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*Florence Nayiga Ssekabira:
Concept and objectives for the measurement of disability*

(Presented by: Winifred Hellen Akot)

CONCEPT AND OBJECTIVES FOR THE MEASUREMENT OF DISABILITY

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Introduction

The paper highlights the sources of disability data in Uganda , gives a profile on the development of the statistics, their use, availability, a conceptualization of disability plus recommendations.

There is no uniform view on what constitutes disability as evidenced by two leading models on the subject – The medical and the social model. Medically, disability is perceived in a physical sense; as an impairment (loss of limb, organ, function or sense) with traumatic physical and psychological effects on a person that he/she can not ensure a reasonable quality of life for themselves (*Ndeezi, 1999:7*). The social model focuses on the society's disabling conditions or environment and attitudes rather than on the individual's impairments. Hence, disability issues are multi-sectoral and deserve due attention. For instance WHO estimates that 98% of People with Disabilities (PWDs) in LDCs are neglected (*WHO Report 1989:7*).

History of Development of Disability Statistics

In Uganda like many African countries, very few surveys have been carried out on disability prevalence. Service providers and advocates of the disability movement have all often used the World Health organisation (WHO) blanket figure of 10% which is now considered inaccurate.

This is due to the fact that this global figure includes the developed countries who generally have much higher disability rates than southern countries. The disability incidence in Less Developed Countries (LDCs) is lower than that in More Developed Countries (MDCs) because in LDCs, most children who are born with a disability or acquire one in life do not live beyond the age of 20 years. Similarly, elderly people do not live long after they acquire a disability (*WHO Report, 2000: 13*).

The 1991 Uganda Population and Housing Census Survey was the first National Census in Uganda's history to include a question on disability.

Due to the long data gap, there was a lot of pressure to include various questions on the census questionnaire. Disability department of the Ministry of Local Government requested the Statistics department to collect important information on disability to determine the disabled persons by sex, age, disability condition and causes. It contained only two questions on disability.

The census revealed a total of 190,435 people with disabilities among the household population in Uganda, a disability rate of 1.1%, a much lower figure than WHO 10%.

However, there were several reservations about quality of the data obtained from the census; hence, it came to be regarded as only indicating a minimum disability rate.

Also, people with Disabilities (PWDs) were under enumerated due to the fact that census enumerators were not trained in identifying disabilities and therefore relied on respondents' identification.

There was also a problem of non-response to the question on disability, the question appeared at the back of the questionnaire form so probably was not seen.

The census, though covered 98.9% of the total population, excluded institutions such as centres and homes for people with disabilities and hospitals where majority of such people are found.

Complementary to the foregoing efforts, the statistics department too has carried out a census of National Household Surveys. These surveys are carried out using samples due to financial constraints. The problem with this is that surveys cannot measure prevalence of relatively rare events such as disability since in small households, sampled cases of disability may not be found.

Objectives for Measurement of Disability

Statistics as indeed all data on disability in Ugandan much as in many other parts of the world is very significant because it can be utilised for different purposes, inter alia;

- ◆ Making informed decisions when planning
- ◆ Developing appropriate referrals for medical education and social rehabilitation
- ◆ Establish gaps existent in the disability sector in order to map out appropriate interventions or safety nets.
- ◆ Identifying environmental links with disability.
- ◆ Needs assessment among people with disability
- ◆ Determining etiology of disability
- ◆ Empowerment of the disabled
- ◆ To determine the geographical distribution of persons with disability.

Sources of Statistical data on disability in Uganda

There are several stakeholders in disability matters in Uganda from whom data on disability is obtained.

These include:

- Non-Governmental Organisation providing Services to people with disabilities such as the National Union of Disabled Persons of Uganda (NUDIPU), Action

on Disability and Development (ADD), Uganda National Institute of Special Education (UNISE), Education Assessment Resource services (EARs), Uganda Society for Disabled Children (USDC) etc.

- Hospital records
- Local Government Councils
- School records
- Community Based Rehabilitation programme (CBR) which is being coordinated by the department of Disability and Elderly in the Ministry of Gender, Labour and Social Development (MoGL & SD)

Problems related to the use and availability of the statistics

The data obtained from the above sources is limited in terms of reliability and even accessibility because:

- Institutional services providers such as hospitals and clinics are usually urban based and only clients who visit these institutions are recorded .
- Use of hospitals/clinics also depends on a person's knowledge of the service and belief in its effectiveness. Some disabilities for example the mentally ill and epileptics are more likely to consult traditional healers than qualified practitioners. In view of the foregoing, data from institutions tends to show bias towards high income.
- Organisations in Uganda rarely produce data for epidemiological reasons. Each organisation produces data for its own needs be it medical, educational, or social (functional). This results in sets of data using classification system which differ from one another and therefore not comparable.
- Another problem with the data or statistics on disability is about the discrepancy on the definition of disability in the first place. For instance where a medical definition is applied, there is a danger of creating a disability where it does not exist. For example in 1995/6, the number of cases of mental retardation identified by Uganda Society for Disabled Children (USDC)

CBR programme accounted for only 1.7%; whereas the 1991 National Population Census found that mental disability was the second most prevalent disability with 16.5% of all recorded disabilities. One reason for low prevalence of mental disability is that persons with that condition especially if it is mild or moderate may not be regarded as disabled in many rural communities, since they can still be able to fulfil many of the societal roles expected of them such as digging, fetching water etc.

- In another development, disabilities resulting from old age may also not be perceived as disabilities by some communities. For instance the Lions Aid Norway Ophthalmic programme had difficulty in identifying and treating elderly persons with visual impairments, since their disability was seen as a natural part of the ageing process.
- There is no sufficient information readily available as to where one can access the statistics on disability from.
- There is poor storage and availability of the data generated due to use of rudimentary storage systems such as filing. This makes it difficult to easily access the data and it is also prone to being mixed up.

Recommendations

As a strategy to improve on the availability and reliability of disability statistics, the following need to be put into consideration:

- The United Nations through its statistics department should issue guidelines on the development of the statistics for use in planning and other purposes.
- Since there are flaws in the current efforts in defining and identifying disability, a measure of self-definition where the disabled him/herself or the carer confesses should be encouraged to identify the condition. Self-identification also takes into consideration the prevailing social and cultural conditions.
- In the process of data collection the following aspects should get due attention:

- Age-sex distribution of people with disabilities
 - Geographical variation on total disability
 - Relative prevalence of different disabilities, nature of disability, causes and condition.
 - Prevalence of disabling conditions
- Because conducting surveys is not only costly but can also unduly raise the expectations of people with disabilities which may afterwards fail to be met when no service materializes to benefit them; It is better to take advantage of the existing resources and fora already in place. In Uganda for instance it could be done through the existing programmes supported by the Ministry of Gender, USDC, EARs, etc.
 - Standardised surveys should be made so that they can meet the needs of all stakeholders in disability. Precisely, organisations involved in conducting surveys on disability should compromise on the methodology used. This would involve discussions on the objectives of the disability survey so that the data generated would meet the needs of all.
 - The Local Council System should be used to trace and monitor people with disabilities in areas of their jurisdiction since they have first hand information about them other than relying on institutions which are faced with several barriers including time in identifying the disabled.

Conclusion

Involvement of PWDs themselves is the only panacea in surmounting the problem of constructing useful and reliable data on disability, otherwise all other efforts remain wanting in terms of reliability.

Finally, let me take this opportunity to thank the organisers for this very important workshop and for the confidence expressed in me and in my country Uganda to merit an invitation. It is a very enriching experience and with no

doubt, the information obtained here shall go along way in helping the PWDs in Uganda improve their lot.

Thank you very much.

FOR GOD AND MY COUNTRY.