**

    – 92 with bipolar disorders **BIP**

    – 78 with Parkinson Disease **PD**

    – 53 with depression **DEP**

- 43.6% of the patients were male.

- 63.1% of them were married or cohabiting

- 52% completed high school or academic studies

- 56.7% had not a remunerative employment

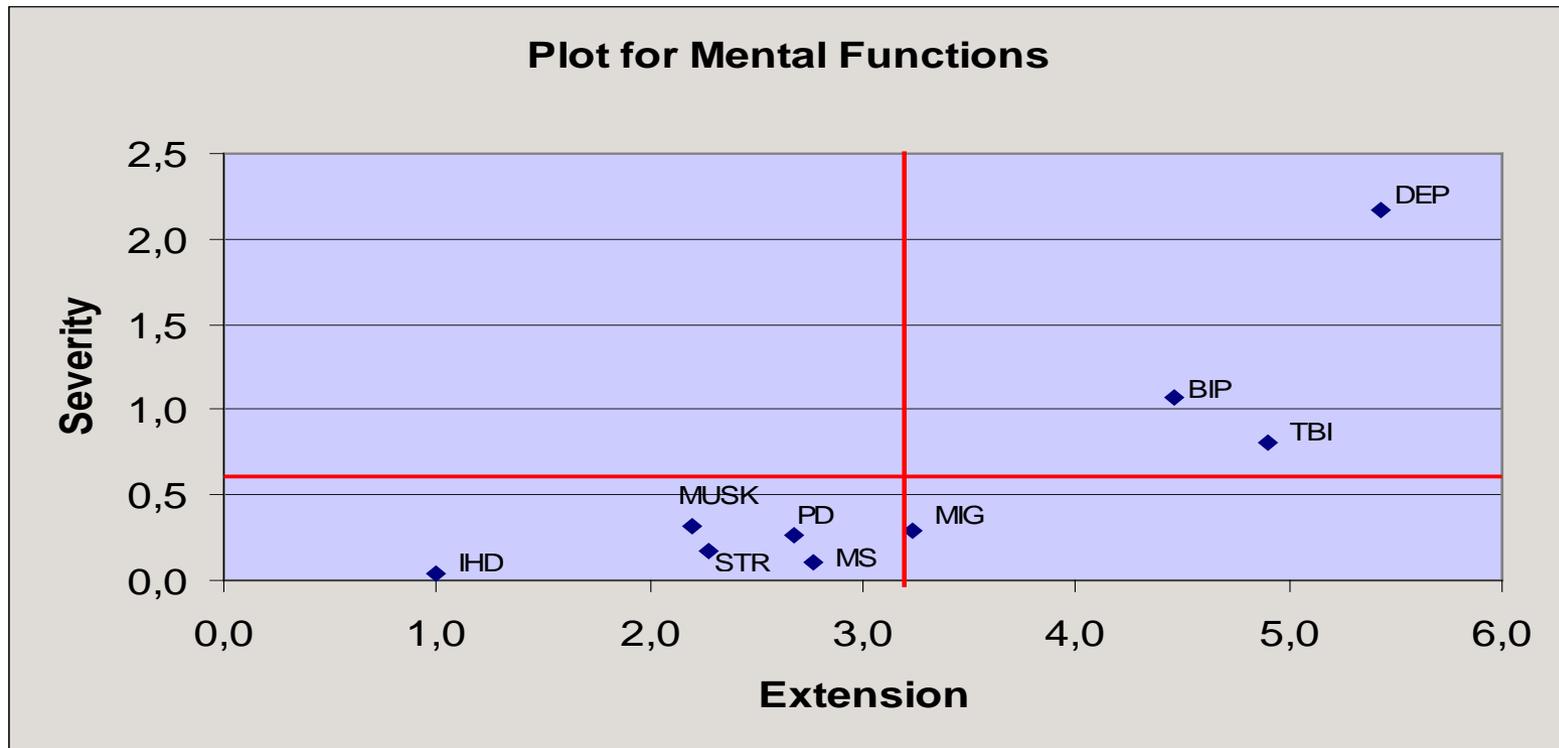# MHADIE results: Impairments in BF

BF problem: T1
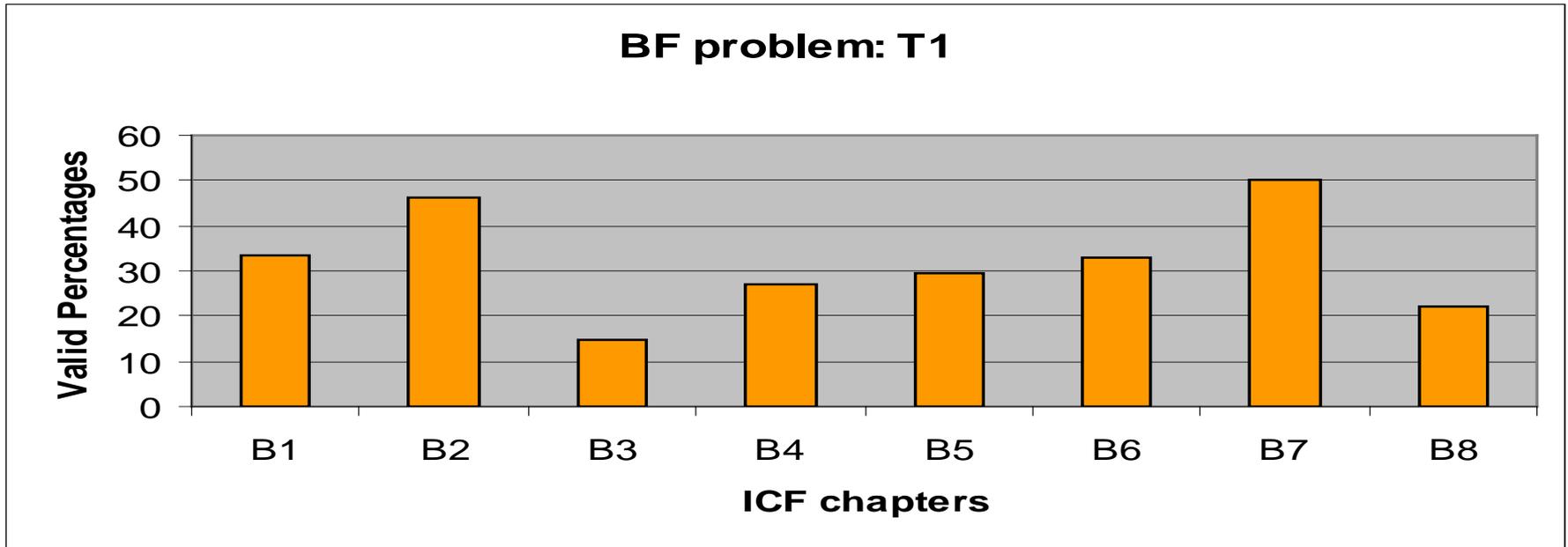
Percentage of persons in which an impairment in Body Functions has been observed. The most impaired domains are

B1 – Mental Functions,

**B2 – Sensory Functions and Pain,**

B7 – Muscoloskeletal Functions.

MHADIE results: ICF B1 Mental functions

Plot for Mental Functions

This plot shows the association between the mean number of -**categories opened with qualifiers 1 to 4 (extension)** -and those opened with qualifiers 3 or 4 (**severity**). **The red line represents the mean values for the whole sample.**

In B1 (Mental Functions) domain, it is possible to observe that Psychiatric disorders report the widest number and severity of impairments.

MHADIE results extension and severity for ICF domain B2 (Sensory functions and pain)


Plot for Sensory functions
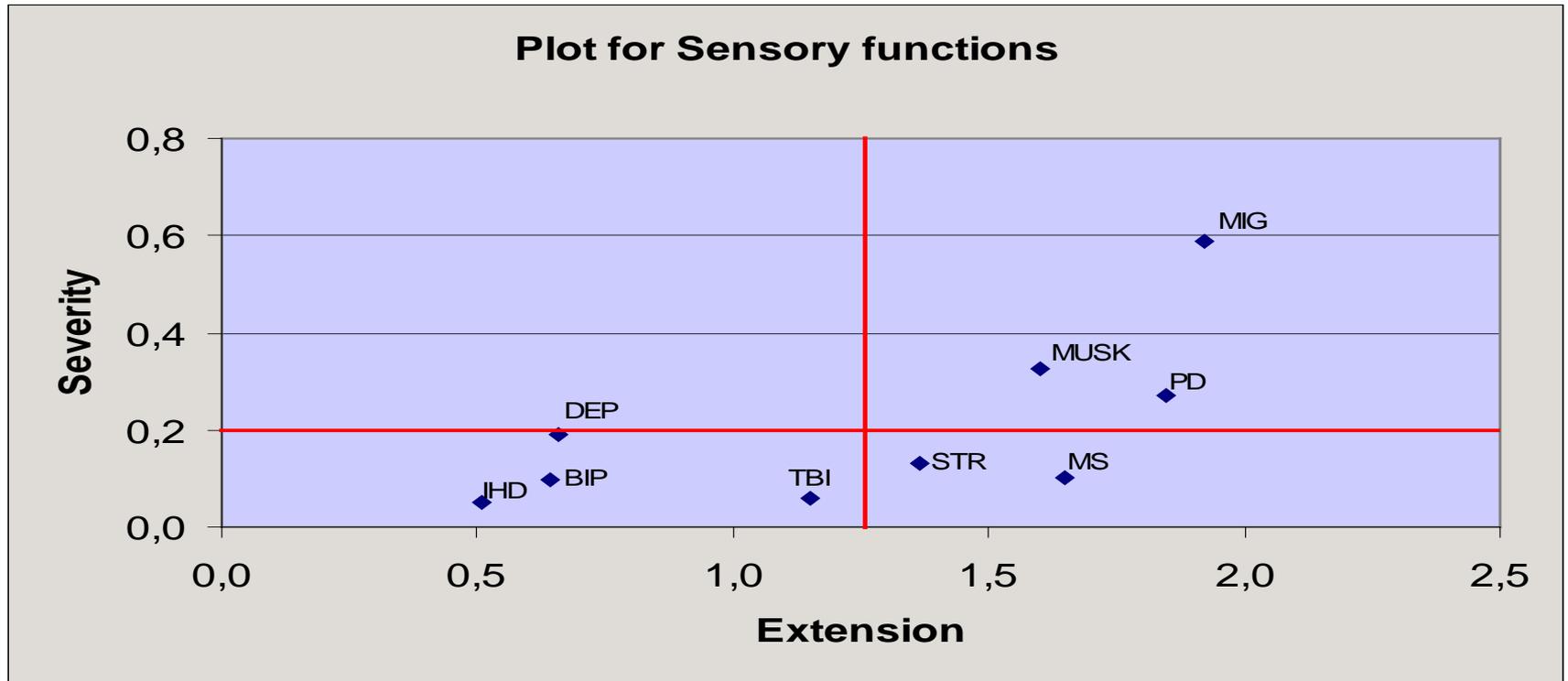
Migraine, Musculoskeletal Diseases and Parkinson Disease are the health conditions in which pain and sensory impairments are very relevant symptoms.

MHADIE results: ICF B7
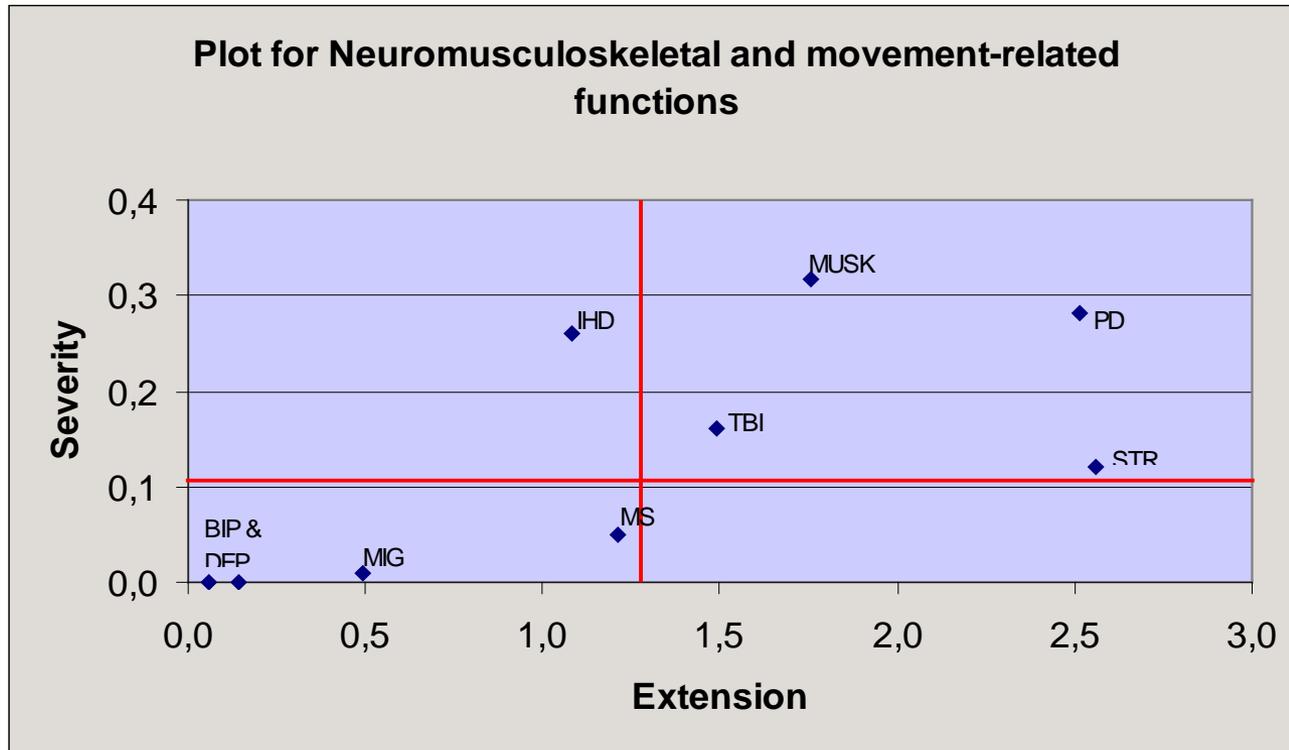
The plot for ICF- B7 (Neuro-musculoskeletal and movement-related functions) clearly reflects symptoms differences between health conditions such as Musculoskeletal Diseases, Parkinson Disease, Traumatic Brain Injury and Stroke, in comparison to the other diseases in which movement functions are not affected.

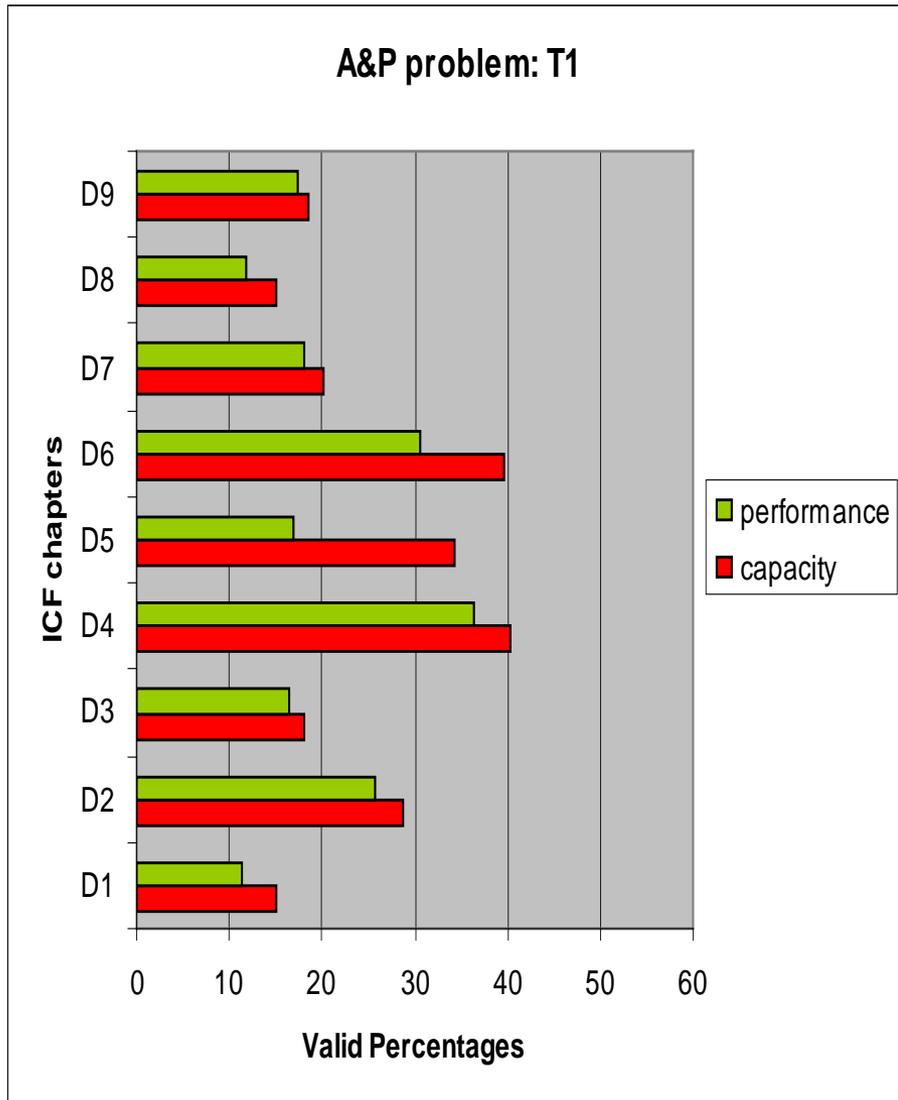# MHADIE results: Body Structures
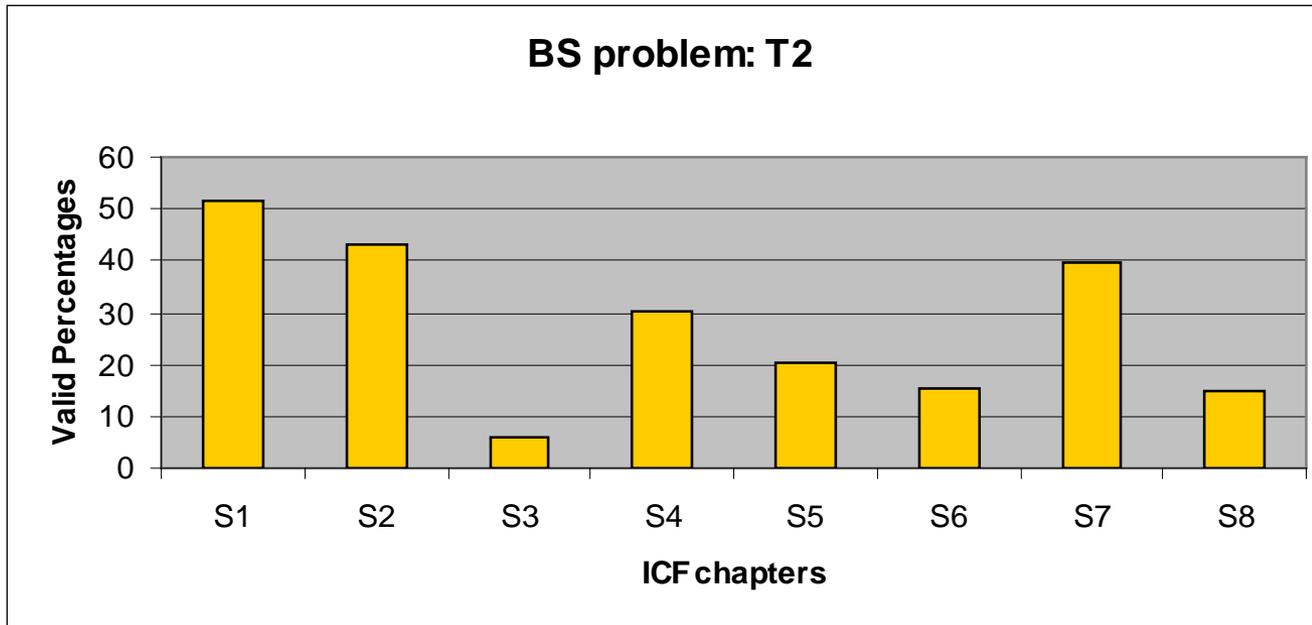
This histogram reports the percentage of persons in which an impairment in Body Structures has been observed. The most impaired areas are

S1 – Structures of the nervous system,

S2 – The eye, ear and related structures,

S7 – Structures related to movement.

MHADIE – Capacity and Performance in AP

A&P problem: T1

ICF chapters: D1, D2, D3, D4, D5, D6, D7, D8, D9

Valid Percentages: 0, 10, 20, 30, 40, 50, 60

Legend: performance, capacity

Percentage of persons in which limitations and restrictions in the domains of Activities and Participation are observed. In each domain, **performance is observed improved respect to capacity,** likely due to the intervention of environmental factors.

The areas in which widest limitations are observed are **D4 – Mobility,   D5 – Self care, D6 – Domestic Life.**

MHADIE results ICF D5 self care C and P

Plot for D5-self care Capacity

Plot for D5-self care Performance
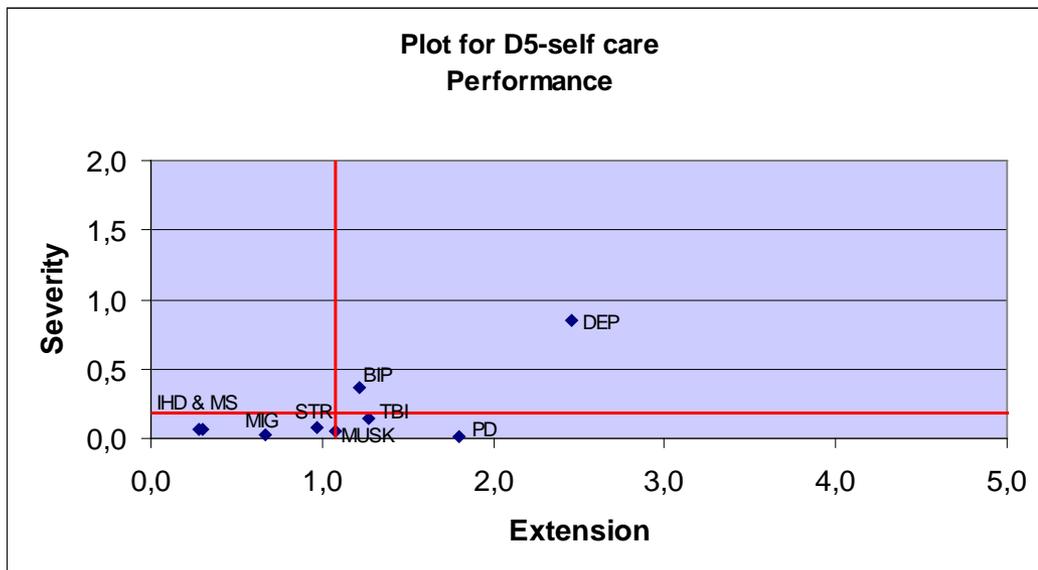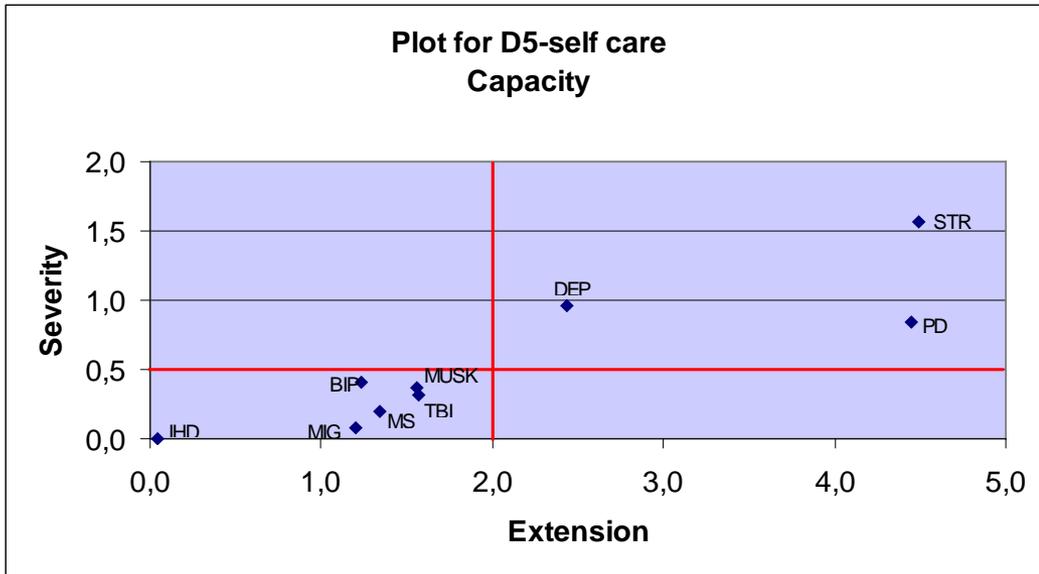
Improvements are observed for Stroke and Parkinson Disease; patients with psychiatric condition report similar levels of difficulty, and for the remaining conditions a non problematic situation is observed.

In D5 activities(self care), it is predominant the supporting role of other persons (Domain E3 of environmental factors) and of assistive devices (Domain E1 of environmental factors).

MHADIE results: ICF Environemntal Factors

EF T1

ICF chapters

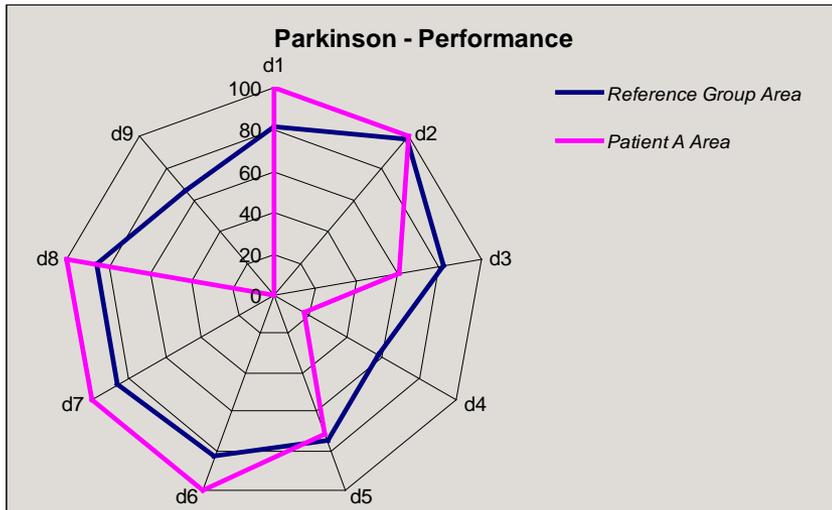- facilitator
- no effect
- barrier

Valid Percentages
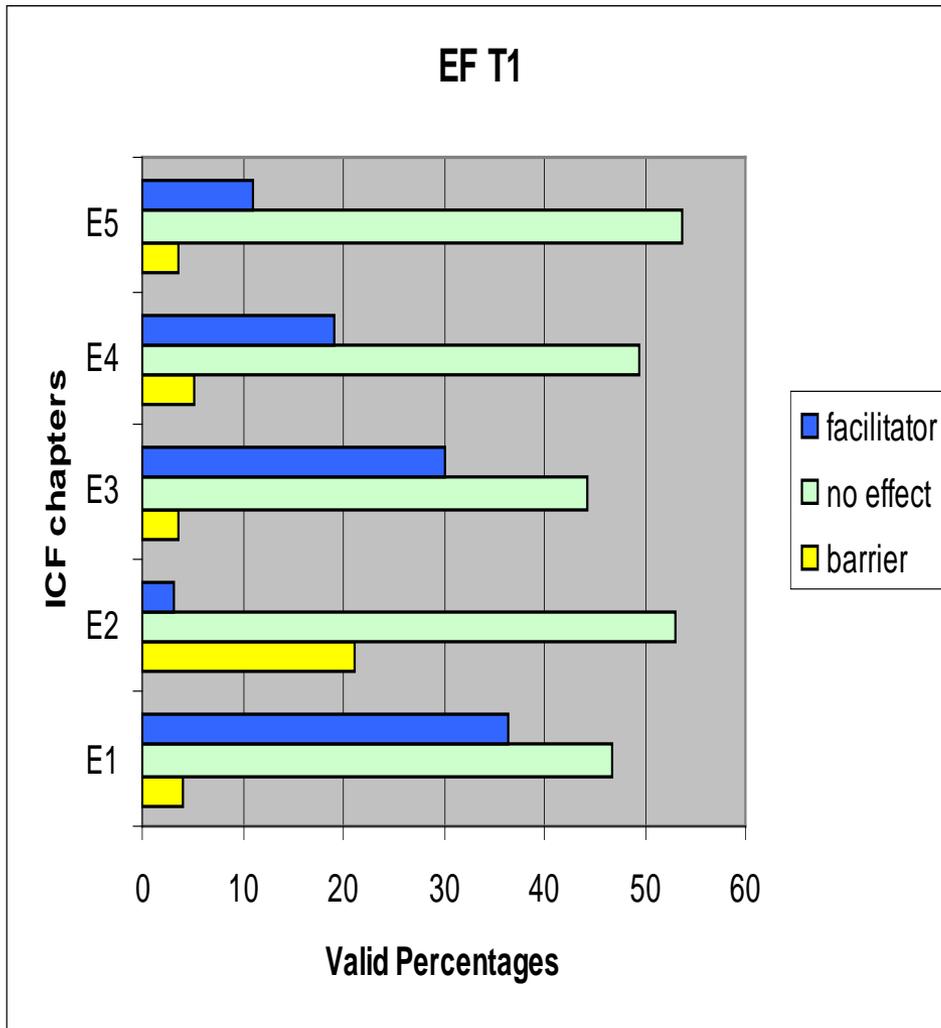
Percentage of persons in which environmental factors were observed as facilitators, as barriers or as having no effect.

For each area, most of the EF are reported as having no effect.

Facilitators are observed in particular in E1 – Products and technology and in E3 – Support and relationships.

Barriers were mainly observed in E2 – Natural environment and human-made changes to environment

MHADIE results ICF to map single cases

Parkinson - Performance

Reference Group Area
Patient A Area

Parkinson - Performance

Reference Group Area
Patient B Area

A very useful function, for implementing ICF in information systems, is the possibility that extension and severity of functioning limitation can be used to map single cases with respect to the average group values in order to evaluate the specific profile of cases.
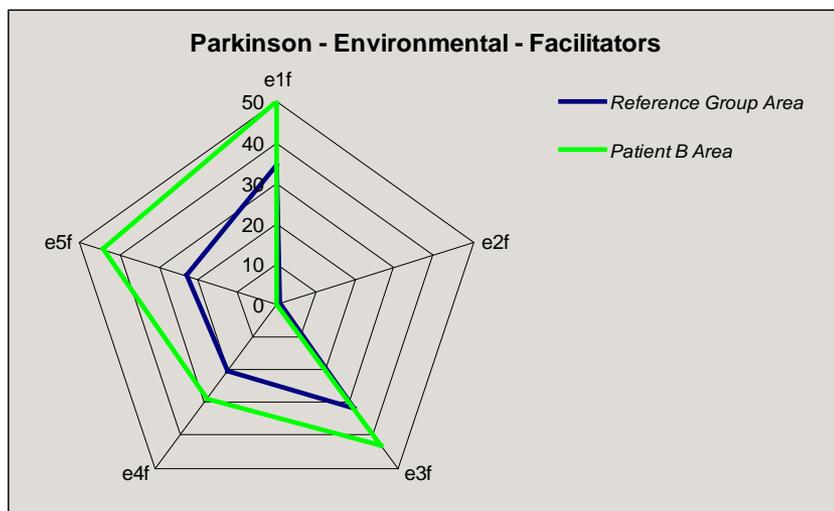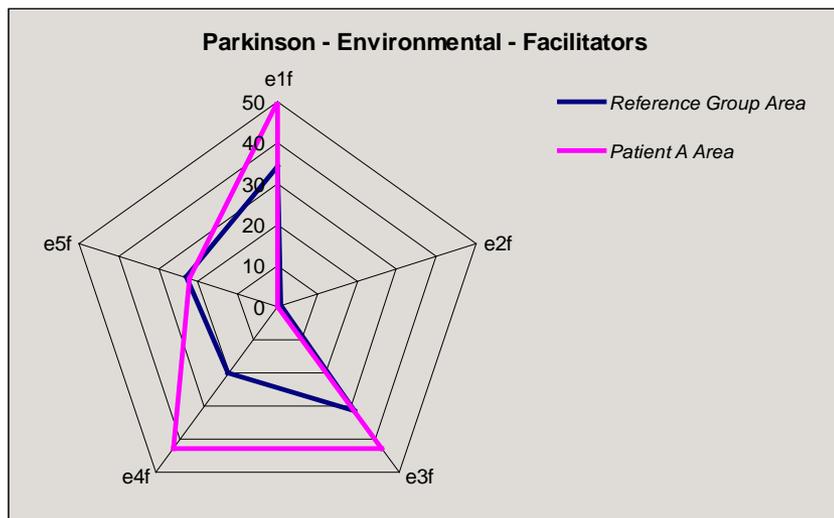
The value 100 represents a complete absence of limitation or restriction in A&P domains.

It is therefore possible to observe individual differences between patients and in comparison with the reference area.
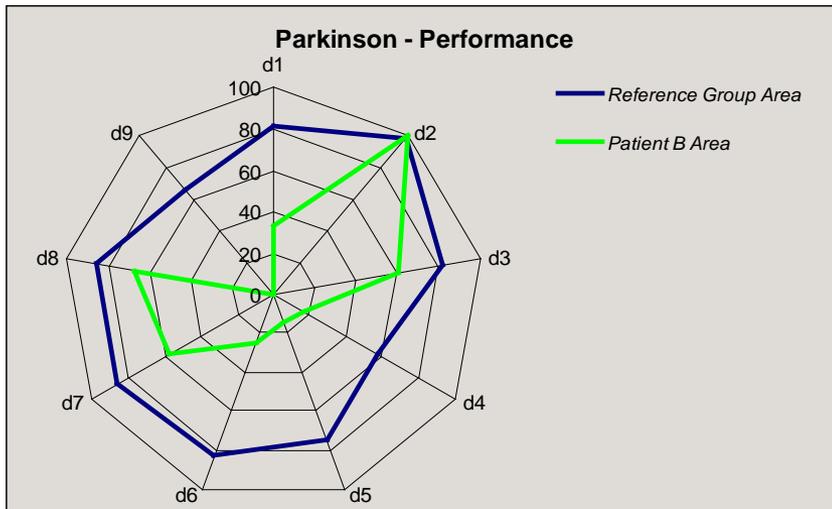
The first patient with PD reports few limitation, less than the reference area, while the second is a patient that experiences several limitations and restrictions.

MHADIE Survey: results

Parkinson - Environmental - Facilitators

The same procedure of normalization can be used for environmental factors: in this case the value 100 represents a complete presence of facilitators.

The comparison between the two patients and with the reference area indicates here that EF are much more present in the contexts of these persons than what is observed for the average of PD sample. In the first patient, that has less limitations, a lower facilitating effect of E5 domain (Services, Systems and Policies) is observed, while in the second patient, that has a worse functional profile, the facilitating effects of Services, Systems and Policies (e.g. social, health, transportation) are more present: it is possible to suppose that this person cannot rely on family members only

MHADIE Survey: Conclusions

ICF-based datasets analyzed in MHADIE project survey demonstrate the utility of the ICF and its related tools in describing functioning, health and disability across a variety of settings, clinical conditions and countries.

ICF can be graphically represented to compare clinical samples for different variables: health condition, clinical setting, age group or country.

The correlations between ICF data and selected clinical variables demonstrates that ICF provides a common base of data for distinguishing functional patterns among different conditions, but also gives the possibility of drawing functional profiles besides the health condition.

# MHADIE Survey: Conclusion

ICF and its related tools' metrical properties have been demonstrated also:

- through RHO correlations, that were sensitive in distinguishing clinical condition;

- through factor analysis to create ICF performance and capacity global scores;

- within each health condition, through one way ANOVA for different severity groups.

WORKPACKAGE 2
"PROJECT PREPARATION ACTIVITIES"

- TASK 2.1 Securing sources of health and education data
  - Systematic review of the state of the art of measurement of impairment has been performed
  - Microdata of the "reccomended " survey has been made available

- TASK 2.2 Data analysis preparation
  - Analysis has been performed on how these sources of data can be adjusted to reflect or be back-coded to ICF concepts
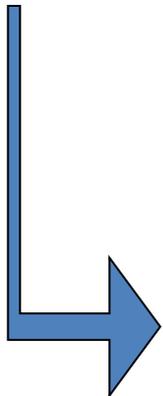
The mapping exercise and the developemtn of ICF survey mapping software

THE MHADIE ITEM DATA BANK

The Regional Health Agency (Friuli Venezia Giulia) developed an item data bank for the comparative analysis of European survey and health and disability database in the

WEB SITE http:// www.icfinitaly.it

General MHADIE recommendations:

- The underlying problem with EU disability policy is not the present of different definitions of disability, but in the failure to create 'fit for purpose' definitions in accordance with the single, underlying conception of disability provided by the ICF.

- Transportation policy has been shown to be a key factor in participation rates of persons with disabilities, so this policy should be reviewed in light of the transportation requirements of persons with disabilities.

- The family, in our non istitutionalized sample, has been shown to be a substantial facilitator in the lives of persons with disabilities, so disability policy should be reviewed to emphasize and support the role of the family.

General MHADIE recommendations:

- MHADIE project and its results is one has been selected by EU as the instruments to " Increase EU Capacity of Analysis"(Disability Action Plan 2006-2007).

- MHADIE results respond, betweeen others, to UN Convention obligation of art 31 " collect appropriate information.. to enable to formulate and implement policies to give effect to the Convention"

MHADIE

**Measuring Health and Disability in Europe:
Supporting Policy Development**

Policy Recommendations
Draft for Comments

M H A D I E
Measuring Health And Disability In Europe

Partners

Italian Neurological Institute C. Besta IRCCS Foundation (I)
World Health Organization (CH)
European Federation of Neurological Associations (B)
Malardalen University (S)
Zurich University of Applied Sciences, School of Education (CH)
Reg. Autonoma Friuli Venezia Giulia, Agenzia Reg. Sanità (I)
Institut Municipal d'Investigació Médica (E)
Regione Lombardia (I)

National Authority for the Persons with Handicap (RO)
National Disability Authority (IRL)
Universidad Autonoma de Madrid (E)
Ludwig-Maximilians-University Munich (D)
Charles University (CZ)
University Hospital of Hamburg (D)
Institute for Rehabilitation, Republic of Slovenia (SI)
CF consulting Finanziamenti Unione Europea s.r.l. (I)

Subcontractors

Disability Italian Network (I)   Don C. Gnocchi IRCCS Foundation (I)

For further information
www.mhadie.it

MHADIE EUROPEAN CONFERENCE

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