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Living conditions among people with disabilities in Namibia and Zimbabwe

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Introduction

The situation for disabled people in developing countries is of concern for Governments, Non-Governmental Organisations as well as the International Community and the rights of persons with disabilities have long been the subject of much attention in the United Nations and other international organisations. The International Year of the Disabled Persons (1981) and the United Nations Decade for Disabled Persons (1983-1992) culminated in the World Programme of Action concerning Disabled Persons (UN 1993). The programme emphasises the right of persons with disabilities to the same opportunities as other citizens and to an equal share in the improvement in living conditions resulting from economic and social development. In 1993, the General Assembly approved The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (Resolution 48/96) (UN, 1994), setting specific targets and implying a strong moral and political commitment on behalf of States to take action for the equalisation of opportunities for persons with disabilities. Both the World Programme of Action and the Standard Rules comprise explicit formulations that reflect the need for information, data collection and research on the situation of the disabled people and particularly so in developing countries.

Knowledge about the current situation is important as a tool for advocacy and practical action. It is a prerequisite when agreeing on acceptable standards, setting priorities and planning for required improvements. Without the necessary knowledge, Governments, NGOs and International Organisations are more or less forced to work arbitrarily on a hit and miss basis.

This paper describes the efforts made by research teams in Namibia and Zimbabwe to develop and test a methodology designed to collect information concerning people with disabilities and their living conditions. Information that can ultimately be used to direct and channel resources to those in greatest need.

Data on Disability in Developing Countries

Most information on disability comes from industrialised countries. Unfortunately the current statistical information is produced without the benefit of common terminology or standard procedures and guidelines. It is further claimed (UN 1996) that there are problems with the quality of existing data and that the quality problems are most pronounced in developing countries.

Data on disability have been actively compiled by the UN since the 1980s and were first published in 1990 as the Disability Statistic Compendium (UN 1990). The compendium included national level data on 12 major topics about disability (including age, sex, residence, educational attainment, economic activity, marital status, household characteristics, causes of impairment and special aids used).

As examples of information from African countries contained in this compendium, the national disability prevalence rate in Swaziland is given at approximately 3%. Reviewing the age specific figures for rural populations in five African countries (Comoros, Egypt, Ethiopia, Mali and Tunisia), the rate varies from 1-4% in younger age groups (under 25 years) and gradually increases with age to reach a level of 2-12% among those 50 years of age. The prevalence rate of disabled persons per 100,000 population is reported for some African countries and varies from just below 1,000 to more than 3,000. It is interesting to register that the figure for Norway is as high as 15,000 – in line with other industrialised countries and reflecting first of all that there are serious methodological problems associated with comparing data from different sources across countries. Definitions of disabilities, methodologies for data collection and data quality vary (UN 1990).

Most countries in Africa, Namibia and Zimbabwe included, have carried out and published population censuses that provide some information on living conditions. Information on disabilities and the situation of the disabled have, however, rarely been included. The population censuses planned for the coming years are, however, expected to cover disability (UN 1997), following the revision of the census recommendations.

The national disability survey undertaken in South African in 1998/99 represents an important exception to the general lack of data in the region. A national representative survey of 1,000 households was carried out to determine the prevalence of disability as well as describe the disability experience as reported by disabled people or their proxy reporters (Schneider et al, 1999). The focus of the survey was on the "traditional" categories of impairment and the results are a count of the number of people with reported disabilities or activity limitations, as well as a quantitative analysis of the respondents' personal experience of their disability.

Although the progress made in this field is quite substantial, data on disability are still hard to come by and are significant by their absence in development reports. A further point to be mentioned is that the international monitoring system developed by the UN will largely be limited to a small number of standardised indicators intended for international comparison. In addition to this, more comprehensive and culturally adapted studies of living conditions offer a wider approach to the measurement of individual welfare, focusing on individuals' capabilities, the utilisation of these capabilities as well as equality (of opportunities) in addition to the more limited, classical economic or material indicators. Thus, the level of living concept as applied today concurs with some of the fundamental ideas concerning participation and equality of opportunities underlying the World Programme of Action as well as the Standard Rules.

Relevant Studies in Namibia and Zimbabwe

In Namibia, the National Housing and Population Census in 1991 contained a small number of questions on disability (classification of disabilities, access to education and work), and this material has later been analysed and published by The Namibian Economic Policy Research Unit (Bruhns et al, 1995). Other than providing prevalence estimates of impairments, the 1991 Census also provided information revealing marked differences in school attendance and employment between people with and without disabilities. It was found that 48% of people with disabilities (aged six years and over) had attended school in comparison with 78% of all Namibians (aged six years and over). Unemployment was reported by 57% of all disabled persons between 15 and 65 years, and 43% of the employed

were self-employed (mostly in the field of agriculture). Differences were also found in rural:urban ratios for the population of disabled (5:1) compared with the general population (3:1). A mapping of the supply of technical devices was carried out in 1998/99 (Strand, 1999). The report states that the supply of different kinds of technical devices in no way meets the demand.

In Zimbabwe, the population census in 1980 comprised a mapping of the number disabled people; the information from this study is very limited. Supported by UNICEF, the Ministry of Labour and Social Welfare carried out a National Disability Survey in 1981 (MLSS 1982). This study revealed that there were approximately 250,000 people with disabilities in Zimbabwe at that time. The most prevalent functional problem was visual impairment (25%) followed by impairment in the lower limbs (24%), upper limbs (12%), mental retardation or disability or emotional illnesses (9.7%), hearing (8.2%), speech (7.4%) and neurological impairment (5.5%). It was further revealed that the risks of disablement during the first four years of life are 15 times greater than in adulthood. Diseases, accidents, war-related incidents and perinatal factors such as those related to malnutrition or hereditary conditions were, in descending order, the most common stated causes of impairment. The study also comprised a few socio-economic indicators, revealing that 52% of persons with disabilities in 1980 had never attended school and that only 1% had progressed beyond secondary school. Disability was further found to reduce dramatically the individual's opportunities in the job market.

The 1992 census did not include any questions on either disability or living conditions among people with disabilities. No updated, nation-wide figures about disabilities and living conditions among people with disabilities are currently available.

The Pilot Studies

The main purposes of these pilot studies have been:

i) to develop a design for the collection of data on the level of living among people with disabilities in the Southern African Region, and
ii) to carry out a pilot data collection among households with and without disabled members in Namibia and Zimbabwe.

A design was developed in 1999-2000 that drew on experiences from South Africa and from Namibia, in addition to the ICIDH-2 classification. Guidelines for data collection and pilot studies were carried out in 2000 in both countries.
Bearing in mind that these are pilot phase studies, they do not claim to be representative to a larger population, and all results presented must be interpreted with care.

The studies were conducted in areas selected on the basis of practical considerations.

Katutura is a suburb of Windhoek, the Namibian capital, and was chosen to reduce travel costs and to simplify data collection. Windhoek has a population of around 200,000 (Residents Survey, 1996). Approximately 60% of the population in Windhoek live in Katutura which is often referred to as a "location", a term similar to the more commonly known term "township". Houses in this area are generally small with a simple albeit varying standard with a mix of permanent structures and shacks that are made out of available material. Unemployment rates are high for both men and women. Almost half the households have 6 members or more (1991 Census). The population in Katutura also represents a cultural mix of different Namibian ethnic groups.

Harare, the capital of Zimbabwe, has a population of more than 1.5 million inhabitants. Mbare and Sunningdale are high-density suburbs and were also chosen to reduce travel costs and to simplify data collection. The populations in the 2 suburbs are approximately 60,000 and 20,000 respectively. These high-density suburbs were originally established to house the male labour force to service the industrial sector in the capital. Since independence in 1980 there has been an influx of families from the rural areas, resulting in overpopulation and new social problems. These resulted in the establishment of numerous non-permanent structures. Houses and flats in the area are generally small with a simple standard. Both suburbs have a number of schools and clinics.

Method

The case/control study approach was selected for both Namibia and Zimbabwe, aiming not only at describing and analysing the situation for individuals with disabilities, but also to compare the situation for households with and without disabled members.

Household Sample Survey

Household surveys are often regarded as the most suitable strategy for collecting representative data on living conditions. According to Heyer (1990) this has long been the view of the United Nations Statistical Office (UNSO) and other bodies in the UN system. Practical considerations make the conducting of representative household surveys in Sub-Saharan Africa difficult. They are also time consuming and relatively expensive. Alternatives include national level indicators or utilising existing information gathered through administrative systems such as health, housing, education (some of the core elements in the concept of living conditions). Another alternative is to carry out so called rapid appraisals that might provide a very good picture of a limited geographical area at a relatively low cost. If representativity for a nation or a larger geographical area is needed however, household surveys are clearly the answer.

Design Development

The methodology and design for collection of data on living conditions among people with disabilities in Namibia and Zimbabwe were developed in several steps.

A. Choice of Research Instruments

Two existing research instruments previously developed and tested in southern Africa were applied.

1. The University of Namibia conducted a general study of living conditions in Namibia in 1998 (Planning Commission 2000). It was decided to use this instrument as it had been adapted to the Namibian context and it was thus assumed that need only minor adjustments to be applied in Zimbabwe.
2. The Community Agency conducted a comprehensive disability study for Social Enquiry (CASE) in South Africa in 1998/99 (Schneider et al 1999). The instrument applied in this study was accessible to the research team through the Department of Rehabilitation, University of Zimbabwe. It was particularly opportune to use this questionnaire as it had been applied in the southern African context and its design was clearly influenced by the ideas behind development of the ICIHD-2. One advantage with using this instrument was

the possibility for comparing Namibia and Zimbabwe with South Africa when representative National Studies are carried out.

A third element in the development of the questionnaire was the application of certain elements of the ICIDH-2 – in particular the concepts of *activities* and *participation*. It was not only our desire to record an individual's disability by type, but also to attempt a classification of an individual's own perception of the degree to which their disability impacted on various activities of daily living. These concepts included the assessment of their capacity to carry out different activities without assistance, and the assessment of their ability to perform activities in their current environment.

B. Adaptation to Context

The research instruments were adapted to local context through workshops held in Windhoek and Harare in October 1999. These involved a number of professionals, researchers, representatives from organisations of disabled people and representatives from relevant government ministries and the central statistical offices in both countries. The purpose of the workshops was to critically assess a draft research design. By combining group work and plenary discussions, all possible aspects and problems connected to the proposed questionnaire were discussed. These discussions resulted in a number of changes in both the questionnaire and in the strategy for data collection.

In Zimbabwe, the final version of the questionnaire was translated into Shona (the main ethnic language spoken in Harare) where the pilot study was carried out.

C. Testing

Pre-tests were conducted among a small number of households (approximately 10) with disabled people, leading to a few additional changes in wordings. It was also important at this point to get input from the research assistants/enumerators (see below) who would be in the field collecting the data. Input was sought not only with respect to the contents of the questionnaire, but regarding the logistics of data collection in the selected sample areas.

D. Sampling

As mentioned previously, the main purpose of data collection in this pilot phase was to test the study design. Achieving representativity in the sample was not one of the goals. The strategy was to define suitable areas and identify households with and without disabled people (case/control).

In Katatura, Namibia, 100 households having a household member with a disability were selected with the help of the local Disability Resource Centre and 100 control households (also in Katatura) were randomly drawn from the data set on Living Conditions collected in 1999 (Planning Commission, 2000).

In Zimbabwe the chosen suburbs were Mbare and Sunningdale. The pilot study comprised of a total sample of 300 households, 150 with a disabled household member, and 150 without (control group). The sample of households with disabled was obtained by taking all the addresses of the households provided by the office of NCDPZ (the National Council of Disabled Persons of Zimbabwe) in Mbare. Additional households were identified through the

disabled research assistants who were familiar with households that were not members of the NCDPZ. The control sample was selected from a register obtained at a local polyclinic in Mbare. The households were chosen by selecting alternative addresses on the register by the Project Co-ordinator and the Assistant Project Co-ordinator.

E. Training of Research Assistants (Enumerators)

In Namibia 8 research assistants (4 disabled) and in Zimbabwe 16 research assistants (4 disabled) were recruited. All research assistants went through a period of intensive training. Training consisted of survey logistics, information and objectives of the study, expectations of the research assistants, the survey instrument and the area of study, identification of households and language (English/Shona in Zimbabwe). Research assistants went step-by-step through the questionnaire and were instructed in how to complete individual questions. Training consisted of both question and answer sessions and role-playing whereby the assistants took turns in testing the questionnaire on each other. The last part of the training consisted of evaluation and reflection.

F. Data Collection

Data were collected by research assistants working in pairs. Research assistants with disabilities were paired with non-disabled research assistants. Trained supervisors assessed all questionnaires handed in before they were accepted as complete.

Lessons Learned During the Pilot Phase

The training component of the project must be further developed and perhaps lengthened for the national studies. The more time and effort invested in making preparations for the study and in the interviewing and training of research assistants will reduce the number of invalid/incorrect responses and the amount of time research assistants use in the field to collect valid and reliable information.

The analysis of the pilot data has given us a good indication of those areas of the questionnaire that should be improved. As a result, certain components of the questionnaires have been further developed. Meetings in Namibia and Zimbabwe in February 2001 were used in part to present the results of the pilot studies and in part to again discuss the revised questionnaires.

It was interesting to note that families with disabled people seemed to be more receptive to the interview as they felt that their welfare was accorded special interest.

The use of research assistants with disabilities was seen as a benefit to the interview technique as they were able to offer a degree of understanding to the process that would otherwise have been missing.

Conclusions

The main purpose with these pilot studies has been to develop and test a design for collection of data on living conditions among people with disabilities. Results were presented at workshops in Namibia and Zimbabwe in February 2001 where further revisions were also discussed before the final research instrument is ready for use in a representative National

studies planned for 2001-2002. Bearing in mind that the data set is limited and not representative, the results nevertheless indicate that households with disabled members have a lower standard of living as compared with households without disabled members. Although the results from this pilot provide some indications on the living conditions among people with disabilities and their relative disadvantage, only representative National studies can provide the data necessary to make a detailed mapping and analysis of the situation. This may again form a good basis upon which to discuss the situation of people with disabilities in Namibia and Zimbabwe, to plan for the development of services, as well as to form a basis for setting priorities.

This paper is based on the two following reports:

Eide AH, Loeb ME, Van Rooy G, Fuller B. (2001) Living conditions among people with disabilities in Namibia. Pilot study. SINTEF report no. STF78 A014502 (ISBN82-14-02193-6). Oslo, SINTEF Unimed.

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