

# **An Exploration of the Involvement of People with Disabilities in Poverty- Reduction Strategies in Malawi**

by  
Bonface Ophiyah Massah

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Supervisor: Dr Margaret Wazakili

Co-supervisor: Ms Gubela Mji

Faculty of Health Sciences

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**DECLARATION**

I, the undersigned, hereby declare that the work contained in this thesis is my original work, and that it has not been submitted in its entirety or in part to any other University for a degree, and that all the sources used have been acknowledged by references.

Name: BONFACE OPHIYAH MASSAH

Signed: 

Date: 14<sup>th</sup> February, 2011

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## **ABSTRACT**

The needs and rights of people with disabilities are often not adequately featured in national development strategies. Furthermore, their aspirations to participate in community activities are denied by socio-economic and cultural barriers in societies. Against this background, the aim of this study was to explore the involvement of people with disabilities in poverty-reduction strategies in Malawi. In particular, the study investigated the factors that promoted or hindered their participation in development strategies and showed how the contributions of people with disabilities were reflected in the Malawi Growth and Development Strategy (MGDS). This study could be a useful resource in bringing about an understanding of disability inclusion in the context of the MGDS in Malawi.

The study was conducted in three main cities of Malawi, namely; Blantyre, Lilongwe and Mzuzu. Qualitative research methods were used employing an exploratory study design. Data was collected using two data collection methods, namely; key informant interviews and focus group discussions. A purposive sample of 15 people was selected to participate in key informant interviews. Using these key informants, a snowballing technique was used to identify 30 respondents that participated in three focus group discussions, each comprising 10 participants. Interviews were conducted until saturation point was reached and no new information was elicited. Interviews were tape-recorded and transcribed verbatim. A thematic content analysis was conducted following a systematic process of coding data and grouping codes into categories from which themes were generated.

This study has shown that there was minimal participation of people with disabilities in consultation meetings of the MGDS formation process. Overall, the study found that people with disabilities have limited education and knowledge to effectively participate at policy-making level. The study also found that the process of including disability in all spheres of life is very slow because of societal stereotypes and negative attitudes towards disability. Although there are several disability legal frameworks, there is no Disability Act that is enforceable by law. Therefore, people with disabilities are not protected by law. This trend should be reversed to improve self-representation of people with disabilities throughout policy formation processes.

## **OPSOMMING**

Die behoeftes en regte van gestremde mense word dikwels nie voldoende ingesluit by nasionale ontwikkelingstrategieë nie. Meer nog, hierdie mense se strewe om deel te wees van aktiwiteite in die gemeenskap word deur sosio-ekonomiese en kulturele grense in gemeenskappe verhinder. In die lig hiervan is die doelwit van hierdie studie om die betrokkenheid van gestremde mense by armoedeverligtingstrategieë in Malawi te ondersoek. Dié studie fokus in die besonder op dié faktore wat gestremde mense se deelname aan ontwikkelingstrategieë bevorder of verhinder, en toon aan hoe die bydraes van gestremde mense in die Malawi Groei- en Ontwikkelingstrategie (MGOS) weerspieël word. Hierdie studie kan 'n nuttige instrument wees om begrip te vestig vir gestremde mense in die konteks van die MGOS.

Die studie is uitgevoer in drie hoofstede van Malawi, naamlik Blantyre, Lilongwe en Mzuzu. Kwalitatiewe navorsingsmetodes is met behulp van 'n proefstudieontwerp gebruik. Inligting is verkry deur twee data-insamelingsmetodes te gebruik, naamlik onderhoude met segspersone en fokusgroepbesprekings. 'n Doelgerigte steekproef van 15 mense is gekies om aan die onderhoude met die belangrikste segspersone deel te neem. Tydens hierdie onderhoude is 'n sneeubaltegniek gebruik om 30 respondentte te identifiseer, wat toe deelgeneem het aan 3 fokusgroepbesprekings wat elk uit 10 deelnemers bestaan het. Onderhoude is gevoer totdat 'n versadigingspunt bereik is en geen nuwe inligting ingewin kon word nie. Onderhoude is opgeneem en verbatim getranskribeer. 'n Tematiese inhoudsontleding is gedoen deur 'n sistematiese proses om inligting te kodeer en kodes in kategorieë te groepeer, waaruit temas dan geïdentifiseer is.

Hierdie studie toon aan dat gestremde mense minimaal betrokke was by konsultasievergaderings oor die MGOS se vormingsproses. Oor die algemeen het die studie gevind dat gestremde mense te min opleiding en kennis het om op beleidsvormende vlak doeltreffend te kan deelneem. Die studie het ook gevind dat die proses om gestremde mense by alle sfere van die lewe in te sluit, baie stadig verloop weens die samelewings se stereotipes en negatiewe ingesteldheid teenoor gestremde mense. Al is daar verskeie regsplanne vir gestremde mense in plek, is daar geen Wet

op On geskiktheid wat afgedwing kan word nie. Daarom word gestremde mense nie deur die wet beskerm nie. Hierdie neiging behoort omgekeer te word om selfverteenwoordiging van gestremde mense in al die beleidsvormingsprosesse te bevorder.

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## **LIST OF ACRONYMS**

ADD	Action on Disability and Development
APDM	Association of the Physically Disabled in Malawi.
CBO	Community-Based Organisation
CDOCS	Chikondi Disability and Orphan Care
CSO	Civil Society Organisation
CONGOMA	Council for Non-Governmental Organisation
DFID	Department for International Development
DDP	District Development Plan
DIWODE	Disabled Women in Development
DPO	Disabled People Organisation
ESAF	Enhanced Structural Adjustment Facility
ECPED	Economic Empowerment Centre for Persons with Disabilities.
EU	European Union
FEDOMA	Federation of Disability Organisations in Malawi
HAFOD	Harry Foundation for Development
HIPIC	Highly Indebted Poor Countries
HIV/AIDS	Human Immune Virus /Acquired Immunal Deficiency Syndrome
IMF	International Monetary Fund
MACOHA	Malawi Council for the Handicapped
MANAD	Malawi National Association of the Deaf
MADISA	Malawi Disability Sports Association
MEGS	Malawi Economic and Development Strategy
MGDS	Malawi Growth and Development Strategy
MUB	Malawi Union for the Blind
NPRSF	National Poverty-reduction Strategy Framework
NGO	Non-Governmental Organisation
NORAD	Norwegian Aid
PODCAM	Parents of Disabled Children Association of Malawi
PPA	Partnership Programme Agreement
PRGF	Poverty-reduction and Growth Facility
PRSP	Poverty-reduction Strategy Paper
SADC	Southern Africa Development Countries
UN	United Nations
USAID	United States Agency for International Development
PWDs	Person with Disabilities
TAPAM	The Association for People with Albinism in Malawi
UNDP	United Nations Development Programme

## DEFINITION OF TERMS

**Disability:** Limitations in activities and social participation.<sup>1</sup>

**Poverty:** “Lack of productive means to fulfil basic needs such as food, water, shelter, education and health, which is common among people with disabilities.”<sup>2 p.4”</sup> It also means deprivation in the well-being of people in terms of basic needs, economic growth and quality of life.<sup>3</sup>

**Vulnerability:** A product of exposure to hazard and limited resilience to hazards.<sup>4</sup>

**Inclusion:** The process of taking necessary steps to ensure that every person is given equal opportunities to develop socially, to learn and to enjoy social life.<sup>5</sup> It is also the process of integrating formerly segregated issues and stigmatized people into main society and in development programme.<sup>6</sup>

**Mainstreaming disability:** The process of promoting inclusion to address barriers that exclude people with disabilities from full and equal involvement in society.<sup>7</sup> “It is a strategy for making disabled people’s concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programme in all political, economic and societal spheres so that disabled people benefit equally, and inequality is not perpetuated.”<sup>8 p.6”</sup>

**Key informants:** Members of society who are particularly more knowledgeable about the research topic and the community as a whole.<sup>9</sup>

**Focus group discussion:** A carefully planned discussion whereby group members are asked specific questions to brainstorm a topic in a permissive and non-threatening atmosphere; to obtain group perceptions, feelings and manner of thinking in the area of interest.<sup>10</sup>

## **CHAPTER ONE**

### **INTRODUCTION**

Persons with disabilities are commonly associated with poverty. This is a result of negative attitudes, non-inclusive policies, isolation practices and unconducive environments for development.<sup>1</sup> In developing countries such as Malawi, people with disabilities are faced with circumstances that limit their participation in everyday life activities. These circumstances have caused people with disabilities to lobby governments for change and increased public awareness about their abilities, including the need to deal with barriers.<sup>11</sup> Without continual lobbying and advocating for sound policies, it is stated that disability affairs will remain absent in policy documents.<sup>12</sup> Most countries have adhered to international guidelines such as the Standard Rules on the Equalization of Opportunities for Persons with Disabilities,<sup>13</sup> Declaration of the Rights of Persons with Disability<sup>14</sup> and the United Nations (UN) convention.<sup>15</sup> Despite these efforts, which were aimed at giving fundamental freedom and equal recognition before the law, people with disabilities are often excluded at all levels of life.<sup>16</sup>

In this study, the term ‘disabled person’ is used synonymously with the term ‘people with disabilities’. In order for disabled people and their organisations to actively participate in community development activities, it is essential for them to understand development strategies and policies that guide disability issues.<sup>17</sup> People with disabilities need to be accepted as part of the human diversity and efforts should focus on provision of equal opportunities for the group. The National Policy for Disabled Persons in Malawi acknowledges disability as a social construct and recognises it as a human rights issue. The underpinning principle is promoting the rights of people with disabilities to play a full and participatory role in society. The policy ensures that tangible steps are taken to allow people with disabilities the equal basic rights and responsibilities as any other Malawian citizen. It is proposed that disability issues should be integrated in all government development strategies and policies.<sup>2</sup> People with disabilities need to demand their rights by raising community awareness regarding possible options for involvement in development initiatives. The needs of disabled people should be known and well represented among family members, care givers and stakeholders so that disability issues are addressed in a consultative process.<sup>8</sup>

In order to address the barriers facing people with disabilities, it is fundamental to understand the contextual condition of Malawi, taking into account the different socio-economic situations associated with disability, poverty and the administrative structure of the government.

#### **1.1 BACKGROUND OF THE STUDY**

In 1993, the poverty levels for Malawi were 60% among the urban population and 65% in the rural population.<sup>18</sup> A report by the United Nation Development Programme (UNDP) in 1998 also confirmed the poverty situation in Malawi. The report revealed the great need to put into place

some action to reduce and even eradicate poverty in the country, especially among the rural poor population. In particular, there is a need to create opportunities for access to credit, employment and sustainable income generation activities for the poor, including people with disabilities.<sup>3</sup> This led the government of Malawi to develop long-term and medium-term policy frameworks for poverty alleviation in all programmes, such as the Vision 2020 from 1996-2015; Poverty-reduction Strategy Paper (PRSP) from 2002-2004; Malawi Economic Growth Strategy (MEGS) from 2004-2006; and the Malawi Growth and Development Strategy (MGDS) from 2006-2011, currently under implementation. Previously, the development strategy paper was called PRSP but now it is called the MGDS. The term MGDS is thus used synonymously with the term PRSP in this study.

International aid assistance to low-income countries like Malawi is often directed at achieving the targets set out in a document drawn up by governments in consultation with stakeholders, that indicate a country's development priorities.<sup>3</sup> Unfortunately, the challenges faced by people with disabilities such as poverty, limited participation in community activities, discrimination and stigma rarely have a high profile in most national policies, and are often entirely absent.<sup>8</sup> Disabled people have limited opportunities and choices for participation in development activities that bring social change. Stubbs<sup>19</sup> argues that inclusive initiatives should benefit the whole society if disability is to be fully included. In the absence of plans to recognise disability as a cross-cutting issue on the agenda of national policies, it would be difficult to channel funding to address the particular challenges faced by people with disabilities. The Malawi Growth and Development Strategy (MGDS) is a developmental tool that is used to inform and guide government and development partners on specific priority focus areas, in terms of budgetary support. It outlines key areas that need adequate action for the development of the nation. The monitoring and evaluation of such crucial national development strategies has been based on quantitative data, with the limited creation of qualitative data.

There is a shift in the new aid instruments by major donors such as the World Bank, European Union (EU), the Department for International Development (DFID) and the International Monetary Fund (IMF), from a project-based approach to a multi-lateral project support. The shift has seen an increase in the inclusion of disability issues in the national poverty-reduction papers in most countries, including Malawi. However, the process of change has been slow. The poverty-reduction process should consider inclusion of disability by acknowledging the needs and rights of people with disabilities, so that such needs are matched with the national poverty-reduction plans, the national budget and indicators of performance.<sup>20</sup> Efforts and targets to reduce poverty among disabled persons should be developed, based on their needs in society.<sup>21</sup> The perceived missing elements on disability issues should be included in the PRSP so that people with disabilities can be involved in and understand the poverty-reduction process.

At a round table discussion on disability knowledge and research (KaR) held in Malawi in 2004, participants observed that for a long time, people with disabilities have been the most marginalised group and continue to be disadvantaged in many countries.<sup>22</sup> People with disabilities form part of every community and often belong to the poorest and underprivileged

groups.<sup>23</sup> In developing nations such as Malawi, discriminatory social attitudes toward disability continue to exist and welfare safety nets often under perform. It is has been stated that poverty among disabled people is perpetuated by lack of access to equal opportunities and their inability to benefit from the existing socio-economic interventions.<sup>24</sup> The relationship between poverty, disability and discrimination faced by people with disabilities has been described pointing out that poverty and disability reinforce each other.<sup>19</sup> Poverty may increase the incidence of disability among poor people while disability creates and exacerbates poverty<sup>25</sup> It is stated that this relationship between poverty and disability is crucial in determining the quality of life for people with disabilities more than any other vulnerable group.<sup>19</sup> People with disabilities are stigmatised based on their impairments, and further excluded because of the negative attitudes of society. There is a need to build the capacity of people with disabilities to empower them with skills for self-advocacy. Disabled people, who are knowledgeable about poverty alleviation initiatives, have a higher chance of participating and influencing decision-making processes regarding the inclusion of disability issues in development processes.<sup>1</sup> Therefore, this study sought to look into the involvement of people with disabilities in the process of formulating development strategies in Malawi. In particular, the study explored factors that promote or hinder such participation in development strategies and how the contributions of people with disabilities were reflected in the PRSP/MGDS.

## **1.2 CONTEXT OF THE STUDY**

The population of people with disabilities in Malawi is heterogeneous and comprises all forms of disability. According to a 1983 national survey, there were 190,000 people with disabilities in Malawi (2.9% of the population). The survey also revealed that 90% of people with disabilities live in rural areas with little or no access to rehabilitation services and other basic amenities.<sup>26</sup> However, a study on the Living Conditions among People with Activity Limitations in 2003 indicated that there was a 30% population growth of people with disabilities in Malawi over a period of 20 years from 1983-1993. The study revealed that there were 480,000 people with disabilities in Malawi (4.18% of the population).<sup>27</sup> The Malawi Population and Housing Census, conducted in 2008, showed that the number of people with disabilities was 498,122. There was no significant difference in population growth representing 4% of the total population, similar to the 2003 study. The population of people with disabilities remains high with 45,379 living in urban areas and 452,743 in rural areas, where access to basic amenities and equal opportunities poses great challenges.<sup>28</sup> The overall finding of the studies was that people with disabilities experience greater limitations in social participation. Access to education was restricted and the level of unemployment was higher, hence the lack of improved quality of life among the group.

The Republic of Malawi has boundaries with Zambia, Tanzania and Mozambique. Malawi is a landlocked country with a total area of approximately 119,000 square kilometres, of which 24,000 square kilometres is water representing 21% of the country's territorial area. It has a population of approximately 13 million people which is growing at a rate of 3.2% per annum.<sup>29</sup> Agriculture is the mainstay of the economy in Malawi. More than 85% of the population live in

rural areas, where most of the agro-production is undertaken.<sup>29</sup> The Malawian economy has shown considerable improvement over the last ten years. The steady increase in economic growth has resulted in Malawi reaching a Gross Domestic Product (GDP) per capita of approximately US\$300 in 2008, as indicated in the Annual Economic Report. The positive performance and success of the Malawian economy can be mainly attributed to recent sound economic policies, political will and favourable weather conditions for agriculture.

### **1.3 MOTIVATION**

This study provides additional research-based evidence that will add value to existing data. In a country like Malawi, there are few studies on disability that explore and explain the problems faced by people with disabilities. It appears that little time has been spent investigating what people with disabilities think about their active participation in the process of developing poverty-reduction plans, and whether their involvement is beneficial to the inclusion of disability. This study provides an opportunity for people with disabilities to participate as researchers as well as key stakeholders and provides them with a sense of ownership. The researcher believes that the findings of this study will promote advocacy and the involvement of people with disabilities in research that will inform poverty-reduction programmes.

In addition, there is a gap in terms of how disability can be included at policy and grassroots level to improve the Disabled People's Organisations (DPOs) situation to participate in development initiatives. The study findings present a linkage between government and the disability movement in the identification and addressing of the challenges facing people with disabilities in Malawi. It is hoped that the integration of the ideas will be a springboard for combating stereotyped attitudes and for raising awareness on disability issues. This will guarantee that stakeholders, in the process of formulating the MGDS, are encouraged to provide equal opportunities for people with disabilities. It is hoped that disability issues would be featured adequately in the poverty-reduction programmes in the future, so that more people with disabilities are self-represented and more meaningfully involved.

### **1.4 RESEARCH PROBLEM**

People with disabilities, and their Disabled People's Organisations, are not fully involved in the process of developing national poverty-reduction strategies and therefore, disability is not included in the national agenda. This impedes the understanding of the process of formulating national poverty-reduction strategies in Malawi.

### **1.5 AIM OF THE STUDY**

The aim of this study was to explore the involvement of People with Disabilities in poverty-reduction strategies in Malawi. In particular, to investigate factors that promotes or hinders such participation in development strategies and to ascertain how the contributions of people with disabilities were reflected in the Malawi Growth and Development Strategy (MGDS).

## **1.6 RESEARCH QUESTIONS**

1. To what extent are people with disabilities involved in PRSP/MGDS processes?
2. What are the factors that promote or hinder the involvement of people with disabilities in the process of formulating poverty-reduction strategies?
3. What is disability inclusion in terms of what should be done to encourage inclusion of people with disabilities in poverty-reduction programmes?

## **1.7 OBJECTIVES OF THE STUDY**

1. To investigate the extent to which people with disabilities participate in poverty-reduction strategies.
2. To identify factors that facilitate or inhibit the involvement of people with disabilities in poverty-reduction strategy initiatives.
3. To examine the nature of inclusion of disability in the context of development initiatives in Malawi.

## **1.8 SIGNIFICANCE OF THE STUDY**

A study of this nature is of importance as the government of Malawi and the public sector may use the findings to address issues of involvement of people with disabilities in an informed and systematic way. This would ensure that the contributions of people with disabilities are reflected in all poverty-reduction strategies and policy documents in the future. In this way, it would assist decision-makers in Malawi in developing good practices, and the understanding of disability issues may facilitate the inclusion of disability in the MGDS and other development plans. The findings will not only provide additional knowledge, but also new research-based evidence that will inform stakeholders to deliberately create a policy environment that encourages the participation of disabled people in government and other programme. The disability federation would utilise the findings to stimulate participation of their member organisations in poverty-reduction programme. This would also ensure self-representation of people with disabilities in fulfilment of development programme at all levels.

## **1.9 CHAPTER SUMMARY AND PROGRESS OF STUDY**

In summary, it appears that people with disabilities have limited opportunities to participate in poverty-reduction programme. There is a need to adopt inclusive practices that will ensure that the rights of people with disabilities are respected and protected. The expected outcome of involving people with disabilities in the process of formulating poverty-reduction initiatives and national policies is that disabled people's needs may be given priority. Overall, the experience and contributions from various stakeholders may lead to a change in negative attitudes towards disability policies.

The study is structured into six chapters:

Chapter 1 sets the background of the study stating the aim, objective and motivation. It also describes how disability is linked with poverty, existing national policies and other disability legislation. The chapter also describes the main research problems to be addressed in the study.

Chapter 2 is setting a broad understanding of the challenges that affect the participation of people with disabilities, explores the literature that provides further understanding of disability issues and the current situation of people with disabilities in Malawi. Using the different existing policies, a sector policy review was conducted to understand how disability issues are mentioned in policy documents. The policy documents were considered important to promote equal access to basic services that would determine participation of people with disabilities in different sectors.

Chapter 3, in general, explains the methodology of the study. It describes details of the sample and study area and how data was collected and analysed. It also gives a picture of the number of stakeholders who participated in the study.

Chapter 4 presents the findings of this study. It gives a description of the main themes that promote or hinder involvement of people with disabilities in the process of formulating poverty-reduction strategies.

Chapter 5 presents the discussion of results, as presented in the previous chapter, focusing on the main issues that have arisen in the study. It discusses the consultation process during the formation of the poverty-reduction strategy paper and the experiences of participants. It gives a description of facilitators and barriers for inclusion of disability issues in the MGDS.

Chapter 6, the final chapter, provides the recommendations of the study. Recommendations are suggested to remove barriers and facilitate the involvement of people with disabilities in the formation of poverty-reduction strategy. It also provides recommendations on how disability could be included to stimulate change in the negative attitudes towards disability issues in society. Recommendations are made on the need to refocus on adjusting policies to adequately feature disability issues. This chapter also provides suggestions for areas of future research.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 NATIONAL ADMINISTRATION AND DEVELOPMENT STRUCTURE

Malawi is divided into three main administrative regions and 28 sub-administrative districts. The northern region has five districts, the southern region has 13 districts and the central region has nine districts (Appendix A). Each of the three regions has a city which is a coordinating hub for all central government and other stakeholders' activities in the region. The districts are further divided into Traditional Authorities (Appendix B and Appendix C), each covering groups of villages presided over by senior chiefs or local chiefs, and they constitute the smallest administrative units in the country. Districts are also divided into constituencies, represented by members of Parliament. Each district has a district development plan which outlines poverty-reduction targets that are reflective of the community needs. At district assembly level, there are development committees at village level and district executive level that initiate all the development plans, implementation, monitoring and evaluation of programme.<sup>30</sup>

There is a political distinction between the three regions of Malawi. Historically, about 30 years during the one-party era of Malawi Congress Party (MCP) before 1993, the northern region was a neglected region commonly described as *the dead north*, compared to the central and southern regions. As Malawi was coming out of the colonial period and gaining independence in 1964, the MCP leadership needed to show political power to gain full authority of the administration of the nation. Due to their autocratic system of leadership and political agenda, there were few people who could speak strongly against government priorities on development programme. During the post and pre-independence period, the capital city of Malawi was Zomba in the southern region. All government administration activities were conducted in Zomba, until the then president of the MCP moved the capital city to Lilongwe in the central region. However, the introduction of multi-party democracy in 1994 brought a slight shift in the development focus among the regions. The United Democratic Front (UDF) party, that was then in power, took advantage of the slow development of the northern region in its manifesto to campaign for political favors. As a result, there were several political appointments and the establishment of development projects in the northern region by the government, donors, non-governmental organisations (NGOs) and civic society organisations (CSOs) such as Mzuzu University and Mzuzu Central Hospital. The mushrooming of these development activities led to increased socio-economic activities and increased population in Mzuzu city, the central administrative unit for the northern region.

The change in political party to Democratic Progressive Party (DPP) in 2004 had also brought noticeable changes in the administrative focus of the three regions. When the president was elected, he ordered all government offices to move to Lilongwe in the central region, which is the capital city of Malawi. As part of this process most donors, NGOs, and CSOs also moved their head offices to the capital city. Lilongwe became the national administrative hub for

Malawi, with several development projects. It can be observed that, although there have been several efforts to develop the regions after 1994, the northern region has taken a long time to gain the same development activities, economic power and support as the central and southern regions. The northern region remains under-developed in terms of social, economic and political power, hence the differences in resource availability and access to services. It is hoped that the current political will on disability issues and development projects could help to ensure that there is equal socio-economic growth and improved community participation. This could include disabled people organisations (DPOs) in development committees in all three regions. It could be argued that political will is just one possible factor for promoting participation of people with disabilities. A broad understanding of the administration and development structure is helpful in considering how disability should be mainstreamed along with the impact of developing a comprehensive and inclusive environment. This could also help to formulate policies and legislations that will promote active participation and improve the quality of life of people with disabilities. It could also be used to understand how policies should be integrated in the planning, implementation and monitoring of the national and district development programme. However, in order to succeed, international and national legal frameworks need to collaborate with each other to ensure that disability issues are included in the national agenda.

## **2.2 INTERNATIONAL AND NATIONAL LEGAL FRAMEWORK ON DISABILITY**

According to studies done by Stubbs<sup>19</sup>, Jones and Reed,<sup>23</sup> disability is a cross-cutting issue of the national agenda that affects all aspects of national development, such as economic, political and cultural issues. As a way of linking poverty, human rights and disability issues in development initiatives, people with disabilities should be empowered. Governments, disabled people organisations and donor partners have realised that there is a need to understand how the existing and new disability legislation would be beneficial in empowering disabled people and establish development collaboration. Development partners, such as the United Nations, European Union, World Bank and International Monetary Fund, have supported the establishment of several international disability legal frameworks, such as the Disability Discrimination Act 1995<sup>31</sup>, Universal Declaration of Human Rights<sup>32</sup>, and The Equality Act 2006.<sup>33</sup> This support was aimed at strengthening the relationship between national government policies and legislation. In most of these legal frameworks developed by governments and international agencies, when it comes to planning and establishing interventions they tend to give disability a low priority. It is argued that disability issues are often driven by a charity rather than developmental model of disability. Hence, disability considered along with other national development goals.<sup>25</sup> The establishment of the United Nations Convention on the rights of people with disabilities,<sup>34</sup> has brought a shift in disability perception and fundamental attitudes to disability. The UN Convention does not just focus on the physical barriers, but also societal attitudes and behaviour, policies and development processes that are inclusive on disability. This was not the case in the past, and nowadays there should be no excuses for not including disability in development processes.<sup>34</sup> The United Nations also sees the Convention as a force that will legally bind governments to treat people with disabilities with due respect for their human rights. Countries like Malawi, who have ratified the Convention, need to apply it into their national policies. For instance, the UN

Convention article 32 on development cooperation provides a foundation on which disability could be included in the national development plan, such as the Malawi Growth and Development Strategy. Equally, the UN Convention has other clauses that allow DPOs to be proactive, recognised before the law, and support their capacity-building and empowerment. It is hoped that these would allow DPOs to effectively participate and engage government with confidence to facilitate inclusive practices in development initiatives. A recommendation from a conference on disability and development cooperation<sup>35</sup> confirms that the impact of these legal frameworks can be measured to reduce poverty and discrimination among people with disabilities. However, this is possible if they are embedded in the social analysis situation during the drafting of national development plans and policies. It was further recommended in the conference that this could successfully encourage governments to adapt to basic principles of universal access and equality. It appears that, at international level, the legal tools are aimed at promoting dialogue and raising awareness among governments and other stakeholders. In doing so, it could encourage the meaningful involvement of people with disabilities and support them in all development activities. It is clear that the understanding of these international legal frameworks is a prerequisite for promoting the involvement of people with disabilities in poverty-reduction processes and disability issues at national level.

The constitution of Malawi<sup>36</sup> is the basic legal instrument that guides all legislations and policies. As a comprehensive legal tool, the constitution addresses various barriers facing people with disabilities and promotes equal human rights as for any other citizen. The constitution prohibits discrimination on the basis of disability in all areas of life such as employment, marriage, health, education, information and participation in community activities. To provide measures to promote the rights of people with disabilities, the Malawi parliament passed and enacted a Handicapped Act in 1971.<sup>37</sup> This law ensured that government and other partners design, implement and evaluate programme that are aimed at uplifting the welfare of people with disabilities. It was after this legal position, that the government of Malawi then established the Malawi Council for the Handicapped (MACOHA), as its agency to oversee the implementation of the Act. The council is fulfilling its mandate and objectives by the promotion of comprehensive rehabilitation services in the fields of vocation evaluation and training to prepare people with disabilities for entrepreneurship. It provides free tertiary education, physiotherapy and occupational therapy services to improve work capacities of people with disabilities. It also provides social guidance and counselling for the community-based rehabilitation programme. As a result of the government establishing MACOHA, people with disabilities realised several factors affecting their living conditions during the implementation of the Act and various disability programs by the council. Hence there was a need to improve and formulate another policy that would address their concerns in the current political, social and economic situation.

The National Policy on Equalization of Opportunities for Persons with Disabilities was then developed and has its roots in the Handicapped Act. The purpose of the policy was to promote the rights of people with disabilities to enable them to participate fully in society<sup>2</sup>. This would be attained by developing concrete steps that promotes access to fundamental human rights. As a

way of establishing an inclusive environment, the policy aimed at integration of disability issues in all government development strategies and policies. Complementary to this process, the policy emphasised the need to develop the capacity of DPOs and civic education to sensitise communities about disability.

It is believed that the formulation process of the disability policy was participatory and that DPOs were actively involved in the process. However, the scope of this study is to look at how these legal frameworks encouraged the inclusion of disability and supported equal opportunities amongst various types of disabilities. The disability policy is linked to other sector policies, such as health policy, agriculture policy, education policy, gender policy and the Employment Act, as a way of mainstreaming disability. As such, this study moves beyond the question of just having the sector policies mentioning disability issues. It looks at how the main national poverty-reduction strategy documents were formulated in Malawi, after a long history of stigma, negative attitudes and limited access to basic resources.

### **2.3 NATIONAL DEVELOPMENT STRATEGIES IN MALAWI**

The evolution of national development strategies in Malawi started when the government of Malawi developed the *Vision 2020*<sup>38</sup> document. As a long-term national development plan, *Vision 2020* focuses on addressing issues of access to land, employment, education and business opportunities for everyone, including people with disabilities in both rural and urban areas.<sup>38</sup> As such, *Vision 2020* inspired the establishment of the disability policy document and disability legislation in order to promote equal opportunities for full participation of people with disabilities in the development plans of the government. To achieve the objectives of *Vision 2020* as a national development plan, the government of Malawi realised the need to develop a district development plan that paved the way for the implementation and monitoring of poverty-reduction programme at district level. The district development plan described development projects in the districts and used the *Vision 2020* documents to solicit funds from development partners on projects in the districts. The objectives of the projects are developed based on fulfilling community needs.<sup>39</sup> The focus of the district development plan is to achieve improved quality of life and socio-economic development in the districts.

The introduction of the multiparty system of government in 1994 led to a radical political shift from a centralized and autocratic system of government, to a democratic and decentralized system.<sup>40</sup> As a result of the political transformation, a new constitution was adopted in 1995, based on the principles of participatory democracy. It was part of the process of political change and of the need to stimulate development activities for the nation. The Malawi government saw the need for poverty-reduction programme to be decentralised in the political and administrative structure at district level. The national decentralisation policy was then approved by government in 1998, which gave power to the district assembly to establish district development plans.<sup>40</sup> The decentralisation policy focus was on creating a democratic environment and eliminating dual administration. The policy promotes good governance, accountability and popular participation of rural masses in socio-economic development. As part of the decentralisation, government

initiated development committees at district level, such as a district executive committee, an area committee and a village committee, to lead the process. These committees were established to allow and promote participation of the local people in order to incorporate the views of the poor in remote areas. By identifying community needs, poverty-reduction programme were then developed to address the needs and encourage equal participation in development programme.

Malawi, along with countries such as Zambia, Mozambique and Tanzania, is regarded as one of Africa's Highly Indebted Poor Countries (HIPC) and eligible for the Poverty-reduction and Growth Facility (PRGF).<sup>41</sup> The International Monetary Fund and the World Bank developed the PRGF initiative to address poverty in low-income countries. The PRGF replaced the Enhanced Structural Adjustment Facility (ESAF) initiative. The PRGF focused on developing a PRSP that was country driven in order to fully achieve poverty-reduction and economic growth among the poor.<sup>42</sup> The PRGF document demanded that governments should include poverty-reduction strategies in the national development plans. The process of formulating the PRSP was driven by the need to access debt relief and concessional assistance from the World Bank and the International Monetary Fund. As a result, the government of Malawi formulated a medium-term plan, the Poverty-reduction Strategy Paper (PRSP). The PRSP focused on providing a crucial link between donor support, civil society organisations and the Malawi government to combine efforts that would ensure sustainable poverty alleviation.

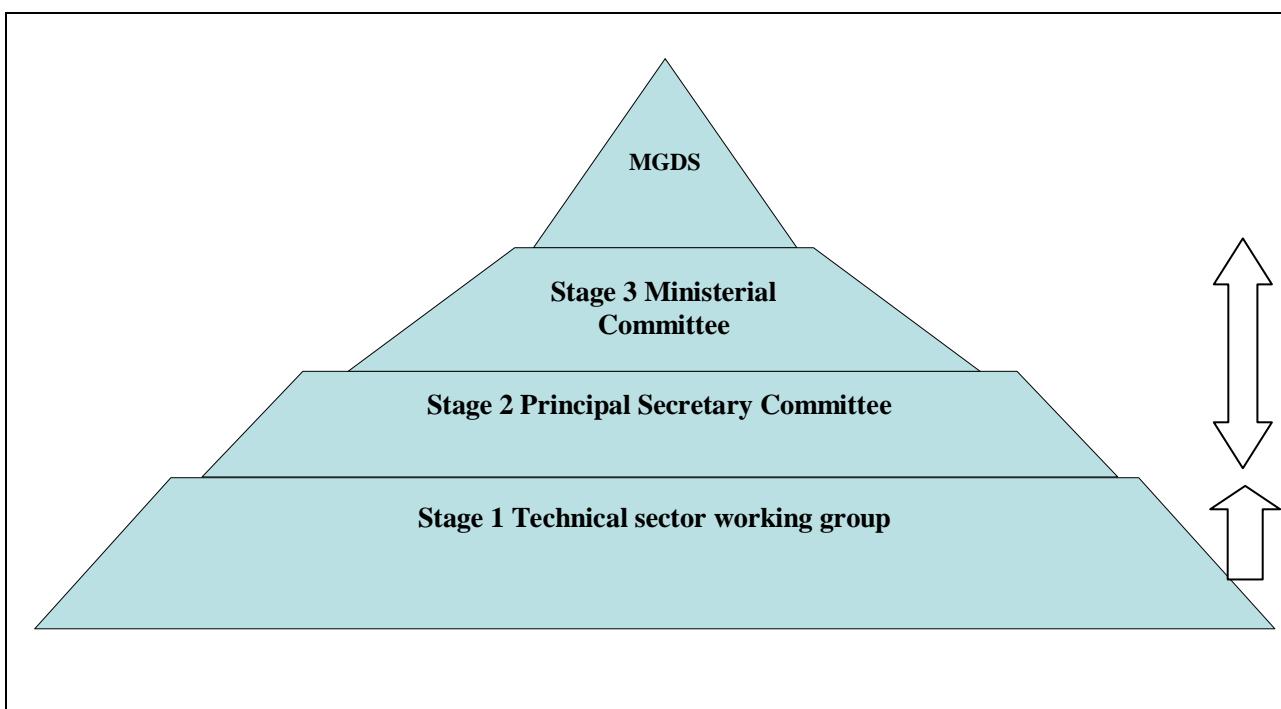
After implementation of the PRSP, it was noted by the government of Malawi and the private sector that there was negative economic growth.<sup>43</sup> This led the government to develop another three-year medium-term strategy plan, the Malawi Economic and Growth Strategy (MEGS). The MEGS focussed on shifting available resources to stimulate private sector investment and trade in order to sustain growth and development of the economy. This strategy also aimed at creating an environment that would attract and promote private sector investment to improve the quality of life of the poor, and achieve sustainable economic growth and development.

After incorporating lessons from the PRSP and the MEGS, the government of Malawi formulated another medium-term strategy plan, the Malawi Growth and Development Strategy (MGDS), currently under implementation. The MGDS aims, among other targets, at creating wealth and reducing poverty among the poor. It was hoped that the MGDS would achieve this by the implementation of the six key priority areas: Agriculture and Food Security; Irrigation and Water Development; Transport and Infrastructure Development; Energy Generation and Supply; Integrated Rural Development; Prevention and Management of Nutritional disorders; and HIV/AIDS. The MGDS is used to provide guidance to the government of Malawi, civil society organisations and other development partners in the process of formulating socio-economic initiatives.<sup>44</sup>

## **2.4 FORMULATING THE MALAWI GROWTH AND DEVELOPMENT STRATEGY**

The process of formulating the Malawi Growth and Development Strategy (MGDS) started with the cabinet establishing a steering committee to look at the vision of the government of Malawi

and to translate it into an operational three-year medium-term plan.<sup>44</sup> The committee set up a Technical Working Group to lead the process. Six thematic groups were established, based on the six priority areas set by the Malawi government namely; agriculture sector: agriculture and food security; water sector: irrigation and water development; transport sector: transport infrastructure development; energy sector: energy generation and supply; rural and urban sector: integrated rural development; health sector: prevention and management of nutrition disorders and HIV/AIDS. Membership of thematic groups composed of stakeholders in the set priority areas was by invitation through the Ministry of Economic Planning and Development Cooperation. The thematic groups formed a technical working team to provide the technical details of the process. The technical information was obtained through consultations at grass root levels to identify the gaps, in terms of areas that need improvement or those that need to be addressed. This information was sent from the technical working group to the committee of principal secretaries who are senior ministerial government officials, for further examination, analysis and critiquing. This group provided recommendations and modifications to improve the content and context of the draft paper. Finally, the document was sent to the ministerial committee, comprised of cabinet officials, before it was approved by the Head of State.



**Figure 1: The process of formulating the MGDS**

Figure 1 describes the process of formulating the MGDS document. Stage 1 is the foundation phase that builds the skeleton structure of the document. Stage 2 is the intermediate phase, where checks and balances are carried out on the content and context of the draft document. At this stage, feedback and links between the technical committee and the ministerial committee is also provided. Stage 3 is the final phase, when the draft document is reviewed before approval.

The above framework is intended to inform DPOs, civil society organisations for disability, human rights advocate groups and programme planners and allow them to recognise the extent to which they can competently lobby and advocate for the inclusion of disability in these processes.

Disabled people are disproportionately over-represented among the poorest of the poor in most Malawian communities. It has been argued that it would be difficult to attain the development targets as outlined in the main national strategy such as *Vision 2020* and international long-term development plans such as the Millennium Development Goals (MDGs) and the PRSPs, if people with disabilities are not included in the poverty-reduction strategy initiative.<sup>27</sup> Sustainable poverty-reduction for the whole society may not be accomplished without the inclusion of people with disabilities in the MGDS.<sup>2</sup> Concrete actions and the needs of people with disabilities should be considered if the development targets that aim at eradicating poverty among the poor are to be achieved.<sup>27</sup> It is clear that if disability is not well featured in the MGDS, it could be a contributing factor to exclusion of people with disabilities in development process.

## **2.5 NATURE OF DISABILITY ISSUES IN NATIONAL POVERTY-REDUCTION PLAN**

The Malawi Growth and Development Strategy (MGDS) outlines the plans that focus on reducing poverty among the poor, which includes people with disabilities. The word disability is mentioned in the thematic areas of social protection, social development and sustainable economic growth. Disability is considered amongst other vulnerable groups, such as orphans, women, children under five years of age, elderly people and households affected by natural disasters.<sup>44</sup> Within the theme on economic empowerment, it is stated that “people with disabilities are usually the most affected in terms of access to assets and other facilities required to become economically empowered. The group experiences difficulties accessing financial services and capital, skills development programme, and technology developments. People with disabilities are also the most affected by poor infrastructure such as roads, communication, and buildings not designed to accommodate or meet their special needs.”<sup>44 p. 40</sup> There is a need to remove such impediments and create an enabling environment for disabled people to get involved in poverty-reduction processes.

It is believed that the general categorisation of people with disabilities as vulnerable may put people with disabilities at risk of not benefiting more from the national development plans and the section budget allocation. It has been shown that the MGDS gives a broad definition of people with disabilities within larger groups of the most vulnerable category.<sup>45</sup> Although the MGDS talks of protecting vulnerable people, there is a need to recognise factors that limit the ability and capacity of individual groups, such as people with disabilities, to meet their needs. It was stated that vulnerability is a complex and multi-dimension concept that needs to be understood in relation to outcomes of interest to the vulnerable groups while adopting responses and policy interventions to address the vulnerability in several distinct ways.<sup>4</sup> The categorisation of vulnerable groups in the MGDS may seem to be a useful tool for analysing different levels of support. As acknowledged in the National Policy on the Equalization of Opportunities for Persons with Disabilities, exclusion of people with disabilities from the social, political and economic activities of developing countries, like Malawi, leads to high rates of poverty and minimal opportunities to break the poverty cycle.<sup>2</sup> The national policy has drawn a close relationship between poverty and disability. Yeo<sup>46</sup>, also agrees that the dynamics between

disability and poverty are complex and bi-directional, hence the need to understand this relationship. In another study, Nhlapo<sup>21</sup> further identified culture as one of the factors that affects the link between disability and chronic poverty, as it varies within and between nations. Therefore, there is a need to understand how the donor partners have included this relationship in their policies and project. This would also help to examine the impact of the various disability legal frameworks on raising awareness on disability and the creation of opportunities for people with disabilities to participate in development programme.

## **2.6 RELATIONSHIP BETWEEN DISABILITY AND POVERTY**

The Poverty Reduction Strategy Paper (PRSP) was developed in a quest to combat poverty through improved health, education, agriculture, population control and conservation of natural resources. Most developing countries, such as Malawi, face pressing demands on limited resources, hence they experience difficulties in addressing the needs of disabled people.<sup>47</sup> In order for the government to adequately provide support for the disability cause, there needs to be collaborative effort between the international community, non-governmental organisations and the government regarding planning and distribution of resources and planning for priority areas. It would be desirable if the financial and technical assistance from the donor agencies would be in line with the priority areas identified by the governments, in terms of the prevention of disability and equalization of opportunities.<sup>47</sup> In seeking to serve better the group effort of reducing poverty for the majority poor people and disabled people in particular, most donor agencies have already the specific responsibility of promoting the development of disability projects and add disability components in their policies in order to respond to the needs of disabled people.

As architects of the Poverty Reduction Strategy Paper, the World Bank and IMF need to play a key role in the implementation and monitoring of the PRSPs in order to ensure that its goals are operational at country level. In a joint report on the poverty-reduction strategy approach, the aforementioned institutions expressed a need for the process to be country-led and that operations of the strategy should be linked to the country budget allocation. By allocating budgetary support to the poverty-reduction strategy, it would facilitate the smooth implementation of the strategy. It was also observed that adequate attention should be given to pro-poor populations, amongst which are people with disabilities.<sup>48</sup> The World Bank has acknowledged mainstreaming disability in its development plan and aid assistance to developing countries, such as Malawi. The World Bank offered support in disability research and financial support to civil society organisations that work with DPOs. In addition, the World Bank gives a high profile to disability when setting policies and ensures that there is full participation of people with disabilities.<sup>48</sup> Regardless of the World Bank stating the need to include disability in policies and provision of support to the various nations to implement such development initiatives, it is observed that there is an omission of disability issues in the MDGs. There is a need for the MDGs, as long term worldwide development strategies, to adequately feature issues of disability. Whereas the eight MDGs would be beneficial to improved living condition of people with disabilities, it is argued that there is a need to effectively include people with

disabilities to adequately participate in all stages of evaluating and implementing the MDGs.<sup>49</sup> It is believed that by assimilating disability issues in MDGs, it would stimulate inclusion of disability at international level during the implementation of the MGDs by governments, donors and non-governmental organisations. Furthermore, it has been pointed out that there is a need to link policy and practice; that process requires full commitment and leadership action by all stakeholders in the process of eradicating poverty.<sup>44</sup> As a constituent of the process, the governments, the private sector and donors should make a deliberate effort to include disability issues during the development and implementation of all poverty-reduction projects

The Department for International Development (DfID) recognises the crucial role played by DPOs in facilitating inclusion of disability issues in development initiatives. DfID has established direct support to DPOs with Action on Disability and Development (ADD) through the Partnership Programme Agreement (PPA). The PPA supports DPOs in developing countries like Malawi, where issues of disability are captured in national development plans and disability legislation. It was suggested that if DPOs are engaged directly by donor partners, it may hasten the process of change in inclusion of disability in development plans.<sup>28</sup> The ADD focuses on capacity-building by empowering people with disabilities so that they are self-represented and able to develop a sustainable democratic organisation. DfID has further diversified assistance to work with civil society organisations (CSOs) that deal with disability in a wider initiative approach. The CSOs provide a crucial link between the donor community and the poor population which often includes people with disabilities. The CSOs are held accountable and responsible by the government on disability projects, supported by the donor partners. It is further pointed out that people with disabilities should be given their rights and entitlement to participate in development initiatives.<sup>28</sup> However, although direct involvement of DPOs with donors may seem to be advantageous, there is a need to look at long-term sustainability of the support rendered to disability organisations. Project support rendered by donors should be reflective of the DPOs needs, and aim to develop their capacity to be independent in managing future projects.

The disability policy of the United States Agency for International Development (USAID) focuses on protecting people with disabilities from being discriminated against. The policy promotes a non-discriminatory environment that ensures equal opportunities for people with disabilities.<sup>50</sup> The agency has a well-developed inclusive approach to disability issues; an approach that enhances full participation of people with disabilities throughout the process of developing poverty-reduction strategies. This organisation has shifted focus from funding large NGOs to linking directly with DPOs for funding. It was proposed that DPOs should not just wait for funding from major NGOs but, rather, they should be given an opportunity for direct funding from donors to enable DPOs to participate in national development plans.<sup>44</sup> In addition, it is important to understand that some of the function of these donor agencies is to supply advisory services, encourage regional and sub-regional networks, and sponsor disability research in DPOs.<sup>47</sup> It is hoped that these activities would increase awareness on disability and increased access to basic needs such as health, education hence improved living conditions for disabled

people. There is often an expectation that donations, provided at central or government level, will trickle down to DPOs for development at that level. Yet there is no matching effort for disability inclusion at policy level, so that DPOs can be supported financially to develop at the same pace as other development efforts in the country.

## **2.7 CURRENT SITUATION OF DISABLED PEOPLES ORGANISATIONS IN MALAWI**

Upon realisation of their rights, people with disabilities started to organise themselves to advocate and lobby for their rights and equal access to basic amenities, gaining experience from those people with disabilities from Zambia, Zimbabwe and South Africa. They inspired and motivated their colleagues in Malawi to fight for their inclusion in society, and so people with disabilities established their own organisation in 1989 called Disabled Persons Association in Malawi (DIPAM). The mission of DIPAM was to improve socio-economic life of people with disabilities through lobbying for equal opportunities.<sup>51</sup> The association played a great role in educating the public on disability issues and initiated the establishment of regional and district committees for people with disabilities in order to reach rural areas. After a successful functioning of DIPAM, the Federation of Disability Organisations in Malawi (FEDOMA) was founded in 1999. This is an umbrella body for Disabled People's Organisations (DPOs) in Malawi with the aim of providing a unified voice for all people with disabilities.<sup>52</sup> DPOs have an institutionalised system and are registered under FEDOMA.

### **Nature of relationship between NGOs**

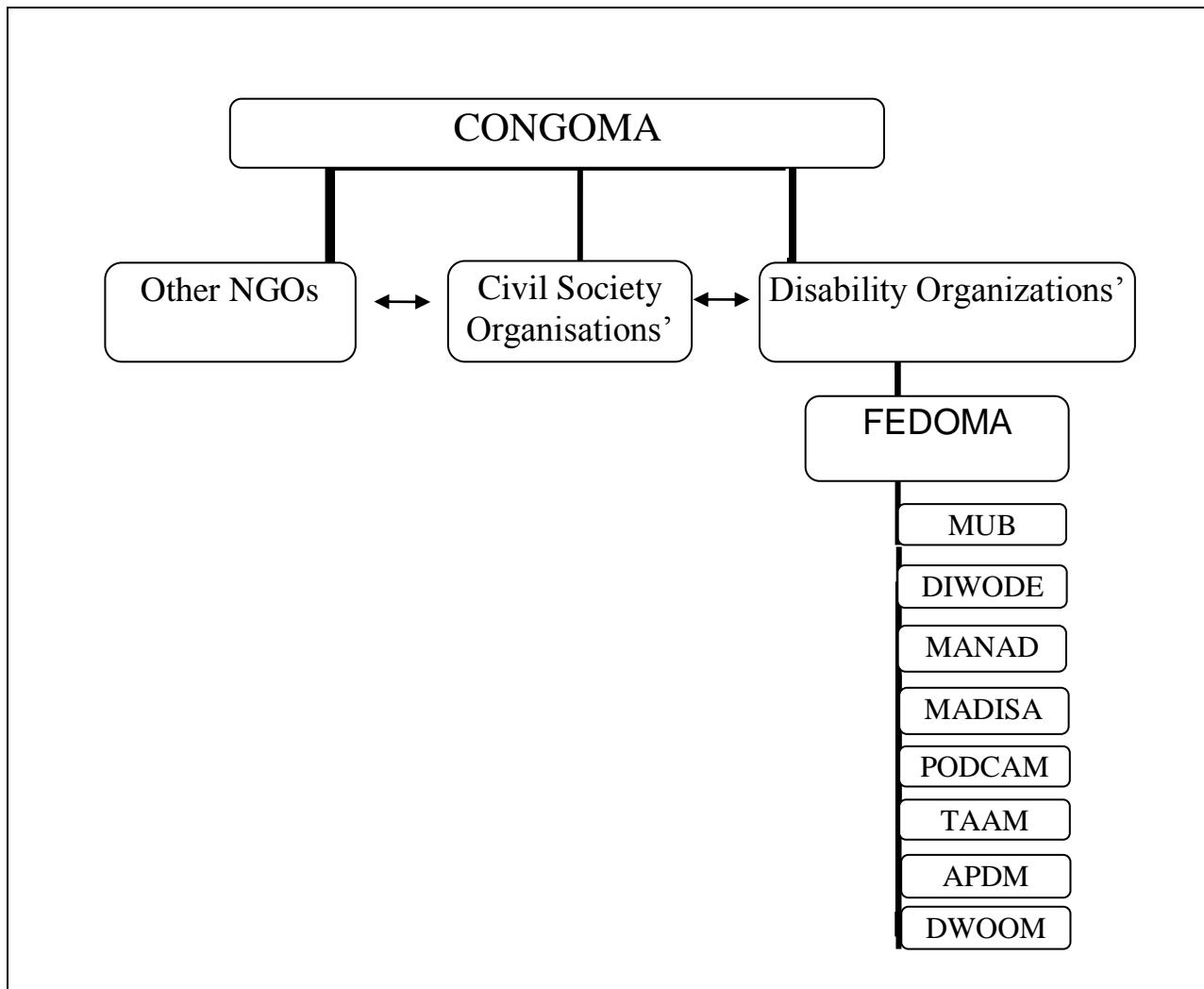


Figure 2: Figure 2 describes the structure of NGOs in Malawi and how FEDOMA is integrated in the institutional system.

The main purpose was to explore how this NGO structure incorporates DPOs to promote their active participation in development cooperation. The nature of the relationship between NGOs and the government in Malawi dates back to 1983 when NGOs formed the Council for Social Welfare Services in Malawi that was functional until 1992 when the Council for Non-Governmental Organisations in Malawi (CONGOMA) was formed.<sup>51</sup> The focus of CONGOMA is on promoting social and economic development of Malawi by facilitating collaboration of different NGOs and the actual impact of NGOs in development of Malawi. FEDOMA is registered through CONGOMA as an NGO representing all DPOs. The current constituents of DPOs include: Malawi Union of the Blind (MUB); Disabled Women in Development (DIWODE); Malawi National Association for the Deaf (MANAD); Malawi Disability Sports Association (MADISA); Parents of Disabled Children Association in Malawi (PODCAM); The Albino Association of Malawi (TAAM); Association of the Physically Disabled in Malawi (APDM); and Disabled Widows Orphans Organisations of Malawi (DWOOM).

DPOs contribute an annual affiliation fee for management and administration of FEDOMA activities. The Norwegian Aid (NORAD) is the sole donor of FEDOMA, hence it is difficult to support all the DPOs financially in order for them to develop their institutional capacity and participate in poverty-reduction processes. FEDOMA is a mouthpiece for all the DPOs in Malawi to advocate and raise awareness on rights and equal opportunities for people with disabilities. Indirect support is also gained from major donors who fund specific projects implemented by DPOs but hosted by FEDOMA, such as the youth development projects; HIV and AIDS projects; disability, poverty and development projects; and education for children with disabilities.<sup>52</sup> In the past three years, a few DPOs, such as Malawi Union of the Blind; Parents of Disabled Children Association of Malawi; Malawi National Association of the Deaf; and Disabled Women in Development have managed to secure funding from international development partners to support their specific projects. DPOs should be empowered to approach donors for financial assistance. Building the capacity of DPOs should be viewed as developing its internal institutional capacity, which will, in turn, influence the internal and external environment in which DPOs operate.<sup>45</sup> There is a need to measure the competence and ability of people with disabilities to influence policy-makers for participation of people with disabilities in development strategies. It has been argued that training or building the capacity of DPOs may not be the only path to reduce poverty among people with disabilities, but rather a means for the group proactively access and control the available resources targeted for them.<sup>44</sup> It has further been asserted that active participation and inclusion of people with disabilities is retarded by lack of basic services.<sup>53</sup> Unavailability and limited access to basic services and amenities make it difficult for people with disabilities to participate in development processes. Developing the capacity of DPOs is vital in establishing a basis for disability issues in the development agenda.

The process of creating an inclusive environment should take into account the provision of disability-friendly services that would ensure total inclusion of DPOs in the development process. As observed in the International Disability and Development Consortium paper, the PRSP process faces numerous challenges in that people with disabilities are still regarded as a social welfare group, rather than an economically active group.<sup>23</sup> In some cases, people with disabilities are not seen as key stakeholders but are considered as guests invited to participate in the process. There is a need to enhance political will and commitment by the Malawi government to invite and involve DPOs in the process of formulating development programme. However, lessons can be learnt from other nations where similar processes of including people with disabilities in development cooperation have been successfully achieved.

## **2.8 EXPERIENCES OF PEOPLE WITH DISABILITIES FROM OTHER NATIONS**

DPOs in Mozambique argue that disability issues are not fully represented and that the basic needs of people with disabilities are not addressed. Due to a lack of capacity, most DPOs fail to participate and demand their inclusion in the development processes. The minimal capacity of people with disabilities puts them at a disadvantage at being actively involved in decision-making in the development programme.<sup>54</sup> It is difficult to influence decision-makers and development actors to address disability issues in the development strategy documents, if disabled people themselves do not present their needs and understand how they may be mainstreamed in society. Capacity-building may mean strengthening DPOs institutional structures. It is stated that developing capacity was like giving DPOs legs with which to walk or on which to stand in order for the society to create an environment that will promote inclusion of disability.<sup>54</sup>

Tanzania was one of the first nations in the Southern African Development Countries (SADC) region to develop a Poverty-reduction Strategy Paper (PRSP). The PRSP process was initially dominated by the donor organisations with limited space for the involvement of civil society and other stakeholders.<sup>55</sup> The Tanzania PRSP addresses disability in its health sector where it mentions the HIV/AIDS prevalence among men and women with disabilities aged 15-35 years; the elimination of all barriers; and improved treatment. It further states the need to improve the nutritional conditions and provision of food supplements to children with disabilities less than five years to promote their quality life.<sup>55</sup> It is argued that the participation of people with disabilities in the PRSP process was very limited in the initial phases. Lack of proper networking between the government, civil society organisation, and DPOs has led to the exclusion of disability issues in the initial processes. Disability issues were gradually addressed in the development plan after participation of DPOs. People with disabilities made demands for the PRSP to address their basic needs and their rights to be respected. Although the PRSP process seems to have been a participatory one, DPOs remained overlooked and were often not invited for consultation. There was limited information exchange and team work among the stakeholders, rather than the sharing of information and involving people with disabilities to contribute to the development of the national strategy.<sup>56</sup> Consequently, there was a need for civil society groups, disability groups, NGOs and other stakeholders to participate and contribute towards the PRSP process. This consultative process

led to the publication of the second PRSP that included disability issues in its development agenda.<sup>57</sup>

In Uganda, although inclusion of disability has taken a central role in the country's development plan, lack of capacity of DPOs poses a serious challenge. DPOs have minimal impact in the planning, implementation, monitoring and evaluation of the development strategies. It is argued that only those DPOs that are well established are invited to participate in this PRSP consultation processes.<sup>58</sup>

The initiatives to reduce poverty in Zambia date back to early 1997 when the then President of Zambia demanded that poverty be reduced from 70% to 50% by 2004. As a result, in 1998 several development strategies aimed at reducing poverty were established, such as National Poverty-reduction Action Plan (NPRAP) and National Poverty-reduction Strategy Framework (NPRS). The NPRS was formed after a consultative process with stakeholders, civil society and government.<sup>59</sup> The PRSP in Zambia was launched in 2002 after nation-wide consultation with stakeholders, civil society, NGOs and donor partners. "The PRSP evolved around the three main themes; economic theme, social theme and cross-cutting theme. The above three themes are developed based on the two approaches (a) Generating sustainable growth and employment; and (b) Providing complementary measures that will directly target the poor and protect them from external and internal factors or the effects of economic reforms."<sup>p.6</sup> Several activities have been implemented as a way of improving inclusion of people with disabilities at all levels, such as the government conducting workshops to raise awareness on disability issues. The United Nations (UN) country team on disability issues has included people with disabilities as representatives of DPOs in their institution to ensure the needs of the group are effectively represented in the developing process of Zambia's 2010-2013 UN development aid framework. International labour law has supported programme, such as the Disability Equity Training for Zambian parliamentarians. The aim was to bring disability awareness at national level, develop capacity for policy-makers to include disability equality in the national parliament. The focus was to encourage the Zambian government to ratify the UN convention; to brainstorm the inclusive initiatives; and to create a favourable atmosphere for people with disabilities.<sup>60</sup> It is hoped that by raising disability awareness, at government and political level, it would promote and facilitate inclusion of disability issues at national level.

## **2.9 DISABILITY MAINSTREAMING**

Mainstreaming disability is "the process of assessing the implications for disabled people of any planned action, including legislation, policies and programme, in all areas of life and at all levels."<sup>8 p.6</sup> Notwithstanding efforts by major donors, governments, and NGOs for people with disabilities, there are indications that there is a slight move towards mainstreaming disability, but that it remains entirely detached from the social and political mainstream.<sup>22</sup> It is a strategy that focuses on making people with disabilities concerns and experiences an integral dimension of the various programmes to ensure that disabled people benefit equally.<sup>61</sup> The International Labour Organisation (ILO)<sup>62</sup> states that disability mainstreaming should aim at transformation of unequal

social, economic and environmental structures or resources to promote equitable participation of people with disabilities at all levels in society. Therefore, it was asserted that the challenges of mainstreaming disability should not be underestimated.<sup>22</sup> Mainstreaming requires involving everyone in the community to understand disability issues. Mainstreaming is not just having people with disabilities present in the consultative meetings, but having the needs and rights of people with disabilities well reflected across all sectors of society.<sup>2,22</sup> Mainstreaming should aim at educating everyone to understand disability issues and bring society to a common level before developing tools for mainstreaming.

Like other forms of disabilities groups, people with physical disabilities still face numerous barriers that delay their needs to be mainstreamed in society. The group has shown dissatisfaction in terms of government support towards their inclusion in community development, loan facilities and inaccessible infrastructures. There is a need for government to pay more attention to empower the group so that they do not lose hope. It is not uncommon for society to have little or no respect or regard for people with physical disabilities, hence no support is rendered to the group to be an integral part of the community. It becomes complex for those involved in small-scale business, because their products can be ignored due to the negative attitudes of people. If the needs of the group are effectively included in the society, it would facilitate an improvement in the quality of life of people with physical disabilities.<sup>63</sup> Furthermore, in Malawi FEDOMA has also called on government to speed up the process of enacting the Disability Bill into a law. It was strongly contested that only through the law could DPOs competently change the negative attitudes of society, policy makers, planners and implementers of various development programmes. In doing so, it would ensure that disability mainstreaming is implemented as a cross-cutting issue in all sectors during the implementation of various projects.

## **2.10 SECTOR POLICY REVIEW ON INCLUSION OF DISABILITY**

In order to appreciate the extent of disability inclusion in the policy environment in Malawi, a policy review of some government sectors was conducted. This was done to examine how the needs of people with disabilities have been built into the sector policies. These policies outline an implementation plan and indicators of success or failure of a particular sector, in terms of contributing to national development strategies. Therefore, policies from selected ministries were reviewed for trends in inclusion of disability: Ministry of Agriculture; Ministry of Transport; Ministry of Health; Ministry of Education; Ministry of Irrigation and Water Development; Ministry of Lands; National HIV/AIDS policy; and Ministry of Labour.

The process of policy review involved collecting all the policies from government departments and those in the private sector who are involved in the policy formation process. They are responsible for ensuring that appropriate consultation occurs during development or review of a policy; procedures are implemented; and compliance is monitored. The context of the policy analysis was on how disability issues have been mentioned in policies and how disability issues have been structured in policies. Some stakeholders involved in the formation and

implementation of the policies, along with particular policy documents and the disability content in which the policies were examined, are presented in Table 1.

Table 1: Stakeholders and context of policy analysis

Stakeholders	Policy documents	Disability content
Government	Food and nutrition policy	How is disability featured in policies?
Faith-based organisations	National transport policy	
Non-governmental organisations	National education policy	Is the language used disability-friendly and acceptable?
Donors	National health policy National water policy National land policy National HIV/AIDS policy National labour policy	How many times is disability mentioned in policy documents?

The MGDS informs all policies, established both by government and the private sector, which aims at reducing poverty, sustaining economic growth, food security, equal opportunities, human rights and improving living condition, of all Malawians. These policies provide technical and administrative guidance in the designing, implementation and management of poverty-reduction interventions, programmes and activities at all levels of the community. The ultimate objective is to achieve the Millennium Development Goals (MDGs) and *Vision 2020*<sup>38</sup>.

### 2.10.1 Food and nutrition policy

The goal of the agriculture sector policy is to significantly improve food and nutrition security for the population. The goal implies a rapid and substantial reduction in the degree and severity of malnutrition, in all its forms; chronic and acute malnutrition and micronutrient deficiencies among men, women, boys, girls, (especially children under five years), and expectant and lactating mothers. The sector policy does not specifically mention the needs of people with disabilities, but gives a general statement on the community, including disability. In its section on social protection the policy states that “Every person has the right to food and nutrition security and a standard of living adequate for health. The policy recognises the pro-poor in society who may require food and nutrition support to reduce their vulnerability and impact of shocks”.<sup>29 p.4</sup>

In the agricultural input subsidies programmes, the policy only mentions targeting the poor farmers in the communities that cannot afford agriculture inputs after exhausting all economic levers.

### 2.10.2 National transport policy

The goal of the policy is to ensure the provision of a coordinated transport environment that fosters a safe and competitive operation which is commercially-viable, financially-sustainable,

and environmentally-friendly. The policy mentioned issues of disability, under the disadvantaged group, who will benefit from the sector plan as one of the overall objectives of the sector. It states that the transport sector will “provide for the needs of the disadvantaged, including people with disabilities, people living with HIV/AIDS, the aged, women and children. Each mode of transport shall recognise and respect the needs of people with disabilities, people living with HIV/AIDS, the aged, women and children without discrimination”.<sup>64 p. 9</sup>

An acceptable level of standards in road traffic management services, with emphasis on road safety, can be ensured on Malawian urban and rural road network. Budgetary provisions should protect the expensive capital investment in the road system and safeguard the interests of people with disabilities. This policy specifically suggests strategies for the establishment of a fund, from which money shall be used for road traffic management and HIV/AIDS mainstreaming.<sup>64</sup> Therefore, there is also a need to put deliberate strategies in the sector that will promote accessibility and mainstreaming of disability issues. The transport system in Malawi encompasses air transport, rail transport, road transport and marine. Although the transport sector has witnessed a rapid growth and development in terms of new roads and road maintenances, private sector involvement is in providing the service, and physical and policy development on road safety. The transport sector still poses a huge barrier when it comes to accessibility by people with disabilities. There are limited road safety measures for people with disabilities, with a lack of public transport such as buses, minibuses and taxis that are accessible for people with disabilities. The water vessels are not user-friendly for people with disabilities.

### **2.10.3 National education policy**

Education is believed to be critical and necessary for economic and industrial growth and poverty-reduction. The Ministry of Education, Science and Technology is the key ministry responsible for basic education, secondary education, tertiary education, technical and vocational education in Malawi. The mission is to provide quality and relevant education to the Malawian nation. This sector promotes education in Malawi, irrespective of race, gender, ethnicity, religion or any other discriminatory characteristics. The education policy seems to have clearly articulated issues of disability, by looking at both interventions that may specifically assist the health status of people with disabilities, as well as influencing government to transform the education curriculum to create a better learning environment for people with disabilities.

Adult illiteracy remains high in Malawi with more women being affected than men. The challenge the sector is facing to mainstream disability is the lack of a special needs curriculum for non-formal education. This has led to limited integration of people with disabilities in adult education programmes. The policy mentions improved provision of teaching and learning materials and also advocates targeting men and other adults with special needs. “The policy mentions the need to develop appropriate tools for special needs such as sign language and Braille and make science and technology visible”.<sup>65 p.7,11</sup>

At secondary and tertiary level, the policy mentions the need to mainstream special needs education in all programmes and among staffs. In order to promote equity and access to

education, the policy has suggested the need to develop a special needs unit to coordinate and monitor special needs programmes and to train special needs teachers.<sup>65</sup> The special needs education unit is under the Ministry of Education headquarters and key in formulating a special needs education policy. The special needs education policy aim at providing quality and relevant educational support to learners with special needs which include people with disabilities.<sup>66</sup> The policy take into account the following impairment or learning difficulties namely; physical disability, intellectual disability, language and communication difficulties and emotional and behavioural difficulties. These learning needs put learners with special needs which include disability at a disadvantage and hinder their participation in education. Often there is stigma and negative attitude in the community and at school that leads to exclusion from school activities, bullying, physical abuse and high risk of school dropout. Therefore, the policy emphasises the need to create a conducive learning environment, modified teaching aids and specialised assistive devices to support the learners. It is important to recognise the effort by government to support the education sector in terms of the encouraging education for disable people and inclusion of disability issues in the sector. Some of these include: introduction of electronic books for people who are visually impaired to be used in schools; promotion of disability sport; introduction of talking computers; and inclusion of special needs curriculum in teacher training institutions. This is as a result of a strong policy framework for learners with special needs and sound action by the Malawi government and donors on disability agenda.

#### **2.10.4 National health policy**

In Malawi, government is on the forefront, developing health care strategies that will indicate disease incidence, distribution and prevention measures. The health care strategy looks at the effect of the various diseases on the patient, family, community and the environment. Health services basically focus on the prevention, treatment, rehabilitation, and management of illness and the wellbeing of the person, both psychological and physical.

The health policy in Malawi is championed by the Ministry of Health and Population and promotes equitable access to health facilities for all. The policy on health promotion, preventive and rehabilitative services (sub-theme medical rehabilitation services), mentions “the need to establish a mechanism for early identification, follow-up and referral of people with disabilities and the "at risk" groups. It also states the need to train more rehabilitation professionals and mid-level rehabilitation workers to be integrated in the district hospitals”.<sup>67 p.56, 57</sup>

The health sector in Malawi still poses great challenges to people with disabilities when it comes to access to free health services - buildings are not accessible and health facilities are situated far away. Worst affected are pregnant women with disabilities and children who need to benefit from the services. Negative attitudes of some health personnel and increased social stigma have led most women with disabilities to avoid proper health facilities and instead prefer traditional birth attendants. Because of the minimal care given to women at these traditional birth attendance services, there is the risk of further disablement and other complications during child birth that may have been prevented.

## **2.10.5 National water policy**

The vision of this sector is *Water and Sanitation for All, Always*, based on the country's central policy of poverty-reduction and economic prosperity and the fact that water is potentially the engine for social and economic development in Malawi. This vision ensures that every Malawian has equitable access to portable water and sanitation services for sustainable socio-economic development and enhancement of the country's natural ecosystems. The overall national water policy goal is sustainable management and utilization of water resources, in order to provide water of acceptable quality and of sufficient quantities, and ensure availability of efficient and effective water and sanitation services that satisfy the basic requirements of every Malawian. The water policy mentions issues of disability in its section on rural water services. The aim of the policy is "to promote active participation of youth, women, people with disabilities and vulnerable persons in planning and implementation of rural water supply and sanitation activities".<sup>68 p.13</sup>

The challenge for the sector is to provide services such as boreholes and latrines that are accessible to people with disabilities. There is a need for the policy to build on strategies that will guide implementers on suitable water facilities that are disability-friendly.

## **2.10.6 National land policy**

The goal of the land policy is to ensure tenure security and equitable access to land, to facilitate the attainment of social harmony and broad-based social and economic development through optimum and ecologically balanced use of land and land-based resources. It consists of a whole complex of socio-economic and legal prescriptions of land tenure, land resources and shows how benefits from the land are to be distributed. The policy objective is to ensure equal opportunities for the acquisition, use and enjoyment of land for all citizens. One of the guiding principles of the policy is targeting the vulnerable groups. The policy states that "land policy is primarily concerned with social actions that influence and control people's use of the land. More often than not, the rights of women, children and the disabled are denied on the basis of customs and traditions that are no longer relevant, or they are totally disregarded due to prejudice and lack of effective representation. A clear policy on gender access and the rights of children and the disabled should always be considered in policy planning and implementation strategies".<sup>69 p 17</sup>

Often people with disabilities are denied access to land and agricultural inputs as they are seen as unproductive. There is little access to agricultural technologies that are user-friendly to people with disabilities for use on their land and this has left the group with no option over the best use of their land. The policy should not only promote access but also address issues of legal land ownership either by the individual with a disability or care givers who will use the land productively to support the disabled person.

## **2.10.7 National HIV/AIDS policy**

The goal of the policy is to prevent further spread of HIV and mitigate the impact of HIV/AIDS on the socio-economic status of individuals, families, society and the nation. The policy aims to

improve provision and delivery of prevention measures, treatment, and cure and support services to people living with HIV/AIDS. The emphasis is to create an enabling atmosphere that will reduce individual and community vulnerability to HIV/AIDS. One of the policy guiding principles is promotion and protection of human rights. It states that “ international human rights law and the constitution of Malawi guarantee the right to equal protection before the law and freedom from discrimination on grounds, singly or in combination of race, colour, sex, language, religion, political or other opinion, nationality, ethics or social origin, disability, property, birth or other status”.<sup>70 p.6</sup>

The policy has indicated that people with disabilities are vulnerable to HIV/AIDS as a result of discrimination that limits the group from getting access to HIV/AIDS information and services. The policy needs to indicate strategies that should be put in place to promote access to HIV/AIDS information, counselling and free treatment. There is also a need to change negative myths, such as that disabled people cannot be affected by the virus and that, in some societies, it is believed that sleeping with a person with a disability cures the disease. The policy should provide a legal framework to protect people with disabilities and raise awareness on such mal-practices by some section of the communities.

### **2.10.8 National labour policy**

In part two of the national labour policy’s fundamental principles, it states that no person shall discriminate against any employee or prospective employee on the ground of race colour, sex, language, religion, political or other opinion, nationality, ethics or social origin, disability, property, birth, marital or other status or family responsibilities in respect of recruitment, training, promotion, terms and condition of employment, termination of employment or other matters arising out of the employment relationships.<sup>71</sup> The policy further states that every employer shall pay employees equal remuneration for work of equal value without difference or discrimination of any kind, in particular on the basis of disability status. The policy has no specific provisions on programmes and activities that may improve equal employment opportunity of people with disabilities. Disabled people face difficulties and challenges in the market place, due to minimal qualifications and training, as well as increased competition in the labour market. Consequently, negative attitudes among employers, who view disability as costly and unproductive, along with inaccessible workplaces, do not support the optimal functioning of people with disabilities.

## **2.11 CHAPTER SUMMARY**

A review of the literature in this chapter has demonstrated that there is a link between disability, poverty and the MGDS. Although disability issues are mentioned in the MDGS, the document does not feature disability as a priority. The MGDS is the main policy document that guides programmes for reducing poverty in Malawi. There is a need for a concerted effort to specifically include disabled people in poverty-reduction programmes. Donors, however, have developed poverty-reduction initiatives within their organisations that may link directly with disability organisations. The emphasis on the poverty-reduction approach is to include disabled people in

the national programmes, so that this group may be empowered to participate in the development process. It is noted that even the inclusion of disability in global initiatives is very slow.

Although disability was mentioned in almost all policy documents that were reviewed, it was not given the necessary and equal priority in these specific sector policies. The policies do not give a specific plan of action that could be implemented to address the needs of people with disabilities. In addition, it was revealed that some policies still use words that are believed to be discriminatory, such as ‘the disabled’ to refer to people with disabilities. Although disability is mentioned in these sector policies, people with disabilities have not moved out of poverty and have little access to key social services. If the needs of people with disabilities are to be addressed and disability mainstreaming promoted, there should be a deliberate monitoring and evaluation tool that will measure the impact of specific policies on disability inclusion in order to ensure a better life for people with disabilities.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1 RESEARCH DESIGN**

This is a qualitative research paradigm, which is a scientific means for providing a complex description of the human side of the research topic.<sup>72</sup> A qualitative research paradigm brings an understanding of a complex subject or issue and gives an in-depth description of that particular subject.<sup>73</sup> An exploratory design was used to achieve the aim of the study. This involved the exploration and description of an ongoing process of developing poverty reduction strategies in relation to participation of people with disabilities. In essence, an exploratory study employs a detailed exploration of a particular situation of a specific interest, usually it uncovers possible avenues and enables a detailed examination of the situation in developing realistic options<sup>74</sup> This design was chosen because it gave the researcher a perspective of the research question and social context of the local population to increase understanding of a concept and to clarify the exact nature of the problem to be solved.

A qualitative exploratory study design helped the researcher to explore the topic in a detailed manner, through in-depth interviews and focus group discussions. Individual in-depth interviews further helped the researcher to show the relationship between events and gave a comprehensive contextual analysis of the process of formulating the development strategies. An exploratory study is advantageous in that it gives an in-depth description of the topic being investigated in a local setting. Thus, according to Yin<sup>75</sup>, observing the unit in their habitat helps to have a contextual understanding of every unit, without manipulating their behavior. It also helped the researcher to examine a wide range of areas in order to have a holistic understanding of the important events in these processes. The disadvantage is that the technique is microscopic in nature, as it is dependent on a single case to give a generalised conclusion.<sup>76</sup>

#### **3.2 STUDY SETTING**

The research was conducted in three cities, one in each of the three regions of Malawi namely, Blantyre in the southern region, Lilongwe in the central region and Mzuzu in the northern region. These cities were chosen because they are central to each of the three regions and they host most government policy makers, donors and NGOs that work for, and with, disabled people.

#### **3.3 STUDY POPULATION AND SAMPLE**

The population consisted of individuals and institutions that are involved in disability issues, poverty-reduction activities, policy development and human rights activities. Included in the study were people with disabilities, government officials, development partners, disability activists, civil society organisations (CSOs), non-governmental organisations (NGOs) and professional organisations (see Appendix D). The study included both people with disabilities and non-disabled people to ensure involvement of all stakeholders throughout the research process. The disabilities that were represented in the study included vision impairment, hearing

impairment, albinism and physical disability. A purposive sample of 45 participants was selected for this study, 18 of whom were people with disabilities. The number of people with disabilities in each region were as follows; six from the central region, ten from the southern region and two from the northern region. This difference in numbers is attributed to the fact that more people with disabilities have easier access to FEDOMA and some DPOs that are mainly based in the South. The researcher developed a semi-structured interview guide that was used in the study (see Appendix E). The semi-structured interview guide allowed the researcher to obtain open responses to the questions. The sequence and wording of the questions was decided upon by the researcher during interviews. Purposive sampling enhanced the selection of information-rich informants that provided insight and understanding into the study,<sup>77</sup> hence the choice of the method for the study. A total of 15 key informants were interviewed, nine from the central region, four from the southern region and two from the northern region. Snowball sampling was used to identify 30 respondents who participated in focus group discussions. In each of the three regions of the country, 10 participants were identified to participate in focus group discussions. The advantage of purposive sampling is that it allows the researcher to select participants who are knowledgeable in the subject being researched and are likely to produce the most valuable data. Hand picking participants is less time-consuming and less costly. The drawback of a purposive sample is that it is not workable to include a large number of participants in the study.

Snowball sampling involves asking key informants to nominate new individuals perceived to be knowledgeable and who should be interviewed to add insight to the research question.<sup>78</sup> One advantage of the snowball sampling is that it helps the researcher to use the social network of the informants to recruit a hidden population that may have the potential to contribute to the study.<sup>79</sup> A limitation of snowball sampling method is that sometimes informants may nominate individuals with whom they share common views. Therefore, it may be difficult to have a candid distribution of views of the targeted population. The actual sample size was determined during data collection and ongoing analysis, when the researcher attained data saturation on the basis that there were no longer new viewpoints to the study.

Among the three regions of the country, there were differences in terms of the number of individuals who were involved in poverty-reduction processes or were knowledgeable about the processes. The central region had six government officers, two donors, one NGO and one individual who participated in the study as key informants who were directly involved in the MGDS process. Out of the 10 participants in focus group discussion in central region, four participants had been personally involved in the MGDS process and six were not involved, but had seen the MGDS document. The southern region had one government officer and two NGOs as key informants who had been active in the MGDS process and none of the participants in the focus group discussion had been personally involved in the MGDS process. In the northern region one key informant from an NGO was involved in the process and none of the participants in the focus group discussion had participated in the MGDS process, but had used the document in their various sector projects. There were eight DPOs, one CSO, two donors, one NGO, one CBO, and 32 participants were individuals holding decision-making positions from government

departments, ministries and disability activists. It can be concluded that the views of these people may have been influenced as a result of the political, social and economic situations in the three regions.

### **3.4 DATA COLLECTION**

The study employed two methods of data collection - key informant interviews and focus group discussions, as presented below.

#### **3.4.1 Key informant interviews (KII)**

These are qualitative in-depth interviews with people who are especially knowledgeable and have actual information on the subject, in this case the involvement of people with disabilities in development programmes and disability issues.<sup>10</sup> Key informant interviews help in establishing the inside views of people and clarifying matters regarding the subject under discussion. They also help in obtaining vital information about the ‘silent’ minority, which included people with disabilities. Key informant interviews provided useful information on inclusion of disability in the development process and allowed the researcher to develop strong relationships with main stakeholders who were involved in the MGDS formulation process.

The drawback of the technique is that it is sometimes difficult to get hold of informants as most of them are very busy people. The method may be subjective because of the relationship between the researcher and the informant. It is complex to develop trust in the informants as some may have biased views.<sup>80,81</sup>

The Ministry of Persons with Disability and the Elderly and FEDOMA were contacted in the initial planning stage to recommend well-informed participants for this study. Each potential participant was contacted either by telephone or by letter, in which the aim of the study and the participants’ expected role was explained such as their availability and ensure co-operation during the study.(see Appendix F). If the participants were willing to participate, the date, time and place of the interviews were decided upon, based on the key informants’ preference. The researcher travelled to meet each participant either at home or work in order to conduct the interview. Prior to commencing the interview, the researcher chose a quiet environment or asked the key informants if they had access to a quiet and comfortable room in which to conduct the interview. The researcher introduced himself and explained the aim of the study to each participant. Participants were assured of confidentiality and informed that they had a right to withdraw from the study at any time should they feel uncomfortable, with no consequences to them. Informed consent was obtained (see Appendix G) and permission was sought to tape record the interviews and each interview lasted about one and a half hours. At the end of each individual interview, the researcher asked the key informant to suggest a list of names of potential people to be included in a focus group discussion.

Probes were used to elicit further information from participants during interviews. Field notes were taken during the interview to supplement the tape-recorded data. The interviews were

transcribed and some clarifications in *Chichewa* (local language) were translated by the researcher.

### **3.4.2 Focus group discussions (FGD)**

A focus group discussion is a qualitative interview of a homogeneous group of six to 10 people that interact to discuss a specific topic under the guidance of a leader.<sup>82</sup> The technique is advantageous in that it offers flexibility for participants to interact. It also allows the researcher to probe and obtain information and clarity on pertinent issues. The weakness of the method is that it is susceptible to bias by the researcher, who has the freedom to choose what information he wishes to transcribe. Participants who are vocal tend to dominate the discussion, hence preventing others from sharing their views. The researcher requires skills in group dynamics and knowledge in conducting successful focus group interviews.<sup>83</sup>

Prior to commencing the FGD interview, the researcher chose a quiet and comfortable environment which was accessible to all participants. Three FDGs were conducted, one in each of the three cities. The first took place at St John of God College of Health Sciences in Mzuzu, the second at the Ministry of Peoples with Disabilities and Elderly in Lilongwe, and the third at the Federation for Disability Organisation in Malawi in Blantyre. The researcher introduced himself and explained the aim of the study to the participants, who were assured of confidentiality and informed that should they feel uncomfortable they had the right to withdraw from the study at any time, with no consequences to them. Informed consent was obtained through signing consent forms (see Appendix H) and permission was sought to tape record the interviews. Each FGD interview lasted between one and two hours. All interviews were conducted in English with clarification in *Chichewa* (English and *Chichewa* are the two national languages) where necessary. Probes were used to elicit more information from participants. All participants were given the same opportunity to express their views, which were respected. Participants would confirm the opinion of others by actively confirming something and nodding their head whilst others might make a different remark. Field notes were taken during the interview to supplement the tape-recorded data. The researcher began with listening to the recorded data, one by one. Interviews were transcribed verbatim and transcripts were taken back to participants for verification.

## **3.5 DATA ANALYSIS**

A thematic content analysis was used to analyse data. Transcripts were read several times until the researcher was familiar with the main issues being raised. Information based on the main objectives was coded using different colors, according to frequently raised issues. The codes were grouped into categories from which main themes were generated to answer the research question.

After verification of the data, the initial analysis of the key informant interviews was conducted. The evidence gathered depended on each key informant's experience and their willingness to share information with the researcher. Participants' viewpoints were common in most interviews.

Each key informant interview was analysed to search for common patterns and categories. As a follow-up step, once the data was analysed from key informants, main issues were taken up for further discussion in three focus groups. It was decided that the interaction of participants in the focus groups would be useful to stimulate more views and explore in-depth ideas on the key issues. The transcripts from each focus group were read independently and data were coded and analysed. This helped the researcher to clarify the categories and sub-categories. After presenting the findings of the key informant and focus group discussion, the data were cross-examined for similarities and differences, based on the aim and objectives of the study.

Data analysis flow chart

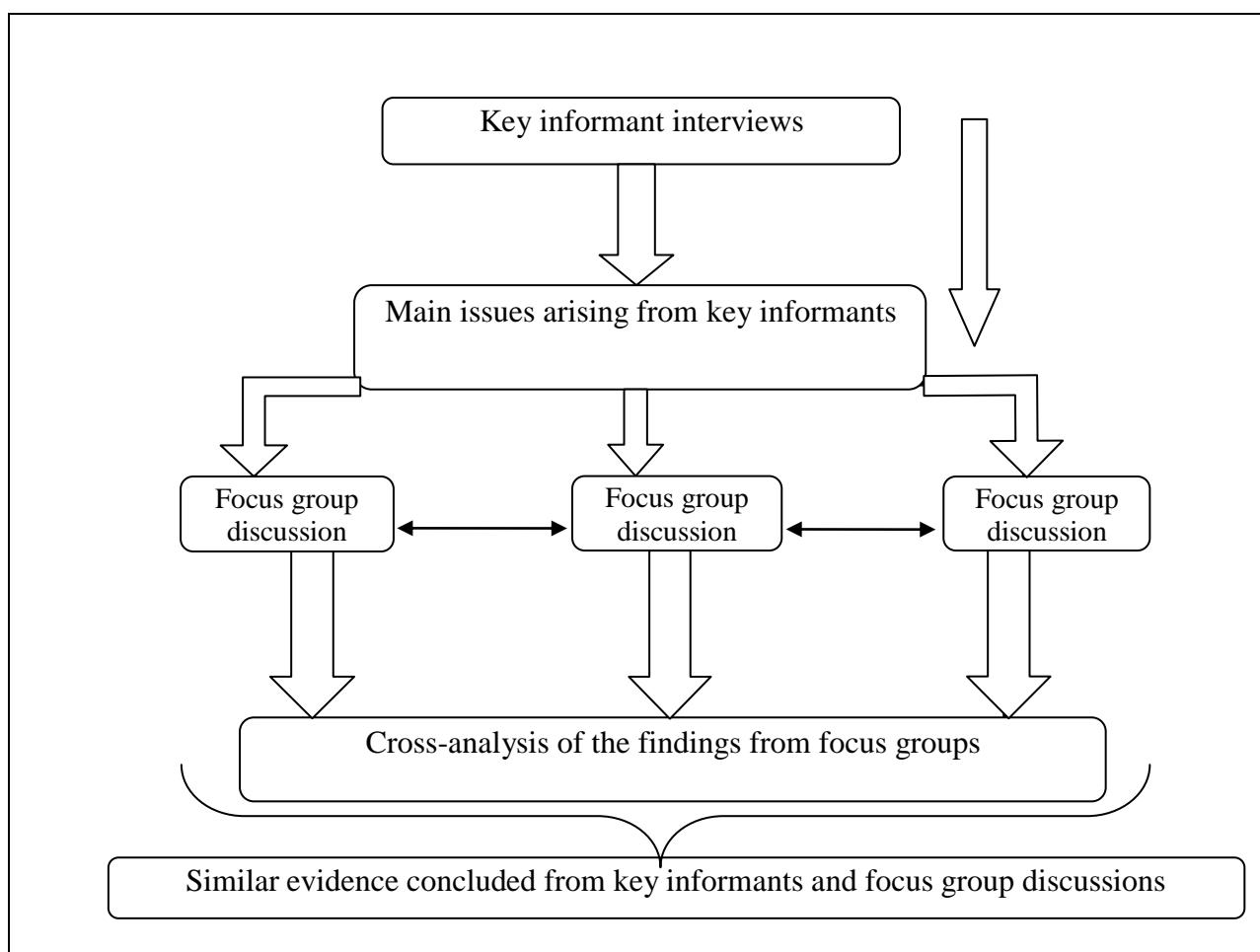


Figure 3 shows how information flowed from key informants' interviews into focus group discussions.

### 3.6 ETHICAL CONSIDERATIONS

Prior to beginning the study, permission was sought from the Stellenbosch University Research Ethics Committee (see Appendix I). Further permission was sought from the National Health Sciences Research Committee in Malawi (see Appendix J). Participants were given information sheets to read and consent forms to sign, should they agree to participate in the study (see Appendix H). They were also assured of their right to withdraw from the study at any time without being required to give reasons, and without any consequences to them. Anonymity and confidentiality was ensured in order to protect key informants' identity. Participants in focus group discussions were assured of confidentiality and told that information from this study would only be used for research purposes.

### **3.7 CHAPTER SUMMARY**

This chapter describes the methodology used in the study. The two different qualitative methods used to collect data were key informants interviews and focus group discussions. Ethical issues were addressed during the study, with each participant signing a consent form to participate in the study. Assurances around confidentiality and liberty to leave the interviews or discussion were given. A context data analysis method was used to analyse data.

## CHAPTER FOUR

### PRESENTATION OF RESULTS

The following chapter presents the findings, based on the objectives of the study. To achieve these objectives, key informant interviews and focus group discussion were used, each guided by a semi-structured interview guide. The component of each interview guide had questions that requested participants in the study to provide answers as to how people with disabilities were involved in the poverty-reduction strategy process; at what point was their involvement in the process initiated; how were their contributions fulfilled; and what were the factors that led to the involvement of people with disabilities. Information from key informants and focus group discussions were analysed thematically. The themes and sub-themes, which emerged from this analysis, are presented in Table 2. Pseudonyms are used to represent key informants and letters of the alphabet (A-F) are used to represent participants from focus group discussions (see Appendix K).

Table 2: Emerging themes

<b>Theme</b>	<b>Sub-themes</b>
4.1 The PRSP/MGDS process	4.1.1 The PRSP process 4.1.2 The MGDS process 4.1.3 Relationship between PRSP and MGDS
4.2 Barriers to participation	4.2.1 Self –representation of people with disabilities 4.2.2 Capacity of disabled people’s organizations 4.2.3 Education Standards 4.2.4 Negative attitudes towards disability
4.3 Disability inclusion	4.3.1 Definition of disability inclusion 4.3.2 Invisibility of vulnerable groups

Table 2 shows the three main themes and seven sub-themes that emerged from the analysis process and these will be used to explain the findings.

#### **4.1 THE PRSP AND MGDS FORMULATION PROCESS**

Although the PRSP and the MGDS are not really different strategies, each process will be discussed separately to bring out some aspects that were not clearly described in the process of formulating the two national development strategies.

##### **4.1 .1 The PRSP process**

This study has established that the development of the PRSP was initiated by the World Bank and the International Monetary Fund. However, participants acknowledged that the consultation process for formulating the PRSP was done across all levels of Malawian society, as stated by a key informant:

Tadalah: *Of course, the idea comes from Washington but it would have been left to the owners. It's like this is our (donor community) idea but do it yourself, it was after the donors that we (government) were discovering the (important) areas. If these exercises are homemade you create a lot of ownership and involvement of everybody and there is commitment by the owners of the process.*

This indicates that although the idea of the PRSP was donor-driven, the actual process was consultative in nature. In fact, it was during the PRSP process that the government identified its own key priority areas for the development strategy. At the end of the exercise, the government was able to own the document because, in the view of a key informant, it had participated fully in its formation:

Mzati: *I would say, I look at it (PRSP) being a Malawian document even if the funding was provided by the donors. But in terms of identifying what kind of areas should be included, it was different stakeholders putting their minds together to say this is what we are supposed to do.*

It is important that the PRSP was recognised as a domestic poverty-reduction strategy. In this way, the government did not only claim ownership, but decided to link the budget to the PRSP. However, one participant's concern was in relation to the power that the donors still have over the country's development agenda:

Tadalah: *We did a situation analysis to identify the priorities, but the donors still come in to say, well, we will support this and that only. We (government) then said that PRSP should be linked to the budget; the national budget should answer the issues in the PRSP.*

In the context of this study, certain criteria were used to select stakeholders to participate in this process. These were that the government wanted everyone to participate, hence it was at liberty to invite the relevant stakeholders to articulate the national agenda for development. The study has established that the government consulted the Council for Non-Governmental Organisations in Malawi (CONGOMA) to provide names of NGOs to be part of a particular work sector group. As an umbrella body for all NGOs and civil society organisations, the council did internal consultations to identify which NGOs would join and participate in a particular work sector group. A key informant in the study explained:

Mzati: *After some consultation CONGOMA would identify which NGO or civil society that can join a particular thematic group in the process of developing the PRSP. Basically it was up to the CONGOMA to say this is the organisation that we want to be our representative in the formulation process in this area and in this thematic group.*

As indicated above, CONGOMA was expected to coordinate the invitation process and bring in sector representatives to the consultation meetings. The participants acknowledged that they do not recall much publicity from the council and the government about the consultation processes. This may have been the reason that there was limited involvement of some DPOs in the formation process. A key informant from the disability movement agreed that publicity of the consultation process was a problem.

Ngozo: *Many of us (DPOs) didn't even know what was there (content and context of PRSP). We did not know about the PRSP because we were not involved in the initial stage during the consultations.*

Although the government and CONGOMA might claim that the PRSP process was consultative at all levels, this key informant reveals that DPOs were not part of the wide consultative

meetings in the sector working group. However, DPOs were involved later in the process, but their participation was minimal:

Participant B: *So to have self-representations in these meeting, we would love to have representation in there, definitely we would show our faces there if at all we (DPOs) were invited.*

The researcher's view is that self-representation would not only influence DPOs' active participation, but would also enable them to challenge other views that affected their participation in the sector working group. In the case of this study, it has been shown that there were gaps in the PRSP process, in terms of disability issues. Apart from the effort by the government to make the PRSP process 'homemade', by involving local stakeholders, it also decided that this document was not comprehensive enough in terms of economic development.<sup>37</sup> It was important to develop another version that would encompass a wider development agenda for the country hence the formation of the MGDS.

#### **4.1.2 The MGDS process**

The study has established a uniform experience and views for both key informants and focus group discussions on the structural framework of the process of developing the MGDS document. The similarities across all interview responses, was that the process started with wide sector consultations at all levels, as it was with the PRSP. Each sector working group included government departments, donors, civil society, private sector, civil society, churches, NGOs and activists. It was after the process of consultation that key areas, which would make economic sense and bring about development, were identified. As a second stage, the key areas were then fed into the national committee for technical and political input.

However, it was during these consultation meetings that people with disabilities had limited participation. As described previously in the PRSP process, the problem of not actively involving people with disabilities was carried over into the MGDS process. According to one key informant:

Mzati: *In the sector working groups' participation at grassroots level was not active for people. DPOs and people with disabilities themselves did not fully contribute to the with disability discussion in the sector groups. One of the things (leant in the MGDS processes) is that it is good to consult, to have as wider participation as possible, in terms of involvement of different stakeholders. In that way, it brings in the issue of ownership, but at the same time it poses a challenge when it comes to inviting various institutions or organisations to participate in the process.*

Additionally, a participant from a focus group discussion emphasised the need for DPOs and government to work in concord with each other. It was important to hear from the government the various functions that the general public could play in the consultation process, before the process begins. This would allow DPOs to recommend what the necessary procedures were; for them to be part of the MGDS process in the early stages; and for them to make a choice on which sector working group to join:

Participant A: *When they are having these meetings (MGDS consultative meetings) it's not as open as we (DPOs) would expect that we hear that these meeting are taking place*

*and they are working on it (MGDS document). The only thing we hear is that they are launching it, so that is also the main problem for us (DPO) to be involved.*

The MGDS was an aspiration of the government. It was the Ministry of Economic Planning and Development that coordinated the consultations and the whole process of formulating the document. The process of monitoring and implementation was supposed to involve everybody. For this reason, ministries and NGOs undertook their own monitoring, and were encouraged to assist communities, including DPOs, to carry out community-based monitoring functions of the development projects.

However, despite participation of NGOs, and their commitment in the monitoring and evaluation of the MGDS process, the participation of faith-based organisations in the consultations was limited. Yet, they are vital in the implementation of various charitable projects and policy reforms, targeting people with disabilities, women, children and the elderly. Faith-based organisation act as a bridge between the community and policy makers, as one key informant pointed out:

*Tadalafil: The church community is part of the NGOs but it was not involved very much, but later in the draft and the launching they were involved.*

As this informant demonstrates, even though the consultation meetings were participatory, and recognised various sectors, there was a need for more commitment by the government to regularly involve DPOs and religious organisations in the sector wide consultation process. This would ensure that people with disabilities are given a chance to participate and contribute in all the stages of formulating the MGDS. It was observed that the process of formulating the PRSP and the MGDS was similar, hence the need to examine their relationship.

#### **4.1.3 Relationship between PRSP and MGDS**

The study has drawn a distinction between the PRSP and the MGDS formulation process. The former involved few stakeholders during the consultation process. The latter was thought through and well-structured with indicators set for each particular sector. However, participants in the study were concerned that the needs of people with disabilities were only vaguely covered in the MGDS. Lack of proper indicators set for the disability sector could be as a result of inappropriate identification and invitation of DPOs in the processes.

*Ngozo: The difference is the process itself of coming up with the two documents. In the PRSP there wasn't much involvement of People with disabilities, to them at that time, I don't know may be their understanding of the DPOs were different.*

The study has revealed that during the PRSP consultation process, the government had involved the Malawi Council for the Handicapped (MACOHA) as a DPO, yet it is a government agency. As a government department, it appears that it was easier for the government to invite MACOHA than the DPOs, whose functions are independently managed by people with disabilities themselves. Participants were concerned that MACOHA would not strongly articulate the real needs of people with disabilities as it would not be able to argue against the government, which is their main sponsor.

Furthermore, it can be argued that the failure of the PRSP to be linked fully to the national budget could be a good reason for not conducting wider consultations and appropriate identification of DPOs. Such positions have come under attack and the reason for this could be because organisations, of and for people with disabilities, are stakeholders who play a key role in implementation, monitoring and evaluation of the strategies at all levels. The link to the budget did not only make the two strategies domesticated, but also ensured sustainable implementation, so that society would receive correct intervention, as outlined in the PRSP and MGDS. A participant in a focus group discussion explained:

*Participant F: There was a series of consultations; chiefs, politicians and civil society organisations were widely consulted in the formulation process of the MGDS than the PRSP. The PRSP was not fully implemented and linked to the budget but there is a strong link between the budget and the MGDS.*

As described above the process of formulating the PRSP and MGDS had limited participation of people with disabilities. Disability issues are not adequately featured in the sector working group, yet this is the level where the situational analysis is done to identify priority areas. There is a need to have a strong voice at this primary level. This is important because the DPOs would be able to articulate their own concerns and provide information so that people with disabilities are not seen as a problem in the process.

## **4.2 BARRIERS TO PARTICIPATION**

Evidence from the study has shown that participants see that there are various factors that may influence active participation of people with disabilities in poverty-reduction programmes and disability awareness initiatives. Dealing with these factors could bring hope and increased abilities of people with disabilities in all stages of the MGDS process. The following section, explores in detail, some of the barriers to participation of people with disabilities.

### **4.2.1 SELF-REPRESENTATION OF PEOPLE WITH DISABILITIES**

The participants in the study acknowledged that people with disabilities were given an opportunity to look at the final MGDS draft, but it was too late to make any substantial changes to the document and be present in the draft consultative meeting. However, in terms of DPO representatives being invited to the initial meeting, there was not always an appropriate representative that could attend these meetings. One key informant was not sure how much the Federation of Disability Organisations in Malawi (FEDOMA) coordinated the other DPOs, particularly if the federation was the only representative of people with disabilities in the process.

*Nambewe: We (disability movement) need to examine to what extent FEDOMA is coordinating effectively the involvement of the DPOs notwithstanding their capacity. We can just look at the aspect of coordination to what extent this link organisation involved with the public sector arrangement in terms of formulation of these poverty-reduction strategies.*

The study has revealed that it was only the executive director of FEDOMA, and those from the Malawi Council for the Handicapped (MACOHA), who actually participated in the MGDS process. Despite having representatives on disability matters, participants were concerned that

the disability sector did not have many advocacy groups or individuals to bring awareness to the process, possibly because it had to do with gender issues. However, one key informant explained the need to have many disability institutions and DPO representatives in the process.

*Yayah: If FEDOMA is the representative and they have also other institutions like the school for the blind, hearing impairment. To me those (individual DPOs) should be part of the process and go to present the various forums in terms of joining in any discussion or negotiations for disability inclusion.*

It is also worth noting that participants expressed a wish that institutions, like the Ministry of People with Disabilities and the Elderly, would bring disability awareness, at policy level, to the process. At political level it is assumed that involving the Ministry of Persons with Disability and the Elderly may be advantageous. In the quotation below, participants in this study were concerned that the ministry might focus too much on the elderly, and argued that there was a need to balance the activities and resources. As a ministry that is championing both the disability sector and the elderly sector, there is a need to develop and implement policies that will address the particular needs of each sector.

*Participant D: The crucial problem we (people with disabilities) are having in the recent years is that the ministry has little focus on disability than the elderly side, all because of dealing with persons not policy. We need to talk about policy not persons, a policy that is disability friendly.*

Furthermore, one of the participants in a focus group discussion explained that policies could ensure that everybody would know about disability issues and would be convinced of the need to address these issues. It is hoped that defining the roles of each sector within the ministry could avoid emotional reactions in the disability sector, which are often assumed to be difficult to deal with. DPOs need to advocate and lobby for equal sharing of meagre resources within the ministry and policy reforms.

*Participant A: Policy makers should understand that when we (people with disabilities) are advocating for inclusion of disability we are talking of managing policy not people. The most important thing is that we should be one as disability groups. We need to work as a team so that any anomaly that we discover in the MGDS process, DPOs should speak with one voice.*

As a cross-cutting issue, disability may not be represented only by MACOHA/FEDOMA and the Ministry of People with Disabilities and the Elderly. The culture of relegating disability issues to a few organisations, may affect how disability issues would be included and represented in all sectors of life. This is because only those institutions in the disability sector would include disability issues in their programme rather than all stakeholders taking the responsibility.

It is important to consider self-representation of people with disabilities in development initiatives. A participant in the key informant interviews was particularly worried about how issues of disability are represented within the structural capacity of the ministry and FEDOMA, in terms of coordinating and uniformly addressing such needs. Specifically, developing a network at grassroots level might provide a foundation to capture the interest of the various disability groups and empower DPOs to participate in various development committees at district, regional and national level.

Tafika: *Everyone leaves the show to FEDOMA in the areas of disability but the problem is that they may be a special interest of groups of disabled people who may not be addressed. If you over centralise, the problem is you might not get what you want because you leave out a lot of players. One would want the FEDOMA to have district committees that would take the needs of the group in the rural areas. The district committee would feed into the regional committee and the national body.*

The study has established that FEDOMA had represented all the DPOs in the process. Lack of focus in relation to the strategic sector approach on disability and identification of the needs of the specific disability groups might be too complex to promote self-representation of DPOs. Not all types of disabilities would have the same opportunity in relation to their specific needs. Limited structural capacity would affect how the ministry and FEDOMA would reach out to the various disability groups in Malawi. There is a need to understand the capacity of each DPO within FEDOMA, to check their potential and competence to participate in the process of formulating national development strategies.

#### **4.2.2 Capacity of DPOs**

The study looked at the structural and contextual dimensions of the institutional culture of FEDOMA and how DPOs are represented in the process. It was important to understand the capacity of DPOs to advocate and lobby for their inclusion and participation in the MGDS consultation meetings. In the researcher's view, this would ensure that DPOs benefit from the MGDS through their contribution and monitoring functions. In this context, capacity was looked at as the ability of DPOs to follow through what is happening at all the stages, and effectively contribute to the MGDS process. Even when DPOs were invited and were involved in the process, there was little benefit in terms of their impact on inclusion of disability in the MGDS. One key informant argued that developing capacity would ensure that DPOs feel strengthened, hence they may influence active participation of people with disabilities in poverty-reduction programmes and disability awareness initiatives.

Nambewe: *You look at the structure of the DPOs and then the capacity of DPOs to know how to competently contribute to the national development strategies. We (Government) need to do a lot of awareness with them, a lot of capacity building training. We need to understand the issue that surround people with disabilities, the MGDS are really quite covering a lot of areas for our society and for DPOs to contribute meaningfully to the development strategy or even the implementation, we need to understand what issues affect our society so that DPOs move in the right direction.*

As described in the previous section, the study has shown the need to have an equal representation of people with disabilities at all levels. However, this is a challenge due to a lack of capacity of DPOs to represent people with disabilities in decision-making positions. This would provide grounds for DPOs to demand for their inclusion. One key informant explained the need to have more people with disabilities at policy level that would facilitate in-depth discussion on disability issues. At cabinet level, it is assumed that the establishment of the Ministry of People with Disabilities and the Elderly would stimulate and facilitate participation of people with disabilities in politics at a decision-making level. It is believed that if there were more people with disabilities in various government departments and the private sector it could raise awareness on disability issues in society.

Dalah: *We need more people (people with disabilities) at that level (policy level) who could discuss with government. We need programmes that will empower and develop capacity of a lot of people with disabilities at that high level in all sectors.*

However, another key informant pointed out that sometimes other organisations were naturally left out in the PRSP and MGDS formation process because the process required technical expertise.

Tafika: *This (process of formulating development strategy) is a technical issue so these other NGOs/DPOs even if you bring them there (consultation process) they will not cope with other big NGOs.*

Disability should be a priority and government should not assume that disability issues are obvious. Despite all the resistance, participants see the process of the establishment of DPOs and realisation of their rights, as a success. As a group, DPOs can support each other to develop their capacity and speak with a strong voice for their needs. One of the key informants hoped that people with disabilities will continue to see similar improvements in technical expertise in these national development processes even though the process of change could be slow.

Ngozo: *Partly, we have done a lot because now people understand when you talk of disability issues they listen to us although it is not much because of negative attitudes. There are a lot of DPOs who are really proactive and understand disability issues. They are now fighting for their rights even if they would not be in a position to start making an influence to change most of the things and move an inch to make real impact.*

Most people with disabilities would need more training in society to ensure that they are actively involved in national development initiatives. There is a need for the disability sector to be more visible and that is why there is a need to promote inclusive education policies.

#### **4.2.3 Education standards**

The study has shown that participants feel that if people with disabilities could get better education, they would be able to stand up and articulate their needs to society. Disabled people were struggling in the PRSP and MGDS process because the sector is not sufficiently developed to understand the technical components of the process. It was observed that most people with disabilities have obtained insufficient education and therefore it was difficult to advocate for their inclusion in the MGDS process.

Timve: *People with disabilities lack education qualification to stand up to the government and address their issue in a manner that the government would understand them. The great challenge is the education capacity of DPOs to engage government and articulate their issues.*

As a sector that is gradually growing, promoting education will stimulate people with disabilities to advocate and lobby for their inclusion at all three stages during the consultation meetings. Education was perceived as vital for people with disabilities as it would allow for a better working relationship between DPOs and policy makers. One of the key informants explained her views on the need to have educated people with disabilities. The researcher believe that education could also empower them to manage their DPOs and present their concerns to FEDOMA in order to raise awareness of their specific needs.

Ngozo: *Issues of how much the DPO understands and manage their concerns, all go down to the illiterate levels of people with disabilities. If people with disabilities are not able to understand the issues then they cannot make any influence in the process. As a*

*result we always fight amongst ourselves, instead of looking at those issues that are affecting us so that we can be included in the MGDS.*

This study has shown that disability awareness should involve educating everybody to understand disability issues and that a deliberate effort should be made for developing the legal instruments that can be used in sensitising society about disability. In doing so, it would ensure that the MGDS process is effective in promoting participation of people with disabilities through monitoring of tools such as, sector policies and implementation of international legal tools like the UN Convention. A way of developing capacity within the disability movement is to ensure that DPOs are well coordinated and optimally managed in order for them to stimulate change. One key informant explained the need to deliberately encourage education for youths with disabilities and empower them with various skills.

*Timve: Another thing is to educate the youth with disabilities, who will manage the movement in future and engage the government at any level.*

There is a need to provide a supportive atmosphere in the education system. Efforts by government to promote inclusive education should focus on making the learning environment accessible and provide assistive devices for young people. It is clear that lack of education among people with disabilities has been shown to affect their active participation in society. Therefore, if people with disabilities gain adequate support, it would result in attitude change from stigma and discrimination behaviours to inclusive practices, at both grassroots and policy levels.

A key informant further explained that there is a need for deliberate policy reforms that would help DPOs in the MGDS process. He cited the need to have a disability law in Malawi that safeguards the needs of people with disabilities and empowers them to effectively advocate for their inclusion in all areas of life.

*Nambewe: We still don't have a law to facilitate and to protect the interest and right of persons with disabilities; we still don't have quite distinct policies to re-address these issues. Our constitution does not capture disability issues clearly. It is difficult to translate it into a meaningful guiding document to have meaningful development in the disability sector. Frogs have the rights but not a person with disability e.g. wild life and natural resources protect the frogs and the grass. The law should protect and provide people with disabilities an opportunity to lobby and contribute in mainstreaming disability in the MGDS and the entire development of the country.*

It is hoped that the law would defend human rights issues of people with disabilities and ensure policy reforms to create opportunities for DPOs. The study has revealed that negative societal attitudes seem to contribute to a hindrance of the involvement of people with disabilities in poverty-reduction processes.

#### **4.2.4 Negative attitudes towards disability**

The attitudes of policy makers and society push the people with disabilities away from society. There is a need to have many awareness programmes, at all levels, to encourage government to include disability issues in day-to-day life. One key informant expressed his views on how policy

makers address the needs of people with disabilities. He explained that disability issues are often dealt with in a negative way.

Nambewe: *Most of the people involved in the consultation process are intellectuals with an academic background and most of these have no appropriate attitudes towards sectors like disability or women. So for this thing (disability issues) to sink in them (policy makers). DPOs need to civic educate them because they have their own understanding of the issue (disability) from an academic point of view. They (policy makers) have inherent attitudes and prejudices that you (disability movement) have to deal with.*

Furthermore, the finding have shown that the attitude of some people with disabilities may also excludes them from main society. In most cases as a result of severe poverty, discrimination and stigma, people with disabilities are involved in begging in order to support their day to day activities. The culture of begging has led society to look at people with disabilities with sympathy, and view them as charity cases, hence negatively affected their mind set. When they are not assisted, people with disabilities can become aggressive in demanding their needs. In the context of this study, that aggression has made society look at people with disabilities as problematic or difficult to handle, and hence they are left out in the community consultation meetings. A key informant explained his concerns:

Tafika: *Sometimes people with disabilities always want charity, so sometimes even when you give them those opportunities to participate and appropriate intervention they will continue begging. Some turn to be so aggressive negatively, and would say you are doing this because am disabled. They don't want to be controlled. So it is realisation and taking charge of their destiny and living a normal life.*

Limited knowledge on disability, stereotypes and negative attitudes at decision-making level has been shown to affect participation of people with disabilities in their community. This could result in disability issues not being adequately featured in policies, hence people with disabilities are grouped under the general category of vulnerable groups. Therefore, there is a need to understand how to integrate disability issues in society and how to promote participation of people with disabilities in development activities.

### **4.3 DISABILITY INCLUSION**

Participants shared a common meaning ascribed to disability inclusion in a Malawian context, which was similar to what the literature has defined. Disability inclusion or mainstreaming is a process of promoting inclusion of disability issues to address barriers such as political, economic and societal that exclude disabled people in policies and programmes in all spheres of life.<sup>7.8</sup>

#### **4.3.1 Definition of disability inclusion**

The study has clearly established that inclusion should place emphasis on ensuring that people with disabilities are part and parcel of all the activities in the MGDS formation process. This would ensure that people with disabilities perform a monitoring function of the whole MGDS process to ensure self-representation at all the stages. A key informant looked at disability inclusion in terms of DPOs' capacity to achieve full participation in society:

Dalah: *It simply means making sure that you check your institutional capacity and look to what extent it is disability friendly. Are People with disabilities able to achieve what they want to achieve when they access your society and your services.*

It is true that services such as health, education, employment and financial assistance in term of loans offered by various stakeholders are disability-friendly and that they address the needs of people with disabilities. Another key informant feels it is important to integrate the needs of people with disabilities in the initial planning of programmes. This could ensure that substantial budget support is allocated to each programme intervention that would change the livelihood of people with disabilities.

Mzati: *When all sectors or ministries are making programmes or budgets they should make sure that disability issues are addressed and involved. Whenever we are formulating these development strategies and implementing them, there is always a need to ensure that issues of disability are clearly captured. So that when, they (government) make interventions they even affect the lives of persons with disabilities.*

Another key informant further agreed that disability inclusion should aim at bringing change to the quality of life of people with disabilities. This means that the rights of people with disabilities should not be infringed upon. They should be able to voice their concerns and participate in society, like any other Malawian.

Ngozo: *I would love to say if we (people with disabilities) are there, let us be many of us, so that our voices should be heard. If we raise an issue, the society should know that yes, people with disabilities are raising an issue. When the lives of people are changing, then I would say mainstreaming is taking place, but not just on paper, that is not mainstreaming, just changing on policies that's not mainstreaming. What is it that governments are putting in place so that the lives of people with disabilities can change?*

The inclusion of disability in development programmes could help to win the interests of stakeholders, who may come up with relevant programmes that would empower people with disabilities to participate in the MGDS process. It is through inclusion of disability that DPOs, society and policy makers would have a meaningful way of addressing the needs of people with disabilities. It is important to consider some of the factors that may have affected the process of including people with disabilities.

#### **4.3.2 Invisibility of Vulnerable groups**

An important aspect, observed by participants, was putting people with disabilities under the category of a vulnerable group, as mentioned in the MGDS and other policies. People with disabilities are very particular about being generalised in the vulnerable category as they feel that this creates a further strain on them.

Participant A: *The issue of disability does not come clearly in the MGDS. Marginalized is a big thing, women, children, orphans depending on the different specific needs and situation you are dealing with.*

Another participant explained that the MGDS must clearly define the sub-groups in the vulnerable category. This, however, is assuming that a weakness in one sub-group would be compensated for in another group. It is not possible to have the needs of people with disabilities separated. If it were so, there would be a need to ensure that specific indicators were set for each disability group, which would be difficult in a budget-strained environment. It is believed that separating people with disabilities from the vulnerable group could result in more resources

being allocated to promote disability issues, as it was in the case of issues related to women, the aged and children, who were given much attention and support.

Timve: *Our concern is when you group people with disabilities under the vulnerable groups you tend to lose out some of the needs for people with disabilities. Do away with the issue of vulnerable grouping because that has done more harm to the sector (disability sector). Like issue of women, disability has to be separated and be given the right interventions.*

Participants felt that government and donors should develop a proper management plan for different forms of disability. Each type of disability has specific problems that need specific interventions. A participant in a focus group discussion feels that the general category of vulnerable groups has led to one form of disability being more superior to others. The needs of different types of disability are often not addressed and there is a lack of representatives from some DPOs.

Participant E: *In disability we go by types of disability, yes, there is disability (In the MGDS) but we (People with disabilities) have different needs, so we can go by the needs of different types of disability. In most cases when they talk of disability it is just physical disability, the other types of disabilities are left out.*

Sometimes, due to national budget limitations, people formulating the development plan place minority groups, such as people with disabilities, under the vulnerable groups. When it comes to specific allocation of resources to the sub-group, it is the groups that makes themselves visible that benefit more from support from the government, private sector and society. This could be the reason why there is a need for more advocacy groups on disability issues or for having the disability group separated and given particular focus to develop capacity and empowerment of its membership.

There are several factors that may have led to limited involvement of people with disabilities in the formation of poverty-reduction strategies. There is a need to understand how disability should be adequately featured in policies to address the needs of people with disabilities, regardless of the barriers that affected their participation in the MGDS process. Participants noted that the MGDS consultation process was a learning process that could help to provide best practice for advocacy and lobbying for the participation of people with disabilities in development activities. This study has established some of the lessons that could help the disability movement, government and society to include disability issues in the national development agenda.

#### **4.3.3 Lessons learned from the MDGS process**

Participants have highlighted the lessons that have been learnt in order to reduce the continued experience of significant barriers to effective participation of people with disabilities in development processes.

For a long time in Malawi, DPOs have been dormant and were only interested in their own activities. It is clear that this study has highlighted the need for DPOs to be proactive and interact with various stakeholders to make their concerns known. Each government has its own priorities that need to be achieved in the development strategy, such as the MGDS for Malawi. Therefore,

if DPOs are not engaging the government to address their needs, disability issues will be omitted in the national development agenda.

*Timve: There is a need to assess the DPOs to make them to be proactive. We should not assume that people (government, CSOs and donors) will always remember us (DPOs).*

The PRSP and MGDS process has shown that there was a need for people with disabilities to be proactive, and who are knowledgeable and educated. This would not only promote self-representation but also ensure that there is integration of personal experience and knowledge from people with disabilities, and the technical knowledge from the government when drafting policies.

*Ngozo: It is unless, people with disabilities are educated that they may actively participate. Any policy need to make sure that people with disabilities are also attaining good education and training so that they are able to articulate development issues, be it at whatever level.*

However, participants in this study still see major gaps in development strategies for many disabled people and policy makers which, when filled, may greatly improve participation.

#### **4.4 CHAPTER SUMMARY**

The findings of the study have shown that people with disabilities are still not recognised and accepted as stakeholders in the MGDS consultation process among grassroots and policy makers, hence they are not invited. There is a need to create a better environment for inclusion of people with disabilities in communities. Successful inclusion of disability issues should result in addressing the capacity issues among DPOs, and ensuring that negative attitudes against disabled people are reversed. Disability inclusion should also address the interest that a social gathering such as DPOs have which often may result in misunderstandings inside the organisation, resulting in internal fights that delay their advocacy and lobbying activities. Addressing these barriers could ensure that stakeholders in the MGDS process utilise the experiences of people with disabilities in the sector working group to promote their participation. Participants perceived that it is important to separate people with disabilities from other vulnerable groups in policy documents. They also expressed a need to improve the policy environment, especially to have a disability law that will encourage policy makers to refocus and adjust their priorities. These findings will be discussed in Chapter five.

## **CHAPTER FIVE**

### **DISCUSSION OF RESULTS**

In this chapter the findings are discussed in order to provide a greater understanding of the issues that have arisen from the study. Literature was used to link the findings to what is happening in studies conducted elsewhere.

#### **5.1 PARTICIPATION IN CONSULTATION PROCESS**

One key finding from the study is that people with disabilities were only involved in the draft stage of the process of developing the PRSP and MGDS. People with disabilities were only asked to produce a position paper on issues they thought were missing in the document. Despite being given the opportunity to come up with a position paper, DPOs noted that it was too late to include their comments in the final document. It was clear that the omission of disability issues in the initial stages was, in particular, as a result of the lack of participation and contributions of DPOs in various sector working group.

In this study, it has been shown that people with disabilities in Malawi are still amongst the poorest and are disadvantaged in various forms in society, as also suggested in other studies by Driedger.<sup>11</sup> He found that people with disabilities are subjected to negative attitudes and non-inclusive policies that need to be removed to promote their participation. Furthermore, it is revealed that disability issues are not set as a priority in the national agenda and policies hence need to advocate for disability inclusion.<sup>12</sup> The study has shown that the MGDS priority areas are developed through wide sector consultations and situational analysis of individual sectors. In the first phase, there are internal consultations within government to develop a framework of priority areas for the MGDS, and an approach on how the priority areas will benefit every Malawian. It is this phase that comprises the principal secretary committee and the ministerial committee in the consultation process. The second phase involves various sectors incorporated in the consultation process. This phase is the sector working group and it is a link between the two phases to get inputs from all sectors on the proposed government key area.<sup>44</sup> Although the in-depth consultations were supposed to be done throughout the two phases in the case of the MGDS, these consultations in relation to people with disabilities were very minimal. These two phases are responsible for identifying and formulating the priority areas that the MGDS will address, in terms of setting targets and indicators to reduce poverty, socio-economic empowerment and improved quality of life of every Malawian. Therefore, it is difficult to identify the needs of people with disabilities, and set indicators in the MGDS, if they are not involved.

Although the consultation process for the poverty-reduction strategy was conducted by Malawians, the idea of having the poverty-reduction strategy paper was initiated by major donor partners such as the World Bank and the International Monetary Fund. The aim was to eradicate poverty in developing nations such as Malawi. This could have been a reason why donor agencies played a major role in influencing key areas where the PRSP and MGDS would focus and plan implementation at national level. The study has established that the PRSP

implementation process was controlled by donors, with limited input from government and local private sector. Limited control of the implementation process of the PRSP by local stakeholders may have caused the gap in inclusion of disability issues. This was because some key stakeholders for the disability sector, such as the DPOs, were not invited. This situation is similar to the PRSP process in Zambia,<sup>59</sup> where the first poverty-reduction strategy process was initially dominated and controlled by donors. It was concluded that the Zambian PRSP process was a failure when it came to implementation, as there was limited consultation among local stakeholders. The joint paper on a review of the PRSP<sup>48</sup> also confirms that in most African nations, because the PRSP process was initially dominated by donors, stakeholders were reluctant to participate in the process as it appeared to be extremely burdensome. The MGDS formation process in Malawi was an improvement of the first PRSP and was coordinated by government, through the Ministry of Economic Corporation and Development. The government had greater control of the MGDS process with more consultations at both grassroots and policy levels, although DPOs were left out. Therefore, compared to the PRSP, the MGDS has more priority areas with an improved implementation plan and indicator of changes in poverty levels in the key areas.

Most participants agreed that the idea of localising and linking the MGDS process to the national budget was important in ensuring that sectors like the disability community are included in the situational analysis. It was stated that, by linking the MGDS to the budget, it would bring appropriate equilibrium between government and donors. The government would own and implement the MGDS, while being held accountable to donors for additional resources to sustain the implementation process. The donor community should be responsible for ensuring a sustainable supply of resources to help improve the quality of implementation of poverty-reduction strategies through localising the process and information-sharing with other nations where the PRSP has successfully included disability issues. This is consistent with literature on the policies of major donors such as the Department for International Development (DfID)<sup>20,28</sup> and the United States Agency for International Development (USAID)<sup>50</sup> who are encouraging the government to give adequate attention to the implementation of existing and new policies, and to include disability issues in national development corporations. Similarly, the United Nations<sup>35</sup> has supported legal instruments, such as the UN Convention, which focuses on capacity-building of DPOs and promotes meaningful participation of disabled people in national development programmes. Therefore, involving the DPOs in the consultation process may help to make them custodians of the MGDS document.

Studies conducted by Miller<sup>57</sup> and Dube<sup>58</sup> in Tanzania and Uganda respectively, indicate that the poverty-reduction papers have successfully managed to fully involve local stakeholders, including people with disabilities, in the consultation process. As a result, these nations have adequately included disability issues in their national development plans and stimulated the establishment of disability policies. However, to what extent the inclusion of people with disabilities in policies has benefited them is not known, as it requires further studies to measure the impact of those policies.

Although there was active participation of CONGOMA in the MGDS process, participants also mentioned that there were very few NGOs for disability, and that the council had virtually no voice on disability issues in these meetings. It could be argued that the disability sector was excluded, even though the taskforce approach seemed to be participatory. The taskforce team on the review of PRSP was dominated by NGOs from other sectors, hence the voices of those NGOs for disability were not sufficiently heard. It is suggested that limited participation of NGOs could be as a result of inappropriate identification of NGOs to represent the disability sector and possibly a lack of knowledge about disability issues by the council. However, CONGOMA is responsible for facilitating the collaboration of NGOs and assessing the actual impact of NGOs in the social and economic development of Malawi.<sup>51</sup>

Since Malawi attained the democratic system of government in 1994, there has been an increase in the activities of NGOs in offering services in particular areas where the government lacks capacity. However, in the past there was slow acknowledgement on the part of government to recognise the role of NGOs in policy development. The general feeling is that there is recent evidence that NGOs have effectively influenced policy change and utilisation of policy in programme implementation.<sup>51</sup> At international level there is a global movement that monitors and reminds world leaders of their commitment to fulfil the Millennium Development Goals (MGDs), hence the founding of the Global Call to Action against Poverty (GCAP) in 2005. As a result of this global call, CONGOMA established a national taskforce to champion the implementation and fulfilment of the Millennium Development Goals in 2006.<sup>51</sup> The taskforce is composed of 24 member NGOs from various sectors that focus on particular Millennium Development Goals and how they will be fulfilled by 2015. Out of the 24 member NGOs, two are NGOs that represent the disability sector. Masina<sup>85</sup> described that, historically in Malawi, religious leaders and traditional leaders have great influence within communities and are vociferous to government on development programmes. Faith-based organisations have a well-established network at all levels and have a long history of coordinating with government in implementing sector projects in education, health and agriculture. As such, they are reliable partners in implementing projects and cooperatives that sensitise communities on the Millennium Development Goals.<sup>51</sup> However, faith-based organisations did not strongly form part of the taskforce. If people with disabilities, who are often among the poorest, are to move out of poverty by 2015, then the Malawi Growth and Development Strategy should target them specifically. The disability federation should engage with faith-based organisations and develop a partnership that would stimulate participation of people with disabilities when implementing programmes. The taskforce on Millennium Development Goals should include more faith-based organisations in order to influence disability-specific priorities. The researcher believes that improved participation would promote inclusion of disability issues, which would be fulfilled during the implementation of the MGDS and other development programmes.

## **5.2 INTERNAL CONSULTATION WITHIN DISABILITY SECTOR**

The study has revealed that, in Malawi, people with disabilities are established under the Federation of Disability Organisations (FEDOMA) which is registered under CONGOMA to

provide guidance on how to manage the DPOs. It was generally observed that as an umbrella body for all DPOs in Malawi, FEDOMA conducted internal consultations on the MGDS with DPO chairpersons through phone calls and meetings on specific concerns of the individual DPOs. It was THE FEDOMA secretariat that represented all DPOs and coordinated the MGDS consultation process with other stakeholders. During the actual participation in the MGDS sector consultation meetings, FEDOMA's executive director was invited. Most participants expressed a need to have had more people with disabilities present, rather than having the director only representing the entire sector. Participants in the study strongly questioned this approach and suggested that chairpersons for DPOs should also be invited to these meetings, so they would have a strong representation of people with disabilities. It is hoped that, by having many people with disabilities who are knowledgeable, it will give a strong voice for the sector and continuity in participation of DPOs during all stages of the MGDS process. The DPOs could be watchdogs to monitor the process and remind government to ensure that disability issues are not omitted at any formation stage.

The study has also highlighted the need for people with disabilities to interact with their communities, share their experiences and work with professionals in the MGDS process. It is clear that the formation of the MGDS is not an event but a process, hence it should never be a one-way process. People with disabilities cannot do it by themselves, they need professionals and professionals need them. It was observed that there is a need for change from what has been happening over the past years, with professionals and people with disabilities giving limited support to each other. This is particularly important as it was clear that, without the support to create opportunities and a more conducive atmosphere, DPOs would not effectively contribute and participate in the MGDS process. Hence, there is a need to look at some of these factors for DPOs, their families and society.

### **5.3 STRUCTURAL CAPACITY OF DISABLED PEOPLES ORGANISATIONS**

In most cases the prosperity of an organisation is influenced by accessibility and availability of both internal and external factors such as human capacity, financial and other resources. Efficiency and effectiveness of the organisation may be retarded or enhanced due to limitations in these factors, hence the need for this to be addressed by all stakeholders in the MGDS processes.

It was generally established that most DPOs depend on the two mother bodies to get their support and benefit, namely: the Ministry of Persons with Disability and the Elderly; and FEDOMA. There is a need for DPOs to consistently and competently fight for inclusion, so that stakeholders may include disability in development initiatives. Despite being a voice for every person with disability in Malawi, FEDOMA has limited structures at national, regional and district levels to be accessible to everyone. This might be one of the major barriers to lack of active involvement of people with disabilities in development programmes at all levels. It is difficult for FEDOMA to represent the needs of the sector if it is over-centralised in its operations. In addition, lack of well-established national structures and capacity for DPOs creates

a gap in identifying and breaking the barriers of different forms of disability. Therefore, it may become more complex for the DPOs to capture all the needs of people with disabilities and present them to FEDOMA. Lack of structures and capacity has led to slow growth of the disability sector in terms of improved access to equal opportunities and increased disability awareness.

It was also observed that there was a strong representation of DPOs in the southern region, followed by the central region, and lastly the northern region in the study. There was one DPO that had its secretariat in the northern region, out of the 10 registered DPOs under FEDOMA. It can be argued that uneven distribution of DPO secretariat offices in the three regions has affected the participation of DPOs at regional level. Lack of self-representation at regional level and participation in the district development plans would affect the allocation of resources and services toward people with disabilities. Similar findings were also shown in Uganda, whereby only the DPOs who were well established, were involved or participated in the PRSP process.<sup>58</sup> There is a need to have strong representation of the DPOs in regional and district development committees to facilitate the creation of awareness around disability issues. Participation in these development committees will ensure that the contributions and needs of people with disabilities are adequately featured in both the district and national development programmes.

### **5.3.1 Education capacity**

This study has established that participants have acknowledged the ever-increasing demand to have more people with disabilities educated in today's society. It appears that, as a result of insufficient levels of academic literacy among disabled people, they do not competently contribute to the process of developing poverty-reduction programmes. According to Bartul<sup>86</sup>, academic education provides a person with the power of knowledge to think critically and logically. Likewise, the UN Convention states that education allows people with disabilities to gain confidence to successfully transform their beliefs and encourage their actions to participate in society.<sup>35</sup> People with disabilities are empowered with the ability to make wise decisions and choose their own lifestyle. Participants reported that people with disabilities frequently have difficulty participating in the formation of the MGDS, due to limited education. Participants noted that the MGDS process may require some technical skills to understand the content and context of the strategy. However, most people with disabilities have insufficient education and technical proficiency to articulate their needs in a manner that policy makers will accord a priority. This finding is consistent with one of the recommendations that came out during the review of the Malawi Constitution, which is that people with disabilities should be knowledgeable and empowered to increase their chances to advocate for their inclusion.<sup>1</sup>

The study also revealed that there is a need to put in deliberate efforts that will ensure availability of assistive devices, accessible schools and special needs teachers. This may help in creating a better education environment for people with disabilities. The effort to implement inclusive education should focus on both children and adults with disabilities, if the sector is to sufficiently benefit from such policies. It is hoped that, if people with disabilities have

appropriate education, they will be in a position to manage their DPOs and move at the same level as other marginalised groups in society. The outcome of this study confirms Ncube's<sup>54</sup> findings that it is very difficult for DPOs to influence decision makers and actors in the PRSP process if they have limited capacity in such areas as education. Additionally, Malawi, as one of the ratifying nations of the UN Convention, needs to make sure there are appropriate materials and accessible means of communication at all levels of education. It is asserted that DPOs need to coordinate and work as a team in advocating and lobbying for adequate action and best practice to implement the disability policies and legislation that will promote their active participation in society.

#### **5.4 LIMITED KNOWLEDGE OF DISABILITY ISSUES**

In the interests of understanding how disability issues should be included in society as well as in development programmes, the study has shown that there is a misunderstanding at policy level of the way that disability issues should be included, hence all disability issues are referred to as one ministry. However, this study has established that inclusion of disability should be a group rather than individual effort, with the Ministry of People with Disabilities and the Elderly as a sole implementer of disability issues. There is a need for all stakeholders to create an environment that may promote equal participation of people with disabilities in the MGDS process. In addition, the study has revealed that a lack of networking between government departments and the disability federation has led to inconsistencies in advocating for disability inclusion. The researcher's view is that one reason could be because of society negative attitude and stigma that has lead to a culture of neglecting disabled people in decision making process. Another reason could also be due to the difference in the institution culture, in terms of how they prioritise resources toward disability issues, as a result disabled people feel that their specific basic needs are either denied or not adequately addressed. Subsequently, little interaction among DPOs might cause further isolation of people with disabilities. It is hoped that networking may help bring noticeable changes of disability issues at both grassroots and policy level, in terms of increased disability awareness among policy makers to recognise the gravity of the challenges that DPOs face.

Policy makers should realise what people with disabilities need when they are advocating and lobbying for full inclusion in these policy documents. It is the government's jurisdiction to pass legislation, while the responsibility is on the DPOs, civil society organisations and donors to hold the government responsible for delivering on disability programmes. It is only by educating policy makers to create a common understanding of disability issues, that disability is not just mentioned in passing in policy documents and during the internal government consultations, but included in the implementation of policies. Policy makers should understand disability as human diversity, not as a problem to be solved. It is suggested that the recognition of such diversity is important to assist people with disabilities. This will allow people with disabilities to make their own decisions, creating a supportive environment in terms of knowledge and understanding of development issues.

The evolution, from needs to rights, as promoted in the disability policy<sup>2</sup> in Malawi has highlighted the need to understand the differences between the needs and rights of people with disabilities. The government, DPOs, civil society organisations, care givers and families should fulfil the needs of people with disabilities. This would ensure that their rights are exercised to achieve optimal independent living. There is a need also to explore the best means for people with disabilities to be included in policies and legislation to have a meaningful change in their quality of life, as in other sectors. It is believed that the way disability issues are featured in policy documents could affect the best practice to deal with the needs and support required by DPOs.

#### **5.4.1 Invisibility of disability issues**

In all the policies that were reviewed in this study, people with disabilities are mentioned as part of the vulnerable groups, such as orphans, women, children under five years of age, elderly people, and households affected by natural disasters. The study has established that people with disabilities did not want to be grouped under the vulnerable groups. Participants were concerned that this would lead to government, donors, and the private sector not viewing disability as a priority within the vulnerable groups, hence giving lesser attention to the needs of people with disabilities. People with disabilities expressed displeasure at being grouped together under the vulnerable groups in the MGDS and policy documents. It was also argued that the general category of grouping different people in one group has pushed disability issues to the periphery over the years. Similarly, it is argued that the approach of generalising people with disabilities in the vulnerable population only promotes the exclusion and segregation of the group in society and development strategies.<sup>62</sup> Specific needs of DPOs may not be addressed when generalised in the vulnerable category. It is also difficult to allocate funds, monitor improved quality of life and develop programmes that would address the specific needs of each sub-group within the main group.

Nankhumwa<sup>87</sup> in his study on the PRSP process in Malawi, has demonstrated that the vulnerability category was an obstacle in the process, as it conceals essential differences in poverty levels and other challenges experienced by the vulnerable sub-groups. As a result, specific needs of people with disabilities were not explicitly defined and addressed. According to Yeo<sup>46</sup> the diversity of disability issues is not homogeneous; there are many different forms of disability that should not be addressed as one unit. Therefore, it is clear that vulnerability is multi-dimensional and it is difficult to put the interests of each group in one basket when developing policies. However, this is contentious, as people with disabilities should not be grouped among the vulnerable groups, but rather be separated and presented independently in the poverty-reduction initiatives. It is hoped that separating people with disabilities from the vulnerable group could ensure that disability issues are accorded the necessary priority, like other sub-groups. As it has been in the last three years, government and donors are deliberately targeting specific sub-groups within the vulnerable groups, such as women, children and the elderly. This deliberate focus is aimed at promoting participation of these sub-groups in community development activities, decision-making positions and politics. People with

disabilities are not specifically targeted, hence there is a risk of becoming poorer and more disadvantaged even among the vulnerable groups.

This study has also established that disability issues are insufficiently mentioned in policy documents. The study has highlighted that policies guide, regulate and control actions towards those outcomes that are most likely to attain the desired inclusion of disability in development processes. Lack of prominence of disability in policies may contribute to limited support given to the disability sector, including the identification of disability program interventions, budget priorities and the basis of choosing disability as a priority area. Participants in the study asserted that national documents such as the Malawi Constitution<sup>36</sup> and *Vision 2020*<sup>31</sup> should adequately mention disability issues as these are the key documents that inspire policies, programmes and services. It is believed that if the Malawi Constitution, which is the main legal instrument in the country, clearly mentions disability issues, all development programmes should be bound to fully include people with disabilities. It has been indicated that the Malawi Constitution is the guiding document that informs all programmes implemented by government agencies, and local and international development partners. All development programmes in Malawi must adhere to the Malawi Constitution and ensure that they will benefit every Malawian, including people with disabilities. It is suggested that a review of the Malawi Constitution, to make it inclusive on disability issues, may be the starting point to promote active participation of people with disabilities in communities, like any other Malawian. The study has shown that the roots of the MGDS are based on the Malawi Constitution and *Vision 2020*. Therefore, a reason that could have contributed to the omission and masking of disability issues in the MGDS, is the lack of a strong voice in the Constitution on disability. In view of the fact that disability does not adequately feature in the Malawi Constitution, the problem was carried over to the MGDS and hence the gap in disability issues.

Malawi adopted the Southern Africa Developing Community (SADC) Gender and Development protocol in 2008. The protocol commits countries to work towards the goal of having 50% of women in politics and decision-making positions.<sup>88</sup> In the May 19, 2009 polls to elect a president and parliamentarians for the next five years in Malawi, there was a campaign to empower women to increase their participation in politics. The programme focused on training women candidates in assertiveness, advocacy, lobbying and campaigning. The newly elected 193-member parliament has 42 female candidates, translating into a 22% representation of women, from the previous 13%. Out of a total of 193 members of parliament in Malawi, there is only one male member of parliament who is a person with a physical disability.

Although there are noticeable improvements in the number of women participating in politics and occupying decision-making position in Malawian communities, it was clear that there were no women with a disability among those women who were elected to parliament from the 50-50 campaign. The 50-50 campaign looks at women as being marginalised, but in the case of women with disabilities the marginalisation may be double because of stigma and negative attitudes. Therefore, it can be argued that even within the women's movement there should be deliberate

action targeting women with disabilities to participate in politics. The programmes should consider that each population comprises 20% of people with disabilities as stipulated by the World Health Organisation standard. Hence, the 50-50 campaign should have specifically considered promoting the 20% of women with disabilities in society to be active in politics and decision-making positions. Resources, such as funds and assistive devices targeting people with disabilities, should be available to assist in mobility and communication during the campaigns. Such specific support towards women with disabilities may promote their active participation in society and development programmes. In particular, increased representation of women with disabilities in parliament might assist understanding on how to advocate and lobby for their inclusion. Active involvement of women with disabilities in politics may also empower them to be more knowledgeable about legislation and policy management, hence be able to engage with government and development partners to push for sound disability policies and minor policy amendments that would promote inclusion of disability issues. The empowerment and capacity-building of women with disabilities may provide them with skills to organise and manage their DPOs and competently advocate as a group for their rights.

There is a need for the NGOs in the 50-50 campaign to deliberately focus on people with disabilities by working closely with DPOs and FEDOMA. It is recommended that FEDOMA engages these NGOs, who have existing capacity and resources, to lobby for the inclusion of women with disabilities in their campaign. It is only when FEDOMA makes itself available to the public that disability may win the interest of other stakeholders who are implementing various development programmes. Developing a working relationship with other NGOs may also change negative attitudes. Most of the participants in the study shared similar views, which is that people with disabilities are not a problem. They thought that programme interventions could provide solutions but they should be taken as development partners, in the process of eradicating poverty and inclusion of disability in development corporations.

The study has shown that there are advantages in the approach of specifically focusing on an individual sub-group within the vulnerable category. It is noted that specific targets, indicators and budgetary support is allocated to the sub-group to implement the change. Participants observed that, but for people with disabilities, there is no specific legislation to protect them. The study has revealed that there was a feeling of concern that, although people with disabilities have drafted their own Disability Bill, it has taken a long time for the bill to be passed into an Act in parliament. Although participants acknowledge the complexity in developing a policy, there is growing frustration that the Malawi parliament may neglect the Disability Bill, yet it has passed other bills such as the Child Care, Protection and Justice Bill number 7 of 2010.<sup>89</sup> It was argued that unless the disability sector has the Disability Bill enacted by parliament, the sector may not have had any meaningful benefit in terms of their contribution and participation in the formation of the MGDS. Hence, it would also cause slow progress in the inclusion of disability at national level because of the inadequate focus on disability as a priority area in development initiatives.

It is believed that the Disability Bill may stimulate disability issues by promoting equal access to opportunities and raise awareness among policy makers. In turn, disability issues may adequately be featured in the national agenda. The Disability Bill may also be a force from which all sector policies may be guided to refocus on their targets to include disability as cross-cutting, as disability will be enforceable by law. This would encourage disability awareness and develop deliberate programme interventions that will target people with disabilities.

#### **5.4.2 Disability inclusion**

Although the study has shown that there is much dialogue about disability inclusion, participants from government agencies, disabled persons and DPOs offered various understandings of disability issues according to their experience in the disability sector, and some based on their sector needs. There was a common meaning ascribed to disability inclusion: as a process of achieving an inclusive atmosphere for people with disabilities by making programme planners and society gain an understanding of the issues affecting disabled people. Progress should be made in reducing barriers that limit participation, while maximising opportunities for people with disabilities in society. This would lead to developing fundamental long-term changes that will allow their equal participation in community activities and universal access to socio-economic needs.

The evidence available from this study offers some insight into understanding disability issues in the context of Malawi. There were significant differences in how participants from the disability movement defined the term ‘disability inclusion’. People with disabilities want to be involved in development activities so that their needs are captured in all spheres of life as a process of inclusion. This would ensure changes in the mind set of people with disabilities and society, resulting in a change in community stereotype behaviour towards disability. The majority of participants from government described disability inclusion as a process of making institutions accessible to people with disabilities. The emphasis was on the fact that disability should be mentioned in policy documents and that implementers are the ones to specifically target the needs of people with disabilities. There is a need to create awareness amongst educate policy makers for there to be self-representation of the disability sector. There should be an integration of people with disabilities into government machinery to represent the disability sector and stimulate change. It is hoped that, by having more self-representation of people with disabilities, the government would provide policy guidance and a strong voice on disability issues.

This study strongly recommends that disability inclusion should ensure that people with disabilities are given a chance to be self-represented and articulate their needs, thus ensuring that their needs are adequately heard by society. The focus should be on providing needed financial resources, and material and institutional support to empower and develop the capacity of DPOs. Disability inclusion will need to involve everyone in the community to understand disability issues, not only people with disabilities. The study finding supports findings by Thomas<sup>20</sup> who understood disability mainstreaming or inclusion as not just having DPOs present in the consultative meetings, but having the needs of the group well-reflected across all sectors of

society. Therefore, disability inclusion should aim at educating everyone to understand disability issues in order to bring society to a common level of understanding of disability issues before developing tools for inclusion.

#### **5.4.3 Role of Ministry of People with Disabilities and the Elderly in disability inclusion**

The establishment of the Ministry of People with Disabilities and the Elderly in Malawi has brought visibility to disability issues at both local and international level. The study has revealed that this ministry has created a platform at policy level where the needs of people with disabilities are channeled and discussed. Participants explained that by creating a separate ministry to specifically look at disability issues, it may show the government's commitment and political will to develop the disability sector. It was emphasised that it is important to link the ministry activities at national and grassroots level, in terms of information flow, to capture the needs of the sector. As a mother ministry for the disability sector, the focal point is to coordinate, facilitate and implement all disability-related programmes together with other partners. The ministry should therefore develop programmes that will raise awareness among the public and other government department so that disability is included at all levels.

However, this study has indicated that there is a perception that, despite wide implementation of activities by the government, little has changed for people with disabilities in terms of their inclusion in development programmes and equal access to social amenities, such as health and well-being, education, transport, decent housing and disability support. The research findings have also shown that people with disabilities still face institutional, attitudinal and environmental barriers that further push them out of the mainstream of society. Changing stigma and discrimination may be crucial in promoting inclusion of people with disabilities. For example, a physically-challenged person is a wheelchair-user, but what society first sees is the wheelchair and then the person. Although there may be advantages for having a disability-specific ministry, there are some disadvantages too. There is limited self- representation of people with disabilities in decision-making positions at ministerial level. People with disabilities expressed their feelings and willingness to form part of the political and technical management team within such a ministry, in order to make a difference. As it is stated in the Malawi disability policy slogan, *Give us a chance*,<sup>2</sup> there is a need to create an environment that will empower people with disabilities to be part and parcel of management teams in various government departments. It was argued that people with disabilities are better placed to advise the ministry regarding pertinent disability specific issues to be incorporated in the development agenda that would benefit DPOs. It is very clear that people with disabilities need to speak for themselves, *Nothing about us without us*<sup>90</sup> as they are the experts in advocating what they need. Therefore, there is a need for people with disabilities to make governments accountable; carry out advocacy for amendment of national legislation in view of the disability legal framework; and promote training in policy advocacy and in media advocacy.

Lack of self-representation of people with disabilities in most decision-making positions and involvement in politics, further broadens the gap between disabled people and their inclusion in

the main society. Participants argued that the ministry must set a good example in implementing best practice of inclusion and self-representation by employing a person with disability at high ministerial level. It was quickly argued that the appointment should be based on merit and not political affiliation, if the officers are to competently and effectively present the needs of the sector. Politicians have looked at improving a person with disability rather than improving policies to promote inclusion of people with disabilities in society. Participants have observed that in the past, political appointments had very little focus on the real needs and rights of people with disabilities but rather looked at them as people who will benefit from the handouts. There should be a marriage of commitment between the Ministry of People with Disabilities and the Elderly and FEDOMA that will ensure that there is a consistent fight for inclusion of people with disabilities and increased public awareness on disability issues. As a mother ministry, it should work closely with disability organisations so that disabled people are involved in the development activities. People with disabilities should provide checks and balances on programme interventions for the ministry to efficiently stand up to its core role of improving the quality of life of people with disabilities in Malawi.

There is a need to promote a social and human rights approach to disability rather than a charity approach, that for so long has increased the discrimination of people with disabilities. The study has established that having a specific ministry can sometimes be disadvantageous to people with disabilities, if the ministry is misguided and used as a political tool to gain international recognition. But if well managed and organised, having a particular ministry to look after people with disabilities is an excellent idea to identify and address the challenges facing people with disabilities.

## **5.5 CHAPTER SUMMARY**

In this chapter, it was shown that people with disabilities were not fully involved in the formulation of the development strategy in Malawi. Lack of involvement of people with disabilities has led to omissions and an inadequate explanation of their needs in national development initiatives. In order for the MGDS to be truly effective and to adequately feature disability issues, an approach towards promoting participation of disabled people needs to be integrated. In particular, integrating their voices and needs within the broader MGDS consultation process is crucial. While specific efforts addressing disability concerns are valuable, policy makers should be encouraged to target the needs of people with disabilities rather than categorising them under vulnerable groups. There is a need for a strong enabling environment, in which disability concerns are included in institutional frameworks and are supported by legislation which is critical to empower people with disabilities.

People with disabilities should be empowered to build their capacity to advocate and lobby for their inclusion. Empowerment would ensure that they are independent and self-represented in the process of formulating the MGDS. Disability inclusion should involve the disability sector at all levels of society - without involving the sector there would be limited inclusion. Society needs to adjust negative attitudes towards disability issues to ensure that disability is included at all levels

of the national agenda. The existence of the Ministry of Persons with Disabilities and the Elderly in Malawi should provide a very good foundation for inclusion of disability and increased disability awareness in society.

## **CHAPTER SIX**

### **CONCLUSIONS AND RECOMMENDATIONS**

This chapter provides conclusions drawn from the findings of the study and makes recommendations that may promote effective inclusion of disabled people in developing, planning, monitoring, and the evaluation and implementation of development activities. The conclusion is guided by the research questions that this study sought to answer.

#### **6.1 INVOLVEMENT IN POVERTY-REDUCTION STRATEGY PROCESS**

The first research question was: To what extent are people with disabilities involved in poverty-reduction strategy processes? The results have shown that there was minimal participation of people with disabilities during the consultation meetings of the MGDS formulating process. It is indicated that the mentioning of disability in the MGDS and other policy documents was a result of a few people with disabilities being partially involved, and only at the later stages of the MGDS. In order to create a more inclusive environment for people with disabilities, more should be done to integrate their needs in the MGDS.

#### **6.2 FACTORS THAT PROMOTE OR HINDER INVOLVEMENT**

The second research question was: What factors promote or hinder the involvement of people with disabilities in the process of formulating poverty-reduction strategies? The study has established various factors that affect people with disabilities, namely: lack of DPOs capacity; limited self-representation of people with disabilities; lack of education; negative attitudes; insufficient financial support; and inadequate and sometimes inappropriate assistive devices such as wheelchairs, cane stick, clutches and technologies that may facilitate function ability of disabled people.

In addressing these factors, the focus should be on improving their impairment by improving accessibility; increasing educational support; and reducing social isolation. This gives an opportunity to have further studies that will explore the feelings of people with disabilities; how to refocus and adjust the set priorities in the programmes; and how to have policies to ensure a positive change in their quality of life.

Overall, it can be concluded that the existence of the Ministry of People with Disabilities and the Elderly is a factor that has also facilitated increased awareness of disability issues. The most significant change has been achieved through programmes initiated and implemented by this ministry and Federation for People with Disability Organisation (FEDOMA) which may have led to improved participation of people with disabilities. Increased involvement of DPOs in the process of reviewing the Malawi Constitution and developing policies such as the education policy, has led to an inclusive special needs education policy and improvement in the teaching curriculum. However, the outcomes of this study have shown that there is a need to increase

disability awareness and to promote self-representation of people with disabilities in decision-making positions and politics in order to influence policies and participation in development processes.

### **6.3 MEANING OF DISABILITY INCLUSION**

The final research question was: What is disability inclusion in terms of what should be done to encourage inclusion of people with disabilities in poverty-reduction programmes? In the context of this study, it is concluded that disability inclusion means that policy documents and poverty-reduction strategy papers should mention indicators and targets that will show the perceived social change for people with disabilities. Specifically, there needs to be targeted budgetary and social support that will promote disabled people's participation in community activities. Disability issues need to be given the necessary attention in all sector policy documents and legislations, in terms of how such inclusion will benefit people with disabilities. It also means that disabled people's organisations (DPOs) should be supported to make better use of social networks, to create greater awareness among their member organisations and other stakeholders. DPOs should be gateways for disability issues by providing an opportunity for forums to discuss and share ideas. This will facilitate the building of confidence among people with disabilities and increased competence in articulating their needs in society. Each DPO should develop a network with other partners to advocate, lobby and raise awareness on human rights issues and other issues that affect them. Additionally, the multi-sector networks will help to bring visibility to the different forms of disability and the concerns that need to be addressed at both grassroots and policy level, to encourage DPO participation.

The study has also concluded that there is a need for a Disability Act. This will ensure that every stakeholder is legally bound to protect the interests of people with disabilities in their programmes, as a way of including disability in development corporations. The law will also be utilised to ensure that people with disabilities have access to basic amenities, such as: health and rehabilitation services; education at all levels and for all disability groups; decent housing; land; clothing; food; and gainful employment.

### **6.4 RECOMMENDATIONS**

Through these recommendations, the researcher offers suggestions for creating an enabling atmosphere, which includes the legal framework by government and service providers as partners in the implementation of the MGDS. The recommendations also focus on strengthening capacity and institutional development of DPOs. These recommendations are based on the aim and objectives of this thesis.

1. The Ministry of People with Disabilities and the Elderly and FEDOMA should be proactive to ensure that people with disabilities are self-represented in each sector working group during the process of revising the MGDS document. This will promote education and confidence

amongst people with disabilities so that they are able to articulate their needs and make contributions during the MGDS consultation meetings.

2. Disabled people should be part of the economic solution towards achieving poverty-reduction, by:

- a. involving DPOs fully in the review of the next MGDS;
- b. engaging and supporting disability-related research; and
- c. empowering people with disabilities to be researchers.

3. Continuously raise disability awareness at all levels of society, from family to policy level, to create an environment that demonstrates the ability and contributions of disabled people in development activities.

4. Specifically target people with disabilities rather than referring to disability groups as ‘vulnerable’. This only serves to marginalise this group and the issues of disability are often forgotten or lost within the many interests of other vulnerable sub-groups.

5. Review policies and other legislations in Malawi so as to stimulate and advocate for the MGDS and ministerial policies to be disability-inclusive.

6. Lobby for the Malawian government to use their ratification of the UN Convention as a tool to facilitate disability inclusion in all national development strategies, and as a way of showing their commitment to developing the disability sector.

7. Parliament should pass the Disability Bill into an Act as it will be utilised in the formulation and implementation of poverty-reduction strategies.

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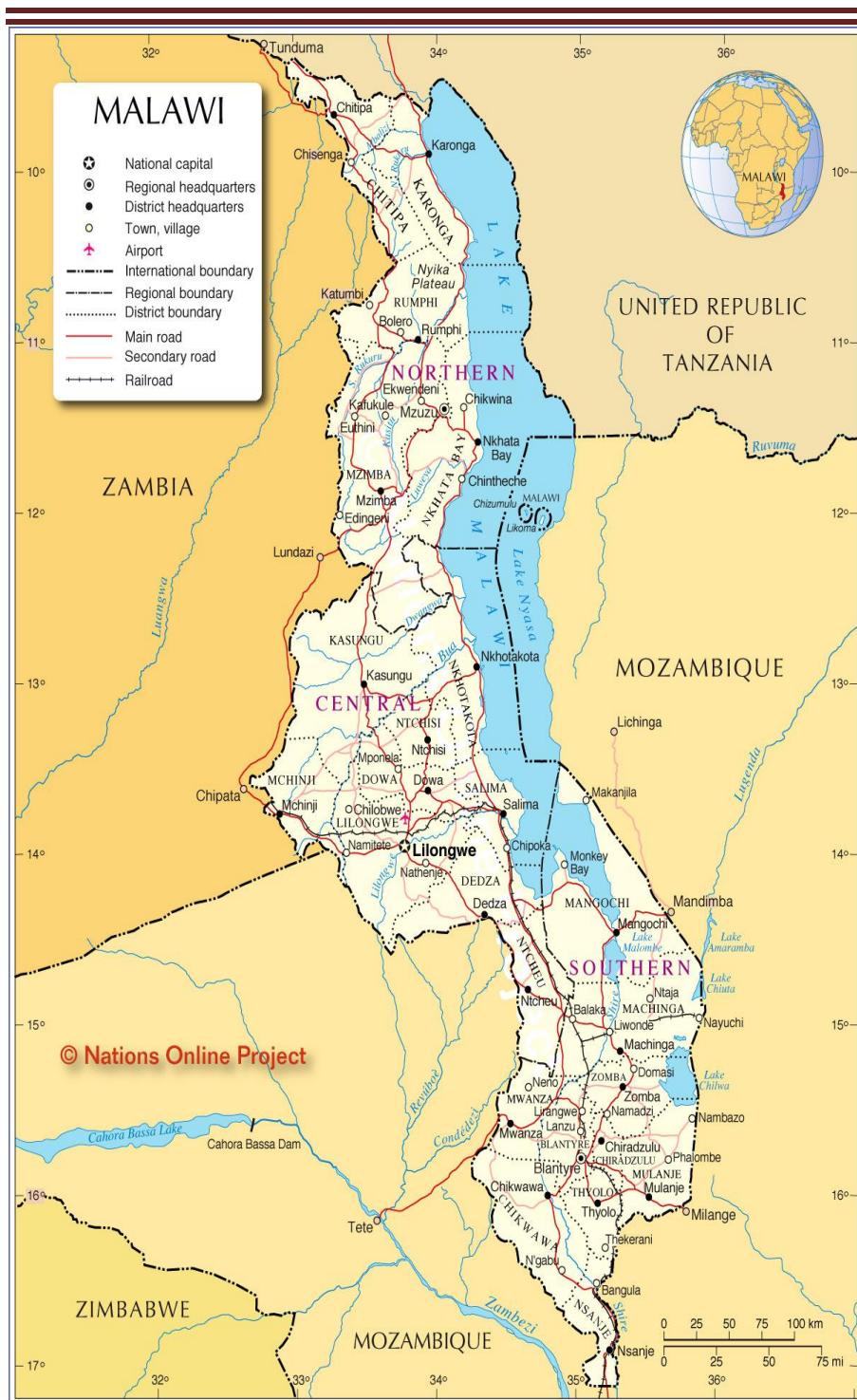
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## APPENDICES

### Appendix A: Map of Malawi



### Malawi administrative districts

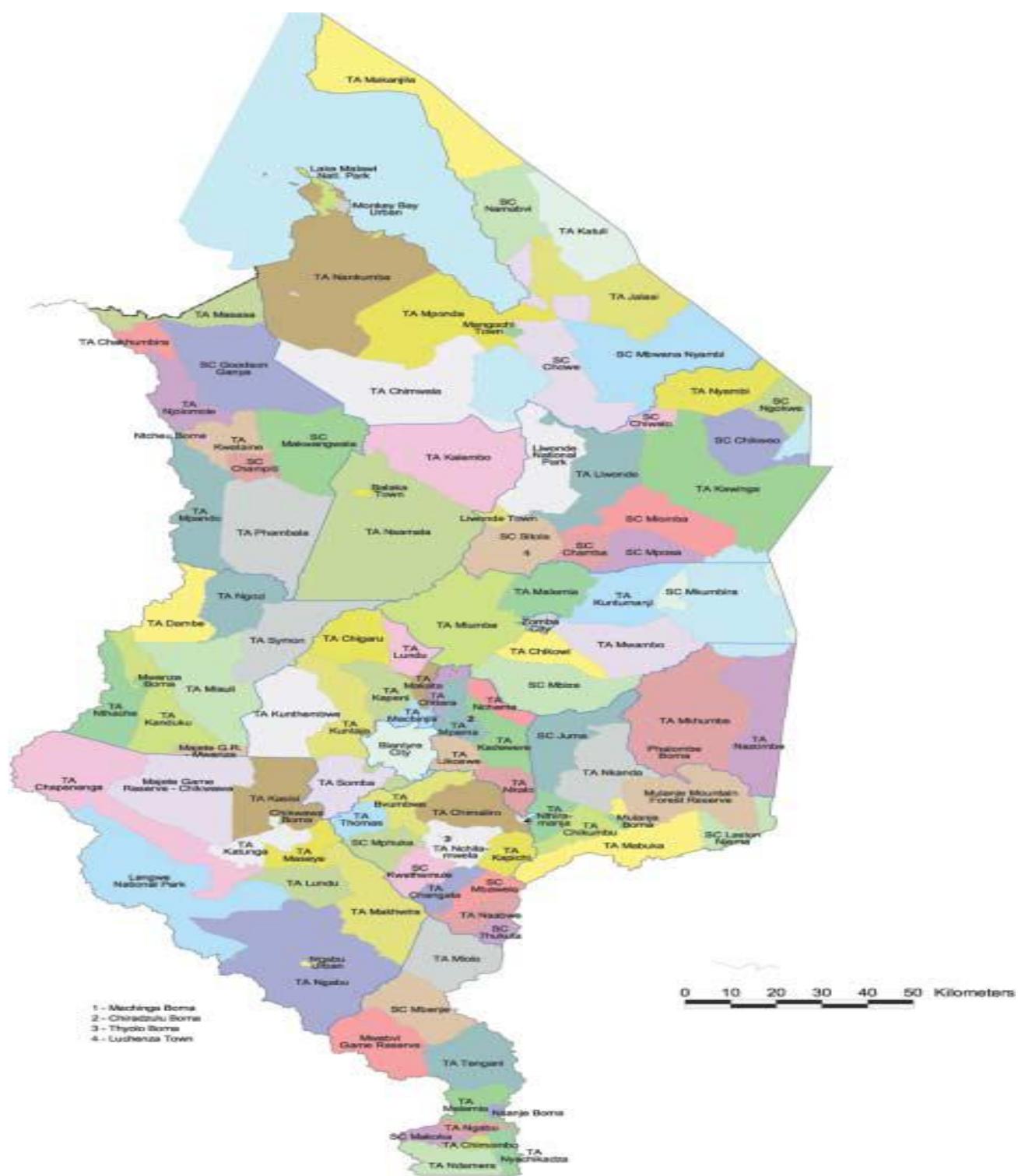
As of 2002, Malawi had 27 administrative districts in three regions. With the exception of Likoma, all are named for the district's administrative headquarters. The four urban centres of Malawi are; Lilongwe, Mzuzu, Blantyre, and Zomba.

## Appendix B: Traditional authorities of northern and part of central Malawi



The traditional authorities (TAs) depicted in this map of the northern and central regions (excluding Ntcheu district) are those used by the National Statistical Office to organise their data-collection efforts. District and local government authorities also recognise additional TAs that are not shown in these Map.<sup>91</sup>

## **Appendix C: Traditional authorities of southern Malawi and Ntcheu district of central Malawi**



Traditional authorities of southern Malawi and Ntcheu district of central Malawi. The traditional authorities (TAs) depicted in this map of the southern region and Ntcheu district of the central region.<sup>91</sup>

## Appendix D: Profile of participants

Name	Organisation
Mr Mzoma	Government Stores
Mr Chiwaula	Federation for Disability Organisations in Malawi
Mr Zimalilana	Ministry of Agriculture
Mr Kaphale	Ministry of Economic Development and Cooperation
Mr Kumbatira	Malawi Economic Justice Network
Mrs Zimpita	Office of the President and Cabinet
Mr Nkondiwa	Ministry of Persons with Disability and Elderly
Ms Chiume	The Association Of People with Albinism in Malawi
Mr Nyirenda	Ministry of Disability and the Elderly
Mrs Mwale	Ministry of Disability and the Elderly
Mr. Msowoya	Malawi Council for the Handicapped
Mr Teddy Sitimawina	Ministry of Economic planning and Development
Mrs Agnes Chimbiri	United Nations Development Programme
Mr Levie Mihowa	Sue Ryder Foundation International,
Rachel Kachaje	Vice Chairperson of Disabled People International.
Segele Kasase	Chairperson of Disabled Women in Development
Mr Chinthochi	Private Consultant
Mr Njaidi	Ministry of Education- Special Needs Unit.
Mrs Kamwendo	World Bank
Susan Chitimbe	Office of the President and Cabinet
Aidan Clohessy	St John of God
Mr Kaunda	Disability advocate and activist
Dr Alister Munthali	Centre for Social Research-University of Malawi
Mr Chimanya	Malawi National Association of the Deaf
Mr Mwase	Malawi National Association of the Deaf
Executive Director	Malawi Union for the Blind
Guide	Malawi Union for the Blind
Ms Kasasi	Disabled Women in Development
Ms Namanja	Parents of Disabled Children Association in Malawi
Mr Matchaka	Malawi Disability Sports Association
Guide	Malawi Disability Sports Association
Mr Khaula	Association of the Physically Disabled in Malawi
Mr Kilembe	Ministry of people with Disability and Elderly
Ms Jane Chasweka	Malawi Council For the Handicapped
Mr Msosa	Ministry of Finance
Ms Jane Mkandawire	Social Welfare Officer
Mr Mhango	Disabled Widows Orphans Organisations of Malawi
Three students	Catholic University

Ms Mule Chikoko	DFID
Mr Juliana Mwase	Malawi National Association of the Deaf
Mr Dofel	Malawi Council for the Handicapped
Mr Frank	Business man

## **Appendix E: A semi-structured interview guide for key informant interview and focus group discussion**

1. How would you describe the poverty in line with disability in the context of Malawi?
2. What is Malawi doing to reduce poverty as an effect of disability?
3. Which organisations are involved in the poverty-reduction process in Malawi?
4. What is the level of involvement of people with disability in poverty-reduction strategies?
5. What is meaning of disability inclusion or mainstreaming in the context of Malawi?
6. How best can people with disabilities be involved in the process of reducing poverty?
7. How accessible are the disability related services in Malawi in terms of health, education, transport, employment and community support?
8. What is your opinion in terms of structure and capacity of disabled organisations to participate in development initiative programmes?
9. Are there any legislation that would support participation of disabled peoples, and how they can be utilised?

## **Appendix F: Letter to participants**

18/11/09

Dear Sir/Madam

### **AN EXPLORATION OF THE INVOLVEMENT OF PERSONS WITH DISABILITIES IN POVERTY-REDUCTION STRATEGIES IN MALAWI**

I am Bonface Massah, a Master student at Stellenbosch University in the Faculty of Health Sciences, Centre for Rehabilitation Studies. I intend to conduct a research study on the above subject in fulfilment of a MPhil in Rehabilitation.

I would be very grateful if you would provide me with information regarding the involvement of persons with disabilities in poverty-reduction strategies in Malawi. I would like you to participate in key informant interviews, focus group discussions or both, depending on your availability.

If you need further information regarding my request, please do not hesitate to contact me or my supervisor.

Many thanks in advance for your consideration of this request.

Yours faithfully,

Bonface Ophiyah Massah

Cell: + (265) 0995442346/ 0881006474; [bonifacemassah@yahoo.com](mailto:bonifacemassah@yahoo.com)

Supervisor: Dr Margaret Wazakili; [mwazakili@sun.ac.za](mailto:mwazakili@sun.ac.za)

## **Appendix G: Key informants consent form**

18/11/09

Dear Sir/Madam

### **AN EXPLORATION OF THE INVOLVEMENT OF PERSONS WITH DISABILITIES IN POVERTY-REDUCTION STRATEGIES IN MALAWI**

I am Bonface Massah, a Master student at Stellenbosch University in the faculty of Health Sciences, Centre for Rehabilitation Studies. I intend to conduct a research study on the above subject in fulfilment of a MPhil in Rehabilitation.

The aim of this study is to investigate the involvement of People with Disabilities in poverty-reduction strategies in Malawi. This is because People with Disabilities are believed to be among the poorest in most African societies. I also intend to investigate factors that may support or delay the participation of People with Disabilities in poverty-reduction strategies, and examine how the contributions of People with Disabilities are presented in development programmes. The study will be conducted in the three major cities of the three regions in Malawi. It will explore how the contributions of People with Disabilities are reflected in development initiatives as outlined in the Poverty-reduction Strategy Paper (PRSP), now known as the Malawi Growth and Development Strategy (MGDS).

A study of this nature is important to the Government of Malawi and the public sector that may use the findings to address issues of involvement of people with disabilities using research evidence. This would ensure that contributions of People with Disabilities are represented in all poverty-reduction strategies and policy documents in the future. It is also hoped that decision makers would use the findings of this study to be aware of, and include, the needs of People with Disabilities in the development agenda in Malawi, and accord it the necessary priority. The study findings may bring to light an understanding of disability inclusion in Malawi. It is hoped that the understanding of disability issues may assist the inclusion of disability in the Malawi Growth and Development Strategy and other development plans.

There are no risks involved in your participation in this study. Confidentiality will be ensured and your name will not be associated with the information you provide.

Findings of the study will be available and utilised through a feedback workshop that will be conducted to share the results of the study with the participants and their communities, including all disabled people's organisations, government ministries and departments, the donor community, the media, civil society organisations, non-government organisations and the general public. Participants will be asked to comment on the findings and provide useful advice. Key issues coming up from the workshop will be fed into the main African Policy on Disability and

Development (A-PODD) report of the study. The final report will be available to stakeholders through the Ministry of Persons with Disabilities and Elderly, Federation for Disability Organisations in Malawi and the University of Malawi. It is hoped that the study will be published as a thesis and in relevant research journals.

The study has been approved by the ethical committee of Stellenbosch University registration number **NO9/10/290**. This study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the National Health Sciences Research Council in Malawi (MHSRC).

I would be very grateful if you would provide me with information regarding the involvement of persons with disabilities in poverty-reduction strategies in Malawi. I would like you to participate in key informant interviews depending on your availability.

I ..... agree to take part in a research study entitled: An Exploration of the Involvement of Persons with Disabilities in the Poverty-reduction Strategies in Malawi.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Phone..... Email.....

Organisation or Institution.....

Signed at (place) ..... on (date) ..... 2005.

.....

.....

Signature of participant

Signature of witness

**Declaration by investigator**

I (name) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (place) ..... on (date) ..... 2005.

.....  
Signature of investigator

.....  
Signature of witness

**Declaration by interpreter**

I (name) ..... declare that:

I assisted the investigator (name) ..... to explain the information in this document to (name of participant) .....

- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Phone..... Email.....

Organisation or Institution.....

Signed at (place) ..... on (date) ..... 2009.

.....  
Signature of interpreter

.....  
Signature of witness

## **Appendix H: Information sheet and consent form**

18/11/09

**Title of the research:** An Exploration of the Involvement of Persons with Disabilities in the Poverty-reduction Strategies in Malawi.

**ETHICS REFERENCE NO: NO9/10/290**

**PRINCIPAL INVESTIGATOR:** Bonface Ophiyah Massah, Federation for Disability Organisations in Malawi, P.O Box 797, Blantyre, Malawi.

**ADDRESS:** Federation for Disability Organisations in Malawi, P.O Box 797, Blantyre, Malawi.

**CONTACT NUMBER:** +(265) 0995442346/0881006474

### **Declaration by participant**

I(name).....of

(address)..... by signing below, agree to take part in a research study entitled: An Exploration of the Involvement of Persons with Disabilities in the Poverty-reduction Strategies in Malawi.

I hereby confirm that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

### **Declaration by interpreter**

I (name) .....of

(address).....declare that I assisted the investigator (name) ..... to explain the information in this document to (name of participant) .....

### **Aim**

The aim of this study is to look at the involvement of People with Disabilities in poverty-reduction strategies in Malawi. This is because People with Disabilities are believed to be among the poorest in most African societies. The other aim is to look into the factors that may support or delay the participation of People with Disabilities in poverty-reduction strategies. The study

also aims to look at how the contributions of People with Disabilities are presented in development programmes.

### **Background to the research**

The study will be conducted in the three major cities of the three regions in Malawi. This research investigates the involvement of People with Disabilities in poverty-reduction strategies in Malawi. It also examines the factors that may encourage or slow down the participation of People with Disabilities in poverty-reduction strategies. It will explore how the contributions of People with Disabilities are reflected in development initiatives as outlined in the Poverty-reduction Strategy Paper (PRSP), now known as the Malawi Growth and Development Strategy (MGDS).

### **Possible benefits**

A study of this nature is important as the Government of Malawi and the public sector may use the findings to address issues of involvement of people with disabilities in an up to date and expected way. This would ensure that contributions of People with Disabilities are revealed in all poverty-reduction strategies and policy documents in the future. It is also hoped that decision makers would use the findings of this study to be aware of and include the needs of People with Disabilities in the development agenda in Malawi, and accord it the needed priority. The study findings may bring to light the understanding of inclusion of disability issues in the situation of Malawi. It is hoped that the understanding of disability issues may assist the inclusion of disability in the Malawi Growth and Development Strategy and other development plans.

### **Risks and Confidentiality**

There are no risks involved in your participation in this study. Confidentiality will be ensured and your name will not be associated with the information you provide.

### **Accessed: to findings**

Findings of the study will be available and utilised through a feedback workshop that will be conducted to share the results of the study with the participants and their communities, including all disabled people's organisations, government ministries and departments, the donor community, the media, civil society organisations, non-government organisations and the general public. Participants will be asked to comment on the findings and provide useful advice. Key issues coming up from the workshop will be fed into the main African Policy on Disability and Development (A-PODD) report of the study. The final report will be available to stakeholders through the Ministry of Persons with Disabilities and Elderly, Federation for Disability Organisations in Malawi and the University of Malawi. It is hoped that the study will be published as a thesis and in relevant research journals.

### **Ethical considerations**

The study has been approved by the ethical committee of Stellenbosch University registration number..... This study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the National Health Sciences Research Council in Malawi (MHSRC).

I ..... by signing below, agree to take part in a research study entitled: An Exploration of the Involvement of Persons with Disabilities in the Poverty-reduction Strategies in Malawi.

I hereby confirm that:

- I have read or had read to me this information and consent form and it is written in a language with which I am comfortable and easy to understand.
- I have had a choice to ask questions and all my questions have been fully answered.
- I understand that taking part in this study is voluntary and I have not been forced to take part.
- I may choose to leave the study at any time and will not be punished in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Phone..... Email.....

Organisation or Institution.....

Signed at (place) ..... on (date) ..... 2005.

.....  
Signature of participant

.....  
Signature of witness

### **Declaration by interpreter**

I (name) ..... declare that:

I assisted the investigator (name) ..... to explain the information in this document to (name of participant) .....

- We encouraged him/her to ask questions and took enough time to answer them.
- I passed on exactly correct translation of what was related to me.
- I am happy that the participant fully understands what has been explained in this informed consent document and has had all his/her question satisfactorily answered.

Phone..... Email.....

Organisation or Institution.....

Signed at (place) ..... on (date) ..... 2009.

.....  
Signature of interpreter

.....  
Signature of witness

**Declaration by investigator**

I (name) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (place) ..... on (date) ..... 2005.

.....  
Signature of investigator

.....  
Signature of witness

## **Appendix I: Letter to Stellenbosch University**

Ethics Committee  
Stellenbosch University  
Faculty of Health Sciences  
P.O. Box 19063, Tygerberg 7505, RSA

18/11/09

Dear Sir/Madam

### **AN EXPLORATION OF THE INVOLVEMENT OF PERSONS WITH DISABILITIES IN POVERTY-REDUCTION STRATEGIES IN MALAWI**

I am Bonface Massah, a Master student at Stellenbosch University in the faculty of Health Sciences, Centre for Rehabilitation Studies. I intend to conduct a research study on the above subject in fulfilment of MPhil in Rehabilitation.

I am writing to ask for ethical approval for the said project. The project aims to analyse and document factors that contribute to the involvement of persons with disabilities in poverty-reduction strategies such as the Malawi Growth and Development Strategy (MGDS), previously known as the Poverty-reduction Strategy Paper (PRSP). The study will be conducted in three major cities of the three regions of Malawi.

Thank you for your consideration on this matter.

Yours Sincerely,

Bonface Ophiyah Massah

Cell: + (265) 0995442346/ 0881006474 [bonifacemassah@yahoo.com](mailto:bonifacemassah@yahoo.com)

Supervisor: Dr Margaret Wazakili; [mwazakili@sun.ac.za](mailto:mwazakili@sun.ac.za)

## **Appendix J: Letter to the National Research Council of Malawi**

National Health Sciences Research Committee  
Ministry of Health  
P.O. Box 30377  
Lilongwe.

18/11/09

Dear Sir/Madam

### **AN EXPLORATION OF THE INVOLVEMENT OF PERSONS WITH DISABILITIES IN POVERTY-REDUCTION STRATEGIES IN MALAWI**

I am Bonface Massah, a Master student at Stellenbosch University in the faculty of Health Sciences, Centre for Rehabilitation Studies. I intend to undertake a research project on the above subject in fulfilment of a MPhil in Rehabilitation.

I am writing to ask for ethical approval for the said project. The project aims to analyse and document factors that contribute to the involvement of persons with disabilities in poverty-reduction strategies such as the Malawi Growth and Development Strategy (MGDS), previously known as the Poverty-reduction Strategy Paper (PRSP). The study will be conducted in three major cities of the three regions of Malawi.

Thank you for your consideration on this matter.

Sincerely yours,

Bonface Ophiyah Massah

Cell : + (265) 0995442346/ 0881006474; [bonifacemassah@yahoo.com](mailto:bonifacemassah@yahoo.com)

Supervisor: Dr Margaret Wazakili; [mwazakili@sun.ac.za](mailto:mwazakili@sun.ac.za)

## **Appendix K: List of key informants participants**

<b>Name</b>	<b>Position</b>
Mr Mzoma	Director- Government Stores
Mrs Kachaje	Vice President SAFOD
Mrs Chimbiri	UNDP
Mrs Zimpita	Director of Policy Unity-OPC
Mr Chiwaula	Executive Director- FEDOMA
Mr Zimarilana	Director of Planning - Ministry of Agriculture
Mr Kumbatira	Executive Director Malawi Economic Justice Network
Mr Kaphale	Ministry of Economic Planning and Development Cooperation
Mr Nkondiwa	Principal Secretary ministry of Persons with Disabilities and Elderly
Mrs Mwale	Director of Disability, Ministry of Persons with Disabilities and Elderly
Mr Msowoya	Executive Director Malawi Council for the Handicapped
Mr Njaidi	Director of Special Need Education Ministry of Education- Special Needs Unit
Mrs Kamwendo	Word Bank
Mrs Chitimbe	Presidential advisor on disability issues Office of the President and Cabinet
Aidan Clohessy	Director St John of God mental hospital

## **Appendix L: Letter to employers**

18/11/09

Dear Sir/Madam

### **AN EXPLORATION OF THE INVOLVEMENT OF PERSONS WITH DISABILITIES IN POVERTY-REDUCTION STRATEGIES IN MALAWI**

I am Bonface Massah, a Master student at Stellenbosch University in the faculty of Health Sciences, Centre for Rehabilitation Studies. I intend to conduct a research study on the above subject in fulfilment of a MPhil in Rehabilitation.

I would be very grateful if one or more of your employees would provide me with information regarding the involvement of persons with disabilities in poverty-reduction strategies in Malawi. I would like him/her to participate in key informant interviews, focus group discussions or both depending on his/her availability.

If you need further information regarding my request, please do not hesitate to contact me or my supervisor.

Many thanks in advance for your consideration of this request.

Yours faithfully,

Bonface Ophiyah Massah

Cell: + (265) 0995442346/ 0881006474; [bonifacemassah@yahoo.com](mailto:bonifacemassah@yahoo.com)

Supervisor: Dr Margaret Wazakili; [mwazakili@sun.ac.za](mailto:mwazakili@sun.ac.za)

