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## Report

# Living Conditions among People with Disabilities in Swaziland

A National Representative Study

#### Editor(s)

Arne H. Eide Bhekie Jele



SINTEF Technology and Society Global Health and Welfare 2011-09-01



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## Report

## Living Conditions among People with **Disabilities in Swaziland**

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#### ABSTRACT

#### Abstract heading

A national, representative household study on living conditions among people with disability was carried out in Swaziland in 2009 – 2010. The Federation of Disabled People in Swaziland has been responsible for the implementation of the study, which was supported by the Norwegian Federation of Organizations of Disabled People. Central Statistical Office, the office of the Deputy Prime Minister and the University of Swaziland, all contributed to ensure the successful implementation of the study. SINTEF has been the

responsible international partner providing technical support and expertise throughout the study and is also responsible for this report. The study has stabled the first comprehensive baseline on the situation for disabled people in Swaziland, and it is part of a regional exercise which so far has covered seven countries in the southern Africa region. It is the intention that the results from the study will provide a basis for advocacy, planning, monitoring and policy development.

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## **1 ACKNOWLEDGEMENTS**

#### Arne H. Eide, SINTEF.

This is a report from a National, representative household survey carried out in Swaziland in 2009 – 2010. A large amount of effort has been put into this two-year exercise until finally we can present the results of the combined efforts. First of all, this is a credit to the Federation of Disabled People in Swaziland (FODSWA): To the Management Committee headed by Ms. Buyie Masuku for being in control of the whole process, and to the Project Co-ordinator Mr. Bhekie Jele who for the most of the study handled all aspects in this comprehensive and complex process. Mr Yusman B Kamaleri from SINTEF played an important role in supporting FODSWA during the implementation of the study.

The Executive Committee for the survey comprised of Mr. Makhosini Makhubu – FODSWA, Mr Choice Ginindza – Central Statistical Office, Mr. Fortune Dlamini – Central Statistical Office, Ms. Sindie Dube – Deputy Prime Minister's Office, and Mr. Mathew – University of Swaziland. They should all be thanked for their support and efforts to make this survey a useful tool for disabled people in Swaziland in the years to come.

A number of disabled individuals have contributed in different roles. Not least has this been an exercise that has proven the capabilities of disabled people, either in the Management Committee, as enumerators or as supervisors. This report and this study had not been possible without their enthusiastic participation, and the inclusion of individuals with disabilities in this exercise is a remarkable achievement, given the difficult situation for many individuals with disabilities in Swaziland and in the region. This effort may be one important step in changing in the role of disabled people, from objectives for research to actors and decision makers in research.



The Central Statistical Office (CSO) has offered assistance in the preparations for the study and personnel from CSO participated actively as supervisors during data collection. Particular thanks CSO, Ministry of Health and University of Swaziland who were represented in the Management Committee of the study and have all been open for consultations during the research process. These are all key institutions for following up the results of the study as well as for further utilization of the data material.

Southern Africa Federation of the Disabled SAFOD) and it's late Executive Director Mr. Alexander Phiri has been a supportive partner in this exercise as in the preceding studies on living conditions in the Region. His passing away during the study in Swaziland was a tremendous blow to us all. Fortunately, Alexander managed to write his contribution to this report before he fell ill, and we have included the chapter in this report in respect of his memory.

## 2 FOREWORD BY FFO

#### Jarl Ovesen & Hanne Witsø

FFO - The Norwegian Federation of Organisations of Disabled People - believes that documentation is the most fruitful means in civil dialogue when change in society is the goal. Research results provide us with national, representative, credible and indisputable documentation. When we lobby for change and improvement of the living conditions for people with disabilities, we are often met by a requirement of documentation. This is why we, through many years, have been collaborating with SINTEF in the area of Living Conditions Studies in southern Africa.

FFO applies for funding for the Living Conditions Studies from NORAD through the Atlas Alliance. In addition to being the principal for the studies, we also take an active part in the whole process. We have a clear vision about how the results are to be presented and how they should be used. It is crucial to FFO that disabled peoples organisations are involved in and also feel an ownership to the studies. The study design takes into account the involvement of both FFO and the national federation of organisations of disabled people in the respective country where the studies are being implemented.

However, documentation in itself is of little use if it is put in a drawer. In collaboration with the national federation, FFO always plans for awareness building in the country when the results are ready. Both FODSWA and SAFOD will be using the results from the study; SAFOD on regional level and FODSWA on national level.

FODSWA now has the "proof" that is often demanded by governments and ministries – solid documentation of the living conditions of people with disabilities, compared to the living conditions of the non-disabled population. Our belief – based on our experience from other countries - is that this will strengthen the position and the action of FODSWA.



FODSWA will continue to lobby, now more targeted, for improved living conditions of people with disabilities. In the long run, we also think that having such useful documentation will improve the visibility of FODSWA in society, the human rights aspect of people with disabilities will be more emphasized, and last, but not least: The living conditions of people with disabilities will improve.

## **3 SUMMARY**

A national, representative household survey on living conditions among people with disabilities was carried out in Swaziland in 2009 – 2010. The study is part of a regional series of similar studies which so far has covered six other countries in the southern Africa region. The content of these surveys are largely similar, forming a regional data base that can be utilized for international comparison.

It is a particular feature of these studies, including this one in Swaziland, that much of the responsibility, including a decisive role during the implementation including the content of the study, practical implementation and later application of results, has been with the national disability federation (in Swaziland: FODSWA).

The design of the study is based on experiences from the previous countries, but adapted to the context of Swaziland through involvement of a range of local stakeholders. The design further builds on current development of disability research including the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) and the work of the Washington City Group on Disability Statistics. The Central Statistical Office provided critically important support by utilizing the current national sampling frame for the selection of areas for data collection. A two-stage cluster sampling was applied. Data collection was carried out by a team appointed by FODSWA, comprising disabled enumerators and staff from the CSO. Data entry was carried out in Swaziland, while SINTEF did the analyses for this report.

The study comprised three questionnaires; one for the households, one for identified disabled members of the sampled households and one for a matched control group of non-disabled. Initially, a listing exercise was carried out in order to identify households with disabled members in the sampled Enumeration Areas. The sample comprised 1635



households with a total of 8734 individuals, of which 876 were identified as disabled according to the applied screening procedure.

Results from the study as presented in this report is organized according to a series of key indicators on level of living. Thus, the indicators comprise demographic differences, socio-economic status, dietary diversity, access to information, education and literacy, employment, causes of disability, experiences of discrimination, access to health and welfare services, accessibility at home and in the local community, assistive devices, assistance in daily life, involvement in family and social life, physical and mental health, knowledge about diseases, awareness about rights. Key results are summarized below.

The findings confirm that there are substantial gaps on a number of key indicators on level of living, to the disadvantage of individuals with disability and disabled women living in rural areas in particular. It is recommended that the evidence base found in this research report is utilized by DPOs in Swaziland in their advocacy work, by Government bodies in their planning and service provision, as a basis for monitoring development. It is further recommended that the data is further utilized by researchers and Central Statistical Office in Swaziland, and not least as a knowledge base for development of the disability policy in the country.

## **SINTEF**

#### **4 PREFACE**

#### Alexander M. Phiri – Director General, SAFOD

In 2000, at the Millennium Summit (in New York), the World leaders committed themselves to "spare no effort to free our fellow men, women and children from the abject and dehumanizing conditions of extreme poverty". This commitment was translated into what later on became to be known as the eight Millennium Development Goals (MDGs) whose main purpose is to halve world poverty by the year 2015.

Interestingly, at the time the Millennium Declaration of 2000 was being enunciated, the disability movement in Africa had just successfully lobbied with its African leadership for an important initiative on the implementation of the African Decade of Persons with Disabilities which was to run from 2000 to 2009. Concurrent with these global developments, and initiatives, the Southern Africa Federation of the Disabled (SAFOD) and its Norwegian Partner, FFO (Norwegian Federation of Organisations of People with Disabilities), agreed to work on a number of joint activities which among other things would include building the capacity of organizations of people with disabilities and undertaking studies on the Living Conditions among people with Activity Limitations in SAFOD member countries. It was further agreed that these studies would be carried out from country to country during the Decade period to collect disability data which would then be used to raise awareness on disability in respective countries. Thus, between 2000 and 2009, the Living Conditions Studies were carried out in Malawi, Mozambique, Namibia, South Africa, Zambia and Zimbabwe.

In 2009 – 2010 it was agreed to do national representative studies in Lesotho and Swaziland simultaneously as these countries were found to be relatively smaller and much easier to handle than other SAFOD member countries. Having done these two



countries, it means that there are now only two countries remaining to do the studies, i.e. Angola and Botswana.

Over the years it has been SAFOD's desire to see governmental and non – governmental organizations utilizing the study findings to improve the quality of life of people with disabilities in the region. Indeed some governments and local authorities are finding the data from these studies useful in designing their development plans. The completion of the study reports in Lesotho and Swaziland have coincided with the debate and adoption by world leaders at the UN of an annual report on "Assessing Progress in Africa towards the Millennium Development Goals (MDGs) 2010". The report presents an African continent that has made progress in a number of key areas such as equality in primary education, political empowerment of women, access to safe drinking water, and reducing the spread of HIV / AIDS and TB. Incidentally, 2010 marks the 10<sup>th</sup> year of the MDGs and 2015 is only five years away. SAFOD's critical question is around the reality of achieving the MDGs when disability is silent in this global poverty reduction strategy.

Perhaps the data from the Living Conditions Studies may be used by governments, the UN itself, and other stakeholders to assess future progress (if any) on the implementation of the MDGs. As SAFOD we are more than happy to work with the MDGs implementers in this area.

Thanks to our Norwegian partner, FFO, for providing the resources that enabled our two member organizations, LNFOD and FODSWA, to carry out these studies under the supervision of another important Norwegian partner, SINTEF Health Research. Our thanks also go to Universities, Government Ministries, Central Statistical Offices, DPOs, individuals and other stakeholders in Lesotho and Swaziland for making these studies a success!

### **5 THE CONTEXT - SWAZILAND BACKGROUND**

#### Mr. Bheki Jele

Covering the area of 17 364 km<sup>2</sup> and situated between South Africa and Mozambique, Swaziland is a small landlocked country with a population of around one million people of which 70% live in rural areas. According to the 1997 Census (CSO 1997), there are 27 698 disabled persons in Swaziland, or 3 % of the population. The large majority, i.e. 86 %, of disabled persons in the country live in rural areas (MoHSW 2000). This is lower than the WHO estimates for disability prevalence of 7 – 10 % of the population, which would put the population of disabled persons at between 65 000 and 95 000. And, if using the recent general estimate of 15 % in the World Disability Report (WHO 2011), the number of disabled persons in Swaziland would amount to approximately 150 000. The political system in Swaziland is an evolving balance between modern institutions and monarchy with constitutional powers entrusted to the King. The new constitution that became effective in January 2006 provides for separation of powers between executive, legislative and judicial arms of Government and stipulates various individual rights.



Map of Swaziland and neighbouring countries in the region

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Map of Swaziland with the four regions

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The human toll of HIV and AIDS in Swaziland is a tragic reality being experienced by families, communities and the nation at large. There is no aspect of life in Swaziland that has not directly or indirectly been adversely influenced by HIV and AIDS, and the pandemic has become the major cause of illness and death among young and middle aged Swazis, depriving households and society of a critical human resource base and thereby reversing the social and economic gains the country has attained.

Swaziland has a relatively high GPD per capita income of US\$2, 415. Despite this, about 69% of the country's 1 018 million people live below the national poverty line (CSO 2001). Income distribution is skewed, and according to the Swaziland Household Income and Expenditure Survey (SHIES) of 2001, 56% of wealth is held by the richest 20% while the poorest 20% own less than 4.3%. The country has recorded a Gini Coefficient of 51%, which is considered great inequality according to the international standard (op.cit.).

People with disabilities form a significant part of the poor majority of Swaziland, and whose human rights have been violated for centuries due to past policies, programs, strategies and attitudes. Conditions of people with disabilities are exacerbated by their systematic exclusion from the mainstream of society and therefore resulting in high rates of infection and affection of the above discussed issues.

#### Situation of people with disabilities in Swaziland

Living with a disability in Swaziland presents significant challenges. There is a general belief that those who have a disability are bewitched or inflicted by bad spirits. Many believe that being around people with disabilities can bring bad luck. As a result, many people with disabilities are hidden in their homesteads and are not given an opportunity to participate and contribute to society.

People with disabilities in Swaziland remain marginalized and vulnerable. The impact of poverty, HIV/AIDS, and the gender imbalance in society compounds the problems of

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disability and discrimination. The absence of any comprehensive laws and policies to address people with disabilities' access to equal opportunities reflect a lack of political will and a failure to recognize disability rights as human rights. The failure by the society to recognize disability as a human right issue contributes to the devaluing and dehumanization of people with disabilities. People with disabilities have the same rights as able bodied and they are entitled to enjoy all citizenry rights. Affording equal opportunities to people with disabilities will achieve the most important and cherished goals for them. It will result in a maximum degree of autonomy and independence for people with disabilities and the benefit will be for the whole society. The attitude of government and the community of treating disability as a medical condition rather than a reflection of many existing social challenges are limiting the participation of people with disabilities in society. It is worth noting that it is the society and inaccessible environment that makes people disabled rather than their physical being. It is therefore important to address the attitudes of society and the inaccessibility of our physical environment so that the integration of people with disabilities is automatic.

Our belief is that people with disabilities in Swaziland today are the agents for and victims of political, economic and socio-cultural changes which the mother continent is experiencing. People with disabilities tend to be more open minded, flexible and less constrained by the negative aspects of "tradition". They have eagerness and ability to learn; they are less afraid of technological and social change and adjustment; they have an instinct for social responsibility, and if appropriately applied to, they have energy ready to be applied to the development objectives of Swaziland.

Despite the availability of basic frameworks for the provision of services and calling for the enactment of legislations appropriate for people with disabilities in Swaziland, they still face extreme levels of inequality and discrimination. The majority of people and their families are therefore forced into depending on the little social grants provided for survival.



Different social, economic and political factors interact and create underdevelopment, marginalization, unequal access to resources and lack of service provision for this sector of the population. This effectively discourages many of those who struggle for autonomy and financial independence. It is no longer denied that the systematic deprivation and disadvantage that disabled people experience is caused by socio-economic barriers and restrictive environments. A critical problem they face is the inaccessibility of the outside world. This refers to buildings, communications intended for deaf, blind, people with mental disabilities as well as services such as public transport and opportunities for social integration.

An important issue is the relationship that exists between the high incidences of disability and poverty. Jointly with unemployment and social isolation, poverty forms part of the key issues that contribute to the exclusion of people with disabilities and is responsible for their cumulative disadvantage.

Paternalistic attitudes and a piece –meal approach to addressing the needs of people with disabilities have hampered their integration into society. Past approaches have focused on the limitations and not on the capacities of people with disabilities.

#### Special Groupings with Disabilities

Selected categories of people with disabilities are particularly vulnerable to discrimination, abuse and encounter barriers to participation in society, due to a number of factors impacting on their disabilities, which require distinct attention.

The consequences of deficiencies and disablement are particularly serious for women and children, who are subjected to social, cultural and economic disadvantages that impede their (women) access to health care, education, vocational training and employment. Not only are women with disabilities discriminated against as disabled



people, but they also experience oppression and marginalization as women in a patriarchal society.

For many children, the presence of an impairment leads to rejection or isolation from experiences that are part of 'normal' development, making them more vulnerable to violence and abuse. Most of their disabilities are as a result of poverty and preventable diseases such a measles, alcohol and drug abuse, or injuries sustained as a result of social and political violence.

Disabled women and girls are more often subject to various types of violence, particularly sexual violence, and are more vulnerable to HIV & AIDS transmission given the increased risk of sexual violence. Inclusive programs, and accessible services that would ensure the necessary special support for women and girls with disabilities, remain the only form of systems of ensuring respect for, protection of the rights and empowerment of women and girls with disabilities.

Children living in rural areas or in informal settlement are the most vulnerable to disablement and HIV & AIDS, more so as facilities for early detection, diagnosis and support are inadequate. Inadequate facilities inevitably lead to an increase in both the extent and the severity of disablement.

People with multiple disabilities, mental disabilities, invisible disabilities, congenital disabilities and severe disabilities are special groupings who require special attention; as mainstream services do not, most of the time, address their social needs adequately. Lack of comprehension of their needs often leads to misunderstandings, exclusion and wrong conclusions on how their needs should be appropriately addressed and their rights promoted.



#### The disability movement in Swaziland

During the late 1970s several philanthropists undertook to establish organisations that would work on addressing issues of people with disabilities. An example is the Swaziland National Society for the Handicapped which was firstly run by the spouses of members of the British government on a charity basis. The organisation served to raise funds to support people with disabilities in many different aspects of their lives. This ranged from providing school fees (to enable them to get an education) to purchasing wheelchairs to enable them to gain a decent mobility level.

The beginning of the disability movement during the 1980s was an appropriate time to enable people with disabilities in the region to begin to question the role of service providers, charity workers, therapists, rehabilitation workers and the Government, on their role as liberators of people with disabilities as an "oppressed" section of the population. Over the years people with disabilities have emerged as leaders, managers and directors of their own cause. This was a great revelation to a nation that, over many years, had believed that people with disabilities were not capable of doing anything for themselves and had to be looked after and provided for by their respective families and the Government. As a predominantly traditional nation; the Swazi nation has very strong family relations even up to the clan level. This therefore provided for a very "protective and supportive" environment for people with disabilities and also created a highly depended group of nationals.

The Federation of Organizations of the Disabled Persons in Swaziland (FODSWA) is a human rights oriented coordinating body of DPOs formed in 1993by organizations of people with disabilities in Swaziland due to lack of coordination of their activities. FODSWA has four affiliates;

- a. Swaziland National Association of the Deaf (SNAD)
- b. Swaziland National Association of the Physically Disabled (SNAPDPe)

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c. Swaziland Association of the Visually Impaired (SAVIP)

d. Parents of Children with Disabilities. (PCDSWA)

The Federation is governed by a National Executive Committee (NEC) elected by its General Assembly formed by delegates from affiliates every four years. Apart from the NEC, FODSWA has a committee responsible for youth and women with disabilities issues whose chairpersons are members of the NEC with the responsibility of ensuring that the needs of the two groups are mainstreamed in all programs of FODSWA. To strengthen and promote working relationship with other organizations, FODSWA is a member of the Coordinating Assembly of Non- Government Organizations in Swaziland (CANGO), the Federation of Organizations of the Disabled Persons in Southern Africa (SAFOD) and Disabled People International (DPI).

#### Government of Swaziland policies and disability (Lang 2008)

a) Disability provisions on Government strategies

People with disabilities in Swaziland have always been on the receiving end of developmental processes, it is necessary that structures and systems be instituted to address the situation. The present government recognizes that people with disabilities are key partners in national development and service delivery. This is in evidence to the involvement of people with disabilities in the following policy formulation:

- i. National Development Strategy (NDS) August 1999
- ii. Population Policy
- iii. Constitution
- iv. SPEED

#### i. NDS (4.8.2.1 Disadvantaged Groups)

The National Development Strategy (NDS) recommends the following strategies for government's implementation in addressing issues of people with disabilities in Swaziland;

## **SINTEF**

- a) Integration and Awareness
  - ✓ Integrate persons with disabilities into economic and social activities.
  - ✓ Ensure the integration of programmes for persons with disabilities into mainstream education.
  - ✓ Provide infrastructure for rehabilitation for those who cannot be integrated. Institutions catering for disabled people (e.g. school for the blind, deaf and vocational training) must be expanded to cater for the existing and expected demand.
  - Create institutional and policy mechanisms through which persons with disabilities can be rehabilitated and integrated effectively with the rest of society.
  - ✓ Raise awareness on how to prevent the various forms of disabilities.
- b) Equity
  - ✓ Enact legislations to protect the disadvantaged groups from abuse and discrimination.
  - Ensure that all infrastructural designs are inclusive of the needs of persons with disabilities.
  - ✓ Introduce measures that will support the operations of NGOs to help specific groups.
  - ✓ Enact legislations to ensure equal opportunities for persons with disabilities.
- ii. Population Policy (Thematic Area Six and Eight page 45, 4.5.16)
  - ✓ Establish a National Unit / framework to deal with issues of persons with disabilities
  - ✓ Strengthen and expand activities to integrate persons with disabilities into mainstream society,

- Develop a national programme to deal with issues of disability, including improving the capacity for testing and early detection of disabilities and the rehabilitation of persons with disabilities.
- ✓ Improve the enforcement of laws and regulations on safety standards
- ✓ Discourage cultural practices that discriminate against persons with disabilities,
- ✓ Improve access to social and public services including transport for persons with disabilities,
- ✓ Sensitize the public on issues concerning persons with disabilities; and
- ✓ Empower communities and extended families to care for persons with disabilities.
- iii. Constitution (Chapter Four section 31)
  - ✓ The rights of persons with disabilities shall be respected. The parliament shall pass laws to enforce the recognition of the rights of the disabled.
- iv. SPEED (Presented to Parliament in August by His Honorable Prime Minister A.T. Dlamini)

#### **Government Vision**

"To build a truly twenty-First Century Kingdom of Swaziland, cultural united, integrated and stable, economically prosperous and socially well organized with equal opportunity for all, irrespective of gender, and responsibility from all".

"To provide a climate and infrastructure that will progressively maximize the quality and security of the life of the people of Swaziland and make the best use of the country's natural and human resources".

**Human Development,** "For the government vision to be sustainable, it is imperative that fellow citizens including people with disabilities should see more meaningful in the quality of their lives and in their living conditions".



Although people with disabilities have participated in the formulation of some of the above policies and strategies, there is still little that is done to implement the contributions made by people with disabilities. This may be due to the fact that there is no government mechanism to coordinate such implementation.

#### The National Development Strategy (1997)

The purpose of the NDS is to formulate a Vision and Mission Statement with appropriate strategies for socio-economic development for the next 25 years, and provide a guide for the formulation of development plans and for the equitable allocation of resources. It is designed to strengthen the Government's development planning and management capacities and anchor it firmly to a national consensus on the direction of future developments in the country.

The National Development Strategy includes a section on people with disabilities. The strategy "recommends" measures to improve the situation of people with disabilities: the enactment of legislation to ensure equal opportunities for people with disabilities and to protect them from discrimination; ensuring that the built environment and public transport are accessible; the integration of programmes for people with disabilities into mainstream education; the creation of institutional mechanisms to rehabilitate and integrate people with disabilities into society; ensuring adequate and accessible sanitation facilities; the introduction of social security payments to disadvantaged groups; the promotion of cooperatives for women, youth and people with disabilities. The strategy calls for "special attention to members of society with disabilities" in human resources development.

The National Development Strategy made the following recommendations with regard to persons with disabilities:

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a) Integration and Awareness: Integrate persons with disabilities into economic and social activities: Ensure the integration of programmes for persons with disabilities into mainstream education: Provide infrastructure for rehabilitation for those who cannot be integrated. Institutions catering for disabled people (e.g. schools for the visually and hearing impaired, and vocational training) must be expanded to cater for the existing and expected demand: Create institutional and policy mechanisms through which persons with disabilities can be rehabilitated and integrated effectively with the rest of society: Raise awareness on how to prevent various forms of disabilities.

b) Equity: Enact legislation to protect the disadvantaged groups from abuse and discrimination: Ensure that all infrastructural designs are inclusive of the needs of persons with disabilities: Introduce measures that will support the operations of NGOs to help specific groups: Enact legislation to ensure equal opportunities for persons with disabilities.

#### Special Education and Accessibility (National Development Strategy 1997)

This strategy promotes the integration of persons with disabilities into the mainstream of the education system; Enable persons with visual impairments to have access to colleges and universities by providing the necessary equipment for their training; Ensure equal access to education and training for women and girls at all levels and in all sections of formal, non-formal and life skills development; Promote education as a basic human right and ensure that males and females receive equal treatment and benefits at all levels and in all areas of the education system; Seek and enforce equitable access to Tibiyo bursaries and scholarships.

There are no secondary schools or special educational alternatives for children with hearing impairments. In July, 2006 the Federation of Disabled Persons in Swaziland complained that there were no schools for approximately 900 visually impaired children of school age. In August 2006, the Minister for Enterprise and Employment told the



Swaziland Association of Visually Impaired People that he was shocked to learn that of the 10,600 visually impaired persons in the country, only three were employed. Consequently, in November 2006 the Ministry of Health and Social Welfare released a report which found that 49 % of interviewed persons with disabilities had not completed primary school, 19 % went beyond primary school, and 25 % were employed, mostly in the private sector.

#### Social Security and Welfare (National Development Strategy, 1997)

The following strategies are recommended:

- a) Rehabilitation: Increase rehabilitation centers for those that have had problems with the law and also ensure the provision of psychological counseling services; Establish rehabilitation centers for people who abuse alcohol and drugs.
- b) Direct Welfare Assistance; Establish temporary shelters for abandoned and abused children and adults. This will entail an acknowledgement that the extended family system is deteriorating and provision of safety nets to those who are in need, particularly the homeless and street children ; Strengthen and promote adoption mechanisms and foster care homes for children;
- c) Education and Information: Educate and sensitize the public on the issue of human rights, such as abuse of children and women as well as sexual harassment, the uses of limiting and inappropriate language and actions towards women, the elderly, youth and persons with disabilities: Improve structures and mechanisms to facilitate proper and effective information dissemination on social welfare matters;
- d) Policy and Legislation; ensure equal opportunities for persons with disabilities to enable them to become more independent.

#### **National Education Policy (1999)**

The National Education Policy is the official policy of the Ministry of Education and is based on the overall objective of "the provision of opportunities for all pupils of school-



going age and adults to develop themselves in order to improve the quality of their own lives and the standard of living of their communities".

Section 5 of the National Education Policy specifically addresses special needs education. The policy aims at including children with disabilities in the mainstream school system. Section 5.3 of the policy states that:-

"The Ministry of Education shall facilitate access to education for all learners with disabilities by improving the infrastructure to make it user-friendly from basic through tertiary level [and] shall support the integration and inclusion of children with special learning needs in the Education System."

The policy also contains a section on Vocational Education and Training (VET). The policy lists four goals of the VET system: "Development of a functional gender sensitive, affordable and efficient VET-System of sufficient capacity according to the needs of the economy, the society and the individual; Enhancement of VET as an attractive and integrated component of a permeable Comprehensive System of Education: Promotion of entrepreneurial skills and values as an integral element of VET at all stages, sectors and areas: Contribution to a foresighted and coordinated National Skills Development Planning and to Business and Employment Promotion Programs."

The policy aims at reducing unemployment, by (1) ensuring that "vocational training becomes an important element in efforts aimed at eradicating inequity and inequality among the people of Swaziland and includes groups thus far neglected, such as women and disabled [persons]"; and (2) change the focus of the VET system from formal economy wage employment to self-employment, thereby balancing skills demand and supply. Another objective is to provide training to the "widest possible range of citizens, irrespective of their level of formal education".

### **6 DESIGN AND METHODS**

#### Mr. Bhekie Jele, Co-ordinator and Programme Officer, FODSWA

#### Introduction

This chapter presents the methodology used for the design and selection of sample of households for the survey.

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

#### Scope of the survey

The scope of the survey in terms of topics covered was guided by similar studies conducted in Malawi, Mozambique, Namibia, South African, Zambia and Zimbabwe between 2001 and 2010 (Kamaleri & Eide 2010, Eide & Kamaleri 2010, Eide & Loeb 2006a; Loeb & Eide 2004; Eide et al. 2003a; 2003b). A continuous process of consultation with organizations of people with disabilities in Swaziland, Government departments responsible for both disability and statistics and other key stakeholders on disability issues, provided technical support in shaping the scope of the survey. As such, the survey only included agreed upon topics of policy relevance.



#### **Determination of Sample Size**

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

The sample used for this study is a sub - sample of the master sample derived from the National Census (2007) of Swaziland from the Central Statistics Office and the methodology is the same as the master sample methodology. A master sample is a sample from which sub-samples can be selected to serve the needs of more than one survey or survey round, and it can take several forms. A master sample with simple and rather common design is one consisting of Primary Sampling Units (PSUs), where the PSUs are Enumeration Areas (EAs). The sample is used for two-stage sample selection, in which the second-stage sampling units (SSUs) are housing units or households.

The survey was designed to cover 359 Standard Enumeration Areas (SEAs) across the 4 regions, approximately 7 200 non-institutionalized private households residing in the rural and urban areas of Swaziland. The survey was carried out for a period of 90 days using a cross sectional sample. The sample was nationally and regionally efficient and was expected to yield reliable estimates at regional, local and national levels. The table below shows a detailed sample size.



Table A: allocation of the 2009 Disability sample into sub-regional strata and sample sizes by region and urban / rural

	Census 2007	Census 2007	DISABILITY	
Sub-Regions	HHs	PSUs	PSUs	House Holds
Hhohho urban	20,554	170	98	1,960
Manzini urban	12,053	100	58	1,153
Shiselweni urban	3,634	22	13	254
Lubombo urban	9,692	81	47	934
Hhohho rural	38,331	397	35	707
Manzini rural	57,373	474	42	844
Shiselweni rural	32,515	395	35	703
Lubombo rural	31,993	352	31	627
Total	206,145	1,991	359	7,180

#### Sampling procedures

It was calculated that a sample of 7 180 households would be adequate to provide estimates of acceptable precision at the national level and the terms of reference dictated that there should be complete enumeration of all people with disabilities in the sampled enumeration areas. The lowest level for which the available frame had information, as discussed above, was the enumeration area and the information comprised of only totals of persons and households. In addition, there was no information on the prevalence of persons with disabilities at the enumeration area level.

Considering the coverage of 7 180 households, and that an enumeration area would contain on average 10 households with at least one disabled member, a sample of 359 enumeration areas were planned to be covered in the study within which all persons identified to have a disability were to be interviewed. Each one of the regions (Hhohho,

Manzini, Lubombo and Shiselweni) as well as each of the four Agro-ecological zones formed a stratum. The stratum distribution is shown in table 2 bellow;

	Census 2007	Census 2007	DISABILITY		
Regions	HHs	PSUs	PSUs	House Holds	
Hhohho	58,885	567	133	2,660	
Manzini	69,426	574	100	2,000	
Shiselweni	36,149	417	48	960	
Lubombo	41,685	433	78	1,560	
Total	206,145	1,991	359	7,180	
Agro-ecological zones	;				
Highveld	63,978	659	151	3,020	
Middleveld	86,902	759	117	2,340	
Lowveld	44,330	453	76	1,520	
Lubombo Plateau	10,935	120	15	300	
Total	206,145	1,991	359	7,180	
Urban/Rural					
Urban	45,933	373	215	4,300	
Rural	160,212	1,618	144	2,880	
Total	206,145	1,991	359	7,180	

Table B – **R**egions and Agro-ecological zones

Apart from enumerating all households having at least a person with a disability in a selected enumeration area (Cases), a similar number of households (designated as minimum 10 per enumeration area) without any disabled persons (Controls) was interviewed. In the absence of households sampling frame within enumeration areas,



the selection of Controls was done by the enumerators in the field. The household listing was also done concurrently with the data collection exercise.





## Map of Swaziland with sampled Enumeration Areas

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#### **Data Collection**

The research teams used maps provided by CSO to locate selected enumeration areas and identified their boundaries. Having identified the boundaries, the members of the team listed all the households that were found to exist at the time of the survey. The listing was done utilizing a household listing and screening form that was designed specifically for this study. The enumerators were required to complete the case questionnaire upon identifying a household with a person with disability and the overall household questionnaire and immediately identify a control household. A total of twenty households were to be interviewed in each enumerating area and further list all households available in the EA.

#### Questionnaires

Data collection questionnaires that had been used in previous similar studies conducted in Lesotho, Malawi, Mozambique, Namibia, South Africa, Zambia and Zimbabwe between 2001 and 2010 (Kamaleri & Eide 2010, Eide & Kamaleri 2010, Eide & Loeb 2006a; Loeb & Eide 2004; Eide et al. 2003a; 2003b;) were combined and adapted for use in Swaziland. In addition, a disability-screening instrument was included as well as a matrix on activity limitations and participation restrictions, drawing on the concepts of the ICF. The design applied in this study in Swaziland is similar to the design applied in the previous study in Lesotho (Kamaleri & Eide 2010) save some differences in formulations of a few questions.

User participation was an important element in the design development. This process included a one-day workshop attended by 30 professionals, researchers, people with disabilities and civil servants who discussed and came up with general information that was used to adapt the general questionnaire into the needs of Swaziland. After revision, four separate questionnaires comprised four key elements; in the 'Levels of Living Conditions Questionnaire':

- i) Household study on living conditions a set of core indicators of living conditions for all permanent members of the household (including control households)
- ii) Screening for disability;
- iii) Detailed Questionnaire for people with disabilities including the Activity and Participation Matrix drawn from ICF and
- iv) Detailed questionnaire to individuals without disability (controls)

The final versions of the questionnaires were developed in English. A few further modifications were done during the supervisors' orientation and enumerators' training workshops. Prior to that, the technical committee also had an opportunity to critic the questionnaire and ensured that it covered all areas of need in Swaziland.

A separate screening instrument was applied during identification of individuals with disabilities. All research instruments applied in the survey are found in the appendices of this report.

- a) The generic household questionnaire covered the following topics:
  - ✓ Demography and Disease burden
  - ✓ Education and Literacy
  - ✓ Economic activities of household members
  - ✓ Reproductive Health of Females aged 12 to 49 years
  - ✓ Household amenities and housing conditions
  - ✓ Household access to facilities
  - ✓ Household asset ownership including land
  - ✓ Household Income and its main source
  - ✓ Household food production
  - ✓ Household monthly Expenditure and rankings


- ✓ Death in the households
- b) The detailed Disability Questionnaire covered the following topics:
  - ✓ Activity Limitations and Participation restrictions
  - ✓ Environmental factors
  - ✓ Health
  - ✓ Awareness, need and receipt of services
  - ✓ Education and employment / income
  - ✓ Assistive devices and technology
  - ✓ Accessibility in the home and surroundings
  - Inclusion in family and social life
  - ✓ Health and general well-being
  - ✓ Knowledge of HIV/AIDS, Malaria, TB and Diabetes.
- c) Control questionnaire for people without disabilities covered the following topics;
  - ✓ Activity limitation
  - ✓ Participation restriction
  - ✓ Environmental factors
  - ✓ Health
  - ✓ Education and employment / income
  - ✓ Accessibility in the home and surroundings
  - ✓ Inclusion in family and social life
  - ✓ Health and general well-being
  - ✓ Knowledge of HIV/AIDS, Malaria, TB and Diabetes.

In each one of the 359 enumeration areas, the Living conditions questionnaire was administered to the head of household of each of the selected 10 case households as well as to each head in the selected 10 control households. The Detailed questionnaire was administered to each of the disabled members found in the 10 case households. A



proxy was interviewed if the individual with disability was not present or was unable to answer.

#### **Understanding the Activity Limitation and Participation Restriction Matrix**

It is important to be able to differentiate between the two concepts or dimensions that we have attempted to capture by using this ICF-based matrix. While on the surface Activity Limitations and Participation Restrictions may appear similar, they do in fact measure two distinct aspects of the disability phenomenon. In considering **activity limitations** we ask: "How difficult is it for you to perform this activity *without any kind of assistance at all*?" The intention is to capture or measure an individual's **capacity** to carry out the 44 different activities of daily living listed in the matrix – it is a measure of the person's level of functioning. **Participation restrictions**, on the other hand, measure an individual's level of **performance** in their current or usual environment (i.e. where they normally are: at home, at school or at work). To capture this aspect we ask: "Do you experience any problem(s) in performing this activity in your *current environment*?" For further discussion on the relationship between the two dimensions, see Eide et al. 2007.

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

#### **The Research Teams**

A total of 20 field personnel were recruited for execution of the study within the required period. CSO recruited three supervisors and three enumerators who were all nondisabled. The remaining 14 members were recruited by FODSWA. All together 11 of the 14 field personnel were disabled. During the training, however, some members were



dropped from the team. There were a total of 4 mobile field teams and each comprised of 4 enumerators, 1 supervisor and 1 driver and assigned to each region. The field supervisor's role was to take a leading role in identifying the boundaries of selected enumeration area, oversee the day-to-day data collection procedures while in the field, problem solving while in the field and checking completed questionnaires. The enumerators' role was mainly the listing of households in the enumeration areas utilizing the screening form and carrying out of interviews with respondents of the selected households. A research coordinator was identified with the responsibility of overseeing and managing all aspects of the data collection process to ensure that all logistics necessary for the successful data collection exercise in the field were being adhered to and solve problems which the field teams could not handle on their own. Three data capturers were recruited by FODSWA and were responsible for data entry. The table below shows the complete team members.



# Table C - The Research Teams per Region

NAME	POSITION	TYPE OF DISABILITY
National		
Mr. Bhekie Jele	Research Coordinator	Physically Disabled
HHOHHO REGION		
Mrs Swane Mdluli – Vilakati	Supervisor	Physically disabled
Mr. Patrick Dlamini	Enumerator	Physically disabled
Mr. Gcina Lukhele	Enumerator	Physically disabled
Mr. Bongiwe Bhembe	Enumerator	Non disabled
Mr. Linda Dlamini	Enumerator	Non disabled
Mr. Musa Mnini	Driver	Non disabled
MANZINI REGION		
Osca Jele	Supervisor	Non disabled
Mbongiseni A. Dlamini	Enumerator	Non disabled
Nelson Dlamini	Enumerator	Physically disabled – wheelchair
Xolile Methula	Enumerator	Physically disabled
Nondumiso Shongwe	Enumerator	Visually Impaired
LUB OMBO REGION		
Sicelo Zwane	Supervisor	Non disabled
Celumusa Dlamini	Enumerator	Non disabled
Samuel Kunene	Enumerator	Physically disabled
Lindiwe Mdluli	Enumerator	Physically disabled
Vusi Mamba	Enumerator	Physically disabled
SHISELWENI REGION		
Mfanasibili Nkambule	Supervisor	Non disabled
Nokwanda Thwala	Enumerator	Non disabled
Nompumelelo Ncongwane	Enumerator	Non disabled
Senelisiwe Khumalo	Enumerator	Non disabled
Bongani Simelane	Enumerator	Visually impaired

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# 7 CONCEPTUAL UNDERSTANDING

# A H Eide, Y Kamaleri

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

# 7.1 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. The recently adopted UN Convention on Rights of People with Disabilities (CRPD) (UN 2006) defines disability as:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1)

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# 7.2 International Classification of Functioning, Disability and Health (ICF)

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

Health Condition

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



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### 7.3 Application of ICF in the current study

The conceptual development from ICIDH to ICF is important here as this shift also has a methodological parallel. The classification forms a basis for the collection of statistical data on disability. The current study does not represent an application of ICF, and it has not been the intention to test the new classification as such. Rather, the study is inspired by the conceptual basis for ICF and has attempted to approach disability as activity limitations and restrictions in social participation. This is pronounced in the screening procedure and in the inclusion of a matrix on activity limitations and social participation restrictions developed particularly for this study. The current study does, none the less, provide a unique possibility for applying some core concepts from the ICF and testing some aspects of the model statistically<sup>1</sup>.

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

# 7.4 Environmental factors

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

<sup>&</sup>lt;sup>1</sup> Will be published separately

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### 7.5 Living conditions

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

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

# 7.6 Disability and living conditions

Research on living conditions is comparative by nature. Comparison between groups or monitoring development over time within groups and populations are often the very reasons for carrying out such studies. The purpose is thus often to identify population groups with certain characteristics and to study whether there are systematic differences in living conditions between groups – or to study changes in living conditions within groups over time and to compare development over time between groups. Population sub-groups of interest in such studies are often defined by geography, gender, age – or



the focus of the current research, i.e. people with disabilities vs. non-disabled. Research in high-income countries has demonstrated that people with disabilities are worse off along the whole spectre of indicators concerning living conditions, and that this gap has also remained during times with steady improvement of conditions for all (Hem & Eide, 1998). This research-based information has been very useful for advocacy purposes, for education and attitude change in the population, as well as for planning and resource allocation purposes.

These same patterns of systematic differences are also at work in low-income countries, as has been documented in our studies in other countries in the region (op. cit.).

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

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



that this development is followed by research on the mechanisms that produce disability in the meeting between the individual and his/her environment.

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

# 7.7 Combining two traditions and ICF

The design that has been developed and tested here aims at combining two research traditions: studies on living conditions and disability studies<sup>2</sup>. Pre-existing and validated questionnaires that had been used in Namibia (on general living conditions – NPC, 2000) and in South Africa (on disability – Schneider et. al., 1999) were combined and adapted for use in the surveys. A third element, on activities and participation, was included to incorporate the conceptual developments that have taken place in connection with 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

<sup>&</sup>lt;sup>2</sup> By "disability studies" we understand a broad specter of different studies that have generated knowledge about the situation of people with disabilities.



information is much more potent in the struggle for improvement of the situation for disabled people, reflecting the developmental target for the current study.

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# 8 RESULTS

The results are presented in two sections: i) Households with and without (controls) disabled members, and ii) Individuals with disabilities and the control sample of matched individuals.

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

# 8.1 Household section

		Number of	
Source	Households	Individuals	Persons with disabilities
Households having	812	4780	876
a person with disability			
Households without a	823	3954	
person with disability (controls)			
Total	1635	8734	

Table 1. Number of households and individuals in the study

Individuals with disabilities in Table 1 qualify as disabled with at least two "some" on the screening question (see below). A total of 876 individuals with disability are included in the sample. A small number of missing explains some variation in the number of individuals and households in the analyses below.

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	Fema	le	Male		Total	
	n	%	n	%	n	%
Disabled HHs	2484	52.0	2291	48.0	4775	100.0
Control HHs	2064	52.4	1875	47.6	3939	100.0
Total	4548	52.2	4166	47.8	8714	100.0

Table 2. Total number of individuals in the households, by gender

There were 4548 females and 4166 males included in the households. Gender difference in the table is not statistically significant. Of the individuals with disabilities,

	Fema	le	Male		Total	
	Ν	%	n	%	n	%
Disabled Non-disabled	405 4117	46.2 52.9	471 3668	53.8 47.1	876 7785	100.0 100.0
Total	4522	100.0	4139	100.0	8661	100.0

Table 3. Total number of disabled in the households, by gender

The proportion of males and females with disability is this study differed between HHs with disabled members and Control HHs, 46.2% and 53.8% females respectively ( $\chi 2 = 13.96$ , df = 1, p < .001).



Disability was screened by means of the Washington City Group six screening questions (Miller et al. 2011) as follows:

Screening question: The next questions ask about difficulties you may have doing a certain activity because of a health problem or impairment (circle only one per row).

		No	Some	A lot	Unable
a)	Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
b)	Do you have difficulty hearing, even if using a hearing aid?	1	2	3	4
c)	Do you have difficulty walking or climbing steps?	1	2	3	4
d)	Do you have difficulty remembering or concentrating?	1	2	3	4
e)	Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4
f)	Using your usual (customary) language, do you have difficulty communicating for example understanding or being understood?	1	2	3	4

The next table shows the result (number of individuals with disabilities) when changing the operational definition of disability.

Table 4. Number of disabled with different qualifiers

Qualifiers	Number of disabled	Percentage of sample who qualify as disabled
At least one "some"	948	10.9
At least two "some"	876	10.0
At least one "a lot"	698	8.0
At least one "unable"	469	5.4

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Table 4 shows three different measures of disability, demonstrating that the WCG questions and "at least two some" as qualifier is the second most sensitive measure among the three in the table. It does however also indicate that the general notion of disability goes further than severe and visible disabilities only. This qualifier (at least two "some") was used for the analyses in this report.

Regions	disab		disab	eholds without led members	Total	
	n	%	n	%	n	%
Hhohho	280	51.0	269	49.0	549	100.0
Lubombo	183	49.7	185	50.7	368	100.0
Manzini	157	49.5	160	50.5	317	100.0
Shiselweni	191	47.8	209	52.3	400	100.0
Total	812	49.7	823	50.3	1635	

Table 5. Households by region

The proportion of HHs with and without disability does not vary substantially between the four regions. Sampling of HHs is not proportionate to the population/number of HHs in the regions. Weighting has thus been included in the analyses below when appropriate (analyses of statistical significance weighted but data in table as in the sample).



# Table 6. Members of households by region

		Household r	nembe	rs		
Regions	Disab	led HHs	Contr	ols	Total	
	n	%	n	%	n	%
Hhohho	1549	46.1	1212	53.9	2761	100.0
Lubombo	1012	56.2	790	43.8	1802	100.0
Manzini	908	54.6	754	45.9	1662	100.0
Shiselweni	1305	52.1	1198	47.9	2503	100.0
Total		54.7		45.3		100.0

Table 6 shows the regional distribution of total numbers of individuals in the two household types (with and without disabled members).

The number and proportion of individuals with disabilities in the sample varies between the regions (Hhohho: 321, 11.6 %, Lubombo: 194, 10.8 %, Manzini: 160, 9.6 %, Shiselweni: 199, 7.9 %), . from 7.9 % to 11.2 %, and the overall proportion of disabled in the sample is 10.0 %. The variation between the four regions does not necessarily reflect differences in prevalence.



	Males	5	Fema	les	Total	
	n	%	n	%	n	%
Disabled	130	86.4	98	85.4	228	86.0
Non-disabled	828	13.6	575	14.6	1404	14.0
Total	958	100.0	673	100.0	1632	100.0

# Table 7. Head of households by gender and disability status

Largely, close to 60 % of heads of households are males, and this goes for both types of households. Out of the total number of HHs (1632), 14.0 % (217) have an individual with disability as household heads. This varied marginally between male vs. female headed HHs.

#### Household size

Household size refers to the number of individuals living in a household. Household size in the current study had a range from one person to 20 persons. Mean household size is 5.3, median size and mode are both 5, and standard deviation is 2.93.

Households with at least one disabled member have significantly higher number of household members than control households. The mean household size for household with disabled members is 5.9 and for households without disabled members 4.8, which is a non-significant difference when applying weighting.



Table 8. Number of disabled members in the household (only households with disabled members)

	n	%
1 person	792	92.8
2 persons	47	5.5
3 persons	7	.8
4 persons	3	.4
5 persons	3	.4
6 persons	1	.1
Total individuals	853	
Total households	830	

Most households with disabled members contain one individual with disability, while 5.2 % have 2 individuals, and 2.2 % have more than 2.

# Age

Comparison revealed higher mean age in households with disabled members (26.1 and 25.1 respectively; F = 5.47, df = 1, p = .019). Mean age for individuals with disability was 32.7 years and 24.9 years for non-disabled (F = 30.41, df = 1, p < .001). The age distribution is skewed towards lower age values, i.e. reflecting the demographic profile of most low-income countries with a large proportion of individuals being below 20 years of age.



# Dependency ratio

Dependency ratio is a measure of the structure of the household. This is a measure of the proportion of a population which is composed of dependents (people who are too young or too old to work). The current definition of dependents is individuals who are below 15 years or over 65 years, while working age is between 15 and 65. The dependency ratio is equal to the number of dependants divided by the number of individuals in working age. Analyses revealed that disabled households have somewhat higher dependency ratio than control households; 0.72 and 0.67 respectively. This implies that households with disabled members tend to have more dependent individuals compared to the control households.

# Gender

Small and non-significant differences were found in the proportion of female members in disabled and control households. In the households with disabled members 52.0 % (2484) were females, while control households had 52.4 % (2064).

Socio-economic status

Socio-economic status (SES) was measured by recording possessions of 26 different items in the household.

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# Table 9. Distribution of household items by household type

Household item		Disab	led HHs	Contr	ol HHs	То	tal
		n	%	n	%	n	%
a.	Radio <sup>1</sup>	590	73.4	693	85.2	1283	79.3
b.	Hi-fi/music stereo <sup>2</sup>	175	21.8	234	28.8	409	25.3
c.	Television <sup>1</sup>	298	37.1	380	46.7	678	41.9
d.	DVD/VHS player <sup>1</sup>	231	28.7	319	39.2	550	34.(
e.	Cell phone <sup>2</sup>	639	79.5	685	84.3	1324	81.9
f.	Telephone in the house <sup>4</sup>	87	10.8	92	11.3	179	11.1
g.	Iron <sup>2</sup>	576	71.6	635	78.1	1211	74.9
h.	Fan <sup>2</sup>	112	13.9	152	18.7	264	16.3
i.	Heater <sup>3</sup>	64	8.0	90	11.1	154	9.5
j.	Air conditioner <sup>2</sup>	12	1.5	28	3.4	40	2.5
k.	Stove with gas/electric <sup>3</sup>	273	34.0	315	38.7	588	36.4
l.	Stove with paraffin <sup>4</sup>	155	19.3	164	20.2	319	19.7
m.	Table and chairs <sup>4</sup>	470	58.5	511	62.9	981	60.7
n.	Refrigerator <sup>2</sup>	279	34.7	348	42.8	627	38.8
0.	Microwave <sup>1</sup>	82	10.2	142	17.5	224	13.9
p.	Electricity <sup>3</sup>	291	36.2	336	41.3	627	38.8
q.	Solar energy system <sup>4</sup>	78	9.7	87	10.7	165	10.2
r.	Electrical generator <sup>4</sup>	12	1.5	20	2.5	32	2.0
s.	Personal computer <sup>2</sup>	29	3.6	51	6.3	80	4.9
t.	Bicycle <sup>2</sup>	56	7.0	94	11.6	150	9.3
u.	Motorcycle <sup>4</sup>	12	1.5	12	1.5	24	1.5
v.	Private car <sup>2</sup>	132	16.4	174	21.4	306	18.9
w.	$\operatorname{Bed}(s)^1$	722	89.8	768	94.5	1490	92.1
x.	Livestock <sup>4</sup>	270	33.6	275	33.9	545	33.7
y.	Washing machine <sup>4</sup>	21	2.6	26	3.2	47	2.9
Z.	Satellite dish <sup>1</sup>	79	9.8	131	16.2	210	13.0

 $^1 \ p < .001, \ ^2 \ p < .01, \ ^3 \ p < .05, \ 4 \ \ n.s.$ 

For 18 out of the 26 items, the difference between disabled HHs and control HHs is significant and all differences implying higher proportion of ownership among control households. Scale analyses of all items in Table 10 yielded Alpha = .86, which is a good

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support for constructing an additive scale. Factor analysis was carried out, and scree plot produced support for one main factor. All 26 items were thus added together in a scale with higher values implying higher number of items/possessions. The scale range was from 0 to 26, while recorded values were from 0 to 22, mean value 7.90, standard deviation 4.53, skewness .64). Analyses of SES difference between households revealed that HHs with disabled members scored significantly lower on this index than control households (7.3 and 8.4 respectively, F = 6.28, df = 1607, p < .001).

# **Dietary diversity**

Household dietary was assessed by the Household Dietary Diversity Score (HDDS) (Swindale & Blinsky 2006). The assessment was based on 12 different food groups consumed in the household in the past two weeks. A sum score of 12 represents the highest food diversity.

Box 1. Food groups included in the household dietary.

a. Cereals	g. Fish
b. Roots and tubers	h. Pulses/legumes/nuts
c. Vegetables	i. Milk and milk products
d. Fruits	j. Oil/fats
e. Meat, poultry, offal	k. Honey
f. Eggs	l. Miscellaneous (condiments, coffee, tea,)

The respondents were asked to answer "yes" or "no" to consumption of the different food types (past two weeks). Scalability of the 12 items was .79 (Alpha). The items were added together, yielding a scale (Dietary diversity) with values from 0 to 12, mean value 8.50, standard deviation 2.82, skewness -.92. Analyses revealed that disabled HHs had



lower dietary diversity compared to control HHs; 8.2 and 8.8 respectively (F = 18.33, df = 1602, p < .001).

A question was further asked about frequency of lack of food over the last two weeks.

Table 10. Lack of food -------\_\_\_\_\_ No food to eat of any Disabled HHs **Control HHs** % kind in the past two weeks % n n \_\_\_\_\_ -----79.8 No 559 69.4 649 Rarely (1 - 2 times)181 22.5 136 16.7 Sometimes (3 – 5 times) 6.7 25 3.1 54 Often (more than 5 times) 12 1.5 3 .4

According to Table 10, HHs with disabled members tend to report higher frequency of lack of food ( $\chi 2 = 7.59$ , df = 3, p = .055).

Access to information

Respondents were asked to report on the availability of 6 different information services to the household.



#### Table 11. Access to information

	Have	e access to/c	own/use reg	ularly
Information service	Disab	led HH	Contro	ol HH
	n	%	n	%
	700	00.7	752	02.8
Telephone/mobile phone	709	88.7	753	92.8
Radio	683	85.3	755	93.1
Television	457	57.3	534	66.0
Internet (including Internet Café)	169	22.1	276	34.6
Newspaper (purchase regularly)	347	43.8	420	52.2
Library (use regularly)	214	27.7	276	34.6

Disabled HHs have less access to radio and television, which are also two of the three most common information sources in this population. The differences between the households with regards to internet, library and newspaper were all near significant at .05 p level. For all items, the tendency is the same; HHs with disabled members have less access. A scale comprising the six information items was produced, with range 0 - 6, mean value 3.41, standard deviation 1.74. HHs with disabled members had significantly lower value on this scale as compared to control HHs (3.29 and 3.55 respectively, F = 11.48, df = 1, p < .001). HHs with disabled members thus had less access to information than control HHs.



# Education

Analyses of education variables included only respondents aged 15 years old and above.

Table 12. Did not receive a formal primary education, by gender and disability status (% of n)

	Disabled	Non-disabled
Males Females	<ul><li>337 16.6</li><li>389 17.5</li></ul>	165 9.9 224 12.2

Significant gender differences between individuals with disability and non-disabled were found as shown in Table 10 (Males:  $\chi 2 = 10.00$ , df = 1, p < .01. Females:  $\chi 2 = 5.90$ , df = 1, p < .01). Although a higher proportion of females than men did not receive any formal education in both groups (disabled/non-disabled), these differences are not statistically significant. Approximately one out of six individuals with disabilities in this data material has not received any formal education, while the corresponding figure for non-disabled is approximately one in ten.

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Reason		led HHs		ol HHs
Because of disability/accessibility	134	19.7	0	.0
Other/don't know	132	19.4	101	27.7
Failing/lack of interest	40	5.9	25	6.9
Illness	28	4.1	8	2.2
Not enough money	347	51.0	230	63.2
Total	681	100.0	364	100.0

Table 13. Reasons for never attending school (n = 1046)

With regards to reasons for not (never) attending school, the response pattern between the two groups (members of HHs with disabilities and Control HHs) differ somewhat ( $\chi 2 =$ 21.45, df = 1, p < .001). The main difference is that individuals in control HHs more often refer to economic reasons, while the disability itself, including accessibility, is relevant for disabled HHs only. More than half of those who did not attend any formal education say that this is due to economic reasons.



Table 14. Reasons for never attending school (n = 1046)

Reason	Disab	led	Controls/no	n-disabled
Because of disability/accessibility	131	41.7	3	.4
Other/don't know	34	10.8	199	27.2
Failing/lack of interest	20	6.4	46	6.3
Illness	23	7.3	13	1.8
Not enough money	106	33.8	471	64.3
Total	708	100.0	732	100.0

Comparing individuals with and without disabilities further confirms that economic reasons are most common and in particular among non-disabled. Of individuals with disability, more than 40 % state that the disability and/or accessibility are the most important reasons for not attending any formal education.

The respondents reported total years of education (years spent studying in school, college, or university.



	Disabled		Non-disa	abled
	Μ	F	Μ	F
Mean number of years	7.2	7.2	7.7	8.1

Table 15. Total years of education by gender and disability status (mean) (15 years +)

The difference between disabled and non-disabled with regards to years of education is statistically significant (F = 6.35, df = 1, p < .05), but breakdown by gender revealed that this was due to the difference between women only (F = 4.59, df = 1, p < .05). Disabled women have less education (measured in years studying) than non-disabled women, but the difference between men is not significant when applying weighting in the analyses. The table further reveals that gender differences within groups (disabled and non-disabled) are small (non-significant).

A significant difference in years of education was found between urban and rural areas, with mean number of years being 8.8 years and 7.2 years respectively (F = 18.67, df = 1, p < .001).

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Table 16. Literacy by gender, location and disability status (mean) (15 years +) (n = 7567)

	Disabled		Non-disabled		
	M n %	F n %	M F n % n %		
Unable to read and write	396 20.1	442 20.4	187 11.4 249 13.9		
	Rural	Urban	Rural Urban		
	n %	n %	n % n %		
Unable to read and write	685 21.3	153 16.6	390 13.8 50 8.1		

Around 20 % of individuals with disability report that they cannot read or write, while the corresponding figure for non-disabled is around 12 % (Males:  $\chi 2 = 13.12$ , df = 1, p < .001. Females:  $\chi 2 = 7.42$ , df = 1, p < .01). The gender differences within groups (disabled and controls respectively) are marginal. Rural-urban differences were also found to be significant in that illiteracy is higher among disabled both in urban and in rural areas ( $\chi 2 = 14.74$ , df = 1, p < .001, and  $\chi 2 = 6.30$ , df = 1, p < .001).



# Employment

# Table 17. Work status according to gender and disability status

Work status	Dis	abled	Cont	trols	To	tal
	n	%	n	%	n	%
Male						
Paid work	277	20.5	373	33.1	650	26.2
Self-employed	82	6.1	71	6.3	326	6.0
Unemployed (health reasons)	166	12.3	43	3.8	209	8.4
Unemployed (other reasons)	396	29.3	250	22.2	646	26.1
Other (homemaker, non-paid volunteer, retired, student, etc.)	430	31.8	391	34.7	821	33.1
Female						
Paid work	196	12.3	231	17.5	427	14.7
Self-employed	91	5.7	82	6.2	173	5.9
Unemployed (health reasons)	120	7.6	36	2.7	156	5.4
Unemployed (other reasons)	488	30.7	314	23.8	802	27.0
Other (homemaker, non-paid volunteer, retired, student, etc.)	694	43.7	656	49.7	829	34.′

Table 17 shows that there are differences in work status between individuals with and without disabilities ( $\chi^2$  Male: 24.39, df = 4, p < .001,  $\chi^2$  Female: 15.70, df = 4, p < .01). A larger proportion of individuals with disability are unemployed (for both health and other reasons), and fewer disabled have paid work. Around one third of individuals without disability are unemployed (both reasons), while the corresponding figure for individuals with disability is close to 50 %. Around one third of the women in the sample describe their work status as "other", with homemaker as the largest subcategory. A higher proportion of males have paid work as compared to women.



Reproductive health

Questions about reproductive health were asked to women above 15 years of age. Of disabled women, 70.8 % (1135) confirmed that they had given birth, while the corresponding figure for non-disabled women was 74.8 % (987). The difference was not statistically significant. Mean number of children was 3.6 and 3.4 respectively (n.s.).

Respondents were asked whether any pregnancies had ended before term. Among disabled women, 7.0 % (111) reported stillbirths, while the corresponding figure for non-disabled was 6.4 % (84) (n.s.). Mean number of stillbirths was 1.6 among disabled women and 1.4 among non-disabled, but this difference is not large enough to be statistically significant. There is thus a weak but non-significant tendency for disabled women to have more stillbirths than the non-disabled control group.

# 8.2 Individual section

Every individual identified with disability during the household interview was invited to participate in a detailed individual interview, including a total of 866 persons. For comparative purposes, 807 persons from control households were also invited to participate in the individual interviews. The detailed questionnaire for the control individuals comprised only a short version of the questionnaire used for interviewing individuals with disability.

Of individuals with disability, 41.7 % (360) of the interviews were with the disabled person him/herself. A total of 45.7 % (394) of the interviews were with proxys, i.e. for the most part the head of the household. In the remaining 12.6 % (109) of the interviews, both the individual with disability and someone else from the household, again mostly the head of the household, participated.



# Demographics

Table 18. Demographic information by disability status.

	Disabled	Control	Total
Age			
Minimum	12	1	1
Maximum	99	92	99
Mean	52.8	31.7	41.9
Median	53	27	42
Mode	60	14	60
Gender			
Female	41.6 (360)	40.5 (327)	100.0 (687)
Male	58.4 (506)	59.5 (480)	100.0 (986)

# Distribution of disability core domains

The criteria for being included as disabled in this study was to answer at least one "some difficulty" on one of the six WCG questions. By definition then all individuals with disability were expected to answer "some difficulty" or higher on at least one of the six disability core domains. A small number (10, 1.2 %) did nevertheless not score on the six questions, indicating a marginal problem with false positives in the data material.

Table 19. shows proportion of the disabled respondents who responded at least "some" on questions about disability core domains (answer categories: No problems, some problems, a lot of problems, unable to do). Respondents have answered each of the



questions and have therefore to a large extent scored at least some on more than one domain.

Table 19. Distribution of disability according to disability core domains and gender (at least one "some difficulty"

Disability core domain	Female	Male	Total	
	% n	% n	% N	р
Vision	17.1 61	17.4 87	17.3 148	n.s.
Hearing	17.1 01 17.1 61	17.4 87 18.6 93	17.3 148 18.0 154	n.s.
Mobility	52.0 185	56.9 284	54.9 437	n.s.
Remembering	46.1 174	47.6 238	47.0 412	n.s.
Self-care	37.4 133	39.5 216	38.6 349	n.s.
Communicating	27.9 99	30.9 154	29.6 253	n.s.
Base = $100 \%^{1}$	360	506	866	

 $^{1}\,\mathrm{n}$  varies among the core domains due to small number of missing

Mobility is the most prevalent Disability core domain among individuals with disabilities, followed by Remembering/Concentrating, Self-care, Communicating, Hearing and Vision.



Table 20. Distribution of disability according to disability core domains and gender (at least one "a lot difficulty")

Disability core domain	Female	Male	Total	
	% n	% n	% N	р
Vision	9.2 33	8.0 40	8.8 77	n.s.
Hearing	11.0 39	9.6 48	10.2 87	n.s.
Mobility	45.2 161	48.7 243	47.3 404	n.s.
Remembering	33.1 118	30.2 151	31.5 269	n.s.
Self-care	19.3 69	22.0 110	20.9 179	n.s.
Communicating	18.6 66	21.2 106	20.1 172	n.s.
Base = 100 %	360	506	866	

<sup>1</sup> n varies among the core domains due to small number of missing

Table 20 shows the distribution of disabilities in the sample (case). The rank order among the core domains remains the same as when including also mild disabilities. Comparing the two tables however indicates that a higher proportion of individuals with mobility impairments have severe disabilities, while a higher proportion of individuals with sensory impairments have mild disabilities. There are no significant gender differences on any of the core domains.

A scale was produced by adding the 6 WCG Core domains together. This Activity Limitation Scale (ALS) ranged from 0 to 18, mean value was 4.0, St. dev. 2.56, and skewness 1.63. Mean value on the scale did not differ between men and women or between urban and rural. Age was on the other hand found to correlate negatively with ALS (Pearson = - .15, p < .01). The correlation is weak, but this nevertheless suggests that the overlap between age and disability when using WCG questions is limited in the

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current population. In fact, the negative correlation may indicate that age-related disability limits activity limitations less than disability acquired early in life.

Table 21. Distribution of number of disability core domains reported simultaneously by gender (mild and severe disability)

Number of disability core domains "some problems" or more	Fei %	nale n	Ma %	ale n	Tota %	
1	41.0	145	39.2	197	40.0	342
2	30.5	108	28.5	143	29.3	251
3	16.4	58	15.3	77	15.8	135
4	7.9	28	10.8	54	9.6	82
5	2.5	9	5.0	25	4.0	34
6	1.7	6	1.2	6	1.4	12

The majority reported "some difficulty" in one or two disability core domains. More than 25 % did however report "some difficulty" in 3 - 6 domains.

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Table 22. Distribution of number of disability core domains reported simultaneously by gender (severe disability)

Number of disability	Fe	male	M	ale	Tot	al
core domains "a lot of	%	n	%	n	%	n
problems" or "unable to do"						
					·	
1	69.8	226	66.5	309	67.8	535
2	18.2	59	23.0	107	21.0	166
3	6.8	22	6.7	31	6.7	53
4	3.7	12	3.0	14	3.3	26
5	1.5	5	.9	4	1.1	9
6						
Base = 100 %		324		465		789

When looking at severe disability only, the large majority report one disability core domain. One and two domains together constitute around 90 % of the respondents. Multiple, severe disability (more than one domain) is reported by one third of the sample. No gender differences were identified.

# Disability onset and causes

Mean age for onset of disability was 17.7 years (st.dev. 27.1). As many as 45.3 % (387) reported "from birth" (0 years), and more than 60 % have acquired their disability at the age of 10. After this age, onset spreads evenly over the whole range from 11 to 90. The gender difference in age of onset was marginal.

Individuals' opinion on the cause of their disability was recorded. This information was not verified medically. The causes are organized in descending order in Table 24.



Table 23. Causes of disability

-----

Cause	Frequency	%
From birth/congenital	408	47.1
Disease/illness	245	28.3
Accident	77	8.9
Witchcraft	31	3.6
Stress related	22	2.5

All other causes not listed in Table 23 were reported less than by 1.5 % of the participants. The main message is that the causes related to birth are pronounced. Disease and illness is also high, and for the most related to early age and childhood. Accident is also an important cause, and witchcraft ranks as number four with 3.5 %. Gender differences on self-reported causes of disability are marginal and non-significant.

Discrimination: personal experience

Three questions were asked about personal experience with being discriminated (answer categories: yes, no, I don't know)


Question Have you ever:	Ma %	ale n		nale n	p value
been beaten or scolded because of your disability?	17.5	126	13.8	87	n.s.
been beaten or scolded by any family member or relatives because of your disability?	12.0	125	8.0	87	n.s.
experienced being discriminated in any public service?	12.3	122	11.8	85	n.s.

More than 1 in 6 males with disabilities have experienced being beaten because of their disability. More than 12 % confirm being beaten by family members and being discriminated in any public service. Females report somewhat lower figures for two of the questions, but these differences are not significant here. Of all disabled in the sample, 23.2 % (201) report "yes" on at least one of the questions in Table 24.

### Welfare and Health Services

Three questions were combined on need for services, awareness of services, and the actual access of services. A "gap analyzes" is shown in Table 25, listing the different welfare and health services and the proportion of people with disabilities who need, are aware of and access these services.



Type of services	Needed	Aware of	Gap <sup>1</sup>
Vocational training	49.3	44.7	85.0
Legal advice	30.7	37.8	84.6
Welfare services	79.4	54.4	82.6
Counselling for persons with disability	55.4	43.6	79.4
Counselling for parent/family	55.9	43.6	76.7
Educational services	55.7	52.9	72.4
Medical rehabilitation	60.5	48.8	69.1
Assistive devices services	57.3	55.1	68.1
Traditional healer/faith healer	36.5	61.9	65.5
Health information	71.5	65.5	56.1
Health services	80.4	74.1	48.1

Table 25. Gap analyses, health and welfare services (N = 866).

<sup>1</sup>Percentage of those who needed a service who actually accessed it

The different services in Table 25 are organized with the highest gap as the first service and then the others in descending order. In this data material, gaps are generally very high, with more than two thirds of those who need eight out of eleven services report that they needed the service but had not accessed it. Even the gap for the three last services is high, with almost half of those who need health services claiming not to have accessed it. Controlling for urban/rural and gender revealed small differences in service gap, but with a tendency for larger service gaps in rural areas.



### Education

Analyses included only respondents aged 15 years old and above (Tables 26 – 28).

	Disabled %	Control %
Female	44.7	78.1
Male	49.2	78.6
Urban	54.8	83.5
Rural	44.8	77.1

Table 26. Received a formal primary education by gender and disability status

For both males and females the difference between case and control is statistically significant (Females:  $\chi 2 = 13.57$ , df = 1, p < .001, Males:  $\chi 2 = 16.71$ , df = 1, p < .001). The gender differences within the two groups (disabled and control) were particularly small among the control group of non-disabled. The case – control differences are however significant (urban:  $\chi^2 = 6.04$ , df = 1, p = .013, rural:  $\chi^2 = 23.88$ , df = 1, p < .001). For both the male/female and the urban/rural comparison, the differences within the disabled group were more pronounced than within the control group. Among individuals with disabilities (aged 15 +) somewhat less than half reported to have received a formal primary education, while the corresponding ratio for non-disabled is more than two thirds.

A question was further asked whether the level of education had helped the respondents to find any work at all.

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	Disabled %	Control %	
		,0	
Female	23.4	34.0	
Male	22.2	31.9	
Urban	32.1	44.1	
Rural	18.4	28.9	

Table 27. Has level of education helped you to find any work? (% yes, N = 688).

The differences between disabled and controls (for gender and location) imply that controls have a better chance of finding work as a result of their education than their disabled counterparts. These differences are however not statistically significant. It nevertheless appears that individuals without disability tend to benefit more from having a formal education. The gender differences within the two groups (disabled and control) are marginal. The case – control difference is however significant with regards to urban-rural ( $\chi^2 = 7.15$ , df = 1, p < .01), but only when the two are analysed together. The urban-rural difference is significant for both disabled and non-disabled with the rural sub-population reporting far less chances of getting a job due to education. Among individuals with disability less than one fourth seem to benefit from having a formal education, while the corresponding ratio for non-disabled is one third.



	Disabled	Control
	%	%
Female	8.8	15.4
Male	8.5	12.2
Urban	14.3	18.4
Rural	6.4	11.8

Table 28. Did you study as far as planned? (> 15 years) (% yes, N = 669)

The differences between disabled and non-disabled on this question are not statistically significant, but there is a tendency for controls to confirm that they studied as far as planes to a larger degree than disabled. Apparently, the large majority do not achieve according to own expectations in the educational system.

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Employment

Respondents with and without disability aged 15 years and above were asked if they were currently working. Currently working includes casual labour, part-time work and those who were self-employed.

Table 29. Current employment status, by disability status (% of N) (NF = 454, NM = 676) NR = 855, NU = 269)

	D:	abled	Car	ntrol	т.	 4 o 1	 
Currently working							
	IVI	F	M	F	IVI	F	
Yes	8.4	4.5	31.7	28.9	19.4	15.9	 
	R	U	R	U	R	U	 
Yes	4.9	13.1	24.6	49.2	14.2	29.7	-

Those who did not respond "yes" in Table 29 covered the reasons "never been employed", "have been employed before", and "housewife/homemaker". The difference between disabled and controls is significant for both males and females ( $\chi 2 = 14.06$ , df = 1, p < .001, and  $\chi 2 = 11.75$ , df = 1, p < .001 respectively). Individuals with disability report substantially less work experience than non-disabled (controls), and a much higher proportion have never been employed. Gender differences within groups (disabled and control) are not significant. The difference between urban and rural is further near significant for disabled and significant for controls (disabled:  $\chi^2 = 3.78$ , df = 1, p = .065, controls:  $\chi^2 = 6.00$ , df = 1, p = .015). The least employed are the rural disabled, while the urban controls have the highest level of current employment. Among individuals with disability, around two thirds have never been employed, while the corresponding proportion for controls is slightly less than half.



#### Accessibility

Disabled respondents were asked about accessibility to different rooms in their home. Availability of these rooms/facilities is presented in Table 31.

Room/facility	Accessible % of n	Total <sup>1</sup> n	Have none % of N <sup>2</sup>
Kitchen	80.4	684	2.9
Bedroom	86.0	731	1.1
Living room	58.3	493	29.2
Dining room	56.2	474	31.4
Toilet	74.2	631	8.1

Table 30. Accessibility at home

<sup>1</sup>Number of respondents who owned the room/facility in their home

<sup>2</sup> Total number of respondents answering the question, varying from 844 to 851

Table 30 reveals that the different rooms/facilities listed firstly are accessible to the majority of the disabled in this study. Around 15 – 20 % cannot access kitchen or bedroom where they live, while 25 % have accessibility problems when it comes to the toilet. Further, close to one third of the respondents do not have living room or dining room in their home, more than half cannot access these rooms, while less than 10 % did not have a toilet. When combining accessibility with availability, a large proportion of the respondents are without living room, dining room, and also toilet. It is for instance more than one in four who do not have a toilet in their house that they can use.

The next table presents the distribution of accessibility of different places or facilities in the community.

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Place/facility	Accessible	Total <sup>1</sup>	$NA^2$
	% of n	n	% of N
Primary health care clinic	82.7	808	3.9
Place of worship	81.5	741	12.0
Hospital	74.8	798	5.2
School	73.6	276	66.7
Sports facilities	73.3	555	33.6
Shops	73.2	680	19.0
Police station	65.4	668	20.7
Workplace	64.4	146	79.3
Public transportation	63.7	813	3.7
Post office	63.4	661	21.2
Recreational facilities	62.3	236	71.7
Bank	60.7	608	27.0
Hotels	59.6	396	52.1
Magistrate office/traditional courts	55.1	572	31.3

## Table 31. Accessibility in the community (N varies between 839 - 844)

<sup>1</sup>Total number of respondents who used the place or facility

<sup>2</sup> Percentage that did not use the place/facility, or the place/facility was not available

Table 31 presents the distribution of accessibility of different places or facilities among disabled persons who had used them or where these places or facilities were available in their area. The most accessible facilities were primary health clinic, place of worship and hospital, while the least accessible were hotels and courts. In general, around 30 - 40 % reported that various facilities were not accessible to them. There are further large variations in the applicability of the different sites, ranging from schools being not applicable for 66.7 of the respondents down to public transport and primary health clinic with 3.7 % and 3.9 % respectively.



### Assistive devices

Of the respondents with a disability, 21.5 % (186) reported that they use an assistive device. The gender difference was marginal, while more urban dwellers confirmed use as compared to the rural sub-population, although this difference did not reach statistical significance.

All those who reported use of assistive devices were also asked the type of device(s) he or she was using. One type of device, for "personal mobility", dominated and was 167 of the 186 (90 %) who reported use of any device. Other devices were not used by more than 1 - 2 % of the respondents. Among disabled persons using an assistive device, 65.8 % (121) report that the device is in good working condition.

Source of device	n	% of all who has a device (183)
Government health service	28	15.3
Other Governmental service	16	8.7
Non-governmental organization	23	12.6
Private	71	38.8
Other	41	22.4
Don't know	4	2.2
	183	100.0

Table 32. Supply of assistive devices

Table 32 reveals that well over one third of assistive devices in this population have been supplied by private sources. The second most common is Government service (health service and other services) with close to one fourth, while NGOs is third with 12.6 %. The category "other" most likely comprises a mix of different sources.



Concerning maintenance of the devices, the answers grouped largely into three: Selfrepair/maintenance with approximately one third (34.4 %), no maintenance was reported by more than one fourth (27.8 %), and family members were reported by one fifth (20.7 %). Basically this implies that for the large part, those who supply assistive devices do not maintain them, and that this is left to the individual device owner/user to sort out by him or herself.

The respondents were also asked to assess the information or help/training they had been given on how to use the device(s). As many as 42.4 % stated that they had not received any information/training, approximately one third (34.2 %) had received some information, while 29.6 % reported complete/full information.

Level of satisfaction	Female %	Male %	Total %
Very content	31.5	34.9	33.5
Content	39.7	42.5	41.3
Less content	20.5	16.0	17.9
Not content	8.2	6.6	7.3

Table 33. Level of satisfaction with assistive device (n = 179)

Table 33 reveals small and insignificant gender differences. Around one fourth (25.2 %) are less content or not content, while the large majority are content or very content with their assistive device.

## Assistance in daily life activities

The need for assistance in carrying out daily life activities may vary with gender, age and severity of disability. In Table 34 below, the basis for the calculation are individuals who answered "yes", "no" or "sometimes". "Not applicable" as a response category was

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coded as missing, explaining for instance the low n on studying, which clearly is relevant only for a certain segment of the population.

Activity	n	Yes	Sometime	No
Emotional support	773	69.2	16.6	14.2
Finances	796	62.4	17.7	19.8
Cooking	800	54.5	18.5	27.0
Transport	789	50.6	19.3	30.2
Shopping	805	49.4	24.5	26.1
Studying	278	33.8	21.6	44.6
Bathing	845	24.6	12.5	62.8
Dressing	846	23.0	14.7	62.3
Moving around	839	20.1	13.2	66.6
Toileting	845	19.1	7.2	73.7
Eating/feeding	844	12.8	5.9	81.3

Table 34. Assistance needed in daily life activities (% of n)

Among the daily life activities in Table 34, the highest ranked (more assistance needed) are activities that all require social engagement in one way or another. On the other hand, all the lowest ranked but one (moving around) are directly related to personal care. The results also show that the need for emotional support is ranked highest and even above financial support which is a strong signal in a poor population. No gender differences were identified.

All variables in Table 34 were included in an additive scale with values 1 (no), 2 (sometime), and 3 (yes) on single items. This yielded a scale with min/max values being 12/36, mean 18.7, St. dev. 6.07 and skewness .78. The scale was included in a regression model with age, gender and severity of disability as predictors.



Table 35. Regression of Gender, Age and Severity of disability on Assistance needed in daily life activities.

R <sup>2</sup> = .29	Beta	t	р
Gender	.04	.39	n.s.
Age	45	4.93	<.001
Disability severity	.28	3.00	< .01

No gender differences in need for assistance in daily life activities are indicated. Need for assistance decreases with increasing age and increases with increasing severity of disability.

Involvement in family, social life and social activities

A series of questions were intended to reflect involvement in family life, social life and social activities. Results presented in Table 36 reveal striking differences between individuals with/without disability. The large majority of individuals with disability do feel involved in family life, but they score significantly lower on all indicators. The difference is particularly pronounced for the three items reflecting social life or activity outside of the family, and the largest nominal difference is found for participating in traditional practices, with voting in elections as the second largest difference.

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## Table 36. Involvement in family and social life

	Disabled (n: 667 - 816)			Control (	Control (n: 648 – 793)		
Measure of involvement	Yes	Sometimes	No	Yes	Sometimes	No	
Are you consulted about making							
household decisions?	47.0	13.5	39.5	68.7	12.0	19.3	
Do you go with the family to events such							
as family gatherings, social events, etc?	51.1	15.9	33.0	80.6	12.1	7.3	
Do you feel involved and part of the							
ousehold or family?	77.8	8.5	13.7	93.4	1.8	4.8	
Does the family involve you in							
conversations?	58.0	11.0	31.0	75.4	11.5	13.2	
Do/did you take part in your own							
raditional practices?	24.7	10.8	64.4	62.0	10.2	27.8	
Do you participate in local community							
neetings?	21.0	8.5	70.5	57.3	12.9	29.8	
Did you vote in the last election?	36.4		63.6	71.1		28.9	

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Individuals with disability were also asked whether they knew about any organizations for disabled people (DPOs) and if they were a member. Concerning the first question, the large majority (84.4 %) were not aware of any DPO. An even larger majority (95.6 %) reported not to be member of a DPO. Males tended to have lower awareness and were less inclined to membership. The major finding here is very low awareness and membership. Both awareness and membership were higher in urban areas, largely due to higher awareness among women and more urban men being members.

#### General health

Assessment of general well-being was done using a standardized 12 - item General Health Questionnaire (GHQ - 12) (Goldberg & Williams 1988). A standard (Likert) scoring procedure was applied with the GHQ - 12 scale, with item scores ranging from 0 to 3 and with higher scores representing higher psychological distress. Mean value on the scale was 10.90, standard deviation 6.72, and range 0 - 36). In addition two general questions on personal assessment of physical and mental health were asked. The GHQ - 12 is constructed to detect psychiatric disorders in community settings and non-psychiatric clinical settings, such as primary care or general practice, and is a general measure reflecting anxiety and depression.



	Disabled (n = 866)	Control (n = 807)
	Mean	Mean
Female	13.47	8.15
Male	13.18	8.45
Rural	13.39	8.52
Urban	12.98	7.69
Total	13.30	8.33

### Table 37. GHQ 12 score by disability status

Missing values replaced with mean

Table 37 reveals a significantly higher GHQ score among disabled (F = 59.22, df = 1665, p < .001). Individuals with disability thus have a higher level of anxiety and depression (as measured by GHQ) than non-disabled. Gender differences were marginal. Rural – urban differences were also small, with the rural sub-population scoring somewhat higher levels of anxiety and depression).

The respondents were also asked to rate their overall physical health and mental health status.

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## Table 38. Overall physical health by disability status (%)

	Disa	abled	Non-	disabled
Physical health	М	F	М	F
Poor	13.5	14.5	1.3	.6
Not very good	33.8	32.0	8.5	11.1
Good	37.6	37.0	52.6	48.3
Very good	15.1	16.6	37.6	40.0
$\chi^2$ Males = 41.02, df = 3, p <	.001, χ2 Females	= 25.82, di		
	Disa	abled	Non-	disabled
Physical health	R	U	R	U
Poor	14.8	11.4	1.3	.0
Not very good	33.8	31.3	10.9	5.2
Good	35.7	41.7	49.6	54.7

15.6

 $\chi^2$  Urban = 17.37, df = 3, p < .01,  $\chi^2$  Rural = 44.68, df = 3, p < .001

15.6

Very good

38.1

40.0

------



## Table 39. Overall mental health by disability status (%)

	Disa	abled	Non-	disabled
Mental health	М	F	М	F
Poor	13.3	14.8	1.1	.6
Not very good	38.7	31.1	5.1	6.2
Good	34.1	39.3	58.0	49.5
Very good	13.9	14.8	35.9	43.7
$\chi^2$ Males = 56.56, df = 3, p < .0		= 34.34, df	= 3, p < .001	
	Disa	abled	Non-	disabled
Mental health	R	U	R	U
Poor	15.6	9.0	1.2	.0
Not very good	36.4	33.3	7.1	.5
Good	34.9	39.5	54.2	55.7
Very good	13.0	14.8	37.5	43.8

\_\_\_\_\_

 $\chi^2$  Urban = 23.55, df = 3, p < .001,  $\chi^2$  Rural = 67.77, df = 3, p < .001

Individuals with disability rate both their physical and mental health to be poorer than their non-disabled counterparts, and this difference is significant for both men and women, as well as for the urban and the rural sub-population. A majority of disabled rate their mental health to be "not very good" or "poor", while the corresponding figures for the controls are in the area of 6 - 8 %. These are substantial differences in subjective health. While gender differences within groups (disabled/ non-disabled) appear to be small, the differences between urban and rural among disabled and non-disabled respectively are pronounced. The rural sub-population rate their physical and mental health as being clearly poorer than among their urban counterparts.



	Do you ha knowledg this diseas	e about	standing/o informatic	ems under- btaining on about	Have you had this di			
	% Disabled	this disease? % yes % yes bled Non-disabled Disabled Non-disabled				% yes Disabled Non-		
Disease 	59.3	86.5	26.0	25.7	9.5	disable		
Malaria	49.3 74.8		25.1	19.3	8.0	7.3		
ТВ	56.278.847.168.8		27.6	21.6	9.7	9.5		
Diabetes			31.1	31.1 24.6		8.8 5.8		

Table 40. Knowledge about some common diseases (% of n)

With regards to knowledge about the four common diseases, a consistent pattern emerges in that individuals with disability report significantly less knowledge than non-disabled, with the gap in percentage being from 17 to 25. The most common diseases are known to approximately half of the disabled sample.

When asked to assess problems understanding and obtaining information about the diseases, for three out of the four diseases individuals with disability report slightly more problems than non-disabled, with HIV/AIDS being the exception. More than 25 % of disabled report that they have problems obtaining or understanding such information, while the corresponding figure for non-disabled is around 20 %.

Respondents were asked to report whether they were infected of the four diseases. Firstly, differences between the two groups are small. However, it is worth noting that individuals

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with disability report somewhat higher level of HIV/AIDS infection, and males with disability report higher level of diabetes than non-disabled males (n.s.). Of the rural sub-population in the sample, 10.6 % of the disabled report that they are HIV infected, while the figure for non-disabled is 6.4 %. The corresponding figures for the urban population is 6.7 and 6.1 %. Of males and females, the figures for disabled and controls are 9.8 % and 6.8 %, and 9.0 % and 5.8 % respectively for rural and urban.

Source	HIV/AIDS		Malari	a	TB	·	Diabetes		
	Dis	Non-dis	Dis Non-dis		Dis	Non-dis	Dis	Non-dis	
Health clinic	40.6	32.3	34.0	23.8	34.9	27.1	36.2	29.7	
Radio/tv	20.9	22.9	32.2	33.7	24.1	24.8	25.3	26.9	
School	15.1	28.3	13.2	22.7	12.4	21.8	8.6	16.1	

Table 41. Where did you get information about the diseases (% of n)

In Table 40 only the most important sources of information are included. Only those who responded "yes" to the question about knowledge were included ( $n_{disabled} = 359$ ,  $n_{non-disabled} = 528$ ).

A relatively clear pattern emerges, with Health clinic being the main source of information for both groups, followed by Radio/tv and School. Non-disabled individuals more often report school as source of information, which reflects higher levels of school attendance. It appears from the results that individuals with disabilities to some extent compensate for low school attendance by obtaining information about these common diseases at health clinics.



## **9 SUMMARY OF RESULTS**

HOUSEHOLD SECTION

- In the current sample, 10.9 % qualifies as being disabled with a "broad" definition of disability, 8.0 % have "moderate" disability, while 5.4 % are "severely" disabled. Due to the sampling strategy, these figures are not precise prevalence estimates for Swaziland but rather indications on prevalence
- Households with at least one disabled member have a higher number of household members than control households
- The dependency ratio is higher in households with disabled members
- Control households score higher on the socio-economic indicator (ownership of household items) than households with disabled members
- Disabled household has lower dietary diversity compared to control households, and tend to report higher frequency of lack of food
- Disabled households have less access to the most common sources of information
- More individuals with disability (in the total sample) have not received any formal education, with the main reason being economic and the disability being the second most important reason
- Individuals with disabilities (in the total sample) have fewer years of education than non-disabled individuals, and they report higher levels of illiteracy
- A larger proportion of individuals with disability (in the total sample) are unemployed
- In general, level of living is lower among females and in the rural population



....INDIVIDUAL SECTION....

- Of the different disability types applied in the Washington City Group screening instrument, mobility is the most prevalent (more than 50 %), followed by Remembering/Concentrating (almost 50 %), Self-care (more than one third), Communication, Vision, and Hearing.
- The major cause of disability is reported to be "From birth/Congenital", followed by "Disease/Illness. These two account for more than two thirds of individuals with disability
- More than one in six males with disability have experienced being beaten or scolded because of their disability, while this figure is somewhat lower for women
- Gaps in services (proportion of those who needed a service and did not access the service) are generally very high with the largest gaps found for Vocational training, Legal advice and Welfare services, and the smallest gaps found for Health services, Health information and Traditional healer.
- Close to half of individuals with disability have not received a formal primary education, while the corresponding figure for non-disabled is somewhat above one in four
- Individuals with disability report substantially less work experience than non-disabled, and a much higher proportion have never been employed
- Around 30 40 % of individuals with disability report that various facilities were not accessible to them
- One fifth of individuals with disability use an assistive device, provision of devices are largely from the private/NGO sector, four out of ten had not received any instruction on use of the devices, and maintenance is largely left to the individual/family



INDIVIDUAL SECTION (continued)

- Among daily life activities, individuals with disability need more assistance with activities that require social engagement, and with emotional support as the highest ranked
- The large majority of individuals with disability report that they are involved in family life, but they score significantly lower on a number of indicators. The difference is particularly pronounced with regards to social life or activity outside of the family
- Individuals with disability have higher levels of anxiety and depression as compared to non-disabled
- Somewhat less than half of individuals with disability rate their physical and mental health to be "not very good" or "poor"
- Individuals with disability rate both their physical and their mental health to be poorer than their non-disabled counterparts
- Individuals with disability report significantly less knowledge about some common diseases, and more than one in four of the disabled report that they have problems obtaining or understanding health information
- Differences between the two groups (disabled and non-disabled) are in general small with regards to self-reported diseases, but individuals with disability report higher levels of HIV/AIDS infection and males with disability report higher level of diabetes than non-disabled males

## **SINTEF**

## 10 DISCUSSION

### Arne H Eide

A national, representative study on living conditions among people with disabilities has been carried out in Swaziland in 2009 – 2011. This report brings some of the key results from this study. LNFOD, FFO, and SINTEF have, in collaboration with Central Statistical Office and other public bodies and institutions in Swaziland as well as SAFOD as a regional disability organization, established the first generation of data about individuals with disabilities and their households in the country. The data base also comprises a sample of non-disabled, which provides a basis for comparing between disabled and non-disabled. Having established evidence for differences between disabled and non-disabled is an important step in the promotion of human rights and improved level of living among individuals with disability. The study offers an opportunity for boosting advocacy, for setting priorities, for assessing impact and developing policies, for monitoring the situation, and for increased knowledge among disabled and the public in general.

The study, which follows similar studies in Namibia, Zimbabwe, Malawi, Zambia, Mozambique and Lesotho, also adds to a growing body of information on the situation among people with disabilities in the southern Africa region. The regional data base provides opportunities for comparing between countries and across the region and may be a vehicle for sharing of experiences and build capacity in the region to improve the situation for people with disabilities. In the long run this can contribute to implement the new Convention on the Rights of Disabled People (UN 2006) which has been signed and ratified by several of the countries.

A particular feature of this and the preceding studies is the broad inclusion of individuals with disabilities in all stages of the research process, and the position of disabled people's

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organizations (DPOs) in initiating and controlling the research and it's future application. Including individuals with disabilities as interviewers have reduced the threshold for individuals with disabilities and their families to come out with information, and it has proven that disabled are contributing members of society when given a chance to be so.

Our experience from neighboring countries implies that this will yield a stronger, more experienced organization with improved standing nationally and in the region. It is anticipated that the study will lead to a further development of the working relationship between FODSWA, other disability organizations, and the relevant authorities in Swaziland. The study and this report is also intended as a tool for policy makers, the ministries and other public bodies that have particular responsibility for disability issues, and for mainstreaming disability across different sectors. This requires that the disability movement and relevant authorities utilize the opportunity provided by this report to engage in a long-term dialogue on how to translate research findings into action at different levels in society.

An interesting feature of household composition that has been found also in the previous studies is that households with disabled members tend to be larger than control households. Further, the Dependency Ratio was also shown to be higher among households with disabled members, reflecting more members at dependent age groups. This implies higher burdens for households with disabled members as compared to control households. As there are few services to support families and individuals with disabilities living at home; practical, economic, social, emotional and other problems will to a large extent have to be solved within the household itself. The studies of disability and poverty by Ingstad & Grut in Kenya (2007) and Yemen (Grut & Ingstad 2006) provide some in-depth information about coping mechanisms at the household level.

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A main finding in the study is that households with disabled members and individuals with disabilities score lower on a number of indicators of level of living conditions as compared to households without disabled members or non-disabled individuals. By and large, this pattern in the data material from Swaziland parallels the pattern that has been observed in the previous studies in the region. Bearing in mind the discussion around household composition above, comparative analyses between household types do not take such differences into account. Thus, the differences shown in this and previous reports will underestimate the differences in living conditions at household level.

It has not been aimed in this study to find a precise estimate of disability prevalence in Swaziland, and the results around prevalence as presented above should be interpreted with care. Previous experience has however shown that using the disability screening procedure developed by the Washington City Group on Disability Statistics will produce higher prevalence rates as compared to other less sensitive and impairment based questions. The results here confirm this, but also contribute to demonstrate that any prevalence reflects the definition of disability that has been applied, and in this case: where the cut-off point between disabled and non-disabled is set (see Loeb & Eide 2008 for further discussion).

Individuals with disability report substantially higher levels of mental health problems than their non-disabled counterparts, and need for emotional support score highest among services needed in daily life. This confirms previous studies in the region and provides a strong message that mental health and disability is an area for further research and intervention. Several authors have underlined the absence of research and need for attention to this problem in low-income countries (e.g. Patel 2007).

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Also with regards to physical health, individuals with disability report substantially more health problems than their non-disabled counterparts. This is in contrast to the lack of knowledge about some common diseases, where more than half report not to have any information at all, and there is a slight tendency for individuals with disability to have greater problems in obtaining and understanding health information. The results further revealed substantial gaps in accessing different types of (health) services. We thus have a situation in which the least healthy have most problems with knowledge and information as well as accessibility problems. This indicates that the particular problems individuals with disabilities may have in relation to health services need some urgent attention and that particular efforts should be made to reduce these barriers. The results further indicate that accessibility problems goes beyond these particular services and that also other sectors need to consider accessibility problems. The evidence provided in this study may form a good basis for pushing this in the right direction.

Education and employment are key elements in any measure of living conditions, and for both indicators individuals with disability are worse off than others. The differences in formal education and literacy may have different reasons, but it is an indication of either discrimination or lack of awareness or both.

Direct and open discrimination and abuse is documented for among 20 % of individuals with disability. More subtle forms of daily life discrimination or exclusion are however also documented in particular with regards to traditional practices, local community meetings and voting. The differences between disabled and non-disabled on these indicators are pronounced and there are also differences in the same direction with regards to other indicators of family and social life. There may be different or rather a combination of reasons for this, and the study does not provide results that can contribute to explain this phenomenon. Most likely, the results indicate that exclusion of disabled takes different



forms and can be found within the family, in the local community as well as in institutional practices. While the current results may be utilized to counter discriminatory practices, further research into this will be necessary in order to reveal causes and solutions to the problems.

Assistive devices are important for many individuals to reduce barriers for an active daily life and participation at home and in the local community. The proportion of disabled who use an assistive device is approximately the same as in other countries in the region, and this also goes for the information about supply with NGOs or other private sources as the most important. Lack of maintenance and information are other problems revealed in this study. Those who currently use a device are however largely happy with their device.

Gender and the urban-rural dimension were included in most of the analyses, revealing differences on several key indicators. Although gender and urban-rural differences are not confirmed on all indicators, the general picture is that the urban population is better off than their rural counterparts and that men fare better than women on key indicators as education, employment, information and health. There is thus ample reason to target individuals with disabilities in rural areas, and in particular rural women, in order to achieve the Millennium Development Goals and to live up to the standards set by the UN Convention on the Rights of Disabled People.



## 11 CONCLUSION

The findings in this study on living conditions among people with disabilities and nondisabled controls confirm that there are substantial gaps on a number of key indicators on level of living, to the disadvantage of individuals with disability and disabled women living in rural areas in particular. It is recommended that the evidence base found in this research report is utilized by DPOs in Swaziland in their advocacy work, by Government bodies in their planning and service provision, as a basis for monitoring development. It is further recommended that the data is further utilized by researchers and Central Statistical Office in Swaziland, and not least as a knowledge base for development of the disability policy in the country.

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APPENDICES



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#### HOUSEHOLD LISTING AND SCREENING FORM

Screening no.

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Region name	Hhohho	1	Shiselweni	3	EA number
	Mazini	2	Lubombo	4	Village/locality name
	-				

							Beca	ause of a HEA	LTH PROBE	M, does ANYON	E in your ho	usehold	Does your
	Household Number/ID		Enter Name of Household Head If the same is very long, write a nick name	have difficulty seeing, even if wearing glasses	have difficulty hearing, even if using a hearing aid	have difficulty walking or climbing steps	have difficulty remembering, concentrating, or both	have difficulty with self- care such as washing all over or dressing	have difficulty, using the usual (customary) language, communicating (understanding or being understood by others)	household have any member with disability? 1=Yes 2=No			
							1 = N	O 2 = SC	DME 3	= A LOT 4	= UNABLE <sup>-</sup>	TO DO IT	
1													
2													
3													
4													
5													
6													
7													
8													
9													
10 11													
12													
12													
14													
15													
16													
17													
18													
19													
20													

To be completed by th	Supervisor	
Date: Time: Name of interviewer:	Day Month Year 2010 Started Completed	Checked Signature
Signature:		

## LEVELS OF LIVING CONDITIONS SURVEY IN SWAZILAND

Identification of household			Code
NAME AND CODE OF REGION*			
EA number			
NAME OF VILLAGE/LOCALITY			
LOCATION 1 = urban 2 = rural			
HOUSEHOLD NUMBER/ID			
NAME OF HOUSEHOLD HEAD			
WAS THIS HOUSEHOLD SCREENED AS: 1 = having at least 1 disabled member 2 = not having any disabled member			
TOTAL NUMBER OF PERSONS IN HOUSEHOLD (should be the same as last Line Number filled in Section A)			
TOTAL NUMBER OF PERSONS WITH DISABILITY			
LINE NO. OF PRIMARY RESPONDENT			
TO BE COMPLETED BY THE INTERVIEWER		Date of in	terview
Time started		Day	
Name of interviewer: Comments:		Month	
		Year	2 0 1 0
Signature			
SUPERVISOR INTERVIEW STATUS Name :	Enumerato return t house	to the	CHECKED by the Supervisor

Signature Complete Incomplete Yes No	Name :		household	Supervisor
	Signature	Complete Incomplete	Yes No	

*CODES FOR REGIONS				
1 = Hhohho	3 = Shiselweni			
2 = Mazini	4 = Lubombo			

#### SECTION A. HOUSEHOLD COMPOSITION: FOR ALL PERSONS

LINE NO.	WHO ARE PERMANENT MEMBERS OF THIS HOUSEHOLD?RELATIONSHIP TO HEAD OF 		SEX AGE		MARITAL STATUS	BURDEN OF DISEASE						
	List the first names and first letter of the surname of all persons in this household, starting with the head of the household	What is the relationship of (NAME) to the head of the household? *	Is (NAME) male or female? 1=Male 2=Female		male or female? 1=Male		male or female?		How old was (NAME) at his/her last birthday?	What is (NAME'S) marital status?**	Has (NAME) been chronically ill during the past 12 months?	What was the illness?***
							Enter age in completed years 99=Don't know	Only 12 yrs and above	1=Yes 2=No 9=Don't know			
(1)	(2)	(3)	L.	4)	(5)	(6)	If 2 or 9 → Q.9 (7)	(8)				
(1)	(2)	(5)	M	+) F	IN YEARS	(0)	(7)	(3)				
01			1	2								
02			1	2								
03			1	2								
04			1	2								
05			1	2								
06			1	2								
07			1	2								
08			1	2								
09			1	2								
10			1	2								

*CODES FOR Q.3	**CODES FOR Q.6	***CODES FOR Q.8
RELATIONSHIP TO HEAD OF HOUSEHOLD	MARITAL STATUS	CHRONIC ILLNESSES
1 = Head 2 = Husband/wife 3 = Son/Daughter 4 = Son/Daughter-in-law 5 = Grandchild of head/spouse 6 = Parent of head/spouse 7 = Brother/Sister of head/spouse 8 = Other relatives 9 = Domestic worker/Non-relative 10 = Other non-relatives 99 = Don't know	<ul> <li>1 = Never married</li> <li>2 = Married with certificate</li> <li>3 = Married traditional</li> <li>4 = Consensual union</li> <li>5 = Divorced/separated</li> <li>6 = Widowed</li> <li>9 = Don't know/refuse</li> </ul>	1 = Cancer 2 = TB 3 = Malaria 4 = Diarrhoea 5 = Malnutrition 6 = Measles 7 = Pneumonia 8 = Heart disease 9 = High blood pressure 10 = HIV/AIDS (related) 11 = Other disease 99 = Don't know

#### SECTION A. HOUSEHOLD COMPOSITION: FOR ALL PERSONS

LINE NO.	Because of a HEALTH PROBLEM						FILTER		
	Does (NAME) have difficulty seeing, even if wearing glasses?	Does (NAME) have difficulty hearing, even if using a hearing aid?	Does (NAME) have difficulty walking or climbing steps?	Does (NAME) have any difficulty remembering or concentrating?	Does (NAME) have difficulty with self-care such as washing all over or dressing?	Using the usual (customary) language, does (NAME) have difficulty communicating for example understanding or being understood?	Mark with <b>X</b> person with a disability	Is (NAME) <b>5 yrs old</b> or above? YES → Q.16 NO → STOP	
	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA		CHECK Q.5	
(1)	(9)	(10)	(11)	(12)	(13)	(14)	(15A)	(15	5B)
01								YES 1	NO 2
02								1	2
03								1	2
04								1	2
05								1	2
06								1	2
07								1	2
08								1	2
09								1	2
10								1	2
#### SECTION A. HOUSEHOLD COMPOSITION: FOR ALL PERSONS - cont. for household member 11 -20

LINE NO.	WHO ARE PERMANENT MEMBERS OF THIS HOUSEHOLD?	RELATIONSHIP TO HEAD OF HOUSEHOLD	SI	EX	AGE	MARITAL STATUS	BURDEN OF I	DISEASE														
	List the first names and first letter of the surname of all persons in this household, starting with the head of the household.	What is the relationship of (NAME) to the head of the household? *	Is (NAME) male or female? 1=Male 2=Female		male or female? 1=Male		male or female? 1=Male		male or female? 1=Male		male or female? 1=Male		male or female? 1=Male		male or female? 1=Male		male or female? 1=Male		How old was (NAME) at his/her last birthday? Enter age in completed	What is (NAME'S) marital status?** Only 12	Has (NAME) been chronically ill during the past 12 months? 1=Yes 2=No	What was the illness?***
					<b>years</b> 99=Don't know	yrs and above	9=Don't know If 2 or 9 → Q.9															
(1)	(2)	(3)	(4	4)	(5)	(6)	(7)	(8)														
			м	F	IN YEARS																	
11			1	2																		
12			1	2																		
13			1	2																		
14			1	2																		
15			1	2																		
16			1	2																		
17			1	2																		
18			1	2																		
19			1	2																		
20			1	2																		

IF THERE ARE MORE THAN 20 PERSONS IN THE HOUSEHOLD, PLEASE USE A CONTINUATION SHEET AND TICK THE BOX BELOW

*CODES FOR Q.3 RELATIONSHIP TO HEAD OF HOUSEHOLD	**CODES FOR Q.6 MARITAL STATUS	***CODES FOR Q.8 CHRONIC ILLNESSES
1 = Head 2 = Husband/wife 3 = Son/Daughter 4 = Son/Daughter-in-law 5 = Grandchild of head/spouse 6 = Parent of head/spouse 7 = Brother/Sister of head/spouse 8 = Other relatives 9 = Domestic worker/Non-relative 10 = Other non-relatives	<ol> <li>1 = Never married/single</li> <li>2 = Married with certificate</li> <li>3 = Married traditional</li> <li>4 = Consensual union</li> <li>5 = Divorced/separated</li> <li>6 = Widowed</li> <li>9 = Don't know/refuse</li> </ol>	1 = Cancer 2 = TB 3 = Malaria 4 = Diarrhoea 5 = Malnutrition 6 = Measles 7 = Pneumonia 8 = Heart disease 9 = High blood pressure 10 = HIV/AIDS (related)
99 = Don't know		11 = Other disease 99 = Don't know

## SECTION A. HOUSEHOLD COMPOSITION: FOR ALL PERSONS - cont. for household member 11 -20

LINE NO.	Because of a HEALTH PROBLEM								
	Does (NAME) have difficulty seeing, even if wearing glasses?	Does (NAME) have difficulty hearing, even if using a hearing aid?	Does (NAME) have difficulty walking or climbing steps?	Does (NAME) have any difficulty remembering or concentrating?	Does (NAME) have difficulty with self-care such as washing all over or dressing?	Using the usual (customary) language, does (NAME) have difficulty communicating for example understanding or being understood?	Mark with X person with a disability	Is (NAI 5 yrs or abo YES NO	old ove? • Q.16
(1)	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	1 = NO 2 = SOME 3 = A LOT 4 = UNABLE 9 = NA	-	CHECK	
(1)	(9)	(10)	(11)	(12)	(13)	(14)	(15A)	(15	5B)
11								YES 1	NO 2
12								1	2
13								1	2
14								1	2
15								1	2
16								1	2
17								1	2
18								1	2
19								1	2
20								1	2

#### SECTION B. LEVEL OF EDUCATION OF HOUSEHOLD MEMBERS - AGED 5 YEARS OR ABOVE

LINE NO.	ATTENDING SCHOOL	YEARS OF EDUCATION	HIGHEST GRADE COMPLETED*	REASONS NEVER ATTTEND SCHOOL**		LITERACY	CON	TROL
Transfer the LINE NO. of persons as listed in Sect. A who are 5 yrs old	Has (NAME) attended any school, college or university? 1 = YES	How many years in all did (NAME) spend studying in school, college or university?	What is (NAME'S) highest standard form or level of education	If (NAME) never attend school, what is the reason?** (Code up to 2 reasons)		e read and write in any language?		ME) ears r ?
or above	2 = NO → Q.19 9 = DON'T KNOW	99 = DON'T KNOW	completed?*	To be asked (NAME) ans in column (2	wered NO	1 = YES 2 = NO 9 = DON'T KNOW	YES→ NO→	
			Q19A & Q19B				CHEC	
(1)	(16)	(17)	(18)	(19A)	(19B)	(20)	(2	1)
							YES 1	NO 2
							1	2
							1	2
							1	2
							1	2
							1	2
							1	2
							1	2
							1	2
							1	2

*CODES FOR Q.18 HIGHEST GRADE COMPLETED	**CODES FOR Q.19A & 19B REASONS FOR NOT ATTENDING/LEFT SCHOOL/COLLEGE OR UNIVERSITY
0 = not completed Grade 1 1 - 11 = Grade 1 - 11 12 = Grade 12 (O-level) 13 = A-level 14 = College/Diploma 15 = University 16 = Post-graduates 99 = Don't know/refuse	0=Not enough money 1=Failing/underachiever 2=IIIness 3=Lack of interest 4=Because of disability 5=School not accessible 6=Pregnancy 7=Other 0 Decrét le pregn
	9=Don't know

## SECTION B. LEVEL OF EDUCATION OF HOUSEHOLD MEMBERS – AGED 5 YEARS OR ABOVE – continue 11 to 20

LINE NO.	ATTENDING SCHOOL	YEARS OF EDUCATION	HIGHEST GRADE COMPLETED*	REASONS NEVER ATTTEND SCHOOL**		LITERACY	CONTROL	
Transfer the LINE NO. of persons as listed in Sect. A who are 5 yrs old	Has (NAME) attended any school, college or university? 1 =YES 2 =NO → Q.19 9 =DON'T KNOW > Q.20	How many years in all did (NAME) spend studying in school, college or university?	What is (NAME'S) highest standard form or level of education	If (NAME) never attend school, what is the reason?** (Code up to 2 reasons)		Can (NAME) read and write in any language?	read and write in any language?	
or above	5-DON T KNOW 2 Q.20	99 =DON'T KNOW	completed?* SKIP Q19A & Q19B	To be asked (NAME) ans in column (2	wered NO	1 = YES 2 = NO 9 = DON'T KNOW	YES→ NO→	► STOP
(1)	(16)	(17)	(18)	(19A)	(19B)	(20)	CHEC (2	<b>K Q.5</b> 1)
							YES	NO
							1	2
							1	2
							1	2
							1	2
							1	2
							1	2
							1	2
							1	2
							1	2
							1	2

*CODES FOR Q.18 HIGHEST GRADE COMPLETED	**CODES FOR Q.19A & 19B REASONS FOR NOT ATTENDING/LEFT SCHOOL/COLLEGE OR UNIVERSITY			
0 = not completed Grade 1 1 - 11 = Grade 1 - 11 12 = Grade 12 (O-level) 13 = A-level 14 = College/Diploma 15 = University 16 = Post-graduates 99 = Don't know/refuse	0=Not enough money 1=Failing/underachiever 2=Illness 3=Lack of interest 4=Because of disability 5=School not accessible 6=Pregnancy 7=Other 9=Don't know			

#### SECTION C. ECONOMIC ACTIVITY OF HOUSEHOLD MEMBERS AGED 15 YEARS OR ABOVE

LINE NO.	WORK STATUS*	POSSESS ANY SKILL?	TYPE OF TRAINING	CONTROL	
Transfer the LINE NO. of persons as listed in Sect. A who are 15 yrs old or above	What is the work status of (NAME)?*	Apart from formal education, has (NAME) received any formal or informal training that has resulted in his/her having a particular skill e.g. carpentering, sewing, running business, farming etc.? 1 = YES 2 = NO Q.25 9 = DON'T KNOW Q.25	Did (NAME) receive any formal or informal training to get the skill? 1= Formal 2= Informal 9= Don't know	Is (NAME) Female? YES → Q NO → S CHECK Q	.26 TOP
(1)	(22)	(23)	(24)	(2	5)
				YES 1	NO 2
				1	2
				1	2
				1	2
				1	2
				1	2
				1	2
				1	2
				1	2
				1	2
				1	2
				1	2

#### \*CODE FOR Q.22

#### WORK STATUS

- 1 = Paid work
- 2 = Self employed, such as own business or farming
- 3 = Non-paid work such as volunteer or charity
- 4 = Student
- 5 = Keeping house/homemaker

6 = Retired

- 7 = Unemployed (health reasons)
- 8 = Unemployed (other reasons)
- 9 = Others
- 99 = Don't know/Refuse

#### SECTION D. REPRODUCTIVE HEALTH OF FEMALE HOUSEHOLD MEMBERS AGED 15 YEARS OR ABOVE

LINE NO.	CHILDREN	NO. OF CHIL	DREN	STILLBIRTHS	NO. OF STILLBIRTS
Transfer the LINE NO. of persons as listed in Sect. A who are 15 yrs old or above	Does (NAME) have any children? 1 = YES 2 = NO> Q.28 9 = DON'T KNOW> Q.28	How many children do (NAME) have today? Don't include those that have died		Does (NAME) have pregnancies ended before term? 1 = YES 2 = NO → STOP 9 = DON'T KNOW → STOP	How many did (NAME) have pregnancies ended before term? 99 = DON'T KNOW
		BOYS	GIRLS		
(1)	(26)	(27a)	(27b)	(28)	(29)

NOTE: The following questions should be completed by the PRIMARY RESPONDENT/HEAD OF HOUSEHOLD

#### SECTION E: INCOME AND EXPENSES

30. What is the PRIMARY source and SECONDARY source (if any) of income in your household?

Income Category	Primary source [Circle one only]	Secondary source [Circle one only]
a. Wage/Salary work (Gross salary)	01	01
b. Remittances received	02	02
c. Cash cropping	03	03
d. Livestock sales	04	04
e. Subsistence farming	<sup>05</sup> → Q.32	05
f. Subsistence fishing	06 → Q.32	06
g. Formal business (registered)	07	07
h. Informal business (non-registered - see below*)	08	08
i. Private insurance/pension	09	09
j. Workman's Compensation	10	10
k. Rent	11	11
I. Other (specify)	12	12
m. No income from any source	13 → Q.32	13
n. Not stated/Refused	14 → Q.32	14

\* This includes payments received for handicrafts, knitting, sewing, repairing shoes, repairing punctures, for providing services (e.g. making thatch roofs for huts, cutting reeds etc.) Also includes income from selling e.g. charcoal, local gin, local beer etc.

**31. Ranking of expense categories:** I'm going to ask you on your household expenses. On a scale of 1 to 5, please rank on the expense categories I'm going to read, where "1" = the least of the household income goes to and "5" = the most of household income goes to. If your household has no expense on a specific category, please say "NONE".

	Least -				→ Most	NONE
a. Food and beverages	1	2	3	4	5	9
b. Rent, building materials, land, house	1	2	3	4	5	9
c. Fuel, power, electricity	1	2	3	4	5	9
d. Agricultural inputs (fertilizer, labour, etc.)	1	2	3	4	5	9
e. Medical care/health services and personal care	1	2	3	4	5	9
f. Cultural and entertainment	1	2	3	4	5	9
g. Cigarettes/tobacco/snuff	1	2	3	4	5	9
h. Clothing/footwear	1	2	3	4	5	9
i. Transportation	1	2	3	4	5	9
j. Education	1	2	3	4	5	9
k. Domestic servants	1	2	3	4	5	9
I. Alcohol	1	2	3	4	5	9
m. Savings/investments	1	2	3	4	5	9

32. Now I would like to ask you about the types of foods that you or anyone else in your household prepared and ate in the past **TWO** weeks during the day and night (food purchased and eaten outside of the home is not included)

	Yes	No
a. Any bread, rice, noodles, biscuits, or any other foods made from millet, sorghum, maize, rice or wheat?	1	2
b. Any potatoes, beetroot, yams, cassava, carrots or any other foods made from roots or tubers?	1	2
c. Any vegetables? (cabbage, spinach, pumpkin leaves or any green leafy vegetables)	1	2
d. Any fruits?	1	2
e. Any beef, pork, lamb, goat, rabbit, wild game, chicken, duck, or other birds, liver, kidney, heart, or other organ meats?	1	2
f. Any eggs?	1	2
g. Any fresh or dried fish or shellfish or any seafood?	1	2
h. Any foods made from beans, peas, pulses, legumes or nuts?	1	2
i. Any cheese, yogurt, milk or milk products?	1	2
j. Any foods made with oil, fat, or butter?	1	2
k. Any sugar or honey?	1	2
I. Any other foods, such as condiments, coffee, tea?	1	2

33. In the past **TWO** weeks did it happen that there was no food to eat of any kind in your household because of lack of resources?

No	1
Rarely (1 – 2 times)	2
Sometimes (3 – 5 times)	3
Often (more than 5 times)	4
Don't know/refuse	9

#### SECTION F: OWNERSHIP

34. Does your household have any of the following?

	Yes	No
a. Radio	1	2
b. Hi-fi/music stereo	1	2
c. Television	1	2
d. DVD/VHS player	1	2
c. Cell phone	1	2
f. Telephone in the house	1	2
g. Iron	1	2
h. Fan	1	2
i. Heater	1	2
j. Air conditioner	1	2
k. Stove with gas/electric	1	2
I. Stove with paraffin	1	2
m. Table and chairs	1	2

	Yes	No
n. Refrigerator	1	2
o. Microwave	1	2
p. Electricity	1	2
q. Solar energy system	1	2
r. Electrical generator	1	2
s. Personal computer	1	2
t. Bicycle	1	2
u. Motorcycle	1	2
v. Private car	1	2
w. Bed(s)	1	2
x. Livestock (cattle etc.)	1	2
y. Washing machine	1	2
z. Satellite dish	1	2

#### 35. Which of the following best describes your dwelling? [Circle ONE only under each heading]

i. Main type of roof	
a. wood	1
b. corrugated iron sheets	2
c. grass/leaves thatch	3
d. tiles/shingles	4
e. paper/plastic	5
f. asbestos sheets	6
g. other(specify)	7

	-
g. other(specify)	7
iii. Main type of walls	
a. poles & mud	1
b. corrugated iron sheets	2
c. grass/leaves	3
d. bricks (burnt or sun-dried)	4
e. compacted earth (mdindo)	5
f. concrete	6
g. other(specify)	7

ii. Main type of floor	
a. mud	1
b. concrete/cement	2
c. wood	3
d. other(specify)	4

## 36. How many bedrooms does your main dwelling have?

(enter number of bedrooms)

#### **37.** Does your household <u>have</u> and <u>use</u> mosquito nets? [Circle ONE only]

YES, all beds	1
Yes, some beds	2
No	3
Don't know/refuse	9

#### **38. Which of the following applies to your housing situation?** [Circle ONE only]

Housing situation	
a. Rented	1
b. Owned	2
d. Rent Free (not owned)	3
e. Provided by employer (government)	4
f. Provided by employer (private)	5
g. Other(specify)	6

39. What is the MAIN source of drinking water in your household at present? [Circle ONE only]

Source of water:	
a. Piped water inside	1
b. Piped water outdoors, on property	2
c. Piped water outside the property	3
d. Public pipe/tap	4
e. Borehole	5
f. Protected well	6
g. Unprotected well	7
h. River/ stream/dam/spring/lake	8
i. Rain-water tank	9
j. Water carrier/tanker	10
k. Other(specify)	11
I. Don't know/refuse	99

40. What is the MAIN source of energy that your household uses for cooking and lighting?

[Circle ONE only]	
i. Source of energy for cooking	
a. Electricity	1
b. Paraffin	2
c. Gas	3
d. Wood	4
e. Coal/charcoal	5
f. Solar	6
i. Dung/grass/stalks	7
j. None	8
k. Other (specify)	9
I. Don't know/refuse	99

[Circle ONE only]

ii. Source of energy for lighting	
a. Electricity	1
b. Paraffin	2
c. Gas	3
d. Wood	4
e. Coal/charcoal	5
f. Solar	6
g. Candles	7
h. Torch	8
j. None	9
k. Other (specify)	10
I. Don't know/refuse	99

41. What kind of sanitation facility does your household mainly use?

a. Flush toilet	1
b. Traditional pit toilet	2
c. Ventilated improved pit toilet	3
d. No facility	4
e. Other(specify)	5
f. Don't know/refuse	9

#### SECTION G: TRANSPORT AND COMMUNICATION

#### 42. How long (in time) does it take to WALK ONE WAY to each of these facilities?

Service/Facility*	
a. Nearest school	
b. Nearest health facility	
c. Nearest market/shop	
d. Nearest sports facility	
e. Post office	
f. Police station	
g. Church/Mosque/Temple	

#### \*Coding:

•

- 1 = Facility not available within walking distance
- 2 = 5 minutes or less
- 3 = 6 15 minutes
- 4 = 16 30 minutes
- 5 = 31 60 minutes
- 6 = more than 60 minutes
- 9 = Don't know/ Not available (NA)

#### 43. What is the MAIN MODE of transport that household members use when visiting each of these facilities?

Service/Facility*	
a. Nearest school	
b. Nearest health facility	
c. Nearest market/shop	
d. Nearest sports facility	
e. Post office	
f. Police station	
g. Church/Mosque/Temple	

*Coding:	
1 = Walk/Wheelchair 2 = Bicycle 3 = Motor bike 4 = Bus	7 = Own car 8 = Company car 9 = Hike lift (car) 10 = Cart
5 = Taxi	11 = Other
6 = Boat	99 = Don't know / NA

#### 44. How available and affordable are the following services to your household?

Service	Availability**	Afford	Affordability		Affordability		**Coding:		
a. Telephone/mobile phone		YES	NO		1 = Own/use regularly*				
		1	2		2 = Have access to				
b. Radio		1	1 2		1 2		1 2		3 = Have no use for
		-	-		4 = Have no access to				
c. Television (TV)		1	2		9 = Don't know/refuse				
d. Internet (including Internet Café)		1	2						
e. Newspaper (*purchase regularly)		1	2						
f. Library (*use regularly)		1	2						

#### **SECTION H: OTHER INFORMATION**

#### 45. Has any household member passed away within the past twelve months? (Circle only one)

Yes	1	
No	2	→ Finish the question
Don't know/refuse	9	→ Finish the question

#### If NO or DON'T KNOW, Go To END – finished with Household Living Conditions Survey

#### 46. If YES, could you please tell me:

	What was deceased	Was the	How old was she/he at	Could you tell me what	Was that person
	person's position in the	deceased person	the time of death?	she/he died of?	disabled?
	household?	female or male?		01 Accident (Car or other)	
			Enter age in completed	02 Violence/Murder	1 Yes
	0 Head	1 Male	years	03 Cancer	2 No
	1 Spouse	2 Female		04 TB	9 Don't know
	2 Son/Daughter of		99 Don't know	05 Malaria	
	head/spouse	(Enter one code)		06 Diarrhoea	(Enter one code)
	3 Spouse of child			07 Malnutrition	
	4 Grandchild of			08 Measles	
	head/spouse			09 Pneumonia	
	5 Parent of			10 Heart disease	
	head/spouse			11 High blood pressure	
	6 Other relative			12 HIV/AIDS (related)	
	7 Domestic			13 Other disease	
	worker/non-relative			14 Old age	
	8 Other non-relatives			15 Witchcraft	
	9 Don't know			16 Suicide	
				99 Don't know	
	(Enter only one code)			(Enter only one code)	
(a)	(b)	(c)	(d)	(e)	(f)
Person 1					
Person 2					
Person 3					
Person 4					
Person 5					
Person 6					

END – Finished with Household Living Conditions Survey.

IF THIS IS A "CONTROL HOUSEHOLD", THANK THE PRIMARY RESPONDENT FOR THEIR TIME IN COMPLETEING THE QUESTIONNAIRE AND ASK TO SPEAK TO A PERSON (randomly selected) TO COMPLETE THE CONTROL QUESTIONANNAIRE.

IF THIS IS A HOUSEHOLD WITH A DISABLED FAMILY MEMBER – a circle in column 14A – , THANK THE PRIMARY RESPONDENT FOR THEIR TIME AND ASK TO SPEAK TO THAT PERSON IN ORDER TO COMPLETE THE DETAILED DISABILITY QUESTIONNAIRE.

Year of birth	Age						
2010	0	1984	26	1958	52	1932	78
2009	1	1983	27	1957	53	1931	79
2008	2	1982	28	1956	54	1930	80
2007	3	1981	29	1955	55	1929	81
2006	4	1980	30	1954	56	1928	82
2005	5	1979	31	1953	57	1927	83
2004	6	1978	32	1952	58	1926	84
2003	7	1977	33	1951	59	1925	85
2002	8	1976	34	1950	60	1924	86
2001	9	1975	35	1949	61	1923	87
2000	10	1974	36	1948	62	1922	88
1999	11	1973	37	1947	63	1921	89
1998	12	1972	38	1946	64	1920	90
1997	13	1971	39	1945	65	1919	91
1996	14	1970	40	1944	66	1918	92
1995	15	1969	41	1943	67	1917	93
1994	16	1968	42	1942	68	1916	94
1993	17	1967	43	1941	69	1915	95
1992	18	1966	44	1940	70	1904	96
1991	19	1965	45	1939	71	1903	97
1990	20	1964	46	1938	72	1902	98
1989	21	1963	47	1937	73	1901	99
1988	22	1962	48	1936	74	1900	100
1987	23	1961	49	1935	75	1899	101
1986	24	1960	50	1934	76	1898	102
1985	25	1959	51	1933	77	1897	103

Table 1: Conversion from Year of Birth to Age in Years

## DETAILED QUESTIONNAIRE FOR PEOPLE WITH DISABILITIES

Identification of person with disability	Code
NAME AND CODE OF REGION*	
EA number	
NAME OF VILLAGE/LOCALITY	
LOCATION 1 = urban 2 = rural	
HOUSEHOLD NUMBER/ID	
NAME OF HOUSEHOLD HEAD	
DETAIL OF PERSON WITH DISABILITY	
NAME	
AGE LINE NUMBER OF PERSON IN HOUSEHOLD LISTING	
IS THIS A FACE-TO-FACE INTERVIEW WITH THE PERSON WITH DISABILITY? [Do not read out. Code by observation]	
<ul> <li>1 = YES (i.e. interview directly with the person with disability)</li> <li>2 = NO (i.e. someone else is reporting on behalf of the person with disability)</li> <li>3 = BOTH (i.e. someone else is reporting together with the person with disability)</li> </ul>	
If NO or BOTH, who is the person reporting? Line number of person as proxy	
TO BE COMPLETED BY THE INTERVIEWER	Date of interview
Time started	Day
Name of interviewer:	Month
Comments:	Year 2 0 1 0
Signature	
SUPERVISOR Enumerator	46
Name : Name : Name :	
Signature Complete Incomplete Yes	No

*CODES FOR REGIONS	
1 = Hhohho	3 = Shiselweni
2 = Mazini	4 = Lubombo

#### ACITVITY LIMITATION

## 1. How difficult it is for you to perform this activity WITHOUT any kind of assistance at all?

[Without the use of any assistive devices – either technical or personal]

Read out the options

ACTIVITY LIMITAION ITEMS*	SCORE	Coding:
a. watching/looking/seeing		0 = No difficulty
b. listening/hearing		1 = Mild difficulty 2 = Moderate difficulty
a. learning to read/write/count/calculate		3 = Severe difficulty
b. acquiring skills (manipulating tools, painting, carving etc.)		4 = Unable to carry out the activity
c. thinking/concentrating		9 = Not specified /Not applicable
d. reading/writing/counting/calculating		
e. solving problems		
f. understanding others (spoken, written or sign language)		
g. producing messages (spoken, written or sign language)		
h. communicating directly with others		
i. staying in one body position		
j. changing a body position (sitting/standing/bending/lying)		
k. transferring oneself (moving from one surface to another)		
I. lifting/carrying/moving/handling objects		
m. fine hand use (picking up/grasping/manipulating/releasing)		
n. hand & arm use (pulling/pushing/reaching/throwing/catching)		
o. walking		
p. moving around (crawling/climbing/running/jumping)		

#### PARTICIPATION RESTRICTION

#### 2. Do you have any difficulty performing this activity in your current environment?

[Current environment where you live, work and play etc for the majority of your time, and with the use of any assistive devices, either technical or personal]

#### Read out the options

PARTICIPATION RESTRICTION ITEMS*	SCORE
a. washing oneself	
b. care of body parts, teeth, nails and hair	
c. toileting	
d. dressing and undressing	
e. eating and drinking	
f. shopping (getting goods and services)	
g. preparing meals (cooking)	
h. doing housework (washing/cleaning)	
i. taking care of personal objects (mending/repairing)	
j. taking care of others	
k. making friends and maintaining friendships	
I. interacting with persons in authority (officials, village chiefs)	
m. interacting with strangers	
n. creating and maintaining family relationships	
o. making and maintaining intimate relationships	
p. going to school and studying (education)	
q. getting and keeping a job (work & employment)	
r. handling income and payments (economic life)	
s. clubs/organisations (community life)	
t. recreation/leisure (sports/play/crafts/hobbies/arts/culture)	
w. religious/spiritual activities	
x. political life and citizenship	

## Coding:

- 0 = No problem
- 1 = Mild problem
- 2 = Moderate problem

3 = Severe problem

- 4 = Complete problem
  - (unable to perform)
- 9 = Not specified /Not applicable

#### **INVENTORY OF ENVIRONMENTAL FACTORS**

3. Being an active, productive member of society includes participating in such things as working, going to school, taking care of your home, and being involved with family and friends in social, recreational and civic activities in the community. Many factors can help or improve a person's participation in these activities while other factors can act as barriers and limit participation.

First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem **daily**, **weekly, monthly, less than monthly, or never.** If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you.

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

### Please CIRCLE only one.

a. In the past 12 months,	1. Daily	2. Weekly	3. Monthly	4. Less than monthly	5. Never	9. Not applicable	2. Big problem	1.Little problem
how often has the availability/accessibility of transportation been a problem for you?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
b. In the past 12 months, how often has the natural environment –								
temperature, terrain, climate – made it difficult to do what you want or need to do?	1	2	3	4	5	9		
		this pro m or a l		ccurs has oblem?	it been a	a big	1	2
c. In the past 12 months, how often have other aspects of your surroundings								
<ul> <li>lighting, noise, crowds, etc – made it difficult to do what you want or need to do?</li> </ul>	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
d. In the past 12 months, how often has the information you wanted or								
needed not been available in a format you can use or understand?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
e. In the past 12 months, how often has the availability of health care services								
and medical care been a problem for you?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2

	1. Daily	2. Weekly	3. Monthly	4. Less than monthly	5. Never	9. Not applicable	2. Big problem	1.Little problem
f. In the past 12 months, how often did you need someone else's help in your				T	T			
home and could not get it easily?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
g. In the past 12 months, how often did you need someone else's help at		-		-	-			
school or work and could not get it easily?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
h. In the past 12 months,		1	1	1				
how often have other people's attitudes toward you been a problem at home?	1	2	3	4	5	9		
	When this problem occurs has it been a big problem or a little problem?				a big	1	2	
i. In the past 12 months,						-		
how often have other people's attitudes toward you been a problem at school or work?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
j. In the past 12 months,								
how often did you experience prejudice or discrimination?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
k. In the past 12 months, how often did the policies and rules of businesses								
and organizations make problems for you?	1	2	3	4	5	9		
		this pro em or a l		ccurs has	it been a	a big	1	2
I. In the past 12 months,	p10010							<u> </u>
how often did government programs and policies								
make it difficult to do what you want or need to do?	1	2	3	4	5	9		
		•		ccurs has	it been a	a big	1	2
	proble	em or a l	ittle pro	oblem?				

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

		No	Some	A lot	Unable
а	Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
b	Do you have difficulty hearing, even if using a hearing aid?	1	2	3	4
с	Do you have difficulty walking or climbing steps?	1	2	3	4
d	Do you have difficulty remembering or concentrating?	1	2	3	4
e	Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4
f	Using your usual (customary) language, do you have difficulty communicating for example understanding or being understood?	1	2	3	4

## (INSTRUCTION TO THE NUMERATOR): [Don't read the control question out loud]

5. Based on the responses in Q.4, where will you categorize the respondent?				
a. Did the person answer "A LOT" or "UNABLE" in ONE of the questions	1			
b. Did the person answer "SOME" difficulty in TWO or more questions	2			
c. None of the above	3	→ STOP		

## 6. What is the cause of your difficulties doing the activities (disability)?

a. From birth/congenital	01
b. Accident	02
c. Fall	03
d. Burns	04
e. Disease/illness	05
f. Beaten by member in the family	06
g. Violence outside the house	07
h. War related	08
i. Animal related	09
i. Animal related j. Stress related	09 10
j. Stress related	10

#### 7. How old were you when it started?

years old	00 = From birth 99 = Don't know/refuse
-----------	---

#### 8. Have you ever been beaten or scolded because of your disability?

Yes	1
No	2
Don't know	9

9. Have you ever been beaten or scolded by any family member or relatives because of your disability?

Yes	1
No	2
Don't know	9

## 10. Have you ever experienced being discriminated in any public services? For example: hospital, clinic, police station, bank etc.

Yes	1
No	2
Don't know	9

#### 11. Do you have any of the following health conditions?

	Yes	No
a.Asthma/breathing problem	1	2
b. Arthritis/rheumatism	1	2
c. Back or neck problem	1	2
d. Fracture or bone/join injury	1	2
e. Heart problem	1	2
f. Stroke problem	1	2
g. Hypertension/high blood pressure	1	2
h. Kidney, bladder or renal problem	1	2

	Yes	No
i. Diabetes	1	2
j. Cancer	1	2
k. Mental retardation	1	2
l. Developmental problem	1	2
m. Depression/anxiety/emotional problem	1	2
n. Missing limbs, amputee	1	2
o. Neurological disorder such as Multiple sclerosis (MS) or Muscular Dystrophy (MD)	1	2

#### 12. Have you ever lived in an institution or special home for people with disabilities?

Yes	1
No	2
Don't know	9

#### 13. Which services, if any, are you *aware* of and have ever *needed/received*?

[Read out; Enter the appropriate code for each column of each row]

	Needed	Aware of	Received
	service	service	service
	1=Yes	1=Yes	1=Yes
	2=No	2=No	2=No
	(1)	(2)	(3)
a. Medical rehabilitation (e.g. physiotherapy, occupational			
therapy, speech and hearing therapy etc)			
<b>b. Assistive devices service</b> (e.g. Sign language interpreter,			
wheelchair, hearing/visual aids, Braille etc.)			
c. Educational services (e.g. remedial therapist, special school,			
early childhood stimulation, regular schooling, etc.)			
d. Vocational training (e.g. employment skills training, etc)			
e. Counselling for person with disability (e.g. psychologist,			
psychiatrist, social worker, school counsellor etc)			
f. Counselling for parent/family			
g. Welfare services (e.g. social worker, disability grant, etc)			
h. Health services (e.g. at a primary health care clinic, hospital,			
home health care services etc.)			
i. Health information (e.g. from media, at schools, clinics,			
hospital etc.)			
j. Traditional healer/faith healer			
k. Legal advice			

#### If no services received, i.e. all 2 ="No" for column (3) above, then go to Section D (Education)

## 14. What can you characterised of the services you have received or still receiving?

[code only ONE main characteristic per service]

SERVICES*	Code
a. Medical rehabilitation	
b. Assistive devices service	
c. Educational services	
d. Vocational training	
e. Counselling for person with disability	
f. Counselling for parent/family	
g. Welfare services	
h. Health services	
i. Health information	
j. Traditional healer/faith healer	
k. Legal advice	

*Coding
---------

- 1 = Satisfy with the service
- 2 = It is very helpful
- 3 = It is too expensive
- 4 = Has communication/language barriers
- 5 = Not really helping me
- 6 = Discriminating
- 7 = Other
- 9 = Don't know/refuse/never receive

## 15. Think of ALL services you have received, if you are no longer getting the service, why did you stop?

[code only ONE main reason for stopping]

SERVICES*	Code
a. Medical rehabilitation	
b. Assistive devices service	
c. Educational services	
d. Vocational training	
e. Counselling for person with disability	
f. Counselling for parent/family	
g. Welfare services	
h. Health services	
i. Health information	
j. Traditional healer/faith healer	
k. Legal advice	

*Coding	
---------	--

- 1 = Not satisfied with services
- 2 = It is too expensive
- 3 = Too far or has no transport
- 4 = Not really helping me
- 5 = No longer available
- 6 = Has communication/language barriers
- 7 = Other
- 9 = Don't know/refuse/never receive

## **EDUCATION**

CHECK PAGE 1 – AGE OF PERSON WITH DISABILITY – AND ASK ONLY PEOPLE WHO ARE 15 YEARS OR OLDER.

### **CONTROL QUESTION**

Is the person 15 years of age or older?

Yes	1	
No	2	→ Q.24

#### 16. Have you received a formal primary education?

Yes	1	
No	2	→ Q.21
Don't know/Don't remember	9	

#### 17. Has your level of education helped you find any work at all?

[Do not read out; Circle only **one** answer]

Yes	1
No	2
Don't know	9

# **18.** What type of school do or did you *mainly* attend in pre-school, primary, secondary or tertiary school? [Do not read out; Circle only **one** answer for each line]

	Mainstream/ Regular school	Special school	Special class in mainstream/ regular school	Did not go to school or N/A
Pre-school/early childhood development services	1	2	3	4
Primary school	1	2	3	4
Secondary school	1	2	3	4
Tertiary education	1	2	3	4
Vocational training	1	2	3	4

## 19. Have you ever been refused entry into a school, pre-school or university because of your disability?

[Circle only **one** answer for each line]

	Yes	No	Not applicable
Regular pre-school	1	2	3
Regular primary school	1	2	3
Regular secondary school	1	2	3
Special school (any level)	1	2	3
Special class (remedial)	1	2	3
University	1	2	3

## 20. Did you study as far as you planned?

[Do not read out; Circle only one answer]

Yes	1	
No	2	
Still studying	3	→ Q.24
Don't know	9	

# 21. If you have NOT received a formal primary education, have you ever attended classes to learn to read and write as an adult?

[This question is only asked if the respondent answer "NO" in Q.16]

Yes	1
No	2
Don't know/Don't remember	9

#### **EMPLOYMENT AND INCOME**

#### ASK ALL PERSONS WITH DISABILITIES 15 YEARS OF AGE OR OLDER.

**22a.** Are you currently working? (include casual labourers, part-time work and those who are self-employed). Circle only **one** answer.

Yes, currently working	1	
No, but have been employed previously	2	
No, never been employed	3	→ Q.24
I am a housewife/homemaker	4	▶ Q.24

#### 22b. What is your income per. month from your job (if previously employed than from previous job)?

0 – 300	1
301 – 500	2
501 – 1 000	3
1 001 – 2 000	4
2 001 – 3 000	5
3 001 – 5 000	6
More than 5 000	7

#### 23. If you are currently unemployed, why did you stop working?

To be answered ONLY if Q.22a is "have been employed previously". Circle only one answer.

Retired	1
Retrenched (due to cut backs)	2
Fired	3
Injury/accident at work	4

Illness	5
Because of disability	6
Other	7
Don't know	9

#### 24. Are you currently receiving social security, a disability grant or any other form of pension/grant?

Yes	1	
No	2	→ Q.28
Don't know	9	→ Q.28

#### 25. What type of grant or pension do you receive?

[Do not read out; circle **ALL** that apply]

Type of grant or pension	Code
a. Disability grant	1
b. Social Security	2
c. Workman's Compensation	3
d. Private insurance/pension	4
e. Old age pension	5
f. Old age grant	6
g. Other (specify)	7
h. Don't know	9

**26.** What are the TWO MAIN THINGS that the money from your disability grant or pension is spent on? [*Do not read out; circle only ONE in Choice A and ONE in Choice B* answers]

Item	Choice A	Choice B
a. Household necessities i.e. food, groceries etc.	01	01
b. Clothing	02	02
c. Rent/accommodation	03	03
d. Recreation/entertainment	04	04
e. Transport	05	05
f. Education	06	06
g. Water and electricity	07	07
h. Rehabilitation and health care services	08	08
i. Assistive devices	09	09
j. Personal assistant/carer (care for self)	10	10
k. Other (specify)	11	11
I. Don't know	99	99

#### 27. Are you the one who mainly decides how to spend your disability grant or pension?

Yes	1
No	2
Don't know	9

YOUR SURROUNDINGS AND HOW EASY IT IS FOR YOU TO GET AROUND. IF YOU USE ONE OR MORE ASSISTIVE DEVICES OR SOMEONE IS HELPING YOU, ANSWER AS IF YOU ARE USING THEM.

ASK BOTH DIRECT & PROXY REPORTERS. PLEASE REMEMBER THE INFORMATION MUST BE ABOUT THE PERSON WITH DISABILITY.

# 28. Let's look at your home first. Are the rooms and toilet accessible? By accessible we mean that you can get there <u>easily</u> and use the facility most of the time.

[Read out; Circle only **ONE** answer for each line]

Home	YES (accessible)	NO (not accessible)	Have none
a. Kitchen	1	2	3
b. Bedroom	1	2	3
c. Living room	1	2	3
d. Dining room	1	2	3
e. Toilet	1	2	3

29. Now let's look at various places you might go to. Think of getting in and out of the places, and tell me for each place whether it is generally accessible to you or not. [*Read out; Circle only one answer for each line*]

Place	YES	NO	Not available/
	(Accessible)	(Not accessible)	Not applicable
a. The place where you work	1	2	3
b. The school you attend	1	2	3
c. The shops that you go to most often	1	2	3
d. Place of worship	1	2	3
e. Recreational facilities (e.g. cinema,			
theatre, pubs, etc) – think of the last three	1	2	3
months			
f. Sports facilities	1	2	3
g. Police station	1	2	3
h. Magistrates office/Traditional courts	1	2	3
i. Post office	1	2	3
j. Bank	1	2	3
k. Hospital	1	2	3
I. Primary Health Care Clinic	1	2	3
m. Public transportation (bus, taxi, train)	1	2	3
n. Hotels	1	2	3

#### ASSITIVE DEVICES:

ASK BOTH DIRECT & PROXY RESPONDENTS: PLEASE REMEMBER THE INFORMATION MUST BE ABOUT THE PERSON WITH DISABILITY

## **30a.** Do you use any medication or traditional medicine for pain that is caused by your disability?

Yes	1	
No	2	→ Q.31

#### 30b. If YES, what type of medication?

Modern	1
Traditional	2
Both	3

**31.** Do you use an assistive device? [For examples, see Q.32 below]

Yes	1	
No	2	→ Q.37

#### 32. Please specify which assistive devices you use.

[Read out; Circle one answer for each row]

Device	Device category	Examples:	Yes	No	Not applicable (don't need it)
1	Information	eye glasses, hearing aids, magnifying glass, telescopic lenses/glasses, enlarge print, Braille	1	2	3
2	Communication	sign language interpreter, fax, portable writer, computer	1	2	3
3	Personal mobility	wheelchairs, crutches, walking sticks, white cane, guide, standing frame	1	2	3
4	Household items	Flashing light on doorbell, amplified telephone, vibrating alarm clock	1	2	3
5	Personal care & protection	special fasteners, bath & shower seats, toilet seat raiser, commode chairs, safety rails, eating aids	1	2	3
6	For handling products & goods	gripping tongs, aids for opening containers, tools for gardening	1	2	3
7	Computer assistive technology	keyboard for the blind	1	2	3
8	Other devices	(specify)	1	2	3

### 33. Is the assistive device(s) mentioned above in good working condition/order?

[If more than one device in one category, choose **most important** device - List device by **name**]

Name of Device:	Good working condition?	CODING
а.		1 = Yes
b.		2 = No
С.		9 = Don't know

#### 34. Where did you get the assistive device(s)?

[Read out; Record only **one** answer for each line]

[If more than one device in one category, choose **most important** device - List device by **name**]

Name of Device:	Where did you get the device?*		
a.			
b.			
С.			

*CODING
1 = Private
2 = Government health service
3 = Other government service (not health)
4 = NGO
5 = Other
9 = Don't know

## 35. Who, if any, maintains or repairs your assistive device(s)?

[Do not read out: record only **one** answer for each line]

[If more than one device in one category, choose most important device - List device by name]

Name of Device:	Maintenance /Repair
a.	
b.	
С.	

CODING
1 = Self
2 = Government
3 = Family
4 = Employer
5 = NGO
6 = Other
7 = Not maintained
8 = Cannot afford to maintain
or repair it
9 = Don't know

#### 36a. Were you given any information or help/training on how to use your device(s)?

Name of Device:	Information or help
а.	
b.	
С.	

CODING
1 = Complete/full information
2 = Some information
3 = No information
9 = Don't know/ Can't
remember

36b. Think of the MAIN assistive device you are using – on a scale from 1 (not content) to 4 (very content) – How would you describe your level of content/satisfaction with the device that it meets your needs?

1	2	3	4	9
not content	less content	content	very content	don't know

#### HOW YOU FEEL AND WHAT YOU THINK ABOUT BEING A PERSON WITH A DISABILITY.

LET'S START WITH YOUR ROLE WITHIN THE HOUSEHOLD AND YOUR FAMILY.

ASK BOTH DIRECT & PROXY RESPONDENTS: PLEASE REMEMBER THE INFORMATION MUST BE ABOUT THE PERSON WITH DISABILITY.

37. Which of the following, if any, do people in the household or family help you with?

[Read out; Circle **one** answer for each row]

[NB: Do not include assistance provided by person paid to care for the person or things you would not normally do because of your age or your culture]

	Yes	Some times	No	Not applicable or not necessary
a. Dressing	1	2	3	4
b. Toileting	1	2	3	4
c. Bathing	1	2	3	4
d. Eating/Feeding	1	2	3	4
e. Cooking	1	2	3	4
f. Shopping	1	2	3	4
g. Moving around	1	2	3	4
h. Finances	1	2	3	4
i. Transport	1	2	3	4
j. Studying	1	2	3	4
k. Emotional support	1	2	3	4
I. Other(specify)	1	2	3	4

# 38. I'm going to ask you some questions about your involvement in different aspects of family, social life and society. Please listen to each one and answer yes, no, sometimes or not applicable.

[Read out and circle **one** answer for each row]

		Yes	No	Sometimes	Not applicable	Don't know
a. Are you consulted about making household decisions?		1	2	3	4	9
-	ou go with the family to events such as atherings, social events etc.	1	2	3	4	9
-	ou feel involved and part of the old or family?	1	2	3	4	9
d. Does	the family involve you in conversations?	1	2	3	4	9
	the family help you with daily s/tasks?	1	2	3	4	9
	IF YES (1) or SOMETIMES (3)					
	Do you appreciate it or like the fact that you get this help?	1	2	3	4	9
g. Do/did you take part in your own traditional practices (e.g. initiation ceremonies)		1	2	3	4	9
h. Are you aware of Organisations for people with disabilities (DPO)?		1	2	3	4	9
i. Are you a member of a DPO?		1	2	3	4	9
j. Do you participate in local community meeting?		1	2	3	4	9
	IF YES (1) or SOMETIMES (3)		1			
	Do you feel your voice is being heard	1	2	3	4	9
k. Did you vote in the last election?		1	2	3	4	9
L	IF NO (2)		1	1	1	1
	Was it related to your disability that you didn't vote?	1	2	3	4	9

- ONLY ASK DISABLED RESPONDENTS WHO ARE <u>15 YEARS OF AGE OR OLDER</u> AND REPORTING FOR THEMSELVES.
- IF THE RESPONDENT IS A PROXY REPORTER FOR A PERSON WITH DISABILITY 15 YEARS OR OLDER, THEN ASK THEM TO ANSWER ABOUT THE PERSON WITH DISABILITY.
- IF PERSON WITH DISABILITY IS YOUNGER THAN 15 YEARS THEN GO TO SECTION 9

#### (INSTRUCTION TO THE NUMERATOR):

[Don't read the control question out loud]

#### **CONTROL QUESTION**

#### 39. Is the person 15 years of age or older?

Yes	1	
No	2	→ Q.45

#### 40. Do you make important decisions about your own life?

[Read out; circle only one answer]

All the time	1
Sometimes	2
Never	3
Don't know	9

#### 41. Are you married or involved in a relationship?

Yes	1	→ Q.42
No	2	→ Q.43
Don't know	9	→ Q.43

#### 42. Does your spouse/partner have a disability?

Yes	1
No	2
Don't know	9

#### 43. Do you have children?

Yes	1	<b>→</b> Q.44
No	2	<b>→</b> Q.45

#### 44. If Yes, how many?



#### **HEALTH AND GENEARAL WELL-BEING**

#### 45. I would like to ask you how your health has been in general, over the past few weeks

For the past few weeks have you .....

	1	2	3	4
1. Been able to concentrate on what you're doing	Better than usual	Same as usual	Less than usual	Much less than usual
2. Lost much sleep over worry	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Felt you were playing a useful part in things	More so than usual	Same as usual	Less so than usual	Much less than usual
4. Felt capable of making decisions about things	More so than usual	Same as usual	Less so than usual	Much less than usual
5. Felt constantly under strain	Not at all	No more than usual	Rather more than usual	Much more than usual
6. Felt you couldn't overcome your difficulties	Not at all	No more than usual	Rather more than usual	Much more than usual
7. Been able to enjoy your normal day-to-day activities	More so than usual	Same as usual	Less so than usual	Much less than usual
8. Been able to face up to your problems	More so than usual	Same as usual	Less so than usual	Much less than usual
9. Been feeling unhappy and depressed	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Been losing confidence in yourself	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been thinking of yourself as a worthless person	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Been feeling reasonably happy, all things considered	More so than usual	Same as usual	Less so than usual	Much less than usual

46. Thinking about your general <u>physical health</u> (things like: sickness, illness, injury, disease etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall physical health today?

1	2	3	4	9
poor	not very good	good	very good	don't know

47. Thinking about your general <u>mental health</u> (things like: anxiety, depression, fear, fatigue, tiredness, hopelessness etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall mental health today?

1	2	3	4	9
poor	not very good	good	very good	don't know

48. We would like to know about your understanding of some common diseases and whether you have access to information about them.

	Do you have any	Where did you get	Did you experience	Have you ever had
	knowledge about	most of the	any problems in	this disease?
	-			this disease?
	[NAME OF DISEASE]?	information about	obtaining/	
		this disease	understanding	
		from?**	information about	1 = Yes
	1 = Yes		this disease?*	2 = No
	2 = No → Finish			3 = Don't know
	3 = Don't know→ Finish		1 = Yes	
			2 = No	
			3 = Don't know	
	(a)	(b)	(c)	(d)
HIV/AIDS				
Malaria				
ТВ				
Diabetes				

### \*\*CODES

- 1 = Health Clinic
- 2 = Doctor
- 3 = At work
- 4 = Magazines/Newspapers
- 5 = From friends
- 6 = From Family
- 7 = Radio/TV
- 8 = Poster and pamphlets
- 9 = School
- 10 = Other
- 99 = Don't know

END – Finished with the questionnaire.

THANK THE RESPONDENT FOR THEIR TIME AND WILLINGNESS TO PARTICIPATE IN THE STUDY.

## QUESTIONNAIRE FOR PEOPLE WITHOUT DISABILITIES

Identification of pers	son as control			Code
NAME AND CODE OF REGION*				
EA number NAME OF VILLAGE/LOCALITY				
LOCATION 1 = urban 2 = rura				
DETAIL OF PERSON AS CONTROL				
AGE LINE NUMBER OF PERSON		 T]		
			Data of	interview
			Date of	
Time started Time cor	mpleted		Day	
Name of interviewer: Comments:			Month	
comments.			Year	2 0 1 0
Signature				
SUPERVISOR           Name :	INTERVIEW STATUS	Enumerator return to househo	the	CHECKED by the Supervisor
Signature	Complete Incomplete	Yes	No	

*CODES FOR REGIONS	
1 = Hhohho	3 = Shiselweni
2 = Mazini	4 = Lubombo

#### **ACITVITY LIMITATION**

## 1. How difficult it is for you to perform this activity WITHOUT any kind of assistance at all?

[Without the use of any assistive devices – either technical or personal]

Read out the options

ACTIVITY LIMITAION ITEMS*	SCORE	Coding:
a. watching/looking/seeing		0 = No difficulty
b. listening/hearing		1 = Mild difficulty 2 = Moderate difficulty
a. learning to read/write/count/calculate		3 = Severe difficulty
b. acquiring skills (manipulating tools, painting, carving etc.)		4 = Unable to carry out the activity
c. thinking/concentrating		9 = Not specified /Not applicable
d. reading/writing/counting/calculating		
e. solving problems		
f. understanding others (spoken, written or sign language)		
g. producing messages (spoken, written or sign language)		
h. communicating directly with others		
i. staying in one body position		
j. changing a body position (sitting/standing/bending/lying)		
k. transferring oneself (moving from one surface to another)		
I. lifting/carrying/moving/handling objects		
m. fine hand use (picking up/grasping/manipulating/releasing)		
n. hand & arm use (pulling/pushing/reaching/throwing/catching)		
o. walking		
p. moving around (crawling/climbing/running/jumping)		

#### PARTICIPATION RESTRICTION

#### 2. Do you have any difficulty performing this activity in your current environment?

[Current environment where you live, work and play etc for the majority of your time, and with the use of any assistive devices, either technical or personal]

#### Read out the options

PARTICIPATION RESTRICTION ITEMS*	SCORE
a. washing oneself	
b. care of body parts, teeth, nails and hair	
c. toileting	
d. dressing and undressing	
e. eating and drinking	
f. shopping (getting goods and services)	
g. preparing meals (cooking)	
h. doing housework (washing/cleaning)	
i. taking care of personal objects (mending/repairing)	
j. taking care of others	
k. making friends and maintaining friendships	
I. interacting with persons in authority (officials, village chiefs)	
m. interacting with strangers	
n. creating and maintaining family relationships	
o. making and maintaining intimate relationships	
p. going to school and studying (education)	
q. getting and keeping a job (work & employment)	
r. handling income and payments (economic life)	
s. clubs/organisations (community life)	
t. recreation/leisure (sports/play/crafts/hobbies/arts/culture)	
w. religious/spiritual activities	
x. political life and citizenship	

## Coding:

- 0 = No problem
- 1 = Mild problem
- 2 = Moderate problem

3 = Severe problem

- 4 = Complete problem
- (unable to perform)
- 9 = Not specified /Not applicable

#### 3. Inventory of Environmental Factors

Being an active, productive member of society includes participating in such things as working, going to school, taking care of your home, and being involved with family and friends in social, recreational and civic activities in the community. Many factors can help or improve a person's participation in these activities while other factors can act as barriers and limit participation.

First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list below has been a problem **daily**, **weekly, monthly, less than monthly, or never.** If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you.

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

a. In the past 12 months,	1. Daily	2. Weekly	3. Monthly	4. Less than monthly	5. Never	9. Not applicable	2. Big problem	1.Little problem
how often has the availability/accessibility of transportation been a problem for you?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
b. In the past 12 months, how often has the natural environment –								
temperature, terrain, climate – made it difficult to do what you want or need to do?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
c. In the past 12 months, how often have other aspects of your surroundings								
<ul> <li>lighting, noise, crowds, etc – made it difficult to do what you want or need to do?</li> </ul>	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
d. In the past 12 months, how often has the information you wanted or								
needed not been available in a format you can use or understand?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
e. In the past 12 months, how often has the availability of health care services								
and medical care been a problem for you?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2

	1. Daily	2. Weekly	3. Monthly	4. Less than monthly	5. Never	9. Not applicable	2. Big problem	1.Little problem
f. In the past 12 months, how often did you need someone else's help in your				T	T			
home and could not get it easily?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
g. In the past 12 months, how often did you need someone else's help at		-		-	-			
school or work and could not get it easily?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
h. In the past 12 months,		1	1	1				
how often have other people's attitudes toward you been a problem at home?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
i. In the past 12 months,						-		
how often have other people's attitudes toward you been a problem at school or work?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
j. In the past 12 months,								
how often did you experience prejudice or discrimination?	1	2	3	4	5	9		
		this pro em or a l		ccurs has oblem?	it been a	a big	1	2
k. In the past 12 months, how often did the policies and rules of businesses								
and organizations make problems for you?	1	2	3	4	5	9		
		this pro em or a l		ccurs has	it been a	a big	1	2
I. In the past 12 months,	p10010							<u> </u>
how often did government programs and policies								
make it difficult to do what you want or need to do?	1	2	3	4	5	9		
	When this problem occurs has it been a big		a big	1	2			
	proble	em or a l	ittle pro	oblem?				

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

		No	Some	A lot	Unable
а	Do you have difficulty seeing, even if wearing glasses?	1	2	3	4
b	Do you have difficulty hearing, even if using a hearing aid?	1	2	3	4
с	Do you have difficulty walking or climbing steps?	1	2	3	4
d	Do you have difficulty remembering or concentrating?	1	2	3	4
e	Do you have difficulty with self-care such as washing all over or dressing?	1	2	3	4
f	Using your usual (customary) language, do you have difficulty communicating for example understanding or being understood?	1	2	3	4

### 5. Do you have any of the following health conditions?

	Yes	No
a. Asthma/breathing problem	1	2
b. Arthritis/rheumatism	1	2
c. Back or neck problem	1	2
d. Fracture or bone/join injury	1	2
e. Heart problem	1	2
f. Stroke problem	1	2
g. Hypertension/high blood pressure	1	2
h. Kidney, bladder or renal problem	1	2

	Yes	No
i. Diabetes	1	2
j. Cancer	1	2
k. Mental retardation	1	2
l. Developmental problem	1	2
m. Depression/anxiety/emotional problem	1	2
n. Missing limbs, amputee	1	2
o. Neurological disorder such as Multiple sclerosis (MS) or Muscular Dystrophy (MD)	1	2

## EDUCATION CHECK PAGE 1 –ASK ONLY PEOPLE WHO ARE <u>15 YEARS OR OLDER</u>.

**CONTROL QUESTION:** [Don't read the control question out loud] 6. Is the person 15 years of age or older?

Yes	1	
No	2	→ Q.14

### 7. Have you received a formal primary education?

Yes	1	<b>→</b> Q.9
No	2	
Don't know/Don't remember	9	→ Q.11

8. If you have NOT received a formal primary education, have you ever attended classes to learn to read and write as an adult?

Yes	1	
No	2	→ Q.11
Don't know/Don't remember	9	

#### 9. Did you study as far as you planned?

[Do not read out; Circle only **one** answer]

Yes	1	
No	2	
Still studying	3	► Q.14
Don't know	9	

#### 10. Has your level of education helped you find any work at all?

[Do not read out; Circle only **one** answer]

Yes	1
No	2
Don't know	9

### EMPLOYMENT AND INCOME ASK ALL PERSONS <u>15 YEARS OF AGE OR OLDER</u>:

**11. Are you currently working?** (includes casual labourers, part-time work and those who are self-employed). Circle only **one** answer.

Yes, currently working	1	
No, but have been employed previously	2	
No, never been employed	3	→ Q.14
I am a housewife/homemaker	4	► Q.14

#### 12. What is your income/month from your job (if previously employed than from previous job)?

0 – 300	1
301 – 500	2
501 – 1 000	3
1 001 – 2 000	4
2 001 - 3 000	5
3 001 – 5 000	6
More than 5 000	7

#### 13. If you are currently unemployed, why did you stop working?

[To be answered ONLY if Q.22a is "have been employed previously". Circle one answer only]

Retired	1
Retrenched (due to cut backs)	2
Fired	3
Injury/accident at work	4
Illness	5
Because of disability	6
Other (specify)	7
Not applicable (employed)	8
Don't know	9

## HOW YOU FEEL AND WHAT YOU THINK ABOUT YOUR SURROUNDING LET'S START WITH YOUR ROLE WITHIN THE HOUSEHOLD AND YOUR FAMILY.

14. I'm going to ask you some questions about your involvement in different aspects of family, social life and society. Please listen to each one and answer yes, no, sometimes or not applicable.

[Read out and circle **one** answer for each row]

	Yes	No	Sometimes	Not applicable	Don't know
a. Are you consulted about making household decisions?	1	2	3	4	5
b. Do you go with the family to events such as family gatherings, social events etc.	1	2	3	4	5
c. Do you feel involved and part of the household or family?		2	3	4	5
d. Does the family involve you in conversations?	1	2	3	4	5
g. Do/did you take part in your own traditional practices (e.g. initiation ceremonies)	1	2	3	4	5
j. Do you participate in local community meeting?	1	2	3	4	5
IF YES (1) or SOMETIMES (3)					
Do you feel your voice is being heard	1	2	3	4	5
k. Did you vote in the last election?		2	3	4	5

#### 15. Do you make important decisions about your own life?

[Read out; circle only **one** answer]

All the time	1
Sometimes	2
Never	3
Don't know	9

#### HEALTH AND GENEARAL WELL-BEING

#### 16. I would like to ask you how your health has been in general, over the past FOUR weeks

For the past four weeks have you .....

	1	2	3	4
1. Been able to concentrate on what you're doing	Better than usual	Same as usual	Less than usual	Much less than usual
2. Lost much sleep over worry	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Felt you were playing a useful part in things	More so than usual	Same as usual	Less so than usual	Much less than usual
4. Felt capable of making decisions about things	More so than usual	Same as usual	Less so than usual	Much less than usual
5. Felt constantly under strain	Not at all	No more than usual	Rather more than usual	Much more than usual
6. Felt you couldn't overcome your difficulties	Not at all	No more than usual	Rather more than usual	Much more than usual
7. Been able to enjoy your normal day-to-day activities	More so than usual	Same as usual	Less so than usual	Much less than usual
8. Been able to face up to your problems	More so than usual	Same as usual	Less so than usual	Much less than usual
9. Been feeling unhappy and depressed	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Been losing confidence in yourself	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been thinking of yourself as a worthless person	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Been feeling reasonably happy, all things considered	More so than usual	Same as usual	Less so than usual	Much less than usual

17. Thinking about your general <u>physical health</u> (things like: sickness, illness, injury, disease etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall physical health today?

1	2	3	4	9
poor	not very good	good	very good	don't know

18. Thinking about your general <u>mental health</u> (things like: anxiety, depression, fear, fatigue, tiredness, hopelessness etc.) – on a scale from 1 (poor) to 4 (very good) – How would you describe your overall mental health today?

1	2	3	4	9
poor	not very good	good	very good	don't know

19. We would like know about your understanding of some common diseases and whether you have access to information about them.

	Do you have any	Whore did you get	Did you ovnorionco	Have you over had
	Do you have any	Where did you get	Did you experience	Have you ever had
	knowledge about	most of the	any problems in	[NAME OF
	[NAME OF DISEASE]?	information about	obtaining/	DISEASE]?
		[NAME OF DISEASE]	understanding	
		from?**	information about	
			[NAME OF	
			DISEASE]?*	
	1 = Yes		1 = Yes	1 = Yes
	2 = No		2 = No	2 = No
	3 = Don't know→ Finish		3 = Don't know	3 = Don't know
	(a)	(b)	(c)	(d)
HIV/AIDS				
Malaria				
ТВ				
Diabetes				

#### \*\*CODES

- 1 = Health Clinic
- 2 = Doctor
- 3 = At work
- 4 = Magazines/Newspapers
- 5 = From friends
- 6 = From Family
- 7 = Radio/TV
- 8 = Poster and pamphlets
- 9 = School
- 10 = Other
- 99 = Don't know

END – Finished with the questionnaire.

THANK THE RESPONDENT FOR THEIR TIME IN COMPLETEING THE QUESTIONNAIRE.



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