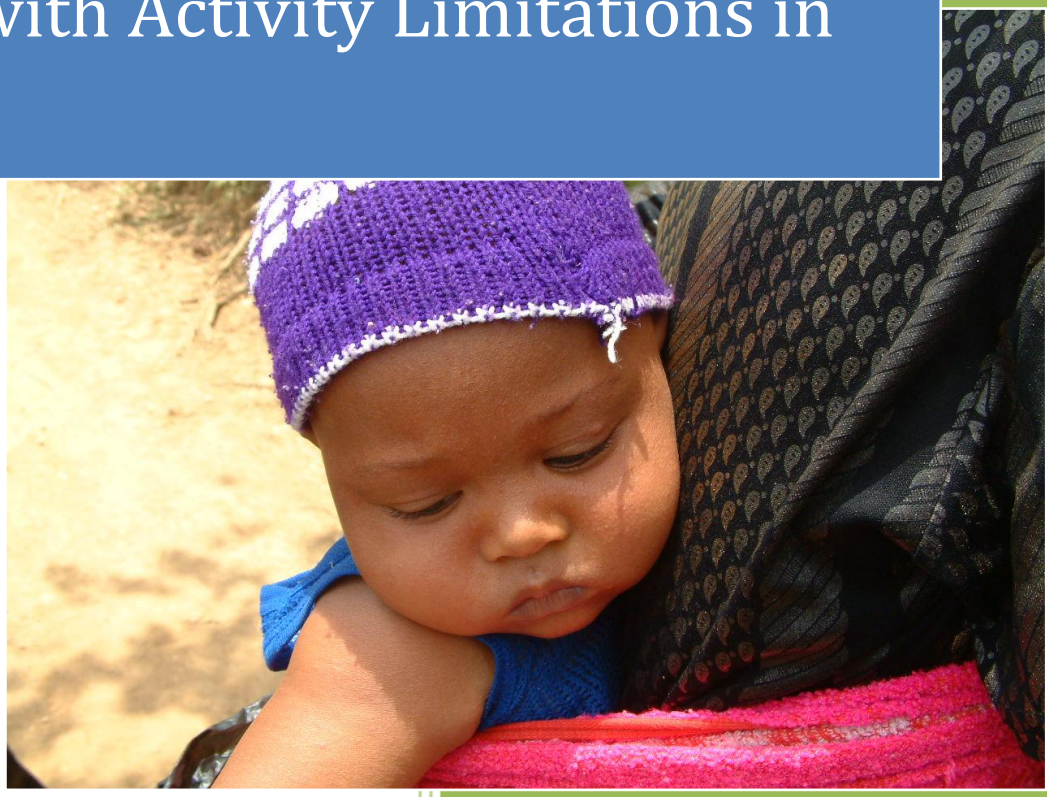
Evaluation of the report 'Living Conditions among People with Activity Limitations in Zambia'



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Preface

The report 'Living Conditions among People with Activity Limitations' was published in September 2006 and funded by the Atlas Alliance on behalf of Norwegian Agency for Development Cooperation (NORAD). The study is a result of an international cooperation between Southern Africa Federation of the Disabled (SAFOD), Zambian Federation of the Disabled (ZAFOD), FFO, University of Zambia Institute for Economic and Social Research, the Central Statistical Office (CSO) and SINTEF. Arne Eide and Mitchell E. Loeb (SINTEF) are the main authors and editors of this report, with contributions from Alexander M.Phiri and Felix Simulunga (ZAFOD) and Goodson Sinyenga (CSO).

The evaluation of the Zambia report, presented in this paper, has been conducted and written by Fafo on request from FFO. A literature review was conducted in order to obtain information concerning disabilities and to place this study alongside with other relevant studies.

The evaluation is a desk study, but is also based on an interview with one of the main authors of the Zambia report. The evaluation team at Fafo aimed at doing a critical analysis of the sampling design, the fieldwork in Zambia, the statistical method used and the proportion between the data and the presentations of the results from the study in Zambia.

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Abbreviations

CSO	Central Statistic Office
DHS	Demographic and Health Surveys
FFO	Norwegian Federation of Organizations of Disabled People
ICF	International Classification of Functioning
ICIDH	International Classification of Impairments, Disabilities and Handicaps
INESOR	Institute for Economic and Social Research
NORAD	Norwegian Agency for Development Cooperation
SINTEF	The Foundation for Scientific and Industrial Research
SAFOD	The Southern African Federation of the Disabled
SPSS	Statistical Package for Social Sciences
UNDP	United Nations Development Programme
UNSD	United Nations Statistics Division
WG	Washington Group
ZAFOD	Zambian Federation of the Disabled

Summary

The Zambia report is based on a survey of 5751 households. It must be seen in the context of the increased attention 'disability' has received in various research settings during the last decade. The Zambia report both illustrates and tries to address the observation that despite improved quality of studies of disability in different countries and situations, there is a lack of comparability between countries and between studies within the same country.

The Zambia reports reflects the World Health Organization's (WHO) shift in its classification of disabled during the last decades, beginning in 1980 when WHO introduced the 'International Classification System for Impairments, Disability and Handicaps' (ICIDH), later elaborated it to the International Classification of Functioning' (ICF) in 2001. The report does not represent a direct application of ICF, but has attempted to move towards a definition of disability as *an activity limitation and restriction in social participation*. This is achieved by combining aspects of ICF with studies on living conditions. The result is very promising, but because it is based on a development, rather than strict adherence to the recommendation of the Washington Group on Disability Statistics, it is difficult to compare results with other surveys.

The Zambia report clearly covers an important topic, and it is a contribution to new knowledge of disability in Sub-Saharan Africa. The design of the survey is similar to three other surveys carried out by SINTEF in Namibia, Zimbabwe and Malawi. This offers the possibility of comparing between the countries, and has been well utilized in the fourth report from Zambia.

While the evaluation team finds the substantive results of the survey as presented in the report reliable, there are a number of technical improvements that could be made. Chief among such improvements is proper consideration of the sampling design of the survey. This pertains to issues such as the sampling procedures used for the households within survey clusters, treatment of non-response, use of sampling based weights to be able to calculate representative estimates, and taking account of the sample structure in tests of significance and calculations of standard errors.

The main strength in the Zambia report is that it provides reliable data and analyses relevant to advocacy and knowledge based policies towards disabled. It has also been an important focus for dialogue between stakeholders, and for academic debate and knowledge development. It if furthermore innovative in its use of disabled staff in the fieldwork.

Introduction

The subject of this evaluation, the study 'Living Conditions among People with Activity Limitations in Zambia', is one of a set of similar studies using the same approach, namely those of Namibia, Zimbabwe and Malawi (Eide, Nhiwathisa, & Loeb 2001;Eide, van Rooy, & Loeb 2003;Loeb & Eide 2004b). The studies must be seen in the context of the increasing attention 'disabilities' as a subject has received during the last decade, and both illustrates and tries to address the observation that despite improved quantity of studies of disability in different countries and situations, there is a lack of comparability between countries and also between studies in the same country (Mayhew 2003).

Much of the increase of studies is due to the inclusion of the subject of disability in national population censuses, with a limited number of questions on the subject. As a result of this, the quality of statistical information is often inadequate for national policy and programme needs (Department of Economic and Social Affairs 2001). The Zambia report is an example of the kind of studies that have been developed to address such policy needs. Before discussing the report in more detail, it is therefore useful to situate it in the wider trends in the field.

The definition of disability

Disability is a 'growing industry' because of a gradually ageing in the population and a significant increase in the likelihood of chronic disabilities in the onset of natural aging (Harwood, Sayer, & Hirschfeld 2003). Most likely, the level of disability is far higher than what most people generally assume, because disabilities are often hidden from general public views as the disabled tend to be house-or institution bound or are affected by cognitive disabilities that are often invisible to an outsider.

Many factors affect a person's experience of their disability, and a generally accepted definition of 'disabilities' has remained elusive and subject of controversy (Waidmann & Manton 1998). This is because disability as a term is used in a wide range of physical and cognitive problems that are difficult to categorize into one framework. Services for disabled are often provided according to the different aspects of disability, according to age, gender, membership etc. The lack of a common framework produces wide variation when attempts to estimate the number or characteristics of the disabled are made. According to Mayhew (Mayhew 2003) the numbers of official and unofficial estimates of disabled vary much and they are often difficult to bring together for comparison.

From ICIDH to ICF

The UN convention on the Rights of Persons with Disabilities has a still on-going discussion of the definition and a final draft on the subject will be submitted to the UN General Assembly for adoption. The World Health Organization (WHO) will produce a world report on disability and rehabilitation by 2009 to collect the best evidence about the prevalence, distribution and trends of disability (Leonardi et al. 2006).

The World Health Organization (WHO) introduced a system called the International Classification System for Impairments, Disability and Handicaps (ICIDH) in 1980. It was later elaborated into the International Classification of Functioning (ICF) in 2001. Under the model of ICIDH impairments are concerned with the abnormalities of the body structure and appearance, and with 'organ system function' that result from a cause. ICIDH is a classification of 'disablements' which systematically collects consequences associated with health conditions (e.g. diseases, disorders or injuries). Disabilities reflect on the consequences of impairment, and handicap refers to the disadvantage experienced by an individual as a result of impairments or disabilities (Cieza et al. 2002;Dahl 2002;Department of Geography, Royal Halloway, & University of London 2004;Mbogoni 2003;Schneidert et al. 2003;Stucki 2005;Üstün et al. 2003).

A new classification seemed necessary in order to include a greater aspect of disabilities, often caused by non-communicable disorders, such as depression and schizophrenia. The ICIDH model was accused of being too closely aligned with disease sequelae and difficult as a structure for classifying aspects of functioning and disabilities. It was further criticized for its limited conceptualization in relation to the integral role of the environment in context to disabilities, and its focus on the individual rather than the environment. The new model, the ICF was formally approved by the World Health Assembly in May 2001, with focus on environmental and personal factors incorporated in the definitions of disabled.

The ICF can be applied in various settings, and Schneidert (Schneidert, Hurst, Miller, & Üstün 2003) describes the complexity of the ICF model through several examples of disabilities:

- A person may have a problem at the body level (an impairment), but without any activity limitations or participation restriction. An example of such can be someone with a scarring face who does not experience any limitations or participation restrictions

- A person with problems with impairments, activity limitations and participation restriction in the society.
- A person with impairment and activity limitation, but no participation restriction
- A person with activity limitation and participation restriction, but no impairment
- A person without any impairments or activity limitation, but with participation restrictions

The examples illustrate how important the dimensions of functioning as well as the environmental and personal factors are in order to understand people's experiences of disability. The ICF model provides a comprehensive conceptual framework in order to gain a wider understanding of the environmental impact of disability. The model describes disability as the outcome of 'an interaction between a health condition and the context (the environment and personal) in which the person with that health conditions finds herself or himself'. Factors, such as rural context, poverty and socio-economic conditions are well-known as important issues in how one determines disability (Cieza, Brockow, Ewert, Amman, Kollerits, Chatterji, Üstün, & Stucki 2002;Dahl 2002;Mayhew 2003;Schneidert, Hurst, Miller, & Üstün 2003;Üstün, Chatterji, Birkenbach, Kostanjsek, & Schneider 2003).

The Zambia report reflects these debates, but is not a direct application of ICF. It is rather inspired by the conceptual basis for ICF and has attempted to move towards a definition of disability as an *activity limitation* and *restrictions in social participation* (the Zambia report: 59). In our understanding, it is the link between disability definitions and the living conditions approach that marks the distinguishing characteristic of the Zambia report.

Disability statistics

In 2001 United Nations Statistics Division (UNSD) published the Guidelines and Principles for the Development of Disability Statistics (Department of Economic and Social Affairs 2001). The UN's methodological guidelines recommend countries to use the ICF in disability measurements as a basis for the definition of the population with disabilities and in the formulation of questions in order to create comparable terms (Mbogoni 2003).

The Washington Group on Disability Statistics (WG) was authorized by the UNSD in the aftermath of the UN International Seminar on Measurements of Disability in June 2001. The main objective was to review the current status of methods used in population-based data collection activities to measure disability in

national statistical systems with special attention to questionnaire design. With the outcome of a small set of general disability measures, suitable for use in censuses, which will provide basic necessary information on disability throughout the world (OECD 2007). The screening questions proposed by the Washington Group are discussed below in the context of the Zambia report.

Disabilities worldwide

The greatest burden of dependency caused by disabilities falls in Sub-Saharan Africa, and large increases is expected in Sub-Saharan Africa, the Middle East, Asia and Latin America (Harwood, Sayer, & Hirschfeld 2003). According to UN and WHO as many as 600 to 650 million people is affected with a disability worldwide, and they represent the world's largest minority (United Nations 2006;World Health Organization 2006). This is based on around 10 percent of the world's population and a higher estimate is commonly used when learning disabilities is included in the definition. Disabled people are often marginalized and belong to the poorest segments of society, and figures by the World Bank estimates illustrates that 20 percent of the world's poorest people are disabled, and they tend to be considered the most disadvantaged in their own communities (Elwan 1999;United Nations 2006).

One estimate of disabilities is conducted by measuring years lost to disabilities (YLD), and this builds on the incidence of diseases, measured on the onset of the duration of the disability, and according to Mayhew (Mayhew 2003) are less developed countries with low life expectancy affected with years spent in disability increase to 11 years on roughly 25% of normal life span. Countries with the most serious problems in this regard include Uganda, Malawi, Zambia and Sierra Leone.

The Report

The report covers an important and under-researched topic in Zambia, and it is a clearly a contribution to our knowledge about the disabled in this country. In particular, we believe that the study includes three important aspects in its approach:

1. The active participation and involvement of people with disabilities and their organizations in the process of the survey
2. A new definition on being disabled for research and policy development

3. The comparison of the living standards of people with disabilities and their families and non-disabled individuals and families without a disabled family.

The overall objective of the study was to contribute to the improvement of the living conditions among people with activity limitations in Zambia.

The specific objectives were:

- Develop a strategy for the collection of comprehensive, reliable and culturally adapted statistical data on living conditions among people with disabilities
- Initiate a discussion on the concepts and understanding of 'disability'
- Include and involve people with disabilities in every step of the research process
- Monitor the impact of government policies, programmes and donor support on the well being of the population with activity limitation
- Identify various forms of activity limitations that people living with disabilities face
- Provide various users with a set of reliable indicators against which to monitor development
- Identify appropriate assistive devices required for specific forms of disabilities
- Identify vulnerable groups in society and enhance targeted policy implementation
- Establish appropriate skills training package for various forms of disability

The report is divided into six main chapters in addition to an introduction and conclusion. The first chapter provides the historical, social and economic context of Zambia, as well as information on health and disability in Zambia.

The second chapter outlines the general approach taken by the researchers to the study of disability.

The third chapter discusses living conditions of people with activity limitations in low income countries, and also introduce additional conceptual tools, such as those of the Washington Group.

The fourth chapter discusses sampling and survey methods.

The fifth chapter is in many ways the main body of the report and presents the main findings.

The sixth chapter discusses the main findings.

In general we find that the chapter structure works well, although the first chapter, on context, probably spend too much time on the general aspects of Zambia, and should perhaps have elaborated the interesting discussion of health policies and stakeholders towards the end of the chapter. The second and third chapter might easily have been merged into a focused conceptual chapter.

The chapter on sampling methods appears to be the proposal from the Zambian statistical office on how the study was intended to be carried out, and would have gained from editing to reflect the situation after the fieldwork had been conducted. Consequently, the chapter lacks information on survey quality indicators, such as non-response or estimates of standard errors. Such indicators could also be placed in an appendix, but should be part of a report from any survey.

The chapter on findings is divided into two parts. The first represents a comparison between the living conditions of the disabled and those of the non-disabled, and the second the results of the detailed questions for the disabled.

The discussion in the sixth chapter sums up the main finding of the previous chapter, namely that households and individuals with disabilities have poorer living conditions than those without. The authors also claim that the study have succeeded in developing a more sensitive measure of disability than present in other literature. For methodological reasons that will be discussed below, we believe that the claim may have merit, but are hesitant to accept it at face value.

Research methodology

As in all surveys, the research methodology represents a compromise between ideal requirements and what is possible within time and budget constraints. On the whole we believe that the SINTEF researchers have found a good balance, but we also find some areas that could be improved upon.

As noted above the study in Zambia does not present a direct application of ICF, but is rather inspired by the conceptual basis for ICF. It attempts to approach disability as an 'activity limitation and restriction in social participation'. This is undertaken by developing a matrix on activity limitations and various reflections in social participation of the respondents in the study. Loeb and Eide's application of the ICF has received international attention, and Mbogoni (Mbogoni 2003) addresses the questionnaires used in Namibia and Zimbabwe in her article and describes the matrix form, that includes the ICF Activity and Participation, and reflects on future value of the results.

The study is inspired and applies some of the core concepts and the conceptual basis of the ICF model and has used a new approach in the study of the disables though their questions of 'what is your difficulties' rather than 'what is wrong with you'.

The implementation of the Washington Group framework

The Zambia report measured the prevalence disability based on the questions developed by the Washington Group (WG) on Disability Statistics (see Table 1). The implementation of the WG questions is innovative in this study, with an attempt to develop a solution to estimation of prevalence in disability studies.

Instead of using the questions for the purpose of a screening procedure in census and surveys (as proposed by the WG), the researchers have used the same questions to develop a special design for the Zambia report: If a respondent in Zambia reported *some* difficulties with two activities, or a lot/unable to perform at least one activity, the respondent was addressed as disabled. The SINTEF researchers anticipated that they would identify a larger population of people with a disability (or an activity limitation) by using this approach, because of its wider inclusion of people with activity limitations. This seemed to work well in this study.

However, the data is not comparable to other surveys because of the specific implementation in the Zambia report. The authors of the report recognize that this approach is a new way of measuring prevalence of disabled, with the aim of developing a basis for future monitoring on the subject matter. Table 1 shows the Washington Screening Questions used in the report. The application is probably one of the first instances of use of these questions in practice. A future development of this screening procedure is recommended in order to compare present data in the Zambia study to future results. A prerequisite for such comparison is that all data is weighted as required by the sampling design. This is further elaborated below.

Table 1 The Washington Screening Questions

	Do you have difficulties doing certain activities because of a HEALTH PROBLEM:	No	Some	A lot	Unable
1	Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
2	Do you have difficulty hearing, even if using a hearing aid?	1	2	3	4
3	Do you have difficulty walking or climbing steps?	1	2	3	4
4	Do you have difficulty remembering or concentrating?	1	2	3	4
5	Do you have difficulty (with self-care such as) washing all over or dressing?	1	2	3	4
6	Because of a physical, mental, or emotional health condition, do you have difficulty communicating (for example understanding or being understood by others)?	1	2	3	4

For the purpose of the Zambia report, a person with a disability is anyone who has some difficulties with at least two activities or a lot/unable to do one activity above

Terminology

The authors of the Zambia report experienced the difficulty of finding an appropriate term for their use of 'disability'. In the absence of a better terminology is 'disability' used as the word for their understanding of the '*activity limitations and restrictions within a theoretical framework of ICF*' in the Zambia report. This works well in this study, although it is sometimes confusing to the reader when the report refers to disability and activity limitation throughout without distinction.

The questionnaire

The questionnaire used for this study was divided into two parts; one on living conditions and one on disabilities. Pre-existing and validated semi-structured questionnaires were used, based on questionnaires used in Namibia (2000) and in South Africa (1999). In addition the researchers of this study added a third

element to the questionnaires, with enquiries on activities and participation for people with disabilities. This was conducted in order in include the conceptual elements of ICF.

The questionnaires used for this survey are extensive and include questions for the general household and more specific questions on disabilities. The household questionnaire includes data on demography and disease burden; education and literacy; economic activities and household members; reproductive health; household amenities and housing conditions; access to facilities; ownership; income; food production; expenditure and deaths in the household. The activity limitation questionnaire covered data on activity limitation and participation restriction; environmental factors; awareness, need and receipt of services; education and employment; assistive devices; accessibility; family inclusion; health and general well-being. The activity and participation matrix (appendix 5) include questions for difficulties in performing various activities in the current environment, while the inventory of environmental factor (appendix 6) uses a 12 month recall period on questions regarding participation difficulties in the society.

Self-reported data

The study is based on self-reported data that reflect the respondents (or the proxy reporters) own perception of their situation. No attempts were made to acquire a medical verification of either type or cause of disability (page 122). Self reporting data on surveys in developing countries is common, and are often used due to low utilization or access to health services (Mock et al. 1999;Mock, nii-Amon-Kotei, & Maier 1997;Moshiro et al. 2005) or because cost considerations preclude the use of qualified medical staff in the interviewer teams. Moreover, a focus on the respondent's own perception may be fruitful in itself.

The semi-structured design of the questionnaire in this study makes it possible for the respondents to give a more detailed description on perceived experiences. This study has attempted through the structure of the questionnaires, to move towards a more sensitive measurement on disability and activity limitations. This study uses disabled vs. non-disabled, with the non-disabled as the reference group, an approach commonly used in several studies (Bryan et al. 1984;Margalit, Raviv, & Ankonina 1992;McHale & Pawletko 1992).

Eide discusses the challenges of conducting a study based on self reported data, with the respondent's potential influence by the prevailing understanding of disability. The perception of activity limitations related to aging are often not included in people's conception of disability, and this was a challenge in the new approach that was conducted in Zambia, with a broader inclusion in the definition of 'disabled'.

Living conditions

The survey questions regarding living conditions are based on a survey carried out in Namibia (2000). This ensures comparability with that survey, but is sometimes non-standard with regard to the rapidly developing international body of statistics, such as those used for the Millennium Development Goals (MDG). For example, the category of 'Flush toilet (private or shared)' on the question on toilet facilities makes it impossible to determine if the household has 'Improved sanitation' in UN MDG terminology.

The interviewers

The study seems to have used well qualified interviewers in the survey through a careful selection process and training of fieldworkers. A notable feature of the fieldwork organisation was the use of disabled staff. This is an important element in the survey, because it is possible that disabled interviewers would obtain better response because of their intuitive understanding of the situation of the respondent. Nevertheless, it is also possible that the quality of response suffers, because the interaction between interviewer and respondent may lead to either over-or under communication of the degree of disability, depending on how sympathy and views on relative disability develop between the respondent and interviewer.

However, it would have been useful for the Zambia study to have included a discussion in the report regarding the feasibility of conducting a study with disabled people performing as supervisors and interviewers. This is particularly the case since it appears that little have been written on the topic.

Reporting by proxy

The study used proxy reporting when the disabled family member was not present at the time of the study, with a result of as many as 60 percent proxy reporters. This could be a confounding factor, depending on the relationship between the proxy reporter and the disabled family member. It is common to use proxy reporters as the respondent in studies of persons with intellectual disability (Umb-Carlson & Sonnander 2006).

Schneider et.al (Schneider et al. 1999) had 47 percent proxy reporters in their study of disabled in South Africa, and 45 percent of them were mothers of people with disabilities. Proxy reporters made up the majority of the respondents for the disabled with intellectual, communication and learning difficulties, and 76 percent of proxy reporters in the study were close family member. When such information is known, it can be used to determine if there are differences between those answers that are reported by proxy and those that are not. Since the Zambia study in fact records the information in the

questionnaire, it would have strengthened the Zambia study if it had discussed the role of the proxy reporters and their effects on the responses.

Recall bias

A possible limitation in the Zambia study is the 12 month recall period: Long recall periods can create bias in a survey. Retrospective recall bias is a common limitation in several studies (de Graaf et al. 2002;Mock, Acheampong, Adjei, & Koepsell 1999;Mock, nii-Amon-Kotei, & Maier 1997;Moshiro, Heuch, Astrom, Setel, & Kvale 2005), and should be considered as a potential limitation in this study. Moshiro (Moshiro, Heuch, Astrom, Setel, & Kvale 2005) recognizes two causes of recall bias: Loss of memory (failing to recall, and therefore under-report events); and telescoping, the tendency to recall events more frequently than they actually did.

In its approach to 'inventory of environmental factors' the Zambia study did not seek to measure frequency in terms of *number of events* but rather an estimate of *perceived frequency of occurrence.* The respondents were asked to rate their experiences as never, seldom, seasonal, often and always. It can be quite subjective to the respondents what they consider seldom or often, and it could have been an advantage to the study to rate these questions in daily, weekly, monthly, less than five times a year etc. This could enable the study to indicate more exact the figures of experiences of difficulties and contribute to reduce recall bias.

In general shorter recall periods are better when recall quality is in focus, but for rarely occurring events (e.g. hospitalisation) short recall periods lead to high variance of estimates. Moreover, the 12 month recall has the benefit of relating to the natural unit of the year, and avoids problems with seasonal variations (e.g. that primary healthcare is unavailable during part of the rainy season because of transport problems).

It is difficult to come up with a specific recommendation for what recall periods that should be used for this type of studies. It is, however, a topic that could be addressed in future surveys.

Ethical considerations

Information on ethical clearance or informed consent was not reported in this study, and apparently not obtained. This is somewhat unexpected in a study that covered several sensitive subjects. The subject of confidentiality is well emphasized in this study, though clear instructions in the interviewer's manual (page 3):

'It is important that you (the interviewer) stress the fact that no one will be identified in this study. For example, in cases where a respondent refuses to give the first name, explain that the name is used only in relation to subsequent information. Names will not be published or listed in any way. Information will only be presented in the forms of numbers, tables and charts and at no time will names be published. The names are entered on the questionnaires, but will not be captured in the data.'

We do not believe that the study posed any particular ethical problems.

Sampling method

The survey employed a standard two-stage stratified cluster sampling. The sample frame for the first stage was the list of standard enumeration areas (SEAs) derived from the 2000 Census of Zambia. In total 350 SEAs across all the nine provinces of Zambia were used. Within each province the sample was divided into an urban and rural stratum, resulting in altogether 18 strata. The SEAs were selected with Probability Proportional to Size (PPS) where the measure of size was the number of households recorded in each SEA in the census. The sample was allocated so that each province received a sample size proportional to the square root of the number of households in each province. The importance of this is that each household in the final sample has a weight in the estimates that is determined by the province which it is in. Small provinces count more in the estimate than they would have if the sample had been allocated proportional to the number of households in each province. There are good reasons for allocating the sample in this way, but it requires that the estimates are weighted when they are calculated.

The Zambia report and the description from the SINTEF researchers diverge somewhat as to how households were selected within each SEA. In the sample description in the Zambia report, all households in the SEAs were listed and 20 households (10 with, and 10 without disabled family members) were independently selected for interview (creating in effect two strata in each SEA). In the interview with one of the main authors (Loeb) the sample selection was described as being a selection of the 10 disabled households, who were then matched by selecting a neighbouring household for each selection.

Both methods enable the survey to compare between households with and without households. However, the latter method makes it impossible (or at least exceedingly difficult) to work out the inclusion probabilities (and thereby the proper weights) for each non-disabled household.

A weakness in the report, especially given the weight put on the criteria of the Washington Group in the development of the theoretical framework, is that the

screening procedure used as basis for dividing the households in a SEA into those with disabled members and those without are not made clear.

Two stage cluster sampling is a very common and well established design for large scale household surveys, both within health research (e.g. Demographic and Health Surveys, UNICEF MICS, and WHO World health Surveys) and in other fields. The benefit of two stage cluster designs is that by first sampling a limited number of clusters (SEAs in this case) and then selecting households within each cluster, substantial cost saving can be achieved in comparison to selecting households directly from all over the country in question (Aliaga & Ren 2006;Bhattacharyya & Johnson 1977).

Non-response

Non-responding household (i.e. selected households that were not at home at the time of the scheduled interview) were substituted by a neighbour household in this survey. The practise is somewhat problematical for three reasons. First, it leaves it to the interviewers to make a selection of a household. That easily leads to biases. Second, substitution generally increases any bias that is associated with the non-response in the first place. For example, if a disabled is working outside of the home, and therefore cannot be contacted, the non response in itself makes the survey under-estimate the proportion of working disabled. If another household, with a non-working disabled, is substituted, then the bias is increased. The third problem with substitution is that it easily hides the true nature of the non-response (Lynn 2004). In the case of the Zambia survey there is no identification of substituted households in the questionnaire.

In general a better strategy to the non-response problem than substitution is first, to increase the planned sample size in proportion to the expected non-response in order to keep the effective sample size as planned (over-sampling). For example, if 10 households per cluster is aimed for, then one might select 11 instead. Second, some sort of non-response correction should be carried out.

Weighted vs. non weighted data

Chapter four in the report addresses the sample weights proposed to be implemented in the analysis of this study; 'Due to the disproportionate allocation of the sample points to various strata, sampling weights will be required to correct for differential representation of the sample at national and sub-national levels' (the Zambia report: 83). The report thereafter describes the process of weighting the data for differential representation. Nevertheless, the data presented in this report (chapter five) are not weighted as described in chapter four.

The tabulations in the analysis are not weighted. As was indicated above, the smaller provinces therefore get a larger (implicit) weight in the analysis than

should have been the case. Another consequence is that households in SEAs that have increased in size since the 2000 Census will have smaller weight than they should have. For example, households in rapidly developing peri-urban areas are likely to be underrepresented in the estimates.

The prevalence of disability in Zambia cannot be reliably estimated from the data without proper weighting. Thus, the estimates in Appendix 2 are probably somewhat biased, but it is difficult to say by much without knowing more about the distribution of disability within each stratum. A similar observation can be made about the estimates in each cross-tabulation.

Design based vs. model based estimation

A basic distinction in survey statistics is that of model based vs. design based estimation. Design based estimation refers to approaching estimation from a sample taking the explicit sampling design into account, while model based estimation assumes that the sample was generated by some random process, or to simplify, approaching the sample as if it was a simple random sample (Korn & Graubard 1999).

Cluster samples are not simple random samples, and their benefit in cost usually comes at the expense of higher statistical uncertainty. The higher statistical uncertainty shows itself, for example, in how statistical tests of significance should be calculated. Since the Zambia report implicitly have used a model based approached, the significance tests have a tendency to show more results as significant than should be the case.

It is quite common to use model based estimation for research papers that attempt to substantiate general hypotheses in the health field. The assumption then is that the population sampled is a 'general population of humans' and not as would be the case for designed based estimation 'a real population of people in Zambia in 2005'. For estimating characteristics of real populations design based estimation is nearly universally used. In the case of the Zambia report design based estimation would have entailed taking into account the weights and the sample structure (i.e. stratification and clustering) as well as non-response in the estimation.

The documentation of data in the Zambia report

The report introduced in the Zambia report presents a well documented overview of the finding in this study, and it communicates results that are similar to other studies on the various topics. This report demonstrates disability by gender, and shows that prevalence among men is higher than women; according to Elwan (Elwan 1999) this is a common trend in developing countries, whereas it is the opposite in the developing world. Lower female rates may show that severe disabilities may be male-dominated or it can indicate that

disabilities among women is under-reported or may receive less attention and care. Another particular note in this study was the proportion of individuals with activity limitation who did not attend primary school, and this should be considered in planning future educational services. The results here are similar to other studies. An analysis undertaken by the World Bank (Filmer 2005) showed that youth with a disability are almost always substantially less likely to be in school than those without.

Conclusion: Strengths and limitations in the report

Like other studies, the study in Zambia has both strengths and limitations; we will consider the main ones.

Can the results be trusted?

This is perhaps the most important question to be posed to any survey. In general, we find that the answer to the question is 'yes'. Nevertheless, as we have discussed above and will summarize below, there are aspects of the design that could be improved in ways that would increase the reliability and validity of the survey.

Use for policy

The main strength in this study is the development of applicable information and data for advocacy purposes and attitude changes in Zambia. The results from this study can be considered as a good basis for a new dialogue between authorities, professionals and organizations for people with disabilities. In addition it is useful for developing policies and for resource allocation purposes. The results are also very useful for development of policies in third world countries more generally.

The authors of the Zambia report have continued with an additional dialogue and advocacy about research on the disabled Zambia (Loeb 2006c;Loeb, Eide, & Mont 2007b).

They have also used the results of the survey in academic contexts through participation in conferences as well as in extensive present and forthcoming publications (Eide et al. 2007;Eide & Loeb 2006b;Eide & Loeb 2006c;Eide & Loeb 2003;Eide & Loeb 2006a;Eide & Loeb 2004;Finkelflügel et al. 2006;Jelsma et al. 2007;Loeb 2002;Loeb 2006a;Loeb 2006b;Loeb 2007;Loeb et al. 2007;Loeb & Eide 2004a;Loeb & Eide 2003;Loeb & Eide 2006;Loeb & Eide 2004c;Loeb & Eide 2004d;Loeb, Eide, & Mont 2007a;Loeb & Hem 2002;Loeb & Loeb 2004;Maart et al. 2007;Schneider, Loeb, & Eide 2003).

Local capacity-building

The employment and cooperation with local actors and stakeholders is one of the strengths of this study. It enabled local fieldworkers and supervisors, both disabled and non-disabled, to participate in the research of people with activity limitations. Local agencies and NGOs were active in the implementation of the study, and this should make them better equipped to utilize the results in this study in their future work among the disabled. In fact, the project managed to bring together two main research institutions in Zambia whose diverse opinions and methodologies in research helped the survey process on disabilities.

Comparison

Given the fact that the survey is designed very similarly to the other surveys carried out by SINTEF (i.e. Namibia, Zimbabwe, Malawi) they offer the possibility of comparing between the different countries. This opportunity has been well utilised by the authors of the report. Since SINTEF's approach is in some ways unique, the results are not directly comparable to surveys not carried out by SINTEF. That may be one reason why relatively few other studies are referenced or used for comparison in the report. Even so, it might have been useful to have included more comparative material in the discussion.

As noted above, despite the screening questions of the Washington Group, there is no single really well established procedure that can be used off-the-shelf. The work carried out by the authors is an important step towards achieving better standardisation of disability statistics internationally, and it should not be faulted for the fact that this goal as yet is not completely achieved.

As noted above future studies would be improved if the statistics on living conditions adhered more to international standards (MDGs etc) than what presently is the case.

Statistical methods

As noted the sample design and implementation are generally standard and carried out in an appropriate fashion. Nevertheless, we would have liked to have seen the implications of the design carried through to the analysis stage, using design based estimates.

References and editing

Some improvements could be made with regard to the final editing of the report. In particular, the references were cited differently from chapter to chapter, and that made it difficult for an outsider to gain a good overview of the references.

The Zambia report refers to other literature in the background material of the study. This is relevant literature that places the report in a greater context. However, a general weakness is the lack of updated references. Examples of this are found in chapter three where references used are WHO, 1981 and UN, 1996 (page 60) rather than more recent material.

Suggestions for improvements

In summary of the discussion on the strengths and weaknesses in the report from Zambia, this evaluation paper recommends the following improvements in future studies;

- ✓ A more specific definition of the term 'disability'
- ✓ Design based estimation

  Calculation and inclusion of sampling weights in the estimates and account taken of the design in calculation of significance tests and standard errors.
- ✓ Improved treatment of non-response
- ✓ Testing the consequences of using a high number of proxy respondents

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