

STF 78 A044511

REPORT



Photo: Jarl Ovesen

Living Conditions among People with Activity Limitations in Malawi

A National Representative Study

September 2004

www.sintef.no

FEDOMA
Federation of Disability Organisations in Malawi
Address: PO Box 2284
Blantyre, Malawi
Contact: fedoma@sdpn.org.mw

University of Malawi
Centre for Social Research
Address: PO Box 278
Zomba, Malawi
Contact: csr@sdpn.org.mw

SINTEF Health Research
Living Conditions and Social Services
Address: PO Box 124 Blindern
0314 Oslo, Norway
Contact: arne.h.eide@sintef.no



Federation of Disability Organisations of Malawi



University of Malawi



SINTEF

**SINTEF****SINTEF REPORT****SINTEF Health Research**Address:
P.O.Box 124, Blindern, NO-0314 Oslo/
NO-7465 Trondheim, NORWAYTelephone:
+47 22 06 73 00 (Oslo)
+47 73 59 30 00 (Trondheim)
Fax:
+47 22 06 79 09 (Oslo)
+47 73 59 63 61 (Trondheim)

Enterprise No.: NO 948 007 029 MVA

TITLE

Living Conditions among People with Activity Limitations in Malawi. A National Representative Study.

AUTHOR(S)

ME Loeb, Arne H Eide (editors)

CLIENT(S)

Norwegian Federation of Organisations of Disabled People

REPORT NO. STF78 A044511	CLASSIFICATION Unrestricted	CLIENTS REF. Jarl Ovesen	
CLASS. THIS PAGE	ISBN 82-14-03510-4	PROJECT NO. 78g026	NO. OF PAGES/APPENDICES 167/5
ELECTRONIC FILE CODE Malawi report		PROJECT MANAGER (NAME, SIGN.) ME Loeb	CHECKED BY (NAME, SIGN.) Karl Gerhard Hem
FILE CODE	DATE 2004-08-26	APPROVED BY (NAME, POSITION, SIGN.) Arne H Eide	<i>Arne H. Eide</i>
ABSTRACT			
<p>This research report provides results from the study on living conditions among people with disabilities in Malawi. Comparisons are made between individuals with and without disabilities and also between households with and without a disabled family member.</p> <p>Results obtained in Malawi are also compared those obtained in earlier studies carried out in Namibia and Zimbabwe.</p> <p>The Malawian study was undertaken in 2003.</p>			
KEYWORDS	ENGLISH	NORWEGIAN	
GROUP 1	People with disabilities		
GROUP 2	Living conditions		
SELECTED BY AUTHOR	Activity limitations		
	ICF		
	National study		

PREFACE

(Rachel Kachaje – Chairperson SAFOD)

As Southern Africa Federation of the Disabled (SAFOD), we feel honoured to have been part of this study on the Living Conditions among People with Disabilities in Malawi and we are very grateful to the Government of Malawi i.e. the Ministry Responsible for People with Disabilities, The Centre for Social Research (CSR), Federation of Disability Organisations in Malawi (FEDOMA) and all its affiliates, Disability Organisations for, and the Disabled Persons themselves and other partners for rendering their support for the realisation of the project.

Studies such as those that have been carried out in Namibia, Zimbabwe and now in Malawi are very important as they provide a more precise indication of the true living conditions of people with disabilities than has previously been available. Furthermore, the survey in Malawi, together with the earlier Awareness Building Campaign, has aided in sensitising society to the plight of people with disabilities and the importance of their inclusion in all developmental activities.

People with disabilities have played an active role in all aspects of this study. While the Centre for Social Research (CSR) at the University of Malawi had accepted the responsibility for overseeing all research aspects of the study, FEDOMA had maintained responsibility for project management at the local level. People with disabilities have been equal partners in the design process, in data collection and supervision, and in the field have proven to be as capable as their non-disabled counterparts. This is a very positive development.

It is common knowledge that people with disabilities in the SADC Region and indeed in the whole of Africa are experiencing problems and difficulties in carrying out their daily activities and in their ability to fully participate in society. People with disabilities experience barriers that may be physical, in the form of reduced accessibility to local services (including schools, hospitals and the workplace), and may be social, in the form of discrimination and negative attitudes in society at large. These are problems that can be avoided, or at least reduced, if the development policies of governments, Donor Organisations and Development Agencies were targeted towards inclusion and addressing the specific needs of people with disabilities in society.

What may however be retarding progress is a lack of clear data in the form of statistics on the actual situation of persons with

disabilities in our respective countries. This report should, at least in part, redress that deficit.

And once research is completed and data are collected, emphasis must be placed on utilising the results of research to not only raise awareness but also to catalyse, to urge all those who have something to do with disability including governments and other relevant institutions to commit themselves, to advocate towards bringing about changes in issues that affect the lives of people with disabilities in Malawi and indeed in the whole of the Southern Africa Region.

Table of Contents

PREFACE	3
Table of Contents	7
Summary	11
Introduction	23
1 Context	27
2 Concepts	37
2.1 Disability	37
2.2 Living conditions.....	41
2.3 Disability and living conditions.....	42
2.4 Combining two traditions and ICF	44
3 Living conditions among people with activity limitations in low income countries	46
3.1 Disability data in low-income countries.....	48
3.2 Relevant studies in Malawi	61
4 Design and Methods.....	63
4.1 Determination of Sample Size	63
4.2 The Sampling Frame	65
4.3 Sampling Procedures.....	66
4.4 Data Collection.....	70
4.5 Questionnaires	71
4.6 The Research Teams	74
4.7 Data analysis	76
5 Results	77
5.1 Results from the study on level of living conditions	78
5.2 Disability study	106
6 Discussion	147
7 Conclusions	157
8 References.....	161
9 Appendices	167

Tables

Table 3.1	Prevalence (%) of disability in selected countries	45
Table 5.1	Number of households and individuals in the study ...	78
Table 5.2	Mean household size	78
Table 5.3	Mean age of household.....	79
Table 5.4	Gender, household type and Region	80
Table 5.5	Mean number of children (under 18 years) in household by Household type and Region	81
Table 5.6	Distribution of Disabled household members by region	82
Table 5.7	Disability by gender	83
Table 5.8	Disability by gender by region	83
Table 5.9	Disability by age and region	84
Table 5.10	Marital status	85
Table 5.11	School attendance	86
Table 5.12	School attendance by Type of disability	88
Table 5.13	School grade completed	89
Table 5.14	Languages written	90
Table 5.15	Unemployment.....	91
Table 5.16	Skills.....	93
Table 5.17	Monthly salary.....	94
Table 5.18	Regional distribution of households	95
Table 5.19	Employment.....	96
Table 5.20	Household income and expenses	97
Table 5.21	Housing ownership.....	101

Table 5.22	Age profile of person with disability	106
Table 5.23	Distribution of the type of main disability by gender.	107
Table 5.24	Cause of disability.....	108
Table 5.25	Age of onset of disability	109
Table 5.26	Which of the services, if any, are you aware of and have ever needed/received?	110
Table 5.27	Gap analysis (services not received) by type of disability	112
Table 5.28	Assessment of services received	114
Table 5.29	Type of school attended.....	116
Table 5.30	Accessibility at home.....	118
Table 5.31	Accessibility from home.....	119
Table 5.32	Type of assistive devices in use	121
Table 5.33	Assistance needed in daily life activities (N = 1574).	123
Table 5.34	Involvement in family life	126
Table 5.35	Characteristics of the severity scales.....	129
Table 5.36	Mean scores on severity scales by type of disability.	129
Table 5.37	Mean scores on severity scales by gender and region.	134
Table 5.38	Mean scores on severity scales by Self-evaluation of Physical and Mental Health	136
Table 5.39	Mean severity scores on severity scales by indicators of living conditions.	139
Table 5.40	Contrasting disability paradigms for research	141

Summary

(ME Loeb, AH Eide)

This representative study on living conditions among people with disabilities¹ in Malawi is the result of an international co-operation between Southern Africa Federation of the Disabled (SAFOD), Federation of Disability Organisations in Malawi (FEDOMA), Norwegian Federation of Organisations of Disabled People (FFO), University of Malawi (Centre for Social Research), and SINTEF Health Research. The study has been funded by the Atlas Alliance on behalf of Norwegian Agency for Development Co-operation (NORAD). In addition to the study itself, a capacity building component has been an important part of the collaboration.

Forming part of a Regional initiative to establish baseline data on living conditions among people with disabilities in Southern Africa, the study in Malawi is the third to be published. The report is designed to provide both an overview of the situation for people with disabilities in Malawi today and a comparison to the situation for those of the population without disabilities.

¹ The terms "disability" and "activity limitation" are used interchangeably in the text. See 2.1)

The report also introduces to Malawi, the conceptual approach of assessing disability as limitations in activities of daily living and restrictions in social participation rather than by means of physical or mental impairment.

The study design was developed in close collaboration with a broad range of stakeholders. Organisations of people with disabilities and individuals with disabilities have played a particularly active role during development of the design and the collection of data. Based on previous studies in the Region, the research instrument comprises a study on living conditions among households with and without disabled members, a screening instrument (for disability), a section with specific questions to individuals with disabilities, and a matrix that represents an operationalisation of core concepts from the International Classification of Functioning, Disability and Health (ICF).

Using a sampling frame provided by the National Statistical Office covering all districts in the country (Likoma Island was excluded for logistical reasons), a total of 1521 households with at least one disabled family member and 1537 households without disabled members were sampled in 157 enumeration areas.

A comparison with results from the Namibian and Zimbabwean studies is included for some major indicators. In general, the patterns observed (both similarities and differences) between

people with and without disabilities demonstrated in Namibia and Zimbabwe were replicated in Malawi.

The study design allows for the following types of comparisons: between individuals with and without disabilities, and between households with and without disabled family members. With regards to demographics, households with disabled members were found to have higher mean age and they were larger, having more children than did control households. These and other socio-demographic differences may be the result of certain coping mechanisms that have been established in households with disabled members, mechanisms intended to cater particularly to the increased care duties found in these households.

As was found in both Namibia and Zimbabwe, school attendance is clearly lower among persons with disabilities. Among children 5 years of age or older, 35% of those with disabilities had never attended school, while the corresponding figure for non-disabled was 18%. Interestingly, however, school performance (measured as highest school grade completed) was not different between the two groups. Among those who had attended school, 13% of those with disabilities had completed Form 1 – 4 as their highest grade, while the corresponding figure for non-disabled was 14%. This result is different than that found in the previous studies where we found that among those who had attended school, performance was lower among those with disabilities, i.e.

fewer of those with disabilities achieved higher levels of education.

Though no official unemployment figures could be found, unemployment in Malawi is high – and we find among our sample a high proportion of both people with and without disabilities who are “not currently working”. However, significantly more (about 58%) of those with disabilities are unemployed compared the non-disabled sub-sample (53%). While these figures are not meant to represent official unemployment figures, they provide an indication of the current situation in Malawi. Unemployment data collected from Namibia and Zimbabwe were, in fact, higher in both countries indicating perhaps that Malawi is in a better economic situation than its neighbours.

While indicators of unemployment are high, it was however shown that among the same group of potentially economically active persons 15 – 65 years of age, 41% of those with disabilities had acquired some skill, compared to slightly fewer, 39% of those without disabilities. This is most likely a reflection of what is offered to children/persons with disability, i.e. skills training is (more) common in the special education services for persons with disabilities. Similar results were obtained in Namibia and to an even larger extent in Zimbabwe where an extensive system of specialized services for individuals with disabilities, in particular employment

opportunities in sheltered workshops, have existed in that country since 1950's.

Furthermore, mean monthly salaries, for those who provided that information, were lower among those with compared to those without.

On most indicators the comparison between the two types of households revealed expected differences; that is, households with disabled members have lower standards of living than the control households. This is demonstrated when assessing employment (fewer households with a disabled family member have someone working) household income, housing standard, and access to information.

The age distribution of people with disability interviewed in our study is found to be relatively evenly distributed, and this deviates somewhat from the population age distribution in Malawi. Twenty percent of our sample for example comes from the age group 10 years or younger. Corresponding population figures place about 30% of the population in that group reflecting an under-representation in that age group. Also about 29% of our sample is in the age group over 50 years which, compared to the population figure of 10%, represents an over-representation.

Around 43% of those with disabilities have a self-reported physical disability (major or minor disability, paralysis), and 42% reported sensory impairments (seeing, hearing and communication), while intellectual disabilities, learning disorders and emotional disorders accounted for 11% of reported cases. It is interesting to note that these figures are similar to those reported in both Namibia and Zimbabwe. The major causes of disability were reported to be either the result of illness, birth-related or congenital, and accidental. Over half of the respondents reported onset of disability before the age of 5 years, indicating a serious challenge to health services for mothers and children in the country.

Among services available to persons with disabilities, health services and traditional healers were found to be available for the majority of those with disabilities, with about 60% of those who needed these particular services having actually received them. At the other end of the scale, the most noticeable shortcomings with regards to service provision were vocational training, welfare services, assistive device services and counselling services. Vocational training and welfare services were received by about 5% of those who claimed that they needed them.

An assessment of various forms of assistance that may be needed by individuals with disabilities in performing daily life activities showed that a large majority of respondents claimed to need emotional support, surpassing all other types of

assistance required. Economic support, or assistance with finances, was the second most often mentioned form of assistance needed. It is interesting to note that, within the family, the role of the individual with a disability does not appear to be much affected by their disability status.

While an overview of accessibility to different services, facilities and institutions gives a mixed picture, it is clear that certain of these facilities are not generally accessible to all. Hotels and banks are accessible to less than 10% of individuals with disabilities. Places of worship, health care clinics, hospitals, shops and public transport are on the other hand reported to be accessible by the majority of those with disabilities (over two-thirds). The most notable shortcomings are schools, accessible to only 20% and the workplace, accessible to only 26% of the disabled population. The mixed picture demonstrated with regards to accessibility indicates that the potential exists for improving accessibility for people with disabilities.

Assistive devices are used by less than one fifth (17%) of those surveyed with disabilities. It is interesting to note that this figure is similar to the corresponding figure for Namibia (18%) but slightly lower than that reported for Zimbabwe (26%). It is further shown that most of the devices in use are functioning well (64%). Depending on the type of device in use, between 35 and 65% have received instructions on their use. With respect to maintenance, about 7% of devices are

maintained through government services, about 40% assumed responsibility themselves (or through their families) and another 40% claimed that their device was either not maintained or that they couldn't afford maintenance/repairs. As was found in Namibia, a higher share of devices is supplied by private sources in Malawi, reflecting a stronger tradition of privately initiated and organised services for individuals with disabilities in those countries. In contrast, the supply of devices in Zimbabwe is more balanced between private and public sources.

Certain elements of the information collected during the survey can be used to define the severity of a person's situation with respect to their disability. For example, data on both an individual's needs for services and the daily activities that a person may need help in accomplishing may be used for this purpose. Simple scores are constructed by adding up the number of services one needs or the number of daily tasks one needs help in accomplishing, to indicate the severity of a person's situation. The more services needed : the worse off that person is; or the more help needed in doing daily tasks : the worse off that person is.

Furthermore, a matrix was developed and applied to map an individual's activity limitations and participation restrictions according to different domains (sensory experiences, basic learning and applying knowledge, communication, mobility, self care, domestic life, interpersonal behaviours, major life areas and community, social and civic life).

For each of the 44 activities listed under these 9 domains, the degree to which an individual is capable of carrying out that activity without assistance (activity limitations) is 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 (participation restrictions) is also recorded on a scale from (0) no problem to (4) unable to perform the activity. By adding up an individual's responses to each of the 44 items a single activity limitation score and a single participation restriction score is developed.

These four severity scores were assessed according to different parameters. It was found that individuals with mental/emotional impairments needed more help in their daily activities than did those in other disability categories. This group also reported more activity limitations and restrictions in social participation than others. Individuals with mental/emotional problems thus reported that they experience more barriers to full participation in society. These results mirror those found in the surveys carried out in Zimbabwe and Namibia.

Activity limitation and participation restriction scores are similar for both sexes. These scores are not meant to be gender dependent – or to differentiate between genders – but to classify according to ability to carry out/perform activities under different circumstances. In contrast, analyses reveal slightly higher service needs score for men and a significantly

higher daily activity help score for women. The individual items in the daily activity help score in particular can be seen as more gender specific.

The constructed disability severity scores are further assessed with respect to self-reported physical and mental health. We find that, apart from the service needs score, the daily activity help score, and activity limitation and participation restriction scores are correlated with these health indices. That is, poorer health status (either physical or mental) is associated with increased need for help with daily activities, and higher degrees of activity limitation and restrictions in social participation.

Assessing the constructed scores based on activity limitations and participation restrictions with respect to indicators of living conditions revealed that both scores are associated with indicators of living situation. The more severe an individual's disability as measured through limitations in daily life activities and restrictions in social participation, the lower the level of school attendance and employment.

The publication of the results of the Living Conditions Survey in Malawi marks three milestones. Firstly, we report on the active participation and involvement of people with disabilities and their organisations throughout the entire process of undertaking this survey. In this regard FEDOMA has assumed a leading role. Secondly, we report on a new approach to

defining disability in a research process. We base our assessment of disability on concepts presented in the International Classification of Functioning, Disability and Health (ICF), in particular activity limitations and participation restrictions. Our intention is to shift focus from an individual's physical or mental impairment (the "what's wrong with you?" approach) to an individual's capacity and performance in their environment (the "what do you need to fully participate in society" approach). Finally, the baseline data and results produced through this study can be applied directly as documentation of the living standards among people with disabilities and their families, and as a basis for comparison with both non-disabled individuals and families without a disabled family member. Furthermore the results can be applied later for monitoring purposes. This information is potentially useful when decisions are made on utilisation of meagre resources, as documentation and evidence to prospective donors or other funding sources, and as a tool for organisations of disabled people in setting priorities, educating their own members and the population in general, and as a basis for advocacy.

It is recommended that the results from this study are considered, together with other relevant sources, as a basis for dialogue between authorities, professionals and organisations of people with disabilities, for setting priorities, and for developing concrete measures within selected areas of priority.

Introduction

(Mussa Chiwaula – Executive Director FEDOMA)

Based on the collaboration between the Southern African Federation of the Disabled (SAFOD) and the Norwegian Federation of Organisations of Disabled People (FFO), an initiative was taken to conduct studies on the living conditions among people with disabilities in the southern African region. The studies were funded by the Norwegian Agency for Development Cooperation (NORAD) through the Atlas Alliance². FFO contracted SINTEF Health Research³ to carry out these studies. To date, completed reports are available from Namibia and Zimbabwe (in Namibia: Eide, van Rooy & Loeb, 2003 and in Zimbabwe: Eide, Nhiwatiwa, Muderezi & Loeb, 2003). Malawi, as a SAFOD affiliate, was identified as the third country in which the study would be conducted.

Since 2002, SINTEF Health and the Federation of Disability Organisations in Malawi (FEDOMA) have been working in close

² The Atlas Alliance is an organization formed by Norwegian organizations of disabled, patients and their relatives, collaborating on support to disabled people in low-income countries. www.atlas-alliansen.no

³ SINTEF Health Research is a contract based research institute in the SINTEF Group and is the largest health service research company in Norway. www.sintef.no/helse (choose "English" in top left corner)

collaboration to initiate and implement the study. FEDOMA identified the University of Malawi's Centre for Social Research (CSR) to contribute as a technical partner. While these institutions guided the research, other Government ministries, NGOs and Disability Service providers have actively supported the process. A list of involved agencies is presented in Appendix 1.

The projects specific aims include:

- to develop a strategy and methodology for the collection of comprehensive, reliable and culturally adapted statistical data on living conditions among people with disabilities (with particular reference to the International Classification of Functioning, Disability and Health - ICF)
- to carry out a representative National survey on the living conditions among persons with disabilities in Malawi so as to provide the much needed data for policy influence and planning
- to lay the groundwork for future and long-term data collection among persons with disabilities in Malawi
- to develop a collaboration in order to improve and strengthen research on the situation of people with disabilities in Southern Africa, and
- to assist in capacity building among Disabled Persons Organisations (DPOs) in Malawi and among government ministries and other disability stakeholders to utilise the research findings.

An important feature of this research is to be found in the operationalisation of certain aspects of the International Classification of Functioning, Disability and Health (ICF). It has been a specific intention of the work presented here to shift the focus of attention away from the individual's particular functional impairments or physical limitations and towards an assessment of the person's ability to actively participate in society. By focusing on activity limitations and participation restrictions, within the individual's particular socio-cultural context, it is the hope of this research to be more inclusive and less discriminatory with respect to defining a subgroup of the population as having a disability.

The main data collection took place in September and October 2003 and involved both persons with and without disabilities working as Research Assistants and Supervisors. From its inception, this study has achieved a major milestone in Malawi in that persons with disabilities were actively involved throughout the entire research process. In addition this study will update the sorely needed data on disability that have remained static since the last national survey on disability was conducted in 1983.

The publication of this report significantly adds to recent research initiatives in the field of disability and living conditions in the southern African region. The Namibian and Zimbabwean studies of Living Conditions among People with Disabilities were published in 2003 (Eide, van Rooy & Loeb,

2003; Eide, Nhiwatiwa, Muderezi & Loeb, 2003). Together these three studies are among the very first representative studies of living conditions among people with disabilities to be carried out in Africa. They offer not only a unique comparative picture of the situation for people with disabilities in the region but also some insight into the development of a research methodology that has been implemented for the first time. A new study is anticipated in Zambia in 2005/2006 and further studies in the SADCC region may follow after this.

Parallel to the collection of information on the level of living conditions among people with disabilities, capacity building workshops have been developed for organisations of disabled people, public authorities and others. These workshops have focussed on further understanding the research process, and how data collected locally in the field can be better understood and used as information directed at influencing the formulation of policy and advocacy.

It is envisioned that these initiatives are followed up by the establishment of a program aimed at ensuring that the results from these studies are applied to the benefit of people with disabilities in the Southern Africa Region.

This report thus presents the results from the study on the Living Conditions among People with Disabilities in Malawi.

1 Context⁴

(A Munthali, S Konyani, ME Loeb)

HISTORY

In 1964, after seventy-three years of British rule, Malawi became an independent nation. The prime minister at the time, Hastings Kamuzu Banda, was elected president for life in 1971 and instituted authoritarian one-party rule.

His control lasted until 1994, when he was defeated by Mr. Bakili Muluzi in Malawi's first multiparty elections. Mr. Muluzi and his United Democratic Front (UDF) party were re-elected in the country's second multiparty elections in June 1999. Local elections were held in the country for the first time in November 2000, and the UDF won 70 percent of the wards, although with very low voter turnout.

⁴ Sources:

World Bank Fact sheet on Malawi, 2003

<http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/MALAWIEXTN>

CIA Fact sheet on Malawi, 2004

<http://www.cia.gov/cia/publications/factbook/geos/mi.html>

WHO Country profile, 2002 <http://www.who.int/country/mwi/en/>

Population and Housing Census, 1998 & Atlas of Social Statistics, 2002, National Statistical Office of Malawi <http://www.nso.malawi.net/>

With the help of foreign aid and investment, Malawi's economy prospered in the 1970s, growing at an annual rate of 6 percent. But thirty years of authoritarian rule stalled any significant and broad-based economic development.

Although the government of Malawi has initiated an economic reform agenda, it faces challenges on several fronts: a rapidly growing population, a high HIV/AIDS infection rate (about 14.9 percent), limited natural resources, and high levels of inequality the result of an unbalanced development strategy, and the corrosive effects of recurring droughts, poor resource management, and environmental degradation. Malawi held a general election in mid 2004 after the conclusion of the two terms of the present President Mr. Bakili Muluzi.

ECONOMY

Landlocked Malawi ranks among the world's least developed countries. Malawi's economy is based largely on agriculture, which accounts for more than 90 percent of its export earnings, contributes 45 percent of gross domestic product (GDP), and supports 90 percent of the population. Malawi has some of the most fertile land in the region. Almost 70 percent of agricultural produce comes from smallholder farmers. Land distribution is unequal with more than 40 percent of smallholder households cultivating less than 0.5 hectares. The country's export trade is dominated by tobacco, tea, cotton, coffee, and sugar.

From 1995 to 1997 the Government of Malawi followed good economic policies; but in recent years the pace of reforms has slowed, expenditure control has weakened, and agricultural prospects have become mixed. Tobacco revenues declined in 2000 because of slumping prices, declining yields, and declining quality. This together with volatile exchange rates, high annual inflation (30 percent in February 2001), and high real interest rates has resulted in slow growth of about 2 percent in 2000 and -1.5 percent in 2001.

Over the last two years, the government—with the support of the Bank and the IMF—has tried to implement a growth-oriented reform program; but results have been mixed. Fiscal slippages in 2002 and early 2003 caused high interest rates and limited progress on reducing inflation. In addition, a severe drought in the 2001/02 agricultural season further weakened Malawi's economy.

The economy is predominantly agricultural, with about 90% of the population living in rural areas. Agriculture accounted for nearly 40% of GDP and 88% of export revenues in 2001. The economy depends on substantial inflows of economic assistance from the IMF, the World Bank, and individual donor nations. In late 2000, Malawi was approved for relief under the Heavily Indebted Poor Countries (HIPC) program and is expected to reach the completion point in the HIPC process towards end 2004. In November 2002 the World Bank approved a \$50 million drought recovery package, which is to

be used for famine relief. The government faces strong challenges, e.g., to fully develop a market economy, to improve educational facilities, to face up to environmental problems, to deal with the rapidly growing problem of HIV/AIDS, and to satisfy foreign donors that fiscal discipline is being tightened. The performance of the tobacco sector is vital to short-term growth as tobacco accounts for over 50% of exports.

POLITICS

Malawi's flag



The Republic of Malawi is governed by a multiparty democracy, divided into 27 administrative districts; Balaka, Blantyre, Chikwawa, Chiradzulu, Chitipa, Dedza, Dowa, Karonga, Kasungu, Likoma, Lilongwe, Machinga (Kasupe), Mangochi, Mchinji, Mulanje, Mwanza, Mzimba, Ntcheu, Nkhata Bay, Nkhotakota, Nsanje, Ntchisi, Phalombe, Rumphu, Salima, Thyolo, Zomba, with the capital located in Lilongwe.

The following political parties are represented in the country; Alliance for Democracy (AFORD), Malawi Congress Party (MCP), Malawi Democratic Party (MDP), Movement for Genuine Democratic Change (MGODE), National Democratic Alliance (NDA), People's Progressive Movement (PPM) and the governing party, the United Democratic Front (UDF).

The president is elected by popular vote for a five-year term; election last held 18 May 2004.

GEOGRAPHY

Malawi lies in south-eastern Africa, bordered to the west by Zambia, north and east by Tanzania, and east and south by Mozambique. The country covers a total area of 118,480 sq. km, 24,400 sq. km (20%) of which are water. The climate is described as sub-tropical with a predominately rainy season from November to May and a predominately dry season from May to November. The terrain is best described as a narrow elongated plateau with rolling plains, rounded hills and some mountains. About 20% of the land is arable. Elevation ranges from a low of 37 m above sea level at the junction of the Shire River and the international boundary with Mozambique to a high of 3,002 m at Sapitwa (Mount Mlanie).

PEOPLE, POVERTY, HEALTH, HEALTH CARE, AND DISABILITY

Recent estimates place the population of Malawi at 11,906,855 persons. Estimates explicitly take into account the effects of

excess mortality due to AIDS; this can result in lower life expectancy, higher infant mortality and death rates, lower population and growth rates, and changes in the distribution of population by age and sex than would otherwise be expected (July 2004 est.)

When the United Democratic Front took over the government from the Malawi Congress Party in the country's first multiparty elections in 1994, it emphasised that its programmes would aim at alleviating poverty. While this was the stated objective, not much has been achieved because currently poverty in Malawi is widespread. The 1998 Integrated Household Survey conducted by the National Statistical Office revealed that 65.3% of the population is poor and this translates to approximately 6.3 million Malawians (National Statistical Office, 1998). According to the Malawi Poverty Reduction Strategy Paper, 90% of the population live in rural areas and of these 66.5% live in poverty. This situation is made worse by the fact that 25% of the households in Malawi, according to the integrated household survey are headed by women.

In terms of health care, services are structured into six levels, namely health posts, health centres, rural hospitals, district hospitals, central hospitals and specialised hospitals (e.g. leprosy and mental hospitals). The Ministry of Health and Population is by far the largest provider of health services, followed by the Christian Health Association of Malawi (CHAM) which runs Christian church-owned health centres and

hospitals. Of the 503 health facilities available in Malawi in 1999, 40 percent were operated by the Ministry of Health and Population, 16 percent by CHAM and the rest by local authorities, NGOs and private practitioners (Ministry of Health and Population, 1999). Unlike CHAM, which charges user fees for its services, the bulk of health services provided by the government are free of charge. Only those admitted to “paying wards” in selected government health facilities who pay user fees.

The Ministry of Health and Population recognises the poor health status of Malawians and attributes this, among other factors, to high levels of poverty, illiteracy, drug shortages in health facilities, inadequate budgetary allocation and poor staffing levels in the Ministry of Health and Population (Ministry of Health and Population, 1995:17-19). While Malawi is one of the countries with the worst health indicators in the world, there have, nevertheless, been improvements in some basic health statistics as documented by UNICEF and the Ministry of Health and Population.

While other health indicators have been improving over the years, the life expectancy rate has been on the decrease since the early 1990s. The life expectancy rate in 2000 was estimated at 40 years (UNICEF, 2002), a drop from 48 in 1992 (United Nations in Malawi and Government of Malawi, 1993). The precipitous drop in overall life expectancy is mostly due to

the HIV/AIDS pandemic which is claiming many lives among the economically productive age group of 15-49 years.

Unlike the life expectancy rate, infant and under-five mortality rates have been decreasing. While the infant mortality rate was at 205 deaths per 1000 live births in 1960, by the year 2000 this figure was down to 117. In 1960, the under-five mortality rate was at 361 and, by 1990 it had dropped to 241 deaths per 1000 live births (UNICEF, 2002; National Statistical Office, 2001). Currently, the under-five mortality rate is 188 per 1000 live births and though still declining it places Malawi among those with highest child mortality in the world. One of the major reasons for the decrease in the under-five mortality rate is the great increase in vaccination coverage, which has considerably reduced deaths from vaccine-preventable diseases like measles, tuberculosis, tetanus, etc. While the infant and under-five mortality rates are on the decrease, they still remain one of the worst indicators and it may not be long before they start increasing again as a result of HIV/AIDS.

The maternal mortality rate still remains very high at 1120 deaths per 100,000 live births. Total fertility rate is 6 children born/woman. 2001 estimates of the HIV/AIDS situation set the adult prevalence rate at 15% and estimates from that year indicate that approximately 850,000 people are currently living with HIV/AIDS, HIV/AIDS having claimed (up to 2001) 80,000 lives.

The population growth rate is estimated at 2.14% while the birth and death rates are 44.35 births/1,000 population and 23.01 deaths/1,000 population respectively.

In terms of education, Malawi is among the countries in the world with a low adult literacy rate. In 1998 this was estimated at 58%, with a female literacy rate estimated at 44%. The introduction of free primary education in 1994 saw the increase in gross enrolment rates from 95 and 85 in 1993/4 to 142 and 131 for boys and girls respectively (Kadzamira et al, 2004) and while such is the scenario, over 70% of the children who start standard one drop out of school before completing standard 8. This explains why the net enrolment rate estimated at 76 for both girls and boys is much lower than the gross enrolment rate (Kadzamira et al, 2004).

As far as the disability sector is concerned, the Malawian Government established the Handicapped Persons Act in 1971. Services in the disability sector between 1971 and 1994 however have been based on charity and not on either development or human rights. Not much was done during this period because, according to the Ministry Responsible for People with Disabilities, there was no policy to guide the implementation of activities in the disability sector. The 1994 Malawi Constitution recognised and incorporated the disability sector and the need to implement programmes based on non-discrimination. While disability issues have in the past been handled by different Ministries including the Ministry of Health,

Ministry of Community Services etc, the creation of the Ministry Responsible for People with Disabilities to look into such issues was a major milestone after 1994.



2 Concepts

(Arne H Eide, ME Loeb)

Disability and living conditions are core concepts to the study presented in this report. Our own understanding of these concepts has progressed in unison with some interesting developments in recent years. Both concepts are open to interpretation and can be perceived in different ways. In addition, it is important to be aware that the understanding and application of these concepts will vary from one socio-cultural context to another (Whyte & Ingstad, 1998). As the concepts are important for the design of the study as well as for the analyses and understanding of results, some clarifications are necessary.

2.1 Disability

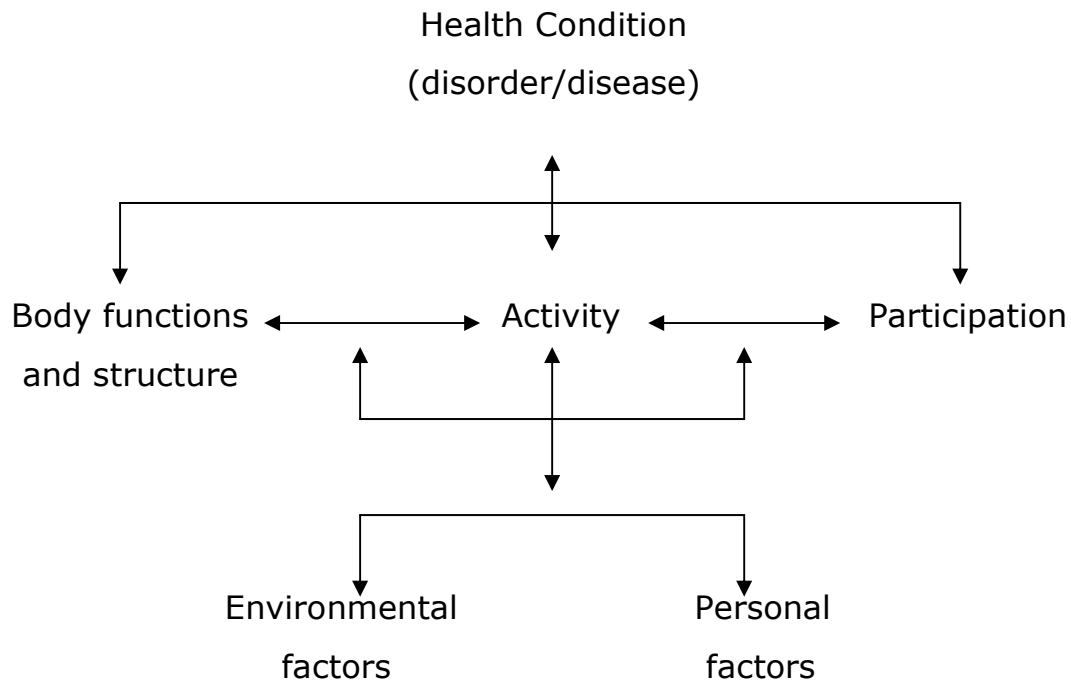
During the 1970s there was a strong reaction among representatives of organisations of persons with disabilities and professionals in the field of disability against the then current terminology. The new concept of disability was more focused on the close connection between the limitations experienced by individuals with disabilities, the design and structure of their environments and the attitude of the general population. Recent development has seen a shift in terminology and an increasing tendency towards viewing the disability complex as a process (the disablement process),

involving a number of different elements on individual and societal levels.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

The adoption of the World Health Organisation's International Classification of Functioning, Disability and Health (WHO, 2001) represents a milestone in the development of the disability concept. From 1980 and the first classification (The International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980)), a 20 year process has resulted in shift in the WHO conceptual framework from a medical model (impairment based) to a new scheme that focuses on limitations in activities and social participation. Although not representing a complete shift from a strictly medical to a strictly social model, the development culminating with ICF nevertheless implies a much wider understanding of disability and the disablement process.

Figure 1 The ICF Model of Functioning, Disability and Health (WHO, 2001)



APPLICATION OF THE ICF IN THE CURRENT STUDY

The conceptual development from ICIDH (WHO, 1980) to ICF is important here as this shift also has a methodological parallel. The classification forms a basis for the collection of statistical data on disability. The current study does not represent an application of ICF, and it has not been the intention to test the new classification as such. Rather, the study is inspired by the conceptual basis for ICF and has attempted to approach disability as activity limitations and restrictions in social participation. This is pronounced in the screening procedure and in the inclusion of a matrix on activity limitations and social participation restrictions developed

particularly for this study. The current study does, none the less, provide a unique possibility for applying some core concepts from the ICF and testing some aspects of the model statistically⁵.

An understanding of disability as defined by activity limitations and restrictions in participation within a theoretical framework as described in Figure 1 underlies this study. The term "disability" is, with this in mind, a problematic concept since it refers to, or is associated with, an individualistic and impairment-based understanding. As a term, it is nevertheless applied throughout this text since it is regarded as a commonly accepted concept, and its usage is practical in the absence of any new, easy to use terminology in this sector.

ENVIRONMENTAL FACTORS

Environmental factors are important elements in the ICF model, and it is fundamental to the present understanding of disability that activity limitations and restrictions in participation are formulated in the exchange between an individual and his/her environment. In the current study, environmental factors are included in an activity and participation matrix (Appendix 3). It is however acknowledged that studies like the current one traditionally focus on the individual and that this is also the case here.

⁵ Will be published separately

2.2 Living conditions

The concepts of “level of living” or “living conditions” have developed from a relatively narrow economic and material definition to a current concern with human capabilities and how individuals utilise their capabilities (Heiberg & Øvansen, 1993). Although economic and material indicators play an important role in the tradition of level of living surveys in the industrialised countries, an individual’s level of living is currently defined not so much by his or her economic possessions, but by the ability to exercise choice and to affect the course of his or her own life. The level of living studies have been more and more concerned with such questions and are currently attempting to examine the degree to which people can participate in social, political and economic decision-making and can work creatively and productively to shape their own future (UNDP, 1997).

A number of core items can be regarded as vital to any level of living study: Demographics, health, education, housing, work and income. Other indicators may comprise use of time, social contact, sense of influence, sense of well being, perceptions of social conflict, access to political resources, access to services, social participation, privacy and protection, etc. The choice of which indicators to include will vary according to the specific requirements of each study and the circumstances under which the studies are undertaken.

2.3 Disability and living conditions

Research on living conditions is comparative by nature. Comparison between groups or monitoring development over time within groups and populations are often the very reasons for carrying out such studies. The purpose is thus often to identify population groups with certain characteristics and to study whether there are systematic differences in living conditions between groups – or to study changes in living conditions within groups over time and to compare development over time between groups. Population sub-groups of interest in such studies are often defined by geography, gender, age – or the focus of the current research, i.e. people with disabilities vs. non-disabled. Research in high-income countries has demonstrated that people with disabilities are worse off along the whole spectre of indicators concerning living conditions, and that this gap has also remained during times with steady improvement of conditions for all (Hem & Eide, 1998). This research-based information has been very useful for advocacy purposes, for education and attitude change in the population, as well as for planning and resource allocation purposes.

These same patterns of systematic differences are also at work in low-income countries, as has been documented in our studies in Namibia (Eide, van Rooy & Loeb, 2003) and Zimbabwe (Eide, Nhiwatiwa, Muderezi & Loeb, 2004).

When the stated purpose of the research is to study living conditions among people with disabilities, it is essential, at the onset, to decide upon a working definition of disability in order to identify who is disabled and who is not. This is a more complex issue than choosing between a “medical model” on one side and a “social model” on the other. How this is understood and carried out has major impact on the results of research, and consequently on the application of results (refer to chapter 3.1 on the disability concept). The ICF may to some extent be viewed as an attempt to combine a broad range of factors that influence the “disability phenomena”.

The authors behind this research report support the idea that disability or the disablement process is manifested in the exchange between the individual and his/her environment. Disability is thus present if an individual is (severely) restricted in his/her daily life activities due to a mismatch between functional abilities and demands of society. The role of the physical and social environment in disabling individuals has been very much in focus during the last 10 – 20 years with the adoption of the Standard Rules, the World Programme of Action, and lately the ICF (WHO, 2001). It is logical that this development is followed by research on the mechanisms that produce disability in the meeting between the individual and his/her environment.

It is true that studies of living conditions among people with disabilities in high-income countries have been criticised for

not evolving from an individualistic perspective. Data are collected about individuals and functional limitations are still in focus. It is a dilemma that this research tradition has not yet been able to reflect the relational and relative view on disability that most researchers in this field would support today. While we agree to such viewpoints, we nevertheless argue that a “traditional” study is needed in low-income countries to allow for a description of the situation as well as comparing between groups and over time. In high-income countries such studies have shown themselves to be powerful tools in the continuous struggle for the improvement of living conditions among people with disabilities. In spite of an individualistic bias in the design of these studies, the results can still be applied in a critical perspective on contextual and relational aspects that represents important mechanisms in the disablement process.

2.4 Combining two traditions and ICF

The design that has been developed and tested here aims at combining two research traditions: studies on living conditions and disability studies⁶. Pre-existing and validated questionnaires that had been used in Namibia (on general living conditions – NPC, 2000) and in South Africa (on disability – Schneider et. al., 1999) were combined and adapted for use in the surveys. A third element, on activities and participation, was included to incorporate the conceptual developments that have taken place in connection with

⁶ By “disability studies” we understand a broad specter of different studies that have generated knowledge about the situation of people with disabilities.

development of ICF. By combining the two traditions, a broader set of variables that can describe the situation for people with disabilities are included as compared to the traditional disability statistics. Secondly, a possibility is established for comparing the conditions of disabled people (and households with disabled people) with non-disabled (and households without any disabled members). It is argued that such comparative information is much more potent in the struggle for improvement of the situation for disabled people, reflecting the developmental target for the current study.

3 Living conditions among people with activity limitations in low income countries

(AH Eide, ME Loeb)

According to UN estimates, the population of disabled people in the world is placed at somewhere between 225 and 350 million people. This is based on a 10% estimated prevalence rate (WHO, 1981) that is intended to cover severe, moderate and mild physical, mental or sensory impairments. The large majority of disabled people live in developing or low-income countries⁷, very often living without optimal technical, medical or social support that could have improved their level of living conditions considerably. Disabled people are often marginalised and belong to the poorest segments of society (UN, 1996).

The situation for people with disabilities in low-income countries is of concern for Governments, Non-Governmental Organisations (NGO), as well as for the International Community. Their rights have been the subject of much attention in the United Nations and other international organisations over a long period of time. The International

⁷ Low-income country will be applied throughout this report to cover terms like developing country, non-industrialised country etc. Likewise, high-income country is applied to cover developed country, industrialised country etc.

Year of Disabled Persons (1981) and the United Nations Decade of Disabled Persons (1983 – 1992) culminated in the World Programme of Action Concerning Disabled Persons (UN, 1993). The Programme emphasises the right of persons with disabilities to the same opportunities as other citizens and to an equal share in the improvements in living conditions resulting from economic and social development. In 1993, the General Assembly approved The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (Resolution 48/96) (UN, 1994), setting specific targets and requesting a strong moral and political commitment on behalf of States to take action for the equalisation of opportunities for persons with disabilities.

Knowledge about the current situation is important as a tool for advocacy and practical action, when agreeing on acceptable standards, setting priorities and planning for required improvements. Without the necessary information and knowledge, Governments, NGOs and International Organisations are more or less forced to work arbitrarily on a hit or miss basis. Under such circumstances resources cannot be distributed and utilised in a rational, efficient manner. Unfortunately, the lack of knowledge is clearly most pronounced in developing countries with scarce resources and thus with the greatest need for cost-effective strategies that would improve the living conditions among people with disabilities.

Both the World Programme of Action and the Standard Rules comprise explicit formulations that reflect the need for information, data collection and research on the situation of disabled people, and particularly so in developing countries. According to the World Programme of Action, member states should develop a programme of research on the causes, types and incidence of impairment and disability, economic and social conditions of disabled persons as well as on obstacles that affect their lives. Such formulations are also found in the Disability Policy of Namibia⁸, South Africa⁹, and in the draft policy document soon to be adopted in Malawi¹⁰, among others.

3.1 Disability data in low-income countries

In recent decades, the collection of data and the production of statistical information on topics relevant to rehabilitation and disability have proliferated (UN, 1996). Rehabilitation programmes, national censuses and survey programmes within different Government sectors are producing increasing amounts of information on impairments, disabilities and handicaps. Needless to say, the bulk of this information is produced in the industrialised countries. In addition, most of the current statistical information is, unfortunately, produced without the benefit of a common terminology or standard procedures and guidelines. It is further claimed (UN, 1996)

⁸ MLRR (1997) National Policy on Disability. Windhoek, Ministry of Lands, Resettlement and Rehabilitation.

⁹ Office of the Deputy President. (1997) White Paper on an Integrated National Disability Strategy. Pretoria, Office of the Deputy President.

¹⁰ Malawi Government. Draft National Disability Policy. Office of the Minister of State Responsible for Persons with Disabilities. December, 2001.

that there are problems with the quality of existing data and that quality problems are most pronounced in developing countries.

The demand for quality statistics on persons with disabilities has increased greatly in recent years following the International Year of Disabled Persons (1981), the World Programme of Action Concerning Disabled Persons, and the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. The World Programme of Action specifically requested the United Nations to develop systems for the regular collection and dissemination of information on disability. The UN provides a web site as a step in implementing this mandate. It provides a convenient statistical reference and guide to the available data, specifically,

- national sources of data
- basic disability prevalence rates
- questions used to identify the population with disability.

3.1.1 The problem of determining disability prevalence

Those interested in determining the extent of disability in a population encounter a few 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. In the past, many African countries have reported disability prevalence rates well under 5% (or below 5000 per 100 000 population). This is far below the rates observed in some western countries where the majority are over 10%, some even approaching 20%, see Table 3.1). That is not to suggest that African rates should be as high as, or higher than those reported in western societies – but there is a real fear of under-reporting among African countries.

Table 3.1 Prevalence (%) of disability in selected countries.

High-income countries			Low-income countries		
	Year	%		Year	%
Canada	1991	14.7	Kenya	1989	0.7
Germany	1992	8.4	Namibia	1991	3.1
Italy	1994	5.0	Nigeria	1991	0.5
Netherlands	1986	11.6	Senegal	1988	1.1
Norway	1995	17.8	South Africa	1980	0.5
Sweden	1988	12.1	Zambia	1990	0.9
Spain	1986	15.0	Kenya	1989	0.7
UK	1991	12.2	Zimbabwe	1997	1.9
USA	1994	15.0	Malawi	1983	2.9

Sources:

Canada	Statistics Canada - Selected characteristics of persons with disabilities residing in households
Germany	Statistisches Bundesamt Wiesbaden, Population and labour market survey
Italy	Instituto Nazionale di Statistica
Netherlands	Central Bureau of Statistics and Netherlands Institute for Research on Social Welfare, Physical Disability
Norway	Statistics Norway - Survey of Level of Living
Sweden	Statistics Sweden
Spain	Encuesta Sobre Discapacidades, Deficiencias y Minusvalias
UK	Office of Population Censuses and Surveys
USA	United States Department of Health and Human Services, National Center for Health Statistics
Kenya	Central Bureau of Statistics, Kenya Population Census
Namibia	Central Statistical Office, 1991 Population and Housing Census
Nigeria	National Population Commission, 1991 Population Census
Senegal	Direction de la provision et de la statistique
South Africa	UNDP-ILO Report
Zambia	Central Statistical Office, Census of Population, Housing and Agriculture
*Zimbabwe	Central Statistical Office, 1997 Inter-Censal Demographic Survey Report
Malawi	National Statistical Office, Survey of Handicapped Persons, Malawi, 1983 (1987)

Note: Each of these surveys used a different set of questions in order to identify persons with disabilities. For more information see:

<http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp>

*Zimbabwean data are derived from a separate report, and are not available on the above website.

Another source of disability prevalence rates is The Human Development Report that has been published by the UNDP since 1990. Included in the 1997 edition of the Report (UNDP, 1997) are estimates of the prevalence of disabilities as percentages of the total population in selected countries. According to this source, the prevalence of disability is 1.6% in Zambia and 2.9% in Malawi. Among the black population in South Africa prevalence of disability (sight, hearing/speech, physical disability and mental disability) has been estimated to 5.1%. Two other studies from South Africa (coloured urban and black rural communities) have reported prevalence rates of 4.4% and 4.75% (Katzenellenbogen et. al., 1995; Concha and Lorenzo, 1995). The national disability survey undertaken in South Africa in 1998/99, a national representative survey of 10,000 households was carried out to determine the prevalence of disabilities as well as describe the disability experience as reported by disabled people or their proxy reporters (Schneider et al., 1999). The focus of the survey was on the "traditional" categories of impairments, and according to this study, disability prevalence rates varied between 3.1% and 8.9% among the selected South African provinces. The recent Census in Namibia reported overall disability in the country at 4.7% of the population (National Planning Commission (NPC), 2003), while the studies on living conditions found 1.6% of the sampled population in Namibia (Eide, van Rooy & Loeb, 2003) and 2.9% of the sampled population in Zimbabwe (Eide, Nhiwathiwa, Muderedzi & Loeb, 2003) as having disabilities.

3.1.2 Comparability of disability statistics

As shown in the preceding table, many countries collect data on disability but the prevalence rates derived from these data vary greatly for a variety of reasons including:

- conceptual issues - disability as the result of an interaction between the person with the disability and their particular environment. Under these circumstances, disability is seen as a non-static, complex phenomenon that can be conceptualised in many ways, including at the level of the body, the person, or the society.
- measurement issues - the questions used, their structure and wording, and how they are understood and interpreted by the respondents all affect the identification of the persons with disabilities in data collection.

Another plausible explanation for the discrepancy between low- and high-income countries may be found in an assessment of disability prevalence along the time axis. It is claimed that disability prevalence rates observed in the United States (and other high-incomes, western countries) in the 1950's were of about the same order of magnitude as those now observed in low-income countries; and that the rates we see in, for example, African states represent a manifestation of the delayed development of these countries (Judith E. Heumann, World Bank Disability Advisor, personal communication).

For these reasons, the observed differences among countries in the disability prevalence rates (or percentages) reflect conceptual and measurement differences, to varying degrees, as well as "true" differences. While prevalence rates for the African continent are *consistently* low, the methods that have produced them vary dramatically and reinforce the need for a standardised approach to an evolving disability phenomenon that would allow for a more equitable comparison of international measurements.

To achieve broader comparability among countries, much work needs to be done to further develop classifications and concepts, such as the International Classification of Functioning, Disability and Health (ICF), as well as measurement instruments to implement them in national statistical efforts.

3.1.3 Methodological considerations in measuring prevalence

Screening for disability

The issue of disability prevalence was discussed at a Workshop on Disability Statistics for Africa (Kampala, 10-14 September 2001) organised by the UN Statistical Office and attended by representatives from 11 African nations. Among the delegates there was general agreement that the figures reported for African countries uniformly reflected the more severe cases of disability in the population – and were in fact not dissimilar to rates for severe cases of disability reported in western countries. It was felt, however, that the reported disability

figures failed to capture the milder to more moderate degrees of disability or activity limitation/ participation restriction. The cause of this particular omission may be simply that individuals do not acknowledge a limitation if they are unaware of the possibility of improving the situation with relatively simple technical aids – or, alternatively, the reason may be linked to the association between "supply and demand" i.e. that fewer demands placed by society on the individual results in fewer counted 'disabilities'.

In line with the earlier impairment-based model of disability (ICIDH, 1980), enquiring after specific impairments has been a common approach to screening for disabilities in the censuses of many low-income countries. For example, the questions used to identify persons with disabilities in the 1983 Malawi survey (presented in the preceding table) were as follows:

1. Is there anyone in this household who has a disability related to:

- Eyesight
- Hearing
- Speech
- Fits
- Limbs
- Walking
- Mental deficiency
- Mental illness, or
- Other disabilities?

2. Is this person able to look after his/her personal needs?

The United Nations Statistical Division provides additional examples on its website:

<http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp> (UN, 2003).

The approach used in the surveys presented here relies rather on an understanding of disability as difficulties in doing day-to-day activities and/or restrictions in social participation. The screening questions used reflect an understanding of disability in accordance with the ICF (WHO, 2001).

Screening question 1: *Does anyone in this household ever have any difficulty in doing day to day activities because of a physical, mental or emotional (or other health) condition?*

(Response categories: yes, often/yes, sometimes/no)

Screening question 2: *Has this difficulty lasted, or is it expected to last six months or more?*

(Response categories: yes, no)

Screening question 2: *Does anyone in this household need assistance to do day to day activities?*

(Response categories: yes, a lot/yes, a little/no)

We found in this survey that prevalence by district varied from a very low level of 1.2% in Mchinji District to 7.8% in Ntchisi District, with a mean, national disability prevalence rate of 4.18% (see Appendix 3). Though this is still quite low by international standards, it is 30% higher than the rate last recorded in Malawi in 1983 (2.9%).

3.1.4 Methodological Work on Disability Statistics

The United Nations Statistics Division (UNSD) publication *Guidelines and Principles for the Development of Disability Statistics*¹¹ 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*,¹² and also on the section on disability in the *Principles and Recommendations for Population and Housing Censuses, Revision 1*.¹³

The *Guidelines* recommend that disability be measured within the conceptual framework of the WHO *International Classification of Functioning, Disability and Health – ICF* (World Health Organisation, Geneva, 2001). The ICF conceptual framework provides standardised concepts and terminology that can be used in disability measurement instead of the unstandardised and often pejorative terms used in many national studies on disability. The use of a common framework

¹¹ Guidelines and Principles for the Development of Disability Statistics (United Nations publication, Sales No. E.01.XVII.15)

¹² Manual for the Development of Statistical Information for Disability Programmes and Policies (United Nations publication, Sales No. E.96.XVII.4).

¹³ Principles and Recommendations for Population and Housing Censuses, Revision 1 (United Nations publication, Sales No. E.98.XVII.8).

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.

3.1.5 International initiatives on disability measurement

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 the by UNSD, UNICEF, Eurostat and the Centres for Disease Control and Prevention (CDC) of the United States. 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.

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 speciality surveys; and (3) To address the methodological

issues associated with the measurement of disability considered most pressing by the WG participants.

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.

Three meetings of the WG have been held to-date with a fourth planned for September-October 2004. Further information about the Washington City Group can be accessed on their website: <http://www.cdc.gov/nchs/citygroup.htm>.

The Statistics Division of the United Nations has established the Disability Statistics Database for Microcomputers (DISTAT). DISTAT contains disability statistics from national household surveys, population censuses, and population or registration systems. The 1990-edition of the Disability Statistics compendium covers 55 nations, among them a few African countries (UN, 1990). 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). For more information about this system go to the following web-site:

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

Most countries in Africa, Malawi included, have carried out and published population censuses that provide some information on living conditions. Unfortunately, information on disabilities and the living situation of people with disabilities have rarely been included. The population censuses after the year 2000 are, however, expected to cover disability (UN, 1997), following the revision of the census recommendations¹⁴. In both Namibia (see above) and Zimbabwe (Census 2002, Preliminary Results Summary, Central Statistical Office, 2003), a few questions about disability have now been included.

Although the progress made in this field is quite substantial, data on disability are still infrequent and are significant by their absence in development reports. A further point to be mentioned here is that the international monitoring system developed by the United Nations will largely be limited to a small number of standardised indicators intended for international comparison. More comprehensive and culturally

¹⁴ National Censuses have recently been carried out in both Namibia and Zimbabwe (2002). In both countries, screening questions influenced by an activity based understanding of disability have been included. At the time of writing this report, no results have however been reported from the two censuses.

adapted studies of living conditions will be necessary in developing countries in order to establish a knowledge basis that can guide development of policy and practice.

3.2 Relevant studies in Malawi

Very little relevant disability research has been conducted in Malawi. A 1983 National Statistical Office (NSO) Survey of Handicapped Persons in Malawi placed the rate of disability in the population at 2.9%. A further NSO survey conducted in 1993 indicated that the prevalence of disability in the population was about 2%. The Population Census was conducted in 1998 but there are no details available in the information base concerning disability, handicaps or impairments in the population.

No updated, nation-wide figures on disabilities and/or disabled people are currently available.

Poverty is, however, a recurring theme among statistical publications emanating from Malawi. The 1998 Integrated Household Survey and Poverty Analysis, includes the Relative Poverty Profile, published in 2001 by National Economic Council in association with the National Statistical Office, and Determinants of Poverty in Malawi published in June 2001 are two examples. These however do not make mention of disability as an issue.

NATIONAL DISABILITY POLICY IN MALAWI

Malawi has recently established a Ministry Responsible for Persons with Disabilities that will deal with matters of concern to people with disabilities in the country. In conjunction with the establishment of this Ministry, a process has recently been underway in Malawi to review relevant legislation and draft a National Disability Policy. Among other things, the Policy will delineate roles and duties in order to both minimise overlap and duplication of function and maximise the limited resources available.

4 Design and Methods

(A Munthali, S Konyani)

This study required that the estimates obtained should be representative nation-wide. A census would have been too expensive given the available resources. However, it is widely known that sample surveys whose design and methodologies are well developed and executed can produce estimates that can be very close to those that would have been arrived at had a census been conducted. Hence, the survey was carried out on a sample basis and the design and methodologies used in the study are discussed below. This chapter covers information on how the sample size was determined, the available sampling frame, sampling and data collection methodologies.

4.1 Determination of Sample Size

From the onset, the target population for sampling was all private households in Malawi excluding institutionalised and homeless people.

The sample size was worked out noting that in a survey of living conditions of people with disabilities, the data user would want to know the estimates of proportions of respondents sharing respective views on issues relating to disability. The

characteristics requiring respondents' views in this study are many and each characteristic would have its own proportion of respondents responding in a particular manner. In this regard, the proportion would vary from characteristic to characteristic. Determination of sample number of respondents that would give a national estimate of the proportion at a given level of precision depends on the variance of the proportion and the sample design adopted. A characteristic with a proportion having a large variance would require a larger sample to arrive at an estimate of the proportion at national level at a given acceptable level of precision than that with a smaller variance. In order to avoid having varying sample sizes for given characteristics of people with disabilities under the study, the largest possible sample number of people with disabilities based on the largest possible variance that a proportion can have at a given level of precision under given sample design was calculated. The variance of a proportion being highest when the proportion equals 50%, the required sample number of disabled persons was calculated based on the assumption that the estimated proportion would take that value with a margin of error equal to plus or minus 3.5 percent at the 95 percent level of confidence. Since the sample, as will be illustrated later, was to be drawn in stages, the design effect was assumed to be equal to 2. The design effect is the effect on the variance of adopting a sampling procedure other than Simple Random Sampling (Bradley and South, 1981). Based on the above assumptions, the national sample of the disabled to be covered was calculated utilizing the formula used to calculate the sample size for a proportion given below:

$$n = \frac{p(1-p)(1.96)^2 de}{e^2}$$

where:

- n is the sample size
- p is the proportion of respondents responding a given manner to an issue relating to disability (this was assumed to be at 0.5)
- 1.96 is the z score corresponding to the 95% level of confidence
- de is the design effect assumed equal to 2
- e is the level of precision or absolute margin of error which was set at ± 0.035 representing $\pm 3.5\%$.

The national sample size derived in this manner was 1570 respondents.

4.2 The Sampling Frame

The sampling frame that was utilized in this survey was obtained from the National Statistical Office (NSO). This frame was developed by NSO through the operations of the most recent population Census in Malawi conducted in 1998. Through a mapping exercise prior to the census, a total of 9206 Enumeration Areas were demarcated covering the whole country. The boundaries of these areas followed physical features such as rivers/streams, roads/paths, galleys, etc. and these enumeration areas were demarcated in such a way that during the census an enumerator would enumerate all the

persons in a given enumeration area within maximum of 21 days. Each enumeration area is estimated to have approximately 300 households or an estimated 1,000 individuals. During the operations of the census, the number of persons as well as the number of households found to exist in each one of the enumeration areas was recorded. However, no list of names and location of the households within the respective enumeration areas were made. This was due to the problems which are inherent in Malawi as well as most developing countries in giving information leading to the location of a household especially in the rural areas. Malawi has a total of 28 Districts divided into Traditional Authorities (TAs). In rural areas, the Traditional Authority is the lowest units for which maps showing boundaries of the enumeration areas are available while in the cities areas called Wards are the lowest unit for which enumeration area maps are available.

4.3 Sampling Procedures

As discussed above, it was calculated that a sample of 1570 persons with disabilities would be adequate to provide estimates of acceptable precision at the national level and the terms of reference dictated that there should be complete enumeration of all the people with disabilities in the sampled enumeration areas. The lowest level for which the available frame had information, as discussed above, was the enumeration area and the information comprised of only totals of persons and households. In addition, there was no

information on the prevalence of persons with disabilities at the enumeration area level.

The study conducted by SINTEF Health Research and the University of Zimbabwe using the ICF definition of disability (Eide, Nhiwatiwa, Muderezi & Loeb, 2004) estimated the proportion of those disabled to be 1.9%; while the one conducted in Namibia (Eide, van Rooy & Loeb, 2003) estimated proportion of disabled in that country to be 1.6%. Lessons learnt from Namibia and Zimbabwe indicate, therefore, that utilizing the ICF definition, the prevalence of disabled persons in Malawi may be closer to the 2.9% estimate of 1983 (NSO, 1987).

In the absence of information on the prevalence of disabled persons in Malawi at enumeration area level, it was assumed that the prevalence of disabled persons in each enumeration area would be 3%. Hence, in order to be able to sample and budget for the study, it was assumed that an enumeration area would contain on average 3% of its total number of households having at least a member with a disability. Based on this assumption and considering an average of approximately 300 households per enumeration area, it was calculated that the household with at least one disabled person would on average equal to 10 in an enumeration area. Considering the coverage of 1570 disabled persons, and that an enumeration area would contain on average 10 households with at least one disabled member, a sample of 157

enumeration areas were planned to be covered in the study within which all persons identified to have a disability were to be interviewed.

Each one of the districts (Likoma Island was excluded for logistical reasons) as well as each of the three cities in Malawi formed a stratum. The total sample of 157 enumeration areas was allocated to the respective strata in proportion to the population of the stratum and the distribution thereof was as given below.

NORTHERN REGION

District	Number of Selected EAs
Chitipa	2
Karonga	3
Nkhata Bay	3
Rumphi	2
Mzimba	8
Mzuzu City	2

CENTRAL REGION

District	Number of Selected EAs
Kasungu	8
Nkhota Kota	4
Ntchisi	3
Dowa	7
Salima	4
Lilongwe	12
Mchinji	5
Dedza	8
Ntcheu	6
Balaka	4
Lilongwe City	7

SOUTHERN REGION

District	Number of Selected EAs
Mangochi	9
Machinga	6
Zomba	8
Chiradzulu	9
Blantyre	5
Mwanza	2
Thyolo	7
Mulanje	7
Phalombe	4
Chikwawa	6
Nsanje	3
Blantyre City	8

The selection of the allocated number of enumeration areas within each stratum was done with probability proportional to size prior to the commencement of the data collection exercise. The size measure was the human population of the enumeration areas as found in the 1998 population census.

Apart from enumerating all households having at least a person with a disability in a selected enumeration area (Cases) a similar number of households (designated as minimum 10 per enumeration area) without any disabled persons (Controls) should also be interviewed. The selection of the enumeration areas was done in the office. In the absence of households sampling frame within enumeration areas, the selection of Controls could only be possible after enumeration teams were deployed and sent to the field where they would conduct a household listing exercise. However, it was decided that a systematic sample of households equal to the Cases listed

(assumed to be 10 on average) should be selected adopting Systematic Sampling procedures.

A pilot data collection exercise done to test the applicability of the sample design as well as the data collection tools was undertaken in chosen enumeration areas in Blantyre and Machinga districts. The results of the pilot especially for the household listing exercise that was intended, as explained earlier, to develop a household sampling frame, showed that the original estimate on the number of households with at least a disabled person (Cases) within an enumeration area was a significant underestimate. This meant an increase in workload in terms of field enumeration as a result of a significant increase in Cases and by implication, Controls.

In order to be able to accomplish the data collection exercise within the limits of the budget, an agreement was made with SINTEF Health Research to sample 10 households with at least one disabled person from the household sampling frame of Cases developed during the listing of respective enumeration areas. These households were selected utilizing a Systematic Sampling Procedure.

4.4 Data Collection

Research teams used maps to locate selected enumeration areas and identified its boundaries. Having identified the boundaries, the members of the team listed all the households that were found to exist at the time of the survey. The listing

was done utilizing a household listing and screening form that was designed specifically for this study. Utilizing this screening form, all households listed in the enumeration area were classified as either cases or controls in two respective columns of the household listing and screening form. Realizing that one of the needs of the study was to derive an estimate of the prevalence of disability in Malawi, research assistants, as advised, recorded the number of disabled persons in each and every household screened to be a case during the household listing exercise.

Having developed a household sampling frame of cases and controls respectively in a given enumeration area, 10 cases and 10 controls were independently selected utilizing systematic sampling procedures. Questionnaires were then administered to these households.

4.5 Questionnaires

As mentioned above, data collection questionnaires that had previously been used in Namibia (on general living conditions – NPC, 2000) and in South Africa (on disability – Schneider et. al., 1999) were combined and adapted for use in Malawi. In addition, a disability-screening instrument was included as well as a matrix on activity limitations and participation restrictions developed specifically for this study and drawing on the concepts of the ICF. The design applied in this study in Malawi is similar to the design applied in the previous studies in Namibia (Eide, van Rooy & Loeb, 2003), and Zimbabwe (Eide,

Nhiwatiwa, Muderezi & Loeb, 2004) save some minor differences in formulations of certain questions.

User participation was an important element in the design development. This process included a two-day workshop attended by 30 professionals, researchers, people with disabilities and civil servants (see Appendix 1) who discussed, tested and assessed the contextual suitability of the draft research instruments.

After revision, two separate questionnaires comprised four key elements; in the 'Levels of Living Conditions Questionnaire': i) household study on living conditions and ii) screening for disability; and in the 'Detailed Questionnaire of People with Disabilities': iii) detailed questions to individuals with disabilities and iv) the ICF-based activities and participation matrix. The final versions of the questionnaires were developed in English.

Simple field tests were carried out during the supervisor training process that lead to a few further modifications.

In each one of the 157 enumeration areas, the Living conditions questionnaire was administered to the head of household of each of the selected 10 case households as well as to each head in the selected 10 control households. The Detailed questionnaire was administered to each of the disabled members found in the 10 case households.

4.5.1 Understanding the Activity Limitation and Participation Restriction Matrix (Appendices 3 and 4)

It is important to be able to differentiate between the two concepts or dimensions that we have attempted to capture by using this ICF-based matrix. While on the surface Activity Limitations and Participation Restrictions may appear similar, they do in fact measure two distinct aspects of the disability phenomenon. In considering **activity limitations** we ask: "How difficult is it for you to perform this activity *without any kind of assistance at all?*" The intention is to capture or measure an individual's **capacity** to carry out the 44 different activities of daily living listed in the matrix – it is a measure of the person's level of functioning. **Participation restrictions**, on the other hand, measure 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). To capture this aspect we ask: "Do you experience any problem(s) in performing this activity in your *current environment?*"

A few simple examples may help to clarify this better.

1. A young boy lost the use of his legs in an automobile accident 25 years ago. He has been confined to a wheelchair since being discharged from the hospital. Today he is an active member of society, working and supporting a family. Because he is dependent on the wheelchair, his scores on certain elements in the matrix will be high: he cannot move about easily without assistance. At the same time this person has

become accustomed to life in a wheelchair, and in his current environment he is able to get around with little hindrance – he will score lower on the scale of participation restrictions.

2. Consider two individuals, 20 years old, both of whom are blind. One was born without the benefit of sight and the other became blind 6 months ago as a result of a work-related accident. Both have identical impairments and their activity limitations will, for the most part be the same – but the person who was born blind has had the benefit of 20 years to live with that condition – and in fact has never experienced living with sight. That person may be able to carry out all or most of their activities of daily living with little or no problem. The person who has been experiencing blindness for only six months may be quite helpless in their current environment.

We find that if disability is measured according to some predefined societal norm then we neglect to take into account the individual's own experiences (interacting with their social and physical environment) with respect to their particular disability. Measurements should rather be based on an individual's experience and capability in their environment.

4.6 The Research Teams

A total of 60 field personnel were recruited for execution of the study within the required period. The Centre for Social

Research recruited persons without disabilities while FEDOMA recruited persons with disabilities as Research Assistants. During the training however some research assistants were dropped from the team because the pilot showed that they still did not understand the questionnaire. There were a total of 10 mobile field teams and each comprised of 4 to 5 research assistants and 1 supervisor and assigned enumeration areas (see Appendix 2). The field supervisor's role was to take a leading role in identifying the boundaries of selected enumeration area, selection of case as well as control households, oversee the day-to-day data collection procedures while in the field, problem solving while in the field, checking completed questionnaires as well as completion of field reports. The research assistants role was mainly the listing of households in the enumeration areas utilizing the screening form and carrying out of interviews with respondents of the selected households.

Two CSR Principal Investigators assisted by representatives of FEDOMA were identified and their role was to oversee and manage all aspects of data collection process to ensure that all logistics necessary for the successful data collection exercise in the field were being adhered to and solve problems which the field teams could not handle on their own. CSR was also responsible for data entry and cleaning.

4.7 Data analysis

The reliability of the results presented is a crucial aspect of all studies – and it is thus important that results are not biased by factors that can influence their interpretation. We know for example that men and women have different traits and characteristics that may influence the way that they respond to certain questions. These types of factors are called confounders. In this study we have attempted to control for the effects of confounders (in particular gender and geographical region) throughout the analysis and presentation of results.

All questionnaires were controlled and signed by a supervisor after the interview. Completed questionnaires were transported to the University of Malawi, Centre for Social Research in Zomba for data cleaning and entry. Data were entered into SPSS data files and upon completion of data entry and data control, the data files were relayed to Norway and furthered analysed using SPSS 11.0.

5 Results

(ME Loeb)

The results are presented in two sub-chapters:

- Results from the study on level of living conditions, comparing individuals with/without disabilities and households with/without disabled persons; and
- Results from the detailed disability survey that specifically addresses the situation of persons identified with disabilities. This section includes a separate analysis of questions dealing with activity limitations and participation restrictions.

Particular care has been taken during analyses to control for both gender and regional differences. Whenever these potential confounders (see 4.7 above) have revealed significant differences these are commented in the text, otherwise not.

Table 5.1 provides an overview of number of households and individuals included in the data collection.

Table 5.1 Number of households and individuals in the study

Source:	Number of:		
	Households	Individuals	Persons with disabilities
Households having a person with disability	1521	8038	1579
Households without a person with disability (Controls)	1537	7326	44*
Total	3058	15364	1623

*44 individuals were identified in "control" households as having a disability. These households remain as "controls" and the individuals identified are not included in the detailed analysis of persons with disabilities. They are however included in the Living condition survey as disabled.

5.1 Results from the study on level of living conditions

Mean sizes of households with and without disabled persons are presented in Table 5.2.

Table 5.2 Mean household size

Region:	Households with disabled	Households without	significance		
	Mean size	Mean size	t	df	p
Northern	6.1	5.4	2.5	358	0.012
Central	5.6	4.8	5.3	1118	< 0.001
Southern	4.9	4.6	2.6	1517	0.009
Total	5.3	4.8	6.0	2998	< 0.001

Analyses revealed that, regardless of geographic region, households having at least one disabled household member were significantly large than those control households without a disabled family member.

Mean ages of permanent family members of households with and without disabled persons are presented in Table 5.3.

Table 5.3 Mean age of household

Region:	Households with disabled	Households without	significance		
	Mean age	Mean age	t	df	p
Northern	24.5	20.3	3.5	294	< 0.001
Central	24.8	20.9	4.8	846	< 0.001
Southern	28.8	22.7	8.7	1307	< 0.001
Total	27.0	21.8	10.4	2441	< 0.001

The mean age of households with a disabled member is significantly higher than those households without disabilities regardless of geographical region.

Concerning gender distribution, 51.2% (N = 4118) of the members in households with disabled people were females, whereas the corresponding figures for the control households was 50.2% (N = 3677). This difference between the two groups is not statistically significant.

Table 5.4 Gender, household type and Region

Region:	Households with disabled		Households without	
	% female	N	% female	N
Northern	51.2	568	51.6	498
Central	50.8	1608	48.9	1357
Southern	51.6	1942	50.8	1822
Total	51.2	4118	50.2	3677

A further look at the composition of households revealed that generally speaking, the number of children under the age of 18 was higher in households with disabled members than in households without. The differences shown in the table below indicate mean number of children under age 18 in the two types of households. While the differences do not appear to be large, and in fact are not significant in the northern or southern regions, they do deserve comment. Allowing for the fact that observed differences may be due to chance, it is noteworthy that despite not being statistically significant in the two regions, in all cases the mean number of children less than 18 years of age is higher in households with disabled than households without. Various explanations may be given for this, including families requiring more assistance to care for a disabled family member to concepts of replacement of the disabled person.

Table 5.5 Mean number of children (under 18 years) in household by Household type and Region

Region:	Households with disabled	Households without	Significance		
	mean	mean	t	df	P
Northern	3.2	3.0			NS
Central	2.9	2.6	3.3	1143	0.001
Southern	2.4	2.4			NS
Total	2.7	2.5	2.6	3029	0.009

In other words, with respect to some important demographic variables there are some similarities and differences between the two types of households. While no significant gender difference was observed in the composition of the households, households with disabled members were, on average, older than their non-disabled counterparts; as well as larger and with more children under 18 years of age.

5.1.1 Disabled and non-disabled

The screening exercise described in Section 3.1.3 was carried out in order to predetermine households having a disabled family member and to select suitable control households.

In addition, as a part of the Living Conditions survey, the entire sample of 15364 individuals was asked about disability in the form of questions identical to the screening questions presented earlier.

Despite all training and precautions, certain households that responded negatively to the screening questions (i.e. control households, not having a disabled family member) in fact answered positively to the disability questions in the Living Conditions Survey. In this part of the analysis these individuals are included as disabled.

A total of 1623 persons with disabilities were identified in the sample (i.e. 10.6% of 15364 individuals). By region the breakdown is as follows:

Table 5.6 Distribution of Disabled household members by region

	persons with disabilities identified	sample population	% disabled
Region:			
Northern	196	2075	9.4
Central	592	5943	10.0
Southern	835	7346	11.4
Total	1623	15364	10.6

Table 5.7 Disability by gender

Gender	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Female	804	49.5	6991	50.9	7795	50.7
Male	819	50.5	6750	49.1	7569	49.3
Total	1623	100.0	13741	100.0	15364	100

No significant gender difference was found in that 49.5% (n = 804) of the disabled were females whereas the corresponding figure for the non-disabled was 50.9% (n = 6991). ($\chi^2 = 1.04$, df = 1, p = NS)

Table 5.8 Disability by gender by region

Region:	Disabled		Non-disabled		significance
	% female	N	% female	N	
Northern	43.9	86	52.2	980	p = 0.027
Central	50.2	297	49.9	2668	NS
Southern	50.4	421	51.3	3343	NS
Total	49.5	804	50.9	6991	NS

The same pattern was observed geographically, see table 5.8, above, except for in the Northern region where there were significantly fewer women (43.9%) and more men (56.1%)

among the disabled than was observed among those without disability (52.2% and 47.8% respectively).

Mean age among the disabled household members was higher than among the non-disabled (33.8 years and 19.9 years respectively, $t = 21.59$, $df = 1702$, $p < 0.001$). This pattern was the same in each of the three geographical regions.

Table 5.9 Disability by age and region

Region:	Disabled		Non-disabled		significance		
	mean age	N	mean age	N	t	df	p
Northern	34.1	180	19.0	1827	9.1	201	< 0.001
Central	30.2	534	18.9	5085	11.2	592	< 0.001
Southern	36.1	808	21.1	6417	16.1	913	< 0.001
Total	33.8	1522	19.9	13329	21.59	1702	< 0.001

Further analyses by gender revealed the same pattern. The mean age for women was 34.3 years and 20.4 years in the households with disabled members and the control group respectively ($t = 15.2$, $df = 830$, $p < 0.001$), and for men the mean ages were 33.3 years and 19.4 years, $t = 15.4$, $df = 871$, $p < 0.001$).

Table 5.10 Marital status

Marital status (age >= 15)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Never married	288	26.9	2135	31.6	2423	31.0
Married with certificate	164	15.3	1185	17.5	1349	17.2
Married traditional	261	24.4	2011	29.8	2272	29.0
Consensual union	74	6.9	736	10.9	810	10.4
Divorced/ Separated	116	26.9	348	26.9	2423	31.0
Widowed	166	15.5	340	5.0	506	6.5
Total	1069	100	6755	100	7824	100

Table 5.10 reveals that there are differences between disabled and non-disabled with respect to marital status. While fewer of those with disabilities reported never having been married, 26.9% compared to 31.6% among those without disabilities; among the disabled far fewer (46.6%) reported living in union (either married with certificate or traditionally, or in a consensual union) than those without disabilities (58.2%). In addition 15.5% of those reporting disabilities were widowed compared to only 5.0% of those non-disabled.

EDUCATION

Table 5.11 School attendance

School attendance (age \geq 5)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Never attended	487	34.8	1946	17.7	2433	19.7
Still attending	263	18.8	4513	41.1	4776	38.6
Left school	649	46.4	4521	41.2	5170	41.7
Total	1399	100	10980	100	12379	100

It is shown here that school attendance is lower among the disabled members of the households as compared to those household members without a disability. ($\chi^2 = 352.4$, $df = 2$, $p < 0.001$). The proportion of those who have never attended school is almost twice as high among the disabled members as compared with the non-disabled (34.8% versus 17.7% respectively).

This finding was again confirmed among females and males separately (41% of disabled females and 29% of disabled males never attended school compared with 21% of non-disabled females and 14% of non-disabled males).

A separate analysis was carried out to explore whether particular types of disabilities were represented among those

who had not attended school. The first part of the table presented below is derived from the 'Living Conditions survey' and the second part is derived from the 'Detailed Disability survey' that will be presented in more detail later.

Among those 5 years of age or older, there is little difference in school attendance (or lack thereof) according to the different categories of disability type. Looking at those who never attended school, 35.7% (or 182 of 510) of those with seeing, hearing or communication (sensory) disabilities said that they had never attended school while 33.0% (or 172 of 522) of individuals who reported a physical disability and 36.1% (53 of 147) of those with psychological disabilities stated the same. (Several reported multiple disabilities, and only the first disability reported is assessed here. For more information on type of disability see Table 5.23)

Among those disabled *before 18 years of age* there is also little difference observed by type of disability. 33.1% of those with sensory disabilities, 31.4% of those with physical disabilities and 36.4% of those with psychological disabilities reported never having attended school. These differences are not statistically significant.

Those with disabilities associated with age or other causes are few and not commented upon in this particular analysis.

Table 5.12 School attendance by Type of disability

	sensory		physical		psychological		age/other	
	n	%	n	%	n	%	n	%
Age >=5 years								
never attended	182	35.7	172	33.0	53	36.1	18	46.2
still attending	110	21.6	73	14.0	29	19.7	7	17.9
left school	218	42.7	277	53.1	65	44.2	14	35.9
Total	510	100	522	100	147	100	39	100
Age >= 5 years & disabled prior to 18 years								
	n	%	n	%	n	%	n	%
never attended	97	33.1	96	31.4	44	36.4	5	26.3
still attending	109	37.2	69	22.5	29	24.0	6	31.6
left school	87	29.7	141	46.1	48	39.7	8	42.1
Total	293	100	306	100	121	100	19	100

Table 5.13 School grade completed

Grade completed (age >= 5)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Standard 8 or less	784	85.2	7747	85.5	8531	85.4
Form 1-4	122	13.3	1236	13.6	1358	13.6
Higher education	14	1.5	83	0.9	97	1.0
Total	920	100	9066	100	9986	100

Table 5.13 shows some similarities between those who had in fact attended school. In the sample of individuals 5 years and older the pattern of highest grade or level achieved is very similar among those with and without disabilities. This same pattern was repeated by geographical region and gender, though, as would be expected, since fewer women attended school in the first place (see comment above) the proportion of women achieving each level of education was lower than that observed among men.

The most striking difference between the two groups with regards to education refers to the higher proportion of non school-attendeess among persons with disabilities.

A further indication of potential skewed distribution of (educational) resources between disabled and non-disabled were found in that a higher proportion of people with disabilities over 5 years of age has no written language abilities (61.1% versus 50.5% among the non-disabled population) ($\chi^2 = 53.3$, $df = 1$, $p < 0.001$).

As above, the same pattern was confirmed in a gender analysis: among those with disabilities, 45.7% of males and 31.8% of females over the age of 5 years have writing skills, compared to 54.4% of males and 44.9% of females without disabilities. Regardless of disability status these figures are high but the contrasts between both disabled/non-disabled and males/females cannot be taken lightly.

Table 5.14 Languages written

Languages written (age \geq 5)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
None	815	61.1	5277	50.5	6092	51.7
One or more	519	38.9	5175	49.5	5694	48.3
Total	1334	100	10452	100	11786	100

Regionally, among those in the north 54.8% of those with disabilities had writing skills compared to 61.1% of those without disabilities. In the Central region the figures were

42.6% and 50.2% and in the south 34.1% of those with disabilities and 46.7% of those without disabilities had writing skills.

EMPLOYMENT AND SKILLS

Table 5.15 Unemployment

Work status (age 15 – 65)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Currently working returning to work	364	42.3	3014	46.7	3378	46.2
Not currently working	496	57.7	3437	53.2	3933	53.8
Total	860	100	6451	100	7311	100

Table 5.15 illustrates the degree of employment/unemployment among persons between the economically active ages of 15 – 65 years. According to the data presented here, it appears that unemployment is currently very high in Malawi: about 54%. Though the difference between those with and without disabilities does not appear to be large, a significantly higher proportion of people with disabilities (57.7%) is currently not working than among people without disabilities (53.2%) ($\chi^2 = 5.9$, $df = 1$, $p = 0.015$).

It is of importance to note that the high unemployment figures reported here may be explained by differences in the questions

that are used to elicit data on employment. The results produced here refer to formal employment (with an employer) or contractual employment including seasonal labour and not self-employment or work at home.

Similar patterns of unemployment were observed across all three regions. Unemployment among disabled and non-disabled respectively in the Northern Region was 63% and 52%, in the Central Region 56% and 54% and in the South 57% and 53%. Only the difference observed in the North (highest among those with disabilities) was statistically significant. Furthermore, when examining men and women separately, statistically significant differences were observed only among males between disabled and non-disabled (unemployment 47% and 41% respectively). Women, however, were more often unemployed than were men; among those with disabilities: 68% unemployed women versus 47% unemployed men ($\chi^2 = 39.3$, $df = 1$, $p = 0.001$); and among those without disabilities: 64% unemployed women and 41% unemployed men ($\chi^2 = 331.1$, $df = 1$, $p < 0.001$).

SKILLS

It was however shown that among the same group of potentially economically active persons 15 – 65 years of age, 41.2% ($n = 354$) of those with disabilities had acquired some skill, compared to slightly fewer, 38.7% ($n = 2489$) of the non-disabled ($\chi^2 = 2.07$, $df = 1$, NS). This is most likely a reflection of what is offered to children/persons with disability, i.e. skills training is (more) common in the special education

services for persons with disabilities. The same pattern was observed in all three regions, though in this case, differences observed in the Central Region were statistically significant. No significant gender differences were observed with respect to disability and possession of skills, though again significantly more males than females had acquired some form of skill.

Table 5.16 Skills

Skills (age 15 - 65)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Yes, formal	49	5.7	294	4.6	343	4.7
Yes, informal	305	35.5	2195	34.1	2500	34.3
No	505	58.8	3949	61.3	4454	61.0
Total	859	100	6438	100	7297	100

As may be expected, more persons with skills (formally or informally trained) are employed as compared to persons without skills (68% versus 32%). Among persons with disabilities, 63% (n = 223) of individuals with skills are employed, as compared to 28% (n = 140) of individuals without skills ($\chi^2 = 106.1$, df = 1, p < 0.001). In the non-disabled group the figures were, 68% (n = 1703) of individuals with skills being employed, as compared to 33% (n = 1301) of individuals without skills ($\chi^2 = 772.0$, df = 1, p < 0.001).

Among the 3378 individuals who said they were currently working or returning to work, 2857 (84.6%) gave their mean monthly salary. There was a statistically significant difference in mean monthly salary between those with and without disabilities (disabled: 2413 MWK, non-disabled: 3305 MWK), ($t = 3.3$, $df = 456$, $p = 0.001$). Significant results were observed in the Central region. Trends in the other two regions were in the same direction but failed to reach statistical significance.

Table 5.17 Monthly salary

	Disabled	Non-disabled	
Mean monthly salary	MWK	MWK	p
Northern	2324	2772	N.S.
Central	1927	3168	< 0.001
Southern	2746	3530	N.S.
Total	2413	3305	0.001

As may have been expected, women's monthly salaries were lower than men's in both groups. Among those without disabilities, women's mean salaries were 2267 MWK versus 3992 MWK for men ($p < 0.001$). Among those with disabilities women's mean salaries were 1905 MWK compared to 2718 MWK for men ($p = NS$).

5.1.2 Comparing households

In the preceding section, the grounds for comparison were *individuals* with and without disabilities in all households. In this section we will look at differences between *households* with and without a disabled family member as determined through the screening process. (Households having a disabled family member identified *after* the screening process are *not* included here.) First we present a regional distribution of households included in the survey.

Table 5.18 Regional distribution of households

Region	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
Northern	182	12.0	178	11.6	360	11.8
Central	568	37.3	577	37.5	1145	37.4
Southern	771	50.7	782	50.9	1553	50.8
Total	1521	100	1537	100	3058	100

EMPLOYMENT

Table 5.19 Employment

Is someone in the household working?	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
No	275	18.1	207	13.5	482	15.8
Yes	1246	81.9	1330	86.5	2576	84.2
Total	1521	100	1537	100	3058	100

Significantly more households with one or more disabled family members have no one employed (18.1%) as compared to the non-disabled households (13.5%) ($\chi^2 = 12.3$, $df = 1$, $p < 0.001$).

Regionally the pattern was the same. In the Northern region 10.4% of households with disabled members had no one working versus 7.9% in non-disabled households ($p = NS$); in the Central Region the corresponding figures were 21% and 17% ($p = NS$); while in the South we found 17.8% of 'disabled' households with no one employed versus 12.1% of non-disabled households ($p = 0.002$).

(Caution: These figures should not be interpreted as employment rates.)

Household income and expenses were measured in MWK (Malawian Kwacha, 1 USD = 107.51 MWK, 01.06.04).

Table 5.20 Household income and expenses

Household income - good month						
	Disabled HH		Non-disabled HH		Total	
	n	%	n	%	n	%
none	18	1.3	10	0.7	28	1.0
<1000	443	31.4	336	23.4	779	27.4
1000-2999	479	34.0	503	35.0	982	34.5
3000-8999	352	25.0	413	28.7	765	26.9
>=9000	118	8.4	175	12.2	293	10.3
Total	1410	100	1437	100	2847	100

$$\chi^2 = 33.3, df = 4, p < 0.001$$

Household income - bad month						
	Disabled HH		Non-disabled HH		Total	
	n	%	n	%	n	%
none	61	4.4	38	2.7	99	3.5
<1000	800	57.2	712	50.0	1512	53.6
1000-2999	296	21.2	345	24.2	641	22.7
3000-8999	180	12.9	220	15.5	400	14.2
>=9000	62	4.4	108	7.6	170	6.0
Total	1399	100	1423	100	2822	100

$$\chi^2 = 30.5, df = 4, p < 0.001$$

Table 5.20 .../continued

Household expenses						
	Disabled HH		Non-disabled HH		Total	
	n	%	n	%	n	%
none	22	1.6	16	1.1	38	1.4
<1000	645	46.4	557	39.3	1202	42.8
1000-2999	434	31.2	489	34.5	923	32.9
3000-8999	249	17.9	300	21.2	549	19.6
>=9000	39	2.8	55	3.9	94	3.3
Total	1389	100	1417	100	2806	100

$$\chi^2 = 17.8, df = 4, p = 0.001$$

In the questionnaire, income and expenses were recorded both as exact amounts and in the form of categories (above) for those who did not want to disclose the exact amounts. For the purposes of analysis, exact Kwacha amounts were re-coded into categories in order to expand the response percent. Results are presented in this form. Being aware that in many households income may fluctuate seasonally (for example dependent on the sale of farm produce), we asked, in addition, for information to reflect income and expenses during a good month and a bad month. Results are presented for both.

As is expected the number of households in the lower income categories is higher in bad months. A total of 807 households (28.4%) have monthly incomes under 1000 MWK in a good month and this increases to 1611 households (57.1%) in a bad

month. Many households are dependent upon incomes that are unstable. Furthermore, it appears from the results presented in Table 5.20 that households with disabled members have in general lower income, less expenses regardless of seasonal fluctuations than households without disabled members. (There are higher percentages in the lower income/expense categories for households with disabled household members than households without.) In all cases these differences are statistically significant (see Table 5.20). By and large, the same pattern is consistent when the data are analysed regionally.

A list of 40 different household possessions was prepared and participants could indicate the items possessed in their household. The list covers a wide range of possessions that may be included in either a rural or urban household. The number and type of possessions in a household will be dependent on its location (rural or urban) as well as its economic status. In this instance we chose to only assess the number of possessions according to the 'disability status' of the household. The maximum number of possessions recorded was 29 and the mean number of possessions for the entire sample was 10.2 items.

Households with a disabled family member have, on average, slightly fewer possessions (10.0) as compared to households without disabled members (10.4). This apparently slight difference is statistically significant ($t = 2.6$, $df = 3044$, $p = 0.009$), but more importantly, these relatively low numbers

are a reflection of the level of living standards in Malawi in general.

Fewer disabled households stated that salaried work was the primary source of income – 22% versus 26% - and this reflects the fact that fewer households with disabled family members had someone working (see above). Other main sources of income did not reveal any appreciable difference between the two types of households: for example, cash cropping 21% in each type of household and informal business 24% and 28%. More disabled households (7%) received their family income through remittances received (including subsidies and disability pensions) than did households without a disabled family member (3.5%).

A family's housing situation was, in part, classified according to type of floor (mud, concrete/cement, wood, other), roof (wood, corrugated iron sheets, grass/leaves thatch, tiles/shingles, paper thatched, other), windows (none, paper/wood, glass, cloth/sacks, reeds, zidina, other), walls (wattle & daub, corrugated iron, grass/leaves, bricks, compacted earth, concrete, other) and number of bedrooms. None of these housing characteristics showed any particular difference with respect to type of household (disabled/non disabled).

Table 5.21 Housing ownership

Ownership	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
Rented	117	7.8	152	10.0	269	8.9
Owner occupied	1290	85.5	1240	81.3	2530	83.4
Rent free, not owner occupied	37	2.5	48	3.1	85	2.8
Provided by employer (gov't)	38	2.5	47	3.1	85	2.8
Provided by employer (private)	20	1.3	34	2.2	54	1.8
Other	7	0.5	5	0.3	12	0.4
Total	1509	100	1526	100	3035	100

It is further shown in Table 5.21 that there are hardly any differences between the two types of households with respect to housing ownership. These similarities in housing structure and ownership illustrate the comparability of the two samples and reflect the chosen methodology of selecting a control household as one neighbouring a household having a disabled family member.

Five questions asked specifically about different aspects of housing infrastructure. These were: main source of water, energy source for cooking, energy source for lighting, type of toilet used by the household, and method of refuse/rubbish

removal. Each of these five questions had different response categories that were coded in an order of descending quality:

Main source of water:

1. piped water inside,
2. piped water outside (on property),
3. piped water outside property,
4. public pipe/tap,
5. borehole,
6. protected well,
7. unprotected well,
8. natural source

Energy sources for cooking or lighting:

1. electricity
2. paraffin/gas/solar
3. wood/charcoal/coal
4. dung/grass etc.
5. none

Type of toilet facility:

1. flush toilet (owned)
2. flush toilet (shared)
3. communal toilet
4. san plat (vip)
5. pit latrine
6. bucket/pan
7. bush/other

Refuse/rubbish removal:

1. communal dump (municipality collects)
2. communal dump (household responsibility)
3. own rubbish pit/burn/use on land
4. own rubbish pit (cover up)
5. own rubbish pit (uncovered)
6. dropped at specified place
7. no provision for waste removal

These individual characteristics of housing standard were ranked according to degree of hygiene or level of technical implementation (in decreasing order from best to worst) i.e. higher score reflects a lower standard. A composite score was devised by adding the above 5 elements into a scale to define housing standard with a possible range from 5 (best standard) to 32 (worst standard). For the 3030 (99.5%) of households that had data recorded for all 5 variables the range was from 5 to 29, mean 19.3 (SD 3.3).

Standards, as defined above, were similar in each of the three regions.

The mean difference between households with a disabled and those without was 19.4 and 19.1 respectively ($p = 0.022$), indicating that, with respect to the five indices included, and despite the similarities in housing situation described above, households with disabled family members, on average, did have a lower standard than did households without a disabled family member.

Another indication of household standard may be derived from availability and access to different forms of communication and information. The questionnaire requested data on the availability of telephone, radio, television, Internet, banking facilities, newspaper and post office. Each of these was coded as:

1. own/use regularly
2. have access to
3. have no access to

As above, a composite score was devised by adding the above 7 elements into a scale to define standard with respect to information access. This scale had a possible range from 7 (full access/availability) to 21 (no access/availability), again higher score reflects a lower level of accessibility. For the 1952 (64%) of households that had data recorded for all 7 variables, the range was 7 to 21, mean 16.9 (SD 2.8).

Access to information, as defined above, was significantly greater in the Northern Region (mean 16.3) than in either the Central Region (mean 17.2) or the South (mean 16.9) ($F = 9.87$, $df = 2/1949$, $p < 0.001$). The mean difference between households with a disabled and those without was 17.1 and 16.7 respectively ($p = 0.001$) indicating that, with respect to the seven information elements included, households with disabled family members, on average, had less access to information than did households without a disabled family member.

Finally, the questionnaire addressed two issues that were more directly related to the health of the household; namely the burden of death and disease experienced.

Households were asked whether any household members had passed away during the past 12 months and they two types of households responded similarly: 13.4% of disabled households and 12.3% of non-disabled households answered positively (difference not statistically significant). An assessment by cause of death also showed no significant differences between the two types of households.

Households were asked whether any household member had been chronically ill during the past 12 months and 41% of households with a disabled family member responded yes compared to 35% of those without disabled family members ($\chi^2 = 10.2$, $df = 1$, $p = 0.001$). That is, in general, the burden of disease is higher in households with disabled family members. Since chronic, incapacitating illness may be included among disabling conditions this finding may not be so surprising and this is further supported when assessing the type of illnesses experienced among households. Most illnesses were experienced to the same degree in both types of households: cancer, tuberculosis, malaria, diarrhoea, malnutrition, measles, pneumonia, heart disease, high blood pressure and HIV/AIDS. However, disabled households claimed to have more instances of "other diseases" than non-disabled households.

5.2 Disability study

Of the 1579 individuals identified as having a disability during the first phase of the survey (Living conditions survey), a total of 1574 (99.7%) responded to the detailed disability survey. In 43% of the cases the person with the disability responded themselves, whereas proxy reporters answered in the remaining 57%.

Table 5.22 Age profile of person with disability

Age group in years	Male		Female		Total	
	n	%	n	%	n	%
0-5	70	9.1	65	8.8	135	9.0
6-10	95	12.3	83	11.3	178	11.8
11-20	137	17.8	131	17.8	268	17.8
21-30	113	14.7	105	14.3	218	14.5
31-40	84	10.9	68	9.3	152	10.1
41-50	58	7.5	67	9.1	125	8.3
51-60	76	9.9	86	11.7	162	10.8
61+	137	17.8	130	17.7	267	17.7
Total	770	100	735	100	1505	100

The age range for the group of disabled was from 0 to 96 years. Mean age was 34 years (males: 33.5 years, females: 34.5 years), and median age was 29 years. Gender distribution in this sub-sample was 51% men and 49% women. No significant age/gender associations were observed.

No significant gender differences were observed among the three geographical regions sampled; however, those with disabilities among the sampled population in the Southern region were significantly older (mean age 37.1 years) than in

Central region (31.1 years) but not significantly older than in the Northern region (34.1 years).

Table 5.23 Distribution of the type of main disability by gender

Type of disability	Male		Female		Total	
	n	%	n	%	n	%
Seeing	154	21.9	168	24.2	322	23.0
Hearing	96	13.7	124	17.8	220	15.7
Communication*	24	3.4	21	3.0	45	3.2
Physical	323	46.0	279	40.1	602	43.1
Intellectual/ emotional	87	12.4	74	10.6	161	11.5
Old age	3	0.4	6	0.9	9	0.6
Other†	15	2.1	23	3.3	38	2.7
Total	702	100	695	100	1397	100

*includes: dumb, stammering and tongue-tied

†includes: goitre, bent back, itching, immature waist, deformed face

Respondents were asked to describe their disability in their own words, and the major disability described was coded. Overall just over 43% of coded disabilities were classified as physical. These include minor and major physical disabilities (including paralysis) and 42% reported some sensory impairment (seeing, hearing and communication). Intellectual disabilities, learning disorders, and emotional disabilities accounted for about 11% of reported disabilities. No significant gender difference was observed.

Table 5.24 Cause of disability

Cause of disability	n	%
Natural/from birth	271	17.2
Physical Illness	760	48.3
Mental illness	51	3.2
Violence	10	0.6
Accident	166	10.6
Animal Related	15	1.0
Witchcraft	60	3.8
Alcohol and drug abuse	4	0.3
Other	235	14.9
Total	1572	100

When asked about the type and cause of the disability, the respondent's own opinion was recorded. No attempt was made to acquire a medical verification of either type or cause of disability. Table 5.24 shows that the main recorded causes of disability are: physical illness (48.3%), congenital (17.2%) and accidents (14.9%). Almost 15% report other causes that include electrification (shock), dehydration, surgery, hard labour, environmental factors, foreign bodies and dizziness. Of interest is the 3.8% who reported that witchcraft was the cause of their disability.

Table 5.25 Age at onset of disability

	n	%
From birth	336	23.0
1-5	374	25.6
6-10	152	10.4
11-20	156	10.7
21-30	97	6.6
31-40	84	5.7
41-50	78	5.3
51-60	86	5.9
61+	99	6.8
Total	1462	100
Missing	112	
Total	1574	

Apart from the 336 individuals (23%) who here reported age of onset as birth, 682 or 46.7% were disabled as children or young adults (age less than or equal to 20 years). 25.6% claimed that they had acquired their disability between birth and the age of 6. (Caution: numbers in the preceding two tables differ slightly with respect to congenital disabilities - "from birth" - due to differences in coding of questions and subjective interpretations.)

An attempt was made to record a respondent's awareness of the different services that are currently available in the country and at the same time determine whether they are in need of these same services and if they had received them.

Table 5.26 Which of the services, if any, are you aware of and have ever needed/received?

Type of service	aware of service		need service		received service	
	n	%*	n	%*	n	%**
Health services	1326	84.2	1312	83.4	800	61.0
Traditional healer	1328	84.4	908	57.7	542	59.7
Medical rehabilitation	949	60.3	938	59.6	223	23.8
Counselling for parent/family	750	47.6	795	50.5	155	19.5
Educational services	899	57.1	691	43.9	140	20.3
Counselling for disabled	725	46.1	830	52.7	89	10.7
Assistive device services	1189	75.5	1025	65.1	183	17.9
Welfare services	910	57.8	1086	69.0	54	5.0
Vocational training	938	59.6	708	45.0	40	5.6

* percentage of total number disabled (n = 1574)

** percentage of those claiming they needed the service

With the exception of counselling services (both for parents/family and for the disabled themselves) well over half (50%) of the sample were aware of the existence of the services. The expressed need for services was in many cases of almost the same magnitude as their awareness; however, fewer expressed a need for:

- traditional healers (awareness:need = 84%:58%)
- educational services (awareness:need = 57%:44%)
- vocational training (awareness:need = 60%:45%)

The relatively low expressed need for traditional healer may indicate that in this particular setting, modern medical and health services are more in demand. The latter two discrepancies are likely due to the fact that educational and vocational services are age related.

Interestingly, more individuals expressed a need for counselling services for the person with a disability (awareness:need = 46%:53%) and to a slightly lesser degree, counselling services for parents/family (awareness:need = 48%:51%) than were aware of the service. That is, even though someone was not aware that the service was available they had expressed a need for it.

More strikingly however, was the gap observed between the expressed need for services and the actual acquisition of that service. For each of the services listed in the table, fewer actually received it than had expressed a need for it. Among the most noticeable shortcomings were, for example, welfare services and vocational training – only 5.0% and 5.6% of those who expressed a need for these services had actually received them. Other services including assistive device services, counselling services for both individuals with disabilities and their families, educational and medical

rehabilitation services were received by less than 25% of those who needed them. On a brighter note, over 61% of those who expressed a need for health services had in fact received them – something that indicates that if priorities are made they can be met.

Table 5.27 Gap analysis (services not received) by type of disability

	Total Gap	Type of disability			
		Sensory	Physical	Mental/ emotional	Age/ other
Health services	39.0	40.0	38.8	37.9	39.2
Traditional healer	40.3	46.2	39.0	26.1	46.9
Medical rehabilitation	76.2	83.3	68.8	77.7	82.4
Counselling for parent/family	80.5	83.6	78.5	76.5	85.3
Educational services	79.7	77.2	81.4	82.1	76.2
Counselling for disabled	89.3	91.5	85.7	92.7	96.7
Assistive device services	82.1	86.0	74.8	100.0	96.8
Welfare services	95.0	95.7	93.5	97.7	95.0
Vocational training	94.4	95.8	92.4	95.9	100.0

In the table above we present an analysis of the gap between services needed and received (here presented as services not received) according to self-reported type of disability. In

general variation by type of disability is small – but it is worth noting that the recorded gap in medical rehabilitation services for those with physical disabilities, while still high at about 70%, was smaller than for those with other types of disabilities. This may indicate that scant services are prioritized for those with physical disabilities. Also the gap experienced by those with mental/emotional disabilities for traditional healers was lower indicating that this particular group more often receives the services of the traditional healer they claim to need.

Most of the persons with disabilities surveyed expressed a need for some service. However 65 individuals (4.1%) expressed no need for any of the services listed (or other services not listed). Only 5.7% or 90 individuals expressed a need for a single service, the majority requiring multiple services and 44.5% listing 5 services or more.

Respondents were asked to assess the services they had received in the past. Their experiences are listed in the table below.

Table 5.28 Assessment of services received

Experience with service	Number experiencing problem	Number responding	%
Too expensive	200	664	30.1
Too far/no transport	193	654	29.5
Not helping anymore	528	896	58.9
Reached level of functioning	28	454	6.2
Service no longer available	87	600	14.5
Not satisfied with service	363	735	49.4
Communication barrier	20	568	3.5
Other	44	250	17.6

Of those who responded to these individual questions, almost 60% found that the service they were using was no longer helpful and 50% claimed that they were not satisfied with the service provided. 200 of 664 (about 30%) claimed that services were too expensive, and the same amount, 193 of 654 or about 30%, said that the service was inaccessible (too far/no transport). 14.5% claimed that the service they were using was no longer available and a few, 6.2% said that they had reached the level of functioning they had set as a goal. A few respondents pointed to a communication barrier or language problem between the users and provider of the service.

EDUCATION

Of those sampled 61.4% (n = 966) were *disabled before 18 years of age*. These were asked about their education and schooling experiences. Table 5.29 on the following page shows the different types of schools attended by those eligible for school according to age. At each level of education, for those who attended school, the majority went to mainstream or regular school. Of particular note is the relatively high proportion (35.5%) of those who did not attend primary school, though eligible (according to age). As might be expected, school attendance declines with age and this is confirmed in that 86.2% of disabled children 15 years and over, (i.e. eligible for high school) did not attend, and over 95% of those over 17 did not attend tertiary or vocational school.

Very few actually reported being refused entry to a regular or special school because of their disability. It is, none the less, worth noting that 7 individuals were refused entry to regular pre-school, 55 were refused regular primary school and 1 was refused regular high school. In addition, 8 individuals were refused entry into a special class or school because of their disability.

Of those who were disabled prior to 18 and were, at the time of the interview, 15 years or older, only 7 (1.3%) said that they had studied as far as they had planned and half (50.6%) said that they had not. In addition, among this group, almost half (47.3%) claimed that their education had not helped them to find employment.

Table 5.29 Type of school attended

What type of school do, or did, you mainly attend?

	Mainstream/ regular school		Special school		Special class in regular school		Did not go to school (NA)		TOTAL	
	n	%	n	%	n	%	n	%	N	%
Pre-school/early childhood (all ages)	65	6.9	8	0.8	3	0.3	870	92.0	946	100
Primary school (age >= 5 years)	535	62.5	11	1.3	4	0.5	306	35.7	856	100
High school (age >= 15 years)	66	12.4	3	0.6	1	0.2	463	86.9	533	100
Tertiary (age >= 18 years)	6	1.3	3	0.7	1	0.2	449	97.8	459	100
Vocational training (age >= 18 years)	7	1.5	8	1.7	1	0.2	442	96.5	458	100

EMPLOYMENT

Asked whether they were currently working or returning to work, those 15 years and older (n=1115) replied:

- 317 (28.4%) currently working,
- 195 (17.5%) not currently working, but have been previously employed,
- 531 (47.6%) never been employed
- 72 (6.5%) housewife

Among those who had never been employed, 46 reported that they were still attending school – leaving at total of 485 individuals aged 15 years or older who had never been employed. Among the 195 who were not currently working but had been previously employed, 25% had terminated employment because of their disability.

ACCESSIBILITY

Accessibility at home is shown in Table 5.30. Generally accessibility in the home does not seem to be a problem. It can be claimed from the data presented here that the majority of those who have the room or facility mentioned also have access to that room or facility. Inaccessibility can only be seen to be a problem (albeit small) in the Central region with respect to the kitchen (8.1% inaccessible) and dining room (8.2% inaccessible) and in the Northern region with respect to toilet facilities (9.9% inaccessible). Few households have separate dining rooms (overall over 61% do not have them)

and almost 18% claim not to have separate living rooms. Overall 8% of households do not have separate toilet facilities (see column "have none").

Table 5.30 Accessibility at home

Room/ facility	Accessible		Not accessible		Have none		Total n
	n	% of those with room/facility	n	% of those with room/facility	N	% of Total	
Kitchen	1297	92.5	105	7.5	163	10.4	1565
Northern	184	94.4	11	5.6	8	3.9	203
Central	476	91.9	42	8.1	46	8.2	564
Southern	637	92.5	52	7.5	109	13.7	798
Bedroom	1404	95.7	63	4.3	98	6.3	1565
Northern	194	96.5	7	3.5	2	1.0	203
Central	488	94.6	28	5.4	48	8.5	564
Southern	722	96.3	28	3.7	48	6.0	798
Living room	1235	96.3	48	3.7	278	17.8	1561
Northern	175	97.2	5	2.8	23	11.3	203
Central	425	95.1	22	4.9	115	20.5	562
Southern	635	96.8	21	3.2	140	17.6	796
Dining room	562	93.5	39	6.5	952	61.3	1553
Northern	108	93.9	7	6.1	87	43.1	202
Central	169	91.8	15	8.2	373	66.8	557
Southern	285	94.4	17	5.6	492	62.0	794
Toilet	1319	92.3	110	7.7	134	8.6	1563
Northern	164	90.1	18	9.9	22	10.8	204
Central	476	93.2	35	6.8	52	9.2	563
Southern	679	92.3	57	7.7	60	7.5	796

Table 5.31 Accessibility from home

	Accessible		Not accessible		Never go		None available		Total N
	n	%	n	%	n	%	n	%	
Place of worship	1185	75.3	135	8.6	238	15.1	16	1.0	1574
Health care clinic	1117	71.0	171	10.9	230	14.6	56	3.6	1574
Hospital	1083	68.8	205	13.0	193	12.3	93	5.9	1574
Public transport	1074	68.2	162	10.3	257	16.3	81	5.1	1574
Shops	1049	67.0	144	9.2	370	23.6	3	0.2	1566
Sports facilities	723	45.9	93	5.9	733	46.6	25	1.6	1574
Post office	498	31.6	152	9.7	874	55.5	50	3.2	1574
Magistrates office	432	27.4	129	8.2	966	61.4	47	3.0	1574
Recreational facilities	422	26.8	87	5.5	928	59.0	137	8.7	1574
Workplace	400	25.7	49	3.1	1066	68.5	42	2.7	1557
Police station	396	25.2	145	9.2	992	63.0	41	2.6	1574
School	319	20.5	62	4.0	1147	73.6	31	2.0	1559
Bank	139	8.8	61	3.9	1025	65.1	349	22.2	1574
Hotels	52	3.3	40	2.5	797	50.6	685	43.5	1574

Apart from places of worship, primary health care clinics and hospitals are among the most accessible facilities a person may need to visit, with almost 70% of respondents stating that these facilities are accessible. It seems unfortunate that schools find a place lower on the list (about 20% classify schools as accessible) and workplaces fare only slightly better (about 25% state that the workplace is accessible).

TECHNICAL AIDES AND ASSISTIVE DEVICES

Respondents were also asked if they used assistive devices – 304 of 1550 (17.1%) responded “yes”. More than one type of device could be registered. Interestingly, significantly more men (25%) than women (14%) claimed to use an assistive device ($\chi^2 = 28.2$, $df = 1$, $p < 0.001$). There appeared also to be some regional differences in use of assistive technology (of all types): in the Northern Region 26% of those identified as having a disability used assistive devices compared to 21% in the Central Region and 17% in the South ($\chi^2 = 8.3$, $df = 2$, $p = 0.016$).

Table 5.32 Type of assistive devices in use

Type of device	Examples	N	% (of those who use devices n=304)
Personal mobility	Wheelchairs, crutches, walking sticks, white cane, guide dog, standing frame	214	70.4
Information	Eye glasses, hearing aids, magnifying glass, enlarge print, Braille	57	18.8
Personal care & protection	Special fasteners, bath & shower seats, toilet seat raiser, commode chairs, safety rails, eating aids	10	3.3
Communication	Sign language interpreter, fax, TTY, portable writer, PC	33	10.9
For handling products and goods	Gripping tongs, aids for opening containers, tools for gardening	5	1.6
Household items	Flashing light on doorbell, amplified telephone, vibrating alarm clock	3	1.0
Computer assistive technology	Keyboard for the blind	4	1.3

Asked whether their device was in good working condition 64% answered "yes".

19% of those using assistive devices had acquired their device from government health services, 9% through NGOs, 34% privately and the rest through other sources. When asked who maintains or repairs the device, 30% replied that they took responsibility for the device themselves, 6.5% stated that the government undertook maintenance and reparations, while 8.3% relied on their families for support in these matters and 38.3% claimed that their device either were not maintained or that they couldn't afford maintenance/repairs.

35% of those using personal mobility devices had received at least some guidance or instructions for use. Among users of information devices and communication devices instructions were received by 63.5% and 37.5% respectively. Overall, less than a third (28.2%) had received information or help on how to use their device.

Table 5.33 Assistance needed in daily life activities (N = 1574)

Do you need help with:	Yes		Sometimes		combined	% responding yes/sometimes				
	n	%	n	%		%	North	Central	South	male
emotional support	721	45.8	294	18.7	64.5	61.8	63.9	65.5	63.7	66.3
finances	712	45.2	187	11.9	57.1	58.3	56.2	57.4	49.3	63.3
shopping	548	34.8	319	20.3	55.1	71.1	51.9	53.2	52.4	57.8
cooking	614	34.6	200	12.7	51.7	68.6	46.8	50.9	48.4	44.3
transport	584	37.1	216	13.7	50.8	55.9	55.1	46.6	45.4	44.0
studying*	137	30.9	63	14.2	45.1	38.6	60.2	34.9	43.1	44.3
moving around	183	11.6	251	15.9	27.6	38.7	33.2	30.7	24.6	29.4
bathing	250	15.9	103	6.5	22.4	27.9	22.6	20.9	21.7	21.6
dressng	195	12.4	105	6.7	19.1	21.0	17.3	19.8	17.9	19.0
toileting	117	7.4	50	3.2	10.6	11.8	10.6	10.3	9.7	10.3
feeding	82	5.2	50	3.2	8.4	9.8	7.8	8.5	8.7	8.0

*N = 444 Those who answered "not applicable" excluded.

The results presented in the table above are obviously dependent on numerous factors; among them the sex and age of the person with disabilities and the severity of the disability. With one exception, these figures are based on the entire sample of 1574 people with disabilities. Help with studying was perhaps the most age dependent – and approximately 70% of the sample said that this was not applicable. This question was therefore based on those who responded yes, yes sometimes or no (n = 444).

We chose to examine the difference in needs based on the region and gender and determine whether these dependencies impacted on perceived needs for assistance. In certain instances, particularly shopping and cooking more help was needed in the Northern Region more assistance was required for studying among those in the Central region. These, and other differences appearing in the table, may be due to random variations in the data, or they may be due to real situations that are present in these regions. More detailed research must be conducted in order to better explain these associations. For example, the results may reflect the difference between the complexities associated with urban dwelling as opposed to rural life.

In typically male dominated societies one may expect men to need more help with what may be considered as female chores such as shopping or cooking while women would need more

help with finances or require more emotional support. In the data presented here, the only large difference was observed for assistance required with finances; 63.3% of women needing assistance compared to 49.3% of men ($\chi^2 = 27.9$, $df = 1$, $p < 0.001$). Otherwise, with respect to gender there do not appear to be any differences that stand out for one sex over the other. The small differences observed in the data were non-significant.

Table 5.34 Involvement in family life

Involvement in family life	N	% yes	% sometimes	% no
Do you go with the family to events?	1487	72.6	12.5	14.9
Do you feel involved and part of the family?	1475	95.7	2.5	1.8
Does the family involve you in conversations?	1442	80.4	8.6	11.0
Does the family help you with daily activities?	1474	79.0	17.82	3.8
...for those over 15 years				
Are you consulted about making household decisions?	1040	73.4	10.3	16.3
Do you make important decisions about your life?	1102	62.3	6.9	30.8
Are you married or involved in a relationship?	1099	47.9		52.1
Does your spouse/partner have a disability?	547	9.1		90.9
Do you have children?	1097	69.3		30.7

While the majority of those questioned were involved at least sometimes in different aspects of family life, it is worth noting

that as many as 15% are not included in family events, 11% are not involved in conversations and 2% do not feel a part of the family. Furthermore, of those 15 years and older, 16.3% are not consulted about making household decisions and 30.8% are not part of the decision-making process concerning their own lives. Certain of these findings may be related to the type or severity of the disability in question, but it is, nonetheless, worth noting the results. No significant gender difference appeared with respect to involvement and integration in family life. However, it appeared that men (57.3%) in this sample were, more often than women (39.7%), married or in a relationship ($\chi^2 = 31.5$, $df = 1$, $p < .001$).

DEFINING SEVERITY:

Measures of Activity limitations and Participation restrictions

A good deal of information has been collected during the survey that could be used to define the severity of a person's situation with respect to their disability. We have seen so far an assessment of an individual's needs for services, and an assessment of daily activities that a person may need help in accomplishing (see Table 5.26 – need for services, and Table 5.33 – need for assistance). Based on the items listed in these tables, simple scores can be constructed by adding up the number of services one needs or the number of daily tasks one needs help in accomplishing, to indicate the severity of a person's situation. The more services needed : the worse off

that person is; or the more help needed in doing daily tasks : the worse off that person is.

In addition, we present a matrix to map an individual's activity limitations and participation restrictions according to 9 different domains: sensory experiences, basic learning & applying knowledge, communication, mobility, self care, domestic life, interpersonal behaviours, major life areas and community, social & civic life. (The complete matrix is shown in Appendix 3. For more background concerning activity limitations and participation restrictions see Section 4.5.1). For each of the 44 activities under these 9 domains the degree to which an individual is capable of carrying out that activity without assistance (activity limitations) is 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 (participation restrictions) is also recorded on a scale from (0) no problem to (4) unable to perform the activity. By adding up an individual's responses to each of the 44 items a single activity limitation score and a single participation restriction score is developed. In addition 9 sub-scales are constructed by adding the individual items under each of the 9 domains.

The characteristics of these 13 scales are presented in the table below.

Table 5.35 Characteristics of the severity scales.

Severity scales	Maximum possible score	n	maximum score in study	mean
Daily activity help score	11	1574	11	3.8
Service needs score	10	1574	10	5.3
Activity limitations	176	1414	155	29.2
Participation restrictions	176	1402	154	23.0
Sensory experiences	8	1571	8	1.2
Learning & knowledge	20	1555	20	3.2
Communication	16	1487	16	1.9
Mobility	44	1524	40	6.7
Self care	20	1571	20	1.4
Domestic life	20	1557	20	3.4
Interpersonal behaviours	20	1555	20	1.7
Major life areas	12	1523	12	1.4
Community & social life	16	1562	16	2.2

These 13 scales are then assessed by type of disability as illustrated in Table 5.36 below.

Table 5.36 Mean scores on severity scales by type of disability.

Severity scales	N	Type of disability			
		sensory	physical/ mobility	mental/ emotional	age/other
		653	667	189	57
Daily activity help score		3.3	4.0	5.0	3.7
Service needs score		5.2	5.3	5.3	5.1
Activity limitations		24.8	31.1	39.1	26.9
Participation restrictions		19.3	24.3	32.7	19.0

.../continued

Table 5.36 .../continued

Severity scales	N	Type of disability			
		sensory	physical/ mobility	mental/ emotional	age/other
		653	667	189	57
Sensory experiences	2.3	0.4	0.4	0.4	1.0
Learning & knowledge	3.4	2.2	6.7	1.3	1.3
Communication	2.7	0.9	3.4	1.3	1.3
Mobility	2.9	11.0	4.2	9.6	9.6
Self care	0.8	1.7	2.5	1.1	1.1
Domestic life	2.5	3.7	5.2	3.5	3.5
Interpersonal behaviours	1.8	1.0	4.3	1.0	1.0
Major life areas	1.2	1.2	2.4	0.6	0.6
Community & social life	1.9	2.1	3.2	1.7	1.7

Looking first at the score based on assistance required for daily activities, while it may appear that there is little variation in mean scores based on type of disability, the observed differences are in fact not insignificant ($F = 25.2$, $df = 3/1562$, $p < 0.001$). In particular, the mean score for mental/emotional disabilities is significantly higher than for the other types of disabilities. No significant differences are observed in the score based on service needs.

Furthermore, the results of an analysis of variance in Table 5.36 shows that both the activity limitation score and the participation restriction score behave similarly with respect to type of disability – but they measure two separate aspects of living with a disability. The activity limitation score is a measure of an individual's capacity to carry out everyday activities without any form of assistance and the participation restriction score measures an individual's ability to participate

in the same activities in their current environment (home, work or school). Mean scores for mental/emotional are, on both scales, significantly higher than scores for all other types of disabilities (Activity limitations: $F = 17.0$, $df = 3/1402$, $p < 0.001$; Participation restrictions: $F = 17.1$, $df = 3/1391$, $p < 0.001$). Generally speaking this indicates that individuals with mental/emotional disabilities experience significantly greater difficulty in performing day to day activities without assistance and are to a greater extent unable to perform daily activities in their current environment. In other words they experience more barriers to full participation in society.

It is interesting to note that participation restriction scores are lower than activity limitation scores. This is an indication that a person's capacity to perform activities in general – without assistance – (i.e. their activity limitations) is more severe than their actual performance (participation restrictions). This is perhaps as might be expected, and is a reflection that many people with disabilities will have had at least some opportunity to adapt to their environments through for example the assistance of others or the use of different forms of assistive technology.

(The 9 individual domains of the activity limitation scale are presented in the table for information and will not be further commented on here.)

A breakdown of the comparison by gender and region is presented in Table 5.37. Gender analyses revealed a significantly higher daily activity help score for women ($t = 3.0$, $df = 1399$, $p = 0.001$) and a marginal, though significantly higher service needs score for men. Activity limitation and participation restriction scores were similar for both sexes. There are several aspects of the analyses that can be highlighted here. For one, we see an association between gender and the need for help with daily activities. Apart from more assistance needed by women in financial matters, we did not find individual gendered-related associations with daily activities (see Table 5.33). However, we see here that women express, overall, a need for more assistance in performing daily activities than do men. On the other hand, we do not find the same relationship with respect to need for services. (While it is shown that men require more services, the difference is not overwhelmingly significant.) Moreover, with respect to activity limitations and participation restrictions, the finding of no gender association is important because these scores are not meant to differentiate between genders – but to classify according to ability to carry out or perform activities under different circumstances and irrespective of gender.

Turning to region, we find that in the Northern Region severity scores based on help in daily activities and services needed were significantly higher than in the other two regions; indicating that people with disabilities in the North more often require help in performing daily activities and more often

require services. The activity limitation score was significantly lower in the Southern region and highest in the North. The same pattern was present in the participation restriction score, though here the differences were not large enough to reach statistical significance.

In order for these particular findings to be more meaningful or to be able to draw conclusions that reflect regional differences, an in-depth analysis based on regional characteristics (similarities and differences) would be required. Unfortunately, we are unable to present that type of analysis at this time and that type of breakdown will be the subject of later publications.

Table 5.37 Mean scores on severity scales by gender and region.

Severity scales:	Gender			Region				
	Male n=704	Female n=700	p value	Northern n=204	Central n=566	Southern n=804	F statistic	p value
daily activity help score	3.6	4.0	0.001	4.4	3.9	3.6	7.03	=0.001
service needs score	5.4	5.1	0.039	6.1	5.3	5.1	11.2	<0.001
activity limitations	29.4	29.3	NS	35.2	31.9	26.5	10.7	<0.001
participation restrictions	23.2	23.1	NS	26.4	23.9	21.9		NS

Respondents were asked to respond to a few questions about their general health and well-being. They were asked:

- How would you describe your general physical health (things like: sickness, illness, injury, disease etc.) on a scale from 1 (poor) to 4 (very good)?
- How would you describe your general mental health (things like: anxiety, depression, fear, fatigue, tiredness, hopelessness etc.) on a scale from 1 (poor) to 4 (very good)?

Responses to these two questions were also assessed with respect to the four disability severity scales in the table below.

We find that, apart from the service needs scale, there is a clear and significant association between self-evaluated physical and mental health and the other measures of disability severity: the better the health of an individual the lower the score. In other words, and not unexpectedly, physical and mental health and disability are correlated. Those who experience poor physical or mental health also experience higher levels of need for assistance in carrying out daily activities as well as more activity limitations and participation restrictions.

With respect to the need for services, highest scores are found among those having the best of physical health and high scores are also reported for those in very good or very poor mental health. It appears that services are to a greater degree associated with more extreme health conditions.

Table 5.38 Mean scores on severity scales by Self-evaluation of Physical and Mental Health

Physical health	poor	Not very good	good	Very good	F statistic	p value
	n=129	n=584	n=483	n=260		
Severity scales:	mean	mean	mean	mean		
Daily activity help score	5.0	3.9	3.7	3.2	16.8	<0.001
Service needs score	5.2	5.0	5.3	5.8	6.5	<0.001
Activity limitations	45.1	33.1	25.3	21.9	31.3	<0.001
Participation restrictions	37.4	26.0	20.2	15.8	28.8	<0.001

Mental health	poor	Not very good	good	Very good	F statistic	p value
	n=121	n=509	n=597	n=316		
Severity scales:	mean	mean	mean	mean		
Daily activity help score	4.9	4.2	3.6	3.1	22.0	<0.001
Service needs score	5.5	5.1	5.1	5.7	3.6	0.013
Activity limitations	52.7	34.0	24.3	21.9	59.9	<0.001
Participation restrictions	42.9	27.2	19.5	14.8	55.8	<0.001

Four of the severity scores were then assessed with respect to certain indicators of living conditions. We looked first at school attendance (re-coded: NO = never attended, and YES = currently attending/left school). Mean scores based on assistance required for daily activities, activity limitation and participation restriction, showed that those who never had attended school scored higher (needed more help, and experienced greater activity limitations and restrictions to full participation in society). The difference in mean service needs score was not significantly different for the two groups.

We then addressed work situation for those 15 years of age or higher (re-coded: currently employed, previously employed, never been employed and housewife). Looking first at the mean scores based on assistance required for daily activities, we found that those currently employed scored significantly lower than the other three groups. This may be interpreted as those who are able to work need less help in their daily activities; or alternatively, that those who need more help are less able to acquire a job. That housewives score high on the daily activity help score may indicate that this group of disabled women need more help than normal to accomplish their duties. Recall that while we did not find any specific gender dependency when looking at the elements in this scale (see Table 5.37), many of the items can be identified with a particular group or gender. The service needs score on the other hand is more independent (both with respect to gender

(above) and social state and this is reflected in the similarity among the groups based on work situation.

The scores based on activity limitations and participation restrictions again showed similar patterns. Both showed that those who are currently employed scored lowest: this again can be seen as a validation of the two scores in that the ability to work represents a situation of less activity limitation and greater social participation. Here also, housewives score lower than those not currently or never employed again reflecting to a degree their level of activity and social participation. The two groups defined as not currently or never employed score highest on both scales; perhaps a reflection of the barriers they face in general.

Interestingly, mean scores based on needs for services were somewhat higher among both the groups currently attending school, those currently employed and housewives. This finding may be explained by the simple fact that those who are more active in society, either through education or employment meet more obstacles and have more requirements for services than those who do not.

We see here that certain indicators of living conditions seem to be associated with these measures of disability severity, in particular activity limitations and participation restrictions.

Table 5.39 Mean severity scores on severity scales by indicators of living conditions.

School attendance (age >= 5)	never attended n = 427	currently attending or finished school n = 795				
Severity scales:	mean	mean	t statistic		p value	
Daily activity help score	4.1	3.5	4.1		<0.001	
Service needs score	5.1	5.4	-1.8		NS	
Activity limitations	34.4	25.5	5.5		<0.001	
Participation restrictions	29.0	19.2	6.4		<0.001	

Work situation (age >= 15)	Currently employed n=320	Previously employed n=195	Never been employed n=534	Housewife n=72		
Severity scales:	mean	mean	mean	mean	F statistic	p value
Daily activity help score	2.7	3.6	4.1	3.9	25.8	<0.001
Service needs score	5.4	5.2	5.1	5.8	1.96	NS
Activity limitations	20.5	35.5	34.0	28.9	22.4	<0.001
Participation restrictions	14.9	27.8	27.9	17.8	24.8	<0.001

TOWARDS A REVISED UNDERSTANDING OF DISABILITY

By altering society's notion of disability – from the concept of physical impairment to one based on activities and participation – it is hoped to shift also the focus of demands set by society while at the same time empowering people with disabilities. Research on living conditions among people with disabilities must ultimately be directed towards the integration, participation and enfranchisement of people with disabilities into society.

Social movements associated with changes in paradigms can influence research, and visa versa, as is evident in the table below whereby the increased emphasis on the role of the environment (both physical and social) has affects on the subject matter under study – in this case persons with disabilities.

Table 5.40 Contrasting disability paradigms for research

<i>Characteristic</i>	<i>Old paradigm</i>	<i>New paradigm</i>
Definition of disability	An individual is limited by his or her impairment.	An individual with an impairment requires an accommodation to perform functions required to carry out life activities
Strategy to address disability	Fix the individual, correct the deficit	Remove the barriers, create access through accommodation and universal design, promote wellness and health
Method to address disability	Provision of medical, psychological, or vocational rehabilitation services	Provision of supporters (e.g. assistive technology, personal assistance services, job coach)
Source of intervention	Professionals, clinicians, and other rehabilitation service providers	Peers, mainstream service providers, consumer information services
Entitlements	Eligibility for benefits based on severity of impairment	Eligibility of accommodation seen as a civil right
Role of people with disabilities	Object of intervention, patient, beneficiary, research subject	Consumer or customer, empowered peer, research participant, decision maker
Domain of disability	A medical "problem" involving accessibility, accommodations and equity	A socio-environmental issue

Source: Brown 2001 : derived from DeJong and O'Day (1999)

Several of these paradigm 'shifts' have been realised through the research we have conducted in Malawi. Most notably

perhaps the definition of disability used in the survey and the role of people with disabilities in the research process, where half of the supervisors and research assistants employed were people with disabilities.

As mentioned previously (see in particular Chapter 3), international standards are important for setting guidelines and establishing routines as much as for quantifying differences among nations, cultures and societies. But, at the same time, it is important not to become too restricted by these same international standards. A certain degree of flexibility must be allowed to be incorporated into these constructs. We are ultimately left with the following challenge: to acknowledge and integrate cultural anomalies and differences when making and interpreting international comparisons.

From the data analysis perspective, the research challenge, we believe, lies in a shift in the dependent variable from a dichotomous outcome measure (disabled, not disabled) to a continuous measure of activity limitation/participation restriction – mirroring the range of disability we see in society. The figures below present such scenarios. A relatively small sub-sample of those in our sample who were identified as NOT having a disability (405 individuals) was asked to complete the activities and participation matrix. Their responses are illustrated in two figures below.

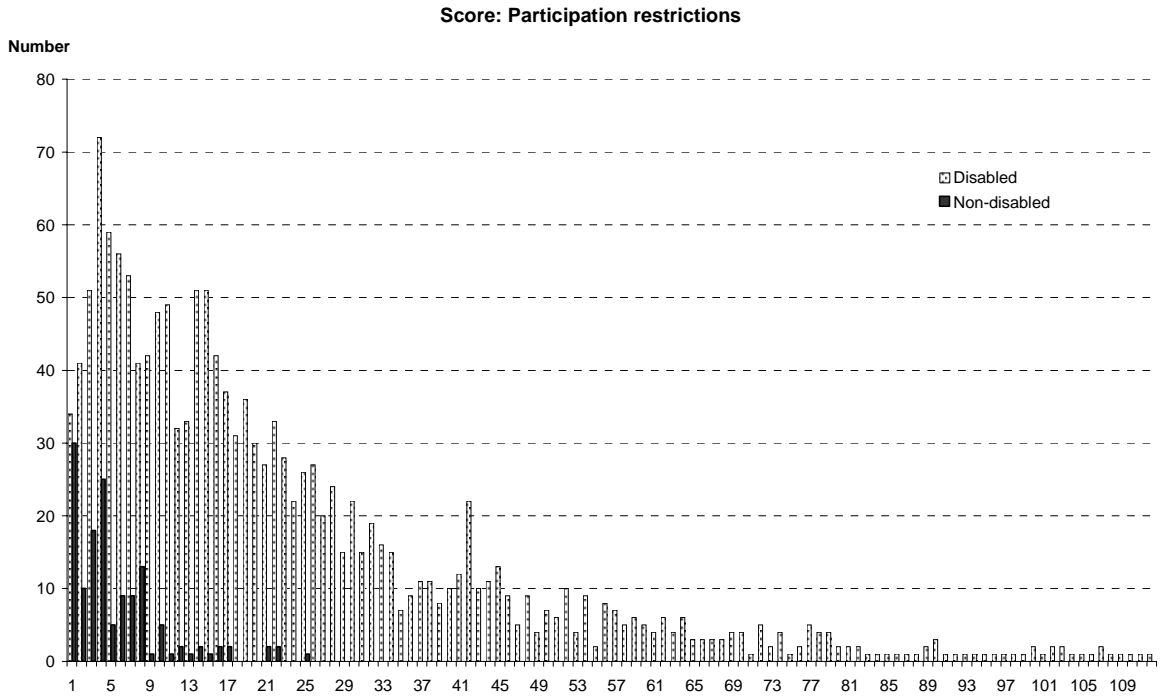


Figure 5.1 Participation restrictions among people with and without disabilities

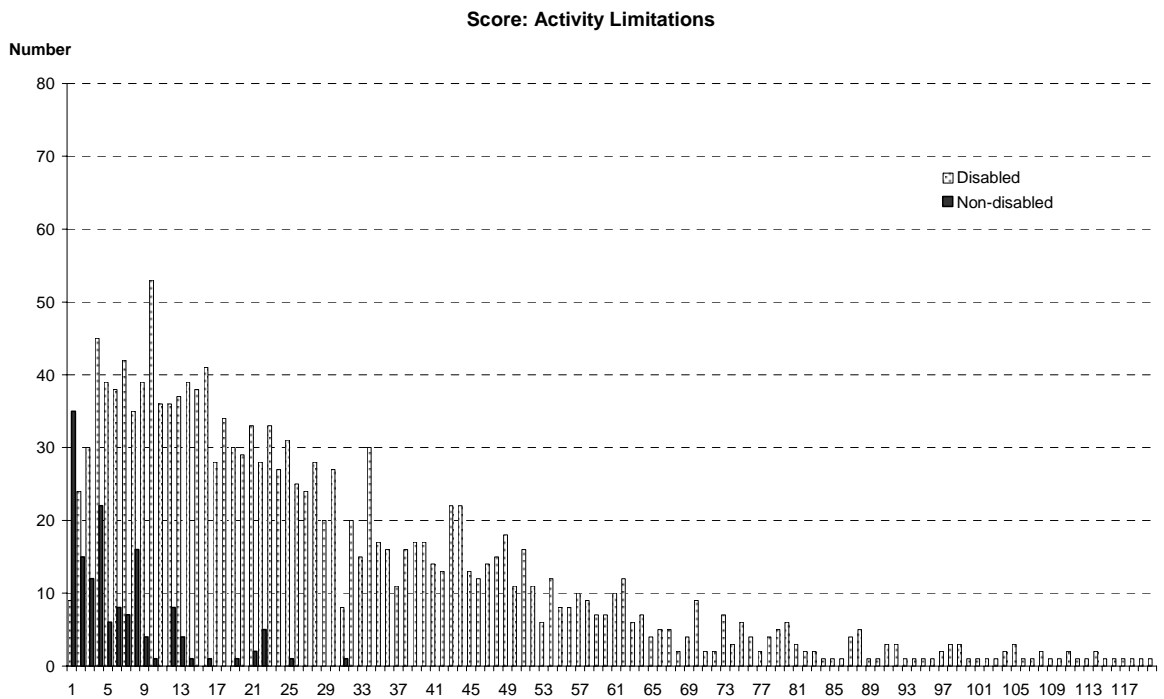


Figure 5.2 Activity limitations among people with and without disabilities

The above figures clearly indicate that there is an overlap; that is, even people without disabilities live with certain limitations in their daily life activities and restrictions in their ability to participate in all levels of social interaction and some people with disabilities are able to function in society with little or no problem. While only 10 (0.6%) of those with disabilities scored 0 on the activity limitation score compared to 63% of those without disabilities, it is important to stress that some of those people identified with disabilities are functioning well in society. Using the same reasoning we found that 37% of those individuals who were identified as not having a disability experienced at least a little problem in their capability to perform certain daily life activities.

Also the range of scores on both activity limitations and participation restrictions reflects the diversity of disability in society – and clearly indicates that being disabled is not a singular, two-dimensional phenomenon but rather a complex process that deserves to be understood as part of the human condition and not as something that represents a deviation from the norm.

Finally, these measures of activity limitations and participation restrictions 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. We have in this

research attempted to meet these challenges through the development of a matrix, based on the concepts inherent in the ICF and have thus taken a step in the direction of a new paradigm, defining a new concept. Disability research can no longer afford to be restricted to counting impairments, handicaps or even people with disabilities – but using a better definition to identify a population based on activity limitations and participation restrictions and ensure that they are enfranchised.

6 Discussion

(AH Eide)

A baseline for data on living conditions among people with activity limitations and restrictions in social participation in Malawi has been established with the finalisation of this study. In addition to establishing a foundation or framework for depicting current living conditions, this study also offers the opportunity for both monitoring the situation over time and assessing the impact of policies through later studies. Furthermore, a unique database has been created allowing for the comparison of living conditions between people with and without disabilities and between households with and without disabled family members. Finally, this study adds to a growing body of information on living conditions among people with disabilities currently being collected in the southern African region. In the future, with data from Namibia (2003), Zimbabwe (2003), Malawi (2004) and Zambia (planned in 2006) there will be possibilities not only for making national or regional comparisons but to share experiences and build capacity in the region to improve living conditions in general and specifically among people with disabilities. Due to different contexts, timeframes and other factors, it is however not the absolute figures that are of interest for the comparison, but rather patterns in the data material.

In this study of living conditions among people with disabilities in Malawi, it was determined that the results obtained should be compared to living conditions in the general population. To this end, a control sample was selected from among the non-disabled population. Since no earlier studies of living standards have been carried out in Malawi, in addition to addressing the situation of people with disabilities, this study also provides a first set of data on living conditions that may be useful for monitoring the general standard of living in the country. This is evidently of interest in a situation where the Malawian economy is struggling and the entire population is affected.

Socio-demographic differences between the two types of households (those with and without disabled family members) were similar among the three studies that have so far been completed (Namibia, Zimbabwe and Malawi). Households with disabled members are larger; mean age of family members is higher; as is the number of children. This may be the result of certain strategies in the households to cope with the situations they encounter. As there are few, if any, services to support families and individuals with disabilities living at home; practical, economic and other problems will have to be solved within the household itself. Further studies are however necessary to reveal coping mechanisms at the household level.

It is a main finding that households with disabled members and individuals with disabilities score lower on a number of

indicators of level of living conditions as compared to households without disabled members or non-disabled individuals. The study thus confirms what was previously expected. Largely, the observed differences in levels of living conditions in the data material from Malawi substantiate the pattern that was first observed in the Namibian and Zimbabwean studies.

The disability component of the survey revealed a relatively even distribution of disabled across age categories. This is very similar to the pattern in Namibia, but deviates from the situation in more developed countries where age is closely and positively associated with disability. This could be due entirely to the particular age profile in Malawi with large proportion of the population being 20 years or less. Bearing in mind however that onset of disability for many of those surveyed is early in life, and that the causes of disability to a large extent are congenital or illness related, the results presented here indicate that age plays a less significant role as cause of disability. Also, the information gathered through this survey is self-reported, and it is not unlikely that responses are influenced by the prevailing understanding of disability and activity limitations and that functional problems related to "normal" ageing are not included in most peoples' conception of disability.

The age profile in the data material implies that disabilities that are to a large extent prevented in more developed countries (through peri-natal and neo-natal health services) are not prevented in Malawi. This should be seen as a serious challenge to the health services in the country, and in less developed countries generally.

Somewhat surprising, it was found that need for emotional support surpassed economic support when asking for what type of assistance that was needed in daily life. Again, this finding replicates the results from the two previous studies. This is important to bear in mind when developing services for people with disabilities, as emotional needs will more readily be neglected when there is so much to do in terms of practical help. Developing mental health support programs at the local community level is very relevant in this regard.

With regards to role in the household, results indicate that the large majority of individuals with disabilities are not overly affected by their disability status. Although further studies will be needed to confirm this, the results here may at least be taken as an indication of positive attitudes towards disabled individuals within their families.

It appears from the study that services (schools, devices, etc.) have what may be termed a "physical disability bias" in that people with sensory or intellectual impairments are worse off

on some important indicators. This information should be of importance in the planning of future services for people with disabilities in Malawi.

Large gaps were observed in the provision of particular services like vocational training, welfare services, assistive devices and counselling. These four services also scored lowest in the Namibian and the Zimbabwean studies. These figures express, to a degree, the frustration of people with disabilities in the community as well as an opportunity for service providers to improve services and accessibility, and not in the least to policy makers to review priorities in the area of service provision. Health services, on the other hand, are apparently available to the large majority of those with disabilities. With respect to the previous comment on health services, this may be an indication that the problem is not availability (quantity) but rather the type or quality of health service offered.

Of particular note is the proportion of individuals with activity limitations who, though eligible, did not attend primary school. It is a situation worthy of attention that more than one third of those surveyed never attended school, and the results clearly indicate that those with disabilities are worse off than non-disabled. A comparison of language abilities amplifies this imbalance. The study thus indicates that access to education is restricted for many individuals with disabilities. As mentioned above, this is particularly a problem for those with sensory and

mental impairments. This information is potentially useful information in planning future educational services.

The level of unemployment in Malawi is high, and even higher among those with disabilities compared to those without. This finding corresponds to the results from the Namibian study. It is further suggested that the results presented here may indicate that having a disabled family member also affects job opportunities for those non-disabled in a household. For example, the complexities of supporting a family member with a disability, in particular the practical obstacles and solutions a family faces and the responsibilities met in terms of care and assistance needed by the disabled family member affect the level of living of the entire household.

The study has documented that the same pattern of differences between those with and without disabilities is found among both men and women. It has however also been demonstrated that women score lower on many of the important indicators of level of living conditions. There are also socio-demographic gender differences that indicate the need for a gender perspective on disability policy in the country.

The research presented in this report offers new insight into the disablement process in the form of a newly conceived matrix based on activity limitations and restrictions in social participation. These constructs are in their developmental

infancy; however, they offer a broader conceptualisation of disability, beyond the dated definition based on physical impairments. By categorizing an individual's capability to accomplish daily activity tasks without the use of assistance, and their social participation within these same activity parameters or domains, in their normal environment, we have been able to re-define disability according to these broader concepts – and to shift focus from impairment to social participation and inclusion.

An analysis of activity limitations and participation restrictions confirms that individuals with mental/emotional impairments experience activity limitations and restrictions in social participation to a greater degree than do others. This is a further indication that there is a need for distinguishing between different types of disability when developing disability policies or specific measures to address inadequacies.

Matrix-derived scores based on activity limitations and participation restrictions, together with scores derived from needs for services and help needed in accomplishing daily tasks were analysed with respect to two living conditions indicators – school attendance and work situation.

Results indicated that those who never had attended school or were unemployed had significantly higher activity limitation and participation restriction scores (and scored higher on help

needed in daily tasks) than did their counterparts who had attended, or currently were attending school, or those who were currently working.

These results confirm the strength of the matrix scores in differentiating between individuals based on their needs rather than their limitations.

Even the healthiest in a population will experience some limitations to their activities or restrictions in their social participation, and it is of particular interest even among a small group of individuals identified as not disabled in this study positive scores indicating some limitations/restrictions were registered on the activity and participation scales. This finding is in accordance with a revised perception of disability (ICF) and thus to the intentions underlying the two scales. Activity limitations and restrictions in social participation are constructs that have been liberated from an impairment-based understanding of disability and should reflect more universal concepts relevant for the daily life of all individuals in a population.

A further indication or confirmation of the social complexity of disability is seen in the fact that mean scores based on needs for services were somewhat lower among the same groups described above (those who never attended school and unemployed). This finding points to the importance of environment in the disablement process: those who are more

active in society, either through employment or education, meet more obstacles in their expanded environments and thus experience more requirements for services than those whose activities and participation are restricted.

7 Conclusions

(ME Loeb)

This study in Malawi has produced unique data on living conditions among people with disabilities and a control sample of people without disabilities. Virtually no other information of this kind has been produced in, or for, Malawi. This survey thus represents a first possibility to study different aspects of the lives of people with disabilities in the country and it also provides a basis for monitoring the situation in the future. Following similar studies in Namibia and Zimbabwe and one to follow in Zambia, the Malawian study is also an important link in an initiative to establish a Regional database.

As with the other published studies in Namibia and Zimbabwe, the main finding in this study from Malawi is that there are systematic differences between those with and without disabilities, and between households with and without disabled family members. Individuals with disabilities and their households are worse off on many important indicators of living conditions.

Furthermore, we have demonstrated that by dissociating physical impairment from an individual's limitations and ability

as measured in terms of physical, mental, emotional and social parameters, the focus of disability can be redirected towards improving an individual's social situation through removing or reducing barriers that limit activities and restrict social participation, and thus facilitating their incorporation as fully active members of society.

The situation among people with disabilities that are highlighted in this report must, however, stand among the other basic human and societal problems that are faced by Malawian society today; and a clear challenge will be to advocate and instigate for improvements in the living conditions of people with disabilities in the current context of a low-income country in Southern Africa.

To this end, it is hoped that this study and other similar studies can contribute to highlight systematic discrimination, inform the public, authorities and the disabled themselves about the situation, and thus create a consciousness that is necessary for action.

It is recommended that the results from this study be considered, together with other relevant sources, as a basis for defining the situation for people with disabilities in Malawi and agreeing upon a path for the future. Setting priorities and developing specific measures will be necessary in order to achieve tangible improvements. A database on living

conditions such as the one presented here is in this regard a potentially important tool for organizations of people with disabilities and relevant authorities.

8 References

Altman BM. (2001) Disability Definitions, Models, Classification Schemes and Applications. In: *Handbook of Disability Studies*. Albrecht GL, Seelman KD, Bury M (ed). Sage Publications Inc, London

Bradley IE and South JB (1981) Introductory Statistics for Business and Economics

Brown SC. (2001) Methodological Paradigms That Shape Disability Research. In: *Handbook of Disability Studies*. Albrecht GL, Seelman KD, Bury M (ed). Sage Publications Inc, London

Concha ME, Lorenzo T. (1993) The prevalence of disability in a rural area of South Africa, with special reference to moving disability. *SA Journal of Occupational Therapy*, November, 6-15.

CCO (2002) Census 2002, Zimbabwe. Preliminary Results. Harare, Central Census Office.

Devlieger PJ. (1995) From Self-help to Charity in Disability Service: the Jairos Jiri Association in Zimbabwe. *Disability & Society*, 10, 1, 39 – 48.

Devlieger PJ. (1998) Vocational rehabilitation in Zimbabwe: a socio-historical analysis. *Journal of Vocational Rehabilitation*, 11, 21 – 31.

Eide AH, Loeb ME. Screening for disability in low-income countries (in preparation).

Eide AH, Loeb ME, Van Rooy G, Fuller B. (2001a) Living conditions among people with disabilities in Namibia. Pilot study. SINTEF Report STF78 A014502. Oslo, SINTEF Unimed NIS Health & Rehabilitation.

Eide AH, Loeb ME, Nhiwatiwa S, Muderedzi J. (2001b) Living conditions among people with disabilities in Zimbabwe. Pilot study. SINTEF Report STF78 A014503. Oslo, SINTEF Unimed NIS Health & Rehabilitation.

EIDE AH, VAN ROOY G, LOEB ME. Living Conditions among people with disabilities in Namibia. A National, Representative Study. STF78 A034503, April 2003, SINTEF Unimed Health & Rehabilitation, Oslo.

EIDE AH, NHIWATHIWA S, MUDEREZI J, LOEB ME. Living Conditions among people with activity limitations in Zimbabwe. A representative regional study. STF78 A034512, November 2003, SINTEF Unimed Health & Rehabilitation, Oslo.

Heiberg M, Øvensen G. (1993) Palestinian Society in Gaza, West Bank and Arab Jerusalem. A Survey of Living Conditions. FAFO Report no. 151. Oslo, FAFO.

Hem KG, Eide AH. (1998) Sakker akterut, tross forbedringer. *Samfunnsspeilet*, 2, 20 – 25.

Kadzamira EC, Nthara K, Kholowa F. (2004). *Financing primary education for all – Malawi*. Sussex: Institute for Development Studies.

Katzenellenbogen G, Joubert G, Rendall K, Coetzee T. (1995) Methodological issues in a disablement prevalence study: Mitchells Plain, South Africa. *Disability and Rehabilitation*, 7, 350 – 357.

Loeb ME, Eide AH. (2004) Exploring the living conditions among people with disabilities in southern areas of Africa. In: Exploring Disabled Peoples' Living Conditions. Tøssebro J (ed). Studentlitteratur, Lund, (in press).

Ministry of Health and Population (1995) *Health policy framework*
Lilongwe: MoH&P

Ministry of Health and Population (1999) *To the year 2020: a vision for the health sector in Malawi* Lilongwe: MoH&P

MLRR (1997) National Policy on Disability. Windhoek, Ministry of Lands, Resettlement and Rehabilitation.

MLSS (1982) Report on the National Disability Survey of Zimbabwe. Harare, Ministry of Labour and Social Services.

NPC – National Planning Commission (2000) Level of Living Conditions Survey. Windhoek, Planning Commission.

National Statistics Office (NSO) (1987) Survey of Handicapped Persons Malawi 1983. Zomba, Malawi: Government Printer.

National Statistical Office (1992) Demographic and Health Survey. Zomba: NSO

National Statistical Office (1998) Integrated Household Survey. Zomba: NSO

National Statistical Office (2001) Demographic and Health Survey. Zomba: NSO

ODP (1997) White Paper on an Integrated National Disability Strategy. Pretoria, Office of the Deputy President.

OMSPWD (2001) National Disability Policy (draft). Blantyre, Office of the Minister of State Responsible for Persons with Disabilities.

Schneider M, Claassens M, Kimmie Z, Morgan R, Naicker S, Roberts A, McLaren P. (1999) We also count! The extent of moderate and severe reported disability and the nature of disability experience in South Africa. Pretoria, Community Agency for Social Enquiry.

UNICEF (2002) *The state of the world's children 2002*.
<http://www.unicef.org/sowc02/>

United Nations (1990) *Statistics on Special Population Groups*, Series Y, No. 4 (United Nations publications, No. E.90.XVII.17). New York, United Nations.

United Nations (1993) *World Programme of Action Concerning Disabled Persons*. New York, United Nations.

United Nations (1994) *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. New York, United Nations.

United Nations (1996) *Manual for the Development of Statistical Information for Disability Programmes and Policies*. (United Nations publication. No. E.96.XVII.4). New York, United Nations.

United Nations Development Programme (1997) *Human Development Report 1997*. Oxford, Oxford University Press.

United Nations (2001) *Guidelines and Principles for the Development of Disability Statistics*. New York, United Nations.

United Nations (2003)
<http://unstats.un.org/unsd/demographic/sconcerns/disability/default.htm>.

United Nations (2003) *The collection and dissemination of statistics on disability at the United Nations Statistical Division: Proposals for the future*. New York, United Nations.

United Nations and Government of Malawi (1993) *Situation analysis of poverty in Malawi*. Lilongwe: UN and GoM.

WHO (1980) ICIDH. *International Classification of Disability and Health*. Geneva, World Health Organisation.

WHO (1981) *Disability prevention and rehabilitation. Report of the WHO expert committee on disability prevention and rehabilitation. Technical Report Series 668*. Geneva, World Health Organization.

WHO (2001) International Classification of Functioning, Disability and Health. Geneva, World Health Organisation.

Whyte SR, Ingstad B. (1998) Help for people with disabilities: do cultural differences matter? *World Health Forum*, 19, 1, 42-46.

9 Appendices

Appendix 1: Participants attending pre-study workshop:

Name*	Organisation
Mussa Chiwaula	Federation of Disability Organisations in Malawi (FEDOMA)
Daniel Dunga	FEDOMA
Towera Masiku	FEDOMA Trustee Chair
Julinana Mabangwe	FEDOMA
RachelKachaje	Southern African Federation of the Disabled (SAFOD)
Charles Khaula	Association of the Physically Disabled in Malawi
Levi Mihowa	Sue Ryder Foundation of Malawi
Cassim Gama	Malawi Union of the Blind
Glyphyns Machaka	Malawi Disability Sports Association
Mirriam Namanja	Parents of Disabled Children Association in Malawi
Grace Maseko	Feed the Children Malawi (formerly Cheshire Homes)
Venancio Wesley	Malawi National Association of the Deaf
Symon Katundu	Malawi National Association of the Deaf
Steven Msowoya	Malawi Council for the Handicapped
Gilbert Dairi	The Albino Association of Malawi
Ken Mdala	MACOHA (CBR)
Erick Mcheka	MACOHA (PRO)
Maria Kangere	Norwegian Association of the Disabled (NAD)
Torild Almnes	NAD – Advisor
Vanja Hellevik	Norwegian Association for Blind and Partly-sighted People (NBF), Oslo Norway
Augustin Sambola	NBF, Oslo Norway
Wellos A Kachingwe	Ministry Responsible for Persons with Disabilities
Rachel Plackett	Ministry Responsible for Persons with Disabilities
Immaculate Chamangwana	Ministry of Health

Simon Chisale	Ministry of Gender and Community Services
John Khozi	Ministry of Education, Science and Technology
Mcloyds Msasata	Ministry of Education, Science and Technology
Mulle Chikoko	Department for International Development
Dr. Alister Munthali	Centre for Social Research, University of Malawi
Sidon Konyani	Centre for Social Research, University of Malawi
Dr. Peter Mvula	Centre for Social Research, University of Malawi
Tove Kristiansen	Norwegian Federation of Organisations of Disabled People (FFO), Oslo Norway
Mitch Loeb	SINTEF Health Research, Oslo Norway
Dr. Arne H Eide	SINTEF Health Research, Oslo Norway

*We apologise for any names that may have been misspelled or any participants who may have been unintentionally omitted from the above list. The participation and contributions of all who attended were greatly appreciated.

Appendix 2: Data collection teams

1. Vincent Gondwe (Supervisor)
 - James Mhango
 - Mawombe Mfuno
 - Francis Saka
 - Joshua Chisambi
 - Kelvin Nawa

2. Tapiwa Nyasulu (Supervisor)
 - Devlin Manda
 - Eric Kaunda
 - Patrick Msukwa
 - Tinashe Saka

3. Pamela Chipungu (Supervisor)
 - Patrick Kastigu
 - Juma Mkandawire
 - Paul Dunga
 - Elizabeth Kaunjika
 - Innocent Helema

4. Phillip Rapozo (Supervisor)
 - George Mikana
 - Senzani Givinala
 - Elinat Longwe
 - Andrew Zulu

5. Paul Butao (Supervisor)
 - Stanley Azizi
 - Ngawina Chisala
 - Henry Mtema
 - George Matthews

6. Lyness Manduwa (Supervisor)
 - Mwanasi Chaima
 - Andrew Kachale
 - Francis Kamungu
 - George Makina

7. Maria Phalula (Supervisor)

- Janet Stima
- White Mwambo
- Agnes Matiki
- Kingsley Nalivata
- Chisomo Mangwiro

8. Maclean Chunda (Supervisor)

- Malizgani Gondwe
- McDonald Chitekwe
- Patrick Chikoti
- Peter Chiwerera
- Gezire Feza

9. Monice Kachinjika (Supervisor)

- Miriam Mwamadi
- Dambula Galeta
- Humphery Yesaya
- Juliet Matambo

10. Titus Ntonyo (Supervisor)

- Ernest Pelete
- Osman Mlumbe
- Chikondi Mangwiro
- Hays Mitha

APPENDIX 3: ACTIVITY AND PARTICIPATION MATRIX

ACTIVITIES & PARTICIPATION <u>Identification of person with disability:</u> Name: _____ Line No.: <input type="text"/> <input type="text"/>	Activity limitation (Capacity) 0 no difficulty 1 mild difficulty 2 moderate difficulty 3 severe difficulty 4 unable to carry out the activity 8 not applicable 9 not specified (level not known)	Participation restriction (Performance in current environment*) 0 no problem 1 mild problem 2 moderate problem 3 severe problem 4 complete problem (unable to perform) 8 not applicable 9 not specified (level not known)
	(1)	(2)
1a. SENSORY EXPERIENCES		
a. watching/looking		
b. listening/hearing		
1b. BASIC LEARNING & APPLYING KNOWLEDGE		
a. learning to read/write/count/calculate		
b. acquiring skills (manipulating tools, learning names)		
c. thinking		
d. reading/writing/counting/calculating		
e. solving problems		
2. COMMUNICATION		
a. understanding others (spoken, written or sign language)		
b. producing messages (spoken, written or sign language)		
c. communicating with others		
d. communicating using devices (phone/typewriter/computer/Braille)		
3. MOBILITY		
a. staying in one body position		
b. changing a body position (sitting/standing/bending/lying)		
c. transferring oneself (moving from one surface to another)		
d. lifting/carrying/moving/handling objects		
e. fine hand use (picking up/grasping/manipulating/releasing)		
f. hand & arm use pulling/pushing/reaching/throwing/catching		
g. walking		
h. moving around (crawling/climbing/running/jumping)		
i. moving around using equipment/assistive devices		
j. using transportation to move around as a passenger		
k. driving a vehicle (car/boat/bicycle/or riding an animal)		
4. SELF CARE		
a. washing oneself		
b. care of body parts, teeth, nails and hair		
c. toileting		
d. dressing and undressing		
e. eating and drinking		
5. DOMESTIC LIFE		
a. shopping (getting goods and services)		
b. preparing meals		
c. doing housework (washing/cleaning)		
d. taking care of personal objects (mending/repairing)		
e. taking care of others		

Appendix 3: ACTIVITIES & PARTICIPATION Matrix (Continued)

	Activity limitation	Participation restriction
6. INTERPERSONAL BEHAVIOURS		
a. making friends and maintaining friendships		
b. interacting with persons in authority		
c. interacting with strangers		
d. creating and maintaining family relationships		
e. creating and maintaining intimate relationships		
7. MAJOR LIFE AREAS		
a. going to school and studying (education)		
b. getting and keeping a job (work & employment)		
c. handling income and payments (economic life)		
8. COMMUNITY, SOCIAL AND CIVIC LIFE		
a. clubs/organisations (community life)		
b. recreation/leisure (sports/play/crafts/hobbies/arts/culture)		
c. religious/spiritual activities		
d. political life and citizenship		
9. OTHER (specify)		

**Your “current environment” is defined as where you spend most of your time: where you live, work, go to school or play.*

Environmental factors

- 1. FACILITATORS:** What makes it EASIER for you to participate? Think of things like products or devices, assistive technology, personal support, services, systems, policies, even attitudes – and tell me specifically what these might be. *(Write down what respondent says in their own words.)*

- 2. BARRIERS:** What makes it HARDER for you to participate? Think of things like products or devices, assistive technology, personal support, services, systems, policies, even attitudes – and tell me specifically what these might be. *(Write down what respondent says in their own words.)*

Appendix 4: Questions related to Activity Limitations and Participation Restrictions

Activity Limitations

1. How DIFFICULT it is for you to perform this activity WITHOUT ANY KIND OF ASSISTANCE AT ALL?

- 0 no difficulty
- 1 slight difficulty
- 2 moderate difficulty
- 3 severe difficulty
- 4 unable to carry out the activity

- 8 not applicable
- 9 not specified (level not known)

1. MUMAVUTIKA bwanji kuti muchite ntchito iyi
POPANDA THANDIZO

- 0 popanda chovuta
- 1 vuto laling'ono
- 2 vuto lapakatikati
- 3 vuto lalikulu kwambiri
- 4 satha kugwira ntchitoyi

- 8 sizikugwirizana
- 9 kuvutika kwake sikukudziwika

Participation Restrictions

2. Do you experience any PROBLEM(S) in performing this activity in your CURRENT ENVIRONMENT*?

- 0 no problem
- 1 mild problem
- 2 moderate problem
- 3 severe problem
- 4 complete problem (unable to perform)

- 8 not applicable
- 9 not specified (level not known)

*where you spend most of your time – where you live, work, go to school or play

2. mumatha bwanji kuchita nawo zinthu zina pamodzi ndi anthu ena M'MALO AMENE MUKUKHALA PAKADALI PANO

- 0 palibe vuto
- 1 vuto laling'ono
- 2 vuto lapakatikati
- 3 vuto lalikulu kwambiri
- 4 sangathe kugwira ntchitoyi

- 8 sizikugwirizana
- 9 kuvutika kwake sikukudziwika

Appendix 5: Summary of Household Screening and Prevalence

SUPERVISOR				# of	# of	# of		#disabled/ EA pop.*	District
District	District pop.	Traditional Authority	EA #	Control HH	Case HH	Disabled	population	Dist.pop.	prevalence
TITUS									
Blantyre	502053	Ndirande South Ward	38	379	46	46	1211	19070,6	
		Ndirande North Ward	9	315	18	18	1526	5922,0	
		Blantyre East Ward	2	81	7	10	2380	2109,5	
		Chigumula Ward	5	211	26	30	510	29532,5	
		Namiyango Ward	12	212	15	15	1307	5761,9	
		Soche West Ward	4	414	24	26	2517	5186,1	
		Likhubula Ward	21	417	18	20	1602	6267,8	
		South Lunzu Ward	14	380	18	19	1444	6606,0	
							10057,0	2,00	
Nsanje	194924	Ndamera	22	255	52	58	985	11477,8	
		Tengani	2	244	60	61	1007	11807,7	
		Malemia	1	172	30	33	728	8835,8	
							10707,1	5,49	
Chikwawa	356682	Lundu	802	324	26	29	1331	7771,4	
		Chapananga	47	313	46	49	981	17815,9	
		Ngabu	81	214	30	31	1161	9523,8	
		Ngabu	21	389	56	57	2183	9313,3	
		Mankhwira	20	325	54	57	1616	12581,0	
		kasisi	3	370	49	49	1779	9824,3	
							11138,3	3,12	
MARIA									
Phalombe	231990	Mkhumba	3	189	49	52	808	14930,0	
		Mkhumba	67	152	30	35	779	10423,2	
		Mkhumba	136	152	29	33	1231	6219,1	
		Nazombe	28	182	33	36	873	9566,6	
							10284,7	4,43	
Mulanje	428322	Chikumbu	58	183	35	37	1008	15722,1	
		Mabuka	47	201	22	26	850	13101,6	
		Mabuka	112	114	17	21	524	17165,6	
		Laston Njema	24	211	19	23	1153	8544,2	
		Juma	61	249	26	29	985	12610,5	
Mulanje (Titus)		Nkanda	84	368	39	40	1290	13281,3	

Mulanje (McLean)		Nkanda	17	184	30	30	817	15727,9	
								13736,2	3,21
Thyolo	458976	Bvumbwe	3	167	24	25	877	13083,7	
		Bvumbwe	18	145	15	19	1031	8458,3	
		Mchilamwera	13	242	26	30	1086	12678,9	
		Khwethemule	26	185	19	21	942	10231,9	
		Nsabwe	29	225	25	28	1201	10700,5	
		Changata	14	149	21	23	1112	9493,2	
		Chimaliro	21	294	61	64	1143	25699,4	
								12906,6	2,81
PAUL									
Lilongwe City	440471	Area 8	2	260	37	37	1271	12822,5	
		Area 21	19	221	41	41	1147	15744,8	
		Area 58	3	247	57	93	1442	28407,6	
		Area 49	8	161	38	40	1526	11545,8	
		Area 56	4	209	30	31	842	16216,9	
		Area 21	12	99	5	5	833	2643,9	
		Area 8	5	196	44	45	1256	15781,2	
								14737,5	3,35
Dedza	486682	Pemba	62	158	94	97	1021	46237,2	
		Kasumbu	17	213	82	88	1450	29536,6	
		Chilikumwendo	30	162	76	81	1101	35804,9	
		Tambala	16	203	37	42	1269	16107,7	
		Kaphuka	50	188	26	27	887	14814,4	
		Kachindamoto	33	216	86	94	1546	29591,3	
		Dedza Township	711	298	27	28	1554	8769,0	
								25837,3	5,31
TAPIWA									
Rumphi	128360	Chikulamayembe	22	48	20	23	308	9585,3	
		Mwankhunikira	4	78	27	29	1162	3203,5	
								6394,4	4,98
Nkhata Bay	164761	Malanda	9	99	76	82	984	13730,1	
		Malanda	3	127	75	82	1519	8894,3	
		Kabunduli	6	36	14	16	1396	1888,4	
								8170,9	4,96
Nkhota Kota	229460	Kanyenda	7	229	92	102	2179	10741,1	
		Kanyenda	803	314	53	57	1731	7555,9	

		Chiputula Ward	2	299	51	55	1674	2857,8	
		Jombo Ward	1	75	18	18	1333	1174,5	
								2016,1	2,32
Mzimba	524014	M'mbelwa	15	231	66	67	1770	19835,6	
		Mtwalo	13	304	90	90	1876	25139,3	
		Mtwalo	68	199	44	48	1525	16493,6	
		Chindi	8	269	56	56	1440	20378,3	
		Chindi	49	217	70	71	1681	22132,7	
		Mabulabo	15	191	71	76	1334	29853,9	
		Mpherembe	13	249	65	66	1732	19968,2	
								21971,6	4,19
McLEAN									
Zomba Municip.	65915	Zomba Central Ward	1	145	24	24	1425	1110,1	
Zomba Municip. (Monice)		Chikamveka Ward	1	206	62	62	1140	3584,9	
								2347,5	3,56
Chiradzulu	236050	Chiradzulu Boma	702	123	43	44	1191	8720,6	
		Mpama	33	185	31	31	870	8411,0	
		Likoswe	13	185	35	35	970	8517,3	
		Kadewere	32	167	34	34	691	11614,6	
		Likoswe	42	179	24	24	992	5710,9	
		Kadewere	68	157	29	29	665	10293,9	
		Nchema	1	198	35	35	1080	7649,8	
		Nkalo	24	174	44	44	684	15184,5	
								9512,8	4,03
Blantyre	307344	Kunthembwe	15	201	29	30	1097	8405,0	
		Kapeni	36	132	22	23	741	9539,7	
		Lundu	803	227	24	24	747	9874,5	
		Kuntaja	40	201	16	16	1087	4523,9	
		Somba	16	190	30	30	942	9788,0	
								8426,2	2,74
Mwanza	138015	Ngozi	1	100	15	15	640	3234,7	
		Kanduku	12	223	40	40	1159	4763,2	
								3999,0	2,90
LYNESS									
Ntcheu	370757	Goodson Ganya	6	268	99	100	1614	22971,3	
		Goodson Ganya	54	278	88	88	950	34343,8	
		Makwangwala	30	179	56	60	1215	18309,0	

		Kwataine	5	268	68	72	886	30129,2	
		Phambala	23	239	83	89	1039	31758,8	
Ntcheu (Paul)		Njolomole	10	213	26	28	1179	8805,1	
								24386,2	6,58
Balaka	253098	Msamala	30	179	57	64	1122	14437,0	
		Msamala	98	101	44	44	829	13433,4	
		Kalembo	74	293	85	87	1094	20127,5	
		Kalembo	12	197	37	37	715	13097,4	
								15273,8	6,03
Machinga	369614	Liwonde	33	215	58	59	1196	18233,5	
		Mlomba	6	202	46	46	1029	16523,1	
		Kawinga	64	196	45	45	1182	14071,6	
		Kawinga	2	259	45	47	1468	11833,7	
		Chikweo	802	232	45	47	1448	11997,1	
		Nyambi	27	252	47	47	1088	15966,8	
								14771,0	4,00
MONICE									
Zomba District	480746	Malemia	802	157	50	50	811	29639,1	
		Mwambo	13	195	71	71	919	37141,4	
		Mwambo	92	148	56	58	1103	25279,5	
		Mbiza	811	174	69	73	943	37215,8	
		Mbiza	25	236	67	71	957	35666,6	
		Mlumbe	79	146	42	43	1041	19857,9	
								30800,0	6,41
Mangochi	610239	Mponda	23	265	54	60	977	37476,3	
		Chimwala	12	291	77	81	1605	30797,1	
		Chimwala	84	267	71	75	1143	40041,9	
		Nankumba	58	130	49	56	943	36239,0	
		Namabvi	16	283	61	61	1089	34182,3	
		Chowe	62	196	64	67	942	43403,4	
		Jalasi	51	291	67	70	1186	36017,5	
		Katuli	907	145	49	58	994	35607,5	
		Mbwana Nyambi	56	277	89	95	1250	46378,2	
								37793,7	6,19
PHILIP									
Lilongwe	905889	Kabudula	66	193	19	19	1119	15381,5	
		Chiseka	802	170	4	4	1121	3232,4	

		Chitekwere	6	148	8	9	952	8564,1	
		Malili	36	233	23	24	1359	15998,0	
		Tsabango	11	400	18	18	1544	10560,9	
		Chadza	802	199	16	18	979	16655,8	
		Chiseka	72	242	15	15	1061	12807,1	
		Chimutu	9	135	11	11	796	12518,6	
		Mtema	3	233	13	13	1285	9164,6	
		Kalolo	85	137	38	38	1494	23041,4	
								12792,4	1,41
Mchinji	324941	Dambe	14	209	25	25	1400	5802,5	
		Nkanda	19	150	17	17	818	6753,1	
		Mduwa	7	254	12	12	1146	3402,5	
		Zulu	4	216	9	9	1256	2328,4	
		Mavwere	7	250	5	5	1265	1284,4	
								3914,2	1,20
MALAWI	9039869							377701,3	4,18