

Executive Summary

Data and statistics on disability in developing countries

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SINTEF Health Research was commissioned by the DFID Disability Knowledge and Research Program in January 2005 to carry out an inquiry on Disability and statistics in developing countries. Methods applied have been a review of relevant international initiatives and a workshop with DPOs and researchers from Southern Africa as participants.

The literature review showed as expected that there is little data on disability in low-income countries in general. A few overview articles describe existing data as suffering from poor quality, lack of comparability and limited applicability. An exception is found in a series of international publications based on large prevalence studies having applied the Ten Question screening instrument.

Three international initiatives to improve disability statistics in low-income countries are however reviewed:

- i) The United Nations Statistics Division has produced guidelines aimed at improving the collection, compilation and dissemination of disability data. UNSD has further established DISTAT which is the Disability Statistics Database for Microcomputers established by United Nations Statistics Division
- ii) The Washington City Group was formed after the International Seminar on the Measurement of Disability held in New York in 2001. The objectives of the WG were to develop standard questions on disability for censuses and population surveys. WG has so far developed questions for censuses that will be tested in 2005
- iii) A series of National, representative household surveys are carried out in Southern Africa by SINTEF Health research and partners. These studies are initiated and controlled by FFO and SAFOD. The studies have drawn on ICF, comprise a large set of indicators on level of living and allows for comparison between groups and contexts

A workshop with main focus on application of research was arranged in Gaborone on 6th June 2005 including representatives from DPOs and research institutes in the Southern Africa Region. Examples of practical application of the research on living conditions were presented and discussed. Crucial issues in the development of disability statistics in low-income countries were found to be anchoring of research, the role of DPOs vs. governments, the need for a long-term working relationship between DPOs and researchers, and capacity building among researchers and DPOs. Mainstreaming research takes a conscious strategy aiming at bringing comparative statistics on living conditions and services into different sectors in society. The workshop agreed that a grass-root strategy was most suitable for doing disability research in low-income countries. The core of this strategy is DPO control and involvement, a close link between research and application, and long-term capacity building among DPOs.

Disability statistics in low-income countries has so far largely comprised impairment based prevalence figures. It is argued that prevalence in itself is of limited interest and that there is a need for data that can describe, analyse and compare the situation among individuals with disabilities, as well as contribute to increased knowledge about the link between disability and poverty. By using the conceptual scheme inherent in the ICF model, an alternative approach to disability statistics may

be developed. As an alternative to dividing the population into disabled and non-disabled, activity limitation and/or restrictions in social participation can be measured as a continuous variable among all regardless of the presence of any impairment. We thus have two different approaches for developing disability statistics, and it is argued that they will both provide useful statistics.

Globally there is a commitment to ensuring disabled people their human rights and equal access to social and economic opportunities (WPA, Standard rules, EUs 1996 Resolution, legislations, policies, etc.). At international and national levels, policies are developed with the intention of fulfilling this commitment. The realisation of the United Nations' Millennium Development Goals is clearly disability relevant in that individuals with disabilities belong to the poorest of the poor. Eradication of poverty, reaching equality between genders, reducing child mortality, improving maternal health, combating HIV/AIDS are all targets which will be met only if the most vulnerable groups (people with disabilities) are included in strategies and measures. High quality statistics will not only be necessary to demonstrate that individuals with disabilities are among the most disadvantaged with regards to individual welfare, but also to produce knowledge about the disability – poverty relationship and thus how to weaken it.

A grassroots based research strategy inspired by participatory research is recommended including DPO control of research, local adaptation of research by involving local human resources including individuals with disabilities and their organisations, anchoring objectives of research at the DPOs, feed-back to the population covered by the research, an explicit and binding applied component in any disability research in low-income countries, long-term capacity building and network building among DPOs and researchers in low-income countries.