Practical application of the ICF in Disability & Development: leprosy as a case study

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Contents
- Review ICF
- Disability according to ICF
  - Application in disability measurement
- Examples of application ICF in low and middle-income countries
  - Descriptive studies
  - Comparative studies
  - Analytical studies
  - Effectiveness studies.

International Classification of Functioning, Disability and Health (WHO, 2001)

Two parts, each with two components:

- Part 1. Functioning
  - Body functions and body structures
  - Activities and Participation
- Part 2. Contextual Factors
  - Environmental factors
  - Personal factors.

ICF components
Definition of disability

"Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors."

(Leonardi et al, Lancet 2006)

Impairments

- Visual impairment
- Hearing impairment
- Nerve damage
- Cerebral palsy
- Contractures

Activities

- Walking
- Running
- Sitting
- Reading
- Eating

Activity limitations

- Important to the affected person
- Not usually measured until recently; systematic figures not available.
Activity limitations

Instruments
- Barthel Index
- Functional Independence Measure
- Washington City Group short measure on disability (screening in surveys)
- Green Pastures Activity Scale (rural areas)
- SALSA Scale (neuro-disability)
- WHODAS II.

Participation

- Mobility
- Work / employment
- Interpersonal relationships
- Education
- Community and social life

Participation restrictions

- Very important to the affected person
- Main focus of rehabilitation
- Not usually measured; systematic figures not available.

Participation scales

- London Handicap Scale
  - Harwood et al. 1994
- Perceived Handicap Questionnaire
  - Tate et al. 1994
- Impact on Participation and Autonomy questionnaire
  - Cardol et al. 2001
- Assessment of Life Habits (Life-H)
  - Nonou et al. 2002
- Keele Assessment of Participation
  - Wilke et al. 2005
- Participation Scale
  - van Brakel et al. 2006 (focus on developing countries)
Dichotomous view of disability

Continuous view of (dis-)ability

Example: measurement of participation restrictions (n=1,574)

Impairment / Function based
- Deaf
- Blind
- Mobility impaired
- Learning disability
- Communication disability, etc.
Distribution of types of disability in Indonesia (n=1.36 million) and Morocco (n=2,777)


ICF based
- Focus on functioning
- Focus on perception / experience of persons with disabilities
- Importance of environmental factors
- Importance of holistic perspective on disability.

Recent data – overall disability

<table>
<thead>
<tr>
<th>Country</th>
<th>Year</th>
<th>N</th>
<th>% disability</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zambia</td>
<td>2006</td>
<td>30,000</td>
<td>11</td>
<td>ICF</td>
</tr>
<tr>
<td>Malawi</td>
<td>2004</td>
<td>15,364</td>
<td>10.6</td>
<td>ICF</td>
</tr>
<tr>
<td>Morocco</td>
<td>2006</td>
<td>54,241</td>
<td>5.1</td>
<td>ICF</td>
</tr>
<tr>
<td>Vietnam</td>
<td>2006</td>
<td>Large (?)</td>
<td>15.3</td>
<td>ICF</td>
</tr>
<tr>
<td>Indonesia</td>
<td>2006</td>
<td>7,100</td>
<td>4.6</td>
<td>ICF</td>
</tr>
</tbody>
</table>
ICF components

Health Condition
(Disorder / Disease)

Impairments → Activity → Participation

Environmental factors → Personal factors

Contextual factors

Environmental factors

- Products and technology
- Natural environment and human made changes to environment
- Support and relationships
- Services, systems and policies
- **Stigma** (attitudes, values, beliefs . . .).

Attitudes and stereotypes

| But you don’t look like you’re one of those mentally ill! | That’s because I’m dignified as a human being today! |

Poverty → **Leprosy-related impairments** → Social exclusion → **Stigma** → Disability
Types of stigma

<table>
<thead>
<tr>
<th>People who are stigmatised</th>
<th>Stigmatisers (e.g. community, health workers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipated stigma (perceived)</td>
<td>Enacted stigma (discrimination)</td>
</tr>
<tr>
<td>Internalised stigma (self-stigma)</td>
<td>Perceived stigma</td>
</tr>
<tr>
<td>Experienced stigma (discrimination)</td>
<td>Fear of the disease</td>
</tr>
<tr>
<td></td>
<td>Symbolic stigma (associations)</td>
</tr>
<tr>
<td></td>
<td>Attitudes</td>
</tr>
</tbody>
</table>

Impact of stigma on people

- Stress and anxiety, depression, etc.: X X X X X X
- Problems in marriage or getting married: X X X X X
- Problems in social relationships: X X X X X
- Problems with employment: X X X X
- Problems with education (own or children): X X X X
- Concealment: X X X X
- Isolation: X X X X
- Increased disability / worse prognosis: X X
- Increased gender differences: X X X X

Impact on public health programmes

- Delay in presentation: X X X X X
- Failure of prevention / continued transmission: X X
- More complicated, more expensive treatment: X X X X X
- Poor adherence and default: X X X X
- Risk of drug resistance: X X X
- Poor image of the public health services: X X X
Applications of the ICF using leprosy as model of disablement

Using a participation profile to describe a sample
(n=1,650 PWD, Nepal)

Participation as binary measure to classify people
(Disability study, Sulawesi, Indonesia)

Experienced stigma leprosy-affected

5 districts in Indonesia
n=1,350
Comparison of activity limitations using the WHODAS II among people with various disabilities in South India

Comparing severity of disability in different conditions

Determinants of participation
(n=262, Disability study, Sulawesi, Indonesia)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Adj OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>1</td>
</tr>
<tr>
<td>Primary school</td>
<td>0.34 (0.17-0.70)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>1</td>
</tr>
<tr>
<td>Married</td>
<td>0.50 (0.24-1.0)</td>
</tr>
</tbody>
</table>

Determinants of participation 2
(n=262, Disability study, Sulawesi, Indonesia)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Adj OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of house</td>
<td></td>
</tr>
<tr>
<td>Stone/concrete</td>
<td>1</td>
</tr>
<tr>
<td>Temporary shelter</td>
<td>6.1 (1.1-33)</td>
</tr>
<tr>
<td>Activity limitation</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>8.5 (4.5-16)</td>
</tr>
<tr>
<td>Stigmatisation</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Yes</td>
<td>3.2 (1.4-7.3)</td>
</tr>
</tbody>
</table>
Differences in perceived stigma between people in CBR and non-CBR areas

Impact of empowerment and CBR interventions on stigma (STEP)

Take-home messages

- ICF widely-accepted tool for work in disability and development field
  - Conceptual framework
  - Uniform terminology
  - Focus on functioning
  - Applicable to all people
  - Focus on perception and experience of persons with disabilities
- Importance of environmental factors
- Various ICF-based instruments available for use in low and middle-income countries
- Leprosy very suitable as model of disablement

Resources

- ILEP
  - INFOLEP
  - www.ilep.org.uk
- Netherlands Leprosy Relief
  - Athena Institute, VU University Amsterdam
  - Summer School on D&D, Indonesia (4-29/7/11)
- Dutch Coalition for D&D (DCDD)
  - www.dcdd.nl
- International D&D Consortium (IDDC)
  - www.iddc.org