



SINTEF REPORT

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Living conditions among people with activity limitations in Namibia. A representative, National survey.

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This research report provides results from a study on living conditions among people with and without disabilities in Namibia. The study was undertaken in 2002.

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Preface

There are numerous reasons for carrying out studies on living conditions among people with disabilities in Southern Africa. Firstly, quality data have been in demand from the United Nation since 1990. Secondly, to the extent that national Disability Policies have been developed in Southern Africa, specific formulations on the need for data on living conditions among people with disabilities are found in the National Disability Policies of Namibia (MLRR, 1997), South Africa (ODP, 1997), Malawi (draft) (OMSPWD, 2001), and others. Thirdly, and most importantly, we who have carried out this work strongly believe that studies like this, in combination with other efforts, have a strong potential for contributing to an improvement of the situation for people with disabilities, as they have in many high-income countries. Lastly, the researchers behind this report are driven by an interest for the conceptual development in the disability field and see this research as a unique possibility for applying certain elements of the theoretical model behind the recently adopted International Classification of Functioning, Disability and Health (ICF).

The initiative to carry out this study in Namibia (and the parallel one in Zimbabwe) was developed in collaboration between

Southern Africa Federation of Disabled People, the Norwegian Federation of Organisations of Disabled People (FFO), and SINTEF Unimed. Major stakeholders in Namibia have been the National Federation of Disabled People in Namibia (NFDPN), Ministry of Lands, Resettlement and Rehabilitation (MLRR), and University of Namibia (MultiDisciplinary Research and Consultancy Centre, MRCC). MLRR has contributed politically, economically as well as directly in the research process. MRCC has been responsible for carrying out all aspects of data collection. NFDPN has provided valuable support during the data collection, taken part in development of research design and recruited enumerators as supervisors. A number of individuals and organisations in Namibia have taken part in the design development phase. Staff at Ministry of Lands, Resettlement and Rehabilitation have taken part and ensured the smooth carrying out of all phases of the study. Good support has also been given by the African Rehabilitation Institute¹. SINTEF Unimed has had the overall responsibility for the study, and funding has been provided through the Norwegian Agency for Development Cooperation (NORAD) and the Atlas Alliance, and by Ministry of Lands, Resettlement and Rehabilitation in Namibia.

At the time of publishing this report, an important phase of this initiative has been completed. The study in Zimbabwe will be published later this year, while results from the study in Malawi

¹ The African Rehabilitation Institute (ARI) is the specialized agency of OAU

can be expected early 2005. Parallel to these studies, capacity building programs for the organisations of disabled people have been developed and carried out. An important next initiative will be to establish a program with the aim of ensuring that the results from these studies are applied to the benefit of people with disabilities in the Southern Africa Region.

member States relating to disability, based in Harare, Zimbabwe.

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Summary

The National, representative study on living conditions among people with disabilities in Namibia is the result of an international cooperation between Southern Africa Federation of the Disabled, National Federation of People with Disabilities in Namibia (NFPDN), Norwegian Federation of Organisations of Disabled People (FFO), University of Namibia (MultiDisciplinary Research and Consultancy Centre), Ministry of Lands, Resettlement and Rehabilitation (MLRR), and SINTEF Unimed. The study has been funded by the Atlas Alliance on behalf of Norwegian Agency for Development Cooperation (NORAD), and by MLRR. Other than carrying out the study, the collaboration project has also comprised capacity building.

Forming part of a Regional initiative to establish baseline data on living conditions among people with disabilities in Southern Africa, the study in Namibia is the first to be published. The report, though largely descriptive, also comprises more sophisticated analyses. Further results from the study will be presented later in more focused scientific publications.

A thorough adaptation process involving a broad range of stakeholders took place before data collection. Organisations of people with disabilities and individuals with disabilities have played a particularly active role during development of the design as well as in the data collection. 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), one section with specific questions to individuals with disabilities, and one matrix that represents an operationalisation of core concepts from the International Classification of Functioning, Disability and Health (ICF).

A two-stage stratified sampling was carried out with enumeration areas as strata. A total of 2286 households with disabled members and 1356 households without disabled members were sampled. This comprises 1.3 % of the population in Namibia. Households with disabled members had both a higher number of individuals and a higher number of children than did control households. On marital status, marginal differences were found between disabled and non-disabled.

School attendance as well as well as performance (measured as school grade completed) is clearly lower among disabled persons. Among children older than 5 years, 38.6 % of the disabled had never attended school, while the corresponding figure for non-disabled was 16.2 %. Among those who had

attended school, 23 % of the disabled had completed 8th – 12th grades as their highest grade, while the corresponding figure for non-disabled was 31 %.

Unemployment is rampant in Namibia, with 77.6 % of the controls reporting that they are “not currently working”. For disabled persons, this figure is 90.9 %. Of those who were employed, the largest group was domestic worker. Mean monthly salary among those who work is significantly lower among disabled persons. The mean figure for non-disabled is approximately 30 % higher than for the disabled (less than USD 4 per day and somewhat more than USD 5 per day respectively).

Comparison between the two types of households revealed systematic differences. On most of the important indicators on level of living, households with disabled members score lower than the control households. This goes for housing standard, number of possessions, access to information, monthly expenses, and income. While mean income in a good month for households with disabled members was approximately N \$ 600, the corresponding figure for control households was N \$ 850 (approximately USD 75 and 106). An important reason for this difference was that households with disabled members had fewer people with salaried work. The study also revealed that a little over one fourth of respondents with disabilities received financial assistance through a disability grant or pension, mostly

a disability grant from Social Services Division. One third of those who received grants had an old age pension.

Prevalence of disability is estimated to 1.24 % in urban areas, 1.75 % in rural areas, and 1.62 % overall. While this corresponds well with results from the National Population and Housing Census 2001 (not published), it is lower than the previous Census and clearly lower than WHO estimates for low-income countries.

Disability was found to be evenly spread with respect to age, although prevalence is somewhat lower among young children. This profile results from the demographic situation in Namibia with more than half the population being under 20 years of age and relatively fewer in the 50 + age ranges. More than 40 % of the disabled had mobility difficulties (major or minor disability, paralysis), more than one third reported sensory impairments, while intellectual disabilities, learning disorders and emotional disorders amounted to 17.2 %. The major causes of disability was reported to be illness, from birth or congenital, and accident. Close to 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.

Health services were on the other hand found to be available for the large majority of disabled, with two thirds of those who needed this service had actually received it. Primary health care clinics and hospitals are also among the most accessible facilities. The most noticeable shortcomings with regards to services were vocational training, counselling services, assistive devices, welfare services and educational services. All were received by less than 30 % of those who claimed that they needed these services.

While an overview of accessibility to many services and institutions gives a mixed picture, it is clearly the case that many important services are reported not to be accessible. Only 25 % classify schools as accessible. Public transport is on the other hand reported to be accessible by almost 60 %. All in all, the results here show that there is a great potential for making various types of services and institutions more accessible for people with disabilities.

Assistive devices are used by less than one fifth of the disabled while two thirds need some type of device. It is further shown that most devices are functioning well, that many have received instructions on the use, but that only one third of devices are maintained professionally. The majority has acquired their devices from Government health services, while one third of the devices have been supplied by private sources.

A matrix was developed for this study to map individual's activity limitations and participation restrictions according to different parameters or domains or life situations (sensory experiences, basic learning and applying knowledge, communication, mobility, self care, domestic life, interpersonal behaviours, major life areas and community, social and civic life). It was found that individuals with physical/mobility impairments needed more help in their daily activities than other disability categories, while particularly hearing impaired but also those with seeing impairments needed less help than others. Seeing and hearing impaired also reported less activity limitations and participation restrictions, while those with communication and mental/emotional problems scored highest and thus experience more barriers to full participation in society.

Assessing the indices on activity limitations and participation restrictions with respect to indicators of living conditions revealed that three out of four of these measures were associated with indicators on level of living. The more severe a persons disability is with respect to daily life activities and social participation, the lower the level of living of the person.

The baseline produced through this study can be applied later for monitoring purposes. Results can be applied directly as documentation of the standard of living among people with disabilities and their families, and as a basis for comparison with non-disabled. This information is potentially useful when

decisions are made on utilisation of meagre resources, as argument towards 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 is considered, together with other relevant sources, as a basis for dialogue between authorities, professionals and organisations of people with disabilities, for setting priorities, and for developing concrete measures within selected areas of priority.

Introduction

Based on the collaboration since 1995 between the Southern Africa Federation of Disabled People (SAFOD) and the Norwegian Federation of Organisations of Disabled People (FFO), an initiative was taken in 1998 to conduct a study on living conditions among people with disabilities in the Southern African Region. Funded by the Norwegian Agency for Development Cooperation (NORAD), through the Atlas Alliance², SINTEF Unimed³ was contracted by FFO to carry out first pilot studies in Namibia and Zimbabwe in 1999-2000 (Eide et. al., 2001a; 2001b), and the main National data collections in 2001/2002. In Namibia, the study was carried out together with University of Namibia⁴ and the Ministry of Lands, Resettlement and Rehabilitation. SAFOD, Ministry of Lands Resettlement and Rehabilitation and the National Federation of People with Disabilities in Namibia (NFPDN) have actively supported the study from the start, and a number of other ministries, organisations and professionals have been involved in the process leading up to the main data collection that was carried

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

³ SINTEF Unimed is a contract based research institute in the SINTEF Group and is the largest health service research company in Norway. www.sintef.no

⁴ Multidisciplinary Research and Consultancy Centre, Social Science Division.

out in May/June 2002 (see list of involved parties in Appendix 1).

This report presents results from the main data collection in Namibia. Results from the corresponding study in Zimbabwe will be published in a separate report.

The developmental objective for this project has been to contribute to the improvement of disabled people's living conditions, including also their level of participation in society.

Specific aims include:

- To carry out representative nation-wide studies on living conditions among people with disabilities in Namibia and Zimbabwe
- To lay the groundwork for repeated and long-term data collections on living conditions among people with disabilities in the two countries
- To assist in capacity building among disabled peoples' organisations and among relevant professionals at ministerial level
- To assist the Southern African Federation of Disabled People in the establishment of The Disability Resource Centre for Southern Africa through training and technical assistance

For the study on living conditions, specific objectives or research topics have been:

- Development of an adapted design for studies on living conditions among people with disabilities in Southern Africa
- Establishment of a baseline on the level of living of people with disabilities in Namibia
- Description and analyses of living conditions among people with disabilities in Namibia
- Comparison of living conditions among people with and without disabilities
- Analyses of sociodemographic distribution of living conditions among disabled and non-disabled
- Applying components from the International Classification of Functioning, Disability and Health (ICF) in order to test their applicability in the context of a low-income country
- Analyse the relationship between ICF components and standard of living

This report will center around these specific objectives and research topics. Other publications will follow this report with specific focus on screening for disability, prevalence and the ICF model (activities and participation).

1 Context⁵

History

The area that comprises Namibia today became a German protectorate in 1884 (except for the small area surrounding the deep-water port Walvis Bay that was declared British Territory in 1876). During World War I, Namibia was occupied by South Africa and later declared a mandated territory under the League of Nations, administered by South Africa on behalf of Britain. Subsequently, the United Nations refused to place the territory under trusteeship and demanded South Africa's withdrawal. In the 1950s, the Ovamboland People's Congress (which later became the South-West Africa People's Organisation [SWAPO]) emerged and led the struggle against South African occupation. The territory won independence in 1990. SWAPO leader Sam Nujoma became president following victory in UN-supervised polls.

⁵ Sources:

World Bank (<http://www.worldbank.org/afr/na2.htm>) Fact sheet on Namibia 2002
CIA (<http://www.odci.gov/cia/publications/factbook/geos/wa.html>) Fact sheet on Namibia 2002

el Obeid S, Mendelson J, Lejars M, Forster N, Brulé G. Health in Namibia: Progress and Challenges. Ministry of Health and Social Services, Service for Co-operation and Cultural Affairs of the French Embassy in Namibia, 2001. (<http://www.healthnet.org.na/grnmhss/htm/healthinnam1.htm>)

Economy

Namibia's economy relies heavily on extraction and processing of minerals as well as on processed fish and other manufacturers for export. Namibia is the world's fifth largest producer of uranium and a primary source of gem-quality diamonds. Agriculture is dominated by cattle and sheep raising. The country has one of the richest potential fisheries in the world. Policies adopted since independence have aimed at sustaining economic growth, diversifying the country's productive base, and attracting foreign investors.

Between 1990 and 1993 real GDP growth averaged 5 percent. Since then, GDP growth has slowed down to an average of about 3% during 1994-2001. Namibia's GNP per capita is about \$2,060 but income distribution is one of the most unequal in the world. Based on the 1994 population estimate of 1.4 million, total expenditures of the richest 7000 people (0.5 percent of the population) equal the total expenditures of the poorest 800,000 people (57 percent of the population). There are marked urban – rural differences with regards to economy and infra structure.

Politics

The 1990 constitution mandates a multiparty democratic system for Namibia. The president and the 72-seat National Assembly are elected by universal adult suffrage every five years. SWAPO remains the leading political party in the country. President Sam

Nujoma, who had been appointed Head of State by the first parliament, was directly elected in 1994 and 1999. A reshuffle of Cabinet ministers took place in August 2002.

Geography

Namibia lies in Southern Africa, bordering the South Atlantic Ocean, between Angola and South Africa. The country covers a total area of 825,418 sq. km, of which reports indicate that 0 sq. km is water. The climate is characterised by desert conditions; hot and dry with sparse and erratic rainfall. The terrain is mostly high plateau bordered by the Namibian Desert along the coast and the Kalahari Desert in the east.

People

Preliminary results of the 2001 Census place the current population of Namibia at 1.83 million. Considering the above area, the average density is just over 2 people per sq. km. The population is however spread very unevenly across the country, with large areas completely uninhabited. It is estimated that in 2001 39% of the population was living in urban areas.

Other sources (World Bank 2002 estimates) describe the age structure:

0-14 years: 42.6% (male 392,706; female 382,690)

15-64 years: 53.7% (male 490,151; female 488,052)

65 years and over: 3.7% (male 29,345; female 37,972)

It is estimated that 55 percent of Namibians are below 20 years of age.

The population growth rate is estimated at 1.19% while the birth and death rates are 34.2 births/1,000 population and 22.3 deaths/1,000 population respectively.

Two leading indicators of development are the Infant mortality rate (IMR: deaths before 1st birthday/1,000 live births) and child mortality rate (CMR: deaths under age 5 years/1,000 live births).

Namibia has recorded some major advancements in reducing both infant and child mortality during the 1990s. Health in Namibia (2001) reports a decline in IMR from 61/1,000 live births in 1992 to 38 in 2000. During the same period the CMR fell from 31 deaths before 5 years/1,000 1-year-olds to 26 in 2000. Life expectancy at birth, on the other hand, has not improved. For the total population life expectancy is currently estimated at about 39 years (for females: 37 years and for males 41 years) down from 61 years in 1991. This decline is primarily due to the HIV/AIDS epidemic.

Total fertility rate is 4.8 children born/woman. 1999 estimates of the HIV/AIDS situations set the adult prevalence rate at 19.54%. It is estimated that as many as 160,000 people are currently living with HIV/AIDS.

2 Living conditions among people with disabilities in low-income countries

According to UN estimates, the population of disabled people in the world is between 225 and 350 million people. This is based on a 10 % estimated prevalence rate (WHO, 1981), intended to cover severe, moderate and mild disabilities. The large majority of disabled people live in developing or low-income countries⁶, 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 disabled people in low-income countries is of concern for Governments, Non-Governmental Organisations, as well as for the International Community. The rights of persons with disabilities have been the subject of much attention in the United Nations and other international organisations over a long period of time. The International Year of Disabled Persons (1981), and the United Nations Decade of Disabled Persons (1983 – 1992) culminated in the World Programme of Action

⁶ Low-income countries will be applied throughout this report to cover terms like developing countries, non-industrialized countries, etc. Likewise, high-income countries are applied to cover developed countries, industrialized countries, etc.

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 implying 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. It is a prerequisite when agreeing on acceptable standards, setting priorities and planning for required improvements. Without the necessary knowledge, Governments, NGOs and International Organisations are more or less forced to work arbitrarily on a hit or miss basis. Thus, 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 in order to 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 Namibia⁷, South Africa⁸, and in the draft policy document soon to be adopted in Malawi⁹, among others.

2.1 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 impairment, disability and handicap. Needless to say, the bulk of this information is produced in the industrialised countries. Unfortunately, most of the current statistical information is produced without the benefit of a common terminology or standard procedures and guidelines. It is further claimed (UN, 1996) that there are problems with the

⁷ MLRR (1997) National Policy on Disability. Windhoek, Ministry of Lands, Resettlement and Rehabilitation.

⁸ Office of the Deputy President. (1997) White Paper on an Integrated National Disability Strategy. Pretoria, Office of the Deputy President.

⁹ Malawi Government. Draft National Disability Policy. Office of the Minister of State Responsible for Persons with Disabilities. December, 2001.

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

Data on disability have been actively compiled by the United Nations since the 1980s and were first published in 1990 as the Disability Statistic Compendium (UN, 1990). The compendium included national level data on 12 major topics about disabilities (including age, sex, residence, educational attainment, economic activity, marital status, household characteristics, causes of impairment and special aids used). A manual for the purpose of collecting data on disabilities and the situation of disabled people has been published by the Statistics Division (UN, 1996), followed by Guidelines for Disability Statistics (UN, 2001). The manual was written specifically for the use of program managers and others concerned with the production and use of statistical information for implementing, monitoring and evaluating disability policies and programs.

The Statistics Division of the United Nations has established the Disability Statistics Database for Microcomputers (DISTAT), and is currently working on the development of a system for data collection. 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).

As examples of information from African countries contained in this compendium, the national disability prevalence rate in Swaziland is given at approximately 3 %. Reviewing the age specific figures for the rural population in five African countries (Comoros, Egypt, Ethiopia, Mali and Tunisia), the rate varies from around 1 – 4 % in the younger age groups (under 24 years) and gradually increases with age to reach a level of 2 – 12 % among 50 year olds. The prevalence rate (of disabled persons) per 100 000 population is reported for some African countries and varies from just below 1000 to more than 3000. It is interesting to register that the figure for Norway is as high as 15000, in line with other industrialised countries and reflecting first of all that there are serious methodological problems associated with the comparison of figures from different sources across countries. Definitions of disability, methodologies for data collection as well as quality of the data collected vary (Eide & Loeb, in preparation).

The Human Development Report, that has been published by UNDP since 1990, included from the 1997 edition (UNDP, 1997) estimates of the prevalence of disabilities as percentage of total population in each country. Figures for Namibia are, however, missing in the table, whereas the prevalence is 1.6 % in Zambia and 2.9 % in Malawi. Among the black population in South Africa prevalence of disability (sight, hearing/speech, physical disability and mental disability) has been estimated to 5.1 % (<http://www.css.gov.za/SABrief/Table8.HTM>). Two separate

studies in South Africa (colored urban and black rural communities) have come up with prevalence rates of 4.4 % and 4.75 % (Katzenellenbogen et. al., 1995; Concha and Lorenzo, 1995).

Most countries in Africa, Namibia included, have carried out and published population censuses that provide some information on living conditions. Unfortunately, information on disabilities and the situation of disabled people 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 recommendations¹⁰.

The national disability survey undertaken in South Africa in 1998/99 represents an important exception to the general lack of representative, National data in the region. A National representative survey of 10000 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 the results are a count of the number of people with reported disabilities or activity limitations, as well as a quantitative

¹⁰ 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.

analysis of the respondents' personal experience of their disability. According to this study, disability prevalence rates varied between 3.1 % and 8.9 % in the different provinces.

Although the progress made in this field is quite substantial, data on disability are still hard to come by 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. Furthermore, the current concept of level of living conditions offers a wider approach to the measurement of individuals' welfare, focusing on individuals' capabilities, the utilisation of these capabilities as well as equality (of opportunities) in addition the more limited, classical economic or material indicators. Thus, the level of living concept as applied today concurs with some of the fundamental ideas concerning participation and equality of opportunities underlying the World Programme of Action as well as the Standard Rules.

2.2 Relevant studies in Namibia

In Namibia, the National Housing and Population Census in 1991 contained a small number of questions on disability (classification of disabilities, access to education and work), and this material has later been analysed and published by The Namibian Economic Policy Research Unit (Bruhns et al., 1995). Other than providing prevalence estimates of impairments, the 1991 Census also provided information revealing marked differences in school attendance and employment between people with and without disabilities. It was found that 48 % of people with disabilities (aged six years and over) had attended school in comparison with 78 % of all Namibians (aged six years and over). Unemployment was reported by 57 % of all disabled persons between 15 and 65 years, and 43 % of the employed were self-employed (mostly in the field of agriculture). Differences were also found in rural : urban ratios for the population of disabled (5 : 1) compared with the general population (3 : 1). A mapping of the supply of technical devices was carried out in 1998/99 (Strand, 1999). The report found that the demand of different kinds of technical devices far exceeded supply.

3 Concepts

Disability and living conditions are core concepts in the study presented in this report. The understanding of these concepts has gone through interesting developments in recent years, and there are obviously different ways of conceiving them. 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.

3.1 Disability

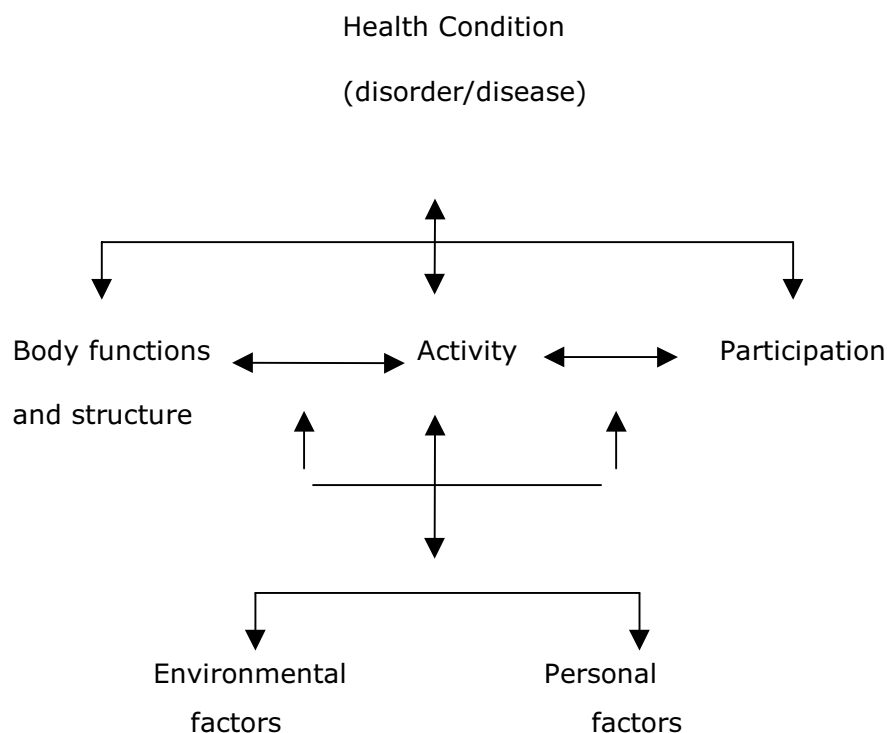
During the 1970s there was a strong reaction among representatives of organisations of persons with disabilities and professionals in the field of disability against the then current terminology. The new concept of disability was more focused on the close connection between the limitations experienced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

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 Model of Functioning and Disability



Application

The conceptual development from ICIDH to ICF is important here as this shift also has a methodological parallel in that the classifications form 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 current 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 restrictions developed particularly for this study. When this is said, the current study provides a unique possibility for applying core concepts from ICF and to test some aspects of the model statistically¹¹.

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 as it refers to or is associated with an individualistic and impairment-based understanding. It is nevertheless applied throughout this text as we regard it as a common and accepted concept, and it is practical in use in the absence of new easy to use terminology in this sector.

COMPARABILITY OF DISABILITY STATISTICS

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 is the result of an interaction between the person with the disability and their particular environment. Disability is, therefore, a complex phenomenon with no static state; can be conceptualised in many ways,

¹¹ Will be published separately

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.

For these reasons, the observed differences among countries in the rates (or percentages) reflect conceptual and measurement differences, to varying degrees, as well as true differences. 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.

UN initiative

In September 2001 the United Nations Statistics Division sponsored a conference in Kampala, Uganda. The objective of the workshop was to strengthen national capabilities in disability statistics by training producers and users in the production, dissemination and use of data on disability for policy development and implementation. The workshop brought together representatives (both data producers and data users) from 11 African nations including Namibia for exchanging information and experiences related to the measurement of disability using varied collection mechanisms.

Several documents were seminal to the conference. The revised UN Guidelines and Principles for the Development of Disability Statistics (2001) provide the primer of disability methods for population-based data. This document will continue to act as the textbook for developing and developed countries working toward harmonisation of data. The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1994) is the guidebook for identifying cogent policy and intervention directions. Finally, the International Classification of Functioning, Disability, and Health (ICF) (2001) recently approved by the World Health Assembly provides the conceptual, classification, and coding scheme for organising disability data. These three documents provide the tripartite foundation for global disability data.

The conference included an analysis of the constraints of data collection systems and emphasised weaknesses according to the system selected, as well as issues related to measurement error, disability definitions, and balancing the needs of data producers and data users. Issues related to cultural influences on reporting limitations were discussed.

Participants were introduced to the *ICF* and its use in framing numerous areas of the *Standard Rules* as elements of the Participation dimension. Initial exercises focused on setting policy priorities using the *Standard Rules*, and then translating the elements into disability items for use in surveys. A second

set of exercises allowed the participants to take already established disability screener items from other surveys and craft them for relevance in their country's data mechanism. The elements of the questions were described using dimensions of the *ICF*. Importance was placed on wording questions so that the relevant policy issue can be addressed.

The Workshop ended with unanimous assent of the participants for the following recommendations;

- Governments should advocate inclusion of disability questions in censuses and surveys
- There is need to involve stakeholders (users, producers, persons with disabilities) in the process of developing data collection instruments to measure disability and in the data collection process as a whole
- The WHO *International Classification of Functioning, Disability and Health (ICF)* concepts should be used in the measurement of disability
- The following principles should apply in the design of questions to measure disability:
 - The question(s) should refer to activity limitations
 - The question(s) should ask for activity limitations in the context of a medical condition
 - The question(s) should ask for type and duration of activity limitation

- The question(s) should include degree or severity of activity limitation

In light of the African Decade of Disabled Persons, there is need to strengthen and streamline the collection of data on disability into the general data collection system. The conference concluded that the United Nations Statistics Division and the United Nations Division for Social Policy and Development should provide guidance towards the realisation of the objectives of the African Decade of Disabled Persons and of the Workshop. Furthermore, countries should maintain a network of persons involved in the measurement of disability in the region to facilitate the exchange of information on methodologies used and results obtained. In this regard, the United Nations Statistics Division should act as a facilitator. Regional statistical institutions should take a lead role in the collection of disability statistics in the region.

The current study and study design draws on the discussions and conclusions from the conference in Kampala. In particular the screening instrument applied here corresponds to the recommended way of screening for disability.

ENVIRONMENTAL FACTORS

Environmental factors is an important element in the ICF model, and it is fundamental to the present understanding of disability

that activity limitations and restrictions in participation is formed in the exchange between an individual and his/her environment. In the current study, environmental factors are included in an activity and participation matrix (Appendix 1). It is however acknowledged that studies like the current traditionally focuses on the individual and that this is also the case here.

3.2 Living conditions

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

A number of core items can be regarded as vital to any level of living study: Demographics, health, education, housing, work

and income. Other indicators may comprise use of time, social contact, sense of influence, sense of well being, perceptions of social conflict, access to political resources, access to services, social participation, privacy and protection, etc. The choice of which indicators to include will vary according to the specific requirements of each study and the circumstances under which the studies are undertaken.

3.3 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 very 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. Whether the same mechanisms of systematic differences and reproduction of differences are at work in predominantly poor contexts, still remains to be documented.

When the purpose is to study living conditions among people with disabilities, we depend on being able to operationalise 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 strong impact on the results of research, and it has impact on the application of results (see chapter 4.1 on the disability concept). ICF may to some extent be viewed as an attempt to combine a broad range of factors that influences 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. This counters a "traditional" or "medical" model whereby the focus has been a (clinical) identification of impairments as the qualifier for being disabled. 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 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 striving for improving the 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.

3.4 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 studies¹². Two research instruments that were already tested and tried out in South Africa (disability study; Schneider et. al., 1999) and Namibia (study on living conditions; Planning commission, 2000) were merged. A third element, on activities and participation, was included to incorporate the conceptual developments that have taken place in connection with 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.

¹² By "disability studies" we understand a broad specter of different studies that have generated knowledge about the situation of people with disabilities.

4 Design and methods

Existing and tested research instruments that had been applied in Namibia on living conditions (Planning Commission, 2000) and in South Africa on disability (Schneider et. al., 1999) were combined and adapted. In addition, a screening instrument (for disability) was included as well as a matrix on activities and participation developed for this study and drawing on ICF.

User participation was an important element in the design development. This process comprised:

- i) A two-day workshop attended by around 30 professionals, researchers, people with disabilities and civil servants who discussed and tested a draft research instrument
- ii) Pilot-testing of the research instrument among 150 households with and 150 households without disabilities in a high-density suburb in Katutura, Windhoek (Eide et. al., 2001)
- iii) Further revisions of the research instrument based on experience from the pilot survey and a second two-day workshop including the same resource persons and stake holders as at the beginning of the process

After revision, the questionnaire comprised four sections; i) household study on living conditions, ii), screening for disability, iii) questions to individuals with disabilities including also the ICF based matrix on activities and participation. The final version of the questionnaire was developed in English. Simple field tests were carried out during training leading to a few adaptations to local dialects.

Target population for the sampling was all private households in Namibia excluding the institutionalised and homeless people. A stratified single-stage cluster sample was carried out. The sampling frame used is an area frame based on the Enumeration Areas (EA's) of 2001 Population and Housing Census. The frame is stratified by regions (13 administrative regions) and within region urban and rural thus creating 26 main strata. Further stratification was carried out within these main strata based on the number of households having disabled persons. The reason for this grouping was to improve the coverage as much as possible by allocating the overall sample of the main strata to these sub groups proportional to their size. The measure of size is the number of households with disabled persons at the time of 2001 Population and Housing Census. The EA's were selected with equal probability in the group where the size measure was the smallest and with probability proportional to size sampling in the remaining groups.

The crude overall disability prevalence rate for Namibia was found to be around 2% from the 2001 Population and Housing Census records. This was taken as the order of the proportion to be estimated. Design Effect was unknown at this stage and it was assumed to be 3. Different options were considered after looking at the available budget, margin of error, sub national estimates and the sub group analysis. Based on these observations it was decided to limit the survey only to yield the national level estimates as well as national urban and national rural estimates. The overall sample size was determined to be around 5000 private households. This was distributed over 351 EAs to get as much representation and coverage. This sample allows for urban – rural comparison but in principle not for comparison between regions.

Sampling was carried out by the Central Bureau of Statistics (CBS) and based on the National Sampling Frame applied when carrying out representative studies in Zimbabwe. Step one was to draw a representative sample of enumeration areas. All together 353 enumeration areas representing 3642 households with 23314 individuals were sampled. Total number of EAs in the country is 4042, and the population is 1.8 million individuals. The sample thus comprises 9 % of EAs and 1.3 % of the country's population. This sample size allows for comparison between urban and rural sub-populations, while it is too small for Regional comparison.

Second step in the sampling was screening for disability by interviewing primarily heads of all households in the sampled enumeration areas. Instead of asking for specific impairments (is anyone in your household, blind, deaf, etc.) which is the most common way of screening for disabilities in censuses in low-income countries (<http://unstats.un.org/unsd/disability/>), the screening was based on an understanding of disability as difficulties in doing day-to-day activities and/or as restrictions in social participation¹³;

Screening question 1: Does anyone in this household ever have any difficulty in doing day to day activities because of a physical, mental or emotional (or other health) condition which has lasted or is expected to last for six months or more? (answer categories: yes, no).

Screening question 2: Does anyone in this household need assistance in participating in any of the following activities? (walking, seeing, speaking, hearing, breathing, mental coping, learning/comprehending) (answer categories: yes, no).

All together 2286 households were identified as having one or more disabled members. These households (with disabled members) were later revisited and comprehensive questionnaire-based interviews were carried out. During this exercise, the screening procedure was repeated and a total of 2600 individuals with difficulties in carrying out day-to-day activities were identified, thus qualifying as being disabled. This

¹³ The screening questions reflect an understanding of disability according to the International Classification of Functioning and Health (ICF) (WHO, 2001).

comprises 1.62 % (95 % CI 1.56 – 1.68) of the 160 214 individuals listed, and which is also the estimated prevalence of disability in Namibia in this study. Prevalence in urban areas was estimated to be 1.24 (95 % CI 1.14 – 1.35) and in rural areas 1.75 (95 % CI 1.68 – 1.82).

University of Namibia (Mutlidisciplinary Research and Consultancy Centre) was responsible for recruiting and training of enumerators, carrying out the data collection, data entry and data cleaning. Data collection was carried out by 13 teams, i.e. one per Region. A total of 84 enumerators fluent in English and in the relevant local languages carried out the data collection. Approximately 7 % were people with disabilities recruited through the National Federation of Disabled People in Namibia (NFDPN).

In order to obtain a control sample of households without disabled members, the household next to each of the identified households with disabled members were systematically selected. The total sample thus comprised 2236 households with disabled members and 1356 households without disabled members. The two groups in the sample are thus representative for the population of households with and without disabled members in Namibia.

The sampled households were visited by one enumerator who carried out the interview with the head of the household. The majority of disabled persons (62 %) answered by proxy. In cases where no one was present to answer when the household was visited by the enumerator, the household was revisited. Missing turned out to be a minor problem, as data collection failed in 54 households with disabled members and 32 control households only. Total number of persons with disabilities in the sampled households that were not interviewed was 72.

All questionnaires were controlled and signed by a supervisor after the interview. Completed questionnaires were transported to Windhoek for data cleaning and entry. Analyses were carried out by means of SPSS 11.0.

5 Results

The results are presented in two sub-chapters:

Study on level of living, comparing individuals with/without disabilities and households with/without disabled persons

Disability study. Separate study among the identified disabled persons, including a separate section with questions about difficulties, activities and participation.

Particular care has been taken during analyses to control for gender and the urban – rural dimension. Whenever these controls have revealed significant differences, this is commented in the text, otherwise not.

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

Table 5.1 Number of households and individuals in the study

Source	Households	Individuals	Persons with disabilities
Living conditions & disability survey	2286	16459	2537
Controls:			
Living conditions survey	1356	6855	

5.1 Results from the study on level of living

Mean sizes of households with and without disabled persons were 7.2 and 5.1 respectively ($t = -17.96$, $df = 3451$, $p < 0.001$). Further analyses revealed that mean sizes in the urban sub-sample were 4.4 and 7.2 ($t = 10.31$, $df = 747$, $p < .001$), while mean sizes in the rural sub-sample were 5.3 and 7.2 ($t = 14.25$, $df = 2484$, $p < .001$). The urban - rural difference in households without disabled members (mean sizes 4.4 and 5.3) was significant ($t = 4.83$, $df = 679$, $p < .001$), while this was obviously not the case for households with disabled members.

Mean age in the households with disabled members was 27.8 years ($N = 2068$, $SD = 11.2$) and 28.3 years ($N = 1293$, $SD = 12.6$) in the control households. This difference is not statistically significant. Concerning gender distribution, 52.7 % ($N = 16425$) of the members in households with disabled people were females, whereas the corresponding figures for the control households was 51.8 % ($N = 6836$). Again this difference between the two groups is not statistically significant. Further analyses revealed that number of children under the age of 18 was higher in households with disabled members (3.4 vs. 2.3, $t = 13.56$, $df = 3390$, $p < .001$).

In other words, with respect to age and gender (two of the most important demographic parameters of a population) the two types of households are similar. However, it is interesting to note that households that include a disabled member are, on

average, larger and that they have more children. It is also worth noting that an expected urban – rural difference in size of households is found for the control households only.

5.1.1 Disabled and non-disabled

The controls were not asked about disability. Comparison between disabled and non-disabled individuals is therefore based on the individuals in the households with disabled members, i.e. all together 16 459 individuals.

Table 5.2 Disability by gender

Gender	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Female	1181	46.6	7472	53.8	8653	52,7
Male	1352	53.4	6420	46.2	7772	47,3
Total	2533	100.0	13892	100.0	16425	100

A total of 2537 persons with disabilities were identified in the 2286 households with disabled members (i.e. 15.4 % of 16459 individuals). A significant gender difference was found in that 46.6 % (n = 1181) of the disabled were females whereas the corresponding figure for the non-disabled was 53.8 % (n = 7472).

Mean age among the disabled household members was higher than among the non-disabled (36.5 years and 24.6 years, $t = 23.35$, $df = 3408$, $p < 0.0001$). Further analyses by gender revealed the same pattern. The mean age for women was 38.4 years and 26.2 years in the households with disabled members and the control group respectively ($t = 16.08$, $df = 1520$, $p < 0.0001$), and for men the mean ages were 34.9 years and 22.7 years, $t = 17.66$, $df = 1898$, $p < 0.0001$).

Table 5.3 Marital status

Marital status (age >= 15)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Never married	1051	53,6	4752	59,5	5803	58,4
Married with certificate	257	13,1	1155	14,5	1412	14,2
Married traditional	278	14,2	1068	13,4	1346	13,5
Consensual union	73	3,7	300	3,8	373	3,8
Divorced/ separated	105	5,4	211	2,6	316	3,2
Widowed	197	10,0	497	6,2	694	7,0
Total	1961	100,0	7983	100,0	9944	100,0

Table 5.3 reveals that there is no appreciable difference between disabled and non-disabled with respect to marital status. Of the disabled, 27.3 % are married (either with certificate or traditionally), whereas this figure for the non-disabled is 27.9 %.

Table 5.4 School attendance

School attendance (age \geq 5)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Never attended	929	38,6	1968	16,2	2897	19,9
Still attending	333	13,8	5340	44,0	5673	39,0
Left school	1145	47,6	4829	39,8	5974	41,1
Total	2407	100,0	12137	100,0	14544	100,0

It is shown here that school attendance is lower among the disabled members of the households as compared to those household members without a disability. ($\chi^2 = 1003.3$, $df = 2$, $p < 0.0001$). The proportion of those who have never attended school is twice as high among the disabled members as compared with the non-disabled (38.6 % versus 16.2 % respectively). This finding was again confirmed among females and males separately (41 % of disabled females and 37 % of disabled males never attended school compared with 17 % of non-disabled females and 15 % of non-disabled males).

Separate analyses were carried out to explore whether particular types of disabilities were represented among those who had not attended school. Among those with disabilities 5 years of age or older, 1216 of 2260 (53.8 %) reported a disability that could be described as seeing, hearing, communication, intellectual or learning. Of these, 547 or 63 % never had attended school. In contrast, 303 of the 949 individuals (35 %) who reported a physical disability had never attended school. (Several reported multiple disabilities, and only the first disability is assessed here.) It appears that individuals with sensory impairments (seeing & hearing) and communication problems are over-represented among those without any formal schooling. For individuals with an impairment that affects the ability to move, the situation is slightly better. These results may indicate that school services are not well adapted to the needs of those who have a sensory impairment.

Table 5.5 School grade completed

Grade completed (age >= 5)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
7th grade or lower	1053	75,9	6599	67,7	7652	68,7
8th - 12th grade	318	22,9	3047	31,2	3365	30,2
Higher education	16	1,2	105	1,1	121	1,1
Total	1387	100,0	9751	100,0	11138	100,0

Table 5.5 shows further differences (and similarities) between those who have attended school. In the sample of individuals 5 years and older, a slightly larger proportion of those with disabilities is found in the lower grade categories (76 % in 7th grade or lower compared to 68 % among the non-disabled) and fewer among those in grades 8 – 12 (23 % among disabled versus 31 % among the non-disabled). The proportion of those with higher education is similar in the two groups. Analysing in subgroups revealed that the above pattern was confirmed but also that it was stronger among women and in the rural sub-sample.

The most striking difference between the two types of households with regards to education refers to the higher proportion of non school-attendees among the households with disabled persons.

A further indication of skewed distribution of (educational) resources between disabled and non-disabled were found in that 48 % (n = 1171) of the disabled persons 5 years of age or older were not able to write, whereas this figure for non-disabled was 23 % (n = 2841). Analyses confirmed the pattern in subgroups but also that it appeared to be stronger among women and in the rural sub-sample.

Table 5.6 Languages

Languages written (age \geq 5)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
None	1171	48,3	2841	23,2	4012	27,3
One	679	28,0	3711	30,3	4390	29,9
Two	452	18,6	4584	37,4	5036	34,3
Three	123	5,1	1111	9,1	1234	8,4
Total	2425	100,0	12247	100,0	14672	100,0

A higher proportion of people with disabilities over 5 years of age has no written language abilities (48 % versus 23 % among the non-disabled population). Furthermore, individuals in households with disabilities are able to write fewer languages than individuals without disabilities ($\chi^2 = 716.3$, $df = 3$, $p < 0.0001$).

EMPLOYMENT AND SKILLS

Table 5.7 Unemployment

Work status (age 15 – 65)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Currently working	132	8.1	1463	20,8	1568	17,7
Returning to work	30	1,8	163	2,4	193	2,1
Not currently working	1776	90,1	5294	77,8	6770	80,2
Total	1638	100,0	6893	100,0	8531	100,0

Table 5.7 illustrates the degree of unemployment¹⁴ among persons between the economically active age of 15 – 65 years. According to the data presented here, unemployment is currently very high: 90 % among those with disabilities and 78 % among the non-disabled ($\chi^2 = 148.7$, $df = 1$, $p < 0.0001$). It is of importance here to note that the figures for unemployment are much higher than in the recent study on living conditions in

¹⁴ Employment understood as formal employment or employment by some form of contract including seasonal labour but not self employment

the general population in Namibia (Planning Commission, 2000). This may be explained by differences in the questions on employment, and that the results produced here refers to formal employment (with an employer) and not self-employment or work at home.

It is interesting to note that the proportion of unemployment among people with disabilities revealed in Table 5.7 corresponds well with the result from the previous study on disability and rehabilitation in Namibia (Bruhns et al., 1995), i.e. 72.2 % and 69 %. The results further indicate that the proportion of employment is higher among the sensory impaired.

SKILLS

It was however shown that among the same group of potentially economically active persons, 19 % (n = 310) of those with disabilities had acquired some skill, compared to 21 % (n = 1422) of the non-disabled (difference not significant). 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.

Table 5.8 Skills

Skills (age \geq 15)	Disabled		Non-disabled		Total	
	N	%	N	%	N	%
Yes, formal	69	4,2	377	5,5	446	5,2
Yes, informal	241	14,7	1045	15,2	1286	15,1
No	1327	81,1	5447	79,3	6774	79,6
Total	1637	100,0	6869	100,0	8506	100,0

Interestingly, more persons without skills (formally or informally trained) are employed as compared to persons with skills (60 % versus 40 %). Among persons with disabilities, 38 % (n = 61) of individuals with skills are employed, as compared to 62 % (n = 98) of individuals without skills ($\chi^2 = 91.3$, df = 1, p < 0.0001). A minimal, non-significant difference was observed in the non-disabled control group.

There is a difference in mean monthly salary between the two groups (disabled: N\$867, non-disabled: N\$1159), and this difference is statistically significant (t = 2.45, df = 109, p = 0.016; N = 889, i.e. total number of individuals 15-65 years of age who report a monthly salary). Women's monthly salary was

significantly lower than men's, but the urban – rural difference was not large enough to produce statistical significance.

Income in kind for disabled and non-disabled in rural areas was reported by 53.8 % and 55.5 % respectively. In urban areas, the corresponding figures were 6.1 % and 1.9 %. These figures primarily reveals major differences in the economy of individuals and households in urban vs. rural areas, and there is also an indication that more disabled in rural areas depend on income in kind than do non-disabled.

5.1.2 Comparing households

In the preceding section, the grounds for comparison were individuals with and without disabilities in households with a disabled family member. In this section we will look at differences between household units with and without a disabled family member. First we present an urban/rural distribution of households included in the survey.

Table 5.9 Urban – rural distribution of households

Urban/rural household	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
Urban	439	19,2	360	26,5	799	21,9
Rural	1847	80,8	996	73,5	2843	78,1
Total	2286	100,0	1356	100,0	3642	100,0

A higher proportion of households with disabled members is found in rural areas ($\chi^2 = 26.8$, $p < .001$). This is as anticipated and according to previous studies (Bruhns et al., 1995).

EMPLOYMENT

Table 5.10 Employment

Is someone in the household working?	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
No	1286	56,3	554	40,9	1840	50,5
Yes	1000	43,7	802	59,1	1802	49,5
Total	2286	100,0	1356	100,0	3642	100,0

Significantly more households with one or more disabled family members have no one employed (56 %) as compared to the non-disabled households (41 %) ($\chi^2 = 80.2$, $df = 1$, $p < 0.0001$). The pattern is consistent in both urban and rural districts. Employment is higher in urban areas with 76 % of households reporting someone working compared to only 42 % in rural areas. (Caution: These figures should not be interpreted as employment rates.) In urban areas 72 % of households with a disabled member report someone working compared to 81 % of non-disabled households; while rural area report 37 % and 51 % respectively (all differences statistically significant, $p < 0.001$).

Income and expenses were measured in N\$ (Namibian Dollars, 1N\$ = 0.10 USD, 01.06.02). Maximum number of possessions was 30.

Table 5.11 Income, expenses and possessions

Household income (month)	Weighted		Weighted	
	N	mean	N	mean
Good month		(category) ¹⁵		N\$
Disability survey	2001	2.4	783	1453
Control group	1208	3.1	538	2154
Bad month				
Disability survey	1882	1.8	651	914
Control group	1149	2.3	429	1692
Expenses				
Disability survey	1961	1.9	635	663
Control group	1187	2.2	434	925
Possessions				
Disability survey	2286	4.2		
Control group	1356	5.2		

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 dollar amounts were re-coded into categories in order to expand the response percent. Results are, however, present in both forms. 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.

It appears from the results presented in Table 5.11 that households with disabled members have lower (mean) income, less (mean) expenses regardless of seasonal fluctuations. (Means are weighted by size of households – and all differences are statistically significant, $p < 0.001$). Furthermore households with a disabled family member have, on average, fewer possessions as compared to households without disabled members.

While figures are lower for rural areas compared to urban areas, the above differences, by area, are consistent.

¹⁵ Categories (amount in Namibian \$): 0 (≤ 250), 1(251 – 500), 2 (501 – 800), 3 (801-1500), 4 (1501 – 2400), 5 (2401 – 4000), 6 (4001 – 10000), 7 (> 10000).

Fewer disabled households stated that salaried work was the primary source of income – 24 % versus 40 % - and this reflects the fact that fewer households with disabled family members had someone working (see above). Slightly more disabled households received their family income from cash cropping or subsistence farming – and 6 % of all such households (128 of 2150) gave disability grant as the family primary source of income.

HOUSING SITUATION

Table 5.12 Housing situation

Type of dwelling	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
Detached house	231	10,1	229	16,9	460	12,7
Semi detached/ townhouse	102	4,5	85	6,3	187	5,2
Apartment/flat	10	0,4	13	1,0	23	0,6
Mobile home			3	0,2	3	0,1
Single quarters	8	0,4	9	0,7	17	0,5
Traditional dwelling/ homestead	1779	78,1	853	63,0	2632	72,5
Improvised housing unit/shack	145	6,4	160	11,8	305	8,4
Other	2	0,1	1	0,1	3	0,1
Total	2277	100,0	1353	100,0	3630	100,0

Ownership	Disabled HH		Non-disabled HH		Total	
	N	%	N	%	N	%
Rented	39	1,7	65	4,8	104	2,9
Owner occupied, with mortgages	253	11,1	160	11,8	413	11,4
Owner occupied, without mortgage	1804	79,3	975	72,1	2779	76,6
Rent free, not owner occupied	53	2,3	53	3,9	106	2,9
Provided by employer (gov't)	17	0,7	18	1,3	35	1,0
Provided by employer (private)	23	1,0	44	3,3	67	1,8
Other	85	3,7	38	2,8	123	3,4
Total	2274	100,0	1353	100,0	3627	100,0

It is shown in Table 5.12 that there are hardly any differences between the two types of households when it comes to type of dwelling. Differences observed are artefacts of the regional distribution of households in the survey with the majority of households surveyed being located in rural districts and thus the predominance of traditional dwellings and homesteads. Detached housing is the most common in urban areas.

With respect to *standard* in terms of type of dwelling, disabled households are fewer among the detached, semi-detached and apartment types and are over-represented among traditional dwellings and homesteads. Housing ownership, on the other hand appears more evenly distributed between the disabled and non-disabled with only small differences differentiating the groups.

Several questions were asked regarding different aspects of housing infrastructure. These included: 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, for example, for Energy source for cooking response categories were:

electricity

paraffin/gas

wood/charcoal/coal

candles

dung/grass etc.

none

Individual variables were ranked according to degree of hygiene or level of technical implementation (from best to worst). 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 39 (worst standard). For the 3456 (95 %) of households that had data recorded for all 5 variables the range was from 5 to 34, mean 20.8 (SD 7.4). The mean difference between households with a disabled and those without was 21.6 and 19.4 respectively ($p < 0.001$), indicating that, with respect to the five indices included, households with disabled family members had, on average, a lower standard than did households without a disabled family member.

The same pattern of difference between the two types of households was found in both urban and rural households. While the housing standard score was 10.2 and 11.8 in the rural subsample and 22.8 and 24.0 in urban households, this also reveals the well-known and large differences in standard of housing and infra structure between urban and rural areas.

Chart 1. Housing standard disabled and non-disabled

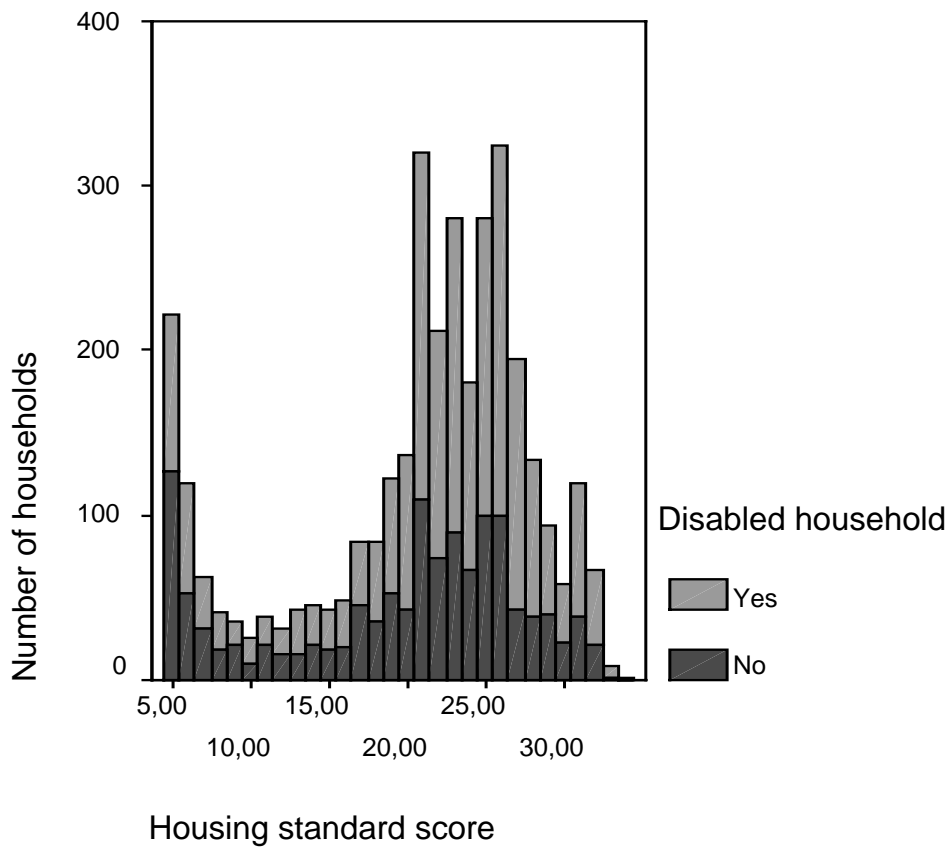
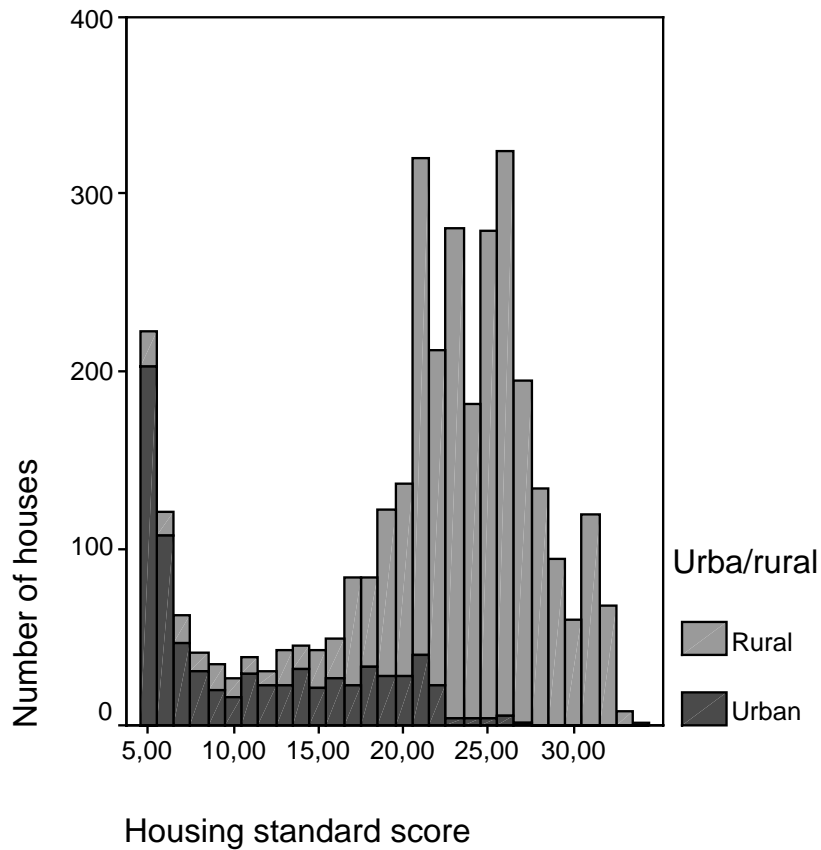


Chart 2. Housing standard urban and rural



Controlling for the urban – rural variable demonstrated the pattern shown in Chart 1 in both sub-samples. Chart 2 illustrates the large difference in housing standard as mentioned above.

Another indication of household standard may be derived from availability and access to different form of communication and information. The questionnaire requested data on the availability of: telephone, radio, television, internet, banking facilities, newspaper and post office. These were all coded as:

own/use regularly

have access to

have no access to

Again, a composite score was devised by adding the above 7 elements into a scale to define standard with respect to information access. This scale had a possible range from 7 (full access/availability) to 21 (no access/availability). For the 3384 (93 %) of households that had data recorded for all 7 variables the range was 7 to 21, mean 16.8 (SD 3.1). The mean difference between households with a disabled and those without was 17.2 and 16.1 respectively ($p < .001$), indicating that, with respect to the seven indices included, households with disabled family members have, on average, less access to information than did households without a disabled family member.

Chart 3. Access to information disabled – non-disabled.

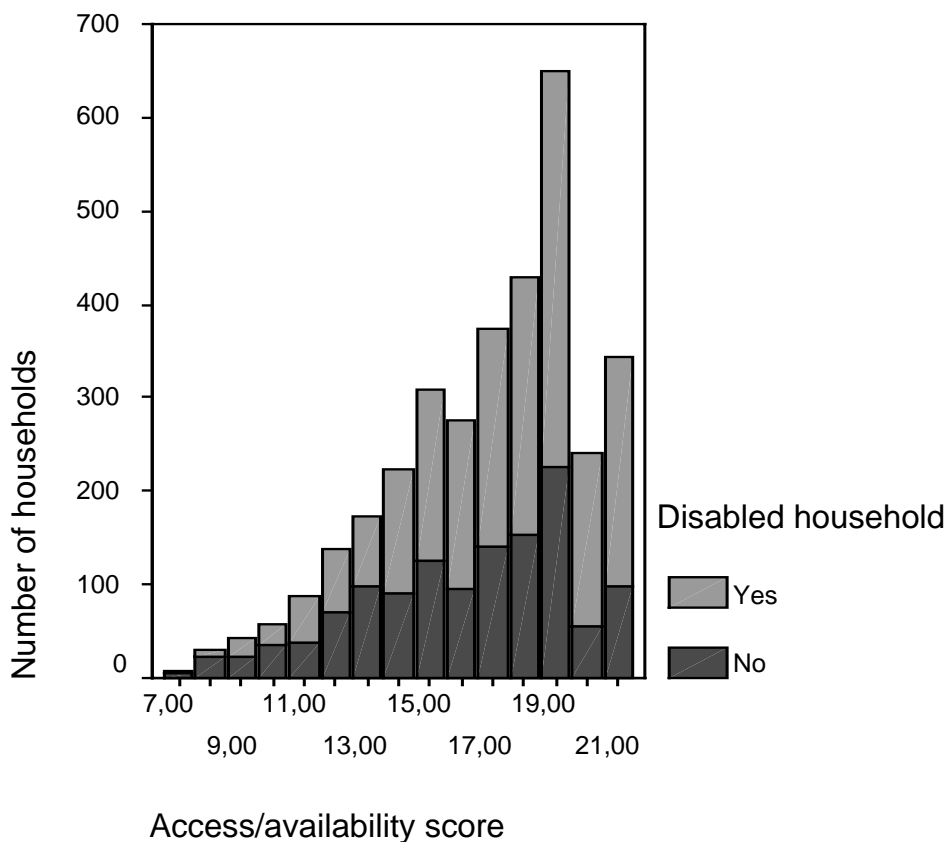
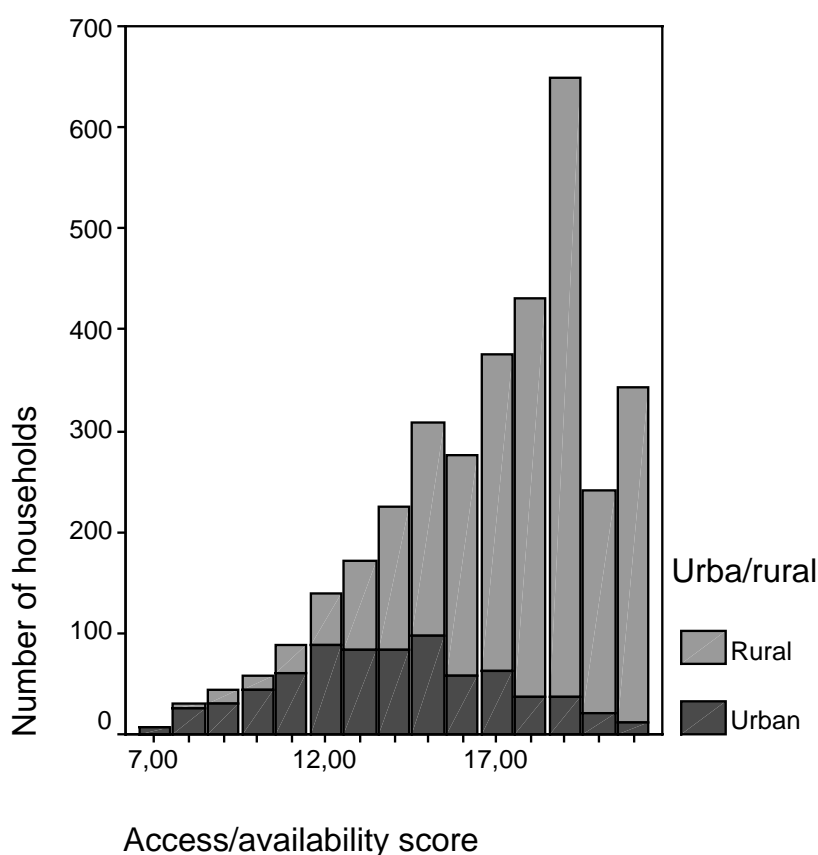


Chart 3 shows the difference in access to information services between the two types of households.

Chart 4. Access to information. Urban – rural.



Differences between urban and rural areas in availability of different information services is clearly demonstrated in Chart 4.

5.2 Disability study

Of the 2537 individuals identified as having a disability during the first phase of the survey (Levels of living conditions), a total of 2528 (99.6%) responded to the detailed disability survey. In 38 % of the cases the person with the disability responded themselves, whereas proxy reporters answered in the remaining 62 %.

Table 5.13 Age profile of person with disability

Age group in years	male		female		total	
	n	%	n	%	n	%
0-5	95	7,2	67	5,9	162	6,6
6-10	124	9,4	77	6,8	201	8,2
11-20	226	17,1	204	17,9	430	17,5
21-30	215	16,3	182	16,0	397	16,1
31-40	175	13,3	130	11,4	305	12,4
41-50	177	13,4	148	13,0	325	13,2
51-60	143	10,8	143	12,6	286	11,6
61+	165	12,5	188	16,5	353	14,4
Total	1320	100,0	1139	100,0	2459	100,0

The age range for the group of disabled was from 0 to 97 years. Mean age was 34.9 years (males: 33.6 years, females: 36.4 years), and median age was 32 years. Gender distribution in this sub-sample was 53 % men and 47 % women. There are slightly more women in the older age groups and slightly more men in the younger age groups.

Table 5.14 Distribution of the type of main disability by gender

	Male		Female		Total	
	n	%	n	%	n	%
Seeing	209	15,5	242	20,6	451	17,9
Hearing	129	9,6	119	10,1	248	9,8
Communication	97	7,2	59	5,0	156	6,2
Physical	561	41,7	446	37,9	1007	39,9
Intellectual/ emotional	228	17,0	178	15,1	406	16,1
Other	121	9,0	133	11,3	254	10,1
Total	1345	100,0	1177	100,0	2522	100,0

Respondents were able to report up to 3 different types of disabilities. However, if we concentrate on the first recorded, or major disability, 40 % are classified as major or minor physical disabilities (including paralysis) and 28 % report sensory impairments (seeing, hearing). Intellectual disabilities, learning disorders, emotional and communication disabilities account for 22 % of reported disabilities. There is a significant gender difference in that more women were registered with seeing disabilities and more men were physically disabled ($\chi^2 = 20.8$, $df = 5$, $p < .001$).

Of those reporting a 2nd disability, almost half claim an intellectual disorder or a communication disability.

Table 5.15 Cause of disability

Cause of disability	n	%
From birth	568	22,5
Illness	676	26,8
Polio	86	3,4
Epilepsy	35	1,4
Accident	313	12,4
Violence	96	3,8
War related	62	2,5
Health service related	31	1,2
Witchcraft	65	2,6
Alcohol and drug abuse	14	0,6
Animal related	19	0,8
Stroke; heart attack	26	1,0
Natural	103	4,1
Tuberculosis	20	0,8
Too much work	2	0,1
Old age	7	0,3
Death of close family member	10	0,4
Stress related	5	0,2
Pimples on eye caused blindness	1	0,0
Parental abuse	4	0,2
Rheumatism/ arthritis	2	0,1
Food poisoning	2	0,1
Noise pollution from mine/ factory	1	0,0
Total	2525	100,0
Missing	380	
Total	2528	

When asked about the type and cause of the disability, the respondent's own opinion was recorded. No attempt was made to acquire a medical verification of either type or cause of

disability. Table 5.16 shows that the main recorded causes of disability are: illness (26.8 %), "from birth" or congenital (22.5 %) and accidents (12.4 %). This distribution corresponds approximately to the results from the disability study conducted in South Africa (Schneider et al., 1999).

Table 5.16 Age of onset of disability

	n	%
From birth	722	30,6
1-5	343	14,5
5-10	159	6,7
11-20	284	12,0
21-30	252	10,7
31-40	197	8,3
41-50	183	7,8
51-60	116	4,9
61+	105	4,4
Total	2361	100,0
Missing	167	
Total	2528	

Apart from the 721 individuals (31 %) who here reported age of onset as birth, 786 or 33.2 % were disabled as children or young adults (age less than or equal to 20 years). As many as 14.5 % 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 5.17 Which of the services, if any, are you aware of and have ever needed/received?

Type of service	aware of		need		received	
	service		service		service	
	n	%*	n	%*	n	%**
Health services	2297	90,9	2288	90,5	1667	72,9
Welfare services	1771	70,1	2011	79,5	469	23,3
Counselling for parent/family	1444	57,1	1705	67,4	711	41,7
Assistive device services	1523	60,2	1694	67,0	293	17,3
Medical rehabilitation	1385	54,8	1634	64,6	430	26,3
Counselling for person with disability	1260	49,8	1634	64,6	248	15,2
Educational services	1464	57,9	1469	58,1	403	27,4
Vocational training	1071	42,4	1196	47,3	62	5,2
Traditional healer	1692	66,9	836	33,1	391	46,8

* percentage of total number disabled (n = 2528)

** percentage of those who claimed that they needed the service

Of the nine services listed above, well over half of those sampled were at least aware of its existence. With the exception

of traditional healers, the need for services equalled or outweighed their awareness; i.e. even though someone was not aware that the service was available they had expressed a need for it. The relatively low expressed need for traditional healer may indicate that in this particular setting, modern medical and health services are more in demand. 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, far fewer actually received it than had expressed a need for it. Among the most noticeable shortcomings, were for example, vocational training – only 5.2 % of those who expressed a need for vocational training had actually received it; and counselling services for the disabled, received by only 15 % of those who need it. Assistive device services, welfare, and educational services were also received by less than 30 % of those who needed them. These figures express, to a degree, the frustration of the disabled in the community as well as an opportunity for service providers to improve services and accessibility, and not in the least to policy makers to perhaps review priorities in the area of service provision. On a brighter note, almost three quarters (73 %) 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.

Most of the persons with disabilities surveyed expressed a need for some service. Only 60 individuals expressed no need for any

of the services listed (or other services not listed). Overall, 82 % of those expressed a need did in fact receive a needed service. Asked to assess the services they had received in the past, over half of these respondents claimed that services were too expensive and nearly half said that the service was inaccessible (too far/no transport). An equal proportion claimed that the service was not helping anymore, they had not improved, or that they were not satisfied with the service provided. Almost 20 % pointed to a communication barrier or language problem between the users and provider of the service and only 15.6 % had actually reached the level of functioning they had set as a goal and no longer needed the service.

EDUCATION

Of those sampled 59 % (n = 1489) were disabled before 18 years of age. Those currently 5 years or older (n = 1378) were asked about their education and schooling experiences. Table 5.19 on the following page show the different types of schools attend by those eligible for school according to age. For those who attended school, the majority went to mainstream or regular school. Of particular note is the high proportion of those who did not attend primary school, though eligible (according to age). 48 % of the disabled aged 5 years or more had not attended primary school. (Raising the cut-off to 7 years of age and over reduced the proportion never attending school to 44 %).

Table 5.18 Type of school attended

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

	Mainstream/ regular school		Special school		Special class in regular school (NA)		Did not go to school		TOTAL N
	n	%	n	%	n	%	n	%	
Pre-school/early childhood (all ages)	423	29,1	65	4,5	15	1,0	952	65,4	1455
Primary school (age >= 5 years)	619	45,9	50	3,7	30	2,2	651	48,2	1350
High school (age >= 15 years)	105	11,6	13	1,4	6	0,7	783	86,3	907
Vocational training (age >= 18 years)	9	1,2	2	0,3	3	0,4	767	98,2	781

While few actually reported being refused entry to a regular or special school because of their disability it is worth noting that as many as 5 % were refused regular pre-school, 10 % refused regular primary school and 2 % refused regular high school. Only about 1 % was refused entry into a special class or school because of their disability.

EMPLOYMENT

Asked whether they were currently working or returning to work, those 15 years and older replied: 94 (5 %) currently working or returning to work, 1858 (95 %) not working with the majority (1405) never having been previously employed. The majority of those who had jobs were employed as domestic and related helpers/cleaners (n=100, 20 %), in the category building construction (n=39, 8 %).

ACCESSIBILITY

Accessibility at home is shown in Table 5.19, for the urban and rural sub-samples separately. Differences in housing standard is found in that less rural households have separate kitchen, living room, dining room and in particular toilet facilities. This reflects that traditional housing is common in the rural areas. It is however interesting that among those who report that their home have the different types of rooms/facilities, accessibility problems seem to be on the same level in the two sub-populations. Approximately 10 % of those surveyed stated that

they did not have access to one or more rooms in their homes. Almost half of the rural households do not have a separate toilet, while this figure is down to 14.9 % in urban areas. dining room. In urban areas, 38.9 % do not have a separate dining room, while this figure increases to 50.6 % in rural areas.

Table 5.19 Accessibility at home

Room/facility	Accessible		Not accessible		Have none		Total	
	n	%	n	%	n	%	n	%
Kitchen	urban	387	80,5	40	8,3	54	11,2	481
	rural	1423	70,5	214	10,6	381	18,9	2018
	Total	1810	72,4	254	10,2	435	17,4	2499
Bedroom	urban	438	90,9	35	7,3	9	1,9	482
	rural	1777	87,8	199	9,8	47	2,3	2023
	Total	2215	88,4	234	9,3	56	2,2	2505
Living room	urban	326	67,6	39	8,1	117	24,3	482
	rural	1158	57,3	210	10,4	653	32,3	2021
	Total	1484	59,3	249	9,9	770	30,8	2503
Dining room	urban	253	52,6	41	8,5	187	38,9	481
	rural	767	38,0	230	11,4	1021	50,6	2018
	Total	1020	40,8	271	10,8	1208	48,3	2499
Toilet	urban	366	75,9	44	9,1	72	14,9	482
	rural	896	44,4	187	9,3	937	46,4	2020
	Total	1262	50,4	231	9,2	1009	40,3	2502

Table 5.20 Accessibility from home

	Accessible		Not accessible		Never go		None available		Total N
	n	%	n	%	n	%	n	%	
Health care clinic	1986	79,2	286	11,4	188	7,5	46	1,8	2506
Hospital	1830	73,2	370	14,8	201	8	98	3,9	2499
Place of worship	1536	61,8	365	14,7	470	18,9	114	4,6	2485
Public transport	1464	58,7	464	18,6	395	15,9	169	6,8	2492
Shops	1294	51,8	480	19,2	619	24,8	104	4,2	2497
Sports facilities	663	26,5	429	17,1	1163	46,5	248	9,9	2503
Post office	644	25,7	484	19,3	1113	44,5	261	10,4	2502
School	637	25,5	403	16,1	1299	51,9	162	6,5	2501
Police station	620	24,8	473	18,9	1166	46,6	245	9,8	2504
Bank	464	18,6	507	20,3	1202	48,2	320	12,8	2493
Magistrates office	442	17,7	488	19,5	1248	49,8	326	13	2504
Recreational facilities	420	16,8	348	13,9	1053	42,2	677	27,1	2498
Workplace	204	8,2	318	12,8	1543	62,3	412	16,6	2477
Hotels	141	5,8	182	7,4	1194	48,8	932	38,1	2449

Primary health care clinics and hospitals are among the most accessible facilities a person may need to visit; with over 70 % of respondents stating that these facilities are accessible. It seems unfortunate that schools find a place lower on the list (25 % classify schools as accessible) and workplaces even lower (fewer than 10 % state that the workplace is accessible).

AIDES AND ASSISTIVE DEVICES

When asked whether the person used any medication (including traditional medicine) for pain that was caused by the disability, almost 30 % of those who replied (726 of 2506) answered yes. These were most often tablets for pain relief, traditional herbs or eye drops, though there were almost 100 different medications listed.

Respondents were also asked if they used assistive devices – 446 (18 %) responded “yes”. More than one type of device could be registered. Gender and urban - rural differences were marginal.

Table 5.21 Type of assistive devices in use

Type of device	Examples	n	% (of those who use devices)
Personal mobility	Wheelchairs, crutches, walking sticks, white cane, guide dog, standing frame	344	77,1
Information	Eye glasses, hearing aids, magnifying glass, enlarge print, Braille	82	18,4
Personal care & protection	Special fasteners, bath & shower seats, toilet seat raiser, commode chairs, safety rails, eating aids	25	5,6
Communication	Sign language interpreter, fax, TTY, portable writer, PC	20	4,5
For handling products and goods	Gripping tongs, aids for opening containers, tools for gardening	8	1,8
Household items	Flashing light on doorbell, amplified telephone, vibrating alarm clock	5	1,1
Computer assistive technology	Keyboard for the blind	2	0,5

Asked whether their device was in good working condition 70 % answered "yes". Over two-thirds had received at least some guidance on usage of the device – but as many as 121 (almost

30 %) had not received any instructions or guidance on use of assistive technology. (These may be associated with less technologically demanding forms of devices).

60 % acquired their device from government health services, 2 – 3 % through NGOs, 30 % privately and the rest through other sources. Finally, asked who maintains or repairs the device about a third (33 %) replied that they themselves took responsibility for the device and another third (36 %) stated that the government undertook maintenance and reparations, 10 % relied on their families for support in these matters and fully 16 % claimed that their device either were not maintained or that they couldn't afford maintenance/repairs.

DISABILITY AND OTHER GRANTS

A little over ¼ of respondents (664, or 26 %) were currently receiving financial assistance through a disability grant or pension. An additional 317 (12 %) had applied but were not currently receiving any assistance (41 % awaiting reply; 23 % rejected; 26 % approved, awaiting funds).

Table 5.22 Type of grant or pension (n = 664)

Type of grant or pension	Amount				
	n	%	min.	max.	mean
Disability grant from Social Services Division (18 years and older)	426	64,2	150	600	225,5
Maintenance grant from the Social Services Division (between 0-17 years)	13	2,0	200	250	212,5
Workman's Compensation/Social Security	6	0,9	200	1500	590,3
Private insurance/pension	4	0,6	200	1200	525
Old age pension (over 60 years)	217	32,7	150	600	234,4
Other	5	0,7	200	800	425

The majority of all grants were in the range 200 to 600 N\$. Over 90 % of all monies received through grants went towards household necessities, in particular the procurement of food. Clothing consumed a further 7 % the remainder being divided among education, rent/accommodation, transport, rehabilitation & health care services, personal assistant, and recreation.

In most cases (60 %) it is the person with disabilities him/herself (alone or in agreement with their partner) who decides how these monies are spent. Taking into consideration the type of disability (77 of 91 individuals with mental impairments) and age of the person disabled (children less than 18 years of age) it is not unreasonable that in as many as 40 % of cases someone other than the person with disability is responsible for deciding how the grant monies are spent.

ROLE WITHIN THE HOUSEHOLD AND FAMILY

Table 5.23 Assistance needed in daily life activities

Do you need help with	Yes		Sometimes		combined %	% responding yes			
	n	%	n	%		urban	rural	male	female
dressing	638	25,2	247	9,8	35,0	26,8	25,4	26,0	25,3
toileting	554	21,9	176	7,0	28,9	25,9	21,5	21,9	22,9
bathing	641	25,4	284	11,2	36,6	26,3	25,7	26,5	25,0
feeding	508	20,1	196	7,8	27,8	20,3	20,6	21,1	19,9
cooking	1061	42,0	374	14,8	56,8	37,0	43,6	47,0	36,9
shopping	864	34,2	601	23,8	58,0	34,7	34,6	34,3	34,9
moving around	563	22,3	657	26,0	48,3	27,6	21,7	22,0	23,9
finances	837	33,1	612	24,2	57,3	31,4	34,2	34,4	32,8
transport	861	34,1	583	23,1	57,1	32,6	35,2	33,8	35,8
studying	264	29,0	136	14,9	43,9	28,6	29,1	27,1	31,5
emotional support	1280	50,6	681	26,9	77,6	56,2	50,2	52,6	49,9

The results presented in the table above are obviously dependent on numerous factors; among them urbanicity, the sex and age of the person with disabilities and the severity of the disability. With one exception, these figures are based on the entire sample of 2528 people with disabilities. Help with studying was perhaps the most age dependent – and approximately 62 % of the sample said that this was not applicable. This question was therefore based on those who responded yes, yes sometimes or no (n = 911).

We chose to examine the difference in needs based on the urban/rural and male/female axes and see whether these dependencies impacted on perceived needs for assistance. Some urban/rural differences may be worth mentioning, among them: more help needed in rural areas for cooking, and more help needed in urban areas for toileting, moving around and emotional support. While no apparent pattern appears here, the results may reflect the difference between complexity associated with urban dwelling as opposed to rural life.

In general, with respect to gender differences there do not appear to be any differences that stand out for one sex over the other. 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. The largest difference observed was that men required more help for cooking than did women. No other differences of note were recorded.

Table 5.24 Involvement in family life

Involvement in family life	% yes	% sometimes	% no
Do you go with the family to events?	67	17	16
Do you feel involved and part of the family?	87	8	5
Does the family involve you in conversations?	78	13	9
Does the family help you with daily activities?	78	17	5
...for those over 15 years			
Are you consulted about making household decisions?	61	16	23
Do you make important decisions about your life?	55	35	10
Are you married or involved in a relationship?	37		63
Does your spouse/partner have a disability?	8		92
Do you have children?	60		40

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 16 % are not included in family events, 9 % are not involved in conversations and 5 % do not feel a part of the family. Furthermore, of those 15 years and older, 23 % are not consulted about making household decisions and 10 % 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. Further analyses showed a tendency towards women being more involved or integrated into family life than men.

DEFINING SEVERITY – Measures of Activity limitations and Participation restrictions

Much information has been collected during the survey that could be used to define the severity of a person's disability. We have seen so far an assessment of an individual's needs for services, and activities that a person may need help in accomplishing in everyday life (see Table 5.17 – need for services and Table 5.23 – need for assistance). Simple scores can be constructed to summate need for services and the total need for daily life assistance.

In addition, we constructed a matrix to map an individual's activity limitations and participation restrictions according to

different parameters or 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. (The complete matrix is shown in Appendix X). For each item or activity under these 9 parameters the degree to which an individual was capable of carrying out the activity (perceived activity limitation) was recorded: on a scale from (0) no difficulty to (4) unable to carry out the activity. In the same manner the person's performance in their current environment (perceived degree of participation restriction) was recorded: on a scale from (0) no problem to (4) unable to perform the activity. Based on recorded observations for each of the 47 items under the 9 domains a single activity limitation score and participation restriction score was developed – as well as 9 sub-scales for each of the domains.

These 13 scales were then assessed by type of disability.

Table 5.25 Mean scores on severity scales by type of disability.

Severity scales	Type of disability					
	seeing	hearing	communi- cations	physical- mobility	mental/ emotional	other/ unknown
N	453	248	156	1009	407	255
Daily activity help score	4,7	4,4	5,0	5,3	5,1	4,8
Service needs score	5,5	5,8	5,5	5,7	6,0	5,6
Activity score	15,9	20,4	32,3	24,2	32,8	22,4
Participation score	15,8	19,7	31,9	24,2	32,7	22,4
Community & social life	1,1	1,7	2,2	1,3	3,1	1,5
Learning & knowledge	2,4	3,1	5,1	1,4	7,7	2,7
Mobility	3,4	1,2	4,4	12,7	2,8	7,6
Self care	1,3	1,1	4,7	2,7	3,1	2,0
Domestic life	2,3	1,3	3,4	3,4	4,6	4,2
Interpersonal behaviours	0,8	3,2	4,5	1,0	5,3	1,9
Sensory experiences	2,6	2,4	0,8	0,2	0,3	0,4
Communication	0,8	4,7	5,5	0,7	3,2	0,7
Major life areas	1,2	1,7	2,1	1,1	3,2	1,8

Looking first at the score based on assistance required for daily activities, while it appears that there is little variation in mean scores based on type of disability, the observed differences are not insignificant ($F = 5.5$, $df = 5/2522$, $p < 0.001$). In particular, the mean score for physical disabilities is significantly higher than for seeing and hearing disabilities, and the mean score for mental disability is higher than hearing disabilities. No significant differences were observed in the score based on service needs.

Controls revealed higher scores on activity limitations and participation restrictions in the rural sub-sample particularly for mental/emotional disabilities, but also for communication, seeing and hearing impairments. Physical/mobility impaired individuals in rural areas did however report marginally higher levels on the two indices than did their urban counterparts. This may indicate a more problematic daily life less participation for people with certain disabilities in rural areas, while it also indicates that physical/mobility impaired may be in a better situation in rural areas as compared to individuals with other types of impairments.

Both the activity limitation score and the participation restriction score behaved similarly ($F = 22.2$, $df = 5/2522$, $p < 0.001$). First, mean scores for seeing and hearing disabilities were, on both scales, significantly lower than scores for all other types of disabilities. Scores for communication and mental/emotional

disabilities were significantly higher than for all other types. Generally speaking this indicates that individuals who are classified as seeing or hearing impaired experience significantly fewer activity limitations and participation restrictions, while those with communication or mental/emotional disabilities experience significantly more barriers to full participation in society. Those with physical disabilities find themselves on a sort of middle ground. (The 9 individual elements of the activity limitation and participation restriction scales are presented in the table for information and will not be further commented on here.)

Table 5.26 Mean scores on severity scales by gender and urban/rural

Severity scales	Gender			Rural	Urban	
	Male	Female				
Count	1345	1177		2041	485	
daily activity help score	5,0	5,0	n.s.	5,1	4,5	t = -5.7 p < 0.001
service needs score	5,7	5,7	n.s.	5,9	5,1	t = -3.8 p < 0.001
activity score	23,3	24,9	n.s.	24,5	22,2	n.s.
participation score	23,3	24,7	n.s.	24,4	22,0	n.s.

As shown in Table 5.26, analyses revealed marginal and non-significant gender differences in severity. It was however shown higher scores on assistance required among the rural sub-sample.

Four of the severity scores were then assessed with respect to certain indicators of living conditions. We looked at school attendance (re-coded: yes = still attending/left school, and no = never attended) and work situation (re-coded: yes = currently working or returning, and no = unemployed). Mean scores based on needs for services were not significantly different in for either school attendance or employment. However, mean scores based on the other indicators of severity, namely assistance required for daily activities, activity limitation and participation restriction, all showed that those unemployed or who never had attended school scored higher (need more services, and experience more activity limitations and restrictions to full participation in society). Results are presented in the following table.

Table 5.27 Mean severity scores on severity scales by indicators of living conditions.

School attendance						
	never attended		currently attending or finished			
	n = 923		n = 1474			
	mean	SD	mean	SD	t	p
Daily activity help score	5,6	2,6	5,8	2,5	-1,7	ns
Service needs score	5,3	2,7	4,7	2,8	4,5	<0,001
Activity score	30,0	31,0	19,4	21,5	9,1	<0,001
Participation score	29,6	31,0	19,5	21,6	8,7	<0,001
Work situation						
	unemployed		currently working			
	n = 1756		n = 176			
	mean	SD	mean	SD	t	p
Daily activity help score	5,7	2,6	5,5	2,5	1,4	ns
Service needs score	5,0	2,7	3,6	2,9	6,5	<0,001
Activity score	23,3	24,3	15,7	17,2	5,3	<0,001
Participation score	23,3	24,4	16,0	17,6	5,0	<0,001

In other words certain indicators of living conditions seem to be associated with these measures of disability severity, in particular activity limitations and participation restrictions.

6 Discussion

This study on living conditions among people with disabilities in Namibia is the first to be reported in what has developed into a Regional initiative backed by the Southern Africa Federation of the Disabled (SAFOD) and the Norwegian Federation of Organisations of Disabled People (FFO). This and the following studies in Zimbabwe and Malawi are unique in the sense that they represent a first effort to establish baseline data on the situation of people with disabilities in the SADCC¹⁶ area.

METHODS

Research instruments that have previously been applied in Namibia and South Africa form the basis of the current study. Results from testing these instruments have however not been reported, creating some uncertainty with regards to the quality. The process leading up to the design of the study in Namibia has however been very thorough and comprised extensive workshops with input from a broad range of experts and stakeholders as well as field testing before the main data collection. We are thus confident that the current research

¹⁶ Southern African Development Community comprises 14 countries in Southern, Central and Eastern Africa (excl. South Africa).

instrument is relevant and well adapted to the context. It is however also the case that the research design to some extent is a compromise between different interests involved in the process and that this might have produced an instrument that is not optimal from a research point of view. The instrument is necessarily long in order to cater to many interests, and allows for largely descriptive analyses.

Sampling, data collection and treatment of data have been carried out in a highly professional manner by the MultiDisciplinary Research and Consultancy Centre at University of Namibia. Inclusion of people with disabilities throughout the process, and in particular as enumerators, turned out to be very positive, increasing the credibility of the study and probably also reducing barriers between respondents and the interviewers. With regards to the identification of households, simple random sampling is not practical in this context, and therefore a two staged approach was used. A design effect is thus inherent in the results from the study, reducing confidence intervals and thus creating a possibility for exaggerated results. We have tried to avoid this problem by taking the design effect into consideration when interpreting and discussing the results.

Screening for disability is a major challenge in studies like this one. As described above, the devised screening instrument based on a broad (social) conception of disability did not yield prevalence rates that exceeded previous rates as was perhaps

expected. Possible explanations to this will be discussed in a separate paper (Eide & Loeb, in preparation). One possible suggestion for the failure to produce increased sensitivity as was expected is that the concept of disability is contextually and even culturally rooted. We mean by this that the screening instrument may have been unable to penetrate prevailing conceptions of disability among enumerators as well as respondents. If this is the case, training around the issue of screening should have been more extensive.

The issue of screening in the context presented here may illustrate an important limitation in such a questionnaire-based household survey. That is, the study in itself was not intended to elucidate the understanding among the sampled population of central concepts (like disability) that was applied in the development of the study instruments. We are therefore left with the possibility that different levels of understandings or meanings attached to certain concepts may have influenced both the stating of questions as well as the responses received and recorded. While this is a general problem in survey research, it is a particular challenge where concepts basically stemming from high-income countries are applied in a rural African setting. It is not certain to what extent this has influenced the results from this study, but it is worthwhile noting as an issue for discussion and not least future studies.

RESULTS

With this study, a baseline for living conditions among people with disabilities and their households has been established in Namibia. It is based on a national, representative sample and thus allows for estimates of the situation for the whole population of people with disabilities in the country. Not only allowing for thorough descriptions and analyses of the situation of disabled people in the country, the base-line also represents an opportunity for studying development in the situation through repeated studies.

In addition to the baseline on people with disabilities and their households, the control sample represents in itself a study on living conditions among non-disabled. This represents a unique possibility for comparison between disabled and non-disabled individuals and their families. Results from the control sample have been compared with the National study on living conditions in Namibia carried out in 1999 (Planning Commission, 2000). With a few exceptions, results from the two studies confirm each other. Where there are deviations in results, this can in many cases be explained by differences in formulations/questions.

Disability prevalence was estimated to be 1.62 % (95 % CI: 1.56 – 1.68) in this study, close to the estimated 1.9 %

determined in the 2001 Population and Housing Census (personal communication, not published). This difference is so small that the two results contribute to confirm each other and together they form a strong basis for assessing the extent of disability in Namibia. It must be underlined though that screening questions are different in the two studies. With the broader understanding of disability underlying the current study, one could have expected that this study came up with higher figures than the Census did.

It is a main finding that households with disabled members and individual disabled score lower on a number of indicators on level of living as compared to households without disabled members and non-disabled individuals respectively. The study thus confirms what was expected and fills in the picture in an area where little research-based information has been available. Although the association between disability and lower standard of living, and poverty for that matter, has been demonstrated in high-income countries, there were reasons to question whether this relationship was valid also for low-income countries. In a context where the large majority lives with limited resources, it could have been anticipated that this association was not present, or that it was different. Apparently, the mechanisms that underlie such systematic differences are also in place in Namibia.

The disability component of the study reveals that there are large gaps in particular services like vocational training, counselling and supply of assistive devices, closely followed by medical rehabilitation and welfare services. Health services seem to be available for most disabled. The response with regards to traditional healers might imply that many people use this for other purposes than the other services. Taken together, results here show that services to people with disabilities are under-dimensioned with the exception of health services and traditional healers. With regards to assistive devices, this confirms results from a previous survey about the situation of persons with disabilities in Namibia (Strand, 1999). The need for assistive devices can be met through import, as is the case today, or production in Namibia, which is almost absent. Other than supplying devices, it is also necessary to look into the service delivery system in order to ensure optimal utilisation of resources.

It is quite dramatic that close to half the population of disabled older than 5 years have not attended primary school. To some extent this may be explained by higher age for school start, but it is nevertheless a clear indication that disabled people are deprived of a basic right to primary education in Namibia. This result corresponds to the findings in the National Disability Study (Bruhns et. al., 1995), thus revealing little progress between 1990 and 2002. School attendance as well as performance is lower among people with disabilities as

compared to non-disabled. The results thus clearly indicate that access to education is restricted for people with disabilities and not properly adapted to those who attend. It appears that those with sensory impairments are particularly worse off in this regard, thus indicating a particular challenge for the responsible authorities.

Socio-demographic differences between the two types of households (with and without disabled members) may contribute to illuminate coping mechanisms when a member is disabled. Households with disabled members are substantially larger, mean number of members is the same in urban and rural areas, mean age of family members is higher, as is the number of children. This implies firstly that the disabled person remains in the household into adulthood, and that this mechanism is present across urban – rural differences. The age difference between household types is largely explained by the higher mean age of people with disabilities, while the difference in size of households are only partly explained by the presence of disabled. Higher number of children cannot be explained by the results from the study, and one can only suggest that that this may in one way or another link up with higher care duties in the households.

In the current data material, there is no association between disability and age, contrary to the situation in high-income countries. This is however in accordance with the previous

disability study in Namibia (Bruhns et. al., 1995) and may be explained by the demographic profile in the country, with the majority of people being under the age of 20. Controlling for this would most likely reveal that there is an association after all. The demographic profile is of course also interesting in relation to disability prevalence, as low prevalence could be expected in a young population. Reality is however that the disabled population in Namibia is evenly spread with regards to age.

Results for onset of disability clearly indicate the particular vulnerability of small children in this context as more than half of the disabled population are disabled before the age of 10. This forms a particular challenge to health services in the country. Distribution of types of disabilities in this study differs somewhat from the National Survey on Disability in Namibia (analysed and reported by Bruhns et. al., 1995). In the current study, prevalence of visual impairment is lower, while physical impairments and mental disorders are similar to the previous study. Classifications as well as screening varies however between the studies, and one should not forget that it 12 years has past between the two data collections. It is also the case that the current study has asked for and registered more than the major disability (1st disability) and that it is not clear whether the first study registered the 1st disability only. If this is the case, comparison is even more questionable.

Measuring activity limitations and restrictions in participation has contributed to confirm the applicability of core concepts in the ICF model in this context. Analyses revealed that three of the four indices based on the developed measures (matrix) were associated with selected indicators of living conditions, indicating not only that severity of disability is relevant in relations to distribution of welfare, but also that the matrix and the indices produce valid information. Further analyses of this matrix will take place and be published later.

Although not found for all indicators, the study has documented that women are worse off with regards to standard of living than men. Furthermore, there are differences with regards to age, disability profile, and family life that underline the need for a gender perspective on disability and policy for improvement of the lives of disabled people in Namibia.

The urban – rural differences are systematic in that living conditions are better in urban areas, also for people with disabilities. Strong differences between urban and rural areas are common in low-income countries, and this is also the case when comparing individuals with disabilities. Higher prevalence of disability in rural areas is very likely a reflection of lower level of living. The demonstrated differences imply that this is another dimension that has to be considered in the development and implementation of measures to improve the living conditions of people with disabilities in Namibia.

7 Conclusions

This study has produced data on living conditions among people with disabilities and their families in Namibia and a basis for comparison with non-disabled individuals and their households. It is a main finding that there are systematic differences and that individuals with disabilities and their households are worse off than their non-disabled counterparts on many important indicators. Socio-demographic differences between households with and without disabled members indicate that certain mechanisms are at work when a household has a member with disabilities and this results in larger households that can more easily cope with this situation in the context of a low-income country. A particular challenge for health services will be to address the marked vulnerability of small children as more than half of the population of people with disabilities are disabled before the age of 10. The study has further demonstrated large gaps in services for people with disabilities. Finally, the study has tested measures on activity limitations and participation restrictions and demonstrated that such measures contribute to explain differences in level of living.

The baseline produced through this study can be applied later for monitoring purposes. Results can be applied directly as

documentation of the standard of living among people with disabilities and their families, and as a basis for comparison with non-disabled. This information is potentially useful when decisions are made on utilisation of meagre resources, as argument towards 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 is considered, together with other relevant sources, as a basis for dialogue between authorities, professionals and organisations of people with disabilities, for setting priorities, and for developing concrete measures within selected areas of priority.

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Appendix

J: ACTIVITIES & PARTICIPATION

Identification of person with disability:

Section A, column (1) and (2).

Name: _____

Line No.:

--	--

ACTIVITY LIMITATION (CAPACITY)	PARTICIPATION RESTRICTION (PERFORMANCE IN CURRENT ENVIRONMENT)	Facilitators in environment (Write down only the MAIN facilitator in the person's own words)	Barriers in environment (Write down only the MAIN barrier in the person's own words)
0 no difficulty	0 no problem		
1 mild difficulty	1 mild problem		
2 moderate difficulty	2 moderate problem		
3 severe difficulty	3 severe problem		
4 unable to carry out the activity	4 complete problem (unable to perform)		
8 not applicable	8 not applicable		
9 not specified (level not known)	9 not specified (level not known)		
	If coded 1,2,3,4 then continue with column (3), else go to next line.		
	(1)		
	(2)		
	(3)		
	(4)		

1a. SENSORY EXPERIENCES

a. watching

b. listening

1b. BASIC LEARNING & APPLYING KNOWLEDGE

a. learning to read/write/calculate

b. acquiring skills (manipulating tools, learning names)

c. thinking

d. reading/writing/calculating

e. solving problems

2. COMMUNICATION

a. understanding others (spoken, written or sign language)

b. producing messages (spoken, written or sign language)

c. conversing with others

d. conversing using devices (telephone/typewriter/PC/Braille)

3. MOBILITY

a. maintaining a body position

b. changing a body position (sitting/standing/bending/lying)

c. transferring oneself (moving from one surface to another)

d. lifting/carrying/moving/handling objects

e. fine hand use (picking up/grasping/manipulating/releasing)

f. hand & arm use pulling/pushing/reaching/throwing/catching

g. walking

h. moving around (crawling/climbing/running/jumping)

i. moving around using equipment/assistive devices

j. using transportation to move around as a passenger

k. driving a vehicle (car/boat/bicycle/or riding an animal)

