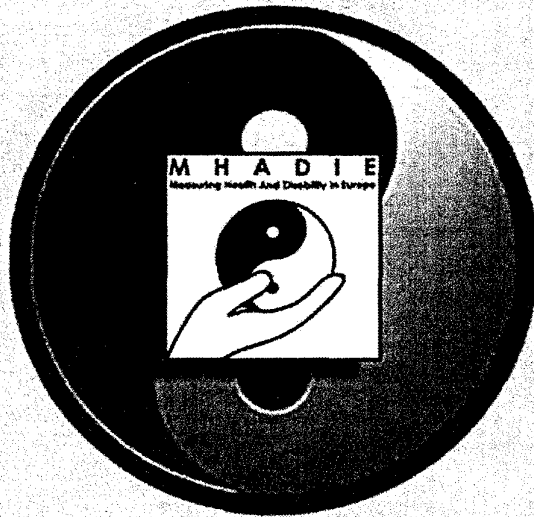


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**M H A D I E**  
**Measuring Health And Disability In Europe**  
**Supporting Policy Development**  
**A European Coordination Action for Policy Support**

**Partners:**

Istituto Nazionale Neurologico "Carlo Besta" (I)	National Authority for the Persons with Handicap (RO)
World Health Organisation (CH)	National Disability Authority (IRL)
European Federation of Neurological Associations (B)	Universidad Autonoma de Madrid (E)
Mälardalen University (S)	Ludwig-Maximilians-University Munich (D)
Zurich University of Applied Sciences, School of Education (CH)	Charles University (CZ)
Regione Autonoma Friuli Venezia Giulia-Agenzia Reg. Sanità (I)	University Hospital of Hamburg (D)
Institut Municipal d'Investigacio Medica (E)	Institute for Rehabilitation, Republic of Slovenia (SI)
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[www.mhadie.it](http://www.mhadie.it)



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*"Definition of Disability" : the contribution of EU-MHADIE Project to the international debate* 1  
Leonardi M. on behalf of MHADIE consortium

**Definition of Disability**  
**The Contribution of EU MHADIE project to the international debate**  
**Measuring Health and Disability in Europe: supporting policy**  
**development (MHADIE).**

**Matilde Leonardi on behalf of the MHADIE consortium<sup>1\*</sup>**

**Introduction: The MHADIE Project**

The European Commission has launched a multi-country coordination action in the Frame of Research Supporting Policy area. The project is called **Measuring Health and Disability in Europe: supporting policy development (MHADIE -- [www.mhadie.it](http://www.mhadie.it))**. Led by Dr. Matilde Leonardi of the Istituto Nazionale Neurologico "Carlo Besta" in Milan, Italy, it involves experts from the Czech Republic, Germany, Ireland, Italy, Romania, Switzerland, Slovenia, Spain and Sweden as well as the World Health Organization and NGOs such as the European Federation of Neurological Associations, EDF and Disabled Persons International.

The MHADIE project focuses on a set of basic questions: *What is disability? Who are people with disability? How many people with disabilities are there in society? How do we assess the health needs of people?* Answers to these questions are essential in order to develop coherent and effective health and social policy for people with disabilities. Valid and reliable information about health and disability is essential to the design, implementation and evaluation of policies and legislation to combat discrimination and promote social integration, participation and enhance opportunities. This is well known, yet, astonishingly, there is no uniform conception of disability that policy makers in different countries – or even within the same country – can use to plan health and social policy.

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Despite the health and disability data gathering efforts of OECD, UNSTAT and EUROSTAT, among other international agencies, prevalence rates of disability across countries and regions of the world are markedly different primarily because of a lack of a common framework and methodology for defining disability. This is one reason why the UN Statistical Office reports that there is a 60-fold difference in the disability prevalence rates among its reporting countries and why a study commissioned by the EC and carried out by researchers at the Brunel University reports that, in Europe, data about disability are substantially different in each of the 15 countries evaluated. This result makes it clear that the underlying model of disability used in these countries lacks comparability.

At the centre of the MHADIE project is a revolutionary new conception of human functioning and disability that is contained in the World Health Organization's international language of health and disability, called **The International Classification of Functioning, Disability and Health (ICF)**.

The ICF provides the framework for documenting the interaction between a person's health status and his or her physical, social and attitudinal environment, thereby giving a portrait of the complete lived experience of disability that can augment diagnostic information about the person's health status. The product of decades of research, refinement, and testing in an international collaborative effort, ICF provides a scientifically valid and reliable model for structuring health and disability information.

At the heart of the ICF's conception of disability – and the reason why it has profound implications for European health and disability policy – is a major paradigm shift in our understanding of disability, a shift captured by two propositions:

- 1) **disability is a universal human phenomenon**, not the mark of a discrete social minority, and as such is a factor in all social policy; and
- 2) **disability is the outcome of an interaction** between the person's health condition, personal factors and features of the person's physical, social, and attitudinal environment.

Together, these features of the ICF conception of disability point the direction towards a realistic achievement of the **political aspirations of persons with disability to integration and full participation in all areas of life**.

In its "Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions: Situation of the disabled people in the enlarged European Union. The European Action Plan 2006-2007", the Commission has identified and proposed four priority actions: 1. Encouraging activity; 2. Promoting access to quality support, care and health services, 3. Fostering accessibility of goods and services, and 4. Increasing the EU capacity of analysis. MHADIE project is one of the instruments selected by the Commission to reach the fourth objective by 2007.

The EU MHADIE project will put Europe in the forefront of international efforts to implement the ICF in ways that capitalize on the inherent strengths of the ICF. Specifically, the MHADIE project will use the ICF model of disability to analyse and evaluate existing sources of European disability data, in order to demonstrate the adequacy of the ICF for measuring patterns of disability in clinical, rehabilitation and education contexts.

With this substantial evidence base, the MHADIE project will then be in a position to develop predictors of disability, and in particular, to identify those environmental barriers – whether physical, human-built, attitudinal, or social – that stand in the way of full participation in society. In light of these results, the MHADIE project will then be in a position to make specific policy recommendations and guidelines concerning the use of ICF for effective and coherent health and social policy for persons with disabilities, and, ultimately for all Europeans.

### **MHADIE and the International Debate on the Definition of Disability**

At a recent scientific meeting of the MHADIE project, held at the Department of Rehabilitation Medicine, Charles University in Prague, a session was devoted to the issue of the Article 2 definition of ‘disability’ in the proposed United Nations International Convention on the Rights of Persons with Disabilities. At this session, a consensus resulted that was submitted to Commissioner Vladimir Spidla, EU Commissioner, Employment, Equal Opportunities and Social Affairs for consideration by the EU.

#### **1. Why a definition of ‘disability’ in the UN Convention is essential**

The issue of a definition of ‘disability’ (or ‘person with a disability’) has proven to be one of the most contentious issue facing the delegates of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities. At the last, seventh session of the Ad Hoc Commission held in New York, 16 January-3 February 2006, Chairman Don MacKay offered the following definition as a working proposal:

*“Disability” results from the interaction between persons with impairments, conditions or illnesses and the environmental and attitudinal barriers they face. Such impairments, conditions or illnesses may be permanent, temporary, intermittent or imputed, and include those that are physical, sensory, psychosocial, neurological, medical or intellectual.*

Over the course of the seven sessions very many different definitions have been proposed by country representatives, and representatives of NGOs and other participants in the discussion. The number of proposals reflects the wide range of existing legal definitions found in national and international legislation and policy.

For its part the European Union has argued that for the purposes of the UN Convention it is not necessary to define the notion of disability. Initially, the European Union argued to

postponed the issue so that a suitable definition could be devised that would “strike an effective balance between the diverse and complex nature of disability and the need to avoid overly broad wording that could be subject to misinterpretation.” When it became clearer that consensus on definition would be difficult to achieve, the European Union argued that no general or overall definition is required, and that where definitions are needed, these should be included in the relevant article where the concept is first used.

The MHADIE researchers and discussion participants came to the conclusion that the European Union position is not tenable. It is, first of all, unlikely that an international legal instrument designed to guarantee the rights of a population of individuals who have historically been denied those rights will be able to guarantee those rights without a consensus about who those individuals are. Secondly, without a general definition of disability, the international cooperation required “to improve the living conditions of persons with disabilities” (Preface to the Convention) would not be possible as there would be no agreement as to whose living conditions needed to be improved. And finally, as the primary goal of the Convention is equality of rights, opportunities and participation in society, inequality can only be identified by comparison of a designated group with those who are already benefiting from the way society is organised. Yet, **if there is no agreement on how to identify members of the protected group, no comparison can be made, and inequality can neither be identified, measured, or remedied.**

Furthermore, since the primary intent of the Convention is to ensure inclusion within the mainstream marginalized members of society in a progressive manner, the document must accommodate the ultimate goal of universal access. Defining the population based on some pre-defined categories or not defining it at all runs the risk of exclusion of a group that in fact may turn out to be most in need or the most vulnerable.

## **2. Why allowing different national definitions is not a solution**

Another proposal was that each State Party to the Convention creates its own definition. But MHADIE participants agreed that this is equally untenable since it would defeat the Convention’s primary goal of “universality, indivisibility and interdependence of all human rights and fundamental freedoms for persons with disabilities” (*Preface*). Moreover, each State would be able to determine the extent to which it wished to fulfill the goals of the Convention by narrowing its definition to limit its responsibilities and the resources required to fulfill them. Monitoring, enforcement or comparability of State implementation of the Convention would become impossible with a multitude of definitions.

## **3. Why relying on a definition of ‘persons with disabilities’ is not a solution**

Some countries, the Czech Republic among them, have suggested that Article 2 should rely, not on a definition of ‘disability’ but ‘persons with disabilities’. It was noted during the discussion that this is hardly a solution since it is impossible to define ‘person with disabilities’ without having some notion of what a disability is (how else would a person with disabilities be distinguished from a person without disabilities). Suggesting that the

definition should be based on those who self-identify as a disabled person would be futile, since any legal enforcement mechanism would inevitably require more than just self-identification, with the result that the onus would be on persons with disabilities to provide evidence that they are disabled, which, in the absence of a definition in the Convention, would merely reopen the controversy. Also, this would place an unfair burden on the person as there would be no benchmark against which to compare whether a person did or did not meet criteria, which could lead to arbitrary exclusions.

#### **4. Principles Governing the Definition of Disability in the UN Convention**

While consensus on a general definition of disability has proven difficult, there has been from the outset agreement on the principles governing the choice of a definition:

- A. The definition must accord with, and facilitate the achievement of the goals of the Convention: full and effective participation and inclusion in society, removal of barriers, and full enjoyment of human rights and freedoms.
- B. It must be consistent with the Convention's adherence to the "universality, indivisibility and interdependence of all human rights and fundamental freedoms."
- C. It must facilitate international cooperation in achieving the goals of the Convention.
- D. It must be consistent with the Convention's guarantees of both anti-discrimination and direct action.
- E. It must be applicable to the full range and diversity of disability experience.
- F. It must incorporate the dynamics of interaction between attributes of the person and the person's complete environmental context.
- G. It must acknowledge that a person's environment may either hinder or facilitate full participation of a person with a disability.
- H. It must be consistent with instruments already agreed upon by State Parties in other contexts.

#### **5. MHADIE proposal: An ICF definition**

It was observed by MHADIE partners during the discussion that it is important to distinguish the task of creating a general definition of 'disability' for the purposes of Article 2 of the Convention – a definition that creates the overall conceptual framework for the scope and application of the Convention – and the task of devising purpose-specific definitions in order to identify the beneficiaries of the different rights and freedoms found in the Convention. An overall definition must be maximally inclusive

and conceptually valid. It should not be identified by diagnostic categories specific kinds of disabilities, as that would inevitably lead to disputes about those persons with disabilities who are not included in the specific diagnostic categories.

Moreover, while the general Article 2 definition must satisfy the principles set out above, a purpose-specific definition (designed for the provision of employment accommodation, access to education, health and rehabilitation services and other such specific areas mentioned in the Convention) should be relevant to the purposes of those provisions.

The MHADIE participants came to the conclusion that the ICF Classification provides the most inclusive, universalistic, and conceptually valid characterization of disability that satisfies all of the principles governing a general definition for the Convention.

The group proposed the following ICF definition of disability:

***Disability is a decrement in functioning at the body, individual or societal level that arises when an individual with a health condition encounters barriers in the environment.***

It can be observed that this definition shares several features of the Chairman's MacKay's proposed definition, given above. There are, however, several reasons for thinking that the ICF definition of disability is superior, as indeed has already been observed by the major disability NGO Disability Persons International. During the discussion, participants made provided the following reasons in favour of the ICF definition:

- The ICF definition is suitably universal and general for the purposes of the UN Convention. It does not refer explicitly to diagnostic or impairment groups ('the blind'), or to a priori severity threshold so, unlike many other proposals, is inclusive and general in application.
- The ICF, as a member of the World Health Organization's Family of International Classifications (FIC) and the UN International Family of Economic and Social Classifications, upon which the suggested definition is based has already been endorsed unanimously by 191 countries as the basis for health and disability statistics and as the conceptual framework for health and disability generally.
- The ICF definition clearly expresses the essential structure of the concept of disability as a result of an interaction between features of an individual with a health condition and features of the physical, social or attitudinal environment.
- The ICF definition clearly identifies the three dimensions of disability (body, individual and societal levels), to increase inclusiveness and to be applicable to the full range and diversity of disability experience. At the same time, it further ensures inclusiveness and the complete coverage of all relevant disability rights

issues, by defining disability as to apply to a person with an impairment alone, or an activity limitation alone, or a participation restriction alone.

- The ICF definition, by identifying the societal level of disability (the ICF dimension of Participation) is fully aligned with the Convention's goals of "full and effective participation and inclusion in society, removal of barriers, and full enjoyment of human rights and freedoms." (Furthermore, by means of the ICF's classification of Activities and Participation, this definition of disability is tied to an exhaustive taxonomy of components of societal participation, thereby encompassing the content of the specific Articles of the Convention.)
- By incorporating the dimension of participation, the ICF definition is suitable, not only for the anti-discrimination applications of the Convention, but also for direct action applications (in particular the removal of environmental barriers to full participation and social inclusion).
- As the UN Convention is intended to be a document that seeks to ensure progressive realisation of rights that will lead to an ever-increasing response to the rights of persons with disabilities, the definition of 'disability' must not be restricted to specific, severe or high-need groups, but be flexible so that as resources become available, the threshold of disability can be adjusted so that more and more individuals can benefit from these resources. Only the ICF definition is consistent with this flexibility, since the ICF categories of disability are continuous and scaleable, rather than a priori and rigid.
- The ICF definition makes explicit reference to environmental barriers and the role they play in the creation of disability, especially at the societal levels. Moreover, instead of vague references to the environment, the ICF dimension links to the Environmental Factors classification of the ICF which provides the basis for an evidence-based approach to collecting data about how, precisely, factors in a person's environment restrict participation.
- More generally, since the ICF definition is linked to the ICF itself, the definition integrates into the UN Convention, not merely a conceptual model of disability, but a scientific tool for classifying all dimensions of disability using a common language, which is a precondition for scientific assessment and measurement of disability. This provides the scientific framework for collecting and analysing evidence for monitoring the effective implementation of the Convention at the level of member states.
- The ICF definition fully embodies the Convention's commitment to "the universality, indivisibility and interdependence" of human rights and fundamental freedoms for all persons. Finally, the ICF definition provides the basis from which other, more purpose-specific definitions of disability can be derived, to be used in specific contexts – such as employment, education, and communication – to meet the needs of the other Articles of the Convention (while still providing an

overarching, and coordinating, definition of the scope and coverage of the convention).

### **Implications of the proposed definition**

The experts involved in the MHADIE project anticipate that the consequences of embedding the ICF Definition in the UN Declaration will be:

- a consistent and coherent approach to disability that is non-exclusionary;
- a uniform concept of human rights and anti-discrimination policy around the globe as it applies to disability;
- a universalistic disability policy as it applies to social services, health and rehabilitation services, transportation, communication and housing services;
- a coherent employment and education policy that benefits persons with disabilities; and
- an approach that is consistent with the progressive realization of rights depending on resources and developments.

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***Further information and documentation available at: [www.mhadie.it](http://www.mhadie.it)***