

KlasifiKon 2019

Praha, Czech Republic, 22-23 October 2019

Development, implementation and use-case driven modernization of the International Classification of Functioning, Disability and Health (ICF)

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**World Health
Organization**

Overview

- **Where do we come from?**

- History (genesis) of ICF and disability/functioning concept

- **Where are we?**

- Current status and use of ICF

- **Where are we going?**

- Outlook on further development and use of ICD-11



Disability vs. Health problem

		DISABILITY	
		No	Yes
Health Problem	No		
	Yes		

Case 1: Blind person

Case 2: Person with flu – cannot work for 10 days

Case 3: Person with epilepsy – not allowed to drive

Case 4: HIV positive person (a- symptomatic) – work denied

Case 5: Coronary Infarct - cannot walk +200 meters for 3 month

Case 6: Paraplegic person - using wheelchair to move around

Case 7: Ex-Depression patient – difficulties in engaging in community activities

Evolution of the disability category

The disabled include “the sick, insane, defectives, aged and infirm”
English Poor Law 1834, 1601, 1388

A disabled person is someone who “because of his physical or mental condition is neither in a position to perform regularly his previous work nor to earn the minimum invalidity pension through other work corresponding to his strengths and capabilities and existing job opportunities”.
German Invalidity and Pension Law 1889

Medical determination of disability by applying the clinical concept of impairment
20th century

"Disability refers to the physical or organic handicap of a person due to natural deformity or deficient functioning of any limb resulting from accident, disease, etc. It includes blind, deaf and dumb, crippled, mentally retarded and insane."
Disability definition used in 1981 census

Evolution of the disability category

“Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

"In the context of health. Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)."

Evolution of the health category

19th Century and before

Health = absence of death & disease
Classification of Causes of Death (ICD)

20th Century

*WHO Constitutional Definition: "a state of **complete** mental and social well-being **not merely the absence of disease or infirmity.**"*

BUT operationalisation focused on

- *Mortality & morbidity (ICD)*
- *Consequences of disease (ICIDH 1980)*

21ST Century

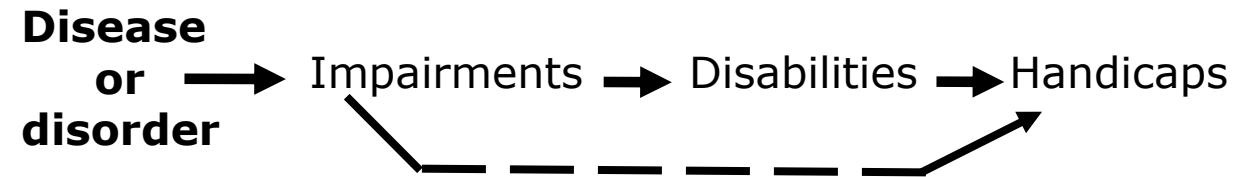
Health operationalised with ICF
ICF classifies health and health related domains

International Classification of Impairments, Disabilities, and Handicaps (ICIDH)



Philip Wood

- Conceptual model of disablement in the ICIDH disentangled disability from disease



- Published by WHO in 1980 for field testing

Development of the International Classification of Functioning, Disability and Health (ICF)

- Pre-Alpha Draft Development 1990-1995
 - Needs and scoping assessment (update vs. revision)
 - Setting up governance structure (WHO CC NCHS, Canada, France, Nordic Centre, Dutch; DPI, Tasks Forces)
- Alpha Drafting and testing 1996
 - Development of main components: Impairment, Disability, Social Participation, Environmental Factors
 - Testing via In-house and expert consultation
- Beta 1 Drafting and testing 1997 – 1999
 - Definitions added, Neutral language: BF,BS, A&P, P, EF
 - Empirical testing (CAR study) in 15 countries: Translation/linguistic analysis, Basic questions, Item Evaluation, Concept mapping, Pile sorting, Focus groups
- Beta 2 Drafting and testing 1999-2000
 - Uniform qualifier for severity provided, Use of blocks, and residuals throughout, EF chapters reordered
 - Field testing: Translation and linguistic evaluation, Basic Questions, Feasibility and Reliability
- Pre-Final, Final draft, WHA approval 2000-2001
 - Revision Meeting with WHO Member States
 - Change in the name of the classification to “International Classification of Functioning, Disability and Health”



Historical significance of ICF

Conversion point for Health and Disability

- Health and Disability categories have different origins and have taken different evolutionary lines
- ICF has brought the two lines in consilience
- Non-fatal Health Outcomes = DISABILITY = Health State less than Perfect Health



Conceptualization of Disability

ICF vs CRPD

ICF Definition of Disability

"In the context of health. Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)."

CRPD Definition of Persons with Disability

"Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

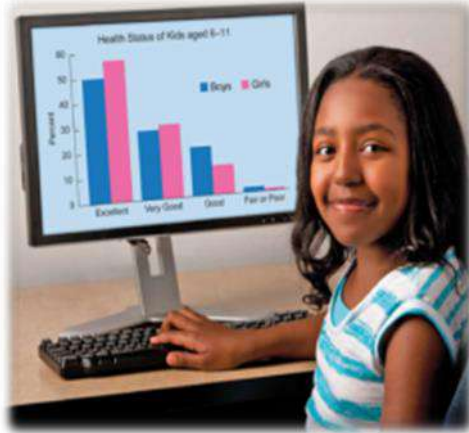
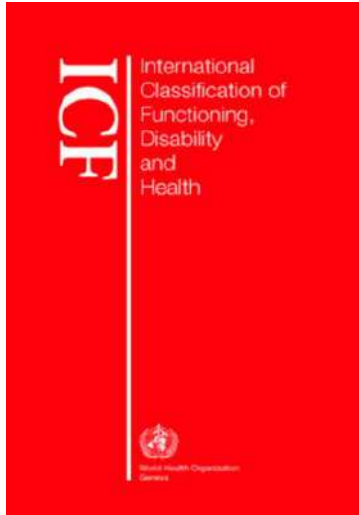
Monitoring CRPD



- Article 9 **Accessibility**
- Article 19 **Living independently** and being included in the community
- Article 20 Personal **mobility**
- Article 21 Freedom of expression and opinion, and **access to information**
- Article 23 Respect for home and the **family**
- Article 24 **Education**
- Article 25 **Health**
- Article 26 Habilitation and **rehabilitation**
- Article 27 Work and **employment**
- Article 28 Adequate **standard of living and social protection**
- Article 29 Participation in **political and public life**
- Article 30 Participation in **cultural life, recreation, leisure and sport**

Data needed on ICF
activity & participation
domains & environmental
factors

ICF



What is it?

- **Hierarchical list** of categories that classify the **universe of human functioning** in a **mutually exclusive** and **jointly exhaustive** manner.
- **Conceptual model** for understanding health and disability
-

Why do we need it?

Provides a **common language and understanding**

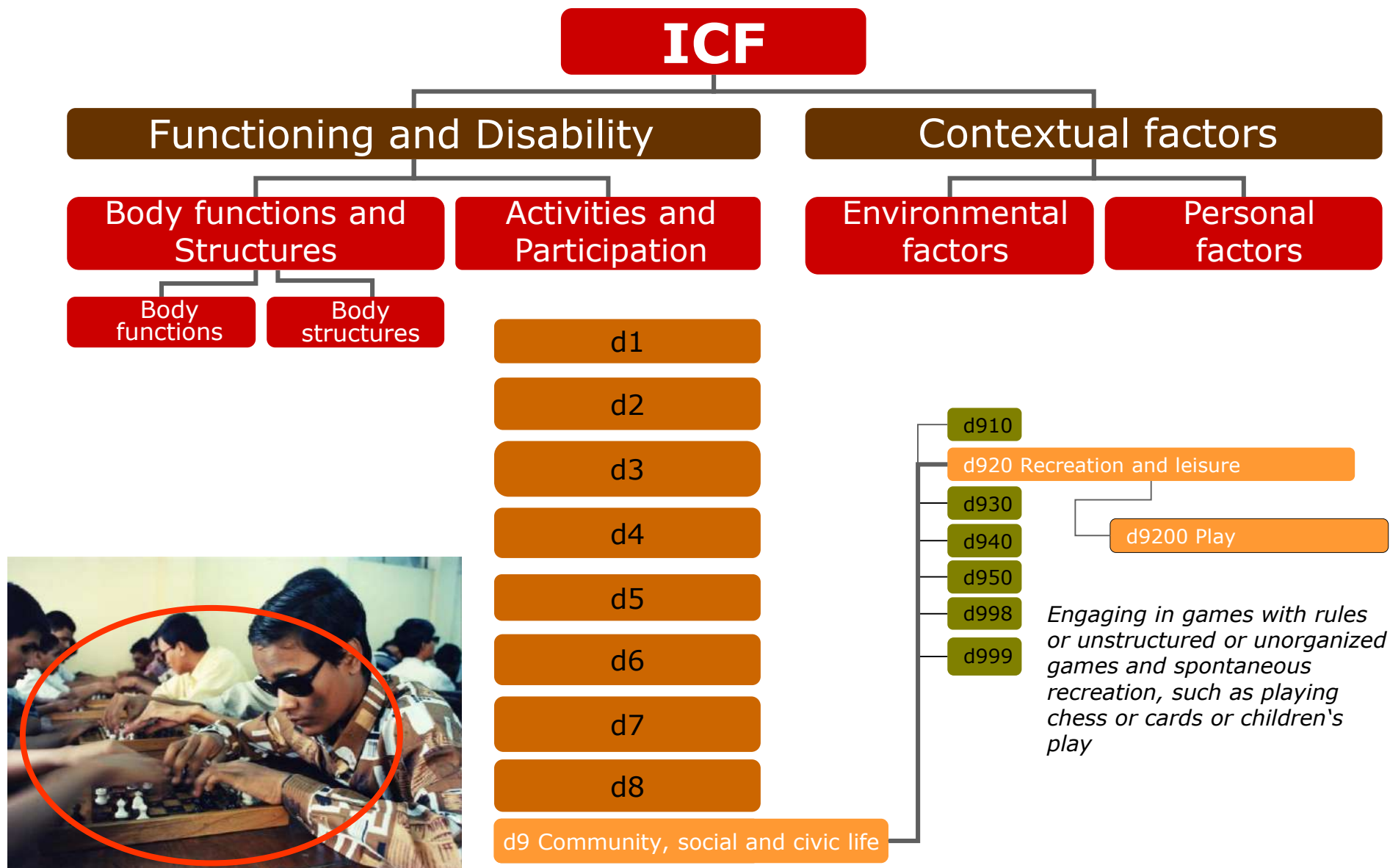
- Definition of disability
- Definition of categories (e.g. walking)

Enables **counting & reporting** in an efficient and comparable manner

- **Transform** complex and **long text into alphanumeric codes**
- Data **aggregation** and comparability

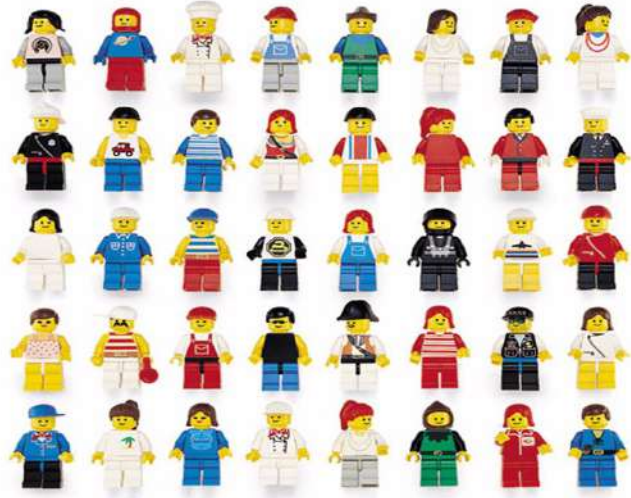


The structure and codes of the classification

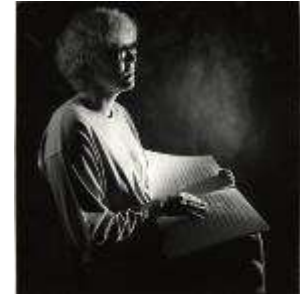


ICF conceptual model

Functioning/Disability is UNIVERSAL not minority
not a dichotomy (black/white) it is a placed on CONTINUUM



Who is disabled?



Single domain

Seeing Functions

10/20

Mild-Moderate vision impairment:
Needs eye glasses, contact lenses...

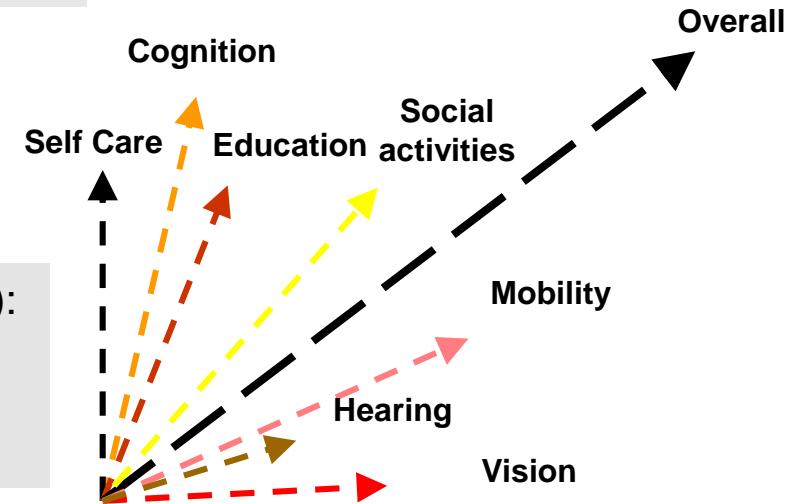
2/20

Severe vision impairment:
Needs operation

1/20

Complete vision impairment (blind):
Needs assistance –
pension, device, assistant
environmental modifications

Multiple domains





Serial number: [redacted] Civil ID: [redacted]
 Name: [redacted] Sex: ذكر
 Date of birth: [redacted] Nationality: كويتي
 Area: [redacted] Block: [redacted] Street: [redacted] House No: [redacted] Tel No: [redacted]
 Job: [redacted]

1. Communication:

- 1) No communication
- 2) Needs Interpreter
- 3) Communication — one Way (receives or expresses)
- 4) Communicates understandably (verbally or non-verbally)

2. Bathing:

- 1) Dependent
- 2) Needs physical help of another person
- 3) Independent In alternate way (bed bath)
- 4) Independent In routine way (bathroom bath)

3. Dressing:

- 1) Dependent
- 2) Needs physical help from other person
- 3) Needs other's supervision
- 4) Independent

4. Toilet Activities:

- 1) Dependent
- 2) Needs help
- 3) Independent In alternate way (bed pan etc...)
- 4) Independent In routine way (as done by the society)

5. Eating:

- 1) Dependent
- 2) Does not use the affected upper extremity at all
- 3) Use the affected extremity also as aid along with the unaffected side
- 4) Independent

(Bladder/Bowel) 6. Sphincter Control

- 1) Incontinent-socially unacceptable (passes urine in Diwaniya or marriage parties)
- 2) Incontinent-socially acceptable (use collective devices)
- 3) Immobility producing Incontinence
- 4) Continent

7. Locomotion

- 1) Immobile and passive locomotion
- 2) Active-trunk parallel to ground (crawling, rolling, etc.)
- 3) Active-trunk vertical to ground (wheelchair, crutch, etc.)
- 4) Normal ambulation

Dr. Comments:

Civil ID: [redacted]
 Sex: ذكر
 Nationality: كويتي
 Tel No: [redacted]

8. Mobility:

- 1) No transfer activities
- 2) Needs help
- 3) Transfer at same level of surface
- 4) Transfer at 'different. Level from basic position

9. Social Obligation

- 1) Unable to take part
- 2) Needs assistance
- 3) Independent in alternate way (does not sit on ground in Diwaniyas)
- 4) Independent in routine way

10. Religious Obligation:

- 1) Unable to perform
- 2) Needs help
- 3) Perform in alternate way
- 4) Perform in routine way

11. Vocational Performance:

- 1) Unemployed, lost the job, u nab led to perform the present job
- 2) Changed the profession
- 3) Regained the same profession in alternate department or job
- 4) Regained the original profession

12. Visual Performance:

- 1) Total blind
- 2) Can visualise objects but does not perceive
- 3) Needs aids
- 4) Normal vision

13. Locomotor Performance for Bidlorespiralry faigilnuent

- 1) Confined to one position
- 2) Dysphnoea during routine ADL
- 3) Dysphnoea during walking
- 4) No Dysphnoea

14. Sexual Activities (when applicable)

- 1) Unable to indulge
- 2) Not interested
- 3) Alternate methods
- 4) Routine methods

15. Satisfaction of Life

- 1) Not satisfied
- 2) Satisfied but complains
- 3) Not satisfied but does not complain
- 4) Fully.satisfied

ICF conceptual model

Functioning is MULTI-DIMENSIONAL not uni-dimensional



BODY
Function/
Structure
(impairment)



PERSON
Activities
(limitation)





SOCIETY
Participation
(restriction)



ICF conceptual model

Functioning/Disability: Context inclusive not person alone


 نموذج طلب تقرير طبي / فحوصات طبية
Medical Report & Investigation Request


• Employee Name:

Patient Name: ██████████	Date: 2018-05-02
Civil ID: ██████████	Sex: انثى
Mobile No: ██████████	Tel No: ██████████
	Nationality: كويتي

• Clinical Diagnosis & Examination:

She was in special needs school.
 I @ 45.
 Significantly depends on her family in managing basic life needs.

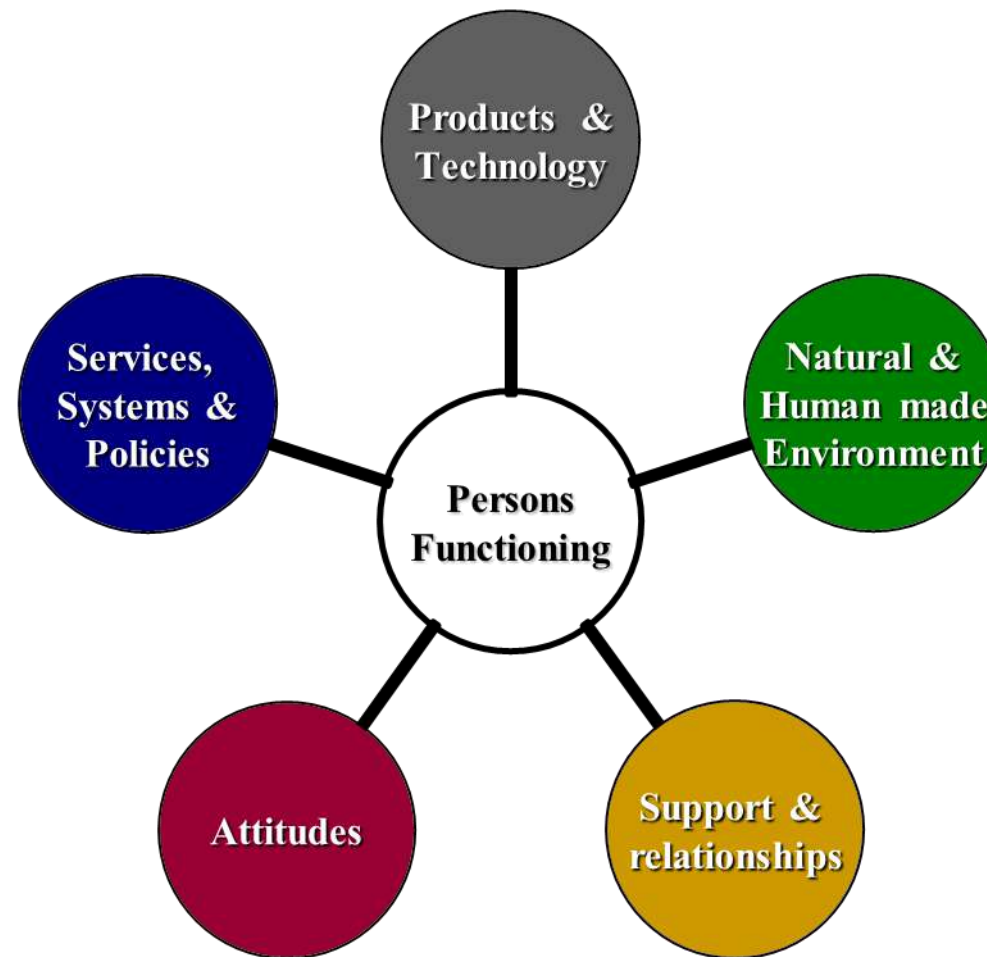
• Diagnosis: ICF:

• Disability: Moderate Intellectual Disability

No	learning	intellectual	motor	physical	psychological	developmental	visual	hearing
لا يوجد	تعليمية	ذهنية	حركية	جسدية	نفسية	تطورية	بصرية	سمعية

• Severity:

Mild - بسيطة	Moderate - متوسطة	Severe - شديدة	unclassified
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ICF conceptual model:

Functioning is not only about what a person **can't do** but also what the person **can do**

Deutsche Rentenversicherung
Deutsche Rentenversicherung

Versicherungsnummer: _____
Geburtsdatum: _____

Ärztliches Gutachten
Schlussblatt Teil 1
Sozialmedizinische Leistungsbeurteilung

A. Letzte berufliche Tätigkeit
Bezeichnung der Tätigkeit: _____

Beurteilung des zeitlichen Umfangs, in dem die letzte berufliche Tätigkeit ausgeübt werden kann:
 6 Stunden und mehr 3 bis unter 6 Stunden unter 3 Stunden

Die getroffenen Feststellungen gelten seit _____ (Tag, Monat, Jahr)
Besserung unwahrscheinlich ja (Begründung zu den Angaben in der Epikrise)
 nein

Dauer der Leistungsminderung voraussichtlich weniger als drei Jahre: nein
 ja, voraussichtlich bis _____

B. Positives und negatives Leistungsbild (allgemeiner Arbeitsmarkt) Zutreffendes ankreuzen (X). Mehrfachnennungen möglich

1. Positives Leistungsbild Folgende Arbeiten können verrichtet werden:

Körperliche Arbeitsschwere schwere Arbeiten mittelschwere leichte bis mittelschwere leichte

Arbeitshaltung
im Stehen ständig überwiegend zeitweise
im Gehen ständig überwiegend zeitweise
im Sitzen ständig überwiegend zeitweise

Arbeitsorganisation
 Tagesschicht Früh-/Spätschicht Nachtschicht

Keine wesentlichen Einschränkungen

2. Negatives Leistungsbild
Einschränkungen beziehen sich auf (Art / Ausmaß müssen differenziert unter Ziffer 3 beschrieben werden):

geistige/psychische Belastbarkeit
(Zu beachten sind insbesondere Konzentrations-/Reaktionsvermögen, Umstellungs-, Anpassungsvermögen, Verantwortung für Personen und Maschinen, Publikumsverkehr, Überwachung, Steuerung komplexer Arbeitsvorgänge).

Sinnesorgane
(Zu beachten sind insbesondere Seh-, Hör-, Sprach-, Sprech-, Tast- und Riechvermögen).

Bewegungs-/Haltungsapparat
(Zu beachten sind insbesondere Gebrauchsfähigkeit der Hände, häufiges Bücken, Ersteigen von Treppen, Leitern und Gerüsten, Heben, Tragen und Bewegen von Lasten, Gang- und Standsicherheit, Zwangshaltungen).

Gefährdungs- und Belastungsfaktoren
(Zu beachten sind insbesondere Nässe, Zugluft, extrem schwankende Temperaturen, inhalative Belastungen, Allergene, Lärm, Erschütterungen, Vibrationen, Tätigkeiten mit erhöhter Unfallgefahr, häufig wechselnde Arbeitszeiten).

3. Beschreibung des Leistungsbildes (insbesondere der unter Ziffer 2 genannten Einschränkungen).

4. Beurteilung des zeitlichen Umfangs, in dem eine Tätigkeit entsprechend dem positiven und negativen Leistungsbild ausgeübt werden kann:
 6 Stunden und mehr 3 Stunden bis unter 6 Stunden unter 3 Stunden

Bitte alle Blätter ausfüllen und jeweils mit Seitenzahl und Versicherungsnummer kennzeichnen!



Capturing the impact of health conditions in terms of functioning is NOT new....

- **Generic functioning measures**

- Activity of daily living (ADL) scales
 - Barthel index (1955)
 - Katz index (1957)
- Instrumental Activities of Daily Living (IADL) scales
 - Fries's Health Assessment Questionnaire (HAQ) (1980)
 - Granger's Functional Independence Measure (FIM) (1987)

- **Condition-specific functioning instruments e.g. Parkinson**

- Parkinson: Webster scale
- United Parkinson disease rating scale
- Self assessment Parkinson's disease Disability scale
- Parkinson symptom Diary
- Parkinson Disease Questionnaire (PDQ-39)

BUT they

- often do not capture functioning as multidimensional experience
- remain in a DATA SILO because they are not derived or linked and coded with an international data standard and conceptual framework.

In health and social service settings ICF allows to



- identify functioning problems & potentials
- set treatment goals & plan interventions
- monitor & evaluate change over time
- determine treatment/care needs

KONZEPTION	REALISATION	EVALUATION
Implantieren (Struktur und Funktion) - Cox-, Gelenk-arthrose - traumatische Luxationen - Knochentumor - angeborene Dysplasie - Infektion des Kniegelenks	Erwartungen der Patienten (aktivitäten) - allgemeine - psychosoziale - sporttherapeutische Zielsetzungen	Erwartungen der Partizipation (partizipation) - allgemeine - psychosoziale - sporttherapeutische Zielsetzungen
med. Maßnahmen - (bei zementierter) nicht zementierter endoprothetischer Verankerung	Erwartungen der Partizipation (aktivitäten) - allgemeine - psychosoziale - sporttherapeutische Zielsetzungen	Erwartungen der Partizipation (partizipation) - allgemeine - psychosoziale - sporttherapeutische Zielsetzungen
Kontraindikationen: Hüfte: Rollstuhl; Aktivitäten = Aufschwimmen; allgemein: Aktivitäten = Kletteraktivitäten, Fußballspielen u. a. Kontaktsportarten; Stuhlbesetzungen (Springer, Spiele) Risikofaktoren: Begrenzungen (z. B. Brustschwimmen, Fußballspielen u. a. Kontaktsportarten; Stuhlbesetzungen (Springer, Spiele))	Erwartungen der Partizipation (aktivitäten) - allgemeine - psychosoziale - sporttherapeutische Zielsetzungen	Erwartungen der Partizipation (partizipation) - allgemeine - psychosoziale - sporttherapeutische Zielsetzungen

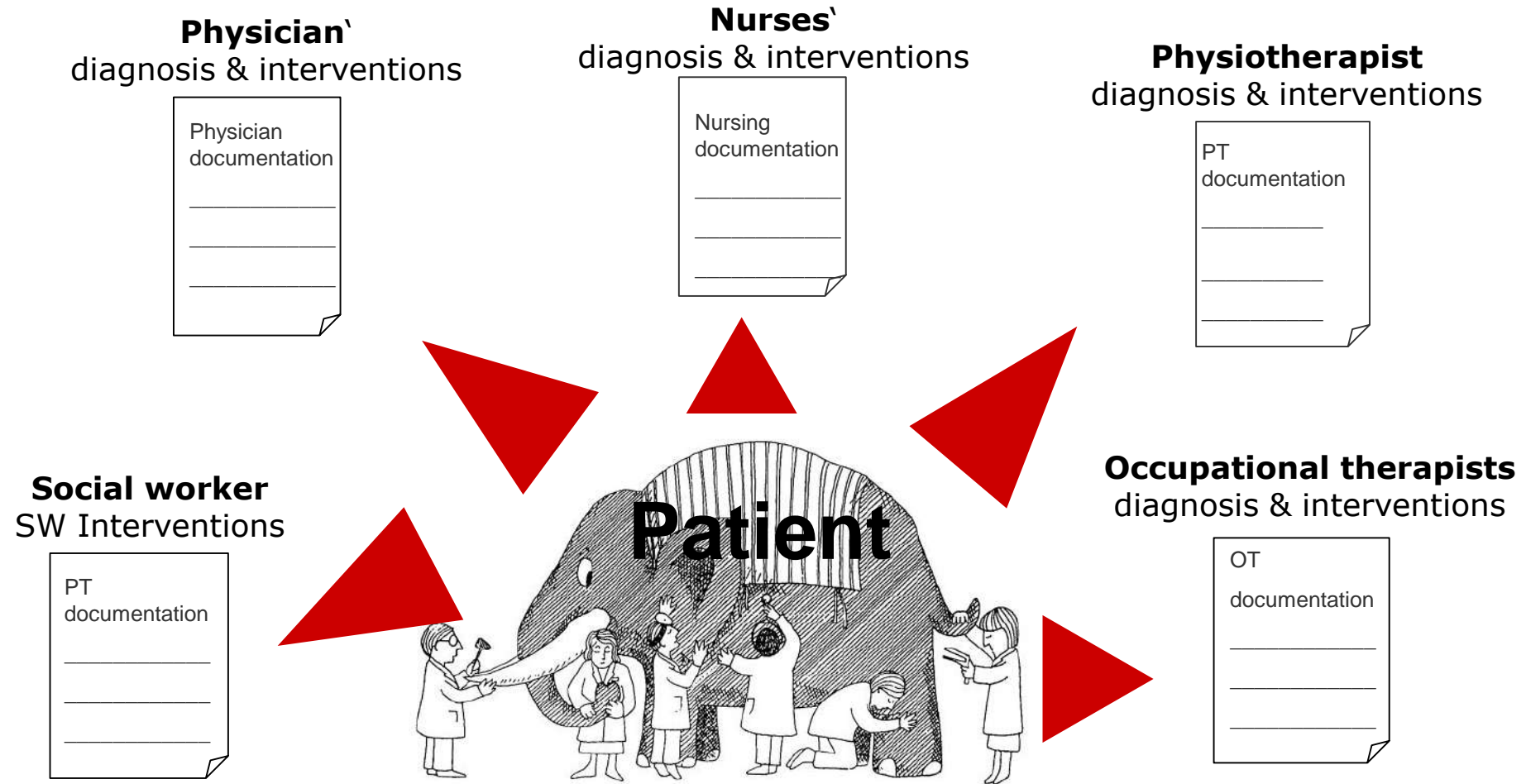


ICF: What difference does it make?

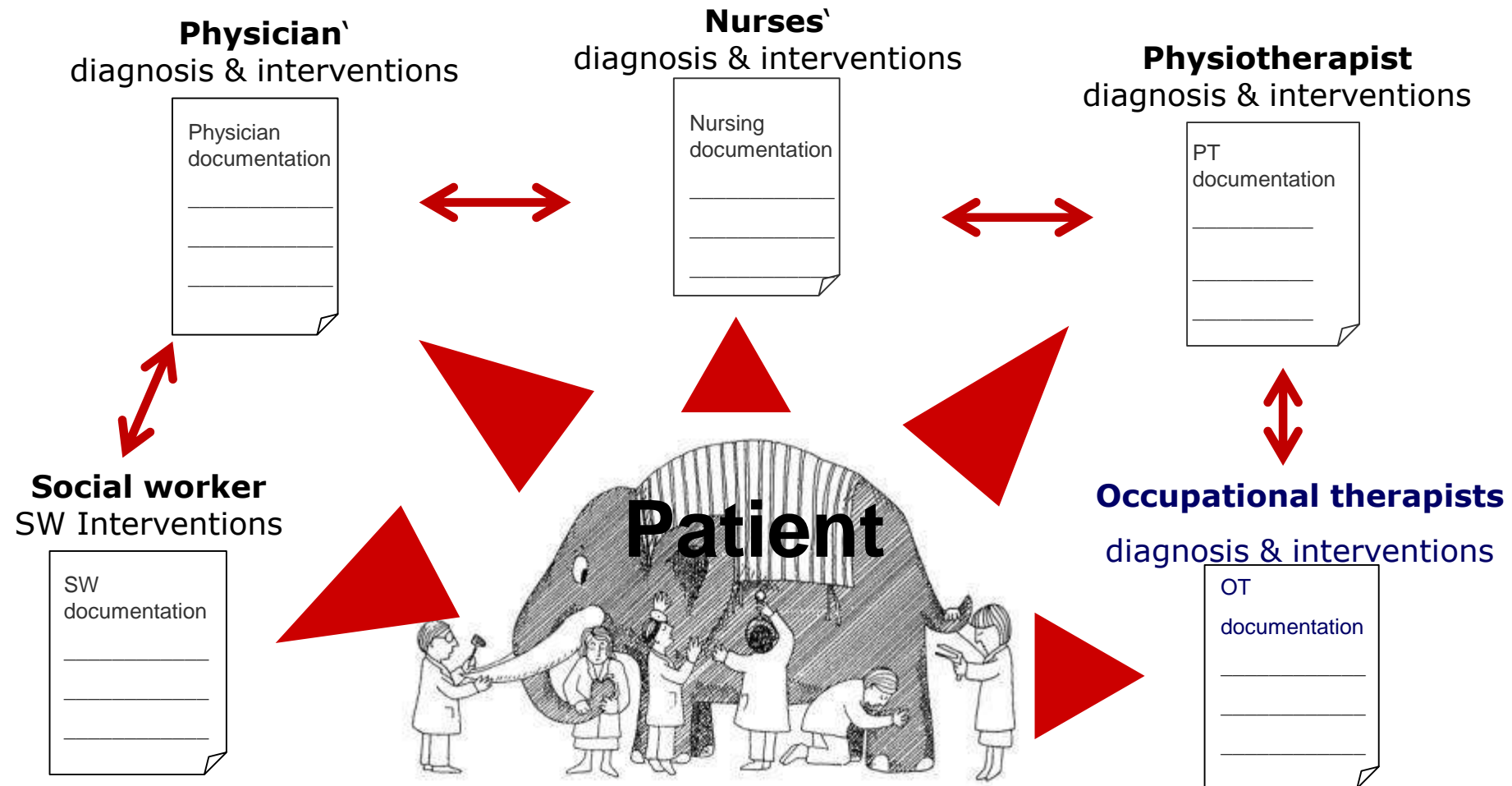
Identify and compare
where the **problem** is and where the **solution** lies

Body Functions & Structures	Activities & Participation	Environmental Factors
<p><i>IMPAIRMENTS</i></p> <ul style="list-style-type: none"> ✓ Pain ✓ Seeing ✓ Breathing ✓ Heart function <p>Intervention:</p> <ul style="list-style-type: none"> ✓ Medication ✓ Eye glasses ✓ Surgery ✓ Functional stimulation devices 	<p><i>ACTIVITY LIMITATIONS PARTICIPATION RESTRICTION</i></p> <ul style="list-style-type: none"> ✓ Walking ✓ Communication ✓ Washing ✓ Domestic responsibilities ✓ Work & Education ✓ Community life <p>Intervention:</p> <ul style="list-style-type: none"> ✓ Prostheses ✓ Wheelchair ✓ Rehab ✓ Exercise 	<p><i>Barriers & Facilitators</i></p> <ul style="list-style-type: none"> ✓ Buildings ✓ Work equipment ✓ Attitudes ✓ Support & Relationships <p>Intervention:</p> <ul style="list-style-type: none"> ✓ Ramps ✓ Workplace modification ✓ Destigma. Campaign

Documentation of functioning information at in health care settings



ICF provides a common language to improve communication across the continuum of care



REHABILITATION

2030

a call for action

- 1 Creating strong leadership and political support for rehabilitation at sub-national, national and global levels.
- 2 Strengthening rehabilitation planning and implementation at national and sub-national levels.
- 3 Improving integration of rehabilitation into the health sector to effectively and efficiently meet population needs.
- 4 Incorporating rehabilitation in Universal Health Coverage.
- 5 Building comprehensive rehabilitation service delivery models to progressively achieve equitable access to quality services, including assistive products, for all the population.
- 6 Developing a strong multidisciplinary rehabilitation workforce that is suitable for country context, and promoting rehabilitation concepts across all health workforce education.
- 7 Expanding financing for rehabilitation through appropriate mechanisms.
- 8 Collecting information relevant to rehabilitation to enhance health information systems including system level rehabilitation data and information on functioning utilizing the International Classification of Functioning, Disability and Health (ICF).
- 9 Building research capacity and expanding the availability of robust evidence for rehabilitation.
- 10 Establishing and strengthening networks and partnerships in rehabilitation, particularly between low-, middle- and high-income countries.

Health information systems and rehabilitation

Key messages

- Health information systems (HIS) underpin decision-making in health policy, management and clinical care through the collection, standardization, coding and management of information relevant to indicators of health status, determinants of health, and health systems.
- Improving the capacity of national HIS to collect reliable and comprehensive information is crucial for health systems strengthening, both nationally and internationally.
- WHO has developed a framework and standards for national HIS and a global reference list of 100 core health indicators to support countries to strengthen their HIS. There are opportunities to further expand this framework to capture the information needs of rehabilitation.
- Including information on functioning in HIS is essential for strengthening rehabilitation in the health system. "Functioning", as introduced in WHO's *International classification of functioning, disability and health* (ICF), refers to the impact of health conditions (injuries, diseases, ageing) on a person's experience in every aspect of his/her life.
- As well as information on functioning, systems level information about all aspects of the delivery and financing of rehabilitation services is necessary. This includes inputs (e.g. policy, financing, human resources and infrastructure) to, and outputs (e.g. service availability and quality) and outcomes (e.g. service coverage and utilization) of, rehabilitation.
- The WHO meeting on Rehabilitation 2030: A call for action calls for stakeholders to enhance HIS by including system level rehabilitation data and information on functioning, utilizing the ICF.

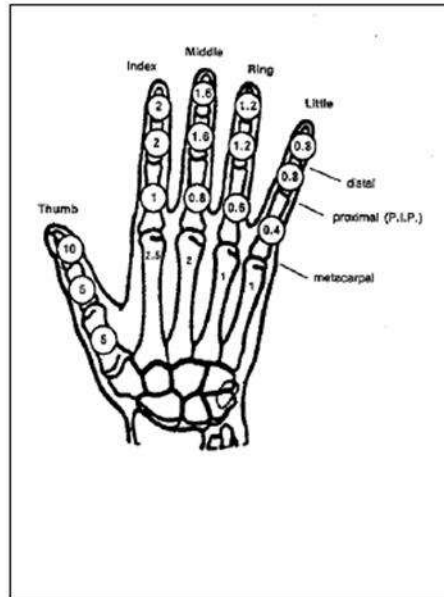
Disability Evaluation process

- **Purpose:** decide about eligibility of an individual for to receive benefits or services
- **Scope varies** according to the states disability policy:
 - health & rehab services incl. access to assistive technology
 - social or income security & pensions
 - health and social insurance benefits
 - short and long term sick leaves
 - general social benefits incl. income support and access to transportation, housing or education services,
 - employment-related benefits incl. workers' compensation, vocational rehabilitation
- **Disability assessment** is an essential component in the disability evaluation process

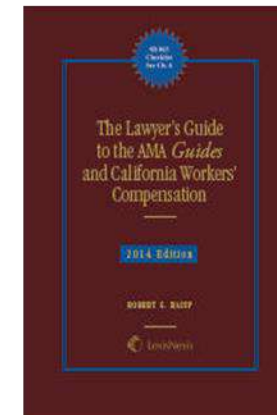
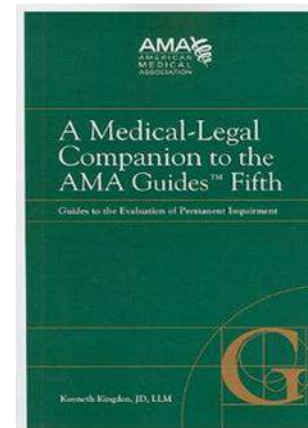
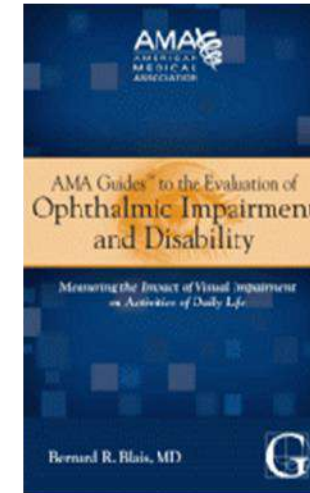
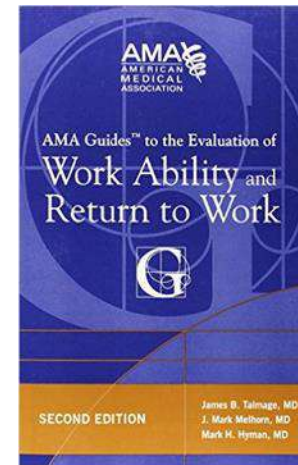
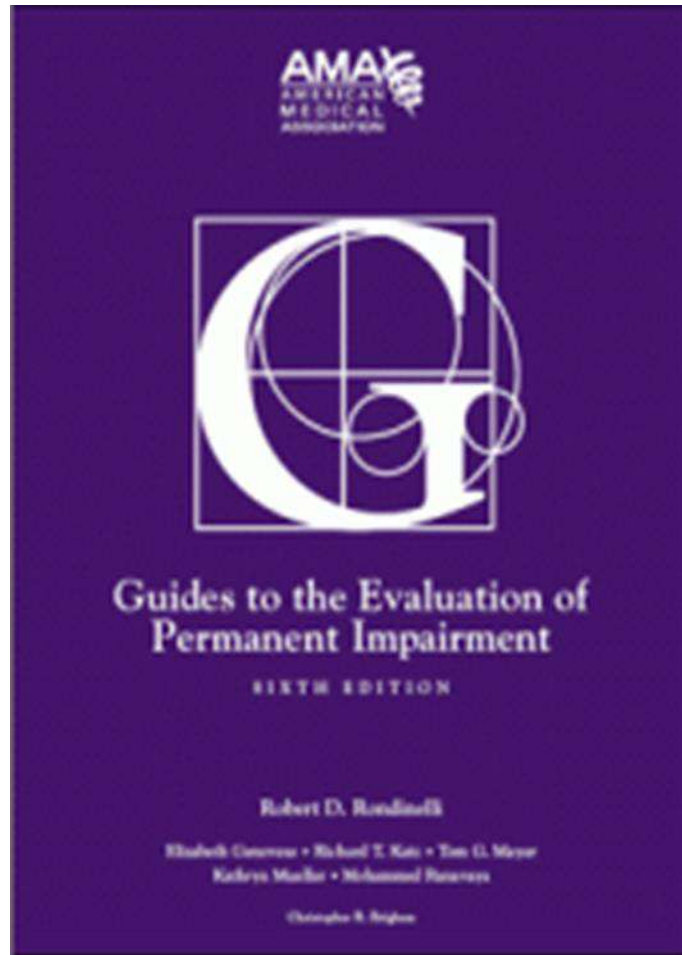
Impairment approach in Disability Assessment: 'Bareme' Assessment (1638-1703)

Figure 2.1: Bareme Table and Chart for the Hand

Hand Amputation	Percentage
Thumb, including metacarpal	20.
Thumb, both phalanges	15.
Thumb, one phalanx	10.
Finger, index	5.
Finger, index at P.I.P.	4.
Finger, index at distal	2.
Finger, middle	4.
Finger, middle at P.I.P.	3.2
Finger, middle at distal	1.6
Finger, ring	3.
Finger, ring at P.I.P.	2.4
Finger, ring at distal	1.2
Finger, little	2.
Finger, little at P.I.P.	1.6
Finger, little at distal	.8



AMA Guidelines for the Evaluation of Permanent Impairments



Problems with “traditional” Disability Assessment approaches

- **Indirect assessment of functioning: Inferences are made from**
 - health condition & impairment type/degree -> whole person disability
 - health condition & impairment type/degree -> ADLs/IADLs
 - Specific ADLs/IADLs -> work capacity
- **Comparability problems:**
 - how to quantitatively rate loss of limb with depression in terms of disability?
 - same impairment may have different impacts in terms persons functioning
- **Socially wasteful and in-efficient**
 - Focus on impairments / basic activities ignores what can be changed to making working feasible
- **Unfair to the individual**
 - Focus on deficits (body and activity level) ignores assets that can be developed
- **Overall too costly:**
 - disputed results, wasted working capacity, increased cost of benefits when employment is possible, inflexibility
- **Assessment ignores the impact of environmental factors (barriers/facilitators) on the persons functioning**
- **No linkage with classification:**
 - no or limited possibilities to compare and aggregate data
- **Validity, reliability, transparency and standardization of the assessment are often compromised by policy objectives or legal rules that govern the evaluation procedure**

ICF in Social Medicine

Country Example: France

- The legal frame of the French disability policy is the **2005-102 Act “For equal rights and opportunities, participation and citizenship of persons with disabilities”**, based on two major principles: accessibility and disabled persons’ support needs.
- In each of the 101 French administrative territorial entities (departments), the authority competent to carry out the disability policy is the **‘Departmental House for Disabled Persons’** (Maison Départementale des Personnes Handicapées).

In each Department two bodies are operating:

- a **multidisciplinary team** (including medical doctors, occupational therapists, psychologists, social workers,...) in charge of assessing the difficulties the person faces and his/her needs;
 - an executive board, the **‘Commission for the rights and autonomy of persons with disabilities’**, taking all decisions related to the provision of aids on the basis of the assessment. The network of local authorities is monitored by a national central authority (National fund of solidarity for autonomy – Caisse Nationale de Solidarité pour l’Autonomie, CNSA) in charge of the implementation of the disability policy throughout the country.
- In order to promote a uniform application of the law and assessment of the needs of persons the central authority has provided the local assessment teams with a **multidimensional assessment guide (called ‘GEVA’)**.

ICF in Social Medicine

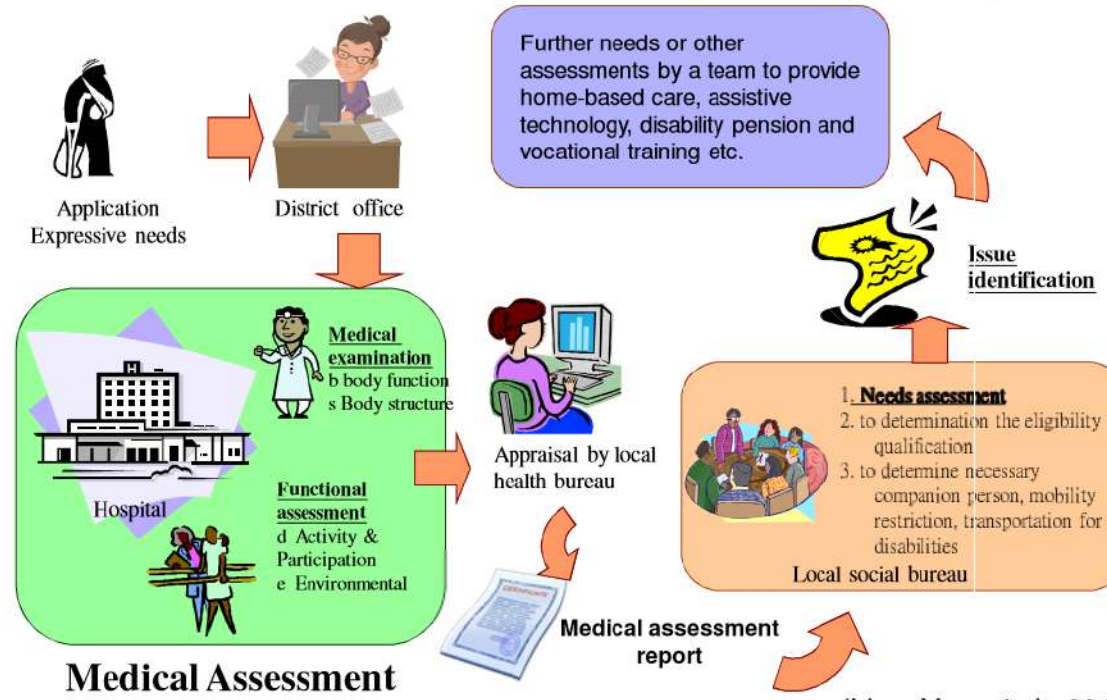
Country Example: France (2)

- **Multidimensional assessment guide (called 'GEVA')** entails 7 sections (touching upon the various components of a person's situation: social, financial, medical, etc.). The basic component related to 'activities and functional capacities' is composed of 8 ICF A&P domains and includes **142 ICF items**.
- Each item is **linked to a series of 5 environmental factors** (human environment, technical aids, animal aids, housing, services) assessed in terms of facilitator or obstacle/lack of).
- Thus each A&P item can be assessed (using the ICF 5 **grades generic scale**) in terms of Capacity and Performance.
- An additional qualifier of performance (activity performed alone; performed partially with human assistance; performed with continued assistance; not performed) allows to assess what performance would require in terms of environmental facilitators and support.

ICF in Social Medicine

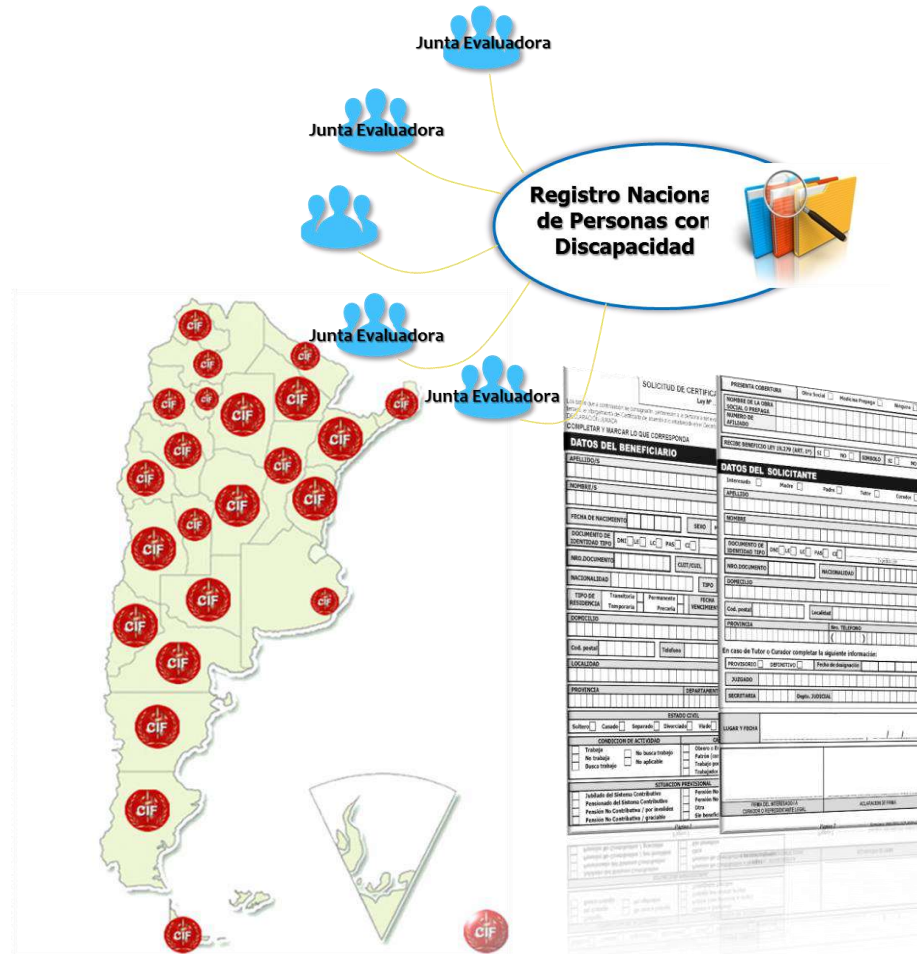
Country Example: Taiwan

Procedure of Disability Eligibility



ICF in Social Medicine

Country Example: Argentina



- Enfoque bio-psico-social
- Equipo evaluador Interdisciplinario
- Normativas Específicas:
 - listas cortas por condición de salud
 - reglas de codificación generales y específicas por componente
 - Calibración de calificadores
 - Concepto: líneas de corte

ICF in Social Medicine

Country Example: Cyprus - Reform of Disability Assessment System

Situation **BEFORE** reform

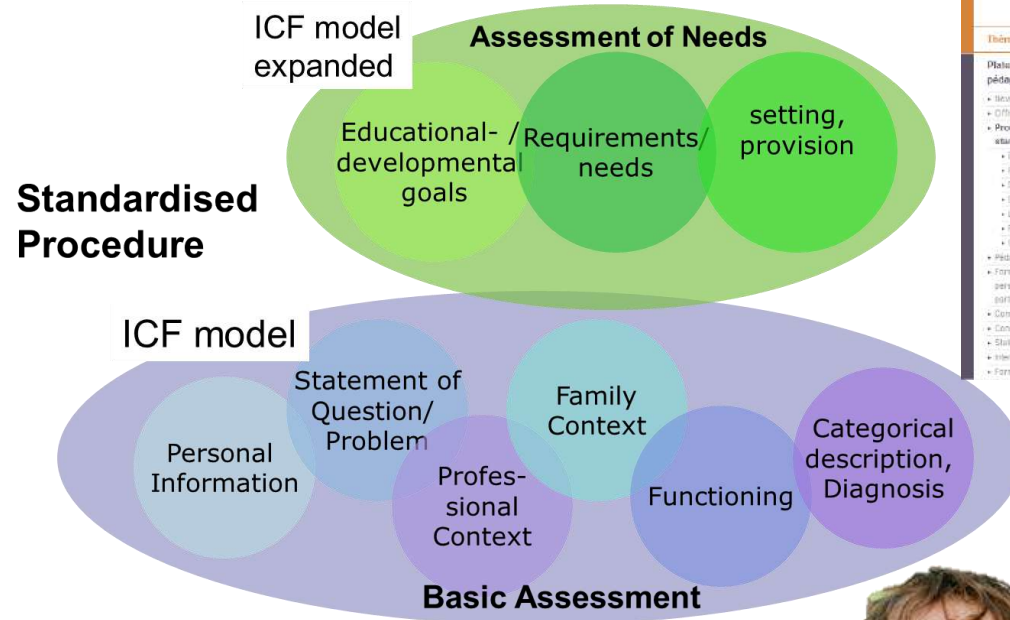
- Absence of clinical & functional assessment
- Multiple clinical assessments
- Absence of any protocols
- Delays between the application & the decision
- Decision only without rehabilitation plan
- Weak legislative platform
- Lack of data for disability population
- Lack for structuring policies

Situation **AFTER** reform

- A home for ICF “Assessment Center”
- Assessment mechanism stages: Preparation (File / vignette , assessment (med/Func) & completion
- Six Focused protocols for disability assessment
- Medical assessment by disability physicians(30 min)
- Functional assessment by rehabilitators (80 min)
- Qualifiers Mechanism
- Final Report
- Medical & Rehabilitative equipment

ICF in Social Medicine

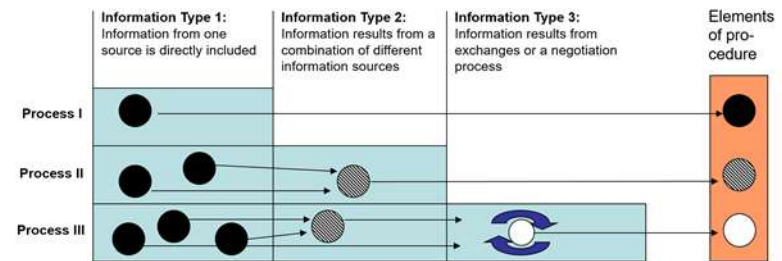
Country example: Switzerland- ICF-based Eligibility Procedure for Education



www.sav-pes.ch



Transparency related to the generation of information



Example Type I: Categorical diagnosis, body functions

Example Type II: Activities and Participation

Example Type III: Educational goals, education setting, needs & requirements, provision

Reasons for using ICF in social medicine

- ICF as an optimal reporting structure provides a
 - state of the art model of disability
 - structure and dimensions of what to measure
 - comprehensive platform to monitor UN-CRPD implementation
 - Rosetta stone for functioning and disability information
- ICF as the basis for process legitimacy
 - Fairness
 - Transparency
 - Impartiality
 - Comparability

Lessons Learned from using ICF

It entails a process of institutional and policy reform which requires:

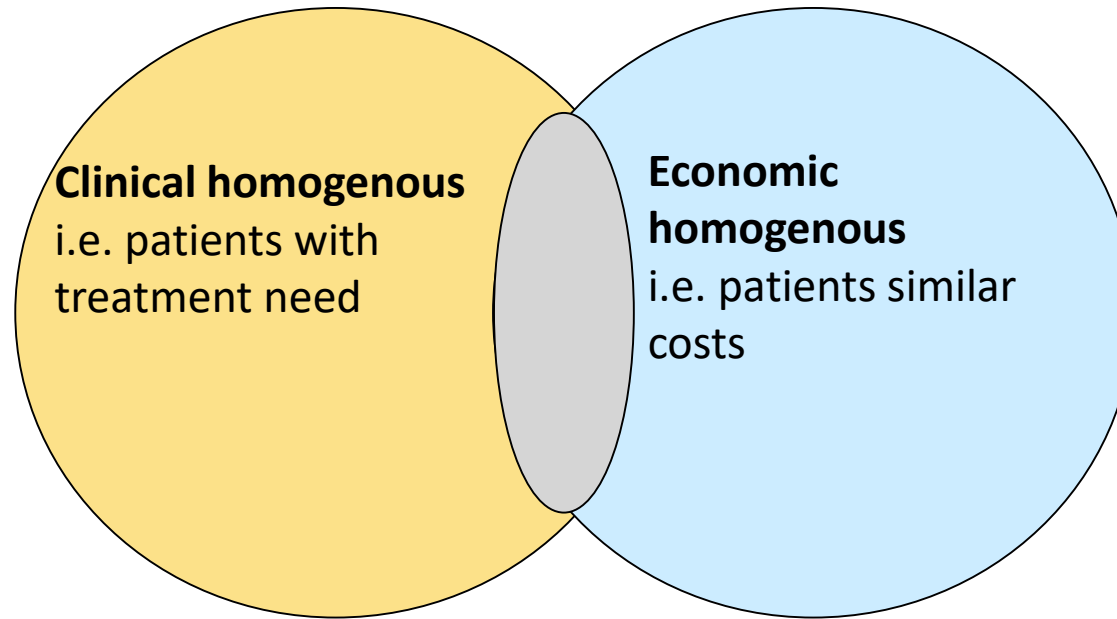
- formal regulation and legislation
- Implementation through institutional and organizational structures
- involvement of a cadre of professionals implementing the rules and in response to legitimate interests of multiple stakeholders
- management of a technical and political process
- consideration of financial implication (i.e. disability assessment is an important fiscal “gate keeper”)
- careful planning and persistent implementation



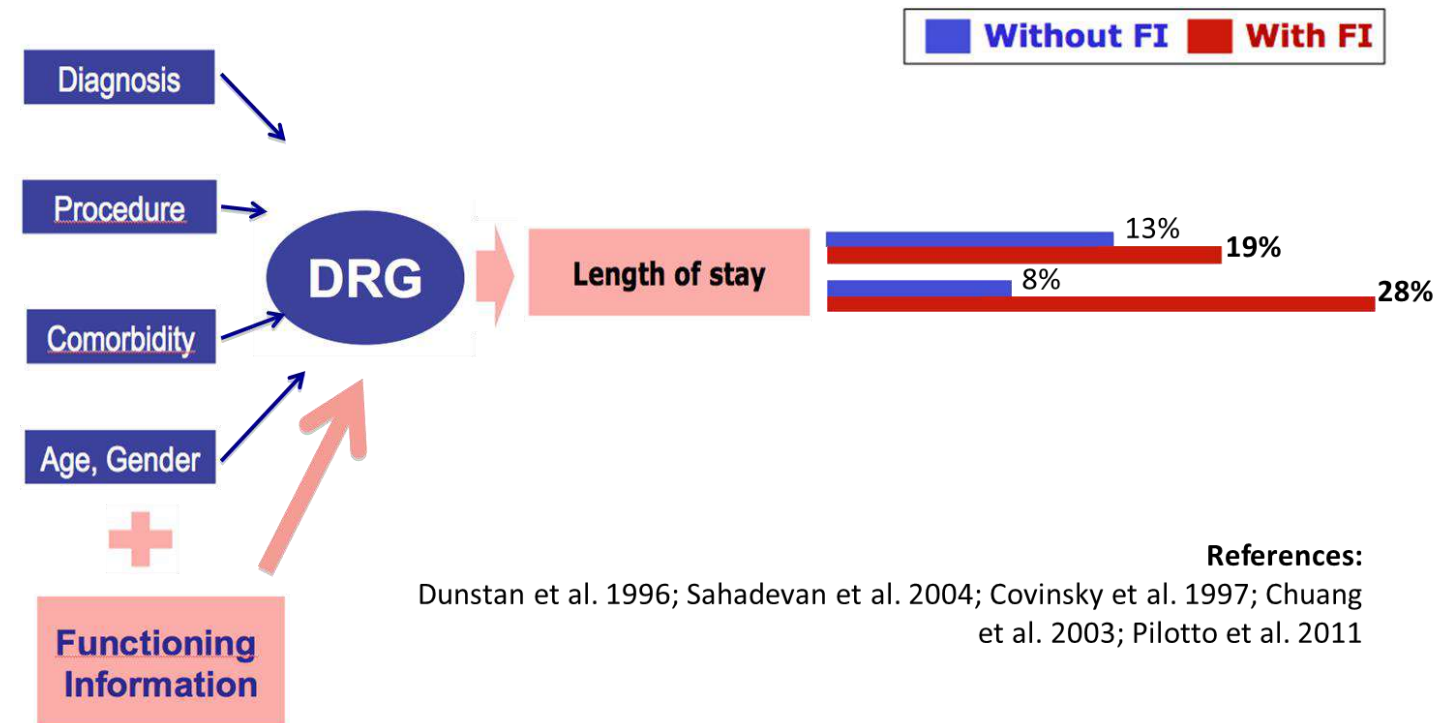
Who is assessing?

- As disability assessors MDs have different roles (therapist vs neutral expert) and objectives (help and heal vs. make informed decision in a admin/legal context)
- MDs vs interdisciplinary teams
- Doctors do not learn disability evaluation
 - No Education in Medical Schools
 - Self-education by a brochure, which is open to the public
 - No studies or investigations on the disability evaluation schemes

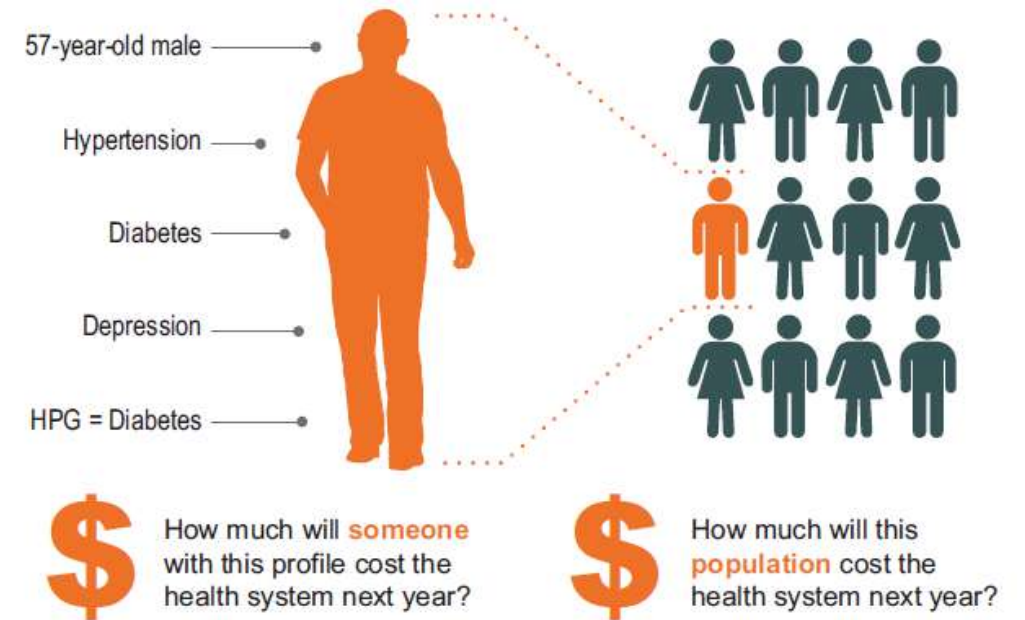
Functioning information & ICF & in reimbursement (case-mix) systems



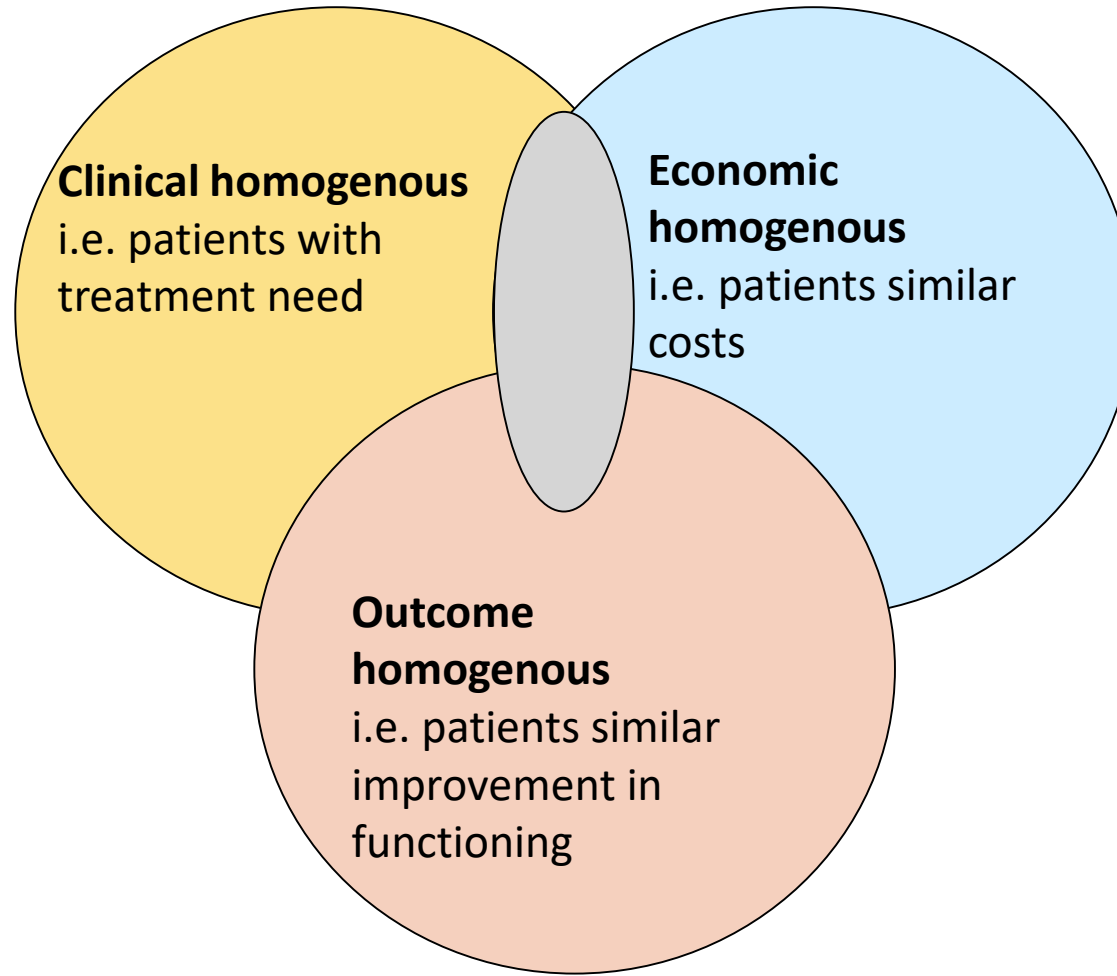
Functioning information & ICF & in reimbursement (case-mix) systems (cont.)



Clinical classification and predictive indicators



Functioning information & ICF & in reimbursement (case-mix) systems (cont.)



Use of ICF in Health and Disability Statistics

● Data collection

- Multi-Country Studies: Global Study on Ageing (SAGE), World Mental Health Survey (WMHS), World Health Survey (WHS), WHO Multi-Country Survey Study (MCSS)
- National surveys

● Data compilation and analysis

- WHO World Report on Disability: ICF based disability prevalence and multi-domain functioning levels
- EU funded Project on Measurement of Health and Disability in Europe (MHADIE)
- Australian Data Dictionary

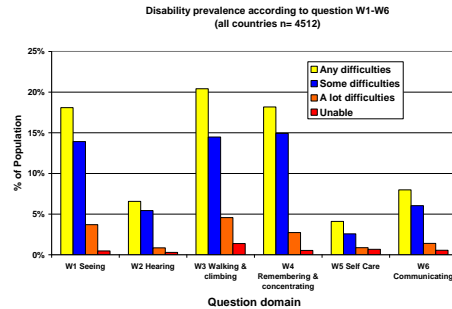
● Module & question set development

- WHO Model Disability Survey (MDS)
- EUROSTAT Survey Module on “Disability and Social Integration”
- Washington Group City Group on Disability Statistics

Advantages of using an ICF based approach in Health and Disability Statistics

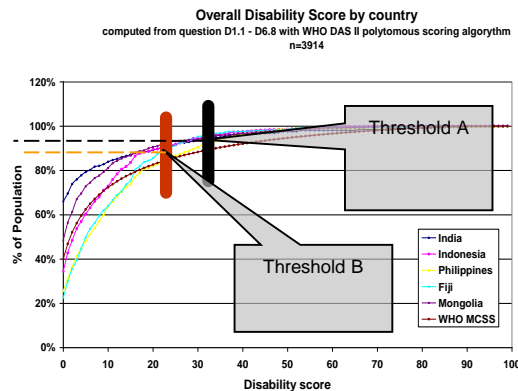
– Impairment based: "counting the disabled"

- Numbers are **limited** in terms of **accuracy and comparability**
 - **Certain groups are missed**
- Data sets have **limited utility**
 - **Fixed prevalence rate** data set cannot be used further exploration
 - Statistics do not indicate the service need



– Based on ICF : Multidimensional, universal & continuum

- Numbers are **more accurate and comparable**
 - Include different life domains
 - Capture **multiple groups** of disability- irrespective of cause
- Data sets have **more utility**
 - Measurement can be tailored to suit the purpose
 - Choices for **threshold can be explicitly stated at point of analysis** (posteriori definition)
 - **Multiple and scalable prevalence rates** same data set can be used for various purposes
 - Can be linked with health & disability surveys
 - Integration and aggregation of population and service-based data sources



Counting disability in the WDR

Achievements & Findings



- Disability is a **major public health issue**
 - **1,000,000,000 people** with disabilities (15% of global population)
 - **110-190 million (2%)** have **severe or extreme** difficulties in functioning
 - First global disability prevalence rate after 40 years
- Comparable measurement of disability
 - **using data standards -> ICF**
- To improve the quality & utility of national reported prevalence data **countries need to measure**
 - **functioning levels at multiple domains**
 - **use a comprehensive measures**

Disability data is multidimensional...

- Information about functioning of basic body parts or organs **IMPAIRMENT**

+

- Information about capacity of person to do basic or complex actions **ACTIVITY**

+

- Information about extent of person's participation in society **PARTICIPATION**

+

- Information about the impact of person's **ENVIRONMENT**

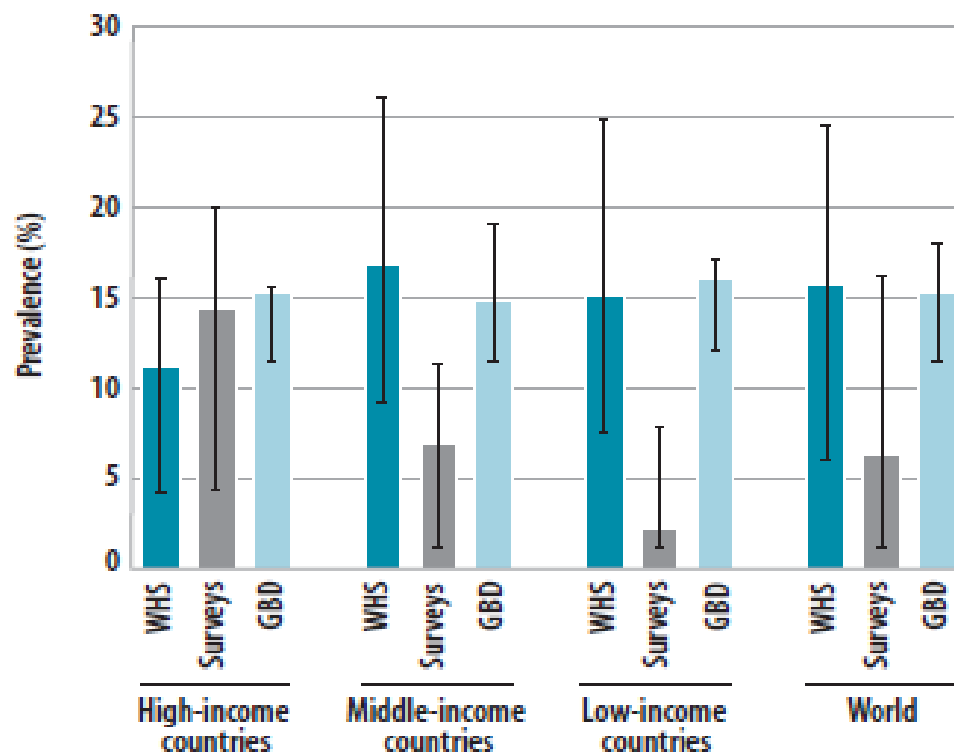
...but:

Only 70 out of 193 countries surveyed in 2011 collect A/P information in census and disability surveys

WRD 2011

Counting disability in the WDR

Fig. 2.1. Global disability prevalence estimates from different sources



Triangulation of three data sources:

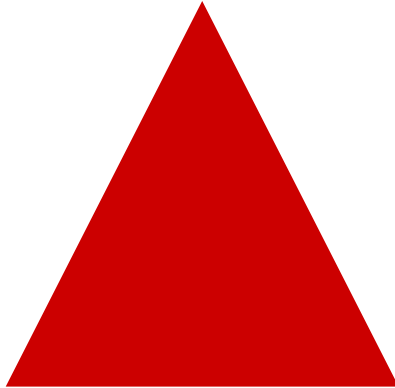
- country reported data
- GBD estimates
- World Health Surveys

- country reported data from LMIC is **under-estimating** disability

- Variation of prevalence data

Order & wording of Disability survey and census questions

Examples

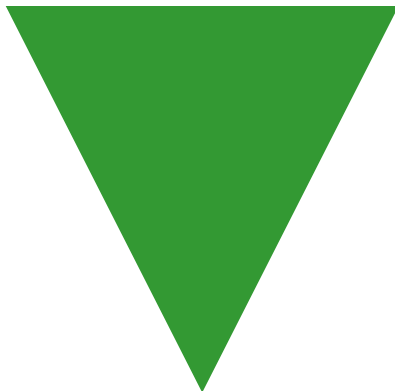


"God forbid someone should have a disability, but if they do are they: blind, deaf/dumb, crippled, mentally retarded/insane, multiple, other?"

How did they become disabled?"

"Are you blind?"

If Yes, do you have any difficulty with the following activities...?"



Do you need someone to help with, or be with them for, self care activities?

For example: doing everyday activities such as eating, showering, dressing or toileting".

"Do you have any difficulty with the following activities...?"

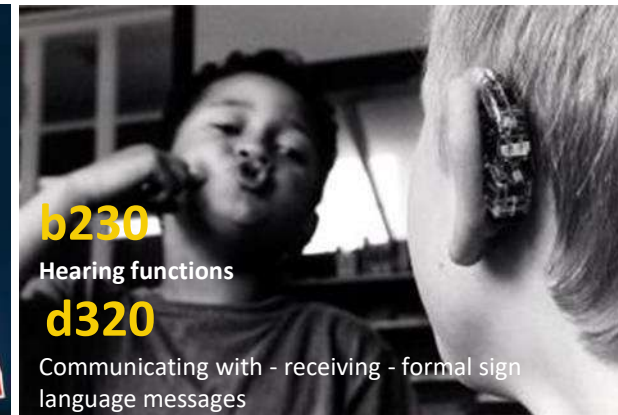
If Yes, are you blind?"

Counting and Reporting starts with a code....

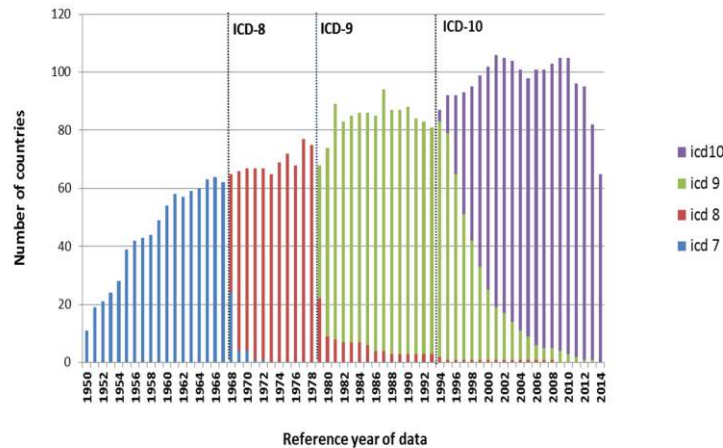
Mortality

Morbidity

Functioning / Disability



Trends in cause-of-death reporting by ICD revision



Title of GBD cause	ICD-9 4digit	ICD-10 4digit
Noncommunicable diseases	140-242, 244-259, 270-279 (minus 279.5), 282-285 (minus 285.9), 286-319, 324-380, 383-459, 470-478, 490-611, 617-629, 680-759, 7980	C00-C97, D00-D48, D55-D64 (minus D 64.9) D65-D89, E03-E07, E10-E16, E20-E34, E65-E88, F01-F99, G06-G98 (minus G14), H00-H61, H68-H93, I00-I99, J30-J98, K00-K92, N00-N64, N75-N98, L00-L98, M00-M99, Q00-Q99, X41, X42, X45, R95
A. Malignant neoplasms	140-208	C00-C97
1. Mouth and oropharynx cancers	140-149	C00-C14
a. Lip and oral cavity	140-145	C00-C08
b. Nasopharynx	147	C11
c. Other pharynx	146, 148, 149	C09-C10, C12-C14
2. Oesophagus cancer	150	C15
3. Stomach cancer	151	C16
4. Colon and rectum cancers	153, 154	C18-C21
5. Liver cancer	155	C22
6. Pancreas cancer	157	C25
7. Trachea, bronchus, lung cancers	162	C33-C34
8. Melanoma and other skin cancers	172-173	C43-C44
a. Malignant skin melanoma	172	C43
b. Non-melanoma skin cancer	173	C44
9. Breast cancer	174, 175	C50
10. Cervix uteri cancer	180	C53
11. Corpus uteri cancer	179, 182	C54-C55
12. Ovary cancer	183	C56
13. Prostate cancer	185	C61
14. Testicular cancer	186	C62
15. Kidney and ureter cancer	189	C64-C66
16. Bladder cancer	188	C67

Technical appendix A

Estimates of disability prevalence (% and of years of health lost due to disability (YLD), by country

Member State	Disability prevalence (with 95% CI)	Year	CI2 (component)	Prevalence	Year	CI2 (component)	YLD (per 100,000 population in 2008)
1 Afghanistan		2005	imp, AL, PR	2.7 (1)			15.3
2 Albania		2008	imp	3.4 (2)			7.6
3 Algeria		1992	imp	1.2 (1)			8.0
4 Andorra							6.8
5 Angola							14.4
6 Argentina and Barbados							8.8
7 Argentina		2002	imp, AL	7.3 (4)			8.7
8 Armenia							7.9
9 Australia		2006		6.4 (1)	2008		20.9 (4)
10 Austria		2002	imp	12.8 (7)			8.7
11 Azerbaijan							8.2
12 Bahamas		2000	imp	8.3 (8)	2003	imp	5.7 (8)
13 Bahrain		1993	imp	0.8 (1)			7.6
14 Bangladesh	31.9				2005	imp	2.5 (7)
15 Barbados		2002	imp	8.6 (1)			8.5
16 Belarus							8.4
17 Belgium		2002	imp, AL, PR	18.4 (7)			8.9
18 Benin		2000	imp, AL, PR	5.9 (1)			18.0
19 Bermuda		2002	imp	2.5 (1)	1999		1.3 (1)
20 Bhutan		2005	imp	3.4 (1)	2000	imp	3.5 (7)
21 Bolivia (Plurinational State of)		2003	imp	3.1 (1)	2003	imp	3.8 (7)
22 Botswana and Kirgizstan	14.8						7.6
23 Brazil		2001	imp	8.5 (4)			11.8
24 Brunei Darussalam	18.9	2000	imp	14.9 (3)	1981	imp	1.8 (7)
25 Bulgaria							7.8
26 Burkina Faso							7.9
27 Burundi							12.3
28 Burkina Faso	13.9						13.5
29 Burundi							13.5

Disease & Disorders are ICD coded...

SGB

Sozialgesetzbuch

Rehabilitation und Teilhabe
behinderter Menschen

Neuntes Buch (IX)



D. Wurde ein Auftrag auf Pflegebedürftigkeit nach dem Pflege-Versicherungs-Gesetz gestellt?

Pflegestufe _____ Schwerbehinderung anerkannt nein ja GdB _____ Merkzeichen _____

II. Klinische Anamnese

Clinical Anamnesis

Beschwerden des Versicherten (seit wann?) und Verlauf

Diabetes mell. seit Jahren bekannt. Vor 1/2 Jahr Myokardinfarkt, AHB/AR nicht durchgeführt.
Seit MI Luftnot beim Treppensteigen und langsamen Spazierengehen. Kann keine Einkaufstaschen mehr tragen. Hat seine Erkrankung noch nicht verarbeitet und ist depressiv gestimmt. Auch in der Familie zieht er sich zurück und spielt beispielsweise nicht mehr mit den Enkeln, weil es ihm zu anstrengend ist.

III. Rehabilitationsrelevante und weitere Diagnosen

1. Chronische ischämische Herzkrankheit

Diagnoses relevant
for Rehabilitation

nach ICD 10

I25.8

2. Diabetes mellitus

E11

3. Leichte depressive Episode

F32.0

Diagnose(n) Nummer(n)

ist/sind zurückzuführen auf

Arbeitsunfall, Schulunfall

sonstiger Unfall

Berufskrankheit

Gesundheitsschaden
nach dem BVG

Original für die Krankenkasse
Durchschlag zum Verbleib beim Vertragsarzt

Quelle: Dr Wolfgang Seger

Functioning profiles are often “only” documented with ICF

Vorname, Name des Versicherten Albert Reiter	Kassen-Nr.	Versicherten-Nr.	61 Teil B
---	------------	------------------	-----------

Verordnung von medizinischer Rehabilitation

IV. Rehabilitationsbedürftigkeit (medizinische Befunderhebung)

A. Rehabilitationsrelevante Schädigungen (ggf. Befundbögen als Anlage) **Impairments of Body Functions and Structures**

Hochgradig reduzierte linksventrikuläre Funktion (EF < 30%).

Mittelschwere Schädigung der kardiopulmonalen Funktion

Vorderwandaneurysma mit Thrombus, deshalb Marcumarisierung

Diabetes mellitus mäßig eingestellt

B. Nicht nur vorübergehende alltagsrelevante Beeinträchtigungen der Aktivitäten und/oder Teilhabe

	keine Beeinträchtigungen	erheblich eingeschränkt (versorgt mit Hilfsmitteln)	personelle Hilfe nötig	nicht durchführbar
Kommunikation (z. B. Sprechen, Sehen, Hören, Schreiben) Communication	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mobilität (z. B. Wechsel Körperhaltung, Tragen, Hand- und Armgebrauch, Gehen, Treppensteigen, Laufen, Bücken) Mobility	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Selbstversorgung (z. B. Hygiene, An-/Auskleiden, Nahrungszubereitung/-aufnahme) Self-Care	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Häusliches Leben (z. B. Haushaltsführung) Domestic Life	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interpersonelle Aktivitäten (z. B. Verhalten, Aufrechterhalten der sozialen Integration) Interpersonal interactions and relationships	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bedeutende Lebensbereiche (z. B. Arbeit und Beschäftigung) Major Life Areas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sonstiges	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other Items

Aktuelle Assessment-Ergebnisse soweit vorhanden (z. B. Barthel-Index) **Ergometrie: Abbruch durch Pat. bei 50 Watt**

6-MGT: 180 m, HbA1c: 8,3 %, BMI 32 kg/m², PHQ-D*: 11 Punkte * Patients-Health-Questionnaire

C. Rehabilitationsrelevante positiv/negativ wirkende Kontextfaktoren, soweit noch nicht ausgeführt

Persönliches und familiäres Umfeld (z. B. familiäre Unterstützung, Wohnsituation, Beziehungskonflikte, Pflege eines Angehörigen, Tod eines nahe stehenden Angehörigen)

Eheprobleme seit MI, die Ehefrau ist zunehmend gereizt. Sie ist der Meinung, ihr Mann lasse sich zu sehr hängen.

Personal Factors and Familial Environment

Berufliches/schulisches Umfeld (z. B. drohender Arbeitsplatzverlust, Überforderungssituation)

Occupational / Scholastic Environment

Soziales Umfeld (z. B. Unterstützung durch soziale Dienste, sprachliche Verständigungsschwierigkeiten)

Pat. fühlt sich mit der Betreuung des Enkelkinds überfordert

Social Environment

Risikofaktoren

Nikotin Alkoholmissbrauch Übergewicht Bewegungsmangel

Risk Factors

Drogenmissbrauch/Medikamentenmissbrauch Sonstiges

Original für die Krankenkasse
Durchschlag zum Verbleib beim Vertragsarzt

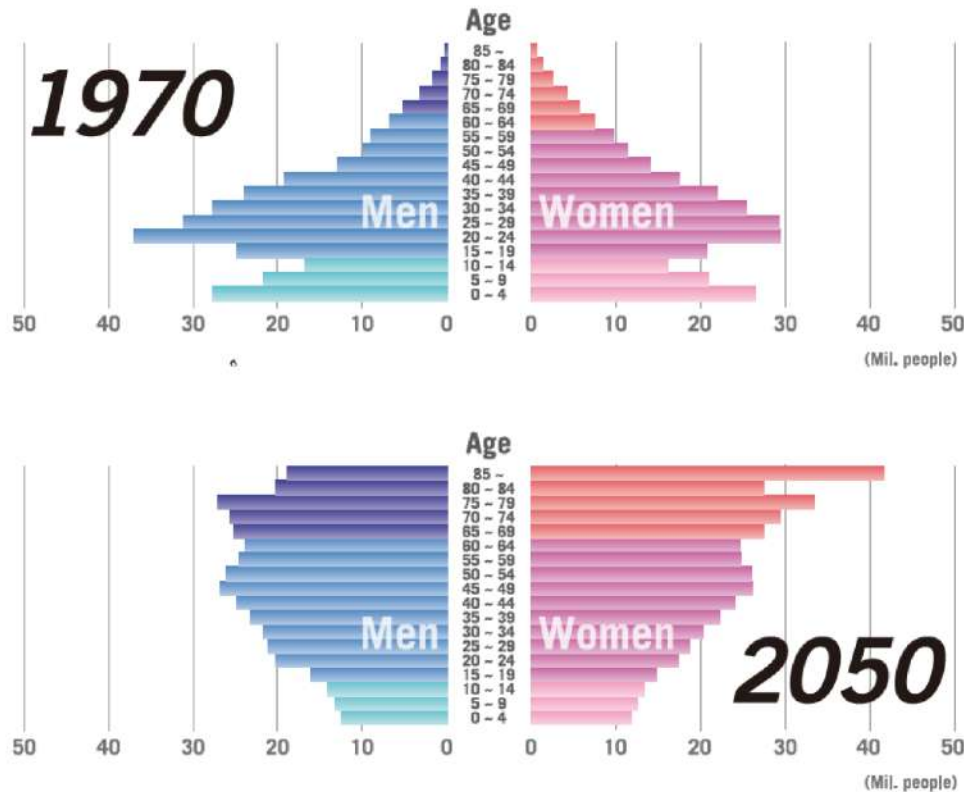
ICF Implementation

- Use of ICF as **conceptual** framework
- Use of ICF categories and definitions for **documentation**
- **Coding** with ICF and **reporting** of ICF coded data



The need for ICF coded functioning data will increase because ...

Population Pyramid of Kanagawa



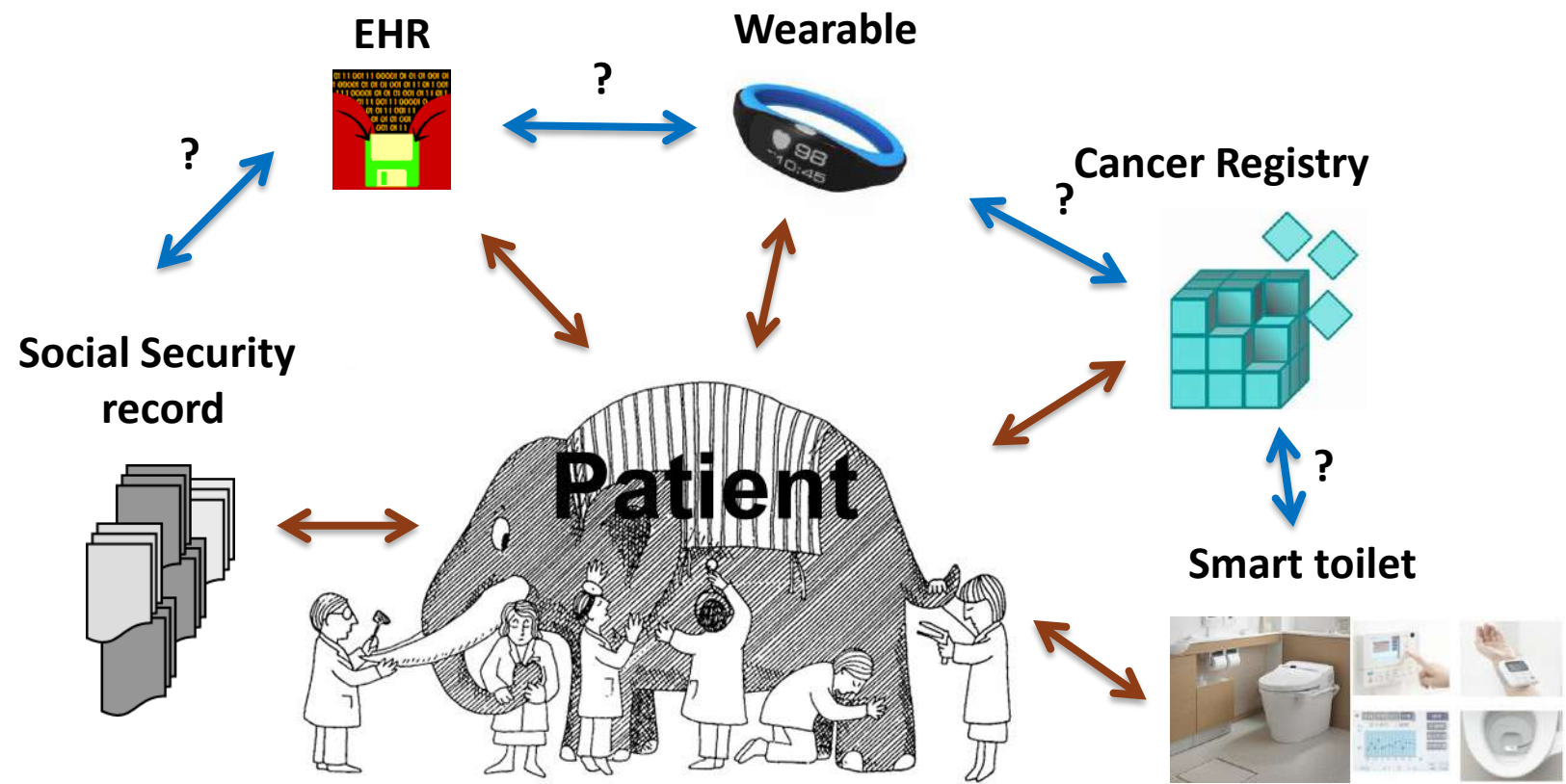
● Epi transition

- Aging & Super-aging societies
- Increased life expectancies & comorbidities and
- Decline in infectious disease, raise in NCDs
- Prolonged and alternating functioning
- Personalised Medicine (Genetics & EF interaction)

● Big data, technology & predictive analytics allows

- to **understand comorbidities** (pattern, drivers, causal mechanisms)
- to **identify** an **individual's** disease and functioning trajectory
- to **know where** on the trajectory an individual's is
- to **change** an individual's disease and functioning trajectories

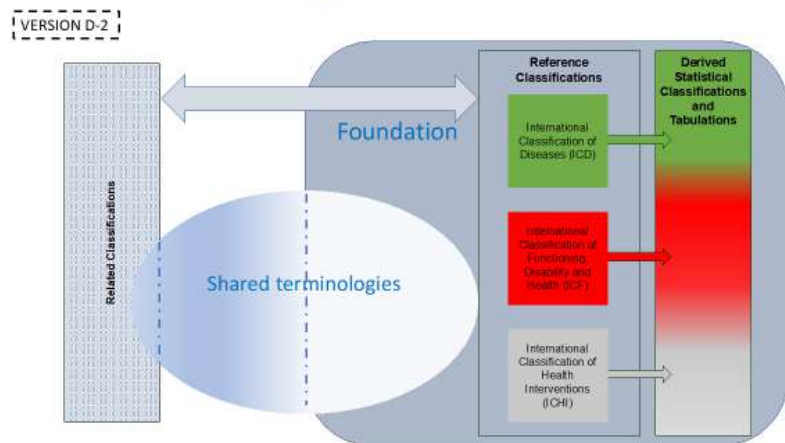
Problems with (BIG) data in health



- Are international data standards used? If yes, how?
- Integration & interoperability
- Governance issues
 - Transparency
 - Open source vs. closed source
 - Privacy & Ethics
- Others

To respond to this needs ICF has to be modernized

The Family – integrated health information



● Needed ICF developments

- Foundation layer
- Index terms
- Unique Identifiers
- Tooling environment (e.g. coding tool, APIs)

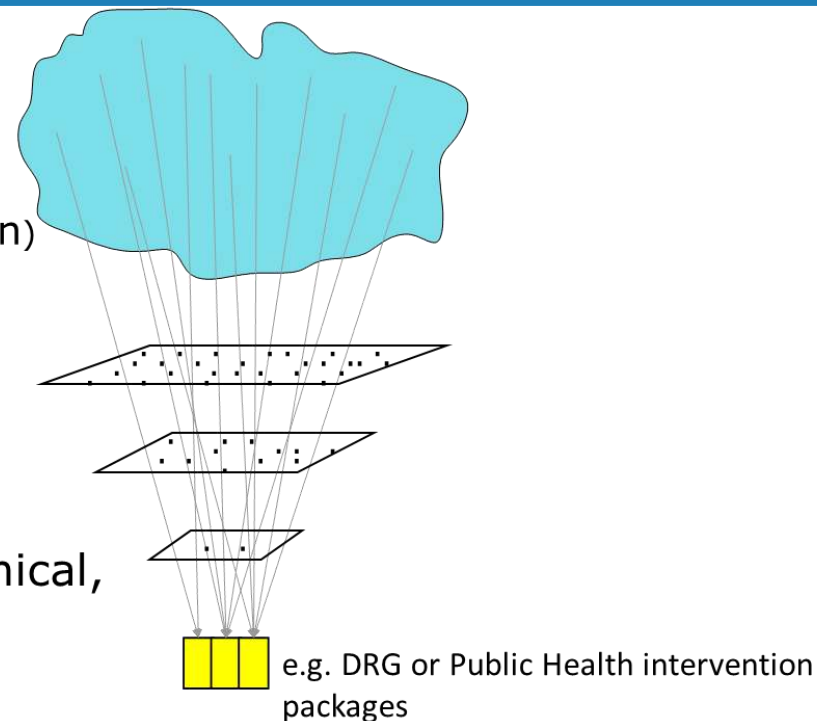
Reality 1: (individual detail)

↓
Free Text (Diagnostic information)

↓
ICD-11 & ICF index terms

↓
ICD-11 & ICF Categories

↓
Reality 2: (public health, clinical, administrative needs)



Adapted from Straub

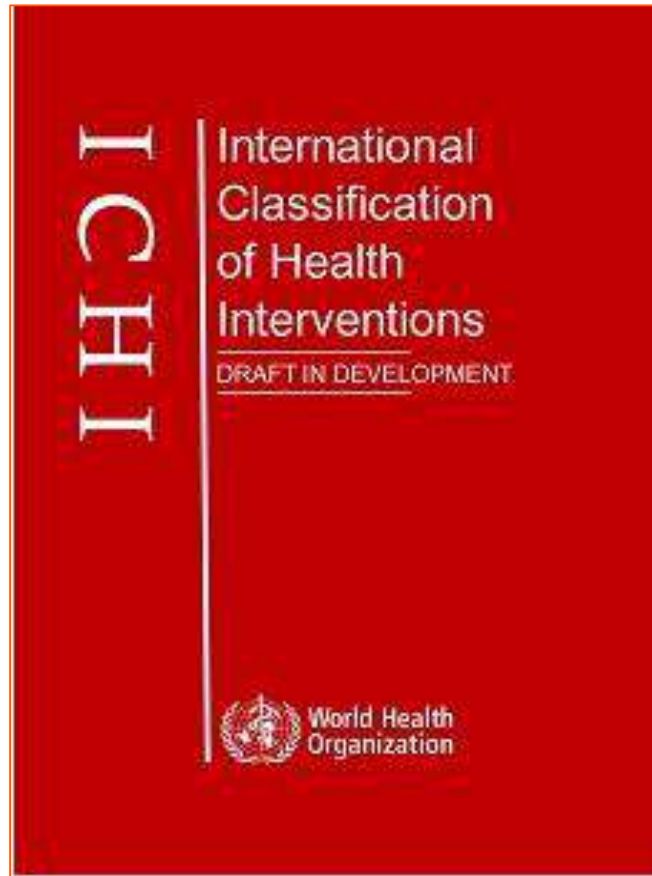
Why a supplementary section for functioning in ICD-11



- Using the Functioning section in ICD-11
 - Option1: **Structured assessment** with WHO-DAS 2.0 allowing to generate an overall and domain specific functioning score
 - Option 2: **Selection of generic functioning domains** allowing to generate a functioning profile
- **Enable**
 - **joint use** of ICD & ICF (code once – use multiple times)
 - **coding** of functioning data & **reporting** of coded
 - **standardization** & international **comparability** of functioning data using global public goods
- **Entry point** ICD users to understand the “value proposition” of ICF - **not recreating ICF in ICD.**

International Classification of Health Interventions (ICHI)

(in development)



Target			
A	Body Part(s) or Anatomical site(s)	D	Environment
B	Body Function	E	Health related Behaviour
C	Activities and Participation		
Action			
A	Diagnostic	C	Managing
B	Therapeutic	D	Preventing
Means			
A	Approach	C	Method
B	Technique	D	Sample
Extension codes (Use when needed)			
A	Therapeutic products		
B	Assistive products		
C	Medicaments		
D	Telehealth		
E	Other (optional) codes		

KBO.JK.AA – Appendicectomy

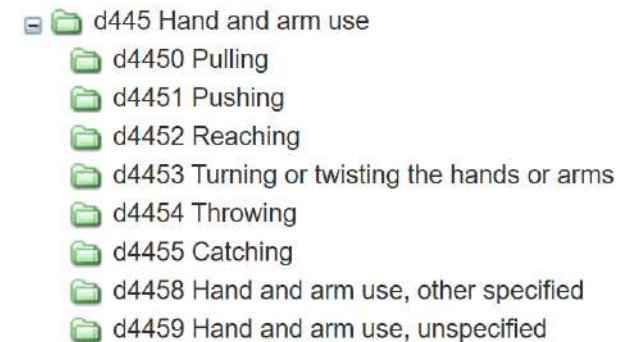
Target KBO - Appendix

Action JK - Excision, total

Means AA - Open approach

Developing ICF index

- Itemization of existing ICF inclusion and exclusion terms
- Identify and analyze resources
 - Raw functioning terms from “real life” records e.g.
 - The patient ambulates with front wheeled walker for 300ft
 - 'pulls', 'move', 'straighten', 'pushed', 'pushing', 'pulled', 'push', 'lift', 'pulling' ->
 - frequency of
 - Standardized vocabularies
 - Linguistic and ontological resources
- Development of ICF tooling environments
- Develop and validate the ICF index terms



Thank you

