

## **A CRITICAL REVIEW OF THE “INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF).”**

**(Presentation at a conference in Bucharest, Romania, 2003)**

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**"Modern society is obsessed by a need to systematize, generalize /and/ examine the individual."**

**Michel Foucault (1926-84)**

**Abstract.** After 30 years of evolution WHO in 2001 published the "Classification of Functioning, Disability and Health (ICF)". It covers 300 pages divided into chapters dealing with 484 body functions, 294 body structures, 382 activities and participation items and 253 environmental factors. Each of these 1,413 items have to be qualified, using 1–3 sets of mostly negative indicators, the total number of combinations is about 240,000.

The conclusions are:

- 1) The system is very complex and time-consuming to apply. Because of its terminology and sophistication only well-trained specialists can apply it. In spite of this complexity it is not operational, 90 % of the work remains to be done, and requires access to national data not available, endless testing and research. Very few nations will have the capacity and resources for that. ICF suffers from an almost incurable incompleteness.
- 2) ICF lacks applicability for existing national legal systems, such as workman's compensation, benefits for disabled people, such as pension rights.
- 3) ICF lacks positive aspects on disabled persons (there are 19 words about their abilities and talents); it concentrates on all that is negative: "problems", "abnormalities", "losses" and "deviations".
- 4) ICF suffers from a quasi-total absence of references to some large-scale daily experience by disabled people in real life: extreme poverty, abuse, neglect, substance abuse, exploitation, lack of security, imprisonment, non-application of human rights. This reflects the lack of experience among ICF's authors and the domination by expertise from the rich countries.

WHO needs to seriously contemplate the future viability of ICF.

## 1. THE ICF "UNIVERSE".

ICF is "clear about what it classifies: its universe, its scope and its units of classification... it is about *all people*... this classification does not classify people, but describes the situation of each person within an array of health or health related domains" (ICF, introduction).

### 1.1 THE PROCESS OF PRODUCING THE ICF.

One of the main activities of the World Health Organization is the development of classification systems for health conditions. This system is a tool, for:

- a) Collection and production of national and comparative international health statistics
- b) Planning of health policies and interventions, development of personnel and facilities, capacity building, and services.
- c) Health economics, cost assessments, cost-effectiveness, comparative studies of utilization.
- d) Creating databases for information and research.

The most important system has been the ICD for the standardisation of diagnoses of diseases, general morbidity and mortality rates. The latest version is the "International Statistical Classification of Diseases and related Health Problems, Tenth Revision, 1992-94."

WHO started in 1973 to develop "**a preliminary scheme ... concerning the consequences of disease**". This new system was to become – according to the plans – "assimilated" into and "compatible with...the ICD system". The preparations started, involving Professor Grossiord, France and Dr Philip Wood, United Kingdom and some collaborating centers. In 1974, after the first drafts, Professor Grossiord disagreed and left. I took part in the early discussions in 1974 –75 and then left for the reasons reviewed below. The ambition to produce a very extensive system was inconsistent with the WHO's priority to meet the needs and develop the capacities for health care of the developing countries; the opportunity costs were high and the utility of a sophisticated system even in the developed nations in doubt. I was told that the ICD programme "had a mandate and the funds to continue" along its own lines. The WHO's Rehabilitation programme produced - parallel to the groups involved in what was eventually to become the ICF – its own alternative, simple assessment system in the context of the Primary Health Care and Health For All initiatives. A summary appears at the end of this article.

In 1980, the International Classification of Impairments, Disabilities and Handicaps (ICIDH-1980) was printed for testing.

In 1993, it was decided to begin the revision of the ICIDH-1980. Among the purposes were: "**it should be simple enough to be seen by practitioners as a meaningful description of consequences of health conditions, and ... it should be useful for practice – i.e. identifying health care needs, tailoring intervention programs (e.g. prevention, rehabilitation, social actions)**".

In 1997 a "Beta-1 draft" was produced, followed by the 1999 "Beta-2 draft. Full version" published by the World Health Organization. After continued revision, WHO in 2001 published the ICIDH-2 in its six official languages under the name of International Classification of Functioning, Disability and Health (ICF). A number of national translations have appeared.

### 1.2 WHO HAS ACKNOWLEDGED THE CO-OPERATION IN ICF BY

about 1200 persons: among them 36 staff at WHO Headquarters, 15 from Regional Offices and 13 consultants and 6 representatives from other UN agencies. Furthermore, 8 WHO collaborating centres, 3 task forces, 2 networks, 7 non-governmental organizations participated, **all of them based in highly developed countries**. To these were added 891 individual participants countries "in the revision process" from 64 countries. Of those 694 participants were from 23 OECD countries (out of 30) and 197 from 41 non-OECD countries (out of 162). In 1999 there had been just 369 participants from 59 countries, so another 522 must have been added during the final year. The ICF authors and advisers have been recruited from and dominated by persons from the very rich countries.

The ICF was endorsed by a World Health Assembly resolution 54.21 in 2001. The past and ongoing costs to the WHO and its collaborators for this 35 yearlong enterprise have not been published.

## 2. REVIEW SUBJECTS.

The final product: **the ICF is far removed from the objectives set both in 1973 and again in 1993. It does not deal with" consequences of diseases", neither has it become a "simple enough...meaningful / tool/ for health practitioners".**

The subjects for this review are:

- The paradox of ICF's enormous complexity with an almost incurable incompleteness.
- Its lack of links to and applicability in the context of existing disability-related national legal systems.
- The lack of positive views on persons with disabilities and its concentration on the negative aspects of persons with disabilities.
- The quasi-total absence in ICF of references to the large-scale daily problems experienced by disabled people in the world.

## 3. COMPLEXITY IN THE MIDST OF "INCURABLE INCOMPLETENESS".

The ICF has divided its classification system into four components:

- 1) **Functioning and disability**, subdivided into
  - a) **Body component** (body functions and body structures) and
  - b) **Activities and participation**,
- 2) **Contextual factors**, subdivided into
  - a) **environmental factors** and
  - b) **personal factors** (these are gender, race, age, fitness, lifestyle, habits, coping styles and other such factors); these are not classified by ICF. (p. 19)

**3.1. BODY FUNCTIONS** (p. 45-104): the basic ones are 112 subdivided into 484 functions and subfunctions, each has to be classified, applying a "generic qualifier" with a scale of 7 steps (fig. 1). Here follows quotes of two random examples:

### Example 1.

**"Psychomotor functions (b 147):** Specific functions of control over both motor and psychological events at the body level. (*basic function*)

Inclusions: functions of psychomotor control, such a psychomotor retardation, excitement and agitation, posturing, catatonia, negativism, ambitendency, echopraxia and echolalia, quality of psychomotor function.

Exclusions: A) consciousness functions with 5 subfunctions (b 110), B) orientation functions with 9 subfunctions (b 114), C) energy and drive functions with 7 subfunctions (b 130); D) attention functions with 6 subfunctions (b 140); E) mental functions of language with 14 subfunctions (b 167), F) mental functions of sequencing complex movements, no subfunctions (b 176). These six exclusions in their turn have an additional 29 exclusions of functions and subfunctions. The total of functions and subfunctions to examine in detail are 51, including the 4 listed below.

Now follow the *subfunctions* (of b 147):

- b 1470 Psychomotor control
- b 1471 Quality of psychomotor functions
- b 1472 Psychomotor functions, other specified
- b 1479 Psychomotor functions, unspecified

All impairments have to be classified using the scale in Fig. 1.

**Table 1. Generic (first) qualifier with a negative scale to indicate the extent or magnitude of an impairment.**

<b>Extent or magnitude of impairment</b>	<b>Percentage loss of function</b>
0. No	0-4
1. Mild	5-24
2. Moderate	25-49
3. Severe	50-95
4. Complete	96-100
8. Not specified	
9. Not applicable	

The problem with that scale is that both b 1470 and b 1471 include several listed further sub-components. When some of them are impaired and others normal, how will the user of ICF apply the negative scales?

There are no precise operational definitions or assessments instruments for instance of "moderate impairment" of any body function listed. For example, at what exact point does a specific function pass the limits of "mild impairment" to become "moderate"? (from 24% to 25%). **The national ICF user has to develop this "standardization", which should "refer to significant variation from established statistical norms (i.e. as a deviation from a population mean within standard norms) and should be used only in this sense."** (p. 213) **All "percentages /of negative coding of problems/ are to be calibrated in different domains with reference to population standards as percentiles. For this quantification to be used in a universal manner, assessment procedures have to be developed through research."** (p. 222)

The "small" problem is that such national population standards based on detailed descriptions rarely exist; and may be subject to frequent changes. **The ICF authors have in their 300 page long monograph left out what I consider about 90 percent of the work that needs to done.** I doubt that any body will have the resources to undertake the future research to establish the statistical norms and continue to recalculate these whenever needed in all parts of the World. Such research is unlikely to be given sufficient priority; its utility is in doubt as there are simpler ways to collect the data for planning. This is what is characterized as ICF's "incurable incompleteness".

Another visible problem is **the ICF language. To master its sophistication, many years of academic training is required.** In developing countries – WHO's main constituencies - very few are able to participate in the future of ICF.

### **Example 2.**

**Water, mineral and electrolyte balance functions (b 545):** functions of the regulation of water, mineral and electrolytes in the body.

**Inclusions:** functions of water balance, balance of minerals such as calcium, zinc and iron, and balance of electrolytes such as sodium and potassium; impairments such as in water retention, dehydration, hypocalcaemia, iron deficiency, hypernatraemia, hyponatraemia, hypercalcaemia and hypokalaemia.

**Exclusions:** A) hematological system functions (b 430); B) general metabolic functions (b 540); C) endocrine gland functions (b 555). **These exclusions in their turn have 37 exclusions of functions and subfunctions. Including the 10 listed below, we arrive at 47 functions and subfunctions to study in detail.**

**Now follow the subfunctions of (b 545)**

b 5450 Water balance

b. 54500 Water retention

b. 54501 Maintenance of water balance

- b. 54508 Water balance functions, other specified
- b. 54509 Water balance functions, unspecified
- b. 5451 Mineral balance. ("Functions involved in the maintaining an equilibrium between intake, storage, utilization and excretion of minerals in the body. " Here are evidently four different body functions.)
- b. 5452 Electrolyte balance; (same explanatory text as 5451)
- b. 5458 Water, mineral and electrolyte balance functions, other specified.
- b. 5459 Water, mineral and electrolyte balance functions, unspecified.

Let us now return to the qualifier "generic" scale (Fig 1). Under b 5451 and b 5452, there are no less than four different functions put together. How to apply the negative scale is unclear when some are normal and some others impaired. Besides, **why are these water, mineral and electrolyte balance functions in ICF at all?** To deal with these is a matter for a department specialized on for example, internal medicine or surgery.

The ICF user will now examine the 484 functions and sub-functions of the **Body Functions**, look up their inclusions and exclusions and rate them, using the negative generic scale. **This means that there are  $484 \times 7 = 3,388$  combinations of classifications for the totality of the impairments of the Body Functions.**

### 3.2. BODY STRUCTURES (p. 105-122): 294 are listed.

(It could have been a lot more detailed, if the ICF had listed, for instance, the 22 muscles of the forearm, each vertebra and the set of muscles of the larynx (needed to "generate speech") or distinguish between the right and left cardiac atria and ventricles, (which have different functions.)

We have to deal with three qualifiers:

1. The one from Fig 1, showing the "generic negative scale".
2. The second qualifier which will describe the "nature of change"
3. The third qualifier about the "location of changes" in Body Structures.

The two latter are shown in Fig. 2.

**Fig 2. Second and third qualifiers of Body Structures**

<b>Second qualifier: Nature of change</b>	<b>Third qualifier: location of change</b>
0 no change in structure	0 more than one region
1 total absence	1 right
2 partial absence	2 left
3 additional part	3 both sides
4 aberrant dimensions	4 front
5 discontinuity	5 back
6 deviating position	6 proximal
7 qualitative changes in structure, including accumulation of fluid	7 distal
8 not specified	8 not specified
9 not applicable	9 not applicable

There are  $294 \times 7 \times 10 \times 10 = 205.800$  possible combinations of Body Structures.

**3.3 ACTIVITIES AND PARTICIPATION** (p. 123-170). ICF lists 382 components and subcomponents. For each there are two sets of qualifiers. One is the "performance qualifier" ("the involvement in life situation") and the other "participation qualifier" (an individual's ability to execute a task or an action... the highest probable level,...measured in a uniform or standard environment, and thus reflects the environmentally adjusted ability of the individual). There are no operational explanations of how the measurement of that ability (graded in percentages) will be made. (p. 123)

Both qualifiers use the system of negative scale shown in Figure 1. That brings us to a total of about  $382 \times 7 \times 7 = 18,718$  combinations.

The pages listing activities and participation have some surprising content: *scuba diving (d 465)*, *using telephone, fax and telex machines (d 3600)*, *riding an elephant (d 480)*, *starting and maintaining romantic relationships (d 7700)*. Then follows "engaging in any form of complex economic transactions that involves the exchange of capital or property, and the creation of profit or economic value, such as buying a business, factory or equipment, maintaining a bank account, or trading in commodities." (d 865). This list of transactions reflects the ignorance of the ICF authors of the extreme poverty in which the great majority of disabled people in the world live.

**3.4 ENVIRONMENTAL FACTORS** (p. 171-207). Here the ICF gives orders: **"These factors must be considered for each component of functioning and coded accordingly"**.

The list includes 253 factors and subfactors, but this number does not give full recognition of all what is listed under each factor. There are two sets of qualifiers: barriers and facilitators. (Fig 3), this gives us (with great reservations)  $253 \times 7 \times 7 = 12,397$  combinations. The environmental factors listed by ICF not that easy to judge, many of them makes you wonder if they have any practical purpose, see examples below.

**Example 3. Physical geography** (e 210): features of land forms and bodies of water.

**Inclusions:** features of geography included within orography and hydrography.

There are 4 subfactors:

e 2100 Land forms

e 2101 Bodies of water

e 2108 Physical geography, other specified

e 2109 Physical geography, unspecified

**Example 4. Flora and fauna** (e 220)

e 2200 Plants: Any of various photosynthetic, eukaryotic, multicellular organisms of the kingdom Plantae characteristically producing embryos, containing chloroplasts, having cellulose walls, and lacking the power of locomotion, such a trees, flowers shrubs and vines. (e 2200)

e 2201 Animals: Multicellular organisms of the kingdom Animalia, differing from plants in certain typical characteristics such as capacity for locomotion, non-photosynthetic metabolism, pronounced response to stimuli, restricted growth, and fixed bodily structure, such as wild or farm animals, reptiles, birds, fish and mammals

Exclusions: Assets (e 165) and domesticated animals (e 350)

For every one of the functions previously classified, the ICF user has to code the environmental factors using the qualifiers shown in Fig. 3.

**Fig 3. Qualifiers for environmental factors: barriers and facilitators.**

<b>Barrier, negative scale</b>	<b>Percentage of barrier function</b>	<b>Facilitator</b>	<b>Percentage of facilitator function</b>
0. No	0-4	0. No	0-4
1. Mild	5-24	1. Mild	5-24
2. Moderate	25-49	2. Moderate	25-49
3. Severe	50-95	3 Substantial.	50-95
4. Complete	96-100	4 Complete	96-100
8. Not specified		8. Not specified	
9. Not applicable		9. Not applicable	

**Example 5.**

*Lunar cycles (e 2451)*, *weather (e 2250-2259)*, *earthquakes (e 230)*, *sounds*: "a phenomenon that is or may be heard, such as banging, ringing, thumping, singing, whistling, yelling or buzzing, in any volume,

timbre or tone, and that may provide useful or distracting information about the world" (e 250). Which are the sounds that may not be heard? Something to do with schizophrenic hallucinations?

I cannot figure out the barriers and facilitators related to lunar cycles either. Looking carefully we will find *tennis balls (e 1400) but no rackets to go with them, Braille tarots cards (e 141), non-motorized vehicles for water transportation; that must be rowing boats (e 1200), wildlife trails (e 1603) and candle lights (e 240)*. What happened to astrology?

About the claim that the items "are ordered in a meaningful way" (p. 5), a possible proof is when one follows e 310 to e 360, this is about "people or animals that provide physical or emotional support, nursing, protection, assistance..." This list starts with the immediate family (e 310), the extended family (e 320), friends (e 320), acquaintances (e 325), people in position of authority (e 330), subordinates (e 335), personal care providers, such as house help and taxi drivers (e 340), strangers (e 345) and domesticated animals (e 350) - *here is the aquarium fish which provides emotional and psychological support!* Finally, the bottom of this list of the universe of ICF is taken by the health professionals (e 355) and social workers (e 360) who perhaps are seen only as second-hand alternatives for giving support.

### Number of combinations

The authors of ICF refer to its "Universe" and claim that ICF "structures the information in a meaningful, interrelated and **easily accessible way**". The number of combinations does not support that view. (Fig. 4)

**Fig 4. Number of basic items and sub-items and the combinations**

Component	Number of basic items and sub-items listed in ICF	Number of qualifiers	Total items in each qualifier	Number of total combinations
Body functions	484	1	7	3.388
Body structures	294	3	7+10+10	205,800
Activities and participation	382	2	7+7	18,718
Environmental	253	2	7+7	12, 397
<b>TOTAL</b>	<b>1,413</b>	<b>7</b>	<b>62</b>	<b>240,303</b>

As we live in a changing world the list of activities, participations and environmental factors - ICF states - will need constant updating; after the 30 years it took WHO to arrive at ICF will it be eternally prolonged?

This classification "does not classify people, but describes the situation of each person within an array of health or health related domains." (p. 8) **It is hard to understand a system claiming to be an "international classification" while at the same time explaining that it is not meant to classify anybody but proposes to be a description system of everybody, requiring an enormous array of data that certainly neither is easily accessible nor action-oriented. The ICF system does not help to calculate health care and other needs of services required for future planning.**

## 4. THE LACK OF LINKS TO AND APPLICABILITY FOR EXISTING DISABILITY-RELATED NATIONAL LEGAL SYSTEMS.

In many countries detailed national legislation exists, for example regarding:

- 1) Impairment evaluations to determine the amount of compensation paid to victims of occupational diseases and accidents,
- 2) Specific laws and regulations related to benefits such as disability pension rights,
- 3) Rehabilitation and ability training programmes for persons who are on long-term sickness payments,
- 4) Economic and social support to families with disabled children,
- 5) Compensations paid for permanent impairments, pain and suffering to traffic accident victims.

- 6) Compensations for victims of malpractice  
 7) Compensations to victims with health consequences of environmental hazards.

ICF states (p. 5): "Since ICF is inherently a health and health-related classification **it is also used** by sectors such as insurance, social security, labor, education, economics, social policy and general legislation development and environmental modification". Here the ICF author may be writing about the ICIDH-1980 during period 1980-2000, but the ICF has little to do with ICIDH-1980 and this statement was made in 2001, written before the ICF was published. Furthermore, ICF writes "ICIDH-1980 was difficult to use... simplification for use was deemed necessary". It would be clarifying if the ICF author could explain in detail the concrete results of its usage in the sectors mentioned before ICF was even published. ICF lacks even a discussion how it can be used for the seven areas listed.

**Example 6: Comparisons between existing legal definitions of mental retardation and classifications by ICIDH-1980, DSM – IV and ICF.**

The term "mental retardation is commonly used, but there are others which in principle are euphemisms, such as "intellectually disabled", "cognitively challenged," and so on. As the term "mental retardation" appears to be the best known, it is used here. "Development disability" (often used in North America) encompasses both mental retardation and other health conditions acquired at before the age of 22 (see below).

The ICIDH-1980 system

WHO (ICIDH-1980, based on ICD) defines impairment **of intelligence** as: "disturbances of the rate and degree of development of cognitive functions, such a perception, attention, memory, and thinking, and their deterioration as a result of pathological processes". Such impairments appear in two forms: **mental retardation and dementia**. According to ICIDH-1980; there are four levels of mental retardation; the IQ calculations are mainly based on the Wechsler scales; the Stanford-Binet scales uses slightly lower IQ levels (Fig. 5)

**Fig. 5. WHO's classifications system for the rating of mental retardation according to ICIDH-1980.**

<b>Degree of mental retardation</b>	<b>IQ level</b>	<b>Description</b>
Profound, 5 standard deviations below mean level	<25	Individuals who may respond to skill training in the use of legs, hands, and jaws
Severe, 4 standard deviations below mean level	25-39	Individuals who can profit from systematic habit training
Moderate, 3 standard deviations below mean level	40-54	Individuals who can learn simple communication, elementary health and safety habits, and simple manual skills, but do not progress in functional reading or arithmetic
Mild, 2 standard deviations below mean level	55-70	Individuals who can acquire practical skills and functional reading and arithmetic abilities with special education, and who can be guided towards social conformity.

The DSM-IV definition of mental retardation.

The **most widely used definition of mental retardation**, by the **American Psychological Association** (*Diagnostic and Statistical Manual IV, DSM IV*), includes three criteria:

- 1) Significantly subaverage general intellectual functioning; (an IQ of 70 or below on an individually administered general intelligence test; for infants, a clinical judgment of the general functioning, since available IQ tests do not yield numerical IQ values), accompanied by.
- 2) Significant limitations in adaptive skills, with
- 3) Onset during the developmental period (18 years of age).

There is no contradiction between the ICIDH-1980 and the DSM IV definitions. About the 'adaptive skills essential for daily functioning' according to the American Association on Mental Retardation (AAMR), skill areas are those "daily living skills needed to live, work and play in the community". The list includes ten adaptive skills; the diagnosis mental retardation is justified when two or more such skills are significantly limited:

- *Communication*: ability to comprehend and express information through symbolic (writing or speaking) or non-symbolic behaviors (facial expression)
- *Self-care*: skills involved in toileting, eating, dressing, hygiene, and grooming
- *Home living*: skills related to home functioning, e.g., clothing care, food preparation, and housekeeping
- *Social skills*: skills related to social exchanges with other individuals, e.g., responding to situational cues and recognizing the feelings of others
- *Leisure*: The development of self-directed leisure activities that reflect personal choice
- *Health and safety*: skills that maintain one's own health and safety, e.g., adequate diet and basic first aid
- *Self-direction*: skills related to making choices, following a schedule, initiating appropriate activities, and maintaining these activities until completed
- *Functional academics*: cognitive abilities related to learning at school that can be applied to life situations (writing, reading, functional mathematics, etc.)
- *Community use and work*: skills related to the appropriate use of community resources, including traveling within the community, shopping at stores, obtaining services, etc.

The AAMR also lists another set of useful evaluations: need of support; it is proposed to rate this need on "four levels of intensity:

- *Intermittent support* refers to support on an "as-needed basis." An example would be support that is needed in order for a person to find a new job in the event of a job loss. An individual may need intermittent support occasionally over the lifespan, but not on a continuous daily basis.
- *Limited support* may occur over a limited time span such as during transition from school to work or in time-limited job training. This type of support has a limit on the time that is needed to provide appropriate support for an individual.
- *Extensive support* in a life area is assistance that an individual needs on a daily basis that is not limited by time. This may involve support in the home and/or support in work. Intermittent, limited and extensive supports may not be needed in all life areas for an individual.
- *Pervasive support* refers to constant support across environments and life areas and may include life-sustaining measures. A person requiring pervasive support will need assistance on a daily basis across all life areas. "

The list of skills from USA does not apply to countries where completely different daily life abilities are needed, such as the developing nations.

### **Developmental disabilities**

Developmental disabilities is a more recent term now commonly used in USA for the legal definition of persons entitled to benefits described in the United States Developmental Disabilities Assistance and Bill of Rights Act, Amendment of 1996 (1). Often both terms are used together, usually in the form of the abbreviation MR/DD. DD term is somewhat wider in scope than MR:

"a developmental disability is a severe, chronic disability of an individual 5 years of age or older that:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the individual attains age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency; and
- reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that are of lifelong or extended duration and are individually planned and coordinated

· except that such a term, when applied to infants and young children, means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided (Public Law 103-120).

A multi-stage process is used to identify individuals with developmental disabilities. The process involves using NHIS-D variables to construct operational definitions for each of the seven areas of functional limitation listed above.

**According to the US law "a person with limits in intellectual functioning who does not have limits in adaptive skill areas may not be diagnosed as having mental retardation."** Unlike mental retardation, classification of developmental disabilities does not relate to a set of standardized assessment instruments, procedures, and professional training programs to operationalize its basic concepts.

### **The ICF definitions.**

In the ICF appears the term "intellectual functions" (b 117): "General mental functions required to understand and constructively integrate the various mental functions, including all cognitive functions and their development over the life span." In this category are included: "intellectual retardation and mental retardation." The differences between these two terms are not clarified, neither why "memory functions (b 144), thought functions (b 160) and higher-level cognitive functions (b 164)" are excluded from being part of intellectual functions. The ICF function has a "generic qualifier with the negative scale" (percentage loss, see Fig 1) - different from those above. ICF carefully avoids the question on what methods to use for this percentage rating.

From the above example it is concluded that the ICF is unhelpful for the purpose of classification of the degree of DD/MR to guide the Government of United States (or other countries) on how to apply their own existing legislation. Neither will ICF with its incomplete texts and non-operational state in the future influence other existing legislation mentioned at the beginning of this Chapter.

## **5. THE ICF'S LACK OF POSITIVE VIEWS OF PERSONS WITH DISABILITIES AND CONCENTRATION ON THE NEGATIVE ASPECTS OF PERSONS WITH DISABILITIES.**

**The ICF text is pre-occupied with "problems and problems "and negative aspects of persons with disabilities. Here are some quotes:**

"All components are quantified using the same generic scale that rates problems in percentages. Having a problem may mean impairment, limitation, restriction or barrier" (222)

"Impairment is a loss or abnormality in the body structure or physiological function including mental functions. Activity limitation are difficulties an individual may have in executing activities...ranging from slight to severe deviations...Participation restrictions are problems an individual may experience in involvement in life situations. " (p. 213)

**ICF has spent only 19 positive words in its 300 pages long book (p.223) where they have mentioned: "Coding positive aspects. At the user's discretion coding scales can be developed to capture the positive aspects of functioning. "**

It is possible to look at disabled persons in a completely different way. That is to first involve the disabled person in a joint discussion, establish a true dialogue, listening to and understanding his/her wishes, and plans for the future. Then follows an assessment of his/her abilities and talents and providing ability training for these positive aspects and develop these to the highest achievable level. A person will not get a job because he or she has some disabilities, but because he or she has useful abilities and talents. The "problems and restrictions" can for many be reduced or their consequences dealt with through a

holistic rehabilitation programme that also seeks to overcome environmental difficulties. In that programme, social and economic supports are important components.

More attention should be given to the Governments' compliance with their international human rights obligations. Where the international law is properly applied, it will ensure disabled people a life where they will share the fruits of development.

## **6. THE QUASI-TOTAL ABSENCE IN ICF OF REFERENCES TO SOME LARGE-SCALE DAILY PROBLEMS EXPERIENCED BY DISABLED PEOPLE IN THE WORLD.**

When looking into the subject index of ICF (p 269-299) the following words are missing:

- Poverty,
- Sexual, emotional, physical and commercial abuse, neglect, exploitation, cruel, inhuman and degrading treatment of disabled children and adults
- Alcoholism, illicit drug use,
- Lack of protection and security, crimes against disabled victims
- Divorce
- Abandonment of infants, institutionalization, disablement caused by deprivation of parental care;
- Infanticide, "mercy killing" of disabled persons
- Imprisonment of disabled persons.
- Human rights

ICF (p.6) states that it "provides an appropriate instrument for the implementation of stated international human rights mandates as well as national legislation". There does not appear to be much substance to prove that claim. Human rights are mentioned in d 940 and "correctional and penal facilities" in e 550 and "safeguarding people and property" in e 545.

Poverty is a health-related subject: poor health leads to poverty. And poverty leads to disease, disability and excessive mortality. Persons with disability are the poorest among the poor, see Box 1. (2)

### **Box 1. The poorest among the poor.**

*"A list of some criteria used by local people in "ill-being" grouping and ranking: sources in Asia and sub-Saharan Africa. Those at the top are seen as worst off by fellow community members:*

- (1) Disabled (e.g. blind, crippled, mentally impaired, chronically sick)
- (2) Widowed
- (3) Lacking land, livestock, farm equipment, grinding mil
- (4) Cannot send children to school
- (5) Having more mouths-to-feed, fewer hands to help
- (6) Lacking able-bodied members who can fend for their families in the event of crisis
- (7) With bad housing
- (8) Having vices (e.g. alcoholism)
- (9) Being "poor in people"; lacking social supports
- (10) Having to put children in employment
- (11) Single parents
- (12) Having to accept demeaning or low status work
- (13) Having food security for only a few months each year
- (14) Being dependent on common property resources."

A recent study in Sri Lanka (3) shows the economic situation of adult disabled persons; the conditions are similar in other developing nations.

**Fig. 6. Socio-economic situation of persons over the age of 18 with disability, Sri Lanka, 2003 (3)**

<b>Disability</b>	<b>Personal income less than US\$ 1/day</b>	<b>Personal income less than US\$ 2/day</b>	<b>Household income less than US\$ 1/day</b>	<b>Household income less than US\$ 2/day</b>	<b>Employment</b>	<b>Skills development</b>
Visual	43%	96%	48%	88%	14%	15%
Speech	88%	97%	54%	88%	11%	15%
Hearing	81%	98%	50%	90%	21%	20%
Mobility	45%	87%	59%	89%	26%	16%
Intellectual	n.a.	n.a.	59%	84%	1%	5%
Psychiatric	72%	90%	47%	85%	7%	11%
Epilepsy	n.a.	n.a.	49%	90%	5%	16%
Non-disabled	6.6%	45.3%	n.a.	n.a.	90%	n.a.

n.a.=not annotated

Disabled people are subjected to a high incidence of all types of abuse. (Fig. 7)

**Fig 7. Sexual abuse of disabled persons, studies in Canada and USA.**

<b>Groups which have been researched for sexual abuse</b>	<b>Cumulative incidence (reference)</b>
Multi-handicapped children in to US psychiatric institution	36 % abused (4)
Women in psychiatric hospital	81 of 100 sexually assaulted (5)
Deaf boys	54 % sexually abused as children (6)
Deaf girls	50 % sexually abused as children (7)
Women with disabilities, Canada	70 % of a sample of 84 (8)
People with ID	88 % sexually exploited (9)
Mentally retarded	35 % of the girls and 37 % of the women had physical evidence of sexual abuse, 6 % had histories of sexual assault and another 6% sexually transmitted disease. (10)
Mentally retarded	Between 25% and 83% of the women, and up to 32 % of the men (depending on the sampling methods) have experienced sexual abuse. (11)
Developmental disabilities	More than 90% experience sexual abuse at some point in their lives.
Developmental disabilities	49% experience 10 or more abusive incidents. (12)
Developmental disabilities	16-30% or all boys and 39-68% of girls will be sexually abused before they are 18 years old. (13)
Women with disabilities, Canada	40% abused, 12 % raped, sample of 245 women (14)
Adolescent girls with MR	25 % (15)
Persons with congenital physical disabilities	31 % (16)
Women blind from birth	50% (17)

The conclusion is that some 50% of all persons with disabilities have been victimized by sexual, physical and/or emotional abuse. Neglect is common and so serious that it causes the early death of large number of children. Govindshenoy and Spencer (24) in 2007 reviewed all population-based studies published from 1996-2006. Fig. 8 shows the result of a survey of disabled persons in India. It appears that

the proportion of males with a disability is twice as high as that of females, this reflects the killing of females by neglect or abuse (gendercide).

**Fig 8. Gendercide of disabled girls and women in India 1997(18)**

<b>Type of disability</b>	<b>% of all disability Both genders</b>	<b>% of all disability Males</b>	<b>% of all disability Females</b>	<b>Difference Male in % of female</b>
Blind	8.4	5.0	3.4	+ 47
Vision impairment	9.2	5.8	3.5	+ 66
Deaf	19.4	13.1	6.3	+ 108
Orthopedic impairment	56.7	38.4	18.3	+ 110
Mental retardation	6.3	4.1	2.2	+ 86
<b>TOTAL</b>	<b>100.0</b>	<b>66.4</b>	<b>33.6</b>	<b>+ 99</b>

Fig 9 shows the distribution of various factors registered among of 1,164 known homicides and 63 attempted homicides of persons with developmental disabilities. These occurred over several years, half since 1992. Two thirds of the victims were male and one third female. In about one third of the cases the crime was committed by a family member, paid carers were responsible for 28 %, neighbours and acquaintances for 23 % and 8 % by complete strangers.

**Fig. 9. Murder of persons with intellectual disability; victims and offenders, Anglophone countries.** (19, 20, 21, 22)

<b>Variable</b>	<b>%</b>
<b>Category of disability among victims</b>	
Intellectual	73
Cerebral palsy	14
Down's syndrome	6
Autism	3
Foetal alcohol syndrome	2
Spina bifida or hydrocephalus	2
<b>Gender of victims</b>	
Male	67
Female	33
<b>Age of victims</b>	
Average	18
Under 13	50
Over 13	50
<b>Offenders</b>	
Family members	36
Paid carers	28
Neighbours and acquaintances	23
Strangers	8
Other disabled people, sharing the same facilities	4

Hasbrouck (22) surveyed 95 newspaper accounts published between 1982 and 1997 of parents who killed their disabled children. Only nine defendants out of the 35 cases with published sentencing

information received any prison time. In contrast, the rate of imprisonment for people convicted of murdering children without disabilities is in USA 95 %.

Several studies have been made of the imprisonment of persons with disabilities. Petersilia (23) in 1997 estimated that 12% of all prisoners in California have a mental retardation; others believe that this is an underestimate. Not until recently did the US Supreme Court decide that persons with mental retardation could not be subjected to capital punishment.

**ICF does not anywhere provide a realistic view of the life of disabled people in the world, poverty, lack of services, abuse and neglect in all its forms, use of alcohol and illicit drugs, their imprisonment, children living without parents (in institutions , on the streets and so on) and other very common problems.** The 37 pages on the details of environment in ICF avoid mentioning "unpleasant realities".

The conclusions appear in the abstract.

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