Angela Me/Margaret Mbogoni: 
Overview of Data Collection Practices 
in Less Developed Countries
Overview of Data Collection Practices in Less Developed Countries

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United Nations Statistics Division

International Seminar on Measurement of Disability

New York, 4 – 6 June 2001
Disability Data Collection in Developing Countries

- Increasing number of countries are collecting data on disability

- Of 180 studies in DISTAT-2, 93 are from developing countries
### Studies by Type of Data Collection

<table>
<thead>
<tr>
<th>Region</th>
<th>Total</th>
<th>Censuses</th>
<th>Surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>38</td>
<td>29</td>
<td>9</td>
</tr>
<tr>
<td>Asia</td>
<td>33</td>
<td>22</td>
<td>11</td>
</tr>
<tr>
<td>Caribbean</td>
<td>7</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Latin America</td>
<td>12</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Europe</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>93</td>
<td>69</td>
<td>24</td>
</tr>
</tbody>
</table>
Type of Data Collection by Region

- Censuses
- Surveys

Regions:
- Africa
- Asia
- Caribbean
- Latin America
- Europe
Disability Estimates in National Studies

- The prevalence rate is below 3% for the majority of studies

- 24 studies <1
- 38 studies 1-2
- 13 studies 2-3
- 4 studies 3-4
- 6 studies 4-5
- 3 studies 5-6
- 6 studies 6+
Distribution of Prevalence Rates
Possible Explanations for Low Prevalence Rates

- The implied definition of the population with disabilities is too narrow

- Questions used lack specificity
Types of Questions Used

• Two broad categories of questions
  • Generic questions (33 studies)
  • Check-list (31 studies)

• Questions are generally impairment-based
Example of a Generic Questions

• Are …’s activities limited because of a long-term physical or mental condition or health problem?

• Does anyone in this household including very young children and women have any longstanding illness or condition, which prevents or limits his/her participation in activities normal for a person his/her age?
Example of a Check-list Question

- Check-list – Is there anyone in the household who has a disability related to 1) eyesight 2) hearing 3) speech 4) fits 5) limbs 6) walking 7) mental deficiency 8) mental illness 9) other disability
Distribution of Prevalence Rates by Type of Question

![Graph showing distribution of prevalence rates by type of question]
Prevalence Rates and Questions Used

- Generic questions show higher prevalence rates than questions based on a check-list

- Average prevalence rate:
  - Generic – 2.5
  - Check-list – 1.6

- More variation in rates based on generic questions than on the check-list
Other Explanatory Factors

- Social stigma attached to being “disabled”
- Interviewer bias
Analysis of Prevalence by Question Characteristics

- Household based/Person based
- Based on a list of disabilities
- Single question/Multiple questions
- Mental disability specifically mentioned
- Simple question/Complex question
- Based on a limited physical/mental disabilities
- The word “disability” or “handicap” is mentioned
- Based on activity limitations
Additional factors

- Type of data collection used:
  - Census
  - Survey
- Region
Significant Differences in Total Prevalence Rates

- Household based: 1.6
- Person based: 2.2
- List based: 1.6
- Not list based: 2.3
- Limited physical/mental disabilities: 1.4
- Not limited: 2.6
Generating extremely Low Prevalence Rates

- The only characteristic that seem to generate lower prevalence rate is the limitation to physical/mental disabilities.

- A question based on a limited physical/mental disabilities is 5 times as likely to have a prevalence rate > 1 as a question base on a limited disabilities.
Generating High Prevalence Rates

- A **Person Based Question** is 5 times as likely to have a Prevalence Rate > 3 as a question household based

- A **Question not based on a limited physical/mental disabilities** is 9.7 times as likely to have a prevalence rate > 3 as a question base on a limited disabilities

- A **Question based on a list** is 3.2 times as likely to have a Prevalence Rate > 3 as a question household based
Analysis of Variance
Total Prevalence Rate

* Adjusted Model

<table>
<thead>
<tr>
<th>Source</th>
<th>Type III Sum of Squares</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
<th>Observed Power</th>
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<tbody>
<tr>
<td>Intercept</td>
<td>178.54</td>
<td>178.54</td>
<td>3.06</td>
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<td>0.16</td>
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<tr>
<td>Single/Multiple Question</td>
<td>8.10</td>
<td>8.10</td>
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<td>Household/Person Based</td>
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<td>11.02</td>
<td>5.15</td>
<td>0.03</td>
<td>0.61</td>
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<tr>
<td>Limited Phy/Ment Dis</td>
<td>39.50</td>
<td>39.50</td>
<td>18.46</td>
<td>0.00</td>
<td>0.99</td>
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</table>
### Analysis of Variance

#### Total Prevalence Rate

- **Hierarchical Decomposition**

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</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>270.11</td>
<td>270.11</td>
<td>6.55</td>
<td>0.21</td>
<td>0.18</td>
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<tr>
<td>Limited Phy/Ment Dis</td>
<td>39.50</td>
<td>39.50</td>
<td>18.46</td>
<td>0.00</td>
<td>0.99</td>
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<tr>
<td>Household/Person Based</td>
<td>5.87</td>
<td>5.87</td>
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<tr>
<td>Single/Multiple Question</td>
<td>0.46</td>
<td>0.46</td>
<td>0.03</td>
<td>0.89</td>
<td>0.05</td>
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</table>
Analysis of Variance
Total Prevalence Rate

Hierarchical Decomposition

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<td>Household/Person Based</td>
<td>11.02</td>
<td>11.02</td>
<td>5.15</td>
<td>0.03</td>
<td>0.61</td>
</tr>
<tr>
<td>Single/Multiple Question</td>
<td>13.23</td>
<td>13.23</td>
<td>5.16</td>
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<td>0.58</td>
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<tr>
<td>Limited Phy/Ment Dis</td>
<td>21.58</td>
<td>21.58</td>
<td>3.10</td>
<td>0.23</td>
<td>0.18</td>
</tr>
</tbody>
</table>
Effect of question characteristics in reporting disability - Elderly

- No Significant effects in generating Lowest prevalence rates (<5)

- Highest Prevalence (>10): Odds Ratios:
  - Person Based question: 2.2
  - World disability not mentioned: 1.9
  - Not activity limitations: 0.5
  - No limited physical/mental disabilities: 1.7
The only variable that seems to have a significant effect is:

Limited Physical/Mental Disabilities
For the same prevalence rate, are there differences in the subpopulation that comprise that prevalence rate?
Elderly

Prevalence 60 plus

Prevalence Total

11/06/2001
Elderly by Region

Prevalence 60 plus

Region
- Latin America
- Europe
- Caribbean Countries
- ASIA
- Arab Countries
- Africa

Prevalence Total

Graph showing the prevalence of elderly (60 plus) by region with data points and trend lines for different regions.
Elderly according to Limited Physical/Mental Disabilities

Prevalence Total

- Limited number of physical/mental disabilities
- No limitation
- Total Population

Prevalence 60 plus
Elderly according to Household/Person based questions

Prevalence Total

Household/Individual
- Household based
- Person based
- Total Population

Prevalence 60 plus
Children

Prevalence 0-14

Islands

Prevalence Total
Islands with a common pattern

- Bermuda 1991, Census
- Saint Vincent and the Grenadines 1991, Census
- Jamaica 1991, Census
- Cyprus 1992, Census
- Malta 1995, Census
Children by Type of Data Collection

![Graph showing prevalence by age group and type of data collection]
## Children by Region

### Prevalence 0-14

<table>
<thead>
<tr>
<th>Region</th>
<th>Total Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latin America</td>
<td>2.5</td>
</tr>
<tr>
<td>Europe</td>
<td>2.0</td>
</tr>
<tr>
<td>Caribbean Countries</td>
<td>1.5</td>
</tr>
<tr>
<td>ASIA</td>
<td>1.0</td>
</tr>
<tr>
<td>Arab Countries</td>
<td>0.5</td>
</tr>
<tr>
<td>Africa</td>
<td>0.0</td>
</tr>
</tbody>
</table>

### Chart Details

- **Poland**
- **Prevalence 0-14**
- **Prevalence Total**
- **Region**
  - Latin America
  - Europe
  - Caribbean Countries
  - ASIA
  - Arab Countries
  - Africa
  - Total Population
Children according to limited Physical/mental disabilities

Prevalence 0-14

Physical/Mental
- Limited number of physical/mental disabilities
- No limitation
- Total Population

Prevalence Total
Children according to Household/Person based questions

Prevalence Total

Household/Individual
- Household based
- Person based
- Total Population

Prevalence 0-14
Children according to Questions based on a List

![Graph showing prevalence of children based on questions with or without a list.](image)
Children according to Single/Multiple Questions

Prevalence 0-14

- Single question
- Multiple question
- Total Population
Example: a census as instrument

**Type of disability:** Seeing, Hearing, Speaking, Hearing and speaking, Moving, Grasping, Mental, Mental and moving, Multiple, Other (1.8%)

**Unable to work:** Persons unable to engage in any type of work due to chronic diseases or disabilities. This category includes all persons unable to work due to old age (1.7%)
Inconsistent Reporting

<table>
<thead>
<tr>
<th></th>
<th>Unable to work</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have disability</td>
<td>13556</td>
<td>23317</td>
<td>36873</td>
</tr>
<tr>
<td>Not have disability</td>
<td>15972</td>
<td>1634563</td>
<td>1650535</td>
</tr>
<tr>
<td>Total</td>
<td>29528</td>
<td>1657880</td>
<td>1687408</td>
</tr>
</tbody>
</table>
Prevalence of disability by type of disability reported

Prevalence of disability

Have disability  Estimates  Unable to work  Unable to work (filtered with no disability)

Male  Female  Total

11/06/2001
Sex biased in Reporting disability

Odds Ratios for (Male/Female) to have disability

- Have disability
- New disability
- Unable to work
- Unable to work (filtered with no disability)
Education biased in Reporting disability

Odds Ratios for Low educated/high educated to have disability

<table>
<thead>
<tr>
<th>Type of disability</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have disability</td>
<td>2</td>
</tr>
<tr>
<td>New disability</td>
<td>4</td>
</tr>
<tr>
<td>No work</td>
<td>8</td>
</tr>
<tr>
<td>No Work (filtered with no disability)</td>
<td>12</td>
</tr>
</tbody>
</table>
Disability Reporting

- Adult Males tend to underreport general disability and report work disability more than Females

- Low educated persons tend to underreport general disability and report work disability more than high educated persons
Lessons learned

• The main characteristics that influence total prevalence rates are:

  • Questions Based on a limited physical/mental disabilities
  • Household/person based
  • Single/multiple questions
Lessons learned

- Given the same total prevalence rate:
  - **Household based questions** tend to generate higher disability rates among the elderly and lower among children
  - **Questions limited to physical/mental disabilities** tend to generate higher prevalence rates among elderly and among children
  - **Questions based on a list** tend to generate higher prevalence rate among children
Lessons learned

- **Single questions** tend to generate lower prevalence rates among children

- **Surveys** tend to generate higher prevalence rates for children

**Region**

Different reporting of children and elderly the different case of the Caribbean
The different case of the Caribbean

Aruba 1991 Census (5.5%)

*Are you (or is he/she) handicapped?*

Belize 1991 Census (6.6%)

*Does … suffer from any long-standing illness, disability or infirmity?*

Saint Vincent and the Grenadines 1991 Census (7.2%)

*Does … suffer from any long-standing illness, disability or infirmity?*
The different case of the Caribbean

Bermuda 1991 Census (7.6)

*Do you have a physical, mental or other health condition or limitation which has lasted for more than six months and which limits or prevents your participation in the activities of daily life e.g. work, recreation, mobility, schooling, etc.*
Lessons learned: Work Disability

A standard question does not capture work disability particularly at the older ages.

An item on the non-economically active population does not capture disability.
Lessons learned: Adjusted disability

![Graph showing the prevalence of adjusted disability across different age groups. The graph compares reported disability and adjusted disability.](image-url)
Limitations of the Analysis

Some information on the instruments used is still missing for some countries.

Information on field operations is missing.

The analysis of the instruments is heavily based on countries with low prevalence rates.
Limitations of the Analysis

Assumption: there are no differences in the disability prevalence of countries

The question characteristics analyzed are highly correlated
What next?

Countries are planning to include a disability question in their census.

The Example of Africa:

Examples of questions

Is there any disabled person in the household?

Has (name) any type of permanent disability or limitation?

Does (the person) have a serious disability/ies that has/have lasted for six months or more, and that prevents his/her full participation in daily activities?
Further research

Can the census be a suitable instrument for estimating disability prevalence?

Are there special problems in a census conducted by interviewers?
Further Research

How does proxy/self reporting relate to the reporting of disability?

How do definition and the characteristics of interviews/interviewers effect the reporting of disability?