Access to health care of persons with disabilities as an indicator of equity in health systems: Research Agenda Post 2015

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Context

- Disability need not be equated with poor health
- Data document that people with disabilities are four times more likely to self-rate health as fair or poor relative to general population

Context

• Disability is almost always connected to a health condition.
• Failure to meet health needs constitutes an important aspect of the discrimination faced by people with disabilities.
• The claim that disability is not a health issue risks obscuring this reality.

Table D.1. Prevalence of moderate and severe disability (in millions), by leading health condition associated with disability, and by age and income status of countries

<table>
<thead>
<tr>
<th>Health condition</th>
<th>High-income countries (with a total population of 977 million)</th>
<th>Low-income and middle-income countries (with a total population of 5,460 million)</th>
<th>World (population 6,437 million)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0–59 years</td>
<td>60 years and over</td>
<td>0–59 years</td>
</tr>
<tr>
<td>1 Hearing loss</td>
<td>7.4</td>
<td>18.5</td>
<td>54.3</td>
</tr>
<tr>
<td>2 Refractive errors</td>
<td>7.7</td>
<td>6.4</td>
<td>68.1</td>
</tr>
<tr>
<td>3 Depression</td>
<td>15.8</td>
<td>0.5</td>
<td>77.6</td>
</tr>
<tr>
<td>4 Cataracts</td>
<td>0.5</td>
<td>1.1</td>
<td>20.8</td>
</tr>
<tr>
<td>5 Unintentional injuries</td>
<td>2.8</td>
<td>1.1</td>
<td>35.4</td>
</tr>
<tr>
<td>6 Osteoarthritis</td>
<td>1.9</td>
<td>8.1</td>
<td>14.1</td>
</tr>
<tr>
<td>7 Alcohol dependence and problem use</td>
<td>7.3</td>
<td>0.4</td>
<td>31.0</td>
</tr>
<tr>
<td>8 Infertility due to unsafe abortion and maternal sepsis</td>
<td>0.8</td>
<td>0.0</td>
<td>32.5</td>
</tr>
<tr>
<td>9 Macular degeneration</td>
<td>1.8</td>
<td>6.0</td>
<td>9.0</td>
</tr>
<tr>
<td>10 Chronic obstructive pulmonary disease</td>
<td>3.2</td>
<td>4.5</td>
<td>10.9</td>
</tr>
<tr>
<td>11 Ischaemic heart disease</td>
<td>1.0</td>
<td>2.2</td>
<td>8.1</td>
</tr>
<tr>
<td>12 Bipolar disorder</td>
<td>3.3</td>
<td>0.4</td>
<td>17.6</td>
</tr>
<tr>
<td>13 Asthma</td>
<td>2.9</td>
<td>0.5</td>
<td>15.1</td>
</tr>
<tr>
<td>14 Schizophrenia</td>
<td>2.2</td>
<td>0.4</td>
<td>13.1</td>
</tr>
<tr>
<td>15 Glaucoma</td>
<td>0.4</td>
<td>1.5</td>
<td>5.7</td>
</tr>
<tr>
<td>16 Alzheimer and other dementias</td>
<td>0.4</td>
<td>6.2</td>
<td>1.3</td>
</tr>
<tr>
<td>17 Panic disorder</td>
<td>1.9</td>
<td>0.1</td>
<td>11.4</td>
</tr>
<tr>
<td>18 Cerebrovascular disease</td>
<td>1.4</td>
<td>2.2</td>
<td>4.0</td>
</tr>
<tr>
<td>19 Rheumatoid arthritis</td>
<td>1.3</td>
<td>1.7</td>
<td>5.9</td>
</tr>
<tr>
<td>20 Drug dependence and problem use</td>
<td>3.7</td>
<td>0.1</td>
<td>8.0</td>
</tr>
</tbody>
</table>
Public Health

- Public health has traditionally focused on the prevention of mortality (death rate), morbidity (rate of incidence of a disease), and disability (prevention)

- But has been silent on how public health could include those who are not prevented from experiencing disability (Example: Polio)
Success Stories

- Small Pox
- Onchocerciasis (river blindness)
- Current thinking on disability: Bio-psycho-social model/Universal model
  - International Classification of functioning, disability, and health
Public Health

- Why too slow to respond?

  - Conventional emphasis of reducing mortality, morbidity, and disability has “led to mindset that equates disability with a failure of the public health system - specifically, to prevent conditions associated with disability” (Lollar and Crews, 2003, p.198)
Public Health

- What has been the consequence?
  - Public health has found it difficult to frame a role toward people with disabilities (MacLachlan, 2012- Oxford Handbook of Rehabilitation Psychology)

- Opportunity to remedy the situation:
  - Disability as an indicator for health systems (MacLachlan, Mannan & McAuliffe, 2011, Open Medicine)
Global Development Initiatives

- Millennium Development Goals
  - Vast majority of the targets; goals; indicators relate to mortality and morbidity: None on Disability!
  - Going forward will it change?
    - Opportunity: Post-2015 agenda
    - Missed opportunity: NCD Global Plan of Action
      - While acknowledges link between NCDs and disability; none of the targets/goals/indicators capture ‘disability’
The action plan for the prevention and control of non-communicable disease (NCD) 2013-2020 aims to reduce the preventable and avoidable burden of morbidity, mortality, and disability (WHO, 2013).

Member States are called to collect routine information on trends in non-communicable diseases with respect to morbidity, mortality by cause, risk factors and other determinants, disaggregated by age, gender, disability, and socioeconomic groups.
World Health Organization Non-communicable Disease Action Plan and Indicators: Missed opportunity?

- The plan then goes on to recognize and acknowledge that non-communicable disease related disability (such as amputation, blindness, or paralysis) puts significant demands on social welfare and health systems (WHO, 2013).
- In addition, it emphasizes that rehabilitation services needs to be a central health strategy in non-communicable disease programmes.
- So far so good..................where does it fall short?
The Action Plan having placed due importance on reducing disability and calling for disaggregated data by disability does not include any indicators or targets.

For example, the target could have called for % reduction in overall disability from any one of health conditions (cardiovascular diseases, cancer, diabetes or chronic respiratory diseases.)
World Health Organization Non-communicable Disease Action Plan and Indicators: Missed opportunity?

- Not only to document the premature mortality but the functional status (activity limitations and participation restriction)

- Treatment efficacy in maintaining and or improving functional status.
World Health Organization Non-communicable Disease Action Plan and Indicators: Missed opportunity?

- Monitoring: (a) prevention, (b) promotion, (c) early identification and intervention, and (d) access to assistive technology vis-a-vis NCD related disability (such as amputation, blindness or paralysis).

- To document the lived experience of people with NCD to enhance the understanding of what life is like for these individuals.
World Health Organization Non-communicable Disease Action Plan and Indicators: Missed opportunity?

- To understand whether NCD precede the disability or vice versa
  - Help focus policy and practice outcomes where they will have greatest impact
- To enable provision of strong and effective evidence base for us to understand health disparities of people with disabilities
Research on access to healthcare

- A recent review of research priorities for health of people with disabilities states that identifying barriers for individuals with disabilities in accessing health services should be the leading research priority (Tomlinson et. al. 2009; Mannan & MacLachlan 2013)
**Public Health:** Identifying public health approaches that enhance participation of persons with disabilities in their economic, civic, social and political life.

**Health Policy:** Analysis of existing policies to ascertain the extent to which they incorporate the core concepts of human rights of people with disability.

**Healthcare Access:** Identifying the constraints and facilitators for access to health care, and incorporating these into a systems-strengthening approach.

**Community Based Rehabilitation:** Developing a global program on disability and inclusive development that will facilitate the collection of comparable data and provide ‘common goods‘ for CBR training, support, monitoring, evaluation and research.

**Research Agenda Post 2015: Disability and Health**

<table>
<thead>
<tr>
<th>Human Resources for Health:</th>
<th>Development of a new cadre for community based rehabilitation, with a broad skill mix and an ethos of evidence-based practice, whose practice can contribute to a developing evidence base.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enabling Technologies:</td>
<td>Developing contextually appropriate and affordable enabling technologies that can facilitate personally meaningful gains for their users?</td>
</tr>
<tr>
<td>Disability and Disaster Response:</td>
<td>Establish and evaluate systems and personal coping responses to disaster situations for people with disabilities, chronic illness and the elderly.</td>
</tr>
<tr>
<td>Disability Metrics:</td>
<td>Develop and apply standardized disability metrics that can be used to strengthen over-all health systems?</td>
</tr>
</tbody>
</table>
Health Care Access

ACKNOWLEDGEMENTS
PROJECT EQUITABLE
EQUITABLE CONSORTIUM
FP7 2009-2013
Health care access in Sub-Saharan Africa (Namibia, South Africa, Sudan, Malawi)

- Urbanity, socio-economic status, and severity of activity limitations are important predictors for perceived barriers, while there is no difference between the access of men and women (Eide, Mannan et al in press).
- The probability of not having received necessary health care was 0.07 for individuals who reported of no activity limitation, the probability of not receiving such care was 0.19 for individuals who had severe activity limitations.
Health care access in Sub-Saharan Africa

- Urban dwellers face higher barriers than rural, with the exception of Namibia, where the difference between urban and rural dwellers was not statistically significant.

- Education appears to have an effect on perceived barriers, but the effect differs between countries:
  - In Namibia and Malawi, education has no effect on perception of barriers; whereas barriers decrease with higher education in South Africa, and increase in Sudan.

- One interpretation of this could be that education reduces barriers to health services only to the extent that it reduces poverty.
Community based rehabilitation in developing countries: Skills and staff requirements

ACKNOWLEDGEMENTS:
DR. MANJULA MARELLA & MR. VISHAL GUPTA
CBR: Skills and staff requirements

☐ To identify optimal skill mix and staff types

☐ Critical Incident Technique
  ■ Positive and Negative experience
  ■ Identifying abilities or characteristics to perform well in their role

☐ Knowledge about disability and services; skills to develop quality parent-professional partnership
Core concepts of Human Rights in Good Practices

Acknowledgements: Ms. Cheryl Emms, University of Melbourne
Analysis of good practices

• Use of case studies to promote disability-inclusive development good practices
Research Question

The extent to which core concepts of human rights are illustrated in disability inclusive development good practices
Methodology

- 42 case studies identified and analyzed using Equiframe Framework ascertains policies level of commitment (4) to core concepts (21) of human rights to vulnerable populations (12)


Analysis

Highest occurring themes (n=42):

1. Human rights core concepts
   Access 55% (23/42)
   Individualised services 48% (20/42)
   Capacity building 46% (19/42)
   Participation 38% (16/42)

2. Vulnerable groups
   People with a disability 100% (42/42)
   Children with special needs 31% (13/42)
Analysis

Lowest occurring themes (n=42):

1. Human rights core concepts
   - Liberty: 0% (0/42)
   - Privacy: 0% (0/42)
   - Autonomy: 3% (1/42)
   - Cultural responsiveness: 3% (1/42)
   - Accountability: 3% (1/42)
   - Efficiency: 3% (1/42)

2. Vulnerable groups
   - Increased relative risk for morbidity: 0% (0/42)
   - Displaced populations: 0% (0/42)
Analysis

• **Strengths:**
  - Access, individualized services, participation & capacity building

• **Gaps:**
  - Lowest occurring core concepts
  - Vulnerable groups: women, ethnic minorities, living away from services
  - Level of commitment
ACKNOWLEDGEMENTS:
DR. JULIE ABIMANYI-OCHOM & PROF. NORA GROCE
DHS 2011

- WG Short Set of Questions
- Knowledge, Attitudes, Behavior:
  - Number of households surveyed: 9,033
  - Number of household members: 44,977
  - Individual level data males (15-59 years old): 2,295
  - Individual level data females (15-59 years old): 8,674
  - 10,969 (for analysis on KAB)
Initial Results

- Odds of people with disabilities perceiving that there is HIV risk from mosquito bites, sharing food is higher than people without disabilities
- Odds of people with disabilities having received last HIV results is lower than people without disabilities
- Odds of people with disabilities having STD in the last 12 months is greater than people without disabilities
- Implications for policy and practice to address access to information related to sexual health
In Summary:

- Evaluating health system accessibility and equity in responding to the right to health of persons with disabilities as a way forward within the emerging global initiatives including the post 2015 agenda and ongoing monitoring of the UNCRPD