Disability KAR
Knowledge and Research

Data and statistics on disability in developing countries

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CONTENTS

Abbreviations

CASE	Community Agency for Social Development
CBR	Community Based Rehabilitation
CDC	Centres for Disease Control
DFID	The Department for International Development
DPOs	Disabled Peoples' Organisations
DISTAT	The Disability Statistics Database for Microcomputers
EU	European Union
FEDOMA	Federation of Disabled Peoples Organisations in Malawi
FFO	The Norwegian Federation of Associations of Disabled People
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disability and Handicaps
KaR	The DFID Disability Knowledge and Research Programme
MDGs	United Nations' Millennium Development Goals
NFDPN	The National Federation of Disabled People in Namibia
NPC	National Planning Commission
SADC	Southern African Development Community
SAFOD	Southern Africa Federation of the Disabled
SIDA	Swedish International Development Agency
SINTEF	The Foundation for Scientific and Technical Research
SSA	Statistics South Africa
TQ	The Ten Questions Screening Questionnaire
UN	United Nations
UNICEF	United Nations Childrens' Fund
UNSD	United Nations Statistical Division
WG	Washington City Group
WHO	World Health Organisation
WPA	World Program of Action Concerning Disabled Persons

Acknowledgements

Executive summary

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' Millenium 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.

Background, objectives and terminology

The Department for International Development (DFID) is the UK Government department
responsible for promoting development and the reduction of poverty.

The DFID Disability Knowledge and Research Programme (KaR)

In September 2000, DFID launched the KaR programme covering the areas of disability and healthcare technology. Since then several projects (both commissioned and in-house) have been completed including the Disability Policy Project, Disability Equity Training, and a research study 'Enabling Disabled People to Reduce Poverty'.

The Disability KaR programme has commissioned a range of research around the theme of Mainstreaming Disability in Development. The principle argument for the mainstreaming of disability within development cooperation has been that poverty and disability are closely interlinked. Furthermore, because disabled people, especially women and children, comprise a large proportion of the poorest of the poor, Millennium Development Goals (MDGs) can not be met unless disability is addressed. However, because of a lack of reliable statistical data it has proved difficult to convince governments and policy makers of the real extent of disability or its functional relationship with poverty. This in turn has been a major reason why it has been difficult to pinpoint where intervention would be most productive, while at the same time making it difficult for DPOs and their allies to succeed in moving disability up the development agenda.

SINTEF Health Research was commissioned in January 2005 by DFID's Programme of Knowledge and Research on Disability to carry out the sub-project "Data and Statistics".

This sub-project has four main components:

   i.   Review of international initiatives on data collection and disability (in low-income countries)

   ii. An inquiry on methods of data collection on disability prevalence

   iii. An inquiry on application of disability statistics

   iv. Recommendations for developing disability statistics in low-income countries

The terminology invoked in this report with respect to disability reflects, to some extent, the state of discord or rather lack of harmony in the international community. As will be explained below, a conceptual development has taken place in the disability field during the last 20 – 25 years that has, on the one hand, broadened and refocused the conceptual understanding of disability, but on the other hand has opened for a degree of imprecision and inconsistency in the application of the resultant terminology to these concepts. The authors of this report have attempted to operationalise the terminology in the International Classification of Functioning, Disability and Health (ICF; WHO, 2001) and apply a disability concept that is founded on activity limitations and restrictions in social participation. The ICF model is shown in Appendix 1.

1 Methods

Methods applied in this project have been a review of relevant international initiatives and a workshop with DPOs and researchers.

1.1 Literature review

A review of international initiatives on data collection and disability in low-income countries has been carried out by means of:

i.   A literature search in the following data bases: Sosig, Social Science Information Gateway, Isi Web of Science, and PubMed

ii. Consultations with individuals representing major relevant stakeholders in the international development of disability statistics (in low-income countries); World Bank, Washington City Group, United Nations Statistical Division, WHO.

iii. An Internet search, i.e. the web sites of the above mentioned international organisations.

1.2 Workshop

A one-day workshop was arranged in Gaborone, Botswana, on 6th June 2005 (List of participants in Appendix 2).

This workshop was seen as an important part of the process towards meeting the objectives of the sub-project on Disability and Statistics. Through this arrangement DPO leadership and researchers from the Region have influenced and controlled the content of the report and the recommendations for development of disability statistics in low-income countries. Participants at the workshop were asked to discuss the following topics:

1. How has the research on living conditions for people with disabilities been utilised so far? (Good examples will be described and documented). Does this research meet its target? Are there other approaches that might have been more suitable?

2. Can national data be regionalised? What are the challenges to regional co-operation? Can national/regional data be internationalised? How important are local cultural issues to the collection and integration of disability data?

3. How can we make sure that disability research in the Region is utilised to the best of disabled people? (What is needed in order to implement disability statistics? How can we/you utilise the information/data you have at your disposal? Discuss the need for: qualified personnel/ money/international support etc.

2 Review of disability statistics in low-income countries

This review covers current international initiatives to develop and improve disability statistics in low – income countries and published results from previous initiatives.

2.1 Methodological Work on Disability Statistics

The following text reviews three ongoing international initiatives to develop disability statistics in low-income countries.

2.2 United Nations Statistics Division

The United Nations Statistics Division (UNSD) publication Guidelines and Principles for the Development of Disability Statistics (UNSD 2003) aimed at assisting national statistical offices and other producers of disability statistics in improving the collection, compilation and dissemination of disability data. The document addresses methodological issues in the area of disability by providing guidelines and principles related to data collection through surveys and censuses and also on the compilation, dissemination and usage of data on disability. The publication builds on the Manual for the Development of Statistical Information for Disability Programmes and Policies, and also on the section on disability in the Principles and Recommendations for Population and Housing Censuses, Revision 1.

The Guidelines recommend that disability be measured within the conceptual framework of the WHO International Classification of Functioning, Disability and Health – ICF (World Health Organization, Geneva, 2001). The ICF conceptual framework provides standardized concepts and terminology that can be used in disability measurement instead of the un-standardised and often pejorative terms used in many national studies on disability. The use of a common framework also contributes to greater comparability of data at the national and international levels, thereby increasing the relevance of the data to a wide set of users.

The Statistics Division of the United Nations has established the Disability Statistics Database for Microcomputers (DISTAT) (UN, 1990). DISTAT contains disability statistics from national household surveys, population censuses, and population or registration systems. DISTAT – 2 covers 179 national studies across all regions of the world. The United Nations Statistical Division will, in 2005, initiate a systematic and regular collection of basic statistics on human functioning and disability by introducing a disability statistics questionnaire to the existing Demographic Yearbook data collection system (UN, 2003). The information collected for DISTAT 2 covers a range of socio-economic and other variables and includes comparison with the non-disabled population. Currently however, published statistics from DISTAT – 2 refer only to the prevalence of disability by age and sex and by country. There are large differences with regards to population covered. Furthermore, statistics in DISTAT – 2 show wide variations in estimates of the prevalence. While this may be due to a number of reasons, methodological and conceptual (disability) differences are likely as major explanatory factors to this variation. While an improved and more systematic collection of disability statistics will provide a better basis for international comparison, standardization of data collection methods across the world will be necessary. For more information about DISTAT go to the following web-site:

http://unstats.un.org/unsd/demographic/sconcerns/disability/default.htm.

2.2.1 Washington City Group on Disability Statistics

The measurement of disability for statistical reporting was the focus of the International Seminar on the Measurement of Disability held in New York 4-6 June 2001 and sponsored by UNSD, UNICEF, Eurostat and the US Centres for Disease Control and Prevention (CDC). The Seminar, which brought together experts in disability measurement from developed and developing countries reviewed and assessed the current status of methods used in population-based data collection activities to measure disability in national statistical systems, and agreed to establish the Washington City Group on Disability Statistics (WG) to implement the Seminar's recommendations for further work to improve the measurement of disability.

An outcome of the New York meeting was the recognition that statistical and methodological work was needed at an international level in order to facilitate the comparison of data on disability cross-nationally. Consequently, the United Nations Statistical Division authorized the formation of a City Group to address some of the issues identified in the International Seminar and invited the National Centre for Health Statistics (in Washington DC - hence Washington City Group), the official health statistics agency of the United States, to host the first meeting of the group.

The objectives of the WG were defined as: (1) To guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample-based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world; (2) To recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population surveys or as supplements to specialty surveys; and (3) To address the methodological issues associated with the measurement of disability considered most pressing by the WG participants (Madans, Altman, Rasch et. al.). Recommendations from the New York meeting are found in Appendix 3.

The WG has also discussed various methodological issues in disability measurement including the purposes of measurement, the ICF model, the UN standard disability tables, global measures of disability, the relationship of global measures to the ICF, the confounding function of assistive device use, cultural practices that influence the nature of the environment or proscribe participation, cultural issues that act as barriers to collecting data and cross-national comparability of information. Four meetings of the WG have been held to-date with a fifth planned for September-October 2005. A draft set of questions for the general disability measure (census questions) has been developed and is ready for testing (Appendix 4).

Further information about the Washington City Group can be accessed on their website:

http://www.cdc.gov/nchs/citygroup.htm.

2.2.2 Studies on living conditions among people with disabilities in Southern Africa[1]

Recently, a data base on living conditions among people with disabilities in Southern Africa has been established and is gradually building up. These national and representative studies started in 1989, cover today Namibia, Zimbabwe and Malawi, and will be further expanded to Zambia (2005-2006) and Mozambique (2006 – 2008).

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[1] Eide et al. 2003a; 2003b; Loeb & Eide 2004.

The studies form a core element in the strategic collaboration between SAFOD and the Norwegian Federation of Organisations of Disabled People (FFO), and with SINTEF as responsible research institute. The role of DPOs in this research has been rather unique in that they have initiated the program, they have the role as "customer", DPOs have been in control of all stages of the research process, individuals with disabilities have been involved as supervisors, enumerators, members of references groups, participants at capacity building programs, in dissemination and application of results.

The studies in Southern Africa are the first generation of studies including a large number of indicators on living conditions, disability specific data, and allowing for a broad comparison between disabled and non-disabled (individual and household level) within and across different contexts (Region, countries, urban/rural). Moreover, the studies also comprise an attempt at utilising core components of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) both in the identification of individuals with disabilities and in the analyses.

The screening questions applied in these studies (Appendix 5) were drawn from recommendations following the Workshop on Disability Statistics for Africa (Kampala, 10-14 September 2001) organised by the UN Statistical Division (see below). One aim with introducing and applying these "new" questions was to increase sensitivity of disability prevalence studies. As the questions are activity based rather than impairment based, it was expected that prevalence would increase when comparing with results from other (impairment based) studies.

2.3 Other published disability statistics

In this section most of the articles found through the literature search in data bases will be presented and systematised.

Moore (2003)

This article states that there is little internationally comparable statistical data on the incidence, trends and distribution of impairment and disability, and much national-level data, particularly in the developing world, is unreliable and out-of-date (Erb & Harris-White 2001, Yeo 2001). The author carried out a search (applying terms like disability, impairment, and handicap) among 44 major international development journals and found the search words in very few articles. Moore argues here that the medicalisation of disability issues is common and one is more likely to find research on disability in developing countries in journals dedicated to health issues rather than poverty issues.

Metts R L (2000)

This discussion paper is intended to provide the World Bank with the information and insights necessary for policy formulation and strategic planning in the area of disability. According to Metts, internationally comparable disability statistics were virtually non-existent prior to the introduction of the International Classification of Impairments, Disabilities and Handicaps (WHO, 1980). ICIDH and later ICIDH-2 were designed to provide standardised disability definitions for systematic use in data collection strategies. United Nations Disability Statistics Data Base (DISTAT) in 1988 represents the first comprehensive attempt to identify and compile the world's existing national disability statistics (see above).

Metts claims that "published estimates of national, regional and global disabled populations are little more than speculation and educated guesswork" (p. 6). While WHO for many years has applied a 10 % estimate[2], the author of the WHO estimate more than 10 years back suggested that the proportion is more likely to be around 4 % in low- income countries and 7 % in high-income countries (Coleridge, 1993). Still today many agencies including the World Bank apply "the 10 % rule" due to the lack of valid and reliable data. Interestingly, UNDP estimates (by using DISTAT data) of the disabled population differentiate between High Human Development (HHD), Medium Human Development (MHD) and Low Human Development (LHD) countries (9.9 %, 3.7 % and 1.0 % respectively of the population being disabled). While UNDP has estimated a global average prevalence rate of 5 % (Coleridge 1993), the organisation has by others been criticised for largely excluding people with learning disabilities, mental health problems and/or invisible disabilities (Moore 2003).

Elwan (1999)

This report is a survey of literature on poverty and disability. It covers both high- and low-income countries, but it is made clear that information on disability in low-income countries is very limited and relies heavily on anecdotal evidence and case studies.

On disability prevalence, the author states that the situation is problematic due to the fact that disability is a relative term. Measurement is a problem and most existing instruments are poorly standardised and they produce non-comparable estimates. Estimated disability rates tend to be higher in developed (high-income) countries, possibly due to variations in definition of disability and in the way information is collected, demographic differences, and greater capacity to diagnose some conditions.

There is little information about the prevalence, incidence or epidemiology of disabling diseases in low-income countries. It is however documented that the proportion of disability caused by communicable, maternal and perinatal diseases are higher than in developed countries. The same goes for childhood disability. Much of the disability in low-income countries is thus preventable.

The Ten question screening questionnaire (Appendix 6)

The Ten question screening questionnaire (TQ) was designed by Durkin et. al. (1994) for children aged 2 – 9 years among young children in surveys of culturally diverse population, and covers six impairments ("disabilities") i.e. motor, visual, hearing, speech and cognitive disabilities. In some studies, TQ has been adapted to include all the under-two year olds, and it has been applied in special surveys on cognitive disabilities (Islam, Durkin & Zaman 1993). It has been applied in large and comparable prevalence studies in Jamaica (Thorburn et. al. 1992), Bangladesh (Zaman et. al. 1990), and Pakistan (Durkin, Hasan & Hasan 1998). The reported prevalence rates for childhood disability from these three countries varies from 82/1000 in Jamaica, 147/1000 in Pakistan and 152/1000 in Bangladesh. The authors explain the difference with the fact that the doctor to patient ratio is considerably higher in Jamaica as compared to Pakistan and Bangladesh, yielding higher child survival prevalence. In other words: in poorer countries with inadequate health services, many disabled children die in infancy.

TQ has also been applied in Kenya (Muga 2003), South Africa (Christianson et. al. 2002; Couper 2002), Saudi Arabia (Milaat et. al. 2001), and Ethiopia (Tamrat et. al.

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[2] The 10 % estimate was also applied in connection with the launch of the UN Decade for Disabled Persons more than twenty years ago and the release of the World Porgram of Action Concerning Disabled Persons (UN 1982)

2001). In the study reported by Cooper, TQ screening produced an overall disability rate of 83/100, which was reduced to 60/100 following medical examination. TQ has also been applied in special surveys on cognitive disabilitiesin Bangladesh (Islam, Durkin & Zaman 1993) and Pakistan and India (Durkin, Hasan & Hasan 1998).

2.4 Censuses and national surveys

Most low-income countries carry out population censuses at regular intervals. Some of these censuses have also included questions to map number of individuals with different types of impairments. While this forms the basis for DISTAT, the information value is limited and often based on outdated screening questions. This situation will improve following agreement on global standard questions for censuses.

There are also examples of National studies with more comprehensive information on disability. One example is the Level of living survey in Namibia (NPC 2000), producing some although limited information on differences in standard of living between disabled and non-disabled. Another example is the CASE study in South Africa (Schneider et. al. 1999) that was carried out to determine the prevalence of disabilities (impairments) as well as to describe the disability experience as reported by individuals with disabilities. A third example is the Census 2001 in South Africa (SSA 2001) that not only attempted to apply an activity based screening question, but also included questions on standard of living, yielding some possibilities for comparison between disabled and non-disabled.

2.5 Comparative studies; disability and poverty; Millennium Development Goals

While there are strong limitations with regards to statistics on disability prevalence and distribution, even more scarce are comparative studies on living conditions and poverty. Several studies have however shown higher incidence of disability among the poorest (DID 200).

SIDA (1995) Poverty and Disability. This report refers to a study carried out in 1994 by the United Nations Statistical Division on the situation of disabled people in Australia, Botswana, China and Mauritius. The categories applied in screening for disability largely correspond to the Impairment categories in the WHO CBR manual by Helander et. al. (1989) (Appendix 7). The study showed that a lower proportion of individuals with disabilities, compared with non-disabled, are engaged in economic activities. The report further states (with no specific source) that people with disabilities have substantially higher death rates and reduced life expectancy compared to non-disabled people. Furthermore, in the Least Developed Countries, mortality for children with disabilities may still remain as high as 60 – 80 % even though the under five mortality rate may have been reduced to less than 20 %.

Yeo & Moore (2003) present a convincing picture of the close link between poverty and disability. The authors present a theoretical model that is supported by literature, showing that chronic poverty can lead to higher risk of illness, accidents and impairment, while impairments can lead to poverty and exclusion. The authors also refer to a number of sources which taken together strongly indicate that disabled people are poorer than their non-disabled counterparts. Yeo and Moore, referring to Erb & Harriss-White (2001) rightly say that "Despite the obvious relationships between impairment, disability and poverty, there is little internationally comparable statistical data on the incidence, trends and distribution of impairment and disability, and much national-level data is unreliable and out-of-date".

Elwan (1999). Because little basic research appears to have been done on poverty and disability in developing countries, Elwan (1999) recommends further investigation in several areas, including: search for additional data sources and existing analysis to allow more detailed examination of poverty-related factors, such as income, education, employment, access to services, etc; modelling of potential "poverty paths" in populations that have a particular disability pattern, a special vulnerability, or are at particular risk of poverty; longer-term studies of income and other poverty indicators, using consistent data sets over at least two points of time, where changes in status can be observed; focused studies of gender, disability and poverty, and validation of measures of disability.

Living conditions among people with disabilities in Southern Africa

Reference is made to 6.2.2. Reports from the first three National representative studies can be downloaded from

www.safod.org

3   Application of disability statistics

The following is the edited outcome of the discussion among researchers and DPO leaders during the Gaborone workshop. First are real examples from the ongoing research, second additional ideas or principal formulations from the discussion.

3.1 Examples of application

Example 1. Zimbabwe is reviewing its transport policy. The intention is to develop a pro-poor policy. SAFOD used this opportunity to ask for a meeting with key Ministers. The meeting took place in December 2004. The research reports on the living conditions study in Zimbabwe were distributed in the meeting, and Alexander Phiri from SAFOD gave a presentation of the research. This generated considerable interest at the meeting, and in particular from the Transport Ministry. In the aftermath of the meeting, a lot of e-mail communication took place. The Ministry of Transport arranged a number of workshops throughout the country to develop the transport policy. Disability issues have become a cross cutting issue in this process. A draft report on transport policy is now underway. Disabled friendly infra structure is a key issue in this document.

These activities have, in turn, resulted in spill-over into other ministries after this meeting. For instance, an audit of accessibility in the aviation sector will take place with SAFOD being invited to participate in the process.

Example 2. A Public Health Advisory Board is in place in Zimbabwe. Alexander Phiri from SAFOD is on the Board. The Board has a practice of inviting resource persons to lecture on relevant topics at the Board meetings. The report on Living Conditions among People with Disabilities was distributed to all members at one of their meetings, and A. Phiri suggested that a representative from Ministry of Health who was involved during the study as a reference group member as well as a supervisor during training and data collection be invited. This has resulted in a renewed and more qualified interest for disability issues among Board members. This will in turn lead to disability issues increasingly being on the agenda at the Board.

Example 3. In Malawi, the Policy on Disability was adopted in 2004. A Task Force was established to formulate this policy, with a majority of DPO representatives on board, including Mussa Chiwaula and others from FEDOMA. Due to their strong involvement in the research on living conditions among individuals with disabilities in Malawi, they were able to actively use the report and the results from the study in this work. Following the adoption of the Disability Policy, legislation is now under way – with the Task Force being responsible for formulating legislation. In Malawi, FEDOMA and other DPOs thus have a unique position in influencing both policy and its application. Having a recent experience with a National research on living conditions among people with disabilities and the results from this research at hand, DPOs are equipped with a powerful tool in this unique opportunity for influence.

Example 4. There is a new ABC (Awareness Building Campaign) in Malawi run by FEDOMA, and they are actively using the results from the studies on living conditions among people with disabilities in this campaign.

Example 5. FEDOMA is involved with European Union (EU) and development of an EU strategy for support to Malawi. EU has carried out a feasibility study and FEDOMA has given information based on the study on living conditions and also given the report to EU representatives in the country. The EU has shown great

interest in working with FEDOMA, and this is an example of how research can contribute to make DPOs attractive partners. It is also an example on how this can lead to, or support, DPO influence on donors and thus influence the balance between north and south in a positive manner.

Example 6. In Namibia, the National Federation of Disabled People in Namibia (NFDPN) has identified the education sector as an area of priority. The organisation has exerted pressure on Ministry of Education to get more individuals with disabilities into schools, using the results from the study on living conditions to demonstrate the reality of the situation to the Ministry. NFDPN is on the National Advisory Council on Education, using the study on living conditions to formulate a strategy for education in Namibia. A National Policy on Education is underway, and this is expected to comprise clear formulations on measures to include children with disabilities in schools. This is an example where the existence of "hard facts" collected through research creates a basis for influence and reduced possibilities for ignorance of the voice of DPOs.

The above examples are in no way exhaustive, and they could also have been described in more detail if needed. The point here has however been to show different ways that the current research on living conditions among people with disabilities has influenced DPOs, Governments, and International Organisations. SAFOD, FEDOMA and NFDPN all report that the studies, i.e. both the research exercise itself and the results in the form of a widely distributed research report, have created a huge amount of interest for the involved DPOs Nationally, Regionally and Internationally.

3.2 Application of research – some important issues

In his paper (Appendix 8), Mr. Tjombumbi touches upon the important issue of anchoring of research. Although the study on living conditions in Namibia has been utilised by NFDPN and has created interest from different stakeholders, Tjombumbi's point is that as long as this research has not been commissioned by the Government, they do not feel an ownership and are thus inclined not to act. Tjombumbi underlines this point by showing that the Government of Namibia actually has acted on research that it has commissioned. As the current research on living conditions, also in Namibia, is DPO initiated and commissioned, this implies that the main responsibility for utilising the results lies with the DPOs themselves. Governments in the Region may be more or less involved in this research and thus more inclined to use it. The message is however that DPO initiated research will have to be followed up by DPOs themselves if it is aimed at tangible results. As some of the above examples have shown, DPOs have already used the results to influence policy and measures in different ways, also in Namibia. The point here is that if DPOs do not take this responsibility, no one else will either.

The above leads to the two other important points made by Mr. Tjombumbi, i.e. the need for long-term capacity building and establishment of a resource pool of researchers and DPO representatives in the Region. There is need for long-term capacity building for the DPOs in this field. With regards to collaboration with researchers and research institutes, the studies on living conditions have contributed to establish good communication and collaboration in these particular research projects. Ensuring a lasting network will however require more. This will take long-term commitment and capacity building, a conscious strategy from DPOs, and researchers who are given the necessary resources to stay in the field for a longer period. Disability research units at some universities could be one possibility. The planned SAFOD Disability Resource Centre is another relevant initiative in this regard.

An important lesson learned from the studies on living conditions in the Region is that it is not sufficient to increase capacity among DPOs in order to develop fruitful collaboration with DPOs. Just as important will be capacity building among researchers and research institutes in participatory research. A conducive working relationship between DPOs and researchers is crucial. Without researchers taking this seriously and in fact giving control of research as much as possible over to DPOs, collaboration will fail and further cement a tradition of weak and even negative relationships between DPOs and academic institutions. Researchers need to acknowledge the rights of people with disabilities and the practical consequences of these rights with regards to research. Participatory research in general, and with DPOs and people with disabilities in particular, is in many ways a sub-discipline in research with its own skills and rules.

As shown through the examples above, it is of great importance that DPOs establish and develop a strategic relationship with the authorities (political and bureaucratic) in their respective countries. Examples from both Malawi and Zimbabwe have shown that being in a good position in this regards yields influence, and research on living conditions provides the influence with content. Together this is highly effective and will ensure application of this research to the best of people with disabilities. This illustrates clearly that DPO leadership should choose this as arena for capacity building and act strategically with regards to both National and Regional authorities.

Mainstreaming research on disability was discussed in relation to the above examples. It is shown for instance in Zimbabwe that the comparative perspective in the current studies on living conditions is a powerful tool in development of any type of policy and services. The studies demonstrate clearly that individuals with disabilities are worse off on a number of indicators of welfare and living conditions. In countries with a National Policy on Disability it is easy to argue that this situation is not acceptable. The Standard Rules as well as the Millennium Development Goals can be applied in the same way. The point here is that the issue of disability and unacceptable differences between groups of people is relevant across sectors and disciplines. In this way, disability may be applied as a cross-cutting issue and thus contribute to a fair distribution of benefits and services.

A grass-root strategy for research was particularly called for during the workshop. This has several aspects:

    i) DPOs should strive for control of research and a working relationship with researchers based on mutual respect.

    ii) Contextual and cultural adaptation of research is ensured through strong involvement of local human resources including individuals with disabilities and their organisations

    iii) Objectives of the research should be anchored at the DPOs and be in accordance with their priorities.

    iv) Feed-back of research should be planned for and resources allocated for this purpose from the start of the research project.

    v) There should be an explicit, binding and measurable component dealing with application in any disability research projects in low-income countries.

    vi) Long-term capacity building among DPOs will be necessary to ensure their active role in dissemination and application of research

In order to take the achievements gained from the studies on living conditions further, it was suggested to arrange a conference on disability, development and research in the SADC Region in 2006 or 2007. DPOs should be in the lead of such a conference, and the purpose should explicitly be to promote research on disability issues in low-income countries, to improve further the relationship between DPOs and research institutes, to enhance application of existing knowledge about living conditions among people with disabilities in the Region, and to develop clear recommendations and a strategy for research to play an active and instrumental role in eradicating the strong link between disability and poverty.
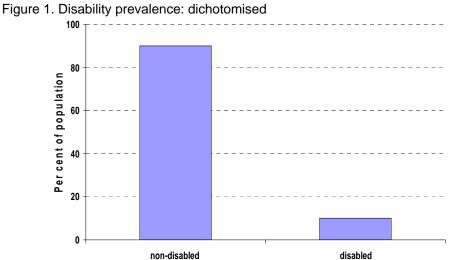
4 Impairment based vs. activity based measures

Those interested in determining the extent of disability in a population encounter (at least) two major problems. One is deciding upon an acceptable definition of disability. There is no commonly accepted definition, no "neutral language" (Altman, 2001) and no standard test for disability that is constant from one population or society to another. A second major problem encountered by disability researchers is the choice of instrument used to measure disability. That is: what question(s) should one ask in order to capture the proportion of disability in a population.

It is difficult to detach the issue of disability prevalence from an impairment based approach to disability, i.e. the possibility of distinguishing between disabled and non-disabled sub-populations by means of a standard procedure for screening. In essence, this is a "medical model of counting" and based on a belief that the condition (impairment) can be described and identified objectively.

In certain circumstances this approach is justified. Sometimes it is important to "count" disability in a population. Politicians can only argue for the provision and distribution of resources based on reliable information on the proportion of the population that need these resources. Disability benefits can only be provided to those who have demonstrated that they are in fact disabled. Similarly, at the service delivery level, the equitable delivery of services must be based on the need manifested in the community. And, comparison between individuals with and without disability can be a powerful tool in improving standards of living among those who have less.

Any standardised screening procedure will bound to be culturally and contextually biased and will consequently produce figures that are confounded by cultural, contextual, and environmental factors. It is difficult to avoid this problem also when applying activity based screening questions (Statistics Canada 2002). It is on the other hand a question how problematic this in reality is. Much can be done by standardising measurement globally, although a requirement will be a continued convergence globally in the conceptual understanding of disability. ICF is already a vehicle in this case.

Figure 1. Disability prevalence: dichotomised

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Figure 1 is a schematic representation of the result of an impairment–based approach for screening and distinguishing between two groups in the population: one with impairments (disabled) and one group without impairments (non-disabled). The proportion will vary according to screening instrument and context, but in theory it is possible to agree on a standard that is tested and that could produce comparable figures across the world, with the inherent weaknesses as described above.
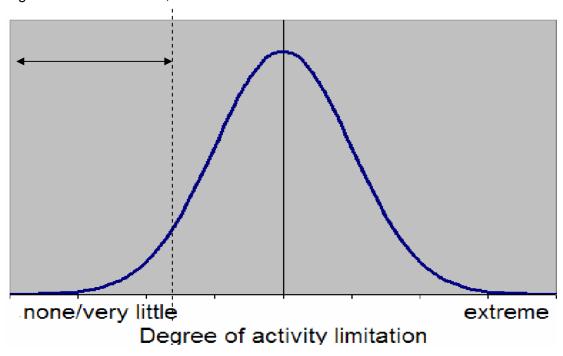

Figure 2. Disability as a continuum

Figure 2 shows a theoretical distribution of activity limitation in a population. Activity limitation is here seen as a continuum from none/very little to extreme. Such a functional representation of disability (activity limitation) in a population will necessarily be more skewed than normal - hence the 'floating' vertical dashed line. The theory behind this representation is that every individual in a population will find themselves somewhere along this distribution. And here lies the intersection between being disabled and having an activity limitation. It is sometimes important to 'count' the amount of disability in a population. However, more often than not, it is important to find out what an individual needs to be an active participant in their family, community or society. All of those with disabilities will not necessarily find themselves above the mean, for example; nor will all those without disabilities be located below the mean. Individuals with the same impairments have different needs, and score differently on degree of activity limitation.

With regards to disability statistics, the challenge presented is to shift from the impairment-based, dichotomous dependent variable (disabled vs. non-disabled, eventually also activity based questions with the same purpose), to a continuous dependent variable based on activity limitations (and restrictions in social participation).

In the studies on living conditions carried out in Southern Africa, a matrix based on 44 daily activities in 9 categories (sensory experiences, basic learning and applying knowledge, communication, mobility, self care, domestic life, interpersonal

behaviours, major life areas and community, social and civic life) was constructed (Appendix 9). This matrix measured:

- an individual's capacity or level of functioning (without assistance) - or activity limitations and

- an individual's level of performance in their current or usual environment (i.e. where they normally are: at home, at school or at work) - or participation restrictions

In the Malawi study Loeb & Eide 2004), this matrix was applied to individuals with disabilities and a sub-population of non-disabled.

For each of the 44 activities, the degree to which an individual was capable of carrying out the activity without assistance (perceived activity limitation) was recorded on a scale from (0) no difficulty to (4) unable to carry out the activity. In the same manner the person's performance in their current environment (perceived degree of participation restriction) was also recorded on a scale from (0) no problem to (4) unable to perform the activity. Based on recorded observations for each of the 44 items a single activity limitation score and participation restriction score was developed as the sum of all 44 items (maximum possible score 176).

A histogram showing the distribution along an activity limitation scale was produced and is shown in Figure 3

Score: Activity Limitations

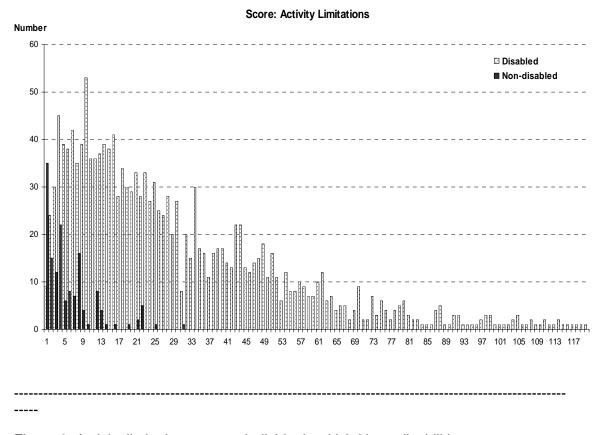-----

Figure 3. Activity limitations among individuals with/without disabilities

The figure shows firstly that there is a wide range in level of activity limitations among individuals with disabilities (according to the activity based screening). Secondly, it is also demonstrated that there is variation in level of activity limitations among those

not screened as disabled (individuals in the control sample). Although the different profiles of the two curves are evident, it is also the case that individuals without disabilities do, in fact, achieve relatively high scores on the activity limitation scale. The impact in a population of activity limitations thus goes far beyond the limitations experienced among individuals with disabilities.

Understood and applied in this way, we are in reality dealing with a different phenomenon, quite detached from a root, medical condition (impairment and diagnosis). Activity limitations (and restrictions in social participation) may thus be regarded as universal phenomena that are relevant to everyone regardless of health condition. It is possible to score on the activity limitation scale without having any chronic health condition or impairment, and it is possible for someone with a health condition or an impairment to score zero or very low.

One implication of the result presented in Figure 3 is that we in reality have two different strategies for developing disability statistics:

i. Impairment or activity based statistics with the purpose of categorising individuals into disabled or non-disabled, studying the disabled sub-population and compare with non-disabled, and

ii. Activity and participation based statistics aiming at studying the distribution of limitations and restrictions in a population, comparing between groups in the population, and to analyse the relationships between individual, social and environmental factors and activity limitations/restrictions in social participation.

In principle, both approaches are meaningful and will provide statistics useful for many purposes. It is however of importance to distinguish between the two and to be explicit about the basis for collecting disability statistics both with respect to analytical and "end-point" requirements. Failure of distinguishing between the two strategies may lead to has often led to confusion in the conceptual basis for disability statistics, leading in turn to problems with respect to comparability, representation and application.

5 Discussion

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' Millenium 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 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.

According to Metts (2000), policy makers (international, regional, national) attempting to design and implement more inclusive disability policies are doing this on a background of meagre information, inadequate data and hardly any coordination of activities:

"At present, information and data on disability are scarce, unreliable and scattered among organisations and institutions around the world, making it extremely difficult to conduct research necessary to fully understand the status of people with disabilities, develop cost-effective disability policies and strategies, or evaluate the cost-effectiveness of competing approaches" (Metts, 2000, p 55).

This description by Metts concerns disability statistics in general, and the situation is even worse in low-income countries. Although there are specific problems related to disability statistics in low-income countries, standardisation and comparability of disability statistics clearly should find its global solution. The work carried out by the Washington City Group is in this regard of great importance to the extent that it is adopted and applied across the world. Due to the character of the disability concept, a development in our understanding is however bound to take place. Although standardisation of screening questions (for disability) is an important goal for everyone involved in disability statistics, we can thus expect a further development of instruments and tools even after a consensus on global screening questions has been reached.

The issue of prevalence has tended to come to the forefront when disability statistics is discussed. The shift in our understanding of disability from being impairment based to the current "bio-psycho-social" ICF model also has important bearings on identification of who is disabled and who is not. While screening in low-income countries has been and still is impairment based to a large extent, activity based screening has been more common in high-income countries. This may explain some of the differences in prevalence globally. Development of a new set of activity based screening questions by the Washington City Group is expected to improve comparability across contexts when implemented.

While it is important in itself to improve the quality and comparability of prevalence measures across contexts and countries, applicability of this type of information is limited. More important here is that measuring prevalence involves a screening procedure. Identifying who is disabled and who is not is useful and necessary for several purposes; in research to provide for comparative analyses within and across contexts, in service provision to allocate resources and benefits to those who are in need, etc.

It is argued that dividing the population into disabled and non-disabled although useful for many purposes also is problematic and probably contributing to uphold a focus on negative differences in abilities. An alternative way of measuring "disability" is to draw on the ICF model and apply "activity limitation" (and/or likewise "restrictions in social participation") as an indicator of a general phenomenon that applies to anyone regardless of health and impairment status. A major advantage with this will be that the problem of where to draw the line between groups (disabled and non-disabled) is avoided. Furthermore, this type of measure will be able to capture the total activity limitation in the entire population and not only among those who qualify as being disabled. This will in turn have a great potential for mainstreaming disability research the phenomenon in question (activity limitation/restriction in social participation) will be measured and perceived as an issue for everyone. The matrix that was applied in Southern Africa, or alternative and probably simpler versions of it, can thus be included in general studies on living conditions, yielding a different measure of "disability" than the traditional dichotomous variable (disabled/non-disabled). It is also suggested that the ICF based measures on activity limitations (or restrictions in social participation) overcomes problems related to measuring "severity" of disability, both because it is theoretically based and because it produces an index with far better statistical properties than most other attempts at grading disability. This in turn makes the "new" type of measure more useful in testing and developing models on disability (e.g. ICF), thus possibly also boosting the theoretical development in the field. The weakness of this alternative is primarily that it is more complex to administer, and not yet fully developed for a broader application. It is clearly not a strategy for censuses that place strict limitations to space allocated for disability related questions, but useful in surveys and in particular in relation to theoretically based research questions.

While the suggested alternative way of measuring and studying disability has many advantages, it is not suggested that this should replace the "traditional" way of collecting disability statistics. We argue that there is need for alternative and complementary ways of measuring and studying disability and that the two strategies both have their own strengths and weaknesses. The existence of two "research strategies" in this field will most likely contribute to reduce the conceptual confusion and thus bring disability statistics one step further. ICF thus has been instrumental in expanding and developing the basis for disability statistics. It is however also important to bear in mind that although including environmental and psychological factors in the model, ICF does not "deliver" in this respect. This is clearly a serious problem, bearing in mind the role of the environment (and society) in the discourse on disability. While ICF may be seen as an attempt to combine a medical and a social model of disability (Shakespeare 2004), the inability to measure environmental and psychological barriers reduces the relevance, confounds comparability and forms important challenges for disability statistics in the year to come.

Application of research is crucial in general, and in particular when poor disabled people in low-income countries are at the focus. The studies on living conditions among people with disabilities in the Region were initiated by DPOs and are controlled by the same organisations. The responsible researchers have thus not only included, employed and listened to people with disabilities and their organisations during the research process, but, as a part of an active strategy, have anchored the control of the research process at the DPOs. This has required both well functioning DPOs as well as a relationship between DPOs and researchers based on trust and mutual respect.

It is argued that this strong involvement and even control from the side of DPOs and involvement of individuals with disabilities at all stages of the research process has contributed strongly both to the quality of the research, sense of ownership among

involved DPOs and to its application at different levels. It is further argued that including individuals with disabilities at all levels in research increases the relevance as important competence is brought into the research process. Individuals with disabilities as interviewers contribute to create a good climate for giving information that may influence the quality of the data positively, and they represent good role models to those who are interviewed. Also when it comes to application of research to the benefit of individuals with disabilities, lobbying and other types of influencing society gains in credibility when this is spearheaded by DPOs and individuals with disabilities.

Application of research takes place at different levels. The examples above have shown the potential for influencing policy, measures and services in different areas, international organisations and DPOs themselves. The latter is of particular interest as it was also deducted from the discussions that DPOs need to take the responsibility for application of research they themselves have initiated and commissioned. DPOs have through these studies been given a tool for influence that has already influenced their strategic collaboration with Ministries and other bodies and boosted their impact on society.

The relationship between DPOs and researchers will be crucial also for the application of results. The organisations will rely on research competence to utilise disability statistics. It is thus important to establish a good working relationship between the two parties. This will again require capacity building and a deliberate strategy on both sides. While the Disability Resource Centre planned by SAFOD could be instrumental in linking DPOs with relevant researchers, it is however difficult to see any substantial development of this relationship without international support to establish resources bases on the DPO side as well as at a university.

A grass-root research strategy will be important in order to ensure relevance and anchor research among DPOs, their members and the public in general. At the same time DPOs must develop a conducive relationship with relevant Ministries and other influential organisations. Formulation of specific strategies in this regard takes in-depth contextual knowledge. The importance of a dialogue with decision makers in different sectors is illustrated by the examples in chapter 6.

Conclusions

High quality disability statistics has the potential for supporting individuals with disabilities in low-income countries in their struggle for basic human rights, equality and a better standard of living. Eradicating the link between disability and poverty is a prerequisite for reaching the Millennium Development Goals.

Current disability statistics is however far from robust or comparable globally and is particular week in low-income countries. There is a strong need for design development and standardisation of measures to be applied in both censuses and representative surveys. Important work in this regard is underway through the work by the Washington City Group and the DPO initiated research in Southern Africa. It is argued that it is important to go beyond the issue of prevalence and produce statistics that can compare and analyse differences in standards of living between disabled and non-disabled. The disability – living conditions – poverty link should be the number one priority for broadening disability statistics (in low-income countries) from the current focus largely on prevalence. While prevalence may be useful to some extent, there is clearly need for data that can give a thorough picture of the situation for disabled people, possibilities for comparing between groups (including disabled and non-disabled), documenting and analysing mechanisms explaining the close link between disability and poverty.

Measuring and screening for disability has been a long-standing issue within disability statistics. In light of the recent conceptual development it is suggested that further development of this field comprises both the "traditional" dichotomisation between disabled and non-disabled, and a new approach where activity limitations and restrictions in social participation are treated as common phenomena. From the data analysis perspective, the research challenge lies in understanding disability as a multidimensional phenomena that can be approached both as a dichotomous measure (disabled, not disabled) and as a continuous measure of activity limitations/participation restriction. In addition, these measures must be interpreted as relevant to the environment, society and culture from which they are derived. This will require an expanded view of disability data and effect substantially greater measurement challenges.

Application of disability statistics to improve the situation for disabled people in particular in low-income countries is of great importance for the relevance and credibility of the research sub-field. Comparative statistics is particularly powerful as a tool for lobbying, sensitising and influencing decision makers as well as the population in general. In low-income countries DPOs will play a critical role in the application of disability data and they should develop strategies for this including necessary capacity building. A strategic working relationship between DPOs and researchers in low-income countries will be necessary for the application as well.

6   Recommendations

Sufficient resources and international collaboration and co-ordination are two central prerequisites for development of relevant and applicable disability research in low-income countries. Anchoring research at DPOs and applying principles from participatory research are also of great importance for both credibility, relevance and applicability of research. A grass-roots strategy for disability research in low-income countries was supported at the Disability and statistics workshop in Gaborone in June 2005. The following recommendations draw on this suggested strategy:

1. Methodology

It is necessary to develop designs for disability statistics globally. This includes standardised measures on disability as well as application of ICF in disability research.

Adaptation of research designs to fit the situation in low-income countries should be given priority

Research application in this field needs to be developed.

2. Control of research

Disability research in low-income countries should as far as possible be initiated and controlled by DPOs in the respective countries and/or regions. This will ensure relevance and is a prerequisite for application of results.

Principles from participatory research should be followed

3. Collaboration

It is necessary to establish and develop collaboration between DPOs, researchers, National and Regional authorities, and international organisations in order to build up disability research as a discipline in low-income countries. This will take both resources and active network building.

4. Application

Application of disability research in low-income countries should be planned for and resources allocated for this purpose from the start of the project. Methods and strategies for applying research in low-income countries should be further developed.

5. Focal points and capacity building

Focal points for disability research should be identified both among relevant research institutions and DPOs.

Long-term commitment to Capacity building among DPOs and researchers to establish and develop a strategic working relationship between the two is needed from international donors and researchers. Structures for developing this relationship should be developed.

6. Resources

DPOs will in particular need long-term training and capacity building in order to play a leading role in disability research. Researchers and research institutions involved in disability research need to be sensitised to the particular challenges inherent in participatory research with DPOs playing a leading role.

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