Assessment of disability for 21st century

ALEKSANDRA POSARAC, LEAD ECONOMIST, WORLD BANK
Preliminaries...

**Disability assessment**: process to determine a) if there is a disability; b) extent of disability

**Disability determination (evaluation)**: process to determine whether person is legally disabled, and satisfies other legal criteria (age, income, geographical location, etc.)

**Disability eligibility**: process to determines needs and eligible for available services and supports.
OVERALL DISABILITY DETERMINATION PROCESS

DISABILITY ASSESSMENT

Disability and extent

Person is legally disabled

Needs and eligible supports and services
Historically, disability assessment has been closely tied to medical sciences and medical professions, both for perceived legitimacy and certainty.
Disability assessment: global review
Three approaches to Disability Assessment:

- IMPAIRMENT APPROACH
- FUNCTIONAL LIMITATION APPROACH
- DISABILITY APPROACH
IMPAIRMENT APPROACH

Making a determination of the existence and extent of ‘disability’ based entirely on medical information about health conditions, morbidity and/or resulting impairments.

*This is the oldest and still most commonly used strategy*
## IMPAIRMENT APPROACH

### 'Bareme' Assessment

<table>
<thead>
<tr>
<th>Amputation</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thumb, including metacarpal</td>
<td>20.</td>
</tr>
<tr>
<td>Thumb, both phalanges</td>
<td>15.</td>
</tr>
<tr>
<td>Thumb, one phalanx</td>
<td>10.</td>
</tr>
<tr>
<td>Finger, index</td>
<td>5.</td>
</tr>
<tr>
<td>Finger, index at P.I.P.</td>
<td>4.</td>
</tr>
<tr>
<td>Finger, index at distal</td>
<td>2.</td>
</tr>
<tr>
<td>Finger, middle</td>
<td>4.</td>
</tr>
<tr>
<td>Finger, middle at P.I.P.</td>
<td>3.2</td>
</tr>
<tr>
<td>Finger, middle at distal</td>
<td>1.6</td>
</tr>
<tr>
<td>Finger, ring</td>
<td>3.</td>
</tr>
<tr>
<td>Finger, ring at P.I.P.</td>
<td>2.4</td>
</tr>
<tr>
<td>Finger, ring at distal</td>
<td>1.2</td>
</tr>
<tr>
<td>Finger, little</td>
<td>2.</td>
</tr>
<tr>
<td>Finger, little at P.I.P.</td>
<td>1.6</td>
</tr>
<tr>
<td>Finger, little at distal</td>
<td>.8</td>
</tr>
</tbody>
</table>

**Figure 2.1: Bareme Table and Chart for the Hand**

- Index
- Middle
- Ring
- Little

- Thumb
- Metacarpal
- Proximal (P.I.P.)
- Distal

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Expanding the Impairment approach by adding information about basic simple actions – lifting, standing, handling, hearing, seeing, and concentrating – to determine ‘disability’ and ‘work capacity’.

The application of this approach has led to development of Functional Capacity Evaluation (FCE) instruments.
<table>
<thead>
<tr>
<th>FIM™ instrument</th>
<th>NO HELPER</th>
<th>HELPER</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Modified Dependence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Supervision (Subject = 100%+)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Minimal Assist (Subject = 75%+)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Moderate Assist (Subject = 50%+)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Complete Dependence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Maximal Assist (Subject = 25%+)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Total Assist (Subject = less than 25%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Self-Care</strong></td>
<td>A. Eating</td>
<td>B. Grooming</td>
</tr>
<tr>
<td><strong>Sphincter Control</strong></td>
<td>G. Bladder Management</td>
<td>H. Bowel Management</td>
</tr>
<tr>
<td><strong>Transfers</strong></td>
<td>I. Bed, Chair, Wheelchair</td>
<td>J. Toilet</td>
</tr>
<tr>
<td><strong>Locomotion</strong></td>
<td>L. Walk/Wheelchair</td>
<td>M. Stairs</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td>N. Comprehension</td>
<td>O. Expression</td>
</tr>
<tr>
<td><strong>Social Cognition</strong></td>
<td>P. Social Interaction</td>
<td>Q. Problem Solving</td>
</tr>
<tr>
<td><strong>Cognitive Subtotal Score</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL FIM Score</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Note:** Leave no blanks. Enter 1 if patient not testable due to risk.

- Eating
- Grooming
- Bathing
- Upper body dressing
- Lower body dressing
- Toileting
- Bladder management
- Bowel management
- Bed to chair transfer
- Toilet transfer
- Shower transfer
- Locomotion (ambulatory or wheelchair level),
- Climbing stairs
- Cognitive comprehension
- Expression
- Social interaction
- Problem solving
- Memory
Providing a full and direct description of all relevant dimensions of, for example, work capacity, including health condition, impairments, functional limitations and personal and environmental factors.

This approach is based on the WHO ICF model of disability.
IMPAIREDMENT APPROACH

FUNCTIONAL LIMITATION APPROACH

DO NOT ASSESS DISABILITY

ASSESS A PROXY FOR DISABILITY

✓ Health conditions
✓ Impairments
✓ Basic activities or ADL
GLOBAL SITUATION:

Impairment or Bareme approach has been standard since late 18th century: simple and politically legitimate.

But has always been seen as invalid and unreliable.

Hence the Functional Capacity approach which is now popular...although it too is known to be invalid and unreliable.
GLOBAL SITUATION:

Although Disability Approach requires more information (cost), in use it reduces overall costs

So: more countries are turning to the Disability Approach
What difference can ICF make in Disability Assessment?
International Classification of Functioning, Disability and Health (WHO, 2001)

ICF

International, evidence-based epidemiological classification based on

the Interactive Model of Disability
The Interactive Model...

'IMPAIRMENT'  "ENVIRONMENT"

FUNCTIONING & DISABILITY
ICF ‘BIOPSYCHOSOCIAL’ model

Health Condition
(disorder/disease)

Body function & structure
(Impairment)

Activities
(Limitation)

Participation
(Restriction)

Environmental Factors

Personal Factors
ICF is the only available basis for the DISABILITY APPROACH to Disability Assessment.
Advantages of using ICF for Disability Assessment

• ICF as an optimal reporting structure
  – Provides What to Measure and How to Measure.
  – International standard for functioning and disability information

• ICF guarantees process legitimacy

• ICF is a platform for assessment and measurement

• ICF-based information relevant to CRPD
Obstacles to transitioning to ICF approach:

- Perceived and real costs of transition
- Perception that ICF will bias toward fewer or more successful beneficiaries.
- Need for progressive transition.
- Need to integrate disability assessment into system-wide changes
ICF

... and the *Convention on the Rights of Persons with Disabilities*
CRPD committee comments on disability assessment

Czech Republic

The Committee calls upon the State party to amend the definitions of disability and persons with disabilities in its legislation and to make explicit reference to the barriers faced by persons with disabilities in the above-mentioned definitions, in order to harmonize them with the definitions in the Convention.

Korea:

The Committee recommends that the State party review the current disability determination and rating system under the Welfare of Disabled Persons Act to ensure that the assessment reflects the characteristics, circumstances and needs of persons with disabilities(…)

Turkmenistan:

The Committee recommends that the State party review and harmonize its legislation with the Convention, including by adopting a social and human rights model of disability. The State party should also ensure the involvement of experts from social, labour and education fields within the assessment panels on disability determination.

The Committee recommends that the process of inclusive education of students with disabilities be not dependent solely and exclusively on the decision of a commission for the medical-educational assessment only but also on providing pupils with disabilities with accessible conditions in schools and on ensuring that they are free to decide on the vocational training they want to receive.

The Committee further recommends eliminating the reported practice of classifying persons with disabilities as “unemployable”.

Costa Rica

It notes with concern that the disability assessment criteria used for purposes of medical or social assistance are limited to the medical model of disability. (...) In addition, it urges the State party to ensure that the disability assessment criteria used by the various services are standardized, in line with the Convention

Sweden

it is also concerned about families with disabilities being subjected to additional investigations, carried out by local authorities and social services in the framework of the national adoption system, to assess their parenting ability.

46. The Committee recommends that the State party ensure the prohibition of discrimination on the basis of disability in adoption procedures.
“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.”
CONCLUSION

The best overall disability determination procedure?
Principles of disability determination

Principles of **NATURAL JUSTICE**

…and scientific adequacy

- ✓ TRANSPARENT
- ✓ PARTICIPATION
- ✓ IMPARTIAL REVIEW
- ✓ EVIDENCE-BASED
- ✓ RELIABLE
- ✓ VALID
Principles of disability determination

Principles of CONTENT

✓ Emphasize work participation, not passive recipient of benefits
✓ Assess strengths as well as deficits
✓ Understand the work environment
✓ Integrates supports into assessment
✓ Be individualized and flexible
Functioning is not only about what a person can’t do but also what the person can do

Assess strengths as well as deficits

AVAILABLE CAPACITY
The best overall disability determination procedure?

Impairment and Functional Limitation

The Disability Approach

Legal

DISABILITY ASSESSMENT

DISABILITY DETERMINATION

ELIGIBILITY
CASE STUDY
CASE STUDY: TAIWAN

**Medical:** Health Condition, Body Functions and Structures

**Rehabilitation:** Activities, Participation and Environment

**ICF Multi-disciplinary Needs Assessment**

**Certificate of Disability Assessment Outcome**

**DISABILITY ASSESSMENT**

**DISABILITY DETERMINATION**

**ELIGIBILITY**
CASE STUDY: TAIWAN

Disabling condition

- Disease, illness, or other health problems
- Injuries
- Mental or emotional problems

Body Functions and Structures

- b110
- b117
- b122
- b139
- b140
- b144
- b147
- b152
- b160
- b164
- b167
- b16701
- b16711
- b210
- b239
- b235
- b310
- b320
- b330
- b320
- s330
- s440
- b410
- b415
- b430
- s510
- s530
- s540
- b610
- b620
- b710
- b730
- b75
- b765
- s730
- s750
- s760
- b810
- b830
- s810

Activities

- FUNDES-Adult version Part d (≥18 years) (86 items)
  - Domain 1: Cognition
  - Domain 2: Mobility
  - Domain 3: Self-care
  - Domain 4: Getting along with others
  - Domain 5: Life activities
  - Domain 6: Participation
  - Domain 8: Motor action
- FUNDES-Child version Participation Part. (6.0-17.9 years old) (40 items)
  - Domain 1: Home participation
  - Domain 2: Neighborhood and community participation
  - Domain 3: School participation
  - Domain 4: Home and community living activities

Environmental Factors

- Child and Adolescent Scale of Environment (18 items)

Personal Factors

- Age, sex, pre-morbid disability, duration of disability, education level, expressed needs, and others.
## CASE STUDY: TAIWAN

### 1. FUNDES

#### FUNDES - ADULT

Appendix 1. Items of the eight domains of the Functioning Scale of the Disability Evaluation System 7.0 - Adult Version.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Items and labels</th>
<th>ICF-code linking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do1 Cognition (6 items)*</td>
<td>D1.1 Concentration</td>
<td>d140 Attention functions; d160 Focusing attention; d110 - d129 Purposeful sensory experiences</td>
</tr>
<tr>
<td></td>
<td>D1.2 Remembering to do important things</td>
<td>d184 Memory functions; d119 Basic learning, other specified and unspecified</td>
</tr>
<tr>
<td></td>
<td>D1.3 Problem-solving</td>
<td>d175 Solving problems; d120 - d159 Basic learning; d177 Making decisions</td>
</tr>
<tr>
<td></td>
<td>D1.4 Learning a new task</td>
<td>d1551 Acquiring complex skills</td>
</tr>
<tr>
<td></td>
<td>D1.5 Understanding</td>
<td>d310 Communicating with - receiving - spoken messages</td>
</tr>
<tr>
<td></td>
<td>D1.6 Conversation</td>
<td>d3040 Starting a conversation; d3001 Sustaining a conversation</td>
</tr>
<tr>
<td>Do2 Mobility (5 items)*</td>
<td>D2.1 Standing for long periods</td>
<td>d4154 Maintaining a standing position</td>
</tr>
<tr>
<td></td>
<td>D2.2 Standing up from sitting</td>
<td>d4104 Standing</td>
</tr>
<tr>
<td></td>
<td>D2.3 Moving around inside home</td>
<td>d4600 Moving around within the home</td>
</tr>
<tr>
<td></td>
<td>D2.4 Getting out of home</td>
<td>d4650 Moving around outside the home and other buildings</td>
</tr>
<tr>
<td></td>
<td>D2.5 Walking a long distance</td>
<td>d5201 Washing whole body</td>
</tr>
<tr>
<td>Do3 Self-care (4 items)*</td>
<td>D2.1 Washing whole body</td>
<td>d5101 Washing whole body</td>
</tr>
<tr>
<td></td>
<td>D2.2 Getting dressed</td>
<td>d5400 Dressing</td>
</tr>
<tr>
<td></td>
<td>D2.3 Eating</td>
<td>d5300 Eating</td>
</tr>
<tr>
<td></td>
<td>D2.4 Staying by self for a few days</td>
<td>d5102 - d550 Combinations of multiple self-care and domestic life tasks</td>
</tr>
<tr>
<td>Do4 Getting along (5 items)*</td>
<td>D4.1 Dealing with strangers</td>
<td>d790 Relating with strangers</td>
</tr>
<tr>
<td></td>
<td>D4.2 Maintaining a friendship</td>
<td>d7500 Informal relationships with friends</td>
</tr>
<tr>
<td></td>
<td>D4.3 Getting along with people close to</td>
<td>d750 Informal social relationships</td>
</tr>
<tr>
<td></td>
<td>D4.4 Making new friends</td>
<td>d7500 Informal relationships with friends</td>
</tr>
<tr>
<td></td>
<td>D4.5 Sexual activities</td>
<td>d7700 Sexual relationships</td>
</tr>
<tr>
<td>Do5 Life activities*</td>
<td>Do5.1 Household responsibilities</td>
<td>d60 Domestic life</td>
</tr>
<tr>
<td></td>
<td>Do5.2 Do important household tasks well</td>
<td>d640 Doing housework; d620 Undertaking a single task; d620 Undertaking multiple tasks</td>
</tr>
<tr>
<td>Do5.3 Do all needed household work</td>
<td>Do5.4 Household work performed as quickly as needed</td>
<td>d640 Doing housework; d620 Undertaking a single task; d620 Undertaking multiple tasks</td>
</tr>
<tr>
<td>Do5.5 Day-to-day work/school</td>
<td>Do5.6 Do important work/school tasks well</td>
<td>d640 Doing housework; d620 Undertaking a single task; d620 Undertaking multiple tasks</td>
</tr>
<tr>
<td>activities (4 items)</td>
<td>Do5.7 Getting done all needed work</td>
<td>d640 Doing housework; d620 Undertaking a single task; d620 Undertaking multiple tasks</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Items with an asterisk (*) indicate activities that are specific to the adult population.
### WHODAS 2.0

**World Health Organization Disability Assessment Schedule 2.0**

#### Section 2: Demographic and background information

This interview has been developed by the World Health Organization (WHO) to better understand the difficulties people may have due to their health conditions. The information that you provide in this interview is confidential and will be used only for research. The interview will take 5-10 minutes to complete.

**For respondents from the general population (not the clinical population) say:**

Even if you are healthy and have no difficulties, I need to ask all of the questions so that the survey is complete.

I will start with some background questions.

<table>
<thead>
<tr>
<th>A1</th>
<th>Record sex as observed</th>
<th>Female</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Male</td>
<td>2</td>
</tr>
<tr>
<td>A2</td>
<td>How old are you now?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A3</td>
<td>How many years in all did you spend studying in school, college or university?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A4</td>
<td>What is your current marital status? (Select the single best option)</td>
<td>Never married</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Currently married</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Separated</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Divorced</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Widowed</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cohabiting</td>
<td>8</td>
</tr>
<tr>
<td>A5</td>
<td>Which describes your present work status best? (Select the single best option)</td>
<td>Paid work</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Self-employed, such as own your business or farming</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Non-paid work, such as volunteer or charity</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Student</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Keeping house/homemaker</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Retired</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unemployed (health reasons)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unemployed (other reasons)</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other (specify)</td>
<td>9</td>
</tr>
</tbody>
</table>
Case study: Greece

- Currently piloting WHODAS12+5 and new administrative processes
- Initial situation:
  - Multiple entry points
  - Multiple assessment systems
  - Different criteria
  - No possibility to monitor, no integration
  - Significant transaction cost on beneficiaries
  - Medical model/ impairment plus chronic diseases, but no links to ICD-10
Greece

Reform (for social welfare benefits, to include contributory social insurance once the pilot is evaluated)

- Administrative processes
  - A single application for social welfare disability benefits
  - One assessment
  - Integrated electronic platform (a unique ID and e-government have enabled it)
  - Medical conditions in line with ICD-10
• Medical assessment (medical board of three physicians)
• WHODAS12+5 assessment

Once the pilot is completed and data analyzed the decision on how to combine/join medical and functionality assessment will be made.
Administration (delivery)

• Absolutely important
• Poor administration can destroy the best design
• A single government body, professional, with high integrity and transparency
• Often under MoL/SA, sometimes under Social Security
• Well defined criteria/ harmonized across agencies, if multiple assessment bodies
• Professional staff
• Electronic platform/ data integration
• Monitoring and evaluation
Useful reading material

Assessing Disability in Working Age Population
A Paradigm Shift: from Impairment and Functional Limitation to the Disability Approach

Jerome Blickenbach, Aleksandra Pesarac, Alarco Cieza, Nenad Kostanjsk

June 13, 2015

GSPO