United Nations Statistics Division
United Nations Children's Fund
Statistical Office of the European Communities
Centres for Disease Control and Prevention
of the United States of America

ESA/STAT/AC.81/2-3
1 June 2001

International Seminar on the Measurement of Disability

New York
4-6 June 2001

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

Overview of Data Collection Practices in Less Developed Countries

Angela Me and Margaret Mbogoni

United Nations Statistics Division

International Seminar on Measurement of Disability

New York, 4 – 6 June 2001

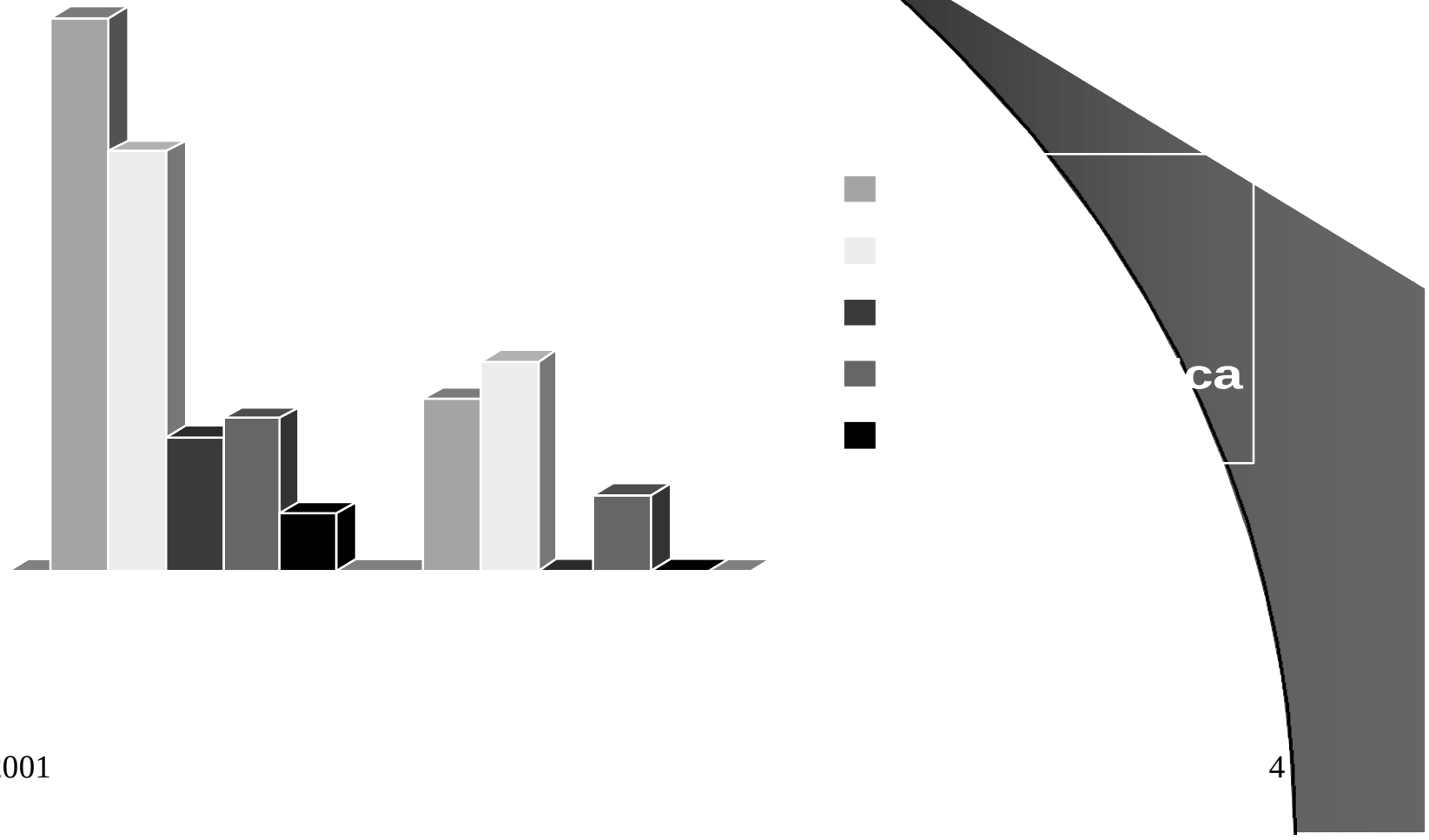
Disability Data Collection in Developing Countries

- 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

Region	Total	Censuses	Surveys
Africa	38	29	9
Asia	33	22	11
Caribbean	7	7	0
Latin America	12	8	4
Europe	3	3	0
Total	93	69	24

Type of Data Collection by Region

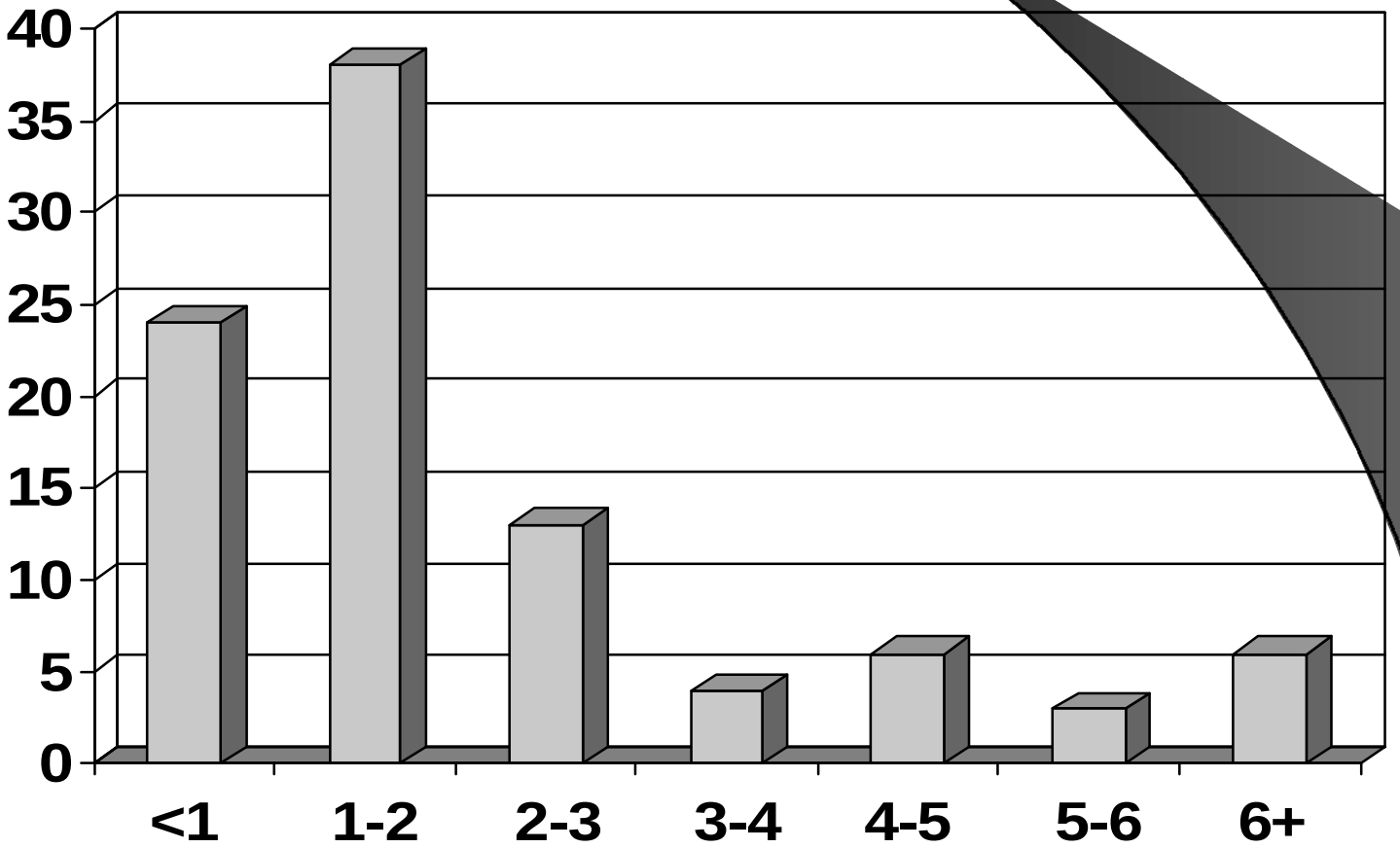


Disability Estimates in National Studies

- 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

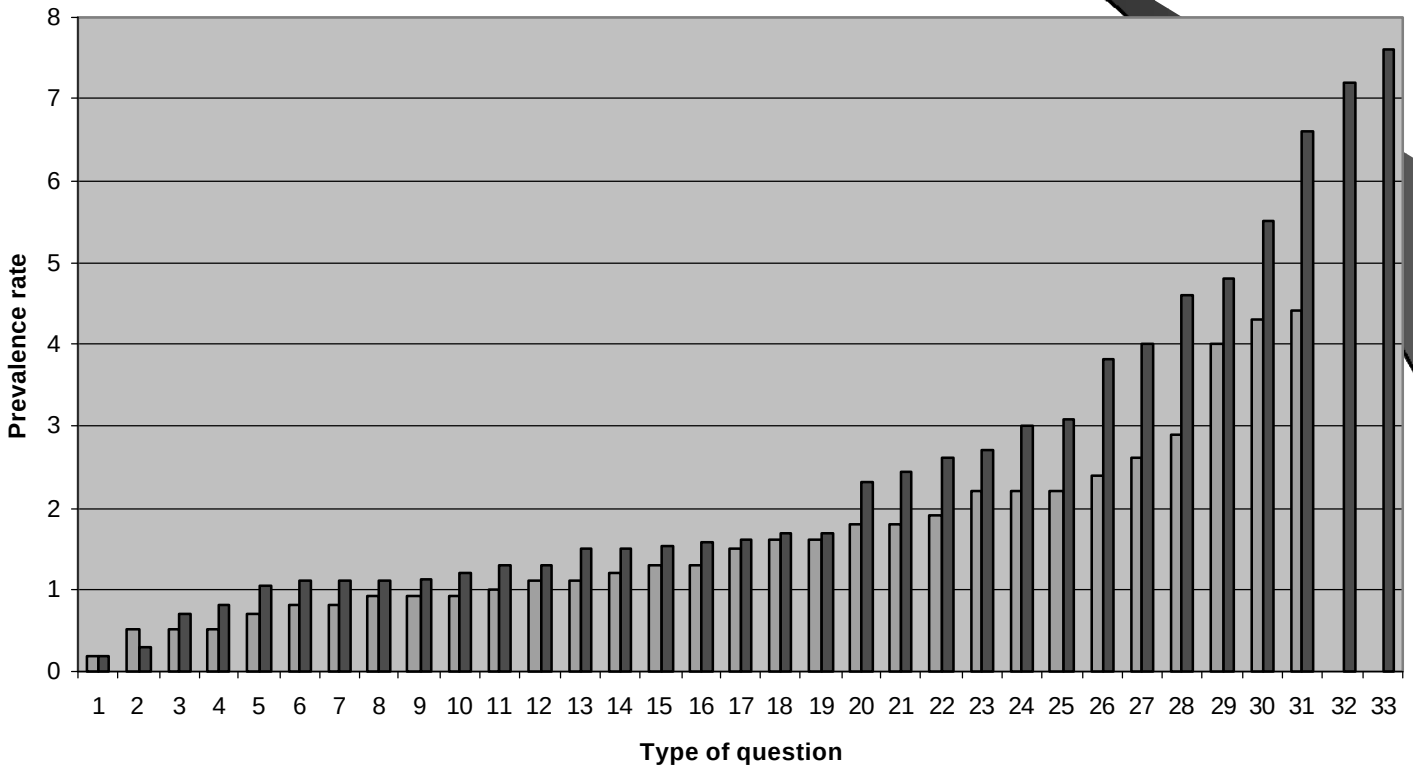
- *Are …'s activities limited because of a long-term physical or mental condition or health problem?*

- *Does anyone in this household including very young children and women have any longstanding illness or condition, which prevents of 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 is 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



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

Source	Type III Sum of Squares	Mean Square	F	Sig.	Observed Power
Intercept	178.54	178.54	3.06	0.25	0.16
Single/Multiple Question	8.10	8.10	3.79	0.06	0.48
Household/Person Based	11.02	11.02	5.15	0.03	0.61
Limited Phy/Ment Dis	39.50	39.50	18.46	0.00	0.99

Analysis of Variance
Total Prevalence Rate

- Hierarchical Decomposition

Source	Type I Sum of Squares	Mean Square	F	Sig.	Observed Power
Intercept	270.11	270.11	6.55	0.21	0.18
Limited Phy/Ment Dis	39.50	39.50	18.46	0.00	0.99
Household/Person Based	5.87	5.87	1.98	0.19	0.25
Single/Multiple Question	0.46	0.46	0.03	0.89	0.05

Analysis of Variance
Total Prevalence Rate

- Hierarchical Decomposition

Source	Type I Sum of Squares	Mean Square	F	Sig.	Observed Power
Intercept	270.11	270.11	5.79	0.12	0.32
Household/Person Based	11.02	11.02	5.15	0.03	0.61
Single/Multiple Question	13.23	13.23	5.16	0.03	0.58
Limited Phy/Ment Dis	21.58	21.58	3.10	0.23	0.18

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: **.5**

  No limited physical/mental disabilities: **1.7**

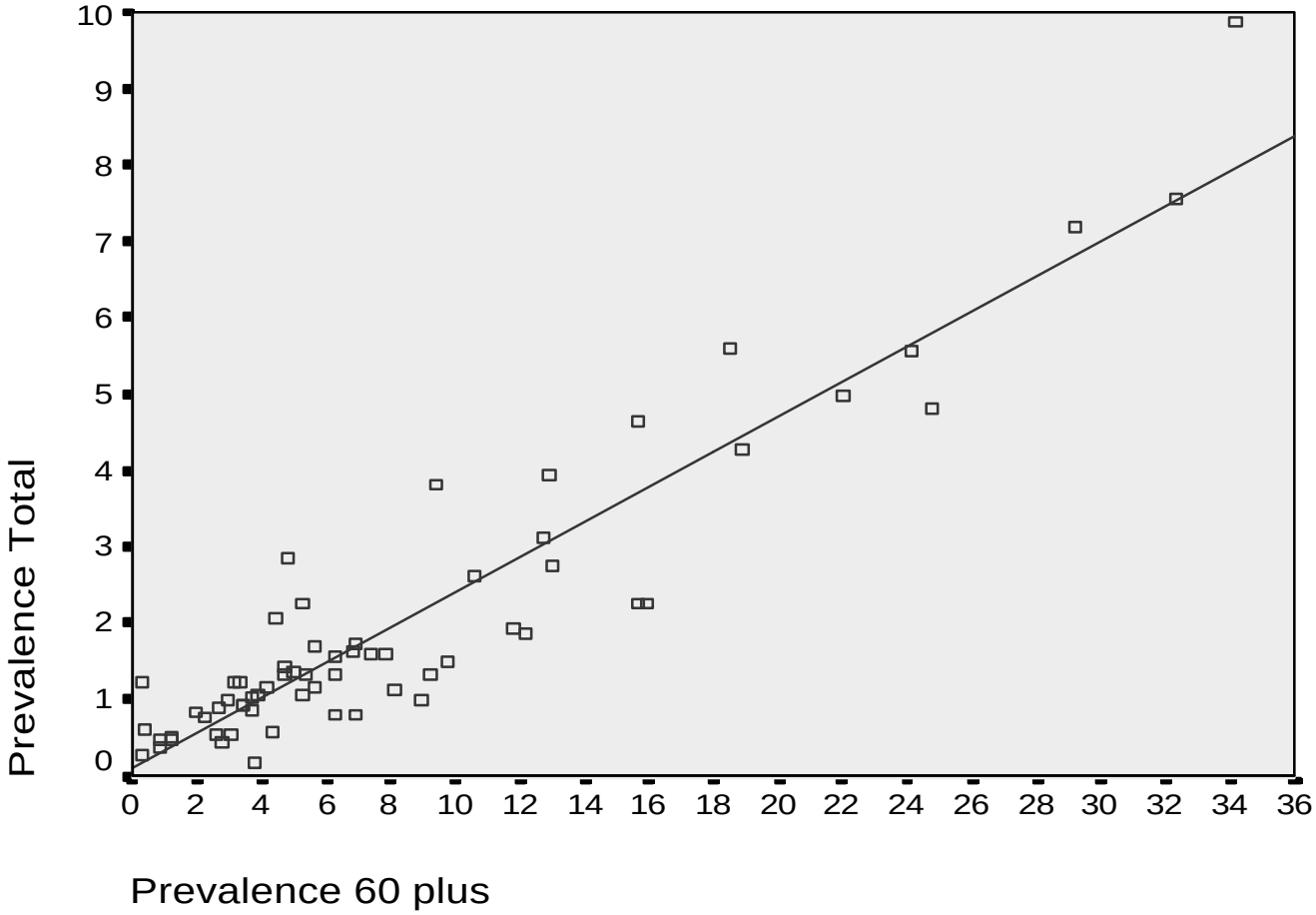
Analysis of Variance
Elderly Prevalence rates

- The only variable that seems to have a significant effect is:

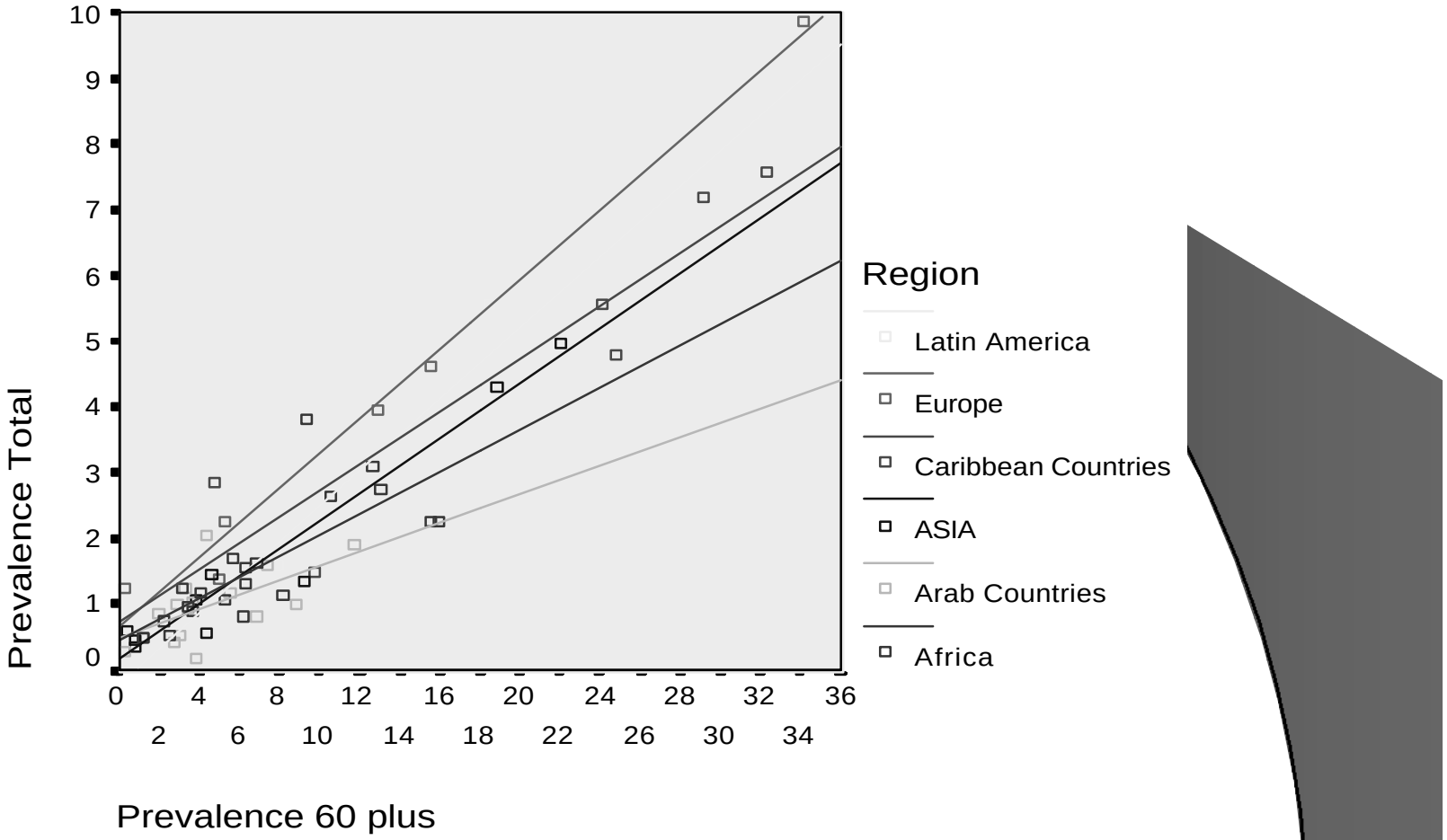
Limited Physical/Mental Disabilities

For the same prevalence rate, are there differences in the sub-population that comprise that prevalence rate?

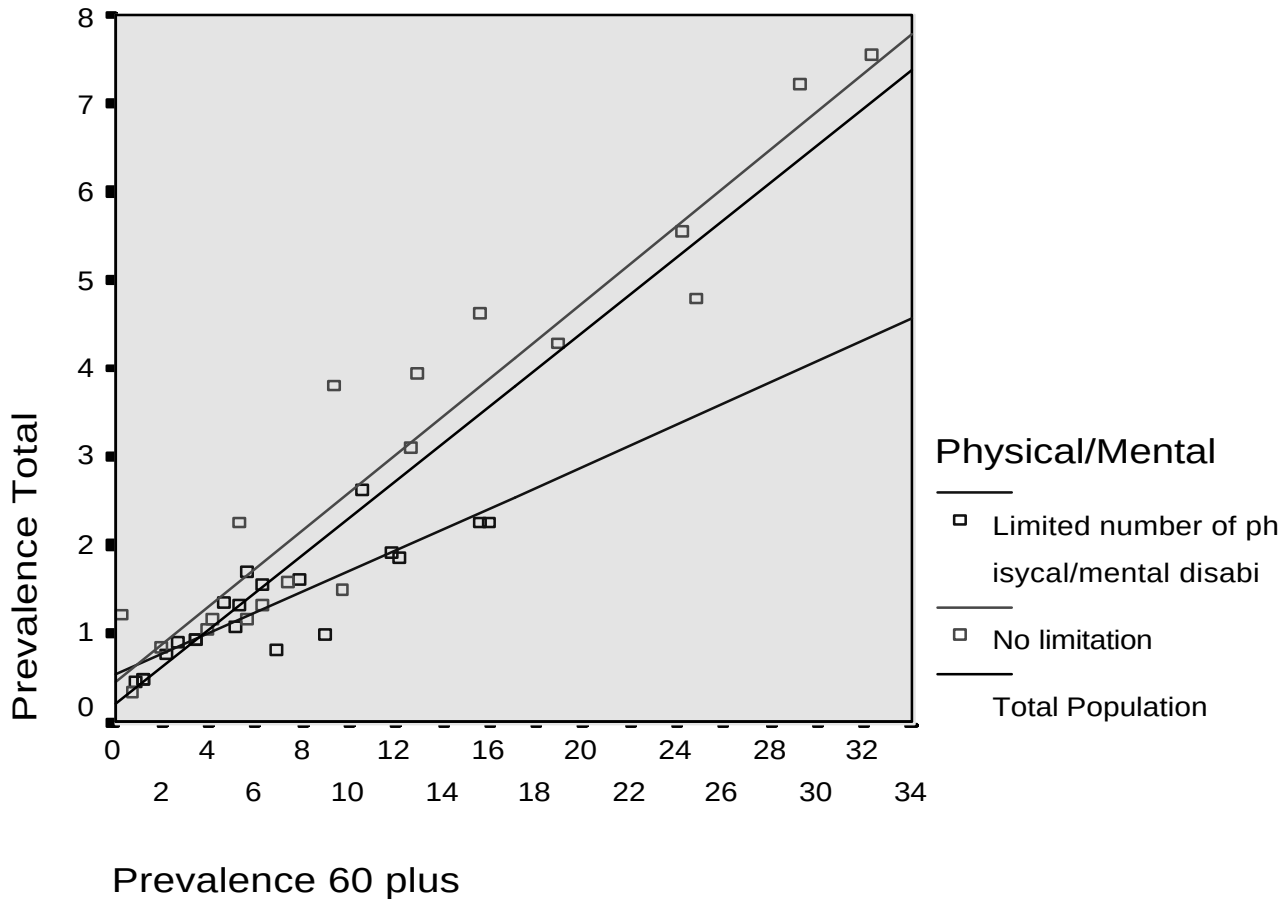
Elderly


Prevalence Total
Prevalence 60 plus
0
1
2
3
4
5
6
7
8
9
10
0
2
4
6
8
10
12
14
16
18
20
22
24
26
28
30
32
34
36

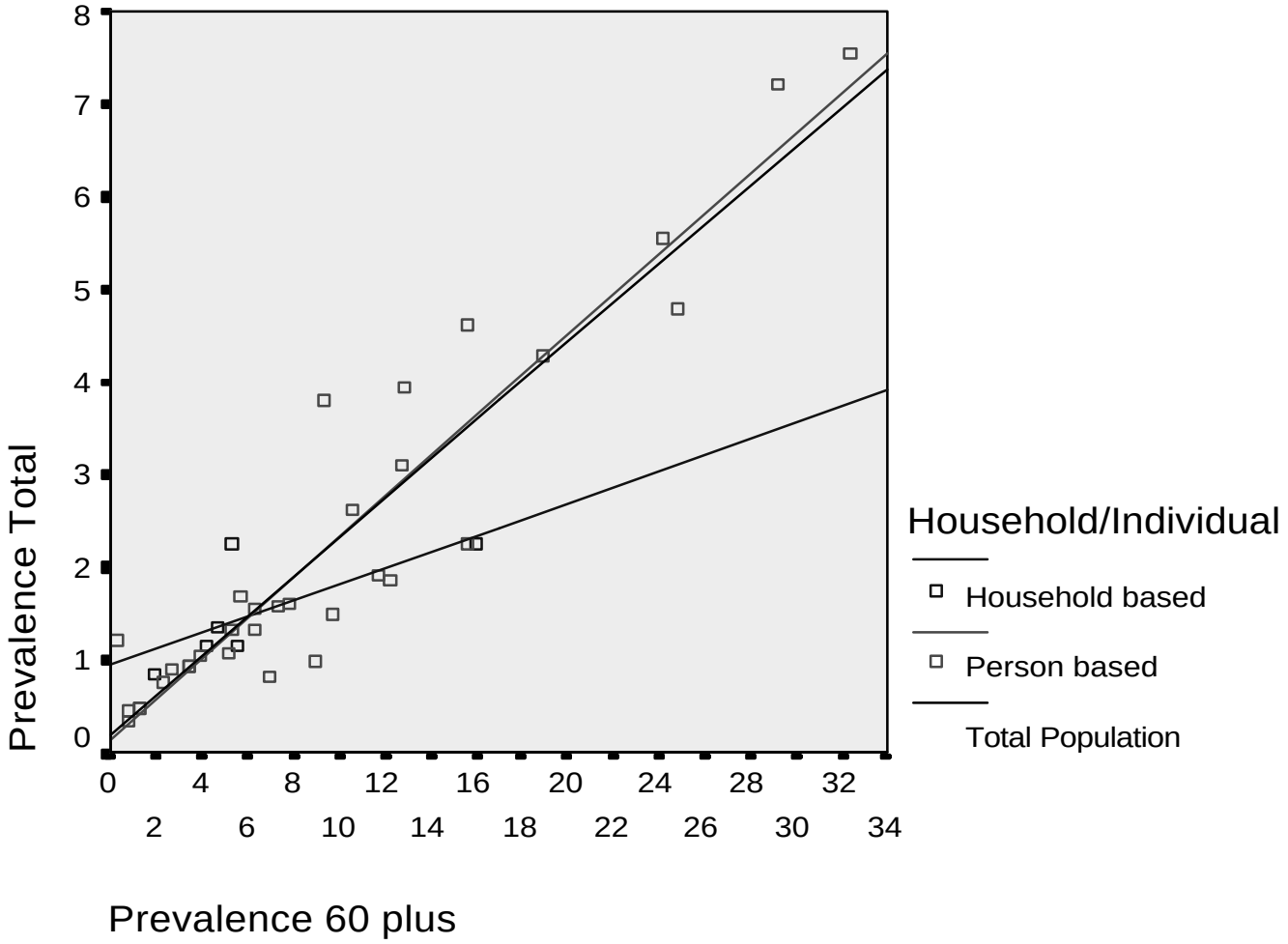
Elderly by Region



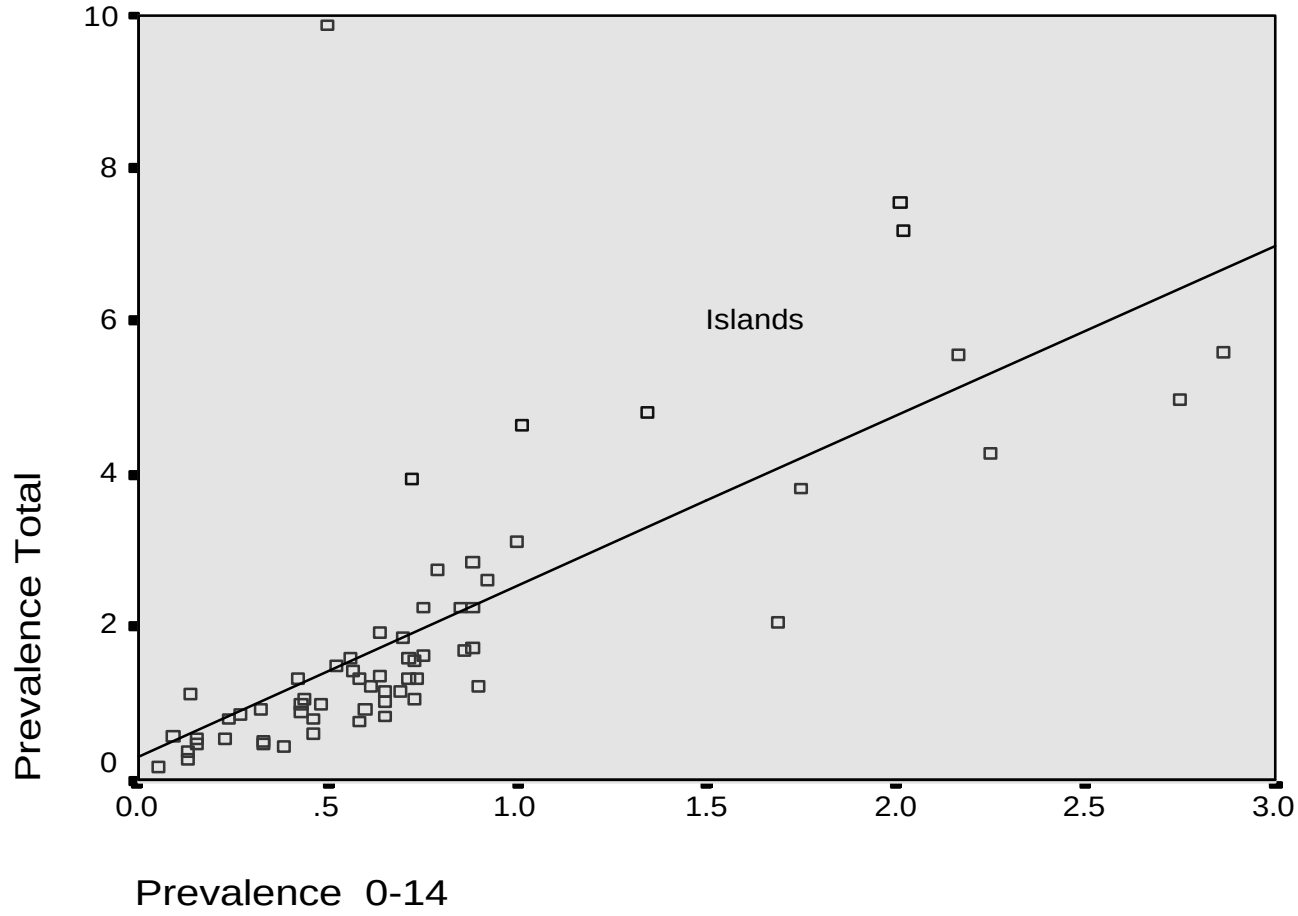
Elderly according to Limited Physical/Mental Disabilities



Elderly according to Household/Person based questions



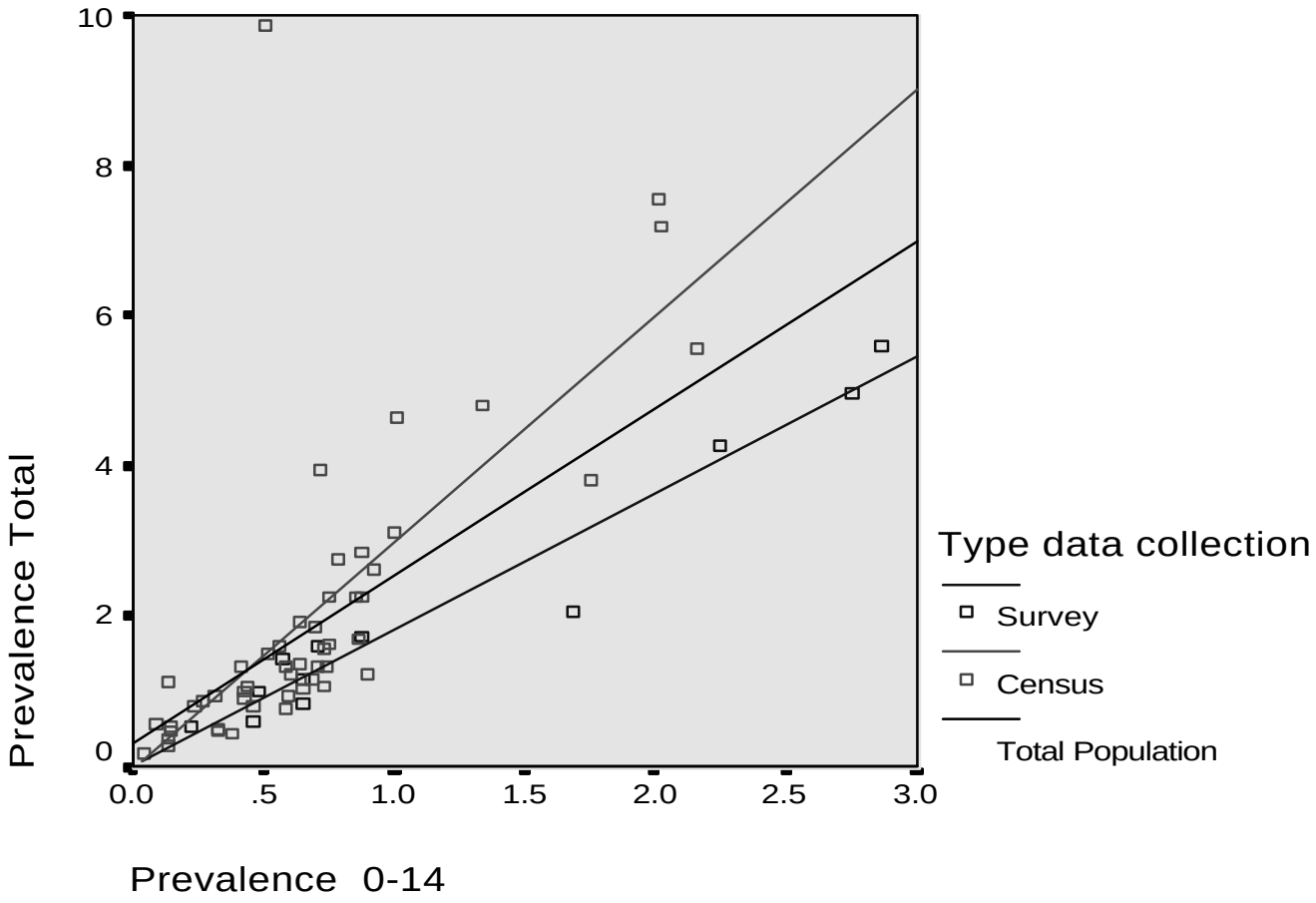
Children


Islands
Prevalence Total
Prevalence 0-14
0
2
4
6
8
10
0.0
.5
1.0
1.5
2.0
2.5
3.0

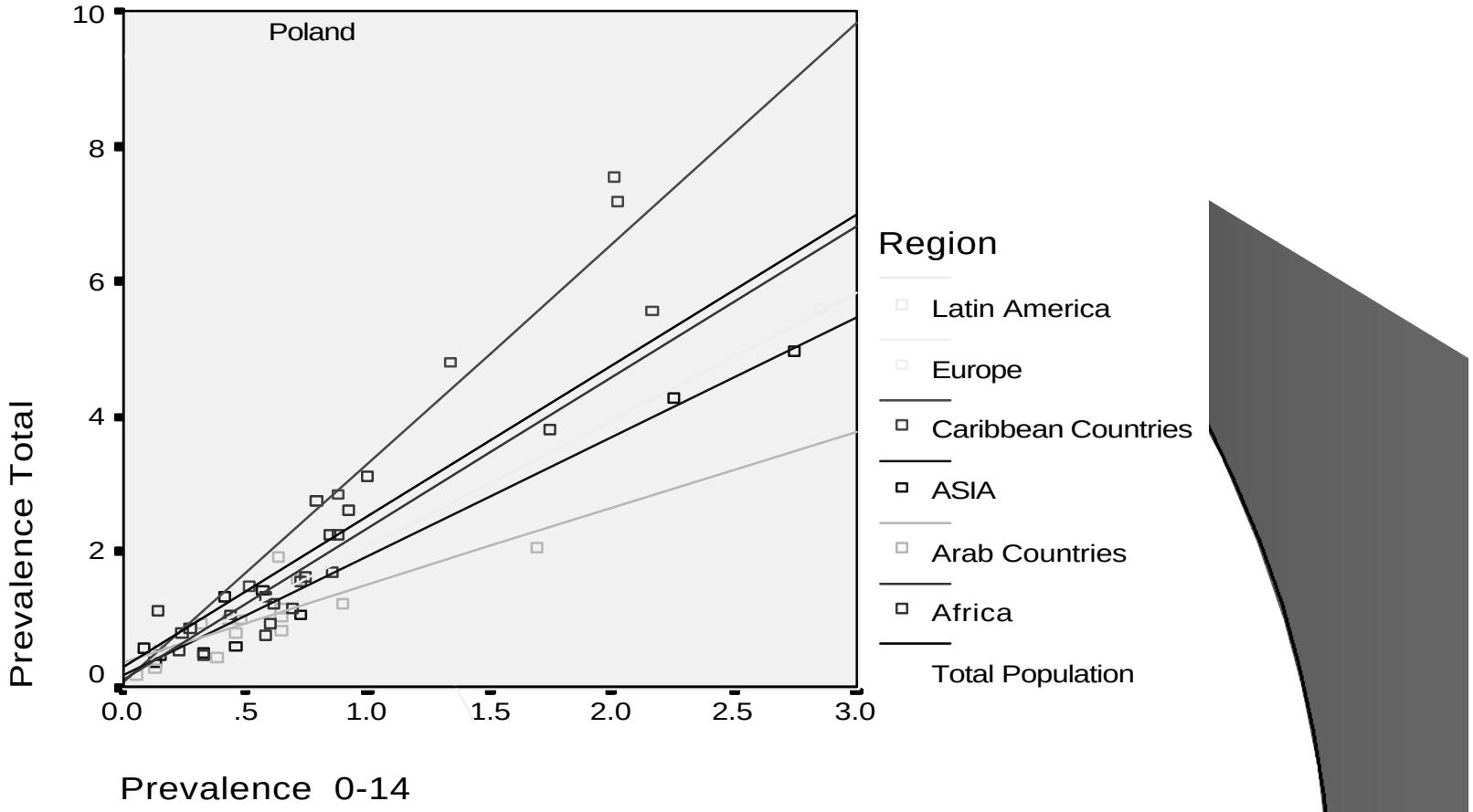
Islands with a common pattern

- Bermuda 1991, Census
- Saint Vincent and the Grenadines 1991, Census
- Jamaica 1991, Census
- Cyprus 1992, Census
- Malta 1995, Census

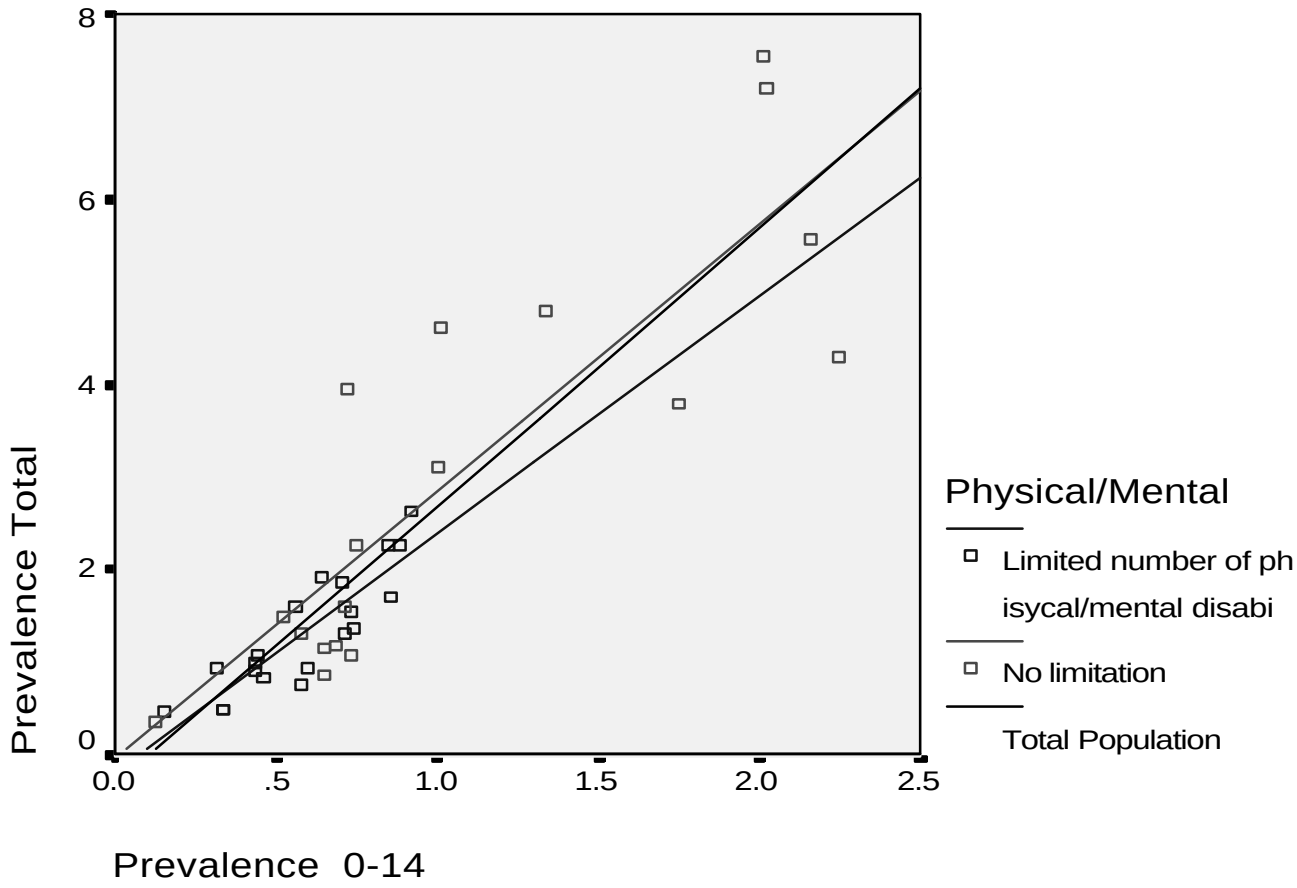
Children
by Type of Data Collection



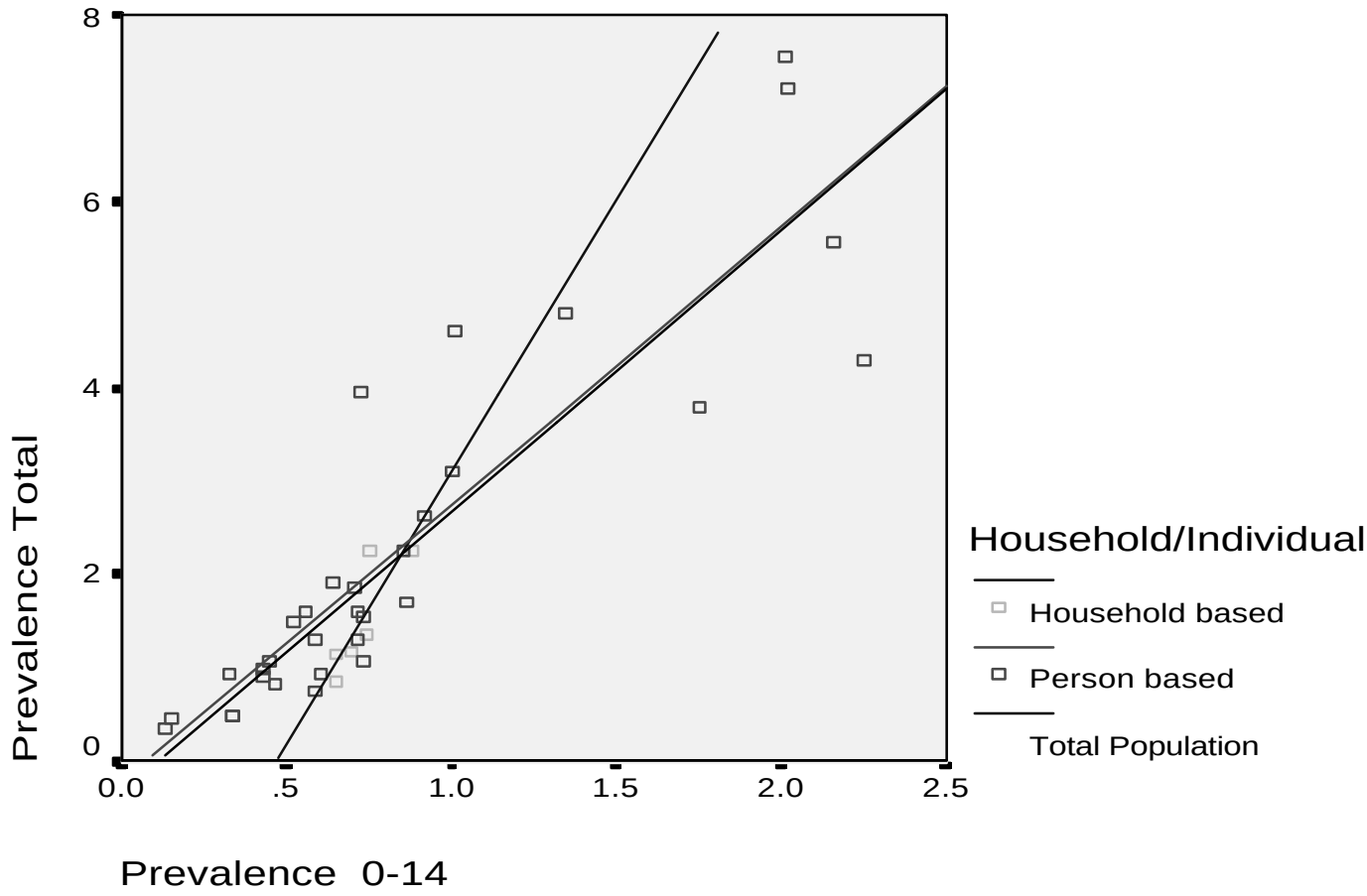
Children by Region



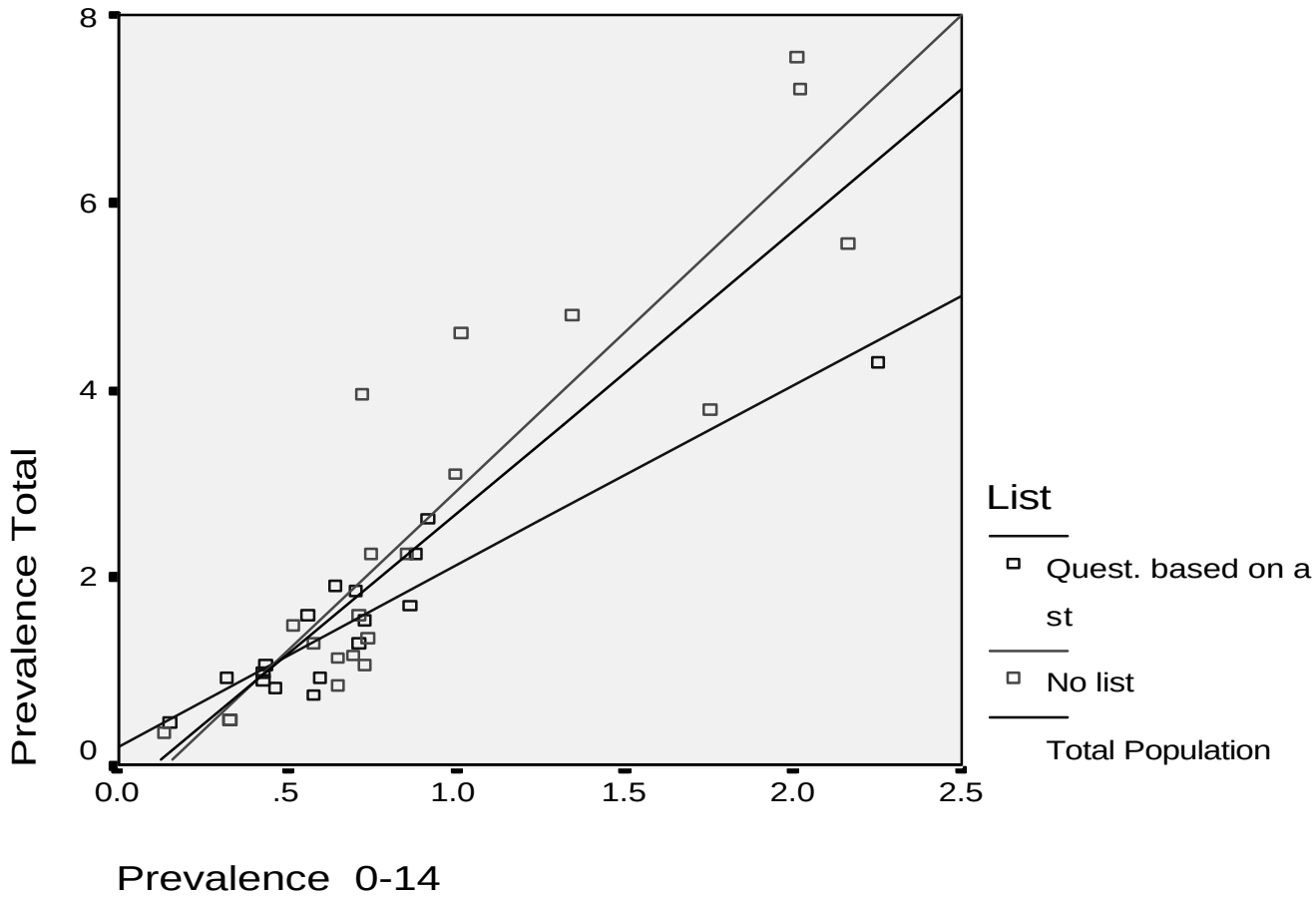
Children according to limited Physical/mental disabilities



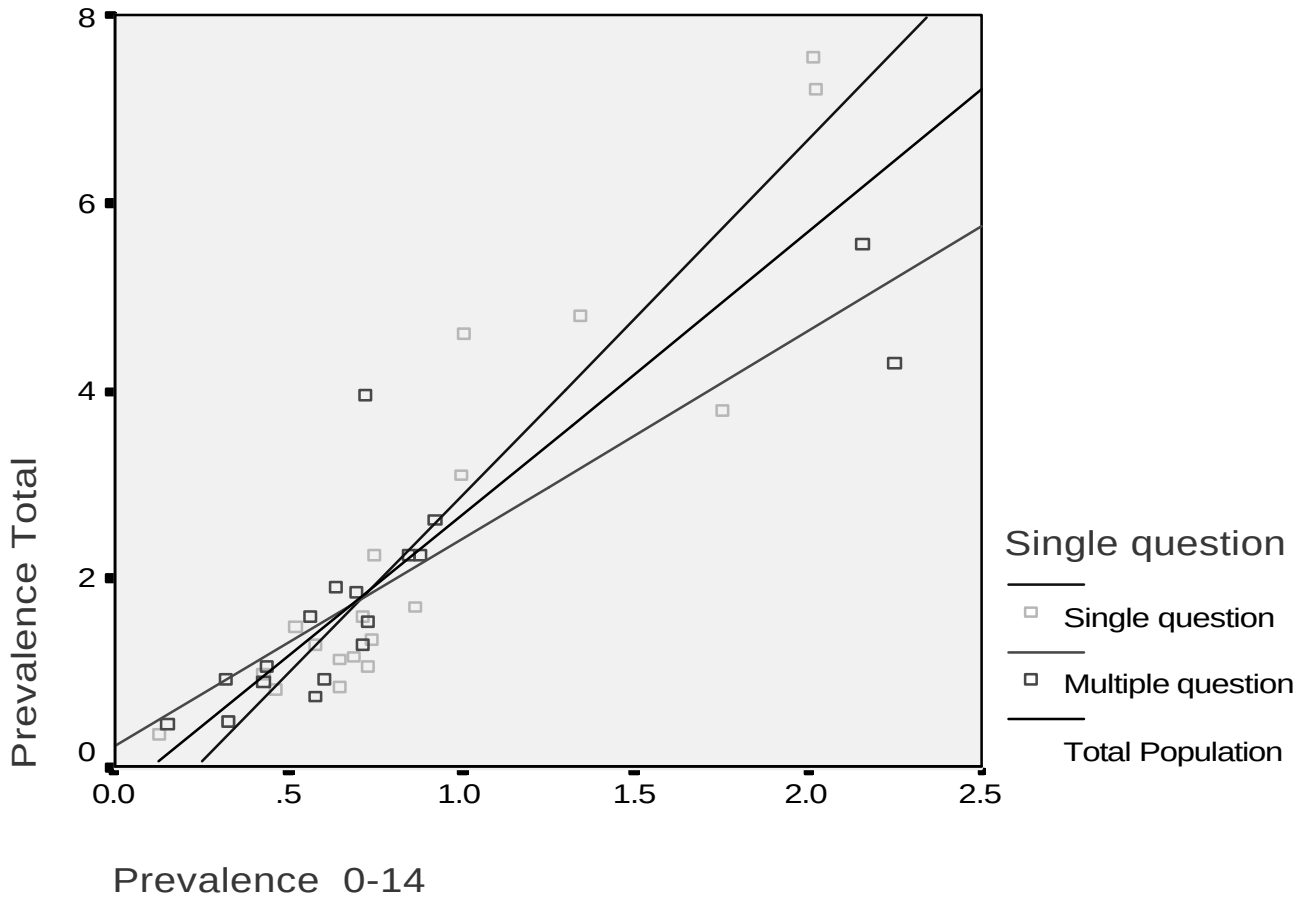
Children according to Household/Person based questions



Children according to Questions based on a List



Children according to Single/Multiple Questions



Example: a census as instrument

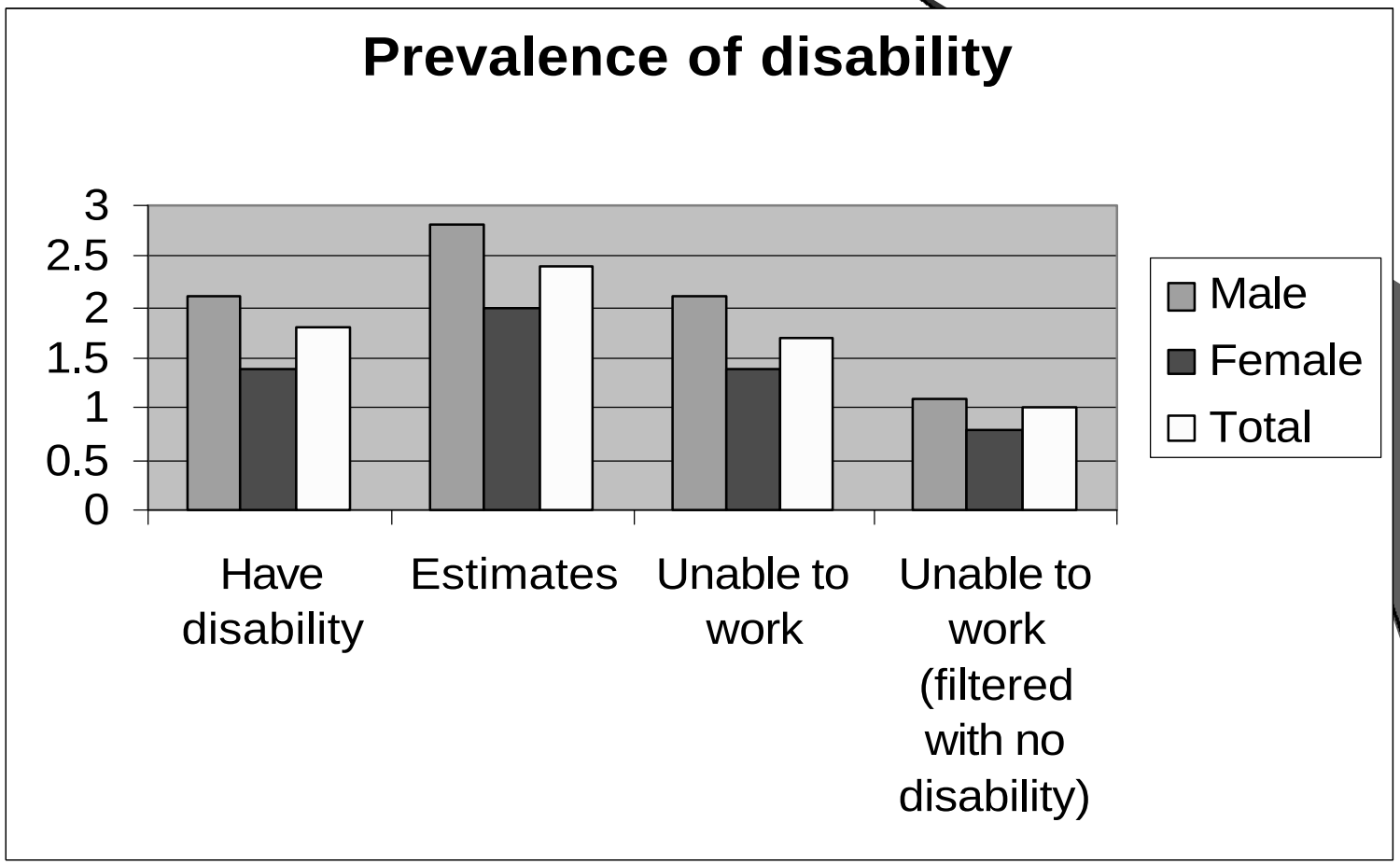
Type of disability: *Seeing, Hearing, Speaking, Hearing and speaking, Moving, Grasping, Mental, Mental and moving, Multiple, Other* **(1.8%)**

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%)**

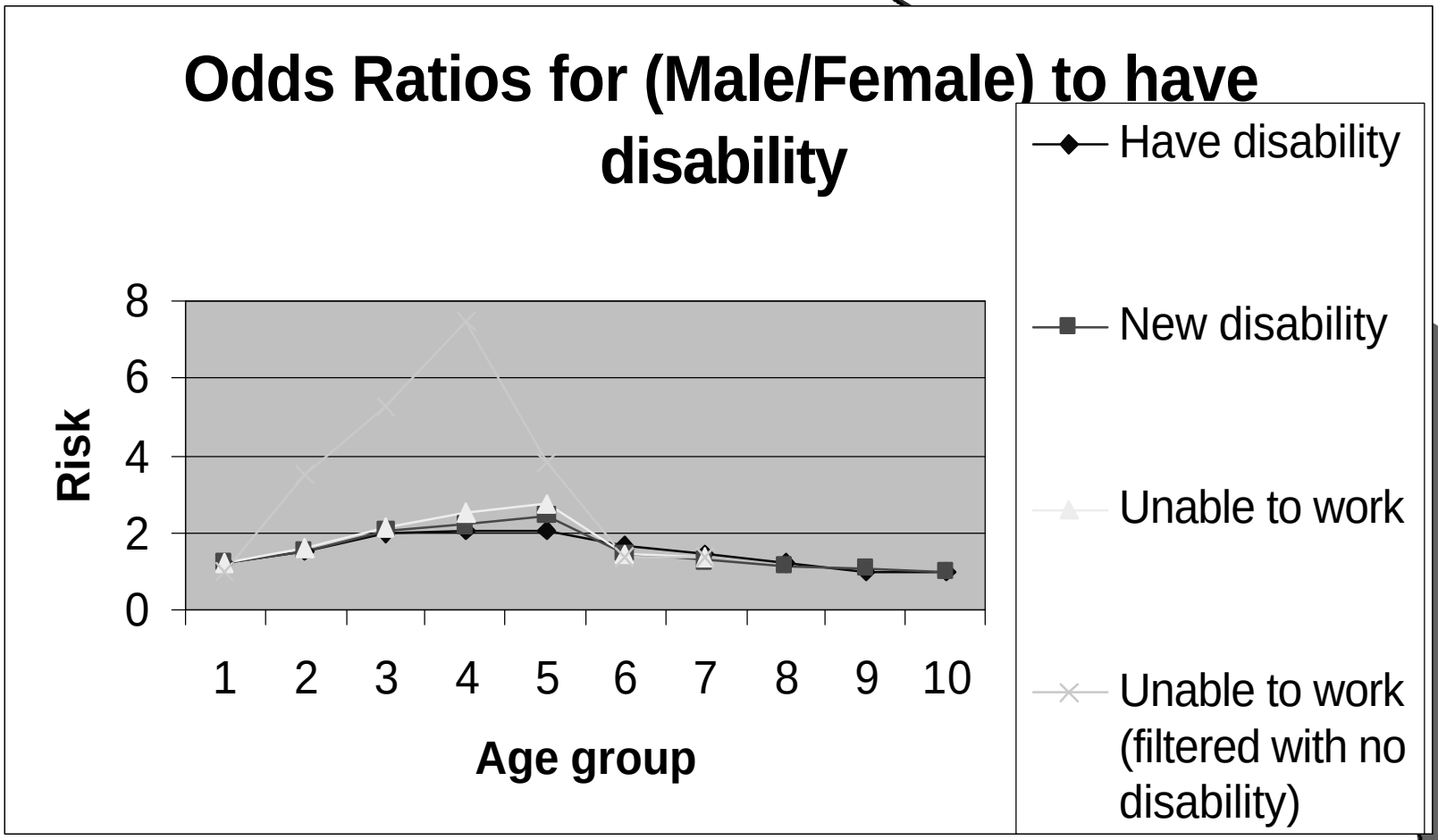
Inconsistent Reporting

	Unable to work	Other	Total
Have disability	13556	23317	36873
Not have disability	15972	1634563	1650535
Total	29528	1657880	1687408

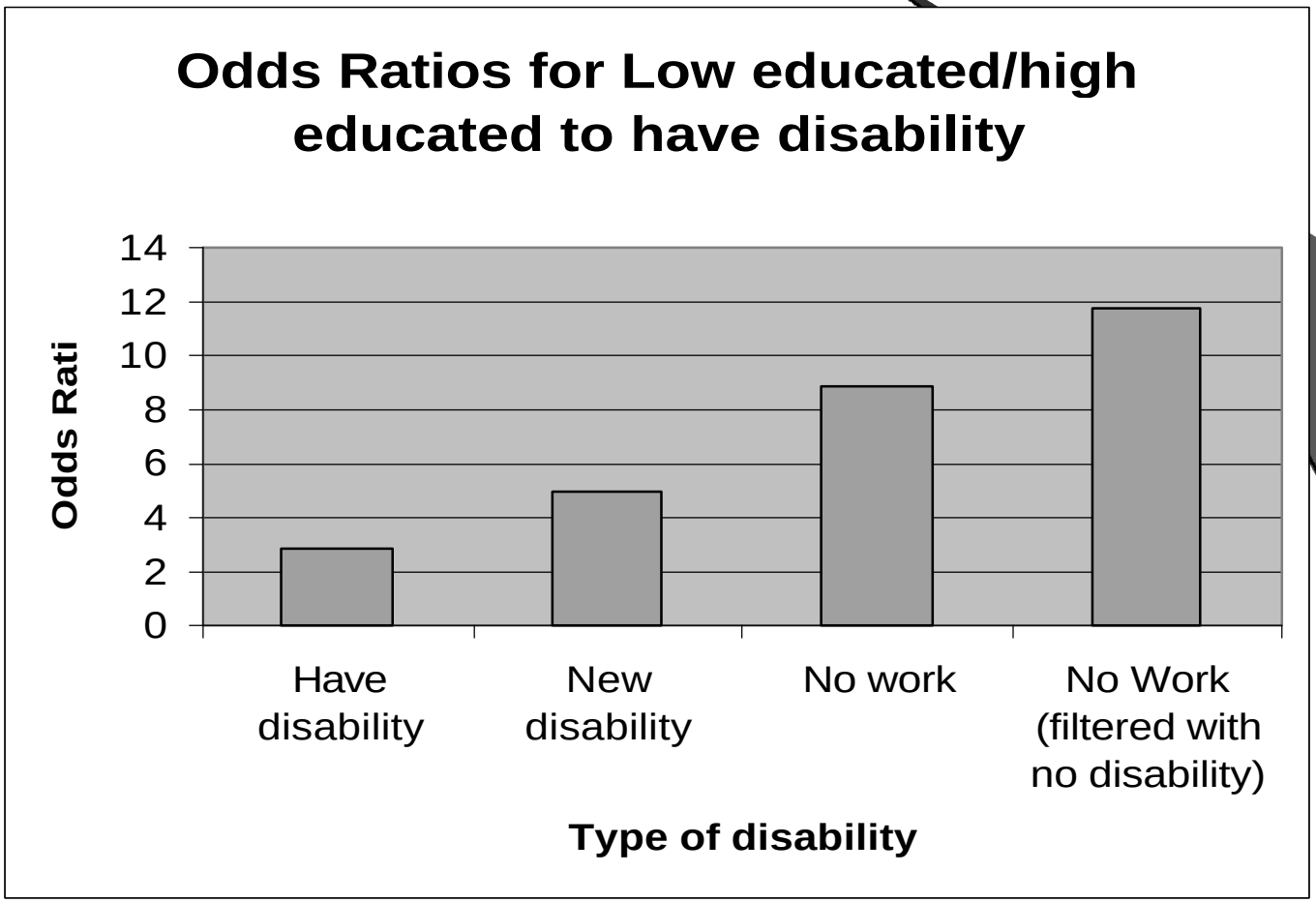
Prevalence of disability by type of disability reported



Sex biased in Reporting disability



Education biased in Reporting disability



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)**

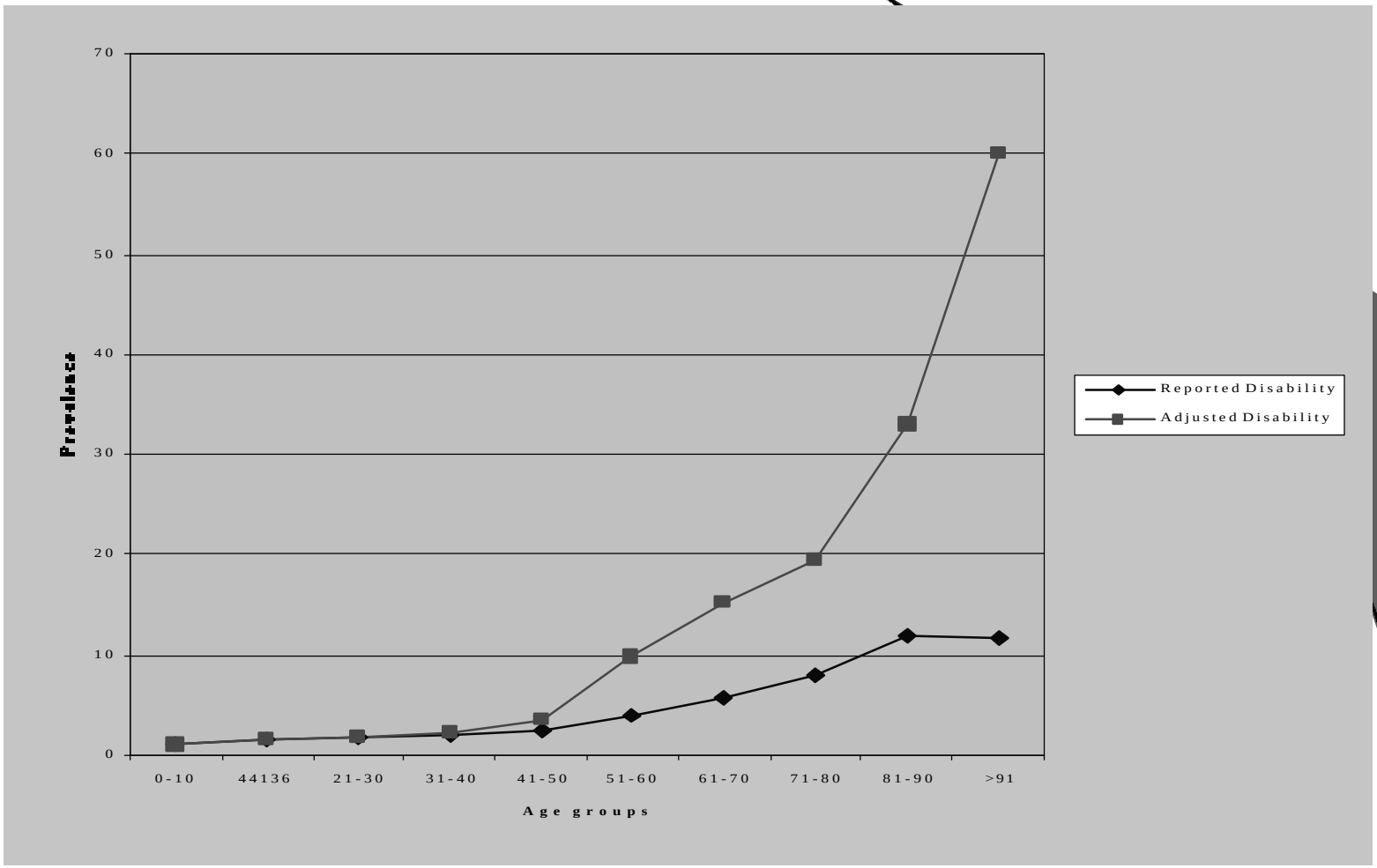
Do you have a physical, mental or other health condition or limitation which has lasted for more than six months and which limits or prevents your participation in the activities of daily life e.g. work, recreation, mobility, schooling, etc.

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



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:

Namibia 2001, Tanzania 2002, South Africa 2001, Botswana 2001, Uganda 2002

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?