

International Classification of Functioning, Disability and Health: Application and Relevance to Chronic Fatigue Syndrome



Rosaly Correa-de-Araujo, MD, MSc, PhD
Deputy Director, Office on Disability
HHS Chronic Fatigue Syndrome Committee Meeting

Washington, D.C., November 8-9, 2011

ICF

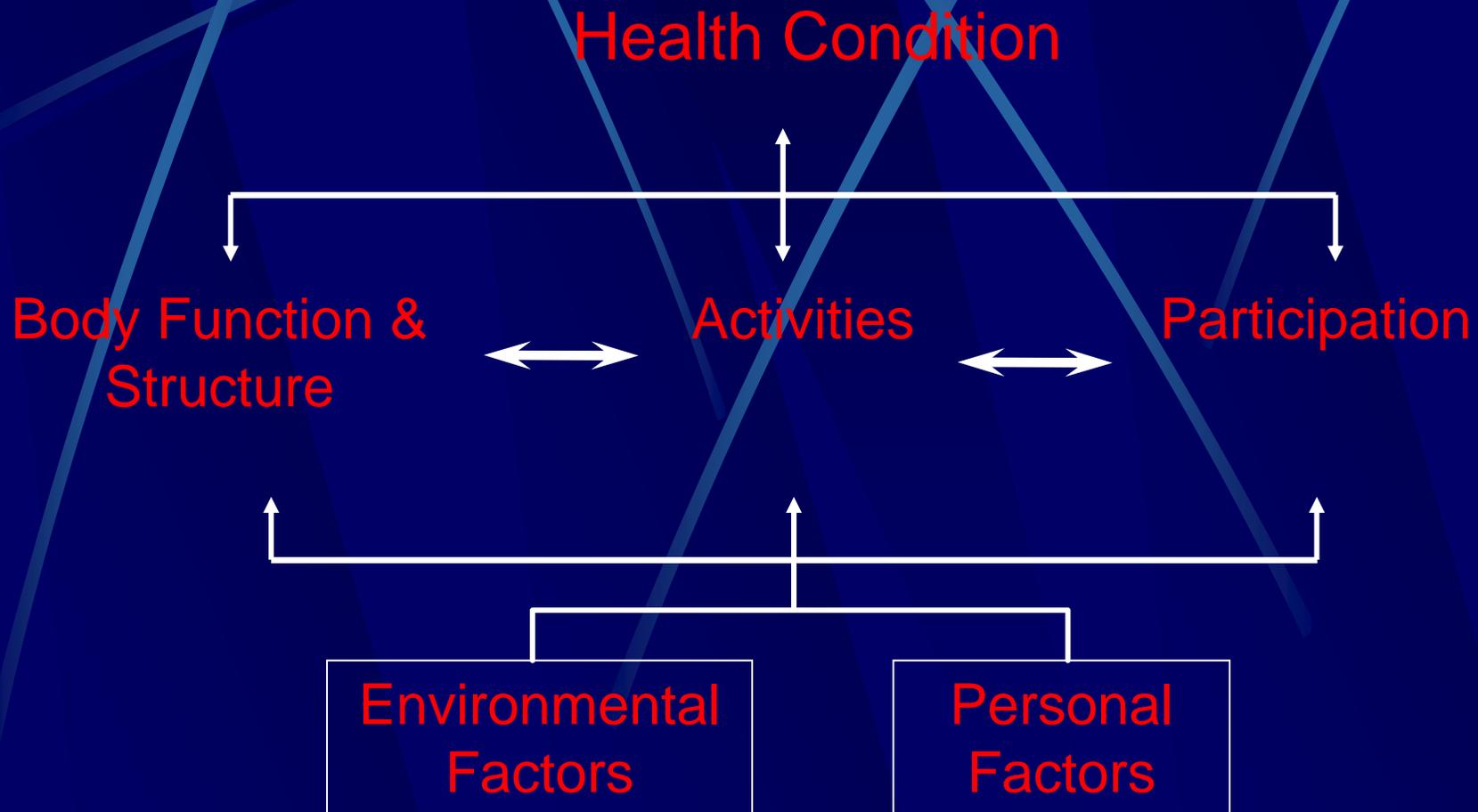
International
Classification of
Functioning,
Disability
and
Health



World Health Organization
Geneva

**WHO - World Health
Organization, 2001**

International Classification of Functioning, Disability, and Health Concepts



Sample Case - International Classification of Disease (ICD-9 Code)

Ms. Harris

- 52 year old female with history of MS with relapsing remitting course
- ADL dependent

Ms. Brown

- 52 year old female with history of MS with relapsing remitting course
- ADL dependent

ICD-9

340 – Multiple sclerosis

Sample Case

Ms. Harris

- Faculty member working over 40 hours per week
- Single mother of a 16-year old daughter
- Helping her daughter in search for college
- Needs help with dressing
- Power wheelchair and adapted equipment user

Ms. Brown

- Early disease onset/ diagnosis, stopped working
- Mother of a child living with family members
- Under institutional 24 hour care
- Unable to speak or eat

Sample Case

Ms. Harris

- Dependent for dressing. d540.44
- Independent moving around the community, uses a power chair; but unable to move around without the chair d460.14
- Job with tenure, reasonable accommodations d845.0
- Parenting, successful d7600.0

Ms. Brown

- Dependent for dressing. d540.44
- Totally dependent for mobility and moving around d460.44
Unable to work d845.4
- Unable to parent d7600.4

Using ICF

ICF Structure



Classification

Parts

Domains

Categories at increasing levels of detail



Part I - Functioning & Disability

Body Functions & Body Structures

- *Body Functions* - physiological and psychological functions
- *Body Structures* - anatomy
- *Impairments* - problems in functions and/or structures

Chapters:

Body Functions & Structures

1. Mental functions	1. Structures of the nervous system
2. Sensory functions and pain	2. The eye, ear and related structures
3. Voice and speech functions	3. Structures involved in voice and speech
4. Functions of the cardiovascular, haematological, immunological and respiratory systems	4. Structures of the cardiovascular, immunological and respiratory systems
5. Functions of the digestive, metabolic and endocrine systems	5. Structures related to the digestive, metabolic and endocrine systems
6. Genitourinary and reproductive functions	6. Structures related to the genitourinary and reproductive systems
7. Neuromusculoskeletal and movement-related functions	7. Structures related to movement
8. Functions of the skin and related structures	8. Skin and related structures

Part I - Functioning & Disability

Activities & Participation

- *Activity* - execution of a task or action
- *Limitation* - problem in executing a task, action, or activity
- *Participation* - involvement in life activities
- *Restriction* - problem in participating

Chapters: Activities & Participation

1. Learning & Applying Knowledge
2. General Tasks and Demands
3. Communication
4. Movement
5. Self Care
6. Domestic Life Areas
7. Interpersonal Interactions
8. Major Life Areas
9. Community, Social & Civic Life

Part II - Contextual Factors

Environmental Factors

- *Environmental Factors*
 - perspective of the person whose situation is being described
 - can serve as *Facilitators* or *Barriers*

Chapters: Environmental Factors

1. Products and technology
2. Natural environment and human-made changes to the environment
3. Support and relationships
4. Attitudes
5. Services, systems and policies

Qualifiers

Body Functions (b codes)

- Magnitude of impairment

Body Structures (s codes)

- Magnitude of impairment
- Nature of change
- Localization

Activities and Participation (d codes)

- Performance in current environment
- Capacity without assistance
- Capacity with assistance
- Performance without assistance

Environmental Factors (e codes)

- Facilitator or barrier

Qualifier Severity Scale

- 0 NO problem (none, absent, negligible,...)
- 1 MILD problem (slight, low,...)
- 2 MODERATE problem (medium, fair,...)
- 3 SEVERE problem (high, extreme, ...)
- 4 COMPLETE problem (total,...)
- 8 not specified
- 9 not applicable

Body Functions Qualifier

Body Function

Item code: Fluency of speech

Qualifier Code (Severity):

3, severe

b 3 3 0 0 . 3

Person presenting with a communication problem.

Activities and Participation Qualifiers

d 4 5 0 2 . 2 1 8 9



Item code: Walking on different surfaces

Qualifier 1 Current performance: moderate

Qualifier 2 Capacity without assistance: mild

Qualifier 3 Capacity with assistance: not specified

Qualifier 4 Performance without assistance: not applicable

Person with balance difficulties.

Sample Case: Functional Status & Environment

Ms. Smith

- 16 year old Deaf white female, using hearing aids
- High school student living with her family

Ms. Cohen

- 16 year old Deaf white female, using hearing aids
- High school student living with her family

Sample Case: Functional Status & Environment

- American Sign Language d320.0
- Reading - 9th grade level d166.0
- Several Deaf and hearing friends d7500.0
- Clear communication d315.0
- Social participation , started her own Deaf group d920.0 and d910.0
- Difficulty in finding a job d845.3994
- Dating, potential abuse d7700.2884

Ms. Smith

- No American Sign Language d320.3324
- Reading - 4th grade level d166.2328
- Few friends, not particularly close friendships d7500.2998
- No expressed communication preferences d315.2218
- Goes home, spends most of her time by herself d920.3889 and d910.2889
- Works at her family's business d845.0
- Dating invitation d7700.0

Ms. Cohen

Sample Case: Functional Status & Environment

- Deaf family members, ASL familiar to family members, native signers. e310+4
 - Social connection with deaf & hearing cultures e425+2
 - Interpreters are easily available in community e535+2
 - Suburb area with opportunities to engage in Deaf culture e215+3
- No hearing deficit in family, no ASL e310.3
 - Limited social connection with deaf culture e425.3
 - Interpreters not easily available in community e535.4
 - Rural area with no opportunities to engage in a Deaf community e215.2

Ms. Smith

Ms. Cohen

Uses of ICF: System Level

- Needs assessment
- Intervention planning
- Outcome assessment
- Utilization patterns
- Comparison of different interventions
- Consumer satisfaction
- Service performance
 - outcomes
 - cost-effectiveness
- Resource allocation
- Electronic records
- Clinical terminology

The Washington Group on Disability Statistics

- Formed in 2001 – City Group
- United Nations International Seminar on Measurement of disability
- Statistical & methodological work needed to facilitate comparison of data cross-nationally

Washington Group Short Set of Questions

- Do you have difficulty seeing, even if wearing glasses?
- Do you have difficulty hearing, even if using a hearing aid?
- Do you have difficulty walking or climbing steps?
- Do you have difficulty remembering or concentrating?
- Do you have difficulty (with self-care such as) washing all over or dressing?
- Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

- A. No- no difficulty**
- B. Yes- some difficulty**
- C. Yes – a lot of difficulty**
- D. Cannot do at all**

The 2007 Institute of Medicine Report: *The Future of Disability in America*

- ICF as the tool for classifying health status among Americans with disabilities

The Future of Disability in America:

Recommendation 2.1: Disability Monitoring

“The National Center for Health Statistics, the U.S. Census Bureau, the Bureau of Labor Statistics, and other relevant government units involved in disability monitoring should adopt the *International Classification of Functioning, Disability and Health* (ICF) as their conceptual framework and should actively promote continued refinements to improve the framework’s scope and utility for disability monitoring and research. The Interagency Subcommittee on Disability Statistics of the Interagency Committee on Disability Research should coordinate the work of these agencies to develop, test, validate, and implement new measures of disability that correspond to the components of the ICF, consistent with public policy priorities.”

The Future of Disability in America:

Box 2-5: “Directions for Further Work on the ICF”

- “Clarifying or otherwise resolving the lack of operational differentiation between concepts of activity/participation.
- Explicitly incorporating quality of life in the framework of key concepts for understanding health, disability, conducting research.
- Developing classifications for personal factors affecting functioning and disability.
- Further developing the classification of environmental factors.
- Incorporating secondary health conditions as an ICF concept.
- Supplementing the ICF with a dynamic model of factors that influence the movement of individuals among states of functioning and disability.”

The 2007 Institute of Medicine Report: *The Future of Disability in America*

“Evidence continues to grow that disability is not an unavoidable consequence of injury or chronic disease but results, in part, from actions that society takes --- both in the public arena and in commerce and other private domains. This report argues that American society should take explicit responsibility for defining the future of disability in this country. *How it does so will reflect the country’s deepest values.* The record of the past 17 years offers reasons for serious concerns, especially given the cost projections for public programs that are critical to people with disabilities and their families.”

- 2007, “Final Thoughts,” pg. 320, italics added

Social Security Administration

- Stanford University – contract with SSA and WHO.
- Ontology (essence of being) work on several projects
- Coding of function in SSA disability determination
- Exploring use of ICF – data mapping with medical listing

NIH – Clinical Center, Rehabilitation Medicine Department

- Reviewed the gap between contemporary models of disability and how SSA defines and operationalizes disability.
- Methods of measurement of human function.
- IRT-CAT technology

Brandt et al. 2011

Department of Defense

- October 12, 2011 – US Army Medical Research and Materiel Command, Telemedicine and Advanced technology Research Center – Fort Detrick, MD
 - RFA – investigator initiated awards – 1.5 million. Application deadline March 2012, award by June 2012.
- ICF-related products in new clinical functional assessment tools.
- Evaluation of impact on disability claims processing.

Examples of ICF Studies on Clinical Applications

- Occupational Therapy - Washington University, St. Louis, MO
- Health System – Italy
- Chronic Conditions – Germany
- Allied Professionals in public health – Ministry of Health, South Africa
- Educational system - Portugal
- Older adults care/services - Japan

Examples of Government Applications

Palmetto GBA, a Medicare subsidiary, "Going Beyond Diagnosis"

Federal Health Architecture Program (HHS)

Basis of Spanish law, used to determine benefits

PALS survey derived from ICF codes, Canada

ICF framework used for Australia's national classification of health and functioning

Studies on ICF Chronic Fatigue Syndrome?

- Prodinge et al, 2011. Measuring functioning in people with fibromyalgia (FM) based on the International Classification of Functioning, Disability and Health (ICF – A Psychometric Analysis. *Pain Pract*
 - 256 participants
 - It is possible to construct sound clinical instruments based on ICF to measure function status – assessing, monitoring body functions, activities and participation (Germany)

Studies on ICF Chronic Fatigue Syndrome?

- Hieblinger et al, 2009. Validation of the International Classification of Functioning, Disability and Health Core Set for chronic widespread pain from the perspective of fibromyalgia patients. *Arthritis Research & Therapy*
 - 33 participants
 - Most ICF categories could be confirmed from patients' perspective.

Conclusions

- Information on functional status – essential to healthy people, populations, and living.
- Understanding across life span of the effects of health conditions on functional status
- Clinically meaningful description of functional status
- Rational, meaningful basis for assessing needs, resources, and outcomes.
- Sociocultural, environmental, biomedical factors considered
- Facilitate communication and care planning
- Demonstration projects among federal payers are needed to align ICF coding with various data infrastructure requirements and systems.



THANK YOU!

TITLE XXXI - DATA COLLECTION, ANALYSIS, AND QUALITY

- “(2) COLLECTION STANDARDS – in collecting data described in paragraph (1), the Secretary or designee shall –
 - “(A) use Office of Management and Budget standards, at a minimum, for race and ethnicity measures;
 - “(B) develop standards for the measurement of sex, primary language, and disability status;
 - “(C) develop standards for the collection of data described in paragraph (1) that, at a minimum –
 - “(i) collects self-reported data by the applicant, recipient, or participant; and
 - “(ii) collects data from a parent or legal guardian if the applicant, recipient, or participant is a minor or legally incapacitated;

Data Standard for Disability Status

- Are you deaf or do you have serious difficulty hearing?
- Are you blind or do you have serious difficulty seeing, even when wearing glasses?
- Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years or older)
- Do you have serious difficulty walking or climbing stairs ? (5 years old or older)
- Do you have difficulty dressing or bathing? (5 years old or older)
- Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)

A. Yes

B. No

TITLE XXXI - DATA COLLECTION, ANALYSIS, AND QUALITY

- (D) Survey health care providers and establish other procedures in order to assess access to care and treatment for individuals with disabilities and to identify –
 - (i) locations where individuals with disabilities access primary, acute (including intensive), and long-term care;
 - (ii) the number of providers with accessible facilities and equipment to meet the needs of the individuals with disabilities, including medical diagnostic equipment that meets the minimum technical criteria set forth in section 510 of the rehabilitation Act of 1973; and
 - (iii) The number of employees of health care providers trained in disability awareness and patient care.