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REPORT

Living Conditions among People with Activity Limitations in Zambia

A National Representative Study

September 2006

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

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Norwegian Federation of Organisations of Disabled People

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ABSTRACT

This research report provides results from the study on living conditions among people with disabilities in Zambia. Comparisons are made between individuals with and without disabilities and also between households with and without a disabled family member.

Results obtained in Zambia are also compared to those obtained in earlier studies carried out in Namibia, Zimbabwe and Malawi.

The Zambian study was undertaken in 2005-2006.

KEYWORDS	ENGLISH	NORWEGIAN
GROUP 1	People with disabilities	
GROUP 2	Living conditions	
SELECTED BY AUTHOR	Activity limitations	
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This is a revised edition of the original Report on Living Conditions among People with Activity Limitations in Zambia published in September 2006.

Of particular note:

- Pages 74/75: the presentation of prevalence data has been appended.
- Table 5.28, page 130 has been revised. Numbers are the same, but percentages displayed are more in line with the interpretation of these data.
- Pages 162/163: the discussion of disability prevalence has been revised.
- A new Appendix 1 (referred to on page 74), page 179 has been added. (Other appendices appear in the same order as previously.)

PREFACE

(Alexander M. Phiri – Director General, SAFOD)

The Southern Africa Federation of the Disabled (SAFOD) is happy to be part of the study on the Living Conditions among People with Activity Limitations in Zambia. It was indeed a pleasure to work with a wide range of dedicated stakeholders on this study, notably our main partner FFO (Norwegian Federation of Organizations of Disabled People), Zambia Federation of the Disabled (ZAFOD), Institute for Economic and Social Research (INESOR) and Central Statistical Office (CSO) in Zambia, the Zambian Government through the Ministry responsible for people with disabilities, and the specialized Norwegian institution that was tasked with the responsibility to conduct the study, SINTEF Health Research.

Over the last few years similar studies have been carried out in Zimbabwe, Malawi, and Namibia, and during that time there have been significant changes in both the philosophy and practice of conducting research with a focus on disability.

Increasingly, our Norwegian partners have been leading the way in terms of placing emphasis on ensuring the active participation

of people with disabilities in carrying out research work. Such shifts and changes in the approach to research have, with no doubt, resulted in a number of challenges as well as opportunities; but on the whole the approach has been empowering the usually marginalized groups. It is hoped that with more such studies, not only in Southern African, but in the whole of Africa, people with disabilities will enjoy and experience the kind of liberation they have never had before. Data on the living conditions of people with disabilities is very important not only as a lobbying tool for the disability movement but as an important guide to governments, development agencies and other stakeholders that have an interest to improve the services they provide to people with disabilities. My dream as the Director General of SAFOD is to have studies and data on the Living Conditions in all SAFOD member countries, i.e. from Zambia we should move to the next country, and the next, and the next, until we cover all the remaining six countries. I am sure our Norwegian partners will continue to support us!

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Summary

(ME Loeb, AH Eide)

This representative study on living conditions among people with disabilities[1] in Zambia is the result of an international co-operation between Southern Africa Federation of the Disabled (SAFOD), Zambian Federation of the Disabled (ZAFOD), Norwegian Federation of Organisations of Disabled People (FFO), University of Zambia Institute for Economic and Social Research, the Central Statistical Office in Zambia (CSO) and SINTEF Health Research, Norway. 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 Zambia is the fourth to be published. The report is designed to provide both an overview of the situation for people with disabilities in Zambia 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 Zambia, 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 Central Statistical Office covering all provinces in the country, a total of 2885 households with at least one disabled family member and 2866 households without disabled members were sampled; altogether 5751 households.

A comparison with results from the Namibian, Zimbabwean and Malawian studies is included for some major indicators. In general, the patterns observed (both similarities and differences) between people with and without disabilities

demonstrated in the other three countries were replicated in Zambia.

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.

Some Results:

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.

Systematic gender differences were found between households with and without a disabled family member; a higher proportion of those with disabilities were men compared to the 'control' non-disabled population. This is in line with the previous studies in the region, but this gender difference was demonstrated to be significantly higher in the Zambian sample as compared to the previous three studies. Subsequent analyses were controlled for the possible confounding effects of gender.

As was found in Namibia, Zimbabwe and Malawi, school attendance is clearly lower among persons with disabilities. Among children 5 years of age or older, 24% of those with disabilities had never attended school, while the corresponding figure for non-disabled was 9%. Interestingly, however, school performance (measured as highest school grade completed) was not different between the two groups. Among those who had attended school, 80% had completed Grade 9 as their highest grade (both those with and those without disabilities). This result is similar to results from Malawi, but different than that found in the other 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.

Unemployment in Zambia 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 55%) of those with disabilities are unemployed compared the non-disabled sub-sample (42%). While these figures are not meant to represent official unemployment figures, they provide an indication of the current situation in Zambia. Unemployment data collected from Namibia, Zimbabwe and Malawi were, in fact, higher.

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, 59% of those with

disabilities had acquired some skill, the same as 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 Malawi 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 (though these differences were not statistically significant).

Overall, on most indicators the comparison between the two types of households no major differences were detected; that is, households with disabled members, in the sample, have similar standards of living as 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. It should be noted that this finding is a direct result of the sampling procedure; i.e. that households without a disabled family member were selected as neighbouring households to the household with a disabled family member. In this way, proximity of 'case' and 'control' households reduces the differences between them.

Around 42% of those with disabilities have a self-reported physical disability (major or minor disability, paralysis), and 47% 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 Namibia, Zimbabwe and Malawi. 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 over 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, educational, assistive device services and counselling services. Vocational training and welfare services were received by about 8% 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.

With respect to the role of the person with a disability in the household, results indicate certain problems of social exclusion which should not be overlooked. Among these problems the most pronounced concern is not taking part in one's own traditional ceremonies, not making important decisions about one's life and the high proportion who are not married and do not have own children. These, and other indicators of social exclusion, imply that awareness creation, information and education directed at the families of individuals with disabilities is urgently needed.

An overview of accessibility to different services, facilities and institutions gives a mixed picture. Hotels and banks are accessible to less than 40% of individuals with disabilities who use them. Places of worship, health care clinics, shops and schools are on the other hand reported to be accessible by the majority of those with disabilities (over three-fourths). Perhaps the most notable shortcomings are public transport, accessible to 65% and the workplace, accessible to 68% of the disabled population. Close to one-third of those with disabilities who use public transport or who work experience barriers to accessing these important services. The mixed picture demonstrated with regards to accessibility indicates that the

potential exists for improving accessibility for people with disabilities.

A minority of those surveyed (13%) claimed to use assistive devices. It is interesting to note that this figure is lowest of the countries surveyed; Malawi (17%), Namibia (18%) and Zimbabwe (26%). It is further shown that most of the devices in use are functioning well (76%). Depending on the type of device in use, between 25 and 75% of those who use a device had received instructions on their use. With respect to maintenance, about 4% of devices are maintained through government services, about 67% assumed responsibility themselves (or through their families) and another 21% claimed that their device was either not maintained or that they couldn't afford maintenance/repairs. As was found in Namibia and Malawi, a higher share of devices is supplied by private sources in Zambia, 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).

By adding up an individual's responses to each of 43 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 Namibia, Zimbabwe and Malawi.

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. Furthermore, analyses reveal similar scores for service needs and help in daily activities between men and women. Though the individual items in the daily activity help score may be seen as more gender specific, no significant differences are detected in the current sample.

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. The service needs score behaves somewhat differently, and, though the results are significant, they show increased needs both for those with more health problems and for those with less – perhaps indicating that those who are most active also have greater needs.

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 conditions. 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.

Applicability of results:

The publication of the results of the Living Conditions Survey in Zambia 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 ZAFOD 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 developing policies, setting priorities, and for developing concrete measures within selected areas of priority.

Introduction

(Felix Simulunga – Federal Coordinator – ZAFOD)

Zambia has a population of about 11,798,678[2] people out of which according to WHO estimates 10% to 20% are expected to be persons with disabilities. However, according to the 2000 Census of Population and Housing in Zambia, Zambia's defacto[3] population then stood at 9,337,425. From this, 256,690 were persons with disabilities (representing approx. 2.7% of the total population) out of which 53% were male and 47% were female.

It has been observed that the large majority of people with disabilities in Zambia very often are living under poor conditions and lack basic support that could play a significant role in improving their lives considerably.

Persons with disabilities are further often marginalized and belong to the poorest segments of society (UN, 1996), further adding to a situation of powerlessness and lack of political influence.

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[2] Zambia's Draft Fifth National Development Plan (FNDP) 2006 - 2010

[3] Usual household members and visitors who spent the census night at that household excluding foreign diplomatic personnel accredited to Zambia and

The most important outcome of the International Year of Disabled Persons (1981), and forming an important tool throughout the United Nations Decade of Disabled Persons (1983 – 1992), was 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 UN General Assembly approved The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (Resolution 48/96) (UN, 1994), setting specific targets and implying a strong moral and political commitment on behalf of States to take action for the equalisation of opportunities for persons with disabilities.

The Standard Rules and The World Program of Action both give high priority to the collection and dissemination of information on living conditions of people with disabilities and promote comprehensive research on all aspects that may affect the lives and opportunities of disabled people.

Also the Continental Plan of Action for the African Decade of Persons with Disabilities (1999 – 2009) (AU, 2000) and the National Plan of Action on Disability in Zambia (2003 – 2008)

Zambian nationals accredited to foreign embassies and their families, Zambian migrant workers and students

(ZAFOD, 2003) explicitly emphasizes support of research as a tool for promoting the interests and participation in society of people with disabilities.

ZAFOD was established in 1990 and is the national non-governmental umbrella organisation for all disabled peoples organisations in the country. The National Plan of Action on Disability in Zambia (2003 – 2008) has been drafted by ZAFOD with participation from a number of Zambian stakeholders and funded by Comic Relief through POWER International, both based in the United Kingdom. Research and disability statistics is covered by the plan. The strategy for action on this point includes establishment of a data bank on disability, initiation of research on social, economic and participation issues affecting the lives of persons with disabilities and their families, and the inclusion of persons with disabilities in data collection and dissemination of data on disability issues.

In keeping up with these needs and ideals, and with funding from the Norwegian Government (NORAD[4]) through the Atlas Alliance[5], Norwegian Federation of the Disabled (FFO) and SINTEF Health Research, the partners involving those highlighted above in collaboration with the Central Statistical Office in Zambia (CSO), the University of Zambia Institute for Economic and Social Research (INESOR), the Zambia

[4] NORAD – Norwegian Agency for International Development

[5] The Atlas Alliance is an organisation formed by Norwegian organisations of disabled persons, patients and their relatives collaborating to support disabled people in low income countries

Federation of the Disabled and the Southern Africa Federation of the Disabled (SAFOD)[6] decided to embark on a national wide research project to ascertain the living conditions among persons with disabilities or activity limitations in Zambia.

On behalf of ZAFOD, I would like to thank all the stakeholders who ensured that this research project on the Living Conditions among Persons with Disabilities or Activity Limitations in Zambia was made possible and without whose participation this exercise would not have been as successful as it has been.

We are especially very grateful to Alexander Phiri of the Southern Africa Federation of the Disabled (SAFOD) who managed to convince the Norwegian Federation of the Disabled (FFO) and SINTEF Health Research Foundation to choose Zambia as their next and fourth destination in their Living Conditions Research Project that they were carrying out in the Southern African region.

FFO (thanks to especially Jarl Oversen and Astrid Westby) should be commended for agreeing to support the work in Zambia and for having confidence in ZAFOD to take the mantle of coordinating the project.

[6] SAFOD – a regional umbrella organisation of disabled people based in Bulawayo in Zimbabwe

We thank Professor Arne H. Eide of SINTEF for managing to put in place an application proposal to the Norwegian Government as well as other members of staff in SINTEF, particularly Mitch Loeb and Karl-Gerhard Hem, for their personal commitment, moral support and interest in ensuring that the project was funded and smoothly implemented in Zambia without which an exercise of this magnitude would have been impossible to carry out.

We are also thankful to our local partners namely the University of Zambia Institute for Economic and Social Research (INESOR) and Central Statistical Office (CSO) for agreeing to partner with ZAFOD, as research experts, in the implementation of the project in Zambia. Specific mention is directed to Dr. Mutumba Bull (Director of INESOR), Dr. T.J. Ngulube (Coordinator of Health Research at INESOR) and Dr. C.A. Njovu (Research Fellow) for their keen interest in uplifting the welfare of persons with disabilities and therefore rendering as much technical and moral support as possible to ensure that the project was launched off the ground. Great kudos also goes to Mr. Goodson Sinyenga of CSO for his invaluable technical expertise in designing the sample and in the production of survey maps.

My thanks would be incomplete if I failed to mention the professional and hard work of members of the ZAFOD secretariat and Board (professionally chaired by Mr John Miyato – once deputy Minister of Finance) as well as to

acknowledge the contribution of all individuals and organisations who participated in making this project a reality.

As in other countries (namely Zimbabwe, Namibia and Malawi) where the survey has been conducted, the overall objective of the Survey was to contribute to the improvement of the living conditions among people with activity limitations in Zambia. In addition, the survey was intended to provide a basis on which to:

a) Develop a strategy for the collection of comprehensive, reliable and culturally adapted statistical data on living conditions among people with disabilities

b) Initiate a discussion on the concepts and understanding of "disability"

c) Include and involve people with disabilities in every step of the research process

d) Monitor the impact of government policies, programmes and donor support on the well being of the population with activity limitations.

e) Identify various forms of activity limitations that people living with disabilities face

f) Provide various users with a set of reliable indicators against which to monitor development.

g) Identify appropriate assistive devises required for specific forms of disabilities

h) Identify vulnerable groups in society and enhance targeting in policy implementation.

i) Establish appropriate skills training package for various forms of disability

The project was launched in March 2005 through a Consultative Conference of various stakeholders to fully brief them on the work being undertaken, the reasons for it and the expected outcome. Senior representatives of Research Institutions, Disabled Peoples Organizations, other Non Governmental Organisations, as well as relevant Government ministries and agencies attended this meeting.

In August 2005, 10 Supervisors (from INESOR and ZAFOD) undertook training on how to supervise the research exercise. In September 2005, 38 Enumerators were trained on how to undertake the research from which the best 20[7] were chosen to go into the first phase of the survey from September to November 2005 covering 5 remote provinces of Zambia namely: Northern, Eastern, Western, North Western and Luapula. From these 20 enumerators who went in the field, 6 were persons with disabilities and 4 were parents of children with disabilities and the rest were able bodied. Also from these, 9 were women and 11 were men.

[7] See Appendix 3: List of Enumerators and Supervisors involved in the Research

From the 20 enumerators, 16 were later chosen - based on their performance in the first phase – to undertake the second phase of the research covering the remaining 4 provinces of Zambia namely Copperbelt, Central, Lusaka and Southern. The 2nd phase research work commenced in February 2006 and ended in May 2006. From these 16 enumerators, 5 were persons with disabilities and 3 were parents of children with disabilities from ZAFOD affiliates while the rest were able-bodied enumerators from INESOR and CSO.

Some of the successes of the project included, but were not limited to the fact that:

- SINTEF, INESOR, CSO and ZAFOD managed to develop a strategy and methodology for the collection of comprehensive, reliable and culturally adapted statistical data on living conditions among people with disabilities in Zambia;

- This activity managed to raise awareness among research participants on concepts and understanding of "disability" as well as to expose persons with disabilities to research concepts and methodologies thus giving them a skill in research work;

- The project, through technical support from SINTEF and financial support from FFO and the Atlas Alliance, helped in increasing the capacity of ZAFOD in its work of being a truly representative umbrella organisation in issues concerning persons with disabilities including the advocacy for disability issues to be incorporated in the Republican Constitution as well as the 5th National Development Plan (2006-2010) both of which are currently in the process of being formulated;

- The project also managed to bring together two main research institutions in Zambia whose diverse opinions and methodologies in research, helped in enriching the survey process on disability. Apart from this, the project also provided an opportunity for the research institutions to learn from each other and also to understand better research issues concerning persons with disabilities;

In conclusion, the research being the first of its kind in Zambia provides a more precise indication of the true living conditions among people with disabilities or activity limitations in Zambia than has previously been the case. This is a great window which the government and other development agencies and partners should be able to utilise in creating policies and other interventions that effectively and positively address the living conditions of persons with disabilities or activity limitations in the country.

1 Context[8]

(Felix Simulunga – ZAFOD)

History

The indigenous Khoisan hunter-gatherer occupants of Zambia began to be displaced or absorbed by technologically advanced migrating tribes about 2,000 years ago. The major waves of Bantu-speaking immigrants began in the 12th century.

Among them, the Tonga people were first to settle in Zambia and are believed to have come from the Far East near the "big sea". Other groups followed with the greatest influx coming between the late 17th and early 19th centuries. These later migrants came primarily from the Luba and Lunda tribes of southern Democratic Republic of Congo and northern Angola but were joined in the 19th century by Ngoni peoples from the south. By the later part of that century, the various peoples of Zambia were largely established in the areas they currently occupy.

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[8] Sources:

Microsoft Encarta Encyclopedia

CIA World Factbook on Zambia 2006

Zambia's Draft Fifth National Development Plan (FNDP) 2006 – 2010

2000 National Housing and Population Census in Zambia by the Central Statistical Office

Except for the occasional Portuguese explorer, the area lay untouched by Europeans for centuries. After the mid-19th century, it was penetrated by Western explorers, missionaries, and traders. In 1855, missionary and explorer David Livingstone became the first European to see the magnificent waterfalls on the Zambezi River. He named them Victoria Falls after Queen Victoria. The falls are known in Zambia as Mosi-O-Tunya (in the Lozi dialect), "the smoke that thunders". The Zambian town, Livingstone, near the falls is named after him.

In 1888, Cecil Rhodes, spearheading British commercial and political interests in Central Africa, obtained mineral rights concession from local chiefs. In the same year, Northern and Southern Rhodesia (now Zambia and Zimbabwe, respectively) were proclaimed to be within the British sphere of influence. Southern Rhodesia was annexed formally and granted self-government in 1923, and the administration of Northern Rhodesia was transferred to the British Colonial Office in 1924 as a protectorate. Mining began in the Copperbelt in 1934.

In 1953, both Rhodesias were joined with Nyasaland (now Malawi) to form the Federation of Rhodesia and Nyasaland. Northern Rhodesia was the centre of much of the turmoil and crisis that characterized the federation in its last years. At the core of the controversy were insistent African demands for greater participation in government and European fears of losing political control.

A two-stage election held in October and December 1962 resulted in an African majority in the legislative council and a coalition between two Zambian nationalist parties, i.e. United National Independence Party (UNIP) and the African National Congress (ANC). The council passed resolutions calling for Northern Rhodesia's secession from the federation and demanding full internal self-government under a new constitution and a new National Assembly based on a broader, more democratic franchise. On 31 December 1963, the federation was dissolved, and Northern Rhodesia became the Republic of Zambia on 24 October 1964.

At independence, despite its considerable mineral wealth, Zambia faced major challenges. Domestically, there were few trained and educated Zambians capable of running the government, and the economy was largely dependent on foreign expertise. Abroad, three of its neighbors--Southern Rhodesia and the Portuguese colonies of Mozambique and Angola--remained under white-dominated rule. Southern Rhodesia's white-ruled government unilaterally declared independence in November, 1965. In addition, Zambia shared a border with South African-controlled South-West Africa (now Namibia). Zambia's sympathies were with forces opposing colonial or white-dominated rule. During the following decade, it actively supported movements such as the National Union for Total Independence of Angola (UNITA), the Zimbabwe African People's Union (ZAPU), the African National Congress of South Africa (ANC), and the South-West Africa People's Organization (SWAPO).

Conflicts with Southern Rhodesia resulted in the closing of Zambia's borders with that country and severe problems with international transport and power supply. However, the Kariba hydroelectric station on the Zambezi River provided sufficient capacity to satisfy the country's requirements for electricity (despite the fact that the hydro control center was on the Rhodesian side of the border). A railroad to the Tanzanian port of Dar-es-Salaam, built with Chinese assistance, reduced Zambian dependence on railroad lines south to South Africa and west through an increasingly troubled Angola.

Until the completion of the railroad, however, Zambia's major artery for imports and the critical export of copper was along the Tanzania Zambia Road (also called Great North Road), running from Zambia to the port cities in Tanzania. Also a pipe-line for oil was built from Dar-es-Salaam to Ndola in Zambia. During certain times, some things were airlifted at a great cost. By the late 1970s, Mozambique and Angola had attained independence from Portugal. Zimbabwe achieved independence in 1980 in accordance with the 1979 Lancaster House Agreement, but Zambia's problems were not solved.

Civil war in the former Portuguese colonies generated an influx of refugees and caused continuing transportation problems. The Benguela railway, which extended west through Angola, was essentially closed to traffic from Zambia by the late 1970s. Zambia's strong support for the ANC of South Africa, which had its external headquarters in Lusaka, created

security problems as South Africa raided ANC targets in Zambia.

In the mid-1970s, the price of copper, Zambia's principal export, suffered a severe decline worldwide. In Zambia's situation, the cost of transporting the copper great distances to international markets was an additional strain. Zambia turned to foreign and international lenders for relief, but as copper prices remained depressed, it became increasingly difficult to service its growing debt. By the mid-1990s, despite limited debt relief, Zambia's per capita foreign debt remained among the highest in the world.

Politics

Politics of Zambia takes place in a framework of a presidential representative democratic republic, whereby the President of Zambia is both head of state and head of government, and of a pluriform multi-party system. Executive power is exercised by the government. Legislative power is vested in parliament. The President, who is elected by popular vote every five years, appoints a Cabinet from among the members of the National Assembly. The Zambian Legislative branch, the National Assembly is comprised of 159 members, 150 of which are elected by popular vote to serve five-year terms, 8 are nominated by the President and 1 is the Speaker.

The last general elections were held on 27th December 2001 with the next elections scheduled to take place on 28th

September 2006 where 5 political parties namely the Movement for Multiparty Democracy (MMD), the United Democratic Alliance (UDA), the Patriotic Front (PF), the Heritage Party (HP) and the All Peoples Congress Party (APC) are contesting the Republican presidency with the rest (of which there are more than six political parties) fielding only Parliamentary and Local Government candidates.

Zambia's legal system is based on English common law as well as customary law with the Supreme Court being the highest court of appeal in the land.

Geography

Zambia is a landlocked country in Southern Africa. It borders the Democratic Republic of the Congo to the north, Tanzania on the north-east, Malawi on the east, Mozambique, Zimbabwe, Botswana, and Namibia to the south, and Angola on the west. Formerly Northern Rhodesia, the country is named after the Zambezi River.

Zambia has a tropical climate and consists mostly of high plateau with some hills and mountains.

Zambia is drained by two major river basins: the Zambezi River basin, in the south; and the Congo River basin, in the north. Of the two basins, the part of Zambia drained by the Zambezi River basin is about three-quarters of the country's total area. The part drained by the Congo River basin is about a quarter of the country's total area.

In the Zambezi River basin, there are four major rivers that either run through Zambia or form the country's borders with its neighbours: the Kafue, the Luangwa, the Kwando and the Zambezi. The last two form part of Zambia's southern borders. The Kwando River forms Zambia's southwestern border with Angola, then it runs eastwards along the northern boundary of Namibia's Caprivi Strip before spreading into the Linyanti Marshes, which finally drain eastwards into the Zambezi. From its confluence with the Kwando, the Zambezi flows eastwards, forming the whole of Zambia's border with Zimbabwe.

The other two rivers, Kafue and Luangwa, lie entirely within Zambia and are major tributaries of the Zambezi. Their confluences with the Zambezi are on Zambia's Zimbabwean border at Chirundu (for the Kafue) and Luangwa town (for the Luangwa River). Before its confluence, the Luangwa River forms part of Zambia's border with Mozambique. From Luangwa town, the Zambezi leaves Zambia and flows into Mozambique, and eventually spills its waters into the Indian Ocean's Mozambique Channel. The Zambezi falls 360 feet (100 m) over the one-mile wide (1.6 km) Victoria Falls,

located in the South West corner of the country and later fills the mighty Lake Kariba.

The Zambezi Valley, running along the southern border, is both deep and wide. Moving northwards the terrain shifts into a high plateau ranging from 3,000-4,000 feet (900–1,200 m) up to over 6,000 feet (1,800 m) in the northern area of the Copperbelt. In the east, the Luangwa valley curves its way south with hills on either side until it enters the Zambezi. In the west, large plains are a key geographic feature, flooding the western plains during the annual rainy season (typically October though April).

As regards the Congo River basin, Zambia hosts two major rivers from the Congo River basin: the Chambeshi and the Luapula; the latter forms part of Zambia's border with the Democratic Republic of Congo. The Chambeshi lies entirely within Zambia and is the furthest headstream of the Congo River. It flows into the Bangweulu Wetlands, which provide the waters that form the Luapula River. The Luapula flows southward then westward before it turns northward until it enters Lake Mweru. The lake's other major tributary is the Kalungwishi River, which flows into it from the east. The Lulua River drains Lake Mweru, flowing out of the northern end.

Lake Tanganyika is the other major hydrographic feature that belongs to the Congo River basin. The lake's south-eastern end receives water from the Kalambo River, which forms part

of Zambia's border with Tanzania. This river has Africa's second highest uninterrupted waterfall, the Kalambo Falls. (The continent's highest waterfalls are the Tugela Falls of South Africa.)

Economy

Over 70 percent of Zambians live in poverty. Per capita annual incomes are as low as $395 thus placing the country among the world's poorest nations. Social indicators continue to decline, particularly in measurements of life expectancy at birth (about 37 years) and maternal mortality (729 per 100,000 pregnancies). The country's rate of economic growth cannot support rapid population growth or the strain which HIV/AIDS related issues (i.e., rising medical costs, decline in worker productivity) place on government resources. Zambia is also one of Sub-Saharan Africa's most highly urbanized countries. Almost one-half (44%) of the country's 12 million people are concentrated in a few urban zones strung along the major transportation corridors, while rural areas are under-populated. Unemployment and underemployment are serious problems.

HIV/AIDS is one of the nation's greatest problems, with about 17% prevalence among the adult population. HIV/AIDS will continue to ravage Zambian economic, political, cultural, and social development for the foreseeable future.

Once a middle-income country, Zambia began to slide into poverty in the 1970s when copper prices declined on world

markets. The socialist government then led by Dr Kenneth Kaunda made up for falling revenue with several abortive attempts at International Monetary Fund structural adjustment programmes (SAPs), which led to his fall after popular outcries from the people.

After democratic multi-party elections, the Chiluba government (1991-2001) came to power in November 1991 committed to an economic reform program. The government privatized most of the parastatals (state-owned corporations), maintained positive real interest rates, eliminated exchange controls, and endorsed free market principles. However, corruption also grew dramatically under the Chiluba government.

The Mwanawasa government, which came to power in 2001, has continued on the path of economic reform. Zambia is still dealing with economic reform issues such as the size of the public sector and improving Zambia's social sector delivery systems. NGOs and other groups have contended that the SAPs, in Zambia and other countries, have had very detrimental effects on the poor. Zambia's total foreign debt exceeded $7 billion when the country qualified for Highly Indebted Poor Country Initiative (HIPC) debt relief in 2000, contingent upon meeting certain performance criteria.

Initially, Zambia hoped to reach the HIPC completion point, and benefit from substantial debt forgiveness, in late 2003. In

January 2003, the Zambian Government informed the IMF and World Bank that it wished to renegotiate some of the agreed performance criteria calling for privatization of the Zambia National Commercial Bank and the national telephone and electricity utilities. Although agreements were reached on these issues, subsequent overspending on civil service wages delayed Zambia's final HIPC debt forgiveness from late 2003 to early 2005, at the earliest. In an effort to reach HIPC completion in 2004, the government drafted an austerity budget for 2004, freezing civil service salaries and increasing a number of taxes. The labor movement and other components of civil society objected to the sacrifices called for in the budget, and, in some cases, the role of the international financial institutions in demanding austerity.

In 2005, Zambia reached the HIPC Completion Point resulting in debt cancellation. In addition to this, Zambia also became eligible for debt relief under the G8 initiative which proposed to cancel 100 percent of all debts owed to the International Monetary Fund (IMF), the African Development Bank (ADB) and the World Bank. Following the debt relief provided as a result of the enhanced HIPC initiative, Zambia’s foreign debt came down to US$4 billion in 2005 and in 2006 when the G8 commitments were effected through the Multilateral Debt Relief Initiative (MDRI), Zambia’s external debt significantly reduced to around US$600 million.

The Zambian economy has historically been based on the copper mining industry. Output of copper had fallen, however, to a low of 228,000 metric tons in 1998, after a 30-year decline in output due to lack of investment, low copper prices, and uncertainty over privatization. In 2002, following privatization of the industry, copper production rebounded to 337,000 metric tons. Further improvements in the world copper market have magnified the effect of this volume increase on revenues and foreign exchange earnings.

The Zambian Government is pursuing an economic diversification program to reduce the economy's reliance on the copper industry. This initiative seeks to exploit other components of Zambia's rich resource base by promoting agriculture, tourism, gemstone mining, manufacturing, construction and hydro power. The Zambian government has recently been granting licenses to international resource companies to prospect for other minerals other than copper such as nickel and uranium.

Demographics

Zambia's population is comprised of about 72 Bantu-speaking ethnic groups but almost 80% of Zambians belong to the seven main ethno-linguistic groups, which are the Bemba, Nyanja-Chewa, Tonga, Lunda, Luvale, Kaonde, and Lozi. Each ethnic group is concentrated in a particular geographic region of the country and many groups are very small and not as well known. Most Zambians are subsistence farmers.

Expatriates, mostly British and South Africans, live mainly in Lusaka and in the Copperbelt in northern Zambia, where they are employed in mines and related activities. Zambia also has a small but economically important Asian population, most of whom are Indians. These have recently been joined by the Chinese. In recent years over 300 dispossessed white farmers left Zimbabwe at the invitation of the Zambian government and have taken up farming in the southern region.

The country is 44% urban. The HIV/AIDS epidemic is ravaging Zambia. Nearly 1 million Zambians are HIV positive or have AIDS. An estimated 100,000 died of the epidemic in 2004. Over a half-million Zambian children have been orphaned. Life expectancy at birth is just under 40.

Religion

The Zambian constitution identifies the country as a Christian nation, but a variety of other religious practices exists. Traditional religious thought blends easily with Christian beliefs in many of the country's syncretic churches. Islam also has a visible presence especially in urban settings. Zambia also has a very small Jewish community.

Within the Christian community, a variety of denominations can be found: Roman Catholic, Anglican, Pentecostal, Lutheran, a variety of Evangelical denominations. These grew, adjusted and prospered from the original missionary settlements (Portuguese and Catholicism in the east from

Mozambique) and Anglican (English and Scottish influences) from the south. Except for some technical positions (e.g. physicians), western missionary roles have been assumed by native believers. After Frederick Chiluba (a pentecostal Christian) became President in 1991, Pentecostal congregations sprouted around the country.

Health and health-care

Health care in Zambia is provided by the Government institutions, churches under the Churches Health Association of Zambia (CHAZ), the mining companies, some parastatal organizations, private clinics and the traditional sector. The structure of public Health services run by the Government comprises: Community Health Care (Health posts), Health Centres, Level one Hospitals, Level Two Hospitals and Level Three Hospitals.

By 1991, the quality of Health service delivery had deteriorated mainly due to increased demand for health services arising from rapid population growth and a declining economy. This compromised the government's ability to provide quality health care. The Government was unable to provide adequate medical supplies, equipment and infrastructure for optimal provision of basic health care services. At the same time the epidemiological situation of the country was also rapidly changing and getting compounded by the HIV/AIDS pandemic.

In an effort to improve the quality and provision of health care delivery, the Zambian government introduced the Health Reforms in 1992. The key tenets of the reforms were decentralisation of health services planning and provision to the district level and a focus on preventive rather than curative care. This innovation also culminated into the introduction of an "Essential Health Care Package", which defined key interventions that the public health system should provide within the available resources. The reforms also emphasized the importance of community participation in the management of health services and coordination of donor support in the framework of sector wide approach involving pooling of resources to finance a jointly approved health sector plan.

Between 1992 and 2002, some health indicators have shown a marked decline in service delivery and quality of care while others have registered a marginal improvement. The Maternal Mortality Rate has increased from 649 deaths per 100,000 live births in 1996 to 729 deaths per 100,000 live births in 2002. On the other hand, infant mortality and under five mortality rate have declined from 109 and 197 per 1000 in 1996 to 95 and 168 per 1000 live births in 2002 respectively.

Table 1.1: Summary of Key Performance Indicators

Indicator	1992	1996	2002
Life Expectancy	45	46.8	51.8
Infant Mortality Rate per 1,000	107	109	95
Under 5 Mortality Rate per 1,000	191	197	168
Maternal Mortality Ratio per 100,000	N/A	649	729
HIV Prevalence Rate	23	20	15.6

Source: *Zambia Demographic Health Survey 2001/2002*

Factors that contributed to the decline of some health indicators include the HIV/AIDS pandemic, brain drain, poor state of health facilities, inadequate drugs and medical supplies and high poverty levels.

Disability in Zambia

According to the 2000 Census of Population and Housing, Zambia's defacto[9] population then stood at 9,337,425. From this, 256,690 were persons with disabilities (representing approx. 2.7% of the total population) out of which 53% were male and 47% were female. The census also revealed that Physical disability was the most common disability in Zambia comprising of 35.2% of the total disability population followed by the Partially Sighted at 27.4%, Hard of Hearing at 11.2%,

[9] Defacto population as compared to dejure population is the usual household members and visitors who spent the census night at that household excluding foreign diplomatic personnel accredited to Zambia and Zambian nationals accredited to foreign embassies and their families, Zambian migrant workers and students

the Mentally ill at 7.4%, the Deaf at 5.7%, the Mentally Retarded at 4.9%, the Blind at 4.8% and the ex-mental patients at 3.3%.

It was also reported that the major causes of disability in Zambia include, Malnutrition, Accidents, Infectious Diseases, Non-Infectious Diseases, Congenital Diseases (acquired at birth or during uterine development, as a result of either hereditary or environmental influences) and other factors (including ageing).

Although disability issues are inter-ministerial with all government ministries expected to play their respective roles, the Ministry of Community Development and Social Services (MCDSS), is implicitly responsible for disability issues supported by the Zambia Agency for Persons with Disabilities (ZAPD), a government institution which was established under the Persons with Disabilities Act No. 33 of 1996. This is further augmented by the National Trust for the Disabled (NTD) established under the same piece of legislation.

Other stakeholders in disability issues include, but are not limited to the following:

Self-help organisations

There are more than 40 self help organisations of and for persons with disabilities in Zambia some of which include:

- Zambia Federation of the Disabled (ZAFOD and umbrella organisation)
- Zambia National Federation of the Blind (ZANFOB)
- Zambia National Association of the Physically Handicapped (ZNAPH)
- Zambia National Association of Disabled Women (ZNADWO)
- Zambia National Association of the Hearing Impaired (ZNAHI)
- Zambia National Association of the Deaf (ZNAD)
- Zambia National Association of the Partially Sighted (ZNAPS)
- Zambia Association for Children and Adults with Learning Disabilities (ZACALD)
- New Foundation of the Blind in Zambia (NEFOBZA)
- Zambia Association of Parents for Children with Disabilities (ZAPCD)
- Zambia Association on Employment for Persons with Disabilities (ZAEPD)
- Parents Partnership Association on Children with Special Needs (PPACSN)
- Disabled Entrepreneurs Association of Zambia (DEAZ)
- Disability Rights and Independent Living Trust (DRILTZ)
- Mental Health Association of Zambia (MHAZ)
- Mental Health Users Network of Zambia (MHUNZA)
- Disability Initiatives Foundation (DIF)
- Zambia National Library and Cultural Centre for the Blind (ZNLCCB)
- Zambia National Association of Sign Language Interpreters (ZNASLI)
- Association of Sign Language Interpreters in Zambia (ASLIZ)
- Disacare Wheelchair Centre Trust
- Zambia Epilepsy Association
- Albinos Association of Zambia

Bilateral Organisations

The known bilateral organisations that have been active in supporting disability organisations in Zambia include among others JICA, SIDA, NORAD, FINNIDA, DFID and some embassies and High Commissions such as those of the United States, Finnish, Swedish, Danish, Germany, Irish and the British.

Multilateral Organisations

Only two multilateral organisations have been active in supporting disability programmes namely:

- International Labour Organisation (ILO)
- European Union (EU)

International & Local Organisations

International & local organisations, based in & outside Zambia, include among others:

- Action on Disability and Development (ADD)
- Finnish Association on Mental Retardation (FAMR)
- Leonard Cheshire Homes International
- Zambia National AIDS Network (ZNAN)
- Sight Savers International Zambia
- KEPA Zambia
- POWER International
- SINTEF Health Research
- Norwegian Federation of the Disabled (FFO)
- Churches

Zambian Disability policy

The rights of persons with disabilities are protected by a combination of special and general legislation. The judicial mechanism adopted to protect the rights of persons with disabilities is due process (legal remedy through the courts). Administrative and other non-judicial mechanisms include a governmental body (administrative).

There is only one piece of legislation on disability namely the Persons with Disabilities Act No. 33 of 1996, which also ushered in the Zambia Agency for Persons with Disabilities. However, since its enactment, the Act hasn't been enforced and its violations are rarely recognized due to mainly ignorance, among the various stakeholders, of what it entails. Also, in 2002, the Ministry of Community Development and Social Services (MCDSS) produced a National Policy on Disability but no Implementation Plan has been put in place to realize its objectives. However, issues of persons with disabilities have been included in the Fifth National Development Plan (FNDP) 2006 to 2010 but allocation of financial resources to those issues has been significantly inadequate.

Legal provisions mandate the representatives of persons with disabilities to participate in policy-making and to work with Governmental institutions. Organizations of persons with disabilities are sometimes consulted when laws and regulations with a disability aspect are being prepared. Consultations

mainly take place at the national level with the exception of the current Draft Republican constitution where different stakeholders (including persons with disabilities) at different levels were consulted.

However, in most situations persons with disabilities have participated to a very limited extent in the formulation of other general/mainstream pieces of legislation. Organizations of persons with disabilities have the role to advocate rights and improved services, mobilize persons with disabilities, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures, and contribute to public awareness.

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

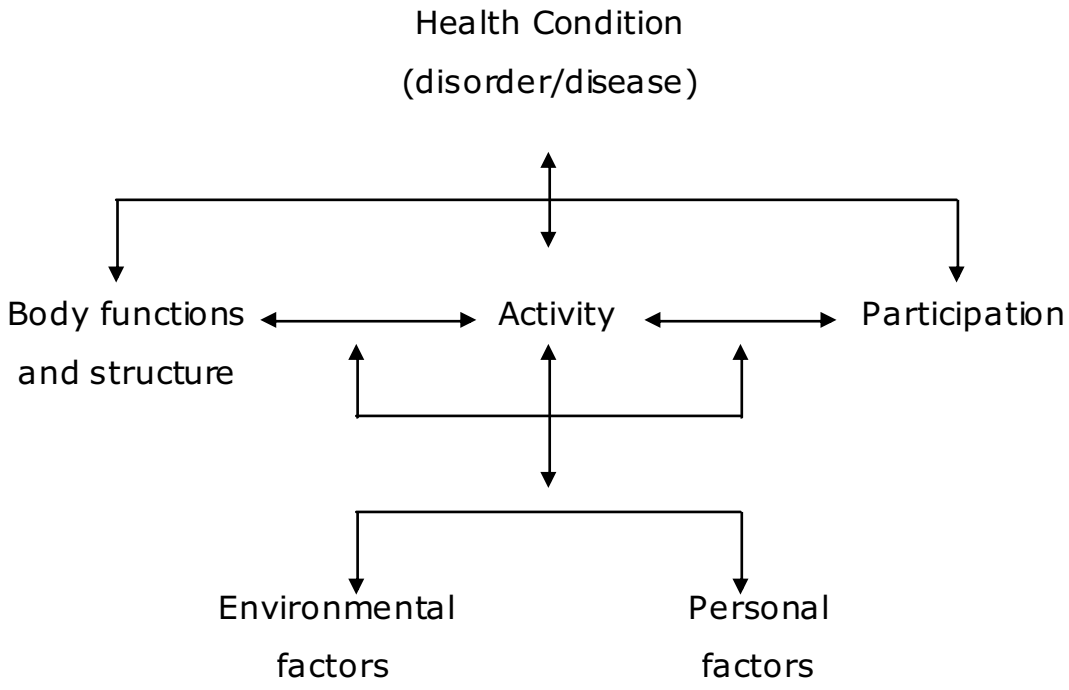
During the 1970s there was a strong reaction among representatives of organisations of persons with disabilities and professionals in the field of disability against the then current terminology. The new concept of disability was more focused on the close connection between the limitations experienced 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 statistically[10].

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 as a separate dimension in the questionnaire (Appendix 5). It is however acknowledged that studies like the current one traditionally focus on the individual and that this is also the case here.

[10] 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 & Øvensen, 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), Zimbabwe (Eide, Nhiwatiwa, Muderezi & Loeb, 2003) and Malawi (Loeb,& Eide, 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 studies[11]. 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

[11] 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 countries[12], 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

[12] 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 Namibia[13], South Africa[14], Malawi[15], and Zambia[16] 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)

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

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

[15] Malawi Government. National Disability Policy. Office of the Minister of State Responsible for Persons with Disabilities. December, 2006.

[16] Zambian Government. Persons with Disabilities Act, No. 33 of 1996

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**	**2000**	**2.7**
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. 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. The Malawian survey of living conditions among people with disabilities found disability prevalence in the country to be 4.2% (Loeb, Eide, 2004).

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 Work on Disability Statistics

The United Nations Statistics Division (UNSD) publication *Guidelines and Principles for the Development of Disability Statistics*[17] 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*,[18] and also on the section on disability in the *Principles*

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

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

and Recommendations for Population and Housing Censuses, Revision 1.[19]

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 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.

3.1.4 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 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 Group on Disability Statistics (WG) to

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

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. 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, Zambia 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 recommendations[20]. In both Namibia (see above) and Zimbabwe (Census 2002,

[20] 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.

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 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.

3.1.5 Methodological considerations in measuring prevalence

Screening for disability

The issue of disability prevalence has been discussed in several workshops, notably 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 at this workshop there was general agreement that the prevalence rates 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 1990 Zambian census were as follows:

Is there anyone in this household who is:

Blind	Yes/No
Deaf/Dumb	Yes/No
Crippled	Yes/No
Mentally retarded	Yes/No

The 1990 census produced a disability prevalence rate of 0.9% while results from the 2000 census placed disability at 2.7%. The 2000 census made use of questions that are more indicative of an individual's limitations in carrying out daily activities, due to long-term physical, mental or health problems.

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 Zambian Living Condition Survey presented here relies on the work of the Washington Group on Disability Statistics (WG – see above). The screening questions used reflect an understanding of disability in accordance with the ICF (WHO, 2001).

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM

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

For the purposes of this report and the analyses carried out, a person with a disability is anyone who has *some* difficulty with at least *two* activities or *a lot* of difficulty/*unable* to do any *one* activity above.

Based on the above criteria, we found in this survey that prevalence varied by province from 7.3% in Luapula to 22.2% in Western province, with a mean national prevalence rate of 13.3% (see Appendix 1). This current rate reflects the changes

in the understanding and approach to disability that has been manifested over the past 25-30 years. In addition, it is possible to examine disability prevalence by severity according to the responses to the six screening questions; 2.4% of registered disabilities were of the most severe type (*unable* to do the activity), 10.4% experienced at least *a lot* of difficulties doing at least one of the activities and 14.4% experienced at least *some* difficulty doing at least one of the activities. In addition, 6.1% experienced at least some difficulty doing more than one activity, i.e. multiple impairments. (Note: these percentages are not additive.)

3.2 Relevant studies in Zambia

While very little relevant disability research has been conducted in Zambia, the Central Statistical Office has been collecting disability data in censuses from 1969. As mentioned above, the most recent (2000) census placed the rate of disability in the population at 2.7%. Based on the documentation available, it is clear that Zambia, and the CSO in particular, is actively incorporating the definitions and methodologies as proposed by the WG and others.

In addition to disability, both poverty and HIV/AIDS are becoming recurring and visible themes among publications emanating from the region. In the future it will become increasingly important to include the disability dimension in all research that touches on these two topics.

4 Design and Methods

(Goodson Sinyenga, CSO)

4.1 Scope of the survey

The scope of the survey in terms of topics covered is to a large extent guided by similar study that was conducted in Malawi in 2002. A continuous process of consultation with key stakeholders has helped shape up the scope of the survey. As such, the survey only includes agreed upon topics of policy relevance. In broad terms, the survey includes: -

(i) A set of core living conditions indicators to be monitored regularly

(ii) A detailed assessment of activity limitations faced by people with disabilities.

To achieve the above stated tasks, the survey will employ 2 survey instruments for data collection namely, the household questionnaire and a detailed Activity Limitation questionnaire for those members of the households identified with such limitations. The generic household questionnaire will cover the following topics: -

- Demography and Disease burden
- Education and Literacy
- Economic activities of household members
- Reproductive Health of Females aged 12 to 49 years
- Household amenities and housing conditions
- Household access to facilities
- Household asset ownership including land
- Household Income and it's main source
- Household food production
- Household monthly Expenditure and rankings
- Death in the households

The detailed Activity Limitation questionnaire will cover the following topics: -

- Activity Limitations and Participation restrictions
- Environmental factors
- Awareness, need and receipt of services
- Education and employment
- Assistive devices and technology
- Accessibility in the home and surroundings
- Inclusion in family and social life
- Health and general well-being

4.2 Sample Design and Coverage

The survey is designed to cover 350 Standard Enumeration Areas (SEAs) across the 8 strata found in 9 provinces or approximately 7,000 non-institutionalised private households residing in the rural and urban areas of Zambia. The survey will be carried out for a period of 50 - 60 days using a cross

sectional sample. This sample is nationally and regionally efficient and is expected to yield reliable estimates at provincial, location and national levels.

4.3 Sample Size Determination

For the majority of human population based studies, the minimum sample requirement assuming Simple Random Sampling (SRS) is 400 observation units. However, this sample size does not take into account the complexity of the sample design. Adjusting the SRS sample with an appropriate design effect factor as well as response rate yields the ideal sample. In Zambia, the design effect factors for common proportions vary from 1.4 to about 2.5. This survey has adopted the factor of 2 to estimate the sample requirement for a province. Therefore, the ideal sample size would be around 7,000 households countrywide or 800 observational units per province (See Appendix 2 for sample size determination).

4.4 Sample Stratification and Allocation

The sampling frame used for the survey will be developed from the 2000 census of population and housing. The Census frame is administratively demarcated into 9 provinces, which are further divided into 72 districts. The districts are further subdivided into 155 constituencies, which are also divided into wards. Wards nest Census Supervisory areas, which in turn nest Standard Enumeration areas (SEAs). For the purposes of this survey, SEAs constituted the ultimate Primary Sampling Units (PSUs). All the SEAs and their corresponding households are further stratified into either rural or urban areas.

In order to have equal precision in the estimates in all the zones and at the same time take into account variation in the sizes of the Zones, the survey will adopt the Square Root sample allocation method, (Lesli Kish, 1987). This approach offers a better compromise between equal and proportional allocation methods in terms of reliability of both combined and separate estimates. The table below shows the distributions of the Primary Sampling Units (PSUs) or SEAs to stratum (location) and provinces. The sample allocation to the explicit rural-urban strata has been approximately proportional.

The Square Root Optimal Method takes the following form;

$$S_h \alpha \sqrt{W_h^2 + H^{-2}}$$

Where:

S_h = Desired domain sample

W^2 = Relative domain weight

H^{-2} =Number of Domains of study

Table 4.1: Sample allocation table

Province	Optimal (Ideal)	Pro-portional	Modified			
			Equal	(Final)	Rural	Urban
Central	37	36	39	36	24	12
Copperbelt	48	56	39	48	14	34
Eastern	42	46	39	42	34	8
Luapula	33	28	39	34	26	8
Lusaka	44	50	39	44	12	32
Northern	41	44	39	42	34	8
N/western	31	20	39	30	22	8
Southern	40	43	39	42	30	12
Western	33	27	39	32	24	8
Total	350	350	350	350	220	130

4.5 Sample Selection

The survey will employ a two-stage stratified cluster sample design whereby during the first stage, 350 SEAs will be selected with Probability Proportional to Estimated Size (PPES) from all the 18 strata across the 9 provinces (Refer to table above). The size measure will be taken from the frame developed from the 2000 census of population and housing. During the second stage, 20 households will be systematically selected from total number of households expected to be residing in the selected SEAs. For the purposes of this survey, half of the households will be those identified with persons

with activity limitations. The survey is designed to provide reliable estimates at provincial, location and national levels.

4.6 Selection of Standard Enumeration Areas (SEAs) or PSUs

The SEAs in each stratum will be selected as follows:

(i) Calculate the sampling interval (I) of the stratum, in this case the Rural-Urban stratum.

$$I = \frac{\sum_i M_i}{a}$$

Where:

$\sum_i M_i$ = is the total stratum size

a = is the number of SEAs allocated to the stratum

(ii) Calculate the cumulated size of the cluster (SEA)

(iii) Calculate the sampling numbers R, R+I, R+2I,…, R+(A-1)I, where R is the random start number between 1 and I.

(iv) Compare each sampling number with the cumulated sizes.

The first SEA with a cumulated size that was greater or equal to the random number was selected. The subsequent selection of SEAs was achieved by comparing the sampling numbers to the cumulated sizes of SEAs.

4.7 Selection of Households

The survey will commence by listing and stratifying all the households in the selected SEAs into the activity limitation and non-activity limitation strata. For the purposes of the survey, a maximum of 10 households will be selected from each stratum, yielding a cluster take (B_{opt}) of 20 households.

The selection of households from the 2 strata will be preceded by assigning fully responding households sampling serial numbers. The circular systematic sampling method will then be employed to select households. The method assumes that households are arranged in a circle (G. Kalton, 1983) and the following relationship applies:

Let N = nk,

Where:

N = Total number of households assigned sampling serial numbers in a stratum

n = Total desired sample size to be drawn from a stratum in an SEA

k = The sampling interval in a given SEA calculated as k=N/n.

4.8 Organisation of the Survey

The survey shall be implemented by 9 teams of roughly 4 Data collectors, 2 drivers and 1 Supervisors. In addition, the survey will be coordinated by the Field Coordinator assisted by 5 Investigators from INESOR and CSO (Appendix 3).

4.9 Data Collection

Data collection will be conducted by way of personal interviews using 2 semi-structured questionnaires. The first survey instrument will be used to collect general living conditions data pertaining to the household being enumerated. The second questionnaire will be employed to collect detailed information from household members identified with various activity limitations and disabilities. In addition to these instruments, a listing form will initially be used to list all households in the selected SEA into the 2 explicit strata.

4.10 Estimation Procedure

4.10.1 Sample weights

Due to the disproportionate allocation of the sample points to various strata, sampling weights will be required to correct for differential representation of the sample at national and sub-national levels. The weights of the sample are in this case equal to the inverse of the product of the two selection probabilities employed above.

Therefore, the probability of selecting an SEA will be calculated as follows:

$$P_{hi}^{1} = \frac{a_h M_{hi}}{\sum_i M_{hi}}$$

Where:

P_{hi}^{1} = the first selection probability of SEAs

a_h = The number of SEAs selected in stratum h

M_{hi} = The size (in terms of the population count) of the i^{th} SEA in stratum h

$\sum_i M_{hi}$ = The total size of the stratum h

The selection probability of the household will be calculated as follows:

$$P_{hi}^{2} = \frac{n_{hi}}{N_{hi}}$$

Where:

P_{hi}^{1} = the second selection probability of the household

n_{hi} = the number of households selected from the i^{th} SEA of h stratum

N_{hi} = Total number of households listed in a SEA

Therefore, the SEA specific sample weight will be calculated as follows:

$$W_i = \frac{1}{P_{hi}^{1} x P_{hi}^{2}}$$

W_i, which is the inverse of the product of the 2 selection probabilities, is called the PPS sample weight. Since there will be 2 strata in every selected SEA, the PSU selection probability will have to be multiplied with separate stratum specific household selection probabilities. Therefore, the number of weights in each SEA will be 2.

4.10.2 Estimation Process

In order to correct for differential representation, all estimates generated from the survey data will be weighted expressions. Therefore, if $\mathbf{y_{hij}}$ is an observation on variable **Y** for the h^{th} household in the $\mathbf{i^{th}}$ SEA of the j^{th} stratum, then the estimated total for the j^{th} stratum is expressed as follows:

$$Y_{jT} = \sum_{i=1}^{a_j} w_{ij} \sum_{k=1}^{n_j} y_{kij}$$

Where:

Yj_T = the estimated total for the j^{th} stratum

i = 1 to a_j: the number of selected clusters in the stratum

h = 1 to n_j: the number of sample households in the stratum

The total estimate for the 18 rural-urban strata will be obtained using the following estimator:

$$Y_T = \sum_{j=1}^{mj} Y_{jT}$$

Where:

Y_T = the national total estimate

j = 1 to mj: the total number of strata (In this case mj=18)

4.11 Data Processing and Analysis

The data from the survey will be entered, processed and analysed using the Statistical Package for Social Sciences (SPSS). Data entry will be done centrally at INESOR/CSO offices.

4.12 Expected Deliverables

Upon completion of data entry, various SPSS data sets will be created and cleaned based on the key themes of the study. In order to ensure data integrity, data cleaning will involve backfilling missing records and values and removal of duplicate cases that may arise during data entry. In short ZAFOD will be expected to submit to SINTEF data sets with very minimum levels of non-sampling errors.

A fully developed weight file will also need to be submitted to SINTEF for use when estimating population totals.

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 (provincial) differences. Whenever these potential confounders 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

	Number of:		
Source:	Households	Individuals	Persons with disabilities
Households having a person with disability	2885	15210	2898
Households without a person with disability (Controls)	2866	12979	192*
Total	5751	28189	3090

*192 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

	Disabled family member:				
	Households with	Households without	significance		
Province:	Mean size	Mean size	t	df	p
Copperbelt	5.2	4.7	2.9	769	0.004
Central	5.0	4.1	6.4	693	< 0.001
Eastern	5.3	4.4	4.3	694	< 0.001
Lusaka	4.4	3.7	4.7	697	< 0.001
Northern	6.0	5.0	3.2	289	0.002
Luapula	5.3	4.9	2.2	568	0.029
North Western	6.1	5.1	5.2	601	< 0.001
Western	5.5	4.7	3.8	640	< 0.001
Southern	5.3	4.5	4.4	782	< 0.001
Total	5.3	4.5	11.9	5749	< 0.001

Analyses revealed that, regardless of geographic region, households having at least one disabled household member were significantly larger 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

	Disabled family member:				
	Households with	Households without	significance		
Province:	Mean age	Mean age	t	df	p
Copperbelt	25.7	24.0	2.4	731	0.017
Central	22.5	24.0	-1.6	689	NS*
Eastern	25.4	25.1	0.2	595	NS
Lusaka	23.8	23.4	0.7	662	NS
Northern	25.1	21.8	2.2	244	0.031
Luapula	26.3	23.6	2.4	494	0.016
North Western	23.3	25.0	-1.6	524	NS
Western	29.1	24.4	4.1	593	< 0.001
Southern	23.2	21.8	2.0	770	0.045
Total	24.8	23.7	3.4	5318	0.001

*NS: not statistically significant

Overall, and with few exceptions geographically, the mean age of households with a disabled member is significantly higher than those households without disabilities regardless of geographical region.

Concerning gender distribution, 49.8% (N = 7572) of the members in households with disabled people were females, whereas the corresponding figures for the control households

was 50.7% (N = 6583). This difference between the two groups is not statistically significant.

Table 5.4 Gender, household type and Region

	Disabled family member:			
	Households with		Households without	
Region:	% female	N	% female	N
Copperbelt	50.8	1012	50.2	922
Central	46.8	814	46.8	672
Eastern	49.8	933	51.5	774
Lusaka	49.1	799	49.4	598
Northern	54.4	467	53.1	391
Luapula	50.4	738	51.5	737
North Western	48.4	901	50.9	769
Western	51.4	902	53.7	816
Southern	49.5	1006	50.4	904
Total	49.8	7572	50.7	6583

Another measure of the structure of households is the dependency ratio. This is a measure of the portion of a population which is composed of dependents (people who are too young or too old to work). The dependency ratio is equal to the number of individuals aged below 15 or over 65 divided by the number of individuals aged 15-64. A rising dependency ratio is of concern to countries with quickly aging populations, since it becomes difficult for pensions systems to provide for

this older, non-working population. A rapidly growing population with a high fertility rate will mean a relatively large proportion of the population consists of children who are dependent on the land and their families for sustenance. A dependency ratio of 1.0 means there is one working-age person for each dependent in the family (e.g. a family of four with two adults and two children). Dependency ratios over 1.0 indicate a burden on the wage earners in the family and dependency ratios under 1.0 are indicative of less burden. It indicates the economic responsibility of those economically active in providing for those who are not.

While the differences in the table below may seem insignificant, they indicates that families with at least one disabled family member have somewhat higher dependency ratios (increased economic burden) than do families without a disabled family member; most notably in Eastern, Lusaka and Northern provinces.

Table 5.5 Mean dependency ratio by Household type and Region

	Disabled family member:				
	Households with	Households without	significance		
Province:	Mean dependency ratio		t	df	p
Copperbelt	0.8	0.8	0.1	749	NS
Central	0.9	0.9	0.6	672	NS
Eastern	1.1	1.0	2.5	651	0.011
Lusaka	0.8	0.7	2.4	689	0.015
Northern	1.3	1.1	2.1	279	0.036
Luapula	1.0	1.2	-1.4	551	NS
North Western	1.1	1.0	0.6	558	NS
Western	1.1	1.1	0.2	596	NS
Southern	1.1	1.0	1.6	769	NS
Total	1.0	0.94	2.5	5530	0.011

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 dependents.

5.1.1 Disabled and non-disabled

The screening exercise described in Section 3.1.5 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 28189 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 3090 persons with disabilities were identified in the sample (i.e. 11.0% of 28189 individuals). By province the breakdown is as follows:

Table 5.6 Distribution of Disabled household members by province

Province:	persons with disabilities identified	sample population	% disabled
Copperbelt	377	3830	9.8
Central	356	3176	11.2
Eastern	409	3375	12.1
Lusaka	344	2837	12.1
Northern	213	1596	13.3
Luapula	310	2896	10.7
North Western	338	3371	10.0
Western	362	3277	11.0
Southern	381	3831	9.9
Total	3090	28189	11.0

Note: the data in the table above are not meant to be indicative of prevalence. These are derived from a selected sub-population based on a screening procedure that identified households with and without a disabled family member. It is anticipated that prevalence data will be presented in later publications

Table 5.7 Disability by gender

Gender	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Female	1345	43.5	12810	51.0	14155	50.2
Male	1744	56.5	12285	49.0	14029	49.8
Total	3089	100.0	25095	100.0	28184	100

A significant gender difference was found in that 43.5% (n = 1345) of those with disabilities were females whereas the corresponding figure for the non-disabled was 51.0% (n = 12810). (χ^2 = 62.0, df = 1, p = < 0.001)

Table 5.8 Disability by gender by region

	Disabled		Non-disabled		
Region:	% female	N	% female	N	significance
Copperbelt	40.6	153	51.6	1781	p < 0.001
Central	34.6	123	48.3	1363	< 0.001
Eastern	46.2	189	51.2	1518	NS
Lusaka	46.8	161	49.6	1236	NS
Northern	50.2	107	54.3	751	NS
Luapula	42.6	132	51.9	1343	0.002
N.Western	46.2	156	49.9	1514	NS
Western	43.1	156	53.6	1562	< 0.001
Southern	44.2	168	50.5	1742	0.023
Total	43.5	1345	51.0	12810	< 0.001

The same pattern was observed is all of the provinces, see table 5.8, above. In some provinces, however, the difference was not statistically significant (Eastern, Lusaka, Northern and North Western).

Mean age among the disabled household members was higher than among the non-disabled (31.3 years and 20.6 years respectively, $t = 26.56$, $df = 3472$, $p < 0.001$). This pattern was the same in each of the provinces.

Table 5.9 Disability by age and region

	Disabled		Non-disabled		significance		
Region:	mean age	N	mean age	N	t	df	p
Copperbelt	29.6	372	22.3	3377	6.7	422	< 0.001
Central	28.4	355	20.4	2812	7.9	430	< 0.001
Eastern	31.2	392	19.6	2835	9.5	446	< 0.001
Lusaka	27.3	339	21.1	2425	6.2	412	< 0.001
Northern	33.9	204	19.2	1317	8.8	234	< 0.001
Luapula	35.3	299	20.2	2498	10.9	335	< 0.001
N.Western	30.3	331	20.9	2883	7.9	380	< 0.001
Western	38.6	356	21.4	2842	12.9	404	< 0.001
Southern	29.0	379	19.7	3433	9.0	432	< 0.001
Total	31.3	3027	20.6	24422	26.6	3472	< 0.001

Further analyses by gender revealed the same pattern. The mean age for women was 31.4 years and 21.0 years in the

households with disabled members and the control group respectively ($t = 17.1$, $df = 1463$, $p < 0.001$), and for men the mean ages were 31.3 years and 20.2 years, $t = 20.5$, $df = 2019$, $p < 0.001$).

Table 5.10 Marital status

Marital status (age >= 15)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Never married	727	34.1	5289	39.6	6016	38.9
Married with certificate	249	11.7	1896	14.2	2145	13.9
Married traditional	703	33.0	4766	35.7	5469	35.3
Consensual union	24	1.1	102	0.8	126	0.8
Divorced/ Separated	124	5.8	463	3.5	587	3.8
Widowed	296	13.9	807	6.0	1103	7.1
Other	9	0.4	20	0.2	29	0.2
Total	2132	100	13343	100	154775	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, 34.1% compared to 39.6% among those without disabilities; among the disabled far fewer (45.8%) reported living in union (either married with certificate or traditionally, or in a consensual union) than those without disabilities (50.7%). In addition 13.9% of those reporting disabilities were widowed compared to only 5.0% of those non-disabled.

EDUCATION

Table 5.11 School attendance

School attendance (age >= 5)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Never attended	646	23.9	1717	8.8	2363	10.7
Still attending	569	21.0	8133	41.9	8702	39.3
Left school	1493	55.1	9572	49.3	11065	50.0
Total	2708	100	19422	100	22130	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. (χ^2 = 781.1, df = 2, p < 0.001). The proportion of those who have never attended school is almost three times higher among the disabled members as compared with the non-disabled (23.9% versus 8.8% respectively).

This finding was again confirmed among females and males separately (28% of disabled females and 21% of disabled males never attended school compared with 11% of non-disabled females and 7% 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 (Table 5.12). 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, an important difference is observed in school attendance (or lack thereof) according to the different categories of disability type. Looking at those who never attended school, 23.6% (or 251 of 1063) of those with seeing, hearing or communication (sensory) disabilities said that they had never attended school and 21.4% (or 204 of 955) of individuals who reported a physical disability, while 35.7% (90 of 252) 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 5.24)

Among those disabled *before 18 years of age* the same over-representation among those with psychological disabilities is seen. 24.1% of those with sensory disabilities, 22.0% of those with physical disabilities and 43.3% of those with psychological disabilities reported never having attended school. Results in both tables are statistically significant ($p < 0.001$).

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 >=5 years	n	%	n	%	n	%
never attended	251	23.6	204	21.4	90	35.7
still attending	246	23.1	193	20.2	42	16.7
left school	566	53.2	558	58.4	120	47.6
Total	1063	100	955	100	252	100

Age >= 5 years & disabled prior to 18 years

	n	%	n	%	n	%
never attended	142	24.1	123	22.0	74	43.3
still attending	224	38.0	168	30.0	37	21.6
left school	224	38.0	269	48.0	60	35.1
Total	590	100	560	100	171	100

Table 5.13 School grade completed

Grade completed (age >= 5)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Grade 9 or less	1589	80.0	13746	79.6	15335	79.6
Grade 10 – A level	279	14.0	2612	15.1	2891	15.0
Higher education	119	6.0	913	5.3	1032	5.4
Total	1987	100	17271	100	19258	100

Table 5.13 shows some interesting results among those who had in fact attended school. It appears that slightly more of those with a disability achieved a higher level of education. Though the differences observed are not statistically significant (χ^2 = 3.1, df = 2, p = NS), they seem to indicate that, given the opportunity to attend school, those with disabilities are able to match the achievements of those 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.

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 (49.9% versus 42.2% among the non-disabled population) (χ^2 = 57.0 df = 1, p < 0.001). The results are similar whether the cut-off is taken at 10 years or 15 years of age or older.

As above, the same pattern was confirmed in a gender analysis: among those with disabilities, 46.1% of males and 55.1% of females over the age of 5 years have no writing skills, compared to 38.3% of males and 46.0% 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 >= 5)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
None	1345	49.9	8376	42.2	9721	43.1
One or more	1350	50.1	11458	57.8	12808	56.9
Total	2695	100	19834	100	22529	100

Table 5.15 Work status: Unemployment

Work status (age 15 – 65)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Currently working or returning to work	785	45.5	7060	58.0	7845	56.5
Not currently working	939	54.5	5105	42.0	6044	43.5
Total	1724	100	12165	100	13889	100

Table 5.15 illustrates the degree of employment/ unemployment among persons between the economically active ages of 15 – 65 years. The data presented here are not meant to provide a statement on the unemployment rate in the country; however, they appear to indicate that the unemployment is currently very high in Zambia. The difference between those with and without disabilities appears to be large, and a significantly higher proportion of people with disabilities (54.5%) is currently not working than among people without disabilities (42.0%) ($\chi^2 = 95.5$, df = 1, $p < 0.001$).

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.

Table 5.16 Unemployment by province

Province:	Disabled	Non-disabled	p-value
Copperbelt	50.2	42.3	0.035
Central	41.2	28.5	< 0.001
Eastern	42.9	26.1	< 0.001
Lusaka	60.4	47.3	< 0.001
Northern	57.3	62.5	NS
Luapula	60.7	41.8	< 0.001
North Western	58.2	46.4	0.003
Western	75.5	62.6	0.001
Southern	49.3	34.0	< 0.001

Similar patterns of unemployment were observed across all provinces. Apart from Northern province, where unemployment was slightly (though non-significantly) higher among those without disabilities, people with disabilities showed higher rates of unemployment than those without disabilities. Highest unemployment was observed in Northern and Western provinces while Central and Eastern provinces provided the lowest rates observed in the survey.

Examining men and women separately, statistically significant differences were observed in unemployment among males (disabled 54% and non-disabled 45%) ($\chi^2 = 25.1$, df = 1, $p < 0.001$), and women (disabled 55% and non-disabled 39%) (χ^2

= 70.6, df = 1, p < 0.001). Interestingly, unemployment among those without disabilities was lower among women than men (39% versus 45%) while the unemployment rates were very similar among those with disabilities (women 55%, men 54%).

SKILLS

It was however shown that among the same group of potentially economically active persons 15 – 65 years of age, 59.0% (n = 741) of those with disabilities had acquired some skill, compared to 58.7% (n = 4907) of the non-disabled (χ^2 = 0.05, 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. Somewhat divergent patterns were seen in the provinces, with higher rates for those with skills among the disabled in Copperbelt, Central, Lusaka, Northern, and North Western provinces, though none of the observed differences were large enough to reach statistical significance. By gender no significant differences were observed with respect to disability and possession of skills, though again significantly more males (64%) than females (54%) had acquired some form of skill.

Table 5.17 Skills

Skills (age 15 – 65)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Yes	741	59.0	4907	58.7	5648	58.7
No	514	41.0	3456	41.3	3970	41.3
Total	1255	100	8363	100	9618	100

As may be expected, more persons with skills (formally or informally trained) are employed as compared to persons without skills (77% versus 41%). Among persons with disabilities, 65% (n = 474) of individuals with skills are employed, as compared to 25% (n = 127) of individuals without skills (χ^2 = 190.5, df = 1, p < 0.001). In the non-disabled group the figures were, 79% (n = 3772) of individuals with skills being employed, as compared to 43% (n = 1447) of individuals without skills (χ^2 = 1130.7, df = 1, p < 0.001).

Among the 7845 individuals who said they were currently working or returning to work, 4389 (56%) gave their mean monthly salary. There was no statistically significant difference observed in mean monthly salary between those with and without disabilities (disabled: 614,627 ZMK, non-disabled: 724,777 ZMK), (t = 0.93, df = 4387, p = NS). Similar trends and results were observed in the provinces. North Western province showed higher mean monthly income among those

with disabilities, though these results were also not statistically significant.

Table 5.18 Monthly salary (in 1000)

	Disabled	Non-disabled	
Mean monthly salary	ZMK	ZMK	p-value
Copperbelt	762	837	NS
Central	541	812	NS
Eastern	516	525	NS
Lusaka	1003	1405	NS
Northern	328	401	NS
Luapula	425	453	NS
North Western	595	584	NS
Western	325	380	NS
Southern	542	596	NS
Total	615	725	NS

As may have been expected, women's monthly salaries were lower than men's among those with and without disabilities. Among those without disabilities, women's mean salaries were 514,619 ZMK versus 858,522 ZMK for men ($p < 0.001$). Among those with disabilities women's mean salaries were 517,245 ZMK compared to 659,445 ZMK 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 5.19 Regional distribution of households

Region	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
Copperbelt	380	13.2	390	13.6	770	13.4
Central	344	11.9	349	12.2	693	12.1
Eastern	356	12.4	340	11.9	696	12.1
Lusaka	366	12.7	325	11.4	691	12.0
Northern	142	4.9	147	5.1	289	5.0
Luapula	276	9.6	293	10.2	569	9.9
North Western	305	10.6	296	10.4	601	10.5
Western	320	11.1	322	11.3	642	11.2
Southern	392	13.6	397	13.9	789	13.7
Total	2881	100	2859	100	5740	100

EMPLOYMENT

Table 5.20 Employment

Is someone in the household working?	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
No	473	16.4	467	16.3	940	16.3
Yes	2413	83.6	2398	83.7	4811	83.7
Total	2886	100	2865	100	5751	100

No significant difference was observed between households with or without a disabled family member in terms of having at least one family member working; about 16% of households, regardless of disability status have no one employed.

Regionally the overall pattern was about the same; however the rate of having no household member in employment ranged from about 4.5% in Central province to 36% in Western and Northern provinces. Only in Northern and Western provinces were the differences between households with and without a disabled family member statistically significant. In Western province significantly more households with a disabled family member had no one employed (39%) compared to 32% among households without a disabled family member, while in Northern province the trend was reversed with significantly more control households having no employed

family members (43%) compared to households with a disabled family member (31%).

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

Household income and expenses were measured in ZMK (Zambian Kwacha, 1 USD = 3,567.5 ZMK, 01.06.06).

Table 5.21 Household income and expenses (in 1000 ZMK)

Household income - good month						
	Disabled HH		Non-disabled HH		Total	
	n	%	n	%	n	%
none	151	7.4	110	5.2	261	6.3
<249	647	31.6	686	32.3	1333	32.0
250-499	394	19.2	403	19.0	797	19.1
500-2 499	732	35.7	806	37.9	1538	36.9
>=2 500	124	6.1	119	5.6	243	5.8
Total	2048	100	2124	100	4172	100
					$\chi^2 = 10.0$, df = 4, p = 0.04	

Table 5.21 …/continued

Household income - bad month

	Disabled HH		Non-disabled HH		Total	
	n	%	n	%	n	%
none	349	18.9	284	14.9	633	16.9
<249	768	41.5	818	43.1	1586	42.3
250-499	314	17.0	333	17.5	647	17.3
500-2 499	357	19.3	397	20.9	754	20.1
>=2 500	62	3.4	68	3.6	130	3.5
Total	1850	100	1900	100	3750	100

$\chi^2 = 10.5$, df = 4, p = 0.03

Household expenses

	Disabled HH		Non-disabled HH		Total	
	n	%	n	%	n	%
none	97	5.0	74	3.7	171	4.3
<249	944	48.5	1023	50.6	1967	49.5
250-499	387	19.9	398	19.7	785	19.8
500-2 499	475	24.4	486	24.0	961	24.2
>=2 500	45	2.3	42	2.1	87	2.2
Total	1948	100	2023	100	3971	100

$\chi^2 = 5.4$, df = 4, p = NS

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 1594 households (38.3%) have monthly incomes under 249 000 ZMK in a good month and this increases to 2219 households (59.2%) in a bad month. Many households are dependent upon incomes that are unstable. Furthermore, it appears from the results presented in Table 5.21 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 5.21).

A list of 39 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 35 and the mean number of possessions for the entire sample was 9.8 items.

No significant difference was observed between households with and those without a disabled family member, each having an average of about 9.8 possessions. Lusaka was the only province to demonstrate a significant difference between household type, with respect to mean number of possessions; households with a disabled family member had, on average, slightly fewer possessions (8.5) as compared to households without disabled members (9.9). This apparently slight difference is statistically significant ($t = 3.4$, $df = 676$, $p = 0.001$). More importantly, these relatively low numbers are a reflection of the level of living standards in Zambia in general.

Fewer disabled households stated that salaried work was the primary source of income – 25% versus 30% - 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, subsistence farming: about 30% in each type of household and informal business about 19%.

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, sun-dried bricks, other), and walls (poles and mud, corrugated iron, grass/leaves, bricks, compacted earth, concrete, other). None of these housing characteristics showed any particular difference with respect to type of household (disabled/non disabled). This is perhaps in part a consequence of the design of the survey, in that we attempted to match households with and without a disabled family member in each of the region surveyed.

It was observed however that the size of the house (as measured in number of bedrooms) was slightly larger in households without a disabled family member (1.8 versus 1.7; $t = 3.1$, $df = 5613$, $p = 0.002$). Moreover households without a disabled family member more often have mosquito nets for some or all beds in the household and these are more often than not treated with chemicals. These results are perhaps reflective of the slightly higher economic status of these households.

Table 5.22 Housing ownership

Ownership	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
Rented	466	16.5	533	18.9	999	17.7
Owned	2096	74.1	1949	69.2	4045	71.7
Rent free, not owned	50	1.8	56	2.0	106	1.9
Provided by employer (gov't)	146	5.2	194	6.9	340	6.0
Provided by employer (private)	65	2.3	81	2.9	146	2.6
Other	4	0.1	4	0.1	8	0.1
Total	2827	100	2817	100	5644	100

Table 5.22 illustrates a slight difference in housing ownership between the two groups; most notably, more households with a disabled family member were home-owners than were households without a disabled family member. The differences in the above table were statistically significant, but by and large the similarities between the two samples is most striking and again illustrates 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 or shared)
2. communal toilet
3. san plat (vip)
4. pit latrine
5. bucket/pan
6. 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 31 (worst standard). For the 5355 (93.2%) of households that had data recorded for all 5 variables the range was from 5 to 29, mean 17.2 (SD 5.1).

Standards, as defined above, varied across the provinces: from best (13.7) in Copperbelt and (14.2) in Lusaka, to worst (19.2) in Northern, (19.6) in Luapula, (20.1) in Western and (20.5) in North Western province.

The mean difference between households with a disabled and those without was 17.3 and 17.2 respectively (p = NS), indicating that, with respect to the five indices included, and despite the differences in housing situation described above, households with disabled family members, on average, did not have a lower standard than did households without a disabled family member. These findings were replicated in each of the nine provinces.

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, post office and library. Each of these was coded as:

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

As above, a composite score was devised by adding the above 8 elements into a scale to define standard with respect to information access. This scale had a possible range from 8 (full access/availability) to 32 (no access/availability), again higher score reflects a lower level of accessibility. For the 5092 (88.6%) of households that had data recorded for all 8 variables, the range was 8 to 32, mean 24.7 (SD 6.4).

Access to information, as defined above, was significantly greater in Central (22.2), Eastern (22.6), Copperbelt (22.8), Southern (23.6) and Lusaka (23.9) provinces; and poorer in Luapula (26.8), North Western (27.7), Western (28.6) and Northern (28.7) provinces.

The mean difference between households with a disabled and those without was 24.8 and 24.6 respectively (p = NS) indicating that, with respect to the eight information elements included, households with disabled family members, on average, had similar access to information as did households without a disabled family member.

Only in Southern province was the difference between households significant; with households having a disabled family member achieving poorer results (24.3) as compared to households without a disabled family member (22.9) ($t = 3.09$. $df = 758$, $p = 0.002$).

5.2 Disability study

Of the 2898 individuals identified as having a disability during the first phase of the survey (Living conditions survey), a total of 2865 (98.9%) responded to the detailed disability survey. In about 40% of the cases the person with the disability responded themselves, whereas proxy reporters answered in the remaining 60%.

Table 5.23 Age profile of person with disability

Age group in years	Male		Female		Total	
	n	%	n	%	n	%
0-5	114	7.3	96	8.3	210	7.7
6-10	206	13.1	139	12.0	345	12.6
11-20	336	21.4	250	21.5	586	21.4
21-30	251	16.0	191	16.4	442	16.2
31-40	220	14.0	134	11.5	354	13.0
41-50	163	10.4	127	10.9	290	10.6
51-60	113	7.2	112	9.6	225	8.2
61+	167	10.6	113	9.7	280	10.2
Total	1570	100	1162	100	2732	100

The age range for the group of disabled was from 0 to 95 ears. Mean age was 30 years (males: 30.1 years, females: 30.2 years). Gender distribution in this sub-sample was 57% men

and 43% women. No significant age/gender associations were observed.

Among the provinces, only Central and Lusaka provinces showed any significant gender differences; in Central province males were over-represented (13.5%) compared to females (9.4%), and in Lusaka females were over-represented (12.3%) compared to males (10.0%). And with respect to mean age, respondents from Western (38.1 years), Luapula (34.4 years) and Northern (36.0 years) provinces were significantly older than respondents from the other provinces (mean age less than 30 years).

Table 5.24 Distribution of the type of main disability by gender

Type of disability	Male		Female		Total	
	n	%	n	%	n	%
Seeing	335	22.6	295	26.4	630	24.2
Hearing	287	19.4	219	19.6	506	19.5
Communication*	51	3.4	38	3.4	89	3.4
Physical	625	42.2	457	40.8	1082	41.6
Intellectual/ emotional	183	12.4	110	9.8	293	11.3
Total	1481	100	1119	100	2600	100

*includes: dumb, stammering and tongue-tied

Respondents were asked to describe their disability in their own words, and the major disability described was coded. Overall, about 42% of coded disabilities were classified as

physical. These include minor and major physical disabilities (including paralysis) and 47% 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.

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. Main recorded causes of disability include physical illness, congenital/from birth and accidents. Of interest is the fact that 6.5% who reported that witchcraft was the cause of their disability.

Almost 30% of disabilities registered were reported as originating at birth. In addition, 43.1% of those who responded claimed that they became disabled as children or young adults (age less than or equal to 20 years). 21.4% 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 5.25 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	2287	79.8	2198	76.7	1738	79.3
Traditional healer	2106	73.5	926	32.3	582	62.9
Medical rehabilitation	1762	61.5	1812	63.2	679	37.5
Counselling for parent/family	1179	41.2	1354	47.3	295	21.9
Assistive device services	1717	59.9	1642	57.3	301	18.4
Educational services	1557	54.3	1347	47.0	239	17.8
Counselling for disabled	1277	44.6	1468	51.2	209	14.3
Welfare services	1500	52.4	1794	62.6	151	8.4
Vocational training	1292	45.1	1006	35.1	84	8.4

* percentage of total number disabled (n = 2865)

** percentage of those claiming they needed the service

With the exception of counselling (both for parents/family and for the disabled themselves) and vocational training services 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 = 74%:32%)
- educational services (awareness:need = 54%:47%)
- vocational training (awareness:need = 45%:35%)

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, for certain services the expressed need was greater than the awareness of the service: welfare services (awareness:need = 52%:63%), counselling services for the person with a disability (awareness:need = 45%:51%) and counselling services for parents/family (awareness:need = 41%:47%). 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 8.4% 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, and educational services were received by less

than 25% of those who needed them. On a brighter note, almost 80% 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 5.26 Gap analysis (services not received) by type of disability

	Total Gap	Type of disability		
		Sensory	Physical	Mental/ emotional
Health services	21.7	23.4	17.1	21.2
Traditional healer	38.1	43.2	39.0	13.6
Medical rehabilitation	62.5	71.5	49.7	69.8
Counselling for family	78.1	81.1	73.1	80.8
Assistive device services	81.6	84.6	74.7	94.9
Educational services	82.2	82.8	80.0	87.6
Counselling for disabled	85.7	89.3	81.6	85.2
Welfare services	91.6	93.5	91.1	91.1
Vocational training	91.6	91.5	91.3	93.5

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 50%, 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 287 individuals (10%) expressed no need for any of the services listed (or other services not listed). Only 8.2% or 232 individuals expressed a need for a single service, the majority requiring multiple services and 56% 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 5.27 Assessment of services received

Service:	Experience with service:						
	N	Too costly	Too far	Not helping	Level reached	Not available	Not Satisfied
Health services	807	8.1	10.2	49.8	14.3	1.5	9.5
Traditional healer	423	5.7	2.1	47.5	5.4	0.7	28.6
Medical rehabilitation	485	16.3	11.5	40.4	19.0	2.5	4.7
Counselling for family	183	1.1	1.6	49.7	12.6	9.3	7.7
Assistive device services	116	19.0	4.3	14.7	17.2	9.5	4.3
Educational services	108	16.7	11.1	13.0	14.8	7.4	2.8
Counselling for disabled	138	2.9	4.3	37.7	18.8	13.8	5.8
Welfare services	87	5.7	11.5	17.2	4.6	24.1	5.7
Vocational training	74	13.5	1.4	6.8	32.4	4.1	5.4

Of those who responded to these individual questions, in many instances almost 50% found that the service they were using was no longer helpful. With the exception of traditional healers, dissatisfaction was not a cause for termination of the service. Other important reasons for termination of service were cost, (in particular for rehabilitation, assistive device and educational services), availability (for welfare services) and accessibility (in terms of distance to service).

EDUCATION

Of those sampled 60.2% (n = 1726) were *disabled before 18 years of age*. These were asked about their education and schooling experiences. Table 5.28 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 (32.9%) 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 66.0% of disabled children 15 years and over, (i.e. eligible for high school) did not attend, and over 90% 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 35 individuals were refused entry to regular pre-school, 187 were refused regular primary school and 70 were refused regular high school. In addition, 9 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, 70 (10.5% of those who responded) said that they had studied as far as they had planned and 153 (23%) were still studying. Almost two-thirds (66.4%) said that they had not studied as far as they had planned.

Table 5.28 Type of school attended

What type of school do/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)	214	83.6	34	13.3	8	3.1	1368	84.2	1624
Primary school (age >= 5 years)	1031	90.1	88	7.7	25	2.2	562	32.9	1706
High school (age >= 15 years)	317	89.3	27	7.6	11	3.1	689	66.0	1044
Tertiary (age >= 18 years)	67	89.3	3	4.0	5	6.7	790	91.3	865
Vocational training (age >= 18 years)	40	66.7	12	20.0	8	13.3	802	93.0	862

*%: percentage of those who DID GO TO SCHOOL

EMPLOYMENT

Asked whether they were currently working or returning to work, those 15 years and older (n=1960) replied:

- 473 (25.3%) currently working,
- 285 (15.2%) not currently working, but have been previously employed,
- 1072 (57.2%) never been employed
- 43 (2.3%) housewife
- 87 no response

Among those who had never been employed, 129 reported that they were still attending school – leaving at total of 943 individuals aged 15 years or older who had never been employed. Among the 285 who were not currently working but had been previously employed, 27% had terminated employment because of their disability.

ACCESSIBILITY

Accessibility at home is shown in Table 5.29. 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. Few households have separate dining rooms (overall over 57% do not have them) and almost 23% claim not to have separate living rooms. Overall 9.4% of

households do not have separate toilet facilities (see column "have none").

Table 5.29 Accessibility at home

	Accessible		Not accessible		Have none		Total
Room/ facility	n	%	n	%	n	%	N
Kitchen	2491	88.1	167	5.9	171	6.0	2829
Bedroom	2649	93.6	137	4.8	45	1.6	2831
Living room	2056	72.7	125	4.4	649	22.9	2830
Dining room	1126	39.8	82	2.9	1619	57.2	2828
Toilet	2364	83.6	197	7.0	266	9.4	2837

Table 5.30 Accessibility from home

	N	Never go		# who use facility	Accessible		Not accessible		None available	
		n	%		n	%	n	%	n	%
Place of worship	2809	384	13.7	2425	2194	90.5	221	9.1	9	0.4
Health care clinic	2805	354	12.6	2451	2076	84.7	287	11.7	88	3.6
Hospital	2798	552	19.7	2246	1350	60.1	407	18.1	489	21.8
Public transport	2794	496	17.8	2298	1501	65.3	465	20.2	332	14.4
Shops	2807	642	22.9	2165	1816	83.9	282	13.0	67	3.1
Sports facilities	2810	1296	46.1	1514	1130	74.6	167	11.0	217	14.3
Post office	2812	1310	46.6	1502	766	51.0	232	15.4	504	33.6
Magistrates office	2806	1438	51.2	1368	833	60.9	203	14.8	332	24.3
Recreational facilities	2811	1591	56.6	1220	737	60.4	139	11.4	343	28.1
Workplace	2800	1864	66.5	936	638	68.2	85	9.1	213	22.8
Police station	2808	1348	48.0	1460	805	55.1	242	16.6	413	28.3
School	2802	1896	67.7	906	691	76.3	129	14.2	86	9.5
Bank	2803	1457	52.0	1346	502	37.3	223	16.6	621	46.1
Hotels	2739	1456	53.2	1283	282	22.0	90	7.0	911	71.0

As can be seen in the table above, accessibility does not seem to be a major problem for people with disabilities in the survey. Places of worship, primary health care clinics, shops and schools are accessible to over 75% of those who responded and who had use for the facility. On the other side, however, it is worth noting that public transport and hospitals are NOT accessible to about a fifth of the population (18.1% and 20.2% respectively).

TECHNICAL AIDES AND ASSISTIVE DEVICES

Respondents were also asked if they used assistive devices – 372 of 2865 (13.0%) responded "yes". More than one type of device could be registered. Interestingly, significantly more men (16%) than women (12%) claimed to use an assistive device ($\chi^2 = 6.9$, df = 1, p = 0.008). There appeared also to be some regional differences in use of assistive technology (of all types): about 18% of those identified as having a disability used assistive devices in Copperbelt and Central provinces and less than 10% reported the same in North Western (7.8%), Eastern (8.3%), Lusaka (8.3%) and Northern (4.6%) provinces. ($\chi^2 = 35.1$, df = 8, $p < 0.001$). The remaining provinces fell between these extremes.

Table 5.31 Type of assistive devices in use

Type of device	Examples	# users	# respondents	%
Personal mobility	Wheelchairs, crutches, walking sticks, white cane, guide dog, standing frame	206	266	77.4
Information	Eye glasses, hearing aids, magnifying glass, enlarge print, Braille	92	221	41.6
Personal care & protection	Special fasteners, bath & shower seats, toilet seat raiser, commode chairs, safety rails, eating aids	1	172	0.6
Communication	Sign language interpreter, fax, TTY, portable writer, PC	22	178	12.4
For handling products and goods	Gripping tongs, aids for opening containers, tools for gardening	1	200	0.6
Household items	Flashing light on doorbell, amplified telephone, vibrating alarm clock	2	171	1.2
Computer assistive technology	Keyboard for the blind	1	171	0.6

Asked whether their device was in good working condition 76% answered “yes”.

14% of those using assistive devices had acquired their device from government health services, 9% through NGOs, 44% privately and the rest through other sources. When asked who maintains or repairs the device, 46% replied that they took responsibility for the device themselves, 3.6% stated that the government undertook maintenance and reparations, while 20.8% relied on their families for support in these matters and 21.1% claimed that their device either were not maintained or that they couldn't afford maintenance/repairs.

73% of those using personal mobility devices had received at least some guidance or instructions for use but almost a quarter (23%) was given no information or help in how to use or maintain their assistive device.

Table 5.32 Assistance needed in daily life activities

Do you need help with:		Yes		Sometimes		combined	% responding yes/sometimes		
	N	n	%	n	%	%	male	female	p-value
emotional support	2642	1954	74.0	354	13.4	87.4	87.4	87.2	NS
finances	2532	1184	46.8	520	20.5	67.3	64.1	72.0	< 0.001
shopping	2537	1135	44.7	477	18.8	63.5	65.5	60.8	0.018
cooking	2575	1421	55.2	293	11.4	66.6	73.0	58.8	< 0.001
transport	2470	1054	42.7	510	20.6	63.3	60.9	66.6	0.004
studying	1057	359	34.0	127	12.0	46.0	43.1	48.5	NS
moving around	2736	509	18.6	447	16.3	34.9	34.7	35.4	NS
bathing	2782	379	13.6	305	11.0	24.6	25.3	23.5	NS
dressing	2774	300	10.8	267	9.6	20.4	20.3	20.3	NS
toileting	2779	210	7.6	174	6.3	13.8	13.7	14.1	NS
feeding	2767	164	5.9	105	3.8	9.7	9.9	9.4	NS

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. These figures are based on the portion of the sample that did not classify the activity as 'not applicable'; the basis, or denominator, for the calculations is found in the column to the left. Help with studying was perhaps the most age dependent – and approximately 60% of the sample said that this was not applicable. As in the other activities, this question was therefore based on those who responded yes, yes sometimes or no (n = 1057).

We chose to examine the difference in needs based on gender and determine whether these dependencies impacted on perceived needs for assistance.

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, statistically significant differences were observed for assistance required with finances; 72% of women needing assistance compared to 64% of men (χ^2 = 16.9, df = 1, p < 0.001), shopping; 61% of women and 66% of men (χ^2 = 5.6, df = 1, p = 0.018), cooking; 59% of women and 73% of men (χ^2 = 57.8, df = 1, p < 0.001), and transport; 67% of women and 61% of men (χ^2 = 8.1, df = 1, p = 0.004). The

other small differences observed in the data were non-significant.

Table 5.33 Involvement in family life

Involvement in family life	N	% yes	% sometimes	% no
Do you go with the family to events?	2640	63.1	14.5	22.4
Do you feel involved and part of the family?	2613	86.3	5.4	9.3
Does the family involve you in conversations?	2634	79.1	9.7	11.2
Does the family help you with daily activities?	2699	81.4	11.3	7.2
Do you appreciate it that you get this help?	2488	91.9	2.8	5.3
Did you take part in your own traditional ceremonies?	2159	49.0	5.5	45.5
…for those over 15 years				
Are you consulted about making household decisions?	1876	74.6	12.8	12.5
Do you make important decisions about your life?	1887	61.2	7.5	31.3
Are you married or involved in a relationship?	1893	47.7		52.3
Does your spouse/partner have a disability?	957	9.1		90.9
Do you have children?	1847	63.9		36.1

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 22% are not included in family events, 11% are not involved in conversations and 9% do not feel a part of the family. Furthermore, of those 15 years and older, 12.5% are not consulted about making household decisions and 31.3% 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.

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 5.25 – need for services, and Table 5.32 – 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 4. For more background concerning activity limitations and participation restrictions see Section 4.5.1). For each of the 43 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 5.34 Characteristics of the severity scales.

Severity scales	Maximum possible score	n	maximum score in study	mean
Daily activity help score	11	2823	11	3.1
Service needs score	9	2834	9	4.8
Activity limitations	172	2854	162	28.8
Participation restrictions	172	2853	161	26.1
Sensory experiences	8	2837	8	1.4
Learning & knowledge	20	2807	20	3.4
Communication	16	2754	16	2.3
Mobility	40	2835	40	6.1
Self care	20	2832	20	1.8
Domestic life	20	2832	20	4.1
Interpersonal behaviours	20	2820	20	2.8
Major life areas	12	2764	12	1.7
Community & social life	16	2799	16	2.8

These 13 scales are then assessed by type of disability as illustrated in Table 5.35 below.

Table 5.35 Mean scores on severity scales by type of disability.

	Type of disability		
Severity scales	sensory	physical/ mobility	mental/ emotional
N	1245	1088	292
Daily activity help score	2.7	3.3	4.0
Service needs score	4.8	4.7	4.8
Activity limitations	22.5	30.8	49.0
Participation restrictions	20.1	27.7	46.5

…/continued

Table 5.35 …/continued	Type of disability		
Severity scales	sensory	physical/ mobility	mental/ emotional
N	1248	1092	296
Sensory experiences	2.6	0.4	0.4
Learning & knowledge	3.3	1.9	9.8
Communication	3.2	1.0	3.8
Mobility	1.9	11.7	3.2
Self care	0.8	2.5	4.1
Domestic life	2.7	4.6	8.1
Interpersonal behaviours	2.5	1.8	7.9
Major life areas	1.3	1.4	4.1
Community & social life	1.9	2.8	6.1

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 ($F = 45.3$, $df = 2/2622$, $p < 0.001$). 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 5.35 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: $F = 150.2$, $df = 2/2650$, $p < 0.001$; Participation restrictions: $F = 145.9$, $df = 2/2649$, $p < 0.001$). 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 than do those with either sensory or physical impairments.

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 5.36. Gender analyses revealed no significantly different scores on any of the scales examined. Activity limitation and participation restriction scores were similar for both sexes. This 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.

Table 5.36 Mean scores on severity scales by gender.

	Gender		
Severity scales:	Male n=1585	Female n=1194	p value
daily activity help score	3.1	3.0	NS
service needs score	4.9	4.7	NS
activity limitations	29.0	28.5	NS
participation restrictions	26.4	25.9	NS

Turning to region, there are some interesting patterns and differences that are worth highlighting. For example, Lusaka province has some of the lowest scores for all measures. This may indicate that services are more prevalent, that the urban centre is more accessible to individuals with disabilities and they thereby experience fewer activity limitations and participation restrictions. Higher scores are reported for

Luapula and Copperbelt provinces on measures of activity limitations and participation restrictions, while Northern and Southern provinces report highest scores on the measure of need for services.

Table 5.37 Mean scores on severity scales by region.

	N	daily activity help score	service needs score	Activity limitations	Participation restrictions
Copperbelt	387	3.0	2.6	31.5	31.9
Central	334	3.5	5.5	30.8	24.4
Eastern	356	3.3	5.6	28.4	25.2
Lusaka	330	2.3	4.5	19.4	19.2
Northern	123	2.6	7.1	24.3	22.1
Luapula	279	3.9	4.3	38.9	35.0
N. Western	323	3.0	3.6	26.2	22.2
Western	333	2.9	5.3	28.3	24.3
Southern	389	3.0	6.0	29.4	28.5
p-value		< 0.001	< 0.001	< 0.001	< 0.001

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.

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, high scores are found among those having both good and poor physical health. While

the association was found to be statistically significant, it is more difficult to explain and may be a reflection of the need for services being 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		
	n=255	n=801	n=1131	n=630		
Severity scales:	mean	mean	mean	Mean	F statistic	p value
Daily activity help score	4.3	3.1	3.1	2.5	33.7	<0.001
Service needs score	4.9	4.3	5.0	5.0	12.9	<0.001
Activity limitations	39.9	31.0	27.7	23.8	27.7	<0.001
Participation restrictions	36.7	28.3	25.8	20.1	29.5	<0.001

Mental health	poor	Not very good	good	Very good		
	n=172	n=476	n=1301	n=857		
Severity scales:	mean	mean	mean	Mean	F statistic	p value
Daily activity help score	4.4	3.7	3.1	2.3	55.9	<0.001
Service needs score	5.2	4.7	5.0	4.4	7.6	<0.001
Activity limitations	60.7	38.3	25.6	22.2	161.5	<0.001
Participation restrictions	55.4	35.1	24.1	18.7	141.7	<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: not currently employed, currently employed). Looking first at the mean scores based on assistance required for daily activities, we found that those currently employed scored significantly lower than the unemployed. 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. Recall that while we did not find any specific gender dependency when looking at the elements in this scale (see Table 5.36), 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. The group defined as not currently 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 very similar between both the groups assessed, based on school attendance and employment. This finding may be explained by the simple fact that, despite their more active social participation through either education or employment, they meet different obstacles and have different requirements for services than those who are not similarly active.

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	currently attending or finished school		
	n = 578	n = 1844		
Severity scales:	mean	mean	t statistic	p value
Daily activity help score	3.4	2.7	6.1	<0.001
Service needs score	4.6	4.8	-1.5	NS
Activity limitations	41.1	25.1	11.7	<0.001
Participation restrictions	38.8	22.3	12.1	<0.001

Work situation (age >= 15)	Not Currently employed	Currently employed		
	n=1168	n=738		
Severity scales:	mean	Mean	t statistic	p value
Daily activity help score	3.0	1.9	12.0	<0.001
Service needs score	4.7	4.7	0.2	NS
Activity limitations	34.5	19.5	14.6	<0.001
Participation restrictions	31.4	17.6	13.5	<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

Characteristic	*Old paradigm*	*New paradigm*
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 Zambia. 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 figure below presents such a scenario. A relatively small sub-sample of those in our sample who were identified as NOT having a disability (107 individuals) was asked to complete the activities and participation matrix. Their responses are illustrated in the figure below.

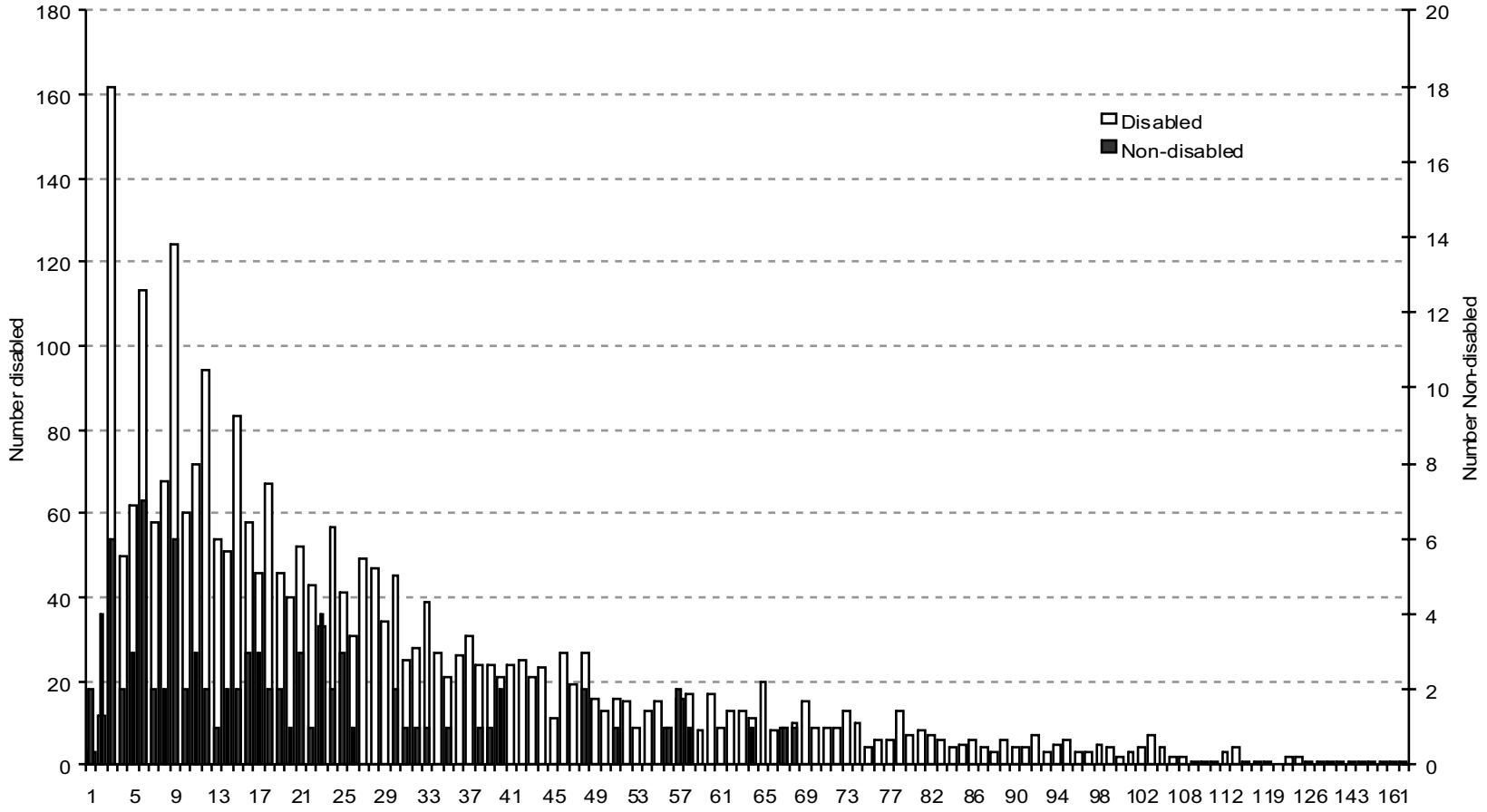


Figure 5.2 Activity limitations among people with and without disabilities

Similar results were seen when participation restrictions were analysed, however, for reasons of simplicity, only the activity limitation graph is presented here.

The above figure clearly indicates 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 9% of those with disabilities scored 4 or less on the activity limitation score compared to 24% 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 75% 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 nationwide representative study on living conditions among people with activity limitations has been carried out in Zambia in 2005 – 2006. This report provides some of the most important results from the study. Partners ZAFOD, INESOR, CSO and SINTEF Health Research have thus established an important basis for promoting better living conditions for people with disabilities in Zambia. The study offers an 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. The study also 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), Zambia, Mozambique (2008) and possibly other SADCC member countries 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.

A particular feature of the study is the inclusion of a control sample of households and individuals without disabilities. Few in-depth studies of living standards focussing on disabilities have been carried out in Zambia. In addition to addressing the situation of people with disabilities, this study also provides a unique set of data on living conditions that may be useful for monitoring the general standard of living in the country.

Conceptually and operationally based on ICF, the study also offers an opportunity to develop a new generation of disability statistics. With ICF, a foundation is established upon which health, functional limitations, personal and environmental factors may be studied together. This provides an opportunity also to move beyond the dominating descriptive disability statistics and to analyse relationships and factors which contribute to exclusion of individuals with disabilities from social participation.

Socio-demographic differences between the two types of households (those with and without disabled family members) were similar among the four studies that have so far been completed (Namibia, Zimbabwe, Malawi and Zambia). Households with disabled members are larger and mean age of family members is higher. Dependency ratio was also shown to be higher among households with disabled members, reflecting primarily a higher number of children in these families (mean number of children 2.6 and 2.2, $p < .001$).

A particular demographic difference was found in that a clearly higher proportion of men were found to be disabled compared to their female counterparts. This is in line with the previous studies in the region, but this gender difference was demonstrated to be significantly higher in the Zambian sample as compared to the previous three studies. Furthermore, individuals with disabilities are younger than those without disabilities. All in all, these household differences 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. Largely, the observed differences in levels of living conditions in the data material from Zambia substantiate the pattern that was first observed in the Namibian, Zimbabwean and Malawian studies.

The disability component of the survey revealed a relatively even distribution of people with disabilities across age categories. This is very similar to the pattern in Namibia,

Zimbabwe and Malawi, 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 Zambia 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 demonstrates a different "causal profile" than in high-income countries. This should have bearings also on service development, rehabilitation, as well as preventive measures.

By using the disability screening procedure proposed by the Washington Group on Disability Statistics, it was anticipated that we would be able to identify a larger population of people with disabilities than what would be possible through the application of the more traditional, impairment based screening procedures. It appears from the prevalence data presented here that this approach has succeeded. It has been shown that by focussing on difficulties in carrying out certain activities (seeing, hearing, walking, remembering, self-care & communicating) rather than measuring impairments, the screening instrument was able to capture 13.3% of the population as having one or more activity limitation compared to 2.7% using a modified ICF approach in the 2000 census and 0.9% using an impairment based approach in the 1990 census.

While the age profile in the Zambian population contributes significantly to explain the prevalence distribution among the population, there are however several other possible reasons for the classical differences observed in disability prevalence between low- and high-income countries. The information gathered through the type of survey described here 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 more often not included in most peoples' conception of disability. In addition to problems with comprehension of the new conceptual framework, traditional beliefs concerning disability, generally higher mortality rates among the population, a more family-oriented, inclusive society, and lower level of social complexity (i.e. a less techno-dependent social structure), are all possible explanations for the marked difference in prevalence. Most researchers in the field will however underline measurement procedures as the most important, and the study in Zambia, together with the other corresponding studies in the Region, may be seen as part of a process towards more sensitive measures on disability and activity limitations (Eide & Loeb 2006).

The age profile in the data material as well as the information about causes of disability imply 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 Zambia, at least not to the same extent. This should be seen

as a serious challenge to the health services in the country, and in less developed countries generally.

It was found that need for emotional support surpassed economic support when asking for what type of assistance that was needed in daily life. This is important to bear in mind when developing services for people with disabilities, as emotional needs will more readily be neglected when the focus of service delivery is generally in terms of practical help and economic and material needs. Developing mental health support programs at the local community level is very relevant in this regard.

With respect to the role of the person with a disability in the household, results indicate certain problems of social exclusion which should also be taken seriously. Among these problems the most pronounced concern is not taking part in one's own traditional ceremonies, not making important decisions about one's life and the high proportion who are not married and do not have own children. These, and other indicators of social exclusion, imply that awareness creation, information and education directed at the families of individuals with disabilities is urgently needed.

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

psychological 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 Zambia.

Large gaps were observed in the provision of several types of services needed by individuals with disabilities. The largest gaps were found with regards to vocational training, welfare services, assistive devices and counselling. These four services also scored lowest in the Namibian, the Zimbabwean and the Malawian studies. The figures point directly to important challenges 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, although 20 % reported that they did not receive health services when this was needed; this may be an indication that the problem is both the type or quality of health service offered, and to some extent also availability.

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 around one fourth of those surveyed never attended school, and the results clearly indicate that those with disabilities are worse off than those without. A comparison of language abilities substantiates 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. The analysis of scholastic achievement (school grade completed) offers some hope to the situation described above. It is clear that, given the opportunity to attend school; those individuals with disabilities were able to match the achievements of those without. This information is potentially useful information in planning future educational services.

The level of unemployment in Zambia is high, and even higher among those with disabilities compared to those without. This finding corresponds to the results from the previous studies in the region. 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 systematically 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 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, disability is re-defined according to these broader concepts – and focus is shifted from impairment to social participation and inclusion. Through the operationalisation of activity limitations and restrictions in social participation, new and robust measures are available and open up for more advanced analyses. This has been utilised to some extent in this report, while further analyses will be presented in later publications.

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.

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.

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. The study thus contributes to develop a new paradigm in disability statistics, in one sense contributing to "mainstreaming" this field of research. This is further discussed by Eide & Loeb (2006) who argues for the need of both strategies, i.e. one that allows for contrasting conditions for people with and without disabilities, and one strategy which includes the population in general in studies of activity limitations.

While ICF represents a shift in focus in the conceptualisation of disability and the disablement process, it is still a classification of health and health related states in the WHO terminology

(ICF 2001). It is not the intention of ICF to detach disability from health entirely, but rather to include other important factors into a model which is able to capture some of the complexity surrounding the phenomenon of disability. It is in this regard interesting to note the demonstrated relationship between subjective health and disability.

The analyses of activity limitations among people with and without impairments contribute to support the idea of functional problems, operationalised as activity limitations and/or restrictions in social participation, as a phenomenon that is generally relevant and not only for those who are identified or labelled as disabled. This opens up for a new generation of disability statistics that has the potential for generating new knowledge about disability and the disablement process. It is however argued that both viewing disability as a dichotomy and as a continuous phenomenon is needed and that it would be problematic to completely abandon the "traditional" disability statistics due to their potential for generating comparisons between groups. Comparative analyses have produced evidence for discrimination of individuals with disabilities in many high-income countries and thus represent very important information for advocacy as well as development of policy and services.

7 Conclusions

(ME Loeb)

This study in Zambia 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, Zambia. This survey thus represents a first possibility to study different aspects of the lives of people with disabilities in the country. It also provides a basis for monitoring the situation in the future. Following similar studies in Namibia, Zimbabwe and Malawi, the Zambian study is also an important link in an initiative to establish a Regional database.

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

Systematic gender differences were found between households with and without a disabled family member; a higher proportion of those with disabilities were men compared to the 'control' non-

disabled population. While this is in line with the previous studies in the region, the gender difference in the Zambian sample was demonstrated to be significantly higher when compared to the previous three studies. The possible confounding effects of this gender imbalance were controlled for in the subsequent analyses.

In this study we have furthermore been able to demonstrate that by dissociating an individual's physical impairment from their limitations and ability as measured in terms of parameters of capacity and performance, the focus of disability can be redirected towards improving an individual's social situation through the removal or reduction of barriers that limit activities and restrict social participation, and thus facilitating their incorporation as fully active members of society. The application and operationalisation of certain conceptual components in the ICF model are seen as among the first steps towards a new paradigm for defining disability statistics.

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 and level of awareness that is necessary for action. 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.

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 Zambia and agreeing upon a path for the future. Setting priorities, developing policy as well as 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. A first important step could be a dialogue between the Government of Zambia including relevant ministries, ZAFOD and other DPOs, as well as researchers and other resource persons, in order to agree on priorities and measures to improve the situation for individuals with disabilities in Zambia.

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9 Appendices

Appendix 1: Summary of Household Screening & Disability Prevalence

Province	Population	Individuals screened	# PWD*	prevalence
Southern	1212124	19155	3266	17.1
Central	1012257	23300	2254	9.7
Lusaka	1391329	12710	1913	15.0
Northern	1258696	6595	1399	21.2
N/Western	583350	7170	1335	18.6
Western	765088	8020	1778	22.2
Luapula	775353	21460	1575	7.3
Eastern	1306173	15940	1729	10.8
Copperbelt	1581221	18460	2475	13.4
Zambia	9885591	132810	17723	13.3

*PWD (people with disabilities): based on the 6 WG screening questions and including those who registered at least *some* difficulty on at least two of the 6 domains listed

Appendix 2: SAMPLE SIZE DETERMINATION

1. **STARTING POINT IS THE CONFIDENCE INTERVAL**

CI: P +- $Se_{t-95\%}$

WHERE
CI = Population Confidence interval
Se = Standard Error (Simple Random Sampling)
t = t-statistic at 95% confidence level (t=1.96≈2)

2. **FIX THE PROPORTION TO 50% IN ORDER TO MAXIMISE VARIANCE**

3. **SEARCH FOR A DESIGN EFFECT FACTOR (DEFF) FOR THE KEY ANALYSIS VARIABLE (BETTER STILL FOR PROPORTION)**

4. **FIX TOLERABLE STANDARD ERROR FROM 5%**

5. $$n_{srs} = t^2 pq / Se^2$$

6. $$n_{srs} = 2^2 \cdot (50.50) / 5^2$$ **(Dots are inner products)**

7. $$n_{srs} = 400$$

8. **NEXT STEP IS TO ADJUST SRS SAMPLE USING APPROPRIATE DESIGN EFFECT (DEFF OR DEFT)**

9. **DESIRED SAMPLE FOR COMPLEX SURVEY= n_{srs} x deff**

10. **TRY TO VARY THE MARGIN OF ERROR THAT YOU CAN TOLERATE FROM 5% TO 1% AND OBSERVE EXPLODING SAMPLE**

11. **IN CONCLUSION, THE MINIMUM SRS SAMPLE FOR ANY DOMAIN OF STUDY IS 400 OBSERVATION UNITS**

Appendix 3: Data collection teams

PHASE ONE

Western Province	Organisation	Gender	Disability
*Richard Zulu**	INESOR	M	None
Charles N. Namukolo	ZNAPH	M	Physically disabled
Mupikana Theo	INESOR	F	None
Fridah Malupande	INESOR	F	None
Henry Taulo	ZACALD	M	Parent of disabled child
Northern			
*Stephen Mwale**	INESOR	M	Speech Impaired
Lango Sinkamba	ZAFOD	M	Physically disabled
Moses Chanda	ZNAPS	M	Partially Sighted
Victor Mwale	ZACALD	M	Parent of disabled child
Lillian Chela	CSO	F	None
Luapula			
*Mukamulumbu Mweemba**	INESOR	F	None
Merlyn Milo	INESOR	F	None
Chilufya Chisenga	INESOR	M	None
Mutale Kalikeka	INESOR	F	None
Patrick Kashimbo	ZACALD	M	Parent of disabled child
Eastern			
*Justine Bbakali**	ADD	M	Physically disabled
Mbachi Muyobo	ZAPCD	F	Parent of a disabled child
Peggy Banda	INESOR	F	None
Yvone Zimba	ZNAPH	F	Physically disabled
Aaron Masaninga Tembo	INESOR	M	None
North-Western			
*Mwazanji Phiri**	INESOR	F	None
James Kapata	ZNAPH	M	Physically disabled
Bostone C. Mwenya	ZNAPH	M	Physically disabled
Chama Kaunda	INESOR	M	None
Mabel Banda	CSO	F	None

PHASE TWO

Southern

*Constance Sachelo**	ZNAPH	F	Physically disabled
Richard Zulu	ZNAPH	M	None
Henry Taulo	ZACALD	M	Parent of disabled child
Patrick Kashimbo	ZACALD	M	Parent of disabled child
Fridah Malupande	INESOR	F	None

Lusaka

*McKenzie Mbewe**	ZNAD	M	Deaf
Mbachi Muyobo	ZAPCD	F	Parent of disabled child
Moses Chanda	ZNAPS	M	Partially sighted
Chama Kaunda	INESOR	M	None
Lilian Chela	CSO	F	None

Central

*Mukamulumbu Mweemba**	INESOR	F	None
Yvone Zimba	ZNAPH	F	Physically disabled
Chilufya Chisenga	INESOR	M	None
Charles N. Namukolo	ZNAPH	M	Physically disabled
Peggy Banda	INESOR	F	None

Copperbelt

*Josephine Shinaka**	ZNADWO	F	Physically disabled
Mutale Kalikeka	INESOR	F	None
James Kapata	ZNAPH	M	Physically disabled
Bostone C. Mwenya	ZNAPH	M	Physically disabled
Mupikana Theo	INESOR	F	None
Mwazanji Phiri	INESOR	F	None

PRINCIPAL INVESTIGATORS

Dr. T.J. Ngulube	INESOR	M	None
Dr. C.A. Njovu	INESOR	M	None
Mr. G. Sinyenga	CSO	M	None
Mr. F. Simulunga	ZAFOD	M	Physically disabled

Key: *=Supervisor

APPENDIX 4: ACTIVITY AND PARTICIPATION MATRIX

ACTIVITY LIMITATIONS: **How difficult is it for you to perform this activity <u>without any</u> kind of assistance at all?** (That is, without the use of any assistive devices – either technical or personal). **PARTICIPATION RESTRICTIONS:** **Do you have any difficulty in performing this activity in your current environment?** (**Current environment* refers to the surroundings in which you live, work, and play etc for the majority of your time).	**Activity limitation score** **(A measure of 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** **(A measure of 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)
1a. SENSORY EXPERIENCES		
a. watching/looking/seeing		
b. listening/hearing		
1b. BASIC LEARNING & APPLYING KNOWLEDGE		
a. learning to read/write/count/calculate		
b. acquiring skills (manipulating tools, painting, carving etc.)		
c. thinking/concentrating		
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 directly with others		
d. communicating using devices (phone/typewriter/computer/SMS)		
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. using transportation to move around as a passenger		
j. 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		

Appendix 4: ACTIVITIES & PARTICIPATION Matrix (Continued)

	Activity limitation	**Participation restriction**
5. DOMESTIC LIFE		
a. shopping (getting goods and services)		
b. preparing meals (cooking)		
c. doing housework (washing/cleaning)		
d. taking care of personal objects (mending/repairing)		
e. taking care of others		
6. INTERPERSONAL BEHAVIOURS		
a. making friends and maintaining friendships		
b. interacting with persons in authority (officials, village chiefs)		
c. interacting with strangers		
d. creating and maintaining family relationships		
e. making 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		

APPENDIX 5: INVENTORY OF ENVIRONMENTAL FACTORS

Being an active, productive member of society includes participating in such things as working, going to school, taking care of your home, and being involved with family and friends in social, recreational and civic activities in the community. Many factors can help or improve a person's participation in these activities while other factors can act as barriers and limit participation. First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem **daily, weekly, monthly, less than monthly, or never.** If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you.

(Note: if a question asks specifically about **school or work** and you neither work nor attend school, check not applicable)

	1. always	2. often	3. seasonal	4. seldom	5. never	8. NA	9. Not spec.	2. big problem	1. little problem
1. In the past 12 months, how often has the availability/accessibility of transportation been a problem for you?									
When this problem occurs has it been a big problem or a little problem?									
2. In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do?									
When this problem occurs has it been a big problem or a little problem?									
3. In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc – made it difficult to do what you want or need to do?									
When this problem occurs has it been a big problem or a little problem?									
4. In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand?									
When this problem occurs has it been a big problem or a little problem?									
5. In the past 12 months, how often has the availability of health care services and medical care been a problem for you?									
When this problem occurs has it been a big problem or a little problem?									
6. In the past 12 months, how often did you need someone else's help in your home and could not get it easily?									
When this problem occurs has it been a big problem or a little problem?									
7. In the past 12 months, how often did you need someone else's help at school or work and could not get it easily?									
When this problem occurs has it been a big problem or a little problem?									

	1. always	2. often	3. seasonal	4. seldom	5. never	8. NA	9. Not spec.	2. big problem	1. little problem
8. In the past 12 months, how often have other people's attitudes toward you been a problem at home?									
When this problem occurs has it been a big problem or a little problem?									
9. In the past 12 months, how often have other people's attitudes toward you been a problem at school or work?									
When this problem occurs has it been a big problem or a little problem?									
10. In the past 12 months, how often did you experience prejudice or discrimination?									
When this problem occurs has it been a big problem or a little problem?									
11. In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you?									
When this problem occurs has it been a big problem or a little problem?									
12. In the past 12 months, how often did government programs and policies make it difficult to do what you want or need to do?									
When this problem occurs has it been a big problem or a little problem?									