

GENERAL DISABILITY MEASUREMENT IN UGANDA, FOCUSING ON IMPROVEMENT IN METHODOLOGY AND CONCEPTS USED

A case study of a population and Housing Census and the Community
Based Rehabilitation programme

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Summary

The paper focuses on improvements in methodology, questions and concepts used in the 1991 and 2002 censuses. It also looks at the Community Based Rehabilitation Programme's approach to data collection on disability, in addition to its linkage to the ICF.

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1.0 Introduction

Population and Housing Censuses remain the major source of Nationwide disability statistics in developing countries because there have been very few disability specific surveys carried out. These specific surveys are done but not on a nation wide basis. In Uganda there are different key players in the area of disability and these institutions collect their own data for specific needs using different concepts, definitions and methodology. These institutions include;

- Uganda Bureau of Statistics
- Ministry of Health
- Ministry of Gender Labour and Social Development
- Ministry of Education and Sports
- Non governmental Organizations

Given the growing concern in the area of disability measurement, a regional workshop on Disability Statistics for Africa in September 2001 was held by United Nations Statistics Division, New York and co-hosted by Uganda Bureau of Statistics in Uganda. The broad objective was to strengthen national capacities in the production, dissemination and utilization of disability data for policy development and formulation.

The workshop was a landmark in the area of disability measurement as it focused on the following areas among others; use of ICF in defining concepts and the design of data collection instruments. It was after this workshop that UBOS realized the need for improvement in the area of general disability measurement, therefore prompting improvement of the question on disability in the 2002 Population and Housing Census.

This paper therefore highlights an improvement in the concept and methods used in general disability measurement, focusing on the two data collection programmes:

1. Population and Housing Census (1991 and 2002)
2. The Community Based Rehabilitation (CBR) programme

2.0 Improvements in Methodology and concepts

2.1 Comparison of the 1991 and 2002 Population and Housing Censuses

Uganda has conducted Population and Housing Censuses since 1911 on a decennial basis but questions on disability were only included in the last 2 censuses (1991 and 2002). A comparison on the different concepts and methodology used is shown below:

	1991 Census	2002 Census
Methodology	<ol style="list-style-type: none"> 2 questionnaires (short and long) were administered. The long questionnaire included questions on disability and was administered on 10% sample The long questionnaire was only administered to household population and excluded institutional population. 	<ol style="list-style-type: none"> Had complete coverage Had 1 questionnaire administered to everyone (both household and institutional population)
Questions asked and concepts used	<p>Question was phrased, as <i>"Is there anyone who was in the household on the census night and is disabled?"</i></p> <p>Codes adopted for:</p> <p>A. Nature of Disability</p> <ol style="list-style-type: none"> Blind Deaf/dumb Amputee Leper Epileptic Cripple/Lame Mentally Retarded Others N.E.S. Not Reported <p>B. Cause of disability</p> <ol style="list-style-type: none"> Born Disease Accident War injury All others Not reported 	<p>Question was phrased as <i>"Does (NAME) have any difficulty in moving, seeing, hearing, speaking or learning, which has lasted or is expected to last 6 months or more?"</i></p> <p>Codes adopted for:</p> <p>A. Type of disability</p> <ol style="list-style-type: none"> None Limited use of legs Loss of leg(s) Limited use of arms Loss of arm(s) Serious problem with back spine Hearing difficulty Unable to hear (deafness) Sight difficulty Blindness Speech impairment Unable to speak (mute) Mental Retardation Mental illness (strange behaviour) Epileptic Rheumatism Others (specify) <p><i>What caused this difficulty (ies)?</i></p> <p>B. Cause of disability</p> <ol style="list-style-type: none"> Congenital (born with a disability) Disease/illness Transport accident Occupational injury Other accident War Natural ageing process Other causes (specify) <p>C. Rehabilitation/assistance of disability</p> <ol style="list-style-type: none"> None Surgical operation Medication Assistive Devices Special education(mentally retarded)

		6. Braille training 7. Skills training (Vocational) 8. Sign language training 9. Counseling 10. Others (specify)
Definition of Disability	Definition as given in the manual, Disability was defined as any condition, which prevents a person from living a normal social and working life.	Definition as given in the manual, "A person with a disability is defined as one who is limited in the kind of or amount of activities that he or she can do, because of ongoing difficulty (ies) due to a long-term physical condition or health problem that has lasted six months or more . This includes all those difficulties that are expected to last more than six months."
Summary	1. The use of the term "disability" was used in the global question 2. Information was collected for one type of disability 3. Results revealed a Prevalence rate of 1.1%	1. Included information on rehabilitation measures 2. The term "disability" was avoided in the global question. 3. Multiple disabilities were taken care of.(at most 2 types) 4. The definition took care of the duration of difficulty

In light of the question matrix, the issue of severity was left out during the 1991 census, because the stakeholders at that time felt that the results would be subjective. Similarly, severity was left out of the 2002 population and housing Census for the same reason.

2.2 Community Based Rehabilitation Programme

In 1992, the Government of Uganda adopted Community Based Rehabilitation (CBR) as an appropriate service strategy to reach more Persons With Disability (PWDs). This programme is being implemented under the Ministry of Gender, Labour and Social development. The programme has since been running in 16 districts out of the 56 districts in the country.

During implementation of CBR, the programme has undergone both internal and external evaluations, which have revealed a number of successes, weaknesses and gaps in specific areas. Some of the weaknesses related to data collection that were pointed out during the 2000 evaluation include;

- Existing gaps in developing specific indicators to measure the impact of CBR on a PWD
- Lack of reliable data and information systems on CBR programme
- Lack of standard periodic reports, making it difficult to collect comparable data within the country
- Assessment forms, which were adopted from WHO at the beginning of the programme, were reported to be too complicated to fill.
- Due to the difficulty of filling existing forms, the CBR programme staff that are the key implementers at the grass root level hardly filled these forms.
- Data collected in some districts was not correlated and systemized.

The evaluation therefore recommended that the Uganda CBR programme should make effort to develop standardized systems to collect information at all levels and to establish an adequate capacity for supervision, monitoring and reporting.

In light of these findings, the national CBR steering committee instituted a task force, which through consultations, agreed that the national CBR programme should develop information systems, which not only satisfy the specified needs but also adapt to the conditions in the districts as regards **collection, compilation** and **presentation** of data on disability.

2.2.1 Data Collection Instruments

The programme divided the information system into 4 sections which cover all administrative levels up to National level to ensure standardized flow of information as follows:

1. Identification, registration and baseline information forms- *used to identify PWDs and as an inclusion or exclusion criterion for all households.*
2. Assessment, follow up and referral forms - consists of 3 forms aimed at collecting information after assessing individuals with disabilities, planning interventions, follow up and referral for intervention. *Its purpose is to gather information on a client's abilities and inabilities before planning a specific intervention. In addition,*

to be able to know the cause of disability in an area, helps in planning strategies for disability prevention.

3. Supervision and monitoring guidelines
4. Reporting guidelines

2.2.2 Characteristics of general measures currently used

Definition

Disability is defined as difficulties/restrictions in performing daily activities leading to failure to participate like other people. If a person experiences difficulty in one or more of the following areas they can be considered to have a disability; seeing, hearing, speaking (using language or conveying messages), moving around or using body parts, learning, if a person gets fits, has strange behaviour, loss of skin feeling, and others not mentioned here.

Methodology of collection

In assessing abilities and inabilities, the CBR volunteer who is responsible for collecting information is required to take care and observe the PWD carrying out specific activities before recording. This form addresses the following areas:

Self-care, speaking and conveying messages, learning, mobility, pain, strange behaviour, gainful occupation, attitude, fits and loss of feeling (skin sensation).

Questions on disability

Severity of disability is recorded as mild, moderate or severe. This is from the community workers point of view. The duration and cause of disability is also recorded. It also takes care of all domains of well being (i.e. seeing, speaking, Education, employment etc.)

Data on environment and Participation

This was recorded using an observation checklist; this data is filled because rehabilitation depends on the home and community environment. Environment factors therefore cover the following: -

- Home environment (in terms of cleanliness, behaviour)
- Accessibility (in terms of space, number of people in the home, facilities, distance to social services, terrain of the place)
- Nutritional practices (whether the family has adequate food supplies).
- Hygiene of PWD
- Waste disposal
- Source of water
- Cultural beliefs/practices related to PWD

2.2.3 Mapping this data to ICF

For international comparison of collected data from the CBR programme is mapped onto the ICF. It can be realized that some of the chapters have not been touched at all, for

the others at least one of the components is mentioned. The constructs/qualifier of 'body structures' is not mentioned at all. This is shown in the appendix .

2.2.4 Conclusion

Nation wide data on disability in Uganda is obtained from censuses and these are not comprehensive. Currently, through administrative data collection from the CBR programme this will be the only comprehensive source on disability data although this is not conducted on nationwide basis.

It is observed that the issues raised under the question matrix were to a great extent included in the last census and the CBR programme. The census covered the issue of " domain, etiology/causes and duration" but omitted issues like severity. Similarly the CBR programme addresses " domain, etiology/causes and duration" and includes severity.

Major group of ICF	Availability of data in CBR assessment form
Body functions	Availed in assessment form
Chapter 1: Mental functions	Yes
Chapter 2: Sensory functions and pain	Yes
Chapter 3: Voice and speech functions	Yes
Chapter 4: Functions of the cardiovascular, haematological, immunological and respiratory	Not Available
Chapter 5: Functions of the digestive, metabolic and endocrine systems	Not Available
Chapter 6: Genitourinary and reproductive functions	Not Available
Chapter 7: Neuromusculoskeletal and movement-related functions	Not Available
Chapter 8: Functions of the skin and related structures	Yes
Body Structures	Not Available
Activity and Participation	Not Available
Chapter 1: learning and applying knowledge	Yes
Chapter 2: general tasks and demands	Yes
Chapter3: communication	Yes
Chapter 4: mobility	Yes
Chapter 5: Self care	Yes
Chapter 6: Domestic Life	Yes
Chapter 7: interpersonal interactions and relationships	Not Available
Chapter 8: Major life areas	Yes
Chapter 9: community, social and civic life	Yes

Environment Factors	Not Available
Chapter 1: products and technology	Not Available
Chapter 2: Natural environment and human-made changes to environment	Yes
Chapter 3: Support and relationships	Not Available
Chapter 4: attitudes	Yes
Chapter 5: services, systems and policies	Not Available

APPENDIX

Table showing mapping of CBR data onto the ICF major groups