



A SITUATION ANALYSIS OF PERSONS WITH DISABILITIES IN MALAWI

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TABLE OF CONTENTS

ABBREVIATIONS	IV
EXECUTIVE SUMMARY	V
1. INTRODUCTION:	1
1.1 BACKGROUND	1
1.2 OBJECTIVES OF THE SITUATION ANALYSIS	2
1.3 METHODOLOGY	2
2. RESULTS	2
2.1 DISABILITY RELATED POLICIES AND LEGISLATIVE FRAMEWORKS	2
2.1.1 <i>The International Context</i>	3
2.1.2 <i>The National Context</i>	3
2.2 PERSONS WITH DISABILITIES IN MALAWI	7
2.2.1 <i>Global Prevalence of Disability</i>	7
2.2.2 <i>Prevalence of Disability in Malawi</i>	7
2.2.3 <i>Causes of Disability in Malawi</i>	8
2.3. ACCESS TO SOCIAL SERVICES BY CBR THEMES	9
2.3.1 <i>Health Services</i>	10
2.3.1.1 The delivery of health services in Malawi	10
2.3.1.2 Access to health services by people with disabilities	11
2.3.1.3 Treatment for Children with Cerebral Palsy	13
2.3.1.3. HIV and AIDS among PWDs	13
2.3.1.4 Seeking care for epilepsy	15
2.3.2 <i>Access to Mainstream Education</i>	16
2.3.3 <i>Livelihoods</i>	19
2.3.4 <i>Social</i>	21
2.3.4.1 The role of Ministry of Gender, Children and Community Development	21
2.3.4.2 Access to social services	22
2.3.5 <i>Empowerment</i>	23
2.4. ROLES OF DIFFERENT STAKEHOLDERS	25
2.4.1 <i>Ministry of Persons with Disabilities and the Elderly:</i>	25
2.4.2 <i>Malawi Council for the Handicapped</i>	26
2.4.3 <i>Federation of Disability Organisations in Malawi</i>	26
2.4.4 <i>Ministry of Education</i>	27
2.4.5 <i>Ministry of Health</i>	28
2.4.6 <i>Ministry of Labour</i>	28
2.5 MAINSTREAMING OF DISABILITY ISSUES	29
3. CONCLUSION AND RECOMMENDATIONS	31
3.1 CONCLUSIONS	31
3.2 RECOMMENDATIONS	33
3.2.1 <i>Effective dissemination of disability information</i>	33
3.2.2 <i>Review the National Disability Policy and enactment of the Disability Bill</i>	34
3.2.3 <i>The Roles of the MoPWDE</i>	34
3.2.4 <i>Operationalisation of NACCODI</i>	34
3.2.5 <i>Meaningful Investments in Disability</i>	34
3.2.6 <i>Develop a National Disability Mainstreaming Strategic Plan</i>	34
3.2.7 <i>Appointment of disability focal persons in the sector ministries</i>	35
3.2.8 <i>The need for a follow up survey on Living Conditions of PWDs</i>	35
4. REFERENCES	36
ANNEX 1: GUIDE FOR INDEPTH INTERVIEWS WITH STAKHOLDERS	39
ANNEX 2: LIST OF INTERNATIONAL CONVENTIONS SIGNED BY MALAWI	40

ANNEX 4: PREVALENCE OF DISABILITY IN SELECTED COUNTRIES	42
ANNEX 5: DISTRIBUTION OF PERSONS WITH DISABILITIES BY TYPE OF DISABILITY	43
ANNEX 6: DISTRIBUTION OF DIFFERENT TYPES OF DISABILITY BY GENDER AND TYPE	44
ANNEX 7: DISTRIBUTION OF PERSONS WITH DISABILITIES BY TYPE OF DISABILITY	45
ANNEX 8: CAUSES OF DISABILITY	46
ANNEX 9: WHERE PEOPLE SOUGHT TREATMENT FOR THEIR DISABILITY	47
ANNEX 10: WHERE PWDS AND PEOPLE WITHOUT DISABILITIES WOULD SEEK TREATMENT	48
ANNEX 11: HEALTH AND RELATED SERVICES PWDS ARE AWARE OF, EVER NEEDED AND EVER RECEIVED	49
ANNEX 12: SOURCES OF INFORMATION ABOUT HIV/AIDS	50
ANNEX 13: NUMBER OF DOCUMENTS ON CBR PRODUCED IN MALAWI BY TYPE	51
ANNEX 14: NUMBER OF PUPILS IN PRIMARY AND SECONDARY SCHOOLS BY TYPE OF DISABILITY	52
ANNEX 15: PERCENTAGE OF DISABLED PERSONS AGED 5 YEARS AND OVER WHO USUALLY DO WORK BY TYPE OF WORK	53
ANNEX 16: MAIN OR PRIMARY SOURCES OF INCOME.....	55
ANNEX 17: ROLES AND RESPONSIBILITIES OF IMPLEMENTATION PARTNERS	56
ANNEX 18: TERMS OF REFERENCE	60

ABBREVIATIONS

CBM	Christoffel Blinden Mission/Christian Blind Mission
CBR	Community Based Rehabilitation
CHAM	Christian Health Association in Malawi
CRW	Community Rehabilitation Worker
CSR	Centre for Social Research
CSO	Civil Society Organisation
CWD	Children with Disabilities
DIWODE	Disabled Women in Development
DPO	Disabled Peoples' Organisation
DSWO	District Social Welfare Office
EHP	Essential Health Package
FEDOMA	Federation of Disability Organisations in Malawi
GoM	Government of Malawi
HSA	Health Surveillance Assistant
HTC	HIV Testing and Counselling
ICF	International Classification of Functioning, Disability and Health
ILO	International Labour Organisation
MACOHA	Malawi Council for the Handicapped
MADISA	Malawi Disabled Sports Association
MANAD	Malawi national Association for the Deaf
MAP	Malawi Against Physical Disabilities
MGDS	Malawi Growth and Development Strategy
MoE	Ministry of Education
MoPWDE	Ministry of Persons with Disabilities and the Elderly
MUB	Malawi Union of the Blind
NAD	Norwegian Association of Disabled
NESP	National Education Strategic Plan
NGO	Non-Governmental Organisation
NSO	National Statistical Office
PODCAM	Parents of Disabled Children Association of Malawi
PWD	Persons with Disabilities
SADPD	Secretariat for the African Decade for Persons with Disabilities
SEN	Special Educational Needs
SNE	Special Needs Education
STI	Sexually Transmitted infection
TEVETA	Technical, Entrepreneurial Vocational and Educational and Training Authority
VHC	Village Health Committee
WB	World Bank
WHO	World Health Organisation
WHS	World Health Survey

EXECUTIVE SUMMARY

Rationale for conducting a situation analysis of PWDs in Malawi

This situation analysis was an initiative by the Secretariat of the African Decade for Persons with Disabilities with the Ministry of Persons with Disabilities and the Elderly and its stakeholders. The study was funded by CBM and the Norwegian Association of the Disabled. The overall objective of the situation analysis was to compile and comprehensively summarize information from a selection of existing studies and documents on the situation of PWDs in Malawi. Specifically, this study was commissioned to (i) establish the existing legislative and policy framework for disability; (ii) Determine the availability and level of access to existing services; (iii) find out the different stakeholders and their existing programmes and interventions; and (iv) identify main gaps and make recommendations on priority intervention areas for the GoM and its development partners in the remaining years of the African Decade. The study will inform the development of the National Disability Mainstreaming Plan for Malawi.

Methodology

This study involved the review of a wide range of studies and reports on disability in Malawi. A few interviews were also done with some key sector ministries namely Ministry of Labour; Ministry of Education; Ministry of Gender, Children and Community Development; Ministry of Agriculture; Ministry of Finance; Ministry of Youth, Sports and Culture; and Ministry of Health. Interviews were also conducted with officials from FEDOMA and MACOHA. These interviews focused on the involvement of these key ministries in the implementation of disability services and the challenges that exist in mainstreaming disability across the sectors.

Results

Disability Related Policies and Legislative Frameworks

At an international level there are a number of conventions that Malawi has signed and ratified that promote the rights of PWDs e.g. the UN Convention on the Rights of Persons with Disabilities which Malawi signed and ratified in 2007. There are also a number of other international conventions and agreements that Malawi has signed and ratified. Malawi has also made progress in the domestication of the UN Conventions in its legislation and policies. At national level the Constitution of the Republic of Malawi and other pieces of legislation promote and uphold the rights of people with disabilities. Malawi is, however, still using the Handicapped Persons' Act (1971) which is old, charity-based and does not promote or protect the rights of PWDs. The Disability Bill, drafted in 2004, to replace the Handicapped Persons Act (1971) is yet to be approved by Parliament. The National Policy on the Equalisation of Persons with Disabilities was launched in 2006 and it promotes the rights of PWDs. The implementation of the policy has been weak mainly because awareness is low, most sector ministries have not taken up the policy, mainstreaming disability across sectors is yet to be done and that there is currently no legal framework within which to enforce the policy. Other policies have also been developed that promote the rights of people with disabilities e.g. the National Special Needs Education Policy. Malawi therefore has an adequate policy and legal environment for promoting and upholding the rights of PWDs.

Prevalence and causes of disability in Malawi:

In 2003 it was estimated that 4.18% of Malawi's population consisted of PWDs. This rate was also found in 2008. These figures are considered low. The 2003 World Health Survey found that 12.97% of people aged 15-65 were PWDs and that disability prevalence was higher among poorest quintiles compared to wealthier quintiles. The most common forms of

disabilities are physical disabilities. In terms of causation, the majority of people with disabilities reported that their disabilities were caused by physical illness. Other causes included accidents and witchcraft. Others believe that persons with disabilities cannot bear children without disabilities; hence children from a person with a disability will also be disabled. There is a need for continued creation of awareness on the causes of disability in the general population and how these can be prevented.

Access to services

Access to health services by people with disabilities

Most PWDs seek treatment for their disability from health facilities. Some, however, go to traditional healers because of the belief that they have been bewitched e.g. for mental illness and epilepsy, a significant proportion of people reported they would seek treatment from traditional healers. The majority of people with disabilities are aware of available health services and that the majority of these people may also require services, however, a much lower proportion report they have received the services they require. This demonstrates that there exist gaps between what services PWDs need and what they receive. In terms of seeking care from health facilities, PWDs experience a lot of problems and these include (i) the lack of money to get to health facilities; (ii) mistreatment by health workers; (iii) communication barriers between health workers and people with hearing impairments; and (iv) long distances to health facilities; among other challenges. The CBR programmes aim at improving access to health services by PWDs through addressing these challenges. The evaluation of these programmes demonstrates increased access to health services by PWDs but coverage of these programs is limited in that it is only in 14 districts.

Access to mainstream education

The GoM has made considerable progress in ensuring that CWDs attend school. Within the Ministry of Education there is a special needs education unit that ensures that CWDs have access to education. Just over a 100 resource centres have been established in mainstream schools and 22 in secondary schools for children with disabilities. The Ministry of Education has also embarked on a campaign aimed at creating awareness about the need for special needs education and as a result of this communities are participating for example in construction of resource centres. The Ministry has also issued a directive to all its institutions that all new structures being constructed should be disability friendly. In terms of enrolment and attendance, 35% of PWDs have never attended school compared to 18% among the non-disabled; hence school attendance among PWDs is significantly lower compared to those household members without a disability. Learners with disabilities experience important challenges in accessing education and these include: the lack of specialist teachers such as those with Braille knowledge and sign language; inadequate instructional materials; inadequate learning support as classes are too large; and inaccessible infrastructure. Other problems include: dropping out of school because of lack of money; and long distances to schools. Albinos may drop out of school because they have problems in reading books and seeing what is written on the board. In districts where CBR programs are being implemented, access to education for learners with disabilities has improved but as has been said earlier it is only 14 districts that are implementing such programs which imply that a significant proportion of people with disabilities are not benefiting from these programs.

Livelihoods

The major source of livelihood for PWDs is farming, both subsistence and commercial. However there are slightly more PWDs involved in subsistence farming compared to people without disabilities. In terms of employment, 58% of the PWDs were not working at the time of the survey compared to 53% among the non disabled. It is also difficult for PWDs to find

employment as discrimination still prevails. CBR programmes equip PWDs with vocational skills for earning a living. A 2007 study found that 48% of the survey population had attended some skills training and 50% of those who attended some skills training were in employment. Most PWDs find vocational skills useful in finding work. CBR programmes have been useful in equipping PWDs with essential skills for earning a living but the coverage of the CBR programs is limited and a good proportion of PWDs still lack vocational skills.

Social

Some studies have shown that some people with disabilities have problems entering and sustaining relationships because of the disability itself. Difficulties in mobility also make creation of relationships problematic. Women with disabilities, especially the poor, are more vulnerable: they suffer sexual abuse and once pregnant cases are uncommon in which they have been abandoned by men. Family members can also discourage men from marrying women with disabilities because of the belief that such a couple will bear CWDs or that such women will not be able to fulfil household chores. In some cases CWDs are also abandoned by fathers. Cases of households sending their disabled children away or hiding them have been reported. A significant proportion of PWDs are not consulted about making household decisions even if such decisions affect and they are also excluded in community benefits. As far as this theme is concerned, not much research has been done.

Empowerment

Some progress has been made with regard to empowerment of PWDs in Malawi. Over the last decade, DPOs have conducted a lot of meetings aimed at sensitizing the wider community on the rights of PWDs but the documentation of such awareness campaigns by DPOs and other stakeholders has been limited. Education empowers PWDs with knowledge and skills; hence the need to address the barriers to implementation of SNE. In addition, CBR programmes have empowered PWDs with training and disbursement of loans in order to economically empower them. In terms of decision making, it seems that organisations especially CSOs are not fully aware of the need for PWDs to participate in civic education and electoral processes. Ballot boxes guides are now in place for PWDs but civic education in electoral processes have not been accessible to PWDs especially for the deaf and blind. Lastly, a directory of disability organisations has been produced for Malawi which provides information on groups and services specifically working in the disability sector in Malawi but it has not been disseminated widely. Empowerment of PWDs in various ways is important but not much research has been done to determine to what extent PWDs have been empowered.

Roles of Different Stakeholders

The National Policy on Equalisation of Opportunities for People with Disabilities says that all Government Ministries, Departments and statutory bodies are responsible for the implementation, monitoring and evaluation of the National Policy on Equalisation of Opportunities for Persons with Disabilities. These organisations are responsible for specific services and they are supposed to cater for PWDs within their sectors and ensure that PWDs have equal access, rights and responsibilities as any other Malawian. While this is what is supposed to be done, not much has been done in terms of ensuring that these organisations are doing their part in terms of inclusion of PWDs in their plans. For example while the Ministry responsible for PWDs is supposed to be in charge of mainstreaming, resource mobilisation, guidance and provision of support to other agencies, not much is being done. The provision of services by MACOHA is hampered by inadequate funding from central government. The Ministry of Education has made some progress in terms of ensuring that CWDs attend school but major challenges remain. The development of the National Disability Mainstreaming Plan and ensuring that it is implemented will ensure that all the stakeholders

are carrying out their responsibilities in terms of ensuring that PWDs have access to services.

Mainstreaming of Disability Issues

Despite the launch of the Policy not much has been done in terms of mainstreaming disability in different sectors. Interviews with stakeholders and review of literature demonstrate that various stakeholders are not fully aware of disability issues including the policy. The Policy has a provision for the establishment and operationalisation of the National Advisory and Coordination Committee on Disability Issues but this was never operationalised. Mainstreaming would require the operationalisation of NACCODI. While the mainstreaming at national level has not progressed, there is good progress in mainstreaming disability in CBR districts. Barriers to mainstreaming disability include (i) shortage of human resource at all levels; (ii) insufficient understanding of mainstreaming; lack of wide dissemination of the policy; and (iii) inadequate financial allocation in various sector; among other factors. It is important therefore to address these issues in order to effectively mainstream disability in different sectors.

Conclusion and recommendations

This situation analysis has demonstrated that PWDs face various challenges in terms of accessing health, education and other services. It has also shown that while the Policy was launched in 2006 most of it has not been implemented. This is partly because it has not been widely disseminated among the key players. The implementation of the policy has also not been done partly because the Disability Bill which was supposed to provide the legal framework for implementation of the policy has yet to be passed by parliament. As the GoM and stakeholders plan to mainstream disability in different sectors, it is important to ensure that the Policy which was for a period of 5 years should be reviewed and that, once revised it should be disseminated widely. In order to ensure the existence of a forum where different stakeholders can discuss disability issues and go back to their respective workplaces and start implementing disability issues, NACCODI should be operationalised. It is also proposed that there is a need for the Ministry responsible for PWDs to revisit its responsibilities and possibly focus on development of policies and legislation and monitoring and evaluation of interventions by different stakeholders including MACOHA. It should also take the lead in terms of mobilising resources from different partners for implementing disability interventions. Lastly, there is also a need to develop a National Disability Mainstreaming Strategic Plan which will guide disability mainstreaming in various sectors.

1. Introduction:

1.1 Background

This situation analysis is an initiative by the Secretariat of the African Decade for Persons with Disabilities (SADPD) with the Ministry of Persons with Disabilities and the Elderly (MoPWDE) and its partners CBM and the Norwegian Association of the Disabled (NAD). The study was funded by CBM and NAD. This study provides the basis for mainstreaming disability in Malawi. The MoPWDE has entered into a partnership with SADPD, CBM, and NAD to develop a National Disability Mainstreaming Plan for the Government of Malawi (GoM). This work has been done in collaboration with the Federation of Disability Organisations in Malawi (FEDOMA).

The purpose of this Plan is that the GoM will in future ensure that:

- People with Disabilities (PWDs) are considered and included in all development activities at all levels;
- All existing government services are also made accessible to PWDs (e.g. education, livelihoods, health); and
- GoM is systematically developing additional, disability specific services, as required.
- Other stakeholders will elaborate their role and contributions to the plan

Consequently, the main target group of the National Disability Mainstreaming Plan will be sector ministries as well as other relevant government institutions and statutory corporations at all levels. In order to effectively institutionalize disability mainstreaming, capacity will be built within government entities on how to mainstream disability in their respective strategies, projects and services and regularly report on their progress and achievements. The line ministry responsible for PWDs is the MoPWDE. The core functions of this ministry as far as mainstreaming is concerned will be to:

- Develop the National Disability Mainstreaming Plan in collaboration with all stakeholders;
- Build the capacity in relevant sector ministries, government institutions and statutory corporations at all levels to mainstream disability in their respective strategies, projects and services;
- Monitor the implementation of the National Disability Mainstreaming Plan and efforts of all relevant sector ministries, government institutions and statutory corporations at all levels to mainstream disability;
- Provide back-stopping and technical assistance to relevant sector ministries, government institutions and statutory corporations to effectively mainstream disability.

For the development of a National Disability Mainstreaming Plan, the existing situation regarding disability and development in Malawi needs to be established to serve as a baseline from which to commence further planning together with other sector ministries, local partners and stakeholders. The situation analysis will be utilized for doing a GAP or SWOT analysis with other stakeholders in Malawi and abroad. It will also be useful when evaluating outcomes and impact at national level after a few years when change can be tracked.

1.2 Objectives of the Situation Analysis

The overall objective of the situation analysis was to compile and comprehensively summarize information from a selection of existing studies and documents on the situation of PWDs in Malawi. Specifically, this study was commissioned to:

- Establish the existing legislative and policy framework for disability;
- Determine the availability and level of access to existing services;
- Find out the different stakeholders and their existing programmes and interventions; and
- Based on the findings, identify main gaps and make recommendations on priority intervention areas for the GoM and its development partners in the remaining years of the African Decade, declared by the African Heads of State and Governments in 1999, and extended in 2009 (until 2019).

1.3 Methodology

A number of studies have been conducted relating to PWDs in Malawi. These studies have been conducted by institutions both inside and outside Malawi. CBM, the MoPWDE, Malawi Council for the Handicapped (MACOHA) and FEDOMA provided the documents that were reviewed as part of this study. In addition to review of research reports, the study also involved the review of policy and legislative documents prepared by the GoM and other stakeholders. Key sector Ministries namely Ministry of Labour; Ministry of Finance; Ministry of Youth, Sports and Culture; Ministry of Gender, Children and Community Development; Ministry of Education (MoE) and Ministry of Health were interviewed to find out their involvement in the implementation of disability services and the challenges that exist in mainstreaming disability across the sectors. Interviews were also conducted with officials from FEDOMA and MACOHA (Lilongwe and Blantyre). The interview guide that was used in these interviews is in Annex 1.

2. RESULTS

The results of this study have been presented in three major sections namely: (1) Disability related policy and legislative framework in Malawi, and disability specific national plans of the GoM; (2) Availability of services in Malawi with regards to the intervention areas of the CBR matrix, and level of access to those services by PWDs; and (3) Mapping of roles and responsibilities of key stakeholders and institutions versus their actual programmes and interventions.

2.1 Disability Related Policies and Legislative Frameworks

One of the major challenges experienced by PWDs is social exclusion from mainstream society. Often PWDs are discriminated against and socially marginalised and have limited or no access to basic social services such as education, health care and employment opportunities. They do not receive the disability related services that they require (WHO and World Bank, 2011). At an international level instruments have been developed that aim at ensuring that PWDs have access to fundamental social and economic rights. Malawi, as is

the case with other developing countries, has domesticated these instruments and recognises PWDs as equal citizens having the same rights and obligations as every other Malawian. This is stipulated in a number of policies and legal instruments. While this is the case, challenges, however, still remain as the majority of PWDs still have difficulties in accessing essential social services for example education, health services and employment among other rights. This section reviews legislation and policies in place that promote the rights of PWDs in Malawi.

2.1.1 The International Context

At an international level there are a number of conventions that Malawi has since signed and ratified that promote the rights of PWDs. In 2007 Malawi signed the UN Convention on the Rights of Persons with Disabilities (Lang, 2008). The signing and ratification of this Convention implies that Malawi has obligations to report to the UN on the status of PWDs. Earlier in 1986 Malawi also ratified the UN Convention No 159 on Vocational Rehabilitation and Employment of Persons with Disabilities and Malawi was the first country to do so. There are also a number of other international conventions and agreements that Malawi has either signed and/or ratified. Annex 2 details the list of international conventions to which Malawi is a party. The ratification of these conventions is an important step towards upholding the rights of PWDs in Malawi.

2.1.2 The National Context

In 1971 the GoM adopted the *Handicapped Persons' Act* which provides for the establishment of MACOHA which is a government agency responsible for promoting the welfare of PWDs, providing rehabilitation and welfare services for PWDs; and administering vocational and special training centres for PWDs. The Act guides organisations that provide rehabilitation programmes and services to PWDs. A major criticism is that the Act is charity-based and does not promote or protect the rights of PWDs (Wapling, 2009).

The Handicapped Persons Act is very old and requires a review to address the current situation. In 2004 a *Disability Bill* was drafted to replace the Handicapped Persons Act (1971). This bill, which is currently with Cabinet, will ensure that the rights of PWDs are protected and upheld. Under this Bill discrimination based on disability is prohibited; access to quality education and other social services for PWDs is assured; and there is a provision for equal opportunities for PWDs to develop their skills. Denial of PWDs for admission by any learning institution is criminalised. It also provides for one integrated public vocational and technical school in each region and that 5% of all positions in public and private establishments be reserved for PWDs. The Bill also provides for special needs education for learners with special educational needs (SNE). The State is further obliged to recognise and promote the formation of Disability Peoples Organisations (DPOs), particularly supporting DPOs in their advisory role as well as with rehabilitation services and programmes. The absence of the Disability Bill makes the implementation of the National Policy on the Equalization of Persons with Disabilities problematic as there is no legal backing to this policy. It is, therefore, imperative that this Bill should be passed into law.

In 1994 at the dawn of multiparty politics, a new *Constitution of the Republic of Malawi* was drafted and adopted which explicitly and implicitly recognises the rights of PWDs. In line with international instruments, the Constitution prohibits discrimination of any kind:

“Discrimination of persons in any form is prohibited and all persons are, under any law, guaranteed equal and effective protection against discrimination on grounds of race, colour, sex, language, religion, political or other opinion, nationality, ethnic or social origin, disability, property, birth or other status” (Section 20, Malawi Constitution).

The Constitution therefore guarantees protection for PWDs against discrimination of kind. Section 13 of the Constitution (Principles of National Policy) says that:

“The State shall actively promote the welfare and development of people of Malawi by progressively adopting and implementing policies and legislation aimed at achieving the following” –

The Constitution then highlights a number of goals and in Section 13g the goal is to support PWDs through greater access to public places; equal opportunities for employment; and the fullest possible participation in all spheres of Malawi society. Even though the Constitution does not explicitly mention PWDs in some sections, it can be implied that these sections especially in Chapter IV on Human Rights are also applicable to PWDs for example that:

- All persons are entitled to education (Section 26).
- Every person shall have the right to freely engage in economic activity, to work and to pursue a livelihood anywhere in Malawi (Section 29).
- All persons and peoples have a right to development and therefore to the enjoyment of economic, social, cultural and political development and women, children and the disabled in particular shall be given special consideration in the application of this right (Article 30).
- Every person shall have the right to fair and safe labour practices and to fair remuneration (Section 31).

The Constitution therefore is an important legislative framework that ensures that the rights of PWDs are upheld and in many aspects it is in line with international policy and legislative frameworks.

In terms of employment, the *Employment Act (2000)* illegalises discrimination against any employee or prospective employee on the ground of disability in respect of recruitment, training, promotion and terms and conditions of employment. The Act also emphasises on equal pay for work of equal value, without discrimination and prohibits against dismissal of an employee because of disability, or any other form of discrimination. *The Technical, Entrepreneurship and Vocational Education and Training Act (1999)* provides for representation of PWDs on its Board thus ensuring that the interests of PWDs are addressed. The Act created the Technical, Entrepreneurial and Vocational Education and Training Authority (TEVETA). The main objectives of TEVETA are: to promote demand-driven, competency-based modular training systems; monitor gaps between supply and demand for skills; promote managerial skills; foster an entrepreneurial spirit “with regard to

both wage and self-employment"; and facilitate sound and sustainable financing for the training system. Although it does not specifically talk about PWDs it however provides for skills development for PWDs.

The *Malawi Growth and Development Strategy* (MGDS) is an overall development agenda for Malawi. It aims at creating wealth through sustainable economic growth and infrastructure development as a means of achieving poverty reduction. Disability and PWDs are mentioned in a few places namely under sub-themes economic empowerment, social development and social protection. With regard to HIV/AIDS, the MGDS seeks to improve knowledge and capacity of young people, orphans and the physically challenged; and to integrate the elderly, orphans and the physically challenged affected by HIV/AIDS into mainstream development.

The use of the phrase *physically challenged* has been described as unsuitable as it implies that only people with visible impairments are included and others such as the deaf or those with learning difficulties are not classified under this definition (Wapling, 2009). The MGDS acknowledges that PWDs are the most vulnerable in terms of access to assets and other facilities required to become economically empowered. Access to financial services and capital, skills development programmes, and technology developments is limited for PWDs. Most infrastructure (including communication systems) is not accessible by PWDs. There is a need, therefore, to address the factors leading to disempowerment among PWDs. The approach in MGDS has been criticised because it has a welfare approach rather than developmental or rights approach; and that the CBR programmes goes beyond the MGDS in its approach to disability (Eggen et al, 2010).

In 2006 Malawi adopted the *National Policy on the Equalisation of Persons with Disabilities*. The policy was drafted by MoPWDE in collaboration with stakeholders. It was approved by cabinet in December 2005. This policy promotes the rights of PWDs to enable them play a full and participatory role in society and consequently have access to the same rights and responsibilities as any other Malawian citizen. Particularly the policy recognises the importance of education, training and employment among PWDs. The Policy also acknowledges the need to engage DPOs in the development, implementation and evaluation of programmes and services. Specifically, the policy further details the roles of different GoM Ministries and departments including the MoPWDE. The Policy aligns well with the requirements of the international policies as well as Malawi's Constitution and other national policies including the National Policy on Special Needs Education. The policy also presents a comprehensive approach to mainstreaming disability across sectors and adopts CBR as a national strategy. While the policy is in place, it has been argued that implementation is weak and weakest in districts where there are no CBR programmes. Most sector ministries have not taken up the policy and mainstreaming disability across sectors is yet to be done in detail. Awareness of the policy seems to be low and dissemination of the policy has been limited (Eggen et al, 2010). These issues were also mentioned by various stakeholders interviewed as part of this study. Other challenges in the implementation of the policy include the lack of a legal framework within which to enforce the policy (i.e. the Disability Bill which is currently with Cabinet) and limited funding of activities (Wapling, 2009).

In terms of education in 2001, the GoM developed the *Policy Investment Framework* which emphasised on GoM's commitment to SNE. A *National Special Needs Education Policy* has since been developed and it guides the implementation of special needs education in Malawi.

The policy focuses on eight major components of SNE which include: early identification assessment and intervention; advocacy, care and support; management planning and financing; access, quality, equity and relevance. Each of these components has policy statements and strategies to ensure their effective implementation. Barriers to implementation of this policy include inadequate funding; inadequate teaching and learning materials; inaccessible infrastructure such as classrooms; long distances to facilities; and shortage of specialist teachers among other factors (Lang, 2010).

The *Malawi National Education Strategic Plan* (NESP) for the period 2008-2017 outlines strategic interventions that will be implemented in Malawi within the education sector. This is the basis for investments in the education sector by GoM and Development Partners. One of the major areas of emphasis in the Plan is that learners with special educational needs (SEN) are taken care of. Some of the strategies that will be implemented over the 10 year period to address the challenges that learners with SEN include:

- Improving the provision of teaching and learning materials for both special needs education and other adults;
- Ensuring CBR programmes run by MACOHA have special needs education component;
- Mainstreaming special needs education at all levels of education and for both out of school and in school youth;
- Mainstreaming special needs education in both primary and secondary school curricula;
- Developing appropriate tools for special needs education for example sign language and braille;
- Increasing enrolment and making selection equitable including those of special educational needs;
- Increasing the enrolment of special needs education teachers in training colleges; and
- Reviewing and revising TEVETA Act to incorporate issues of special needs and inclusive education.

The NESP, therefore, addresses most of the problems relating to SNE. Eggen et al argue that while the Plan is in place the actual delivery of services for learners with various forms of disabilities especially the deaf and those with learning difficulties continues to be a challenge (Eggen et al, 2010). If the Plan is implemented successfully then access to education by learners with SEN will improve. The Plan also has in place indicators that will be used to monitor progress in the implementation of activities (MoE, 2008).

It is evident that Malawi has an adequate policy and legal environment for promoting and upholding the rights of PWDs. The major setback, however, is that the Disability Bill which is supposed to provide legal backing to the National Policy on the Equalisation of Opportunities for People with Disabilities has not yet been approved by Parliament. As shall be demonstrated later, access to services such as education, employment and health is still a challenge despite the existence of national and international policy and legal frameworks.

2.2 Persons with Disabilities in Malawi

This section outlines prevalence and some major causes of disability in Malawi. However, global prevalence of disability will also be looked at.

2.2.1 Global Prevalence of Disability

The 2011 World Report on Disability (WHO/WB) uses two approaches to measuring disability namely the 2004 Global Burden of Disease and the 2004 World Health Surveys (WHS). In 2004, the Global Burden of Disease estimated that the prevalence of disability was at 19.4% of the global population while the World Health Survey estimates give a prevalence of 15.6%. Using these proportions, it is estimated that between 785 million and 975 million people in the world have disabilities. Eighty percent of the PWDs worldwide live in developing countries and 82% live below the poverty line (Hope, 2003). The World Bank estimates that individuals with disabilities now comprise about 20% of the poorest of the poor (Elwan, 1999). Annex 3 shows the estimated prevalence of both severe and moderate disability in WHO regions in 2004 based on the 2004 Global Burden of Disease. These estimates as well as the 2010 estimates are much higher compared to earlier estimates which suggested that 10% of the world population consisted of PWDs (WHO and World Bank, 2011).

The prevalence of disability, as reported in the 2011 World Report on Disability, is consistent with prevalence reported in earlier studies in high income countries where prevalence has been over 10% and some even approaching 20% as can be seen in Annex 4. It is evident that over the last two decades African countries have continued reporting significantly lower rates compared to high income countries at around 5% or less. Loeb and Eide (2004) suggest that there might be under-reporting of disability in low income countries. These differences might also be due to differences in the definitions of disability and assessment tools. More recent surveys on disability conducted by SINTEF in African countries have also revealed lower rates of disability among sub-Saharan African countries (for example, see Loeb and Eide, 2004). While this is the case, it should be acknowledged that most of the PWDs live in the South and that over the last decade disability data has become more available.

2.2.2 Prevalence of Disability in Malawi

There have been three major studies to estimate the prevalence of disability in Malawi. In 1983 it was estimated that 2.9% of Malawi's population was comprised of PWDs: 93% lived in rural areas while 7% lived in urban areas. In absolute numbers, there were 190,000 PWDs and 102,000 were men and 88,000 were women. About 11% of the households had at least one person with a disability; and 4% of the households were headed by PWDs. Among PWDs, 32% were heads of households which demonstrates the level of decision making that PWDs have at household level. Annex 5 shows the proportion of different forms of disabilities as found in the 1983 survey. The survey showed that at the time the major types of disabilities were total or partial loss of sight in one or both eyes (20.5%), fits or epilepsy (18.8%), crippled limbs (18.2%) and deafness (13.3%). Persons with mental illness constituted 8.3% of the PWDs (National Statistical Office, 1987). About 90% of the PWDs

had one form of disability. Another national survey was done in 1993 and the prevalence of disability was just the same as that found in 1983¹.

In 2003 the Centre for Social Research of the University of Malawi conducted the World Health Survey on behalf of the WHO. Analysis of the results of this survey demonstrate that the prevalence of disability among working individuals aged 15-65 in Malawi is estimated at 12.97% with prevalence being higher among females at 13.49% than males at 12.45% and also being higher in rural areas at 14.05% compared to urban areas at 7.48%. Disability prevalence also is higher among poorest quintiles compared to wealthier quintiles: in Malawi it is estimated that among the bottom quintile prevalence of disability is at 15.08% while among the upper 4 quintiles it is at 12.27% (Mitra et al, 2011). These figures are much higher than the two earlier studies conducted by NSO, namely in 1983 and 1993, possibly because it only looked at persons with the working age group and not across the whole population spectrum. In 2003 the prevalence of disability in Malawi was found to be 4.18%. Taking into consideration the population size at the time, this implied that there were nearly half a million PWDs in Malawi. This was higher than the two earlier national surveys conducted in 1983 and 1993. In the 2003 survey 50.7% of the PWDs were females while 49% were males. As can be seen in Annex 6, the major forms of disabilities as determined by the 2003 survey were physical disabilities (43%), seeing (23%), hearing (15.7%) and 11.5% had intellectual/emotional disabilities (Loeb and Eide, 2004). The *Living conditions* study (as the 2003 survey is commonly referred to) was different from earlier studies because it used the International Classification of Functioning, Disability and Health (ICF) model which defines disability in terms of activity limitations and participation restrictions.

More recently the 2008 Malawi Population and Housing Census showed that there are 498,122 PWDs in Malawi and this translates into a national prevalence of 4.0% of the population which is similar to the results from the *Living conditions* survey. Annex 7 shows the number of PWDs by type and residence and it demonstrates that there are more PWDs in rural areas compared to urban areas and that the major types of disability were visual and walking impairments (National Statistical Office, 2010). Some small-scale prevalence surveys have also been conducted in selected geographical locations to inform the development of interventions. In 1992 a small survey in one ward in Ntchisi District found that there were 206 PWDs and this was below 2.9% disability prevalence estimated from the 1983 survey. In this study physical disabilities were as well the most common (McDonald, 1992). The 2003 *Living conditions survey*, the WHS and the census has helped Malawi to determine the prevalence of disability for purposes of informing policy and programming. Before this, Malawi just like other countries used an estimate from WHO of 10% of people in developing countries being PWDs. Currently, in most cases baseline surveys are not undertaken to determine the number of PWDs: stakeholders estimate this using the 2003 *Living conditions of people with activity limitation* study.

2.2.3 Causes of Disability in Malawi

Annex 8 shows the main causes of disability as perceived by the respondents in the 2003 *Living conditions* survey. Nearly half of the PWDs interviewed reported that their disability was caused by physical illness. Nearly a fifth reported that their disability was natural or from

¹ Researcher did not access this report.

birth and 10.6% mentioned accidents as a cause of disability. Twenty three percent of the persons with disabilities reported that their disability was from birth; 46.7% became disabled between 1 and 20 years of age. These figures generally demonstrate that most of the disabilities are preventable. While traditional beliefs still prevail, only 3.8% of the persons with disabilities reported that their disability was caused by witchcraft (Loeb and Eide, 2004). Some people do not actually know how they became disabled while others feel that disability can be inherited (Kvam and Braathen, 2006).

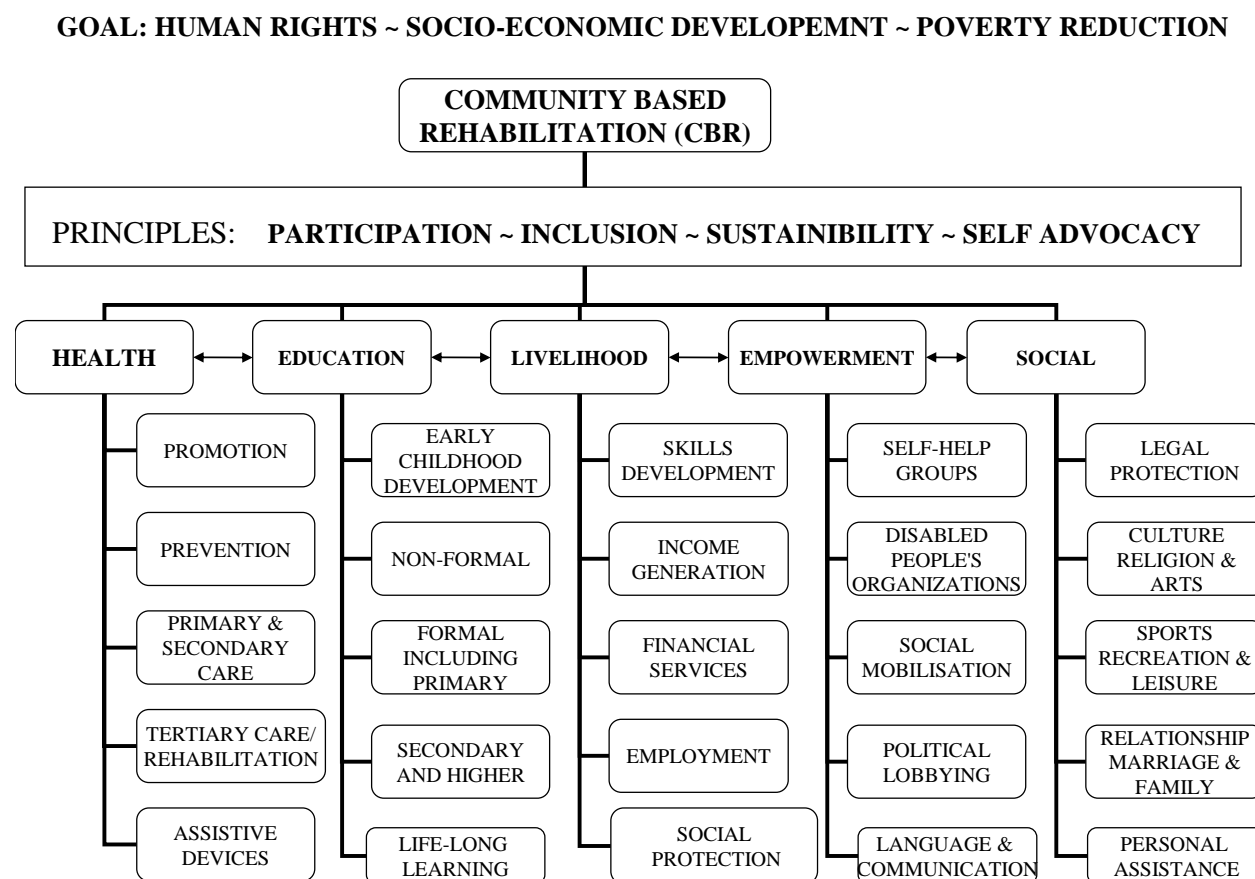
In 1983 46% of respondents believed that their disabilities occurred before reaching the age of 5 years (NSO, 1987). In 1985 a baseline survey conducted in Karonga, Salima and Machinga by the Demographic Unit at Chancellor College showed that 25% of the disabled population had disabilities which were either congenital or began at birth and the remaining 75% acquired it later in their life (Demographic Unit, 1985). In 2003 47% of the PWDs reported acquiring the disability by the age of 20 while 26% acquired the disability by the age of 6 years (Loeb and Eide, 2004). There have also been some small scale studies that have looked at causes of disability in Malawi. For example, Mji et al in their study of HIV/AIDS among PWDs reported that some people believe that persons with disabilities cannot bear children without disabilities; hence children from a person with a disability will also be disabled (Mji et al, 2010). In 1992 McDonald found that people attributed disability to diseases such as polio, accidents, burns and witchcraft (McDonald, 1992).

Some studies have explored the causation of specific forms of disability for example albinism and cerebral palsy. The 2003 *Living conditions* study did not capture albinism. While some people explain that albinism is a natural illness and hence God's will (see Global Health Study, 2008), others attribute this condition to "*mwanamphepo*" or that a pregnant woman who looks at an albino may also deliver an albino as well and this is why some people spit on the ground when they see an albino so that they should not bear an albino themselves (Braathen, 2006). Cerebral palsy is a major disabling condition among children in Malawi. Biomedically, cerebral palsy is caused by conditions such as injury, hypoxia, hypoglaecemia, jaundice, infection and intrapartum asphyxia. Although the studies on cerebral palsy do not mention it, in Malawi where malaria is endemic, fever due to this condition can also be an important cause of this disease. While some parents and guardians of children understand the biomedical explanations of the causes of cerebral palsy others do not understand and they attribute the condition to witchcraft and other related powers (Chimowa, 2007 and Mwafulirwa, 2008). This discussion generally shows that people are aware of the causes of disability but there are still others who attribute this to witchcraft and other traditional beliefs. There is a need for continued creation of awareness on the causes of disability in the general population and how these can be prevented.

2.3. Access to Social Services by CBR Themes

PWDs are in some cases systematically excluded from accessing services such as education, health, employment, leadership and decision making and participation in development activities in general. The CBR matrix, adopted in 2008, promotes access to five major intervention areas namely: health, education, livelihood, empowerment and social. Each of the components has five elements. The components and elements are underpinned by a number of principles. The principles are intended to be translated into tangible ways of working through programme activities. Figure 2.1 below shows the CBR matrix:

Figure 2.1: The CBR matrix



The discussion below explores the levels of access to services by these CBR themes.

2.3.1 Health Services

This section describes the delivery of health services in Malawi and then explores access to these services by PWDs.

2.3.1.1 The delivery of health services in Malawi

In Malawi health care services are delivered by the public and the private sector. The public sector includes health facilities under the MoH; Ministry of Local Government and Rural Development (MoLGRD); the Army, Police and Prisons; and the Ministry of Forestry. CHAM is private and charges user fees. Its health facilities constitute 14% of health facilities in Malawi (Centre for Social Research, 2008). The provision of services in the public sector is done free of charge. At the central level, the MoH is mainly responsible for policy formulation and enforcement and setting of standards, planning and mobilising health resources for the health sector, providing technical support supervision and coordinating research, monitoring and evaluation². The responsibility for the provision of health services lies at district level under the responsibility of the MoLGRD.

² Ministry of Health. (2004). *Handbook and guide for health providers on the Essential Health package in Malawi*. Lilongwe: Ministry of Health.

The delivery of health services in Malawi is structured at three levels namely: primary, secondary and tertiary. The primary level is the lowest level of health care and consists of community initiatives, health posts, dispensaries, maternities, health centres and community and rural hospitals. The health services at this level are provided by HSAs (the lowest cadre in the MoH resident in the community), volunteers and Non-Governmental Organisations. The services delivered at community level are mainly promotive and preventive in nature but more recently HSAs have become involved in community case management of childhood illnesses³. The HSAs are also involved in the establishment of VHCs which are also involved in the provision of promotive and preventive health services. There are also health centres, clinics and dispensaries at this level which provide health services to Malawians.

The types of services that are delivered at primary level mainly address the Essential Health Package which is a list of diseases and conditions. These conditions are as follows: malaria, adverse maternal and neonatal outcomes, tuberculosis, acute respiratory infections, acute diarrhoeal diseases, HIV/AIDS and STIs, vaccine preventable diseases, schistosomiasis, nutritional disorders, eye, ear and skin infections and common injuries. All Malawians including PWDs are supposed to have access to these services at all levels of health care.

District hospitals and CHAM hospitals constitute secondary level of health care and are referral centres for health centres. They also service the local town population. The MoH headquarters has devolved the provision and management of health services to the MoLGRD. Health services are managed by the District Health Management Team (DHMT) headed by the District Health Officer (DHO) who is also part of the District Council and reports to the District Commissioner.

While Central Hospitals provide specialist health services, they also provide EHP services which should be the responsibility of district health system. There are 4 central hospitals one in each region. They provide specialist referral care for their respective regions. Specialist hospitals offer very specific services such as mental health services and inpatient care for Tuberculosis. Central Hospitals are also teaching hospitals.

With regard to traditional medicine, there has not been much collaboration with traditional healers. A policy now exists that defines the framework for the cooperation between traditional healers and MoH. However, over the years MoH has been working very closely with TBAs whose role has now been redefined: instead of conducting deliveries they should refer pregnant women to health facilities for delivery. In order to promote universal access to health services, the MoH has introduced service level agreements with CHAM facilities in which DHOs transfer a specified amount of money to CHAM facilities so that members of the community can receive free services instead of paying user fees. Initially the SLAs were mainly for mother and child services. These agreements are however being reviewed.

2.3.1.2 Access to health services by people with disabilities

This theme covers issues such as health promotion, prevention, primary and secondary care, tertiary care and rehabilitation and assistive devices. Previous studies have not covered all these issues comprehensively. Gaps still exist. Most studies have investigated access to

³ Ministry of Health. (2004). *Handbook and guide for health providers on the Essential Health package in Malawi*. Lilongwe: Ministry of Health.

health services and barriers to accessing these services by PWDs. Most PWDs seek treatment for their disability from health facilities. Some, however, go to traditional healers because of the belief that they have been bewitched. Seeking care from both modern facilities and traditional healers is not uncommon. In 1992 51% of the PWDs in one community in Ntchisi sought medical help from health facilities, 18% from traditional healers while 4% sought both medical and traditional treatment, and 28% did not seek treatment (see Annex 9). For epilepsy most people sought help from traditional healers as they believed that this disease was caused by witchcraft (see McDonald, 1992). In 2005 3% of the PWDs reported having ever had an STI and the majority sought treatment from health facilities (Munthali et al, 2005).

In 2008 PWDs and people without disabilities were asked where they would seek treatment if they had conditions listed in Annex 10. This was a hypothetical question. Both PWDs and people without disabilities reported that they would mainly seek treatment for all these conditions from health facilities. For mental illness and epilepsy however a significant proportion said that they would go to traditional healers: in both cases there were more PWDs than people without disabilities who reported they would go to traditional healers for these conditions⁴.

A number of studies have generally demonstrated that PWDs have problems in terms of accessing health services. The 2003 *Living conditions study* showed that the majority of PWDs were aware of the services available and that a significant proportion of the PWDs needed the services. However, a considerably lower proportion of PWDs actually received the services they needed. Annex 11 shows that 84% of the PWDs were aware of the health services available, 83% required these services but only 64% received the services. In terms of access to other health and related services, similar trends were found: while 59.6% of the PWDs needed this service, only 23.8% received it; and 69% of the PWDs ever needed assistive device services but only 5% received them. The trend for counselling services for both the PWDs and their parents/family is the same: more people needed services but much fewer received these services. This demonstrates that there exist gaps between what services PWDs need and what they receive (Loeb and Eide, 2004). Loeb and Eide (2004) also found that 17% of the respondents with disabilities used assistive devices. There were more men (25%) who used assistive devices compared to women (14%). Seventy percent (70%) of the respondents who were using assistive devices used personal mobility devices such as wheelchairs, crutches and walking sticks etc. Some used more than one assistive device. Thirty four percent (34%) of those using devices acquired them privately, 19% from government and 9% through NGOs and the rest through other sources

This discussion generally shows that the majority of PWDs seek or would seek treatment from health facilities during illness episodes. While this is their wish PWDs experience problems in accessing modern health services and these include: failure to seek treatment timely because of beliefs in witchcraft ((Kvam and Braathen, 2006); lack of money for them to get to health centres (Kvam and Braathen, 2006); mistreatment e.g. during antenatal clinics, delivery and postnatal services as if PWDs are not supposed to reproduce (Mji et al, 2008); communication barriers between health workers and people with hearing impairments (Mji et al, 2008) as health workers do not know sign language; mobility challenges from places of

⁴ Global Health Study implemented by SINTEF and CSR supported by the Norwegian Research Council, 2008.

residence to health facilities (McDonald, 1992); long distances to health facilities (MoPWDE, 2010); and the failure by health workers to effectively communicate health messages PWDs especially those with hearing and visual impairments e.g. visually impaired persons failing to access HIV/AIDS messages because of lack of Braille information materials (Munthali et al, 2005).

The CBR programmes in Malawi aim at improving access to health services by PWDs. These programmes are currently being implemented in 13 districts. They register PWDs, provide them with home-based treatment and teach about home-based treatment the family can implement. When there is a need CBR programmes also refer PWDs to hospitals or other service providers. The evaluation of these programmes demonstrates increased access to health services by PWDs: e.g. in one programme, it was demonstrated that the number of cases referred to health facilities improved; access to treatment for epilepsy went up; people have regained sight and hearing after screening and treatment of infections; and people with visual and hearing impairment have also been referred to specialist institutions and access to physiotherapy services has also increased (Makoko, 2002). However, the majority of the PWDs in the remaining 14 districts are not benefitting from CBR programmes.

2.3.1.3 Treatment for Children with Cerebral Palsy

The prevalence of cerebral palsy among children in Malawi remains unknown. In institutions such as Feed the Children Malawi, the number of children with cerebral palsy who seek rehabilitation services is quite high (Alfazema, 2007, Nieuwenhuizen, 2001 and Mwafulirwa, 2006). At Feed the Children Malawi (one of the rehabilitation centres) it is reported that more than 50% of the children who seek treatment there suffer from cerebral palsy. In most cases children with cerebral palsy attend therapy with their mothers and grandmothers. In cases where children attend therapy with others it is because mothers are at work. Transport costs constitute one of the major barriers for guardians to seek therapy for children with cerebral palsy and that more time is given to the child than any other productive work (Alfazema, 2007). Knowledge about cerebral palsy among mothers is also generally low (Mwafulirwa, 2008) and that some communities have bad attitudes towards children with this condition (Alfazema, 2007). Because some people believe that cerebral palsy is caused by witchcraft, mothers or guardians consult traditional healers. However, they stop consulting them when they see the benefits of the treatment they get at institutions such as Feed the Children Malawi (Mwafulirwa, 2008). Most of the studies done on cerebral palsy have been at a very small scale and by students. A comprehensive national study on this condition is therefore required.

2.3.1.3. HIV and AIDS among PWDs

With regard to HIV, the GoM and stakeholders are providing a wide range of services such as HIV awareness campaigns, HIV testing and counselling (HTC), ARVs and PMTCT services among others. The Reach Trust is currently preparing a nationwide survey on prevalence of HIV among people with disabilities as well as exploring TB/HIV co-infection. This study will be useful as it will enable Malawi to estimate the proportion of PWDs accessing HTC services. While currently over 200,000 Malawians have ever been started on ARVs, the proportion of PWDs on ARVs is unknown. This section therefore discusses the level of awareness about HIV and AIDS among PWDs and access to HTC services. Levels of access to ART and PMTCT are still unknown. A wide range of organisations are offering

HIV and AIDS services for examples numerous NGOs are involved in awareness campaigns, the MoH and other stakeholders are providing HTC, ART and PMTCT programs and these have been rolled out nationwide; hence they should be available to all Malawians regardless of disability status. FEDOMA, MACOHA and MoPWDE and other stakeholders have been involved in various HIV and AIDS programs among PWDs.

It is now just over 25 years since the advent of the HIV and AIDS epidemic. As part of the national response to the epidemic, in the late 1980s the GoM instituted a massive campaign to create awareness about HIV and AIDS. This campaign still continues. The rationale is that an informed society will be able to take up preventive measures against HIV infection. In 1992 the radio was the most common source of information on HIV and AIDS. This was followed by health workers and friends and relatives. These still constitute important sources of information on HIV and AIDS. With the introduction of HIV in school curricula, teachers have also become an important source of information on AIDS. Other sources of information include newspapers and magazines, TVs and religious institutions (see National Statistical Office, 1992; 2000; and 2004). Among PWDs the major sources of information on HIV/AIDS include the radio, health facilities and friends as can be seen in Annex 12. In this study only one person talked about sign language as a source of information on HIV and AIDS (Munthali et al, 2005).

It seems that PWDs were neglected in terms of ensuring that they are targeted with information on HIV and AIDS. PWDs experience problems accessing HIV and AIDS information and these include the lack of radios, lack of outreach programs targeting PWDs, lack of materials, long distances to health facilities and mobility problems. The bulk of HIV and AIDS information is in print form hence not accessible to persons with visual impairment who require information in Braille (Munthali et al, 2005 and Mji et al, 2008). The production of materials, not only on AIDS but also in general, in Braille has been limited as was demonstrated by a NAD funded study in early 2011 where only 4% of the CBR documents were in Braille (Munthali, 2011); hence denying people with visual impairments from accessing information (Annex 13).

Ninety percent (90%) of the PWDs have heard about HIV while 94% have heard about AIDS. Knowledge about HIV transmission and prevention is not universal among PWDs especially among the deaf-blind the knowledge is lower (Chavuta, 2010 and Mji et al, 2008). Such a scenario is mainly due to the lack of programmes that especially target PWDs (Chavuta, 2010). It is evident that HIV information is not properly packaged to effectively reach PWDs; hence making them more vulnerable to HIV infection. PWDs are also vulnerable because there is a belief that a person with a disability is a cleanser of HIV meaning that if an HIV+ person has sex with a person with a disability the disease will be cured. Some people also believe that having sex with PWDs would increase one's wealth (Mji et al, 2008). PWDs are also vulnerable to HIV infection for various reasons: the physically challenged cannot run, the blind cannot sense danger, the speech impaired cannot shout hence all these are vulnerable to HIV infection (Mji et al, 2008). Another factor that makes PWDs vulnerable to HIV infection is poverty. A community health worker in Mangochi said that PWDs may be exposed to HIV if they lack things in their lives and once someone offers them something they may be exposed⁵. In terms of sexuality, there are no differences between PWDs and people without

⁵ Global health study data, 2008.

disabilities. PWDs are equally sexually active. A 2004 study showed that three quarters of PWDs interviewed reported having had sex and of those who had had sex 17% reported that they were forced (Munthali et al, 2005). PWDs are therefore equally at risk of HIV infection as they are also sexually active.

As part of the national response, the GoM promotes HIV testing and counselling (HTC). The uptake of this service among PWDs is low. Only 10% reported having been tested in 2004 (Munthali et al, 2004). HIV prevalence among PWDs remains unknown (Mji et al, 2008). It is only in 2011 when the Reach Trust planned to conduct a national HIV prevalence survey. Issues of confidentiality are important. Among PWDs who cannot talk and who need a sign language interpreter there may not be confidentiality with regard to HIV testing and counselling. Other challenges include lack of a guide to take persons with visual impairment to HTC sites and long distances to HTC sites (Mji et al, 2008). Other reasons which deter PWDs from going for HTC include the thinking that they are okay and the fear that blood will be pumped from their bodies (Munthali et al, 2005).

Condom use among PWDs is also low. Out of 42% of the PWDs who knew about condoms, only 27% reported that they have ever used condoms. A number of reasons were given for non-use of condoms, for example never having had sexual intercourse, not liking the condoms, not being promiscuous i.e. being faithful. Some reported having difficulties in using condoms because of disability; hence they need for them to be assisted by their partners (Munthali et al, 2005). Research on access to ART and PMTCT services by PWDs in Malawi is however rare.

Knowing that HIV and AIDS is also a problem among PWDs, some CBR programmes have been involved in the implementation of HIV activities in order to improve access by PWDs to HIV services. Makoko has shown that, because of CBR programmes, the number of PWDs going for HTC increased significantly in one district and so did the uptake of condoms (Makoko, 2007). As has been mentioned earlier, these CBR programmes are only in 13 districts and this denies access to such services by PWDs; hence justifying for mainstreaming disability in different sectors.

2.3.1.4 Seeking care for epilepsy

There aren't many studies that have been carried out in Malawi on epilepsy. This condition was also not previously given much attention as it was not in the EHP during the 2004-2010 Health Sector Program of Work. The new Health Sector Strategic Plan (2011-2016) has however included epilepsy as one of the conditions in the EHP. In 2004 the WHO estimated that the prevalence of epilepsy in Malawi was at 5.2 per 1,000 people. This was however based on assumptions. In 2010 a national wide survey was carried out in Malawi by the Federation of Disability Organisations in Malawi and found a national prevalence of 2.8 per 1,000 persons. There were more males (55%) with epilepsy compared to women (45%) and the condition was also more prevalent among children aged 6-18 (see Amos and Wapling, 2010). Most people with epilepsy will seek treatment from health facilities. However, 28% are not fully compliant with this treatment and this is mainly because of lack of understanding of the causes and long term management of the condition (Amos and Wapling, 2010). Another study shows that long distances to health facilities, the shortage of epilepsy medicines in health facilities, misdiagnosis of epilepsy and poverty are some of the factors that delay

access to effective epilepsy treatment. The biomedical causes of epilepsy are not universally accepted. Other people also believe that epilepsy is caused by witchcraft; hence the resort to seeking cares from traditional healers (Munthali et al, 2011).

2.3.2 Access to Mainstream Education

The MoE is responsible for the ensuring that all Malawians have access to education and the education system is based on the 8-4-4 system where one spends 8 years in primary school 4 years in secondary school and another 4 years in the university. In terms of enrolment the number of pupils enrolled in primary school reached 1 million in 1986/87. In 1993/94 enrolment was at 1.9 million and the following year in 1994/94 enrolment jumped to 2.9 million. The massive increase in enrolment in primary school was as a result of the introduction of free primary education. The number of primary schools is estimated at 5,400 while that of secondary schools is at 1,127. On the other hand the number of teachers is currently at 46,000 and 11,400 in primary and secondary schools, respectively (MoE, 2009). The National Education Sector Plan (2008-2017) highlights a number of problems facing the education sector in Malawi and these include: shortage of teachers, poor strategic management of teachers, inadequate teaching and learning materials, inadequate and inferior physical infrastructure and poor access for children with special needs among others (MoE, 2008).

In 2009 the Malawi Education System had an estimated number of 83,666 learners with SEN in primary school while in secondary schools in was at 2,780. In 2011, according to an official from the MoE, currently there are 88,636 learners with SEN in primary schools. This demonstrates government continued effort to increase access to education by PWDs. Annex 14 shows the number of learners with SEN by type of disability. In 2009 there were 3,671,481 learners in primary schools and 243,838 in secondary schools in Malawi. The proportion of pupils with SEN in primary school (2.3%) was twice that in secondary school (1.1%). In primary school 52.4% of the learners with SEN were boys while the rest (47.6%) were girls. In secondary school, however there were slightly more girls (50.6%) compared to boys at 49.4% (MoE, 2009). These statistics however do not capture all learners enrolled in mainstream classes with impairments or learning difficulties such as intellectual disability, emotional and behavioural difficulty, specific learning disability, health impairment, language and communication difficulty⁶. These statistics from EMIS do not take into consideration of school going age children with disabilities who are not attending school; hence population-based surveys are more informative.

Enrolment of CWDs in school is quite low. In 1983 among disabled persons aged 5+ only 42% ever attended school, 96% of these went up to primary school and only 4% went to secondary school or higher (National Statistical Office, 1987). A study conducted in 1992 in one ward in Ntchisi District showed that only 19% of those aged 6+ years were attending school at the time of the survey and that 52% of the disabled had never been to school (McDonald, 1992). The *Living conditions study* shows that 35% of PWDs have never attended school compared to 18% among the non-disabled; and 19% of PWDs were still attending school compared to 41% among the non-disabled. This study also found that 41% of males with disabilities and 29% of the females with disabilities never attended school

⁶ SNE Policy Summary Document).

compared to 21% of the non-disabled females and 14% of the non-disabled males (Loeb and Eide, 2004). This shows that school attendance among PWDs is lower compared to those household members without a disability.

Accessing education and ensuring that PWDs remain in school is a major challenge experienced by PWDs and their families. Learners with disabilities are accepted in mainstream classrooms but they face important challenges namely: the lack of specialist teachers who can teach learners with diverse needs; the school environment not being suited for learners who are deaf-blind; inadequate instructional materials such as Braille; and most teachers do not have communication skills for communicating with learners who are deaf-blind; inadequate learning support as classes are too large; learners with mild deafness have problems in following lessons and inaccessible infrastructure and information (Chavuta, 2010, MoE, 2009). The critical shortage of teachers of SNE affects the quality of education delivered to PWDs. The MoE says that there are only 1,000 specialist teachers but there is a need for 12,000 teachers; hence there is a long way to go to fill these vacancies. The lack of specialist teachers is being address by Montfort Special Needs Education College in Chiradzulu which trains such teachers at diploma level now. These are posted to various primary and secondary schools. Most of these are also picked up by NGOs. Because of lack of a defined career path, some specialist teachers leave and join mainstream teaching. This explains why enrolment of learners with disabilities in schools is generally low. One mother of an 18 year old child with hearing impairment reported that her daughter and other children with hearing impairments were dismissed from a mainstream school in Mangochi because teachers could not communicate with them. Even though these CWDs were brought back into the school after appealing to authorities the problem of ineffective communication was still prevalent⁷.

While both boys and girls with disabilities experience problems in mainstream schools, it is girls especially who are vulnerable. Suka (2006) in her study conducted with school girls with visual impairment outlines forms of violence that are perpetrated against girls with visual impairment in schools. These include threats and actual sexual abuse from for example specialist teachers; verbal abuse such as belittling them, saying that no one would be interested in having an affair with them; and extensive teasing such as leading them to wrong classrooms among other factors. Suka argues that there are high dropout rates among girls with visual impairment because of girls' lack of interest in school and violence perpetrated against them in school. As a result of these experiences very few girls with visual impairment make it to secondary school (Suka, 2006). In general learners with disabilities in most cases are happy learning in same schools as those without disabilities as they assist each other for example identifying what is written on the board, escorting them to the toilet and reading aloud to those who have hearing impairment (Chavuta, 2010).

Some children with disabilities quit school because of lack of money (Kvam and Braathen, 2006; and MoPWDE, 2009) and because of mobility problems as in some cases they crawl around the schools and most schools are not really suited for CWDs (Kvam and Braathen, 2006; and McDonald, 1992). In addition to these problems, there are also reports that some schools do not allow learners using wheelchairs to enrol as doors are quite narrow and there are steps. Learners with hearing impairment also fail to participate in class since teachers fail

⁷ Global Health Study Data, 2008.

to communicate with them (Chavuta, 2010). In case of albinos they may drop out of school because they have problems in reading books and seeing what is written on the board (Kvam and Braathen, 2006) and this impacts negatively on their performance. Albinos are also afraid of sunshine. Because of the potential for skin cancer, Albinos avoid sunshine thereby making it more difficult for them to attend school.

Recognising the challenges faced by PWDs the GoM has established special schools to cater for learners with visual and hearing impairments. Most of learners in speciality schools such as the Schools for the Blind (e.g. Chilanga School for the Blind in Kasungu) started their education in other schools but because of lack of facilities for the learners with visual impairment had to be transferred to special schools. The learners with visual impairment liked being in these special schools because teachers were available who knew Braille, unlike teachers in mainstream schools (Kaliwa, 2006). Learners with special educational needs are identified mostly by teachers, parents and the community. The specialist teachers conduct advocacy work but their impact is limited because their numbers are low. On the other hand, mainstream teachers and the community lack knowledge and skills on how to identify learners with SEN (MoE, 2009).

While GoM established special schools for learners with SEN, the current policy encourages inclusion of CWDs in mainstream schools through the establishment of resource centres in these mainstream schools. Currently, there are 104 resource centres in primary schools nationwide while there are 22 resource centres in secondary schools. The MoE has also embarked on creating awareness amongst community members about disability issues and the importance of community participation in addressing educational needs of PWDs. Because of these initiatives some communities are mobilising resources and constructing resource centres for PWDs in existing mainstream schools. An official from the MoE gave an example of Gumbo Resource Centre in Ntcheu and Migowi Resource Centre in Phalombe as resource centres that have been initiated and constructed by community members. In addition to this, the private sector has also participated in addressing the educational needs of CWDs for example, Airtel provided teaching and learning materials for SNE and additional remuneration package for specialist teachers. One of the problems with resource centres however the DEMs feel that these centres are managed from the centre but sensitisation is underway in line with decentralisation policy for services delivery by GoM. The demand for SNE is high in Malawi but it seems this demand is not being met.

In terms of access to structures, the MoE issued a directive to all its institutions in which it gives instructions that all structures should be accessible to PWDs. The Education Infrastructure Management Unit has guidelines on how to construct structures that are disability friendly. In discussions with an official from the MoE, he indicated that all the new structures are complying with these standards and gave examples of the Liwonde Teachers Training College and the World Bank funded 20 recently constructed secondary schools (e.g. Bangwe in Blantyre, Kasakula in Ntchisi and Chinsapo in Lilongwe) that are disability friendly.

Because of the problems that PWDs experience, there are a number of CBR projects that have been implemented in order to ensure that CWDs stay in school. For example, the Msakambewa CBR programme included CWDs into mainstream schools, referred them to special schools and trained teachers in SNE. This training of teachers reduced the problem of the shortage of teachers of specialist teachers in the catchment area of the project. The

project also paid school fees for some students with SEN who were in secondary schools. As part of the project community rehabilitation workers (CRWs) were also visiting the CWDs included in schools to observe how they were doing and offer support (Makoko, 2002). Another project which initially targeted children with visual impairment in Balaka district, as a way of improving access to education for children who are visually impaired, had two specialist teachers trained at Montfort and deployed to the area. Braille textbooks were made available to the visually impaired (Makoko, 2007). Massa has also given an example of a parent who appreciated the impact of the CBR interventions as her child was able to go to school without being escorted (Massa, 2010). Unfortunately, CBR programs are only in selected districts; hence the impact is limited.

2.3.3 Livelihoods

The World Bank says that In a number of studies, PWDs have been asked about their sources of livelihoods. As is the case with the general population in Malawi a number of studies have shown that the major source of livelihood for PWDs is farming, both subsistence and commercial (National Statistical Office, 1987; Mji et al, 2008 and McDonald, 1992). In 1983 respondents in the survey of PWDs were asked about the work activities, paid or unpaid, that they were engaged in. Annex 15 shows that the main activity done by PWDs aged 5 years and above were farming/fishing (38.8%), household duties/heading livestock (26%), brewing beer (2%) and other businesses and pottery/handicraft (1%). The rest were not doing anything at all. This study also looked at the proportion of PWDs who received some form of help, 12 months prior to the survey and the results show that only 3% received some form of help with a higher proportion (5%) being in urban areas compared to rural areas at 3%. The type of help that they received included: 22% received clothes; 17% received some cash; 11% crutches, 10% spectacles; 7% shoes/callipers, 3% scholarships; 2% wheel chairs and the rest other forms of assistance (NSO, 1987). Other more recent studies have shown that farming is a major source of income for PWDs (MoPWDE, 2009; Living Conditions Data (2004)). There were more people without disabilities who reported that their main source of income was wage/salaried work. For cash cropping as a source of income, there were no differences between PWDs and people without disabilities. There were slightly more PWDs involved in subsistence farming compared to people without disabilities as can be seen in Annex 16(Loeb and Eide, 2004).

In terms of employment in 2003, 58% of the PWDs were not working at the time of the survey compared to 53% among the non disabled. This emphasises the high unemployment rate in Malawi. Among PWDs, it was also found that 47% of women with disabilities were unemployed compared to 41% of men with disabilities. Significantly more households with one or more members with disabilities had no one employed (18.1%) as compared to 13.5% non-disabled households (Loeb and Eide, 2004). There is also a need to acknowledge that it is also difficult for PWDs to find employment as discrimination still prevails. For example, a community health worker in Mangochi gave an example of a person with a disability who had one leg and has problems finding employment because of discrimination⁸. In an interview with one official, it was cited that PWDs are still discriminated: one GoM ministry was recruiting people for some community level work but one PWD even though he was qualified for the job; he was told that he should instead visit MACOHA to see if the organisation can

⁸ Global Health Study data, 2008.

give him a job. This official even said that some organisations employ PWDs out of sympathy.

In order to improve the livelihoods of PWDs, it is important that they should be equipped with requisite vocational skills which they can use to get employed or self employed. The CBR programmes being implemented in Malawi have been very useful in equipping PWDs with essential vocational skills for PWDs to earn a living. There is generally a lack of skills needed for employment among PWDs for example a 1985 survey found that 46% of respondents had no useful skills for employment (Demographic Unit, 1985; see also Makoko, 2002). In 2003 a slightly higher proportion of PWDs (41.2%) had acquired some skills compared to 38.7% of people without disabilities (Loeb and Eide, 2004). In 2007 one study found that 48% of the survey population had attended some skills training and 50% of those who attended some skills training were in employment. In this study PWDs acquired skills at training centres of MACOHA and TEVET or at primary schools where handcraft lessons were provided. They can also get training through local craftsmen as well as through private training centres (International Labour Office, 1985). The trainees are in most cases identified by MoPWDE, CROs, DSWO, MACOHA and DPOs. The most common vocational skills acquired by PWDs were tailoring, weaving, agriculture, carpentry and home economics and women were more likely to be trained in home economics and weaving compared to men who were mostly trained in agriculture and tailoring (International Labour Office, 2007). After being equipped with vocational skills PWDs are recognised by society and have been able to take up jobs (Massa, 2010). The majority of the respondents found the vocational skills they had acquired useful in finding work.

While some PWDs would want to attend vocational training, there were some barriers to attending such trainings. Some cannot afford training fees; there is no opportunity of taking time off because of family responsibilities; transport challenges of getting to and from training centres; communication difficulties among PWDs; unwillingness of trainers to train PWDs with others being sent back home because of disability; and lack of training materials in Braille among other factors (International Labour Organisation, 2007). A good proportion of PWDs were in self employment engaging in trades such as bicycle and radio repairing; selling foods; and tailoring. Others were in formal employment: they either found their jobs through the training centres where they got vocational skills or on their own, or through help from friends and relatives. This study also looked at the barriers for PWDs in finding work and these included: lack of skills training that could empower PWDs; lack of jobs; mobility challenges; lack of access to credit for small scale businesses; and lack of awareness among employers about the rights of PWDs (International Labour Organisation, 2007). In addition to these problems albinos also experience other problems: they have problems in finding employment as it is believed that they die young and some of them have been rejected in training institutions (Braathen, 2006). In order to increase employment opportunities for PWDs, skills training should be made available to PWDs and that PWDs need access to loans to start businesses (International Labour Organisation, 2007).

In order to improve livelihoods of PWDs a number of CBR programmes have been implemented. These programmes have been useful in equipping PWDs with essential skills for earning a living. Some of these have also disbursed loans to PWDs as can be seen from the examples given below:

- An evaluation of a CBR programme targeting persons with visual impairment in 1990 found that a good proportion of PWDs who were given loans had paid back the loans because of the business they were engaged in. Some people who got loans were unable to do anything meaningful with the money because the price of equipment they planned to purchase had gone up and the amount of the loan was inadequate to do the business they had wanted (Fagan et al, 1990).
- In 2002 a final evaluation of the Msakambewa CBR programme showed that 183 PWDs were given loans of up to MK10,000 and that most people who got these loans were paying back and unlike in the past the majority of those who got loans were able to support their families. The people who got loans were able to successfully engage in activities such as farming, carpentry bakery, and beer brewing among others. In the Msakambewa CBR program PWDs acquired skills in carpentry, knitting, tailoring and tinsmithing. MACOHA paid the training fees because there were problems in terms of PWDs being able to pay such fees. After the training PWDs in the Msakambewa CBR programme were given loans to purchase tools and start operating on their own. While the Msakambewa CBR programme aimed at training 150 PWDs only 79 were trained because of lack of local artisans in the area (Makoko, 2002).

An earlier study also identifies quite a number of problems that PWDs faced in running businesses such as lack of business administration skills, business location, market limitations and understaffing at MACOHA (Manda, 1989). This explains why in some cases PWDs who were given loans had to be trained before they started running their business as was the case in the Balaka/Machinga Comprehensive Eye Care Services Loan Scheme. While some cases in this project were hopeless and could not even return the loan. Others were quite successful in that they managed to build better houses, others bought livestock, paid school fees for their children and their homes became food secure (Manda, 1989). Hence, this demonstrates that the provision of loans to PWDs if properly managed can help to better transform the lives of PWDs but such initiatives are, however, limited. A good proportion of PWDs still lack vocational skills that they can acquire in order to increase their opportunities of getting employed or being self employed.

2.3.4 Social

2.3.4.1 The role of Ministry of Gender, Children and Community Development

The Ministry of Gender, Children and Community Development (MGCCD) is a line ministry that deals with social welfare services. The ministry has three Departments namely Gender Department, Children Affairs Department and Community Development Department. Social welfare is within the Department of Children Affairs. A lot of social welfare functions are also divided and being carried out by other ministries such as that of People with Disability and Labour. The MGCCD is responsible for a wide range of social welfare issues such as probation of child justice services, social rehabilitation services, care and support services dealing with Orphaned and Vulnerable Children (OVCs), family and child welfare, social protection (deals with social cash transfer program), public assistance (e.g. emergency relief) and social rehabilitation. A MoGCCD official said that a professional social welfare officer by training will have to learn issues of disability and that at district level their responsibility is to detect then make referrals for disability cases. It also trains volunteers and advocates for

disability friendly infrastructure. In addition to this the Ministry also links PWDs to economic empowerment for example Micro Finance Institutions (MFIs).

2.3.4.2 Access to social services

This theme looks at legal protection; culture and arts; sports, recreation and leisure; relationships, marriage and family and personal assistance. Not many studies have been done in this area. With regard to legal protection, while it is acknowledged that there are international conventions that Malawi has ratified and that nationally legislative and policy environment are conducive for PWDs to enjoy their rights. The Disability Bill that supports the implementation of the National Policy on the equalisation of Opportunities for People with Disabilities has not been enacted into law. The enactment of this Bill will ensure legal protection of PWDs.

In terms of sports and recreation, the Malawi Disabled Sports Association (MADISA) was formed in 1998 to promote mass participation and provide opportunities for PWDs to participate in sporting activities that are compatible and suited to their needs. MADISA is affiliated to FEDOMA, the Malawi National Council of Sports and the African Sports Confederation of the Disabled. The organisation has been able to lobby, advocate and create awareness on disability sports issues and has also organised disability sports events and related training (Kerac, 2006). While a number of initiatives have been implemented, coverage of the activities of the association, however, remains unknown; hence there is a need for more research in order to determine coverage of its activities as well as barriers to active participation in sports by PWDs.

In terms of social relationships a good proportion of PWDs are married (Mji et al, 2008). Some studies have shown that some women with disabilities would want to get married and have children but they do not have boyfriends or husbands and it is the disability itself that makes these women less attractive. In some cases women with disabilities have been dumped by their husbands because of the disability they have and some are even tricked into having sex with men and once they are pregnant they are abandoned (Kvam and Braathen, 2006 and also see Mji et al, 2008). It has been argued that poverty makes women with disabilities accept men who in some cases will just sexually abuse them and abandon them. Even if PWDs are abused there is silence about this. In some cases when a non-disabled man falls in love with a women with a disability, it is family members who discourage him from such a marriage because of the belief that such a couple will bear CWDs (Mji et al, 2008) or that such women will not be able to fulfil household chores. Some men fall in love with PWDs because they just want to see *how she was born* and then leave her (Mji et al, 2008). In terms of relationships, women with disabilities are vulnerable as cases of abuse are common.

It is not only women with disabilities who experience problems in forming and sustaining relationships with the opposite sex, men too have problems as they are in some cases rejected by the women they propose to. Both men and women with disabilities may have difficulties entering into intimate relationships due to stigma. Difficulties in mobility makes creation of relationships problematic as it decreases the opportunity of meeting new people (Munthali et al, 2005). While women with disabilities may have problems forming relationships, a significant proportion of men and women with disabilities get married. In

some cases fathers of CWDs (e.g. children with albinism) also abandon such children and marry other women as they think that such children are not theirs. While mothers of albinos love their children, reactions from other members of the community are sometimes not good and such children also experience discrimination especially with strangers (Kvam and Braathen, 2006). Women also have a duty in the home such as carrying water on their heads, cooking, lifting heavy things and women with disabilities sometimes cannot fulfil these duties effectively hence their chances of getting married or being in relationships is further reduced (Kvam and Braathen, 2006).

The *Living conditions study* also showed that about 15% of the PWDs are not involved in family life and that nearly a fifth are not consulted about making household decisions even those decisions that have an impact on their lives (Loeb and Eide, 2004). Most of the PWDs are excluded deliberately in community benefits and trainings yet they participate in other community development activities (MoPWDE, 2009). Within the family, the birth of a child with a disability can be a cause of shame; hence there are reports that in some cases parents leave the care of such children to their parents as they feel ashamed to have such a child towards their neighbours (see Kvam and Braathen, 2006). Wapling also says that sometimes families with persons who are disabled hide them or send them away to be looked after by elderly relatives (Wapling, 2009). Exclusion is also observed when PWDs have problems in terms of reaching big buildings because of steps.

In terms of culture there are quite a number of beliefs surrounding disability. A number of studies reveal that in most communities there is a belief that witchcraft is a cause of disability⁹ (Global Health Study, 2008); that while canes are stolen for purposes of making juju (Mji et al, 2008); that PWDs are sinners (Mji et al, 2008); having sex with a disabled person makes people wealthier (Mji et al, 2008) and that if a person is HIV+ having sex with a disabled person would cleanse the person of HIV (Mji et al, 2008 and Munthali et al, 2005).

Lastly, the GoM is also implementing a social cash transfer program that targets the ultra poor and labour constrained households. This program was piloted in Mchinji District but has now been extended to a few more districts. Some of the targeted households have PWDs. Community members play an important role in identifying beneficiaries of this scheme. The amount of money that these households receive ranges from MK600 to MK1,800 per month depending on the number of children going to school. On average in 2006 the average cash transfer per household amounts to MK1,700.00. A preliminary evaluation of the program showed that there was improved food availability in the households, improved school attendance, improved availability of school materials and improved access to health services. In addition some households had better shelter and even acquired livestock (see Schubert and Huijbeugs, 2006). While it is likely that PWDs have benefited from this scheme, data available does not show how many PWDs have benefited. As far as this theme is concerned, not much research has been done; hence the need for more research.

2.3.5 Empowerment

This theme covers issues such as self help groups, DPOs, social mobilisation, political lobbying and language and communication. Some progress has been made with regard to

⁹ Global Health Study data, 2008.

empowerment of PWDs in Malawi for example in areas such as developing a conducive legislative and policy environment, creating awareness about disability, vocational skills training and provision of loans targeting PWDs and ensuring a conducive environment for PWDs to vote during elections.

Disability is a human rights issue but initially with the enactment of the Handicapped Persons Act (1971) disability was construed from a charity perspective. Due to advocacy work and political lobbying by the disability movement, Malawi currently has a Ministry of Persons with Disabilities and the Elderly. Stakeholders in the disability sector have ensured that disability issues are incorporated in the Constitution of the Republic of Malawi where it is treated as a human rights issue. In 2006 the National Policy on Equalisation of Opportunities for PWDs was launched in order to promote the rights of PWDs. Despite advocacy work by the disability movement in Malawi Parliament is yet to pass the Disability Bill. Advocacy has therefore helped in creating a conducive legal and policy environment for PWDs.

In terms of creating awareness about disability issues, over the last decade or so DPOs have conducted a lot of meetings aimed at sensitizing the wider community on the rights of PWDs. However, the documentation of such awareness campaigns by DPOs and other stakeholders has been limited (Munthali, 2011). The Constitution provides for access to education for all Malawians. However, as it has been discussed earlier, PWDs experience a lot of challenges in accessing education. The introduction of SNE ensures that PWDs have access to education so that they have the knowledge and skills they require in order to get employed or be self employed. In order to effectively empower PWDs with requisite knowledge and skills, there is a need to address the barriers to implementation of SNE as has been discussed earlier.

CBR programmes have been running in Malawi since the 1980s. These programs aim at improving the lives of PWDs and ensuring that Malawians are aware of the rights of PWDs. A number of CBR programmes have empowered PWDs with training and disbursement of loans in order to economically empower them. Such an approach has been carried out because in most cases PWDs are often discriminated against in programmes that offer cash or in kind benefits such as public works programs. PWDs are in most cases integrated in programmes that do not come along with any monetary benefits such as building school blocks or clearing the graveyard (MoPWDE, 2009).

With regard to decision making, it is important that PWDs participate actively during for example general elections. It seems that organisations especially CSOs are not fully aware of the need for PWDs to participate in civic education and electoral processes. Ballot boxes guides are now in place for PWDs. It seems that civic education has not been accessible to PWDs in Malawi. This is especially critical for those who are deaf as they are not aware of the issues that political parties are campaigning for. For people with visual impairments there is a need for introduction of Braille ballot papers (see Wapling, 2009). There has also not been attempts to specifically sensitise PWDs in the electoral process.

Lastly, one of the most valuable resources on empowerment is the directory of organisations providing disability services in Malawi. This directory, produced by Marko Kerac in 2006, provides information on groups and services specifically working in the disability sector in Malawi. The goal is to benefit PWDs, their families and the wider community (Kerac, 2006).

Earlier on, Msiska also produced a list of resources and facilities that are available for PWDs (Msiska, 1990). However, these directories have not been widely disseminated to stakeholders; hence the need to do this. Empowerment of PWDs in various ways is important but not much research has been done to determine to what extent PWDs have been empowered.

2.4. Roles of Different Stakeholders

The National Policy on Equalisation of Opportunities for People with Disabilities has listed the different roles of various stakeholders in the implementation of the policy. These roles are in Annex 17. However, not much has been done in terms of ensuring that these GoM Ministries and departments are carrying out their responsibilities as stipulated in the Policy and Draft National Plan of Action for PWDs. The Policy is a 5 year policy and it is now exactly 5 years since the policy was approved. It is important that it should be evaluated to determine to what extent it has been implemented including exploring various factors that have affected the implementation of the Policy. Once it has been evaluated, it should also be reviewed so that it guides implementation of disability services over the next 5 years. This section describes the roles of stakeholders and the challenges that have affected the implementation of the Policy. The role of the MGCCD has been described earlier.

2.4.1 Ministry of Persons with Disabilities and the Elderly:

It is a government line Ministry that deals with disability issues in Malawi. The core functions of this Ministry are as follows: (i) to prevent disability; (ii) to rehabilitate PWDs; and (iii) ensure equalisation of opportunities for people with disabilities (Lang, 2010). The Ministry was created in 1998. Before this, disability issues were being dealt with on an ad hoc basis; hence this Ministry was created in order to ensure coordination of disability issues in Malawi. Since the creation of the Ministry a lot of progress has been made including the drafting and development of the National Policy on Equalisation of Opportunities for People with Disabilities (2006); the drafting of the Disability Bill which is anti-discriminatory but this has not yet been enacted; and the creation of a Special Needs Education Department within the MoE which provides a basis for mainstreaming. It is also during this period that disability issues have come to the fore in Malawi. The Ministry has been able to achieve this because it has worked collaboratively with stakeholders, especially, the civil society.

In terms of roles, the National Policy on Equalisation of Opportunities for Persons with disabilities is very clear that:

“The Ministry as the political and government administrative head on disability issues shall be responsible for policy formulation and review; and oversee the policy implementation. It will also ensure that disability issues are mainstreamed in all sectors”.

The implementation of the interventions is the responsibility of all Ministries and other stakeholders. A recent evaluation of the CBR programme shows that GoM funding for disability services is channelled through the MoPWDE and MACOHA. The Ministry is supposed to be in charge of mainstreaming, resource mobilisation, guidance and provision of support to other agencies. Not much has been done in this area; hence the need to revisit

the roles. A lot of resources, however, are being allocated to the MoPWDE for implementation of interventions which is not the mandate of the Ministry as far as the policy is concerned. Budgetary allocations to MACOHA are inadequate and this has affected the delivery for it to effectively deliver disability services and yet it is supposed to be the implementing agency (Eggen et al, 2010).

2.4.2 Malawi Council for the Handicapped

It was established as a government agency and its responsibilities include: provision of rehabilitation services (including extension services); identification and treatment of children, youths, and adults with disabilities and referral for surgery as required (especially for orthopaedic and visual services); treatment of epileptic patients at community level; provision of shelter employment (production units); development of strategies and disability related services and provision of counselling and vocational training to PWDs; education sponsorship to PWDs and encouraging community participation in Community-Based Rehabilitation (CBR) programmes. Production Units in Bangwe and Lilongwe offer on-the-job training and provide employment opportunities for PWDs. MACOHA has also been restructuring its training centres and diversifying the courses it offers. Since 2001, it has added information technology, secretarial skills, motor vehicle mechanics, bricklaying, technical installation and refrigeration to its course list. The centres have since included nondisabled persons amongst their students who will pay fees, while PWDs will receive scholarships.

The CBR programme in Malawi was initiated by MACOHA with technical and financial support from UNDP/ILO to cater for the needs of PWDs. The CBR programme started as a pilot in Blantyre but has since expanded and is now in 13 districts. In districts where the CBR programme is being implemented especially with support from CBM, MACOHA promotes the capacity of PWDs so that they have a stronger say on development issues affecting them. This is done through the promotion of representation of PWDs at VDC, ADC and DDC; hence the inclusion of PWDs in mainstream development activities is being promoted at district and lower levels. In districts where there are CBR programs supported by CBM especially representation of PWDs at different levels is encouraging but GoM ministries at district level have not really taken up advice.

While the National Policy on Equalisation of Opportunities for Persons with Disabilities says that MACOHA shall implement government policy, the funding for activities is much less and as has been mentioned above the bulk of the funding for interventions goes to the MoPWDE. CBR programmes are supposed to be implemented by MACOHA. Currently MACOHA is donor dependent and experiences constraints to its operations (Eggen et al, 2010). It has some degree of autonomy as the bulk of its funding comes from donors (Wapling 2009). MACOHA has 399 field staff on its payroll but programme costs in donor driven CBR programmes are paid by donors. It relies on FEDOMA to carry out awareness raising and empowerment activities (Wapling, 2009).

2.4.3 Federation of Disability Organisations in Malawi

FEDOMA has played an important role in policy development and the development of the Disability Bill. It is an umbrella organisation for DPOs. Currently, it has six affiliates namely

Malawi Union of the Blind (MUB), Malawi National Association for the Deaf (MANAD), DIWODE, Albino Association of Malawi, Association for the Physically Disabled and the Parents of Disabled Children Association in Malawi (PODCAM). However, there are no specialised support groups for those with epilepsy, dyslexia, down syndrome, cerebral palsy, intellectual disabilities, deaf-blind; those with mental illness and complex disabilities; hence these groups are underrepresented (see Wapling, 2009). Specifically the aims and objectives of FEDOMA are as follows (www.fedoma.org):

- To support and encourage the formation of persons with disabilities organisations in Malawi and to strengthen existing ones;
- To promote and encourage development efforts and self-help projects among persons with disabilities and their organisations;
- Coordinate the work for equal rights and equalisation of opportunity for persons with disabilities in Malawi Society;
- Promote training for leaders on the organisations and the administrative personnel;
- To promote, support and complement government policies and programmes directed at persons with disabilities;
- Facilitate the exchange of information in the field of disability through research, civic education programmes and seminars; and
- Affiliate and co-operate with other national, regional and international organisations that work in disability".

FEDOMA implements the empowerment strand of the CBR program; raises the voices of the PWDs and promotes the participation of PWDs in various activities (Eggens et al, 2010). While DPOs are playing an important role there are also a number of challenges they are experiencing namely:

- The lack of financial resources to implement their programs.
- Lack of capacity to carry out lobbying and advocacy.
- Lack of capacity in policy analysis and budget tracking.
- Negative attitudes from communities who believe that PWDs have no potential to achieve independence or contribute to their communities (Wapling, 2009).

Despite these challenges, FEDOMA and other stakeholders have contributed significantly towards ensuring that disability issues are widely disseminated and the development of policy and legislative frameworks.

2.4.4 Ministry of Education

The MoE has the responsibility of providing education to all Malawians including PWDs. With regard to PWDs the MoE strategic objectives include increasing equitable access to education by PWDs, improving quality of education provided to PWDs and improving governance and management of education for PWDs. The MoE has a Directorate of Special Needs Education which has the responsibility of ensuring a conducive school environment where learners with SEN can easily access education without any hindrances. While special schools have been established targeting CWDs with various forms of disabilities, GoM encourages the establishment of resource centres for PWDs within mainstream schools following inclusive education policy. The MoE is also responsible for the training of specialist

teachers at Montfort SNE College. To some extent the MoE is fulfilling the roles as described in the Policy and this has been possible because of the presence of the Directorate of Special Education within the Ministry. It is, however, yet to implement some of the provisions as contained in the Disability Bill such as establishing a government vocational training centre in every region of the country in collaboration with the Ministry of Labour and Vocational Training. Responsibility for implementing the SNE element is already the responsibility of the MoE.

In addition, the MoE is responsible for the technical education and vocational training in Malawi. As indicated before, the Technical, Entrepreneurial, Vocational Education and Training Authority (TEVETA) is responsible for developing and supervising TEVET policies in Malawi and for administering the TEVET Fund. The three main functions it is charged with are to: foster and promote entrepreneurial skills; promote vocational training for “*disadvantaged groups*” (without naming them); and ensure that the TEVET system is demand-driven and responsive to the needs of the labour market, in both the formal and informal economy. The TEVETA Board is made up of 14 members, who are all appointed by the Minister. Significantly, the Board includes one person representing PWDs.

2.4.5 Ministry of Health

Currently, the MoH provides health care to all Malawians including PWDs. There is no discrimination. It is also responsible for the prevention of disability e.g. through provision of polio vaccines to children and the provision of adequate nutritional care to malnourished children. If malnutrition in children is not properly addressed it can lead to children being disabled. The health centres are also responsible for identification of PWDs and then provision of treatment including referral of cases to MAP for rehabilitation. The follow-up of patients with disabilities is done by MAP with assistance from health facilities as they know when MAP will be visiting the area. Within the MoH, medical rehabilitation is done in central hospitals but plans are underway to extend rehabilitation services to district hospitals. The MoH also has occupational therapists at Mzuzu and Queen Elizabeth Central Hospitals as well as at Zomba Mental Hospital. These are responsible for teaching patients activities of daily living such as bathing, dressing, and eating. However, there are only 3 occupational therapists in Malawi. In addition, the Ministry provides mobility aids and appliances to PWDs.

2.4.6 Ministry of Labour

On labour, Section 31 of the Constitution of the Republic of Malawi states that:

- Every person shall have the right to fair and safe labour practices and to fair remuneration.
- All persons shall have the right to form and join trade unions or not to form or join trade unions.
- Every person shall be entitled to fair wages and equal remuneration for work of equal value without distinction or discrimination of any kind, in particular on basis of gender, disability or race.
- The State shall take measures to ensure the right to withdraw labour.

These provisions in the Constitution apply to all people in Malawi including PWDs. The mandate to implement these constitutional provisions lies with the MoL. In addition to the Constitution, the legislative mandates of the MoL are also stipulated in other Acts such as the Labour Relations Act (1996); Occupational Safety, Health and Welfare (1997); the Employment (2000) and the Workers' Compensation Act (2000). The MoL promotes equal access to open employment opportunities by people with disabilities as stipulated in the Employment Act; among other things, the Workers' Compensation Act makes provision for compensation for injuries suffered or diseases contracted by workers in the course of their employment, or for death resulting from such injuries or diseases; and the Occupational Safety, Health and Welfare Act makes provision for the regulation of conditions of employment in workplaces with regard to safety, health and welfare of employees and the prevention and regulation of accidents occurring to persons employed or authorised to go into the workplace; among other issues. The MoL is therefore key in terms of ensuring a safe workplace hence preventing disability and disease as well as the prevention of discrimination in the workplace based on a number of factors including disability.

2.4.6 Other Government Ministries and Departments

The policy says that all Government Ministries, Departments and statutory bodies are responsible for the implementation, monitoring and evaluation of the National Policy on Equalisation of Opportunities for Persons with Disabilities is the responsibility of all GoM Ministries and Departments, Statutory Corporations and other stakeholders. These organisations are responsible for specific services and they are supposed to cater for PWDs within their sectors and ensure that PWDs have equal access, rights and responsibilities as any other Malawian. Using this approach would ensure that PWDs are playing a full and participatory role in national development.

The successful integration of persons with disabilities in the mainstream of society, therefore, requires a multidisciplinary approach in Government. While this is what is supposed to be done, not much has been done in terms of ensuring that these organisations are doing their part in terms of inclusion of PWDs in their plans. Government line ministries, departments and statutory bodies have no personnel well qualified to plan and manage disability issues. This negatively impacts disability mainstreaming process. There is no institution in Malawi currently providing degree courses in disability studies. This is also partly due to the fact that, as will be discussed below, NACODDI has not been operational.

2.5 Mainstreaming of Disability Issues

The National Policy on Equalisation of Opportunities for Persons with Disabilities outlines the roles and responsibilities of various stakeholders including providing guidance on mainstreaming. While such an important document was developed and launched not much has been done in terms of implementation including mainstreaming of disability. Table 2.1 below shows a list of key sector ministries and whether they have desk officers for disability and whether they have mainstreamed disability:

Table 2.1: Mainstreaming in key sector ministries

Ministry	Desk officer for Disability	Mainstreamed disability or not
Agriculture	No	No
Labour	No	No
Youth, Sports and Culture	No	No
Finance	Yes	No
Gender, Children and Community Development	No	No
Education, Science and Technology	Yes	No

It is evident from Table 2.1 that in all the Ministries there is no desk officer for disability with an exception of the Ministry of Education and Ministry of Finance where all disability issues are handled by the Department of Special Needs Education. No sector Ministry has also mainstreamed disability so far. It should also be mentioned that currently it is only the Ministry of education that has indicators for disability: the proportion of children with disabilities in mainstream schools. The rest of the Ministries do not have any indicators on disability.

For mainstreaming to be successful, stakeholders should be aware of disability issues. Various stakeholders, however, are not fully aware of these issues including the national disability policy i.e. institutional awareness about the policy and related disability issues is limited. The Policy has a provision for the establishment and operationalisation of the National Advisory and Coordination Committee on Disability Issues. The ToRs for NACCODI were as follows:

- Provide a forum for all stakeholders on disability issues through networking and resource mobilisation.
- Advise Government on all technical aspects of disability issues.
- Commission research and prepare technical documents required by Government.
- Provide Government with annual reports on progress with implementation of the National Policy on Equalisation of Opportunities for Persons with Disabilities.
- Assist Government in the execution of its functions directed towards the attainment of the goals of the policy.
- Provide policy guidance to the Ministry responsible for persons with disabilities.
- Ensure that disability is mainstreamed in all line Ministries and Departments and that the requisite funds are allocated in the respective budgets and utilised accordingly.
- Oversee the implementation, monitoring and evaluation of disability-related projects and programmes.

The idea was that when people from various government ministries meet they should be able to go back to their Ministries and start implementing disability activities. However, over the last 5 years, NACCODI has never met and hence the proposed structure was never operationalised. One of the challenges was that members of NACCODI were supposed to foot their bills for attendance of these NACCODI meetings. The establishment of new structures, however, requires a corresponding investment in financial and human resources. Mainstreaming was supposed to be strengthened through operations of NACCODI. There is

need for the MoPWDE to operationalise NACCODI as this would help in pushing the agenda of mainstreaming of disability forward. Operationalisation would also help in ensuring that key stakeholders including policy makers to have adequate information on disability issues for them to make informed decisions.

While the mainstreaming at national level has not progressed as much over the last 5 years, it is evident that there is good progress in mainstreaming disability in CBR districts. Eggen et al give examples of CBR districts where District Development Plans have included disability issues; where district health plans have included provision of medical services for PWDs and that where CBR programmes are operational new buildings are being constructed with accessibility concerns. It has also been reported that in these districts the delivery of education for children with visual impairment has also been mainstreamed and that in such districts PWDs are also being targeted for handout programmes such as agricultural subsidies among other services (Eggen et al, 2010). There are a number of barriers to implementation of mainstreaming of disability in different sectors and these include:

- Shortage of human resource at all levels;
- Insufficient understanding of mainstreaming;
- The National Policy on Equalisation of Opportunities for Persons with Disabilities has not been disseminated or rolled out and that the national implementation plan is still in draft form;
- The key ministry personnel are not aware of the policy;
- The lack of integration of disability in national monitoring and evaluation systems – hence no disability level indicators; and
- Financial allocation in various ministries is inadequate (Eggen et al, 2010).

It is important therefore to address these issues in order to effectively mainstream disability in different sectors.

3. Conclusion and recommendations

3.1 Conclusions

The GoM and stakeholders plan to mainstream disability in different sectors. For this to be effectively done it was imperative that a situation analysis be conducted. The overall objective of this study was to compile and comprehensively summarise information from a selection of existing studies and documents. With regard to policy and legislative framework, Malawi has done quite well in terms of ratifying interventions (such as the Convention on the Rights of Persons with Disability) that have a direct bearing on PWDs. Most of the international instruments have been domesticated. At national level, there are a number of policies and legislative frameworks that promote the rights of PWDs. These include the Constitution of the Republic of Malawi, the MGDS, the Employment Act, the NESP and the Special Needs Education Policy and the National Policy on Equalisation of Opportunities for Persons with Disabilities among others. The policy is a good document but most of the issues contained in this policy have not been implemented. It has not been disseminated widely; hence most people do not know about it. The policy has also since expired as it was supposed to be for five years; hence the need for review. As far as the policy and legislative environment is concerned, it is evident that there are adequate laws and policies that

promote the rights of PWDs. The major drawback, however, is that the Disability Bill, submitted to Cabinet in 2004, has not been enacted. This is one of the factors that have affected the implementation of the National Policy on Equalisation of Opportunities for People with Disabilities.

This study has also demonstrated that prevalence of disability in developed countries is higher than in low income countries. In developing countries there is however under-reporting of disability prevalence and this might also be due to the definitions of disability and assessment tools that are used. In Malawi a number of studies have been done to determine prevalence: earlier studies mainly looked at physical disabilities but the 2003 Living conditions study used the ICF model in defining disability. Using this study as well the prevalence was much lower compared to developed countries. There is a need to acknowledge that disability data is becoming more available and for the first time the 2008 Population and Housing Census included questions on disability. This will ensure that every 10 years disability data is collected. The living condition study was conducted in 2003 and it might be important to do it again in order to determine if anything has changed.

In terms of access to health services, this review has revealed that while the majority of the PWDs seek treatment from health facilities as is the case with everyone else there are others who seek treatment from traditional healers because of the belief that their disability or illness has been caused by witchcraft. This report, based on findings from the Living conditions study, shows in general PWDs are aware of the health and related services that are available and that even if the majority of the PWDs require these services very few actually receive these services. While PWDs would want to seek health care from health facilities this review shows that there are a number of barriers for them to access services which need to be addressed if PWDs will access health care at anytime.

In the education sector, Malawi has made some notable progress. The number of CWDs in primary schools has doubled over the last 5 years. Resource or so; resource centres have been established within mainstream schools. There is a functional special need education directorate within the MoE. Specialist teachers are being trained annually. All new school structures are disability friendly and CBR programmes are being implemented to address barriers to education by PWDs. However, barriers still exist as enrolment and school attendance by PWDs (especially among females with disabilities) is still much lower compared to people without disabilities. These barriers (e.g. lack of specialist teachers, lack of communication skills with deaf-blind CWDs, poverty etc) need to be addressed in order to improve school attendance and retention.

In terms of livelihoods, slightly more people without disabilities are employed compared to PWDs; and discrimination against PWDs in employment still exist as evident from examples presented in this report. While CBR programmes low interest loans have been provided to PWDs; PWDs are being provided with vocational skills While CBR programs and other stakeholders have been key in equipping PWDs with vocational skills, still the majority of PWDs do not have the requisite skills to improve their livelihoods. Evidence shows that acquisition of vocational skills by PWDs has significantly improved their livelihoods. Barriers, as has been discussed, however exist in terms of PWDs accessing these skills; hence the need to address these.

Regarding the theme “social”, Malawi has ratified important international conventions and also developed the national disability policy but the disability bill which would ensure that PWDs have legal protection has since not been approved for close to a decade now. Initiatives to promote PWDs’ participation are being advocated for by MADISA but its operations are hampered by lack of financial resources. In terms of relationships, the review shows (sexual) abuse of PWDs especially women; challenges that women with disabilities experience in getting into relationships as some may not be able to fulfil their responsibilities as women in the home; some parents are ashamed of having CWDs hence they are sent away to live with relatives; among other issues. As is the case with other issues, cultural beliefs still prevail regarding disability that need to be addressed.

Some progress has also been made with regard to empowerment of PWDs. A number of DPOs have been established which are playing important roles such as advocacy and awareness creation. As part of empowerment, in health promotion, PWDs especially those who are deaf-blind are being provided with information in required formats. Processes are underway to ensure participation of PWDs in electoral processes and a directory of disability organisations was drafted in 2006 to let PWDs know where they can access services among other issues. It should be highlighted however that, while these attempts are being made to empower PWDs, challenges still exist as only a few PWDs have been able to access these services.

In Malawi CBR programmes are operational in 13 districts. This shows that the rest of the districts (15) do not have such programmes. Mainstreaming of disability in different sectors would help to address the challenges that are currently being experienced. While mainstreaming is the recommendation in the National Policy on Equalisation of Opportunities with Disabilities, not much has been achieved since the policy was approved in December 2005. This is partly because NACCODI which was supposed to ensure that mainstreaming is done has never been made operational. The other reason is the general lack of awareness among institutions regarding the disability issues. In order to address barriers to mainstreaming, the MoPWDE should provide the required leadership to other sectors.

3.2 Recommendations

Based on the results of this study, a number of recommendations have been made in order to effectively mainstream disability:

3.2.1 Effective dissemination of disability information

In the disability sector, a lot of documents (e.g. the Disability Bill, the National Policy on Equalisation of Opportunities for Persons with Disabilities and the draft National Plan of Action) have been produced. Some studies have also been done for example *the Living condition for people with activity limitations in Malawi*. These documents have not been disseminated adequately and others (including policy makers) even said that they were not aware of the National Policy on Equalisation of Opportunities for People with Disabilities. For mainstreaming to be successful it requires that stakeholders be given adequate information about disability and this has not been done adequately. An institutional awareness campaign therefore needs to be done for people to be aware of the disability issues and what role they can play. In these awareness campaigns the target should be government ministries,

planners and implementers. The MoPWDE (with support from DPOs) should take the lead in ensuring that these documents are disseminated widely.

3.2.2 Review the National Disability Policy and enactment of the Disability Bill

The National Policy on Equalisation of Opportunities for People with Disabilities was launched in 2006 by the MoPWDE. It was a five year policy and there is a need to evaluate what has been achieved since its implementation and review it. Anecdotally, it seems that a significant proportion of issues as contained in the policy have not been implemented much. The review of the policy itself will not have much impact but it should be accompanied by the enactment of the Disability Bill which will provide a conducive legal environment for the implementation of the Policy.

3.2.3 The Roles of the MoPWDE

The roles of the MoPWDE are clearly highlighted in the national disability policy: it is mainly responsible for the development of policy and monitoring and evaluation of the progress being made in the implementation of national policies and strategic plans. It is also supposed to advise other sector ministries and stakeholders on disability issues. Currently, the MoPWDE is also involved in the implementation of disability services. The implementation of activities, according to the policy, is the responsibility of the MACOHA. As the policy is being reviewed, it will be necessary to revisit these responsibilities and ensure that all the stakeholders are fulfilling their responsibilities.

3.2.4 Operationalisation of NACCODI

NACCODI is a forum where different sector ministries and other stakeholders meet to discuss disability issues. Unfortunately this was never operationalised despite the fact that it presents an opportunity for ensuring mainstreaming of disability issues. The Secretariat of NACCODI lies within the MoPWDE' hence it should ensure that this is operationalised. This could also promote collaboration between a wider network of disability stakeholders.

3.2.5 Meaningful Investments in Disability

In order to mainstream disability there needs to be substantial financial and human investments in disability issues. HIV and gender, just like disability, are crosscutting issues. However, unlike disability, in HIV and gender there have been huge investments of financial and human resources. While advocacy is important, this needs to be complimented by corresponding investments in financial and human resources for moving forward the disability agenda. The MoPWDE therefore has the responsibility of mobilising resources for the disability sector. There is need to have well qualified personnel in the disability sector. This can only be realised if the MoPWDE and its key stakeholders introduce a degree course in disability studies. While this is the case, there will be other activities that will not cost much for example the dissemination of information to all stakeholders to construct structures that are disability friendly.

3.2.6 Develop a National Disability Mainstreaming Strategic Plan

The MoPWDE should take a lead in mainstreaming disability in the different sectors. Financial and human resources need to be mobilized to ensure that this is done. In order to

ensure that disability mainstreaming is done, it will be important for the Ministry and other stakeholders to develop a comprehensive and costed disability mainstreaming strategic plan covering a period of 5 years which will spell out a detailed list of activities that will be implemented including a list of indicators to monitor progress.

3.2.7 Appointment of disability focal persons in the sector ministries

The National Policy on Equalisation of Opportunities for People with Disabilities recommended that there was a need for focal persons in each sector ministry who would be responsible for disability issues. It is also therefore recommended that in order to effectively mainstream disability there will be a need for desk persons for disability issues to be appointed in all the sector ministries and it will be the responsibility of the Ministry responsible for Persons with Disabilities and the Elderly who will train these people.

3.2.8 The need for a follow up survey on *Living Conditions* of PWDs

The last comprehensive surveys on people with disabilities were conducted in Malawi in 2003 namely: the WHS and the *Living Conditions* survey. The conduct of these studies has enabled Malawi to have data on disability including levels of access to services. It is now close to 10 years since these studies were done. It is therefore important to conduct another more comprehensive study looking at the prevalence of disability where disability is determined through screening questions developed by the Washington Disability Statistics Group.

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ANNEX 1: GUIDE FOR INDEPTH INTERVIEWS WITH STAKHOLDERS

1. What services does this ministry offer?
2. Are disability issues relevant in the work of your Ministry? How?
3. Do you have disability sensitive indicators in your indicator sets to measure achievement of targets of your respective services?
4. Are there any services that particularly target people with disabilities? What services?
5. Are there any policies or plans by your Ministry that guide your work on disability issues?
6. Are there any specific initiatives or plans in your Ministry that target people with disabilities?
7. To what extent have you mainstreamed disability into your programmes? What has made mainstreaming easy/possible in your ministry?
8. Do you have anchored disability as a cross cutting issue / theme in your ministry, such as HIV/AIDS, gender?
9. Do you have a focal point for disability in your Ministry?
10. What challenges on mainstreaming disability into your programmes have you experienced?
11. How have you dealt with these challenges?
12. What areas would you like more help with regarding mainstreaming disability?
13. To what extent do you work with other organisations in the disability sector? What role do they play?
14. As per your perception, what is the role of the Ministry of Persons with Disability versus the other Ministries of the Government of Malawi?
15. Are you aware of any legislative or policy commitment by Government of Malawi towards people with disabilities? What are these?

ANNEX 2: LIST OF INTERNATIONAL CONVENTIONS SIGNED BY MALAWI

- **Universal Declaration of Human Rights (1948):** The Declaration promotes fundamental human rights to all. Each article applies to every individual regardless of disabilities, gender, race, color, religion or any other status of life. Any form of discrimination violates the principle of Equality.
- **The International Convention on Civil and Political Rights (1966):** It uses language similar to Universal Declaration of Human Rights to protect the right to privacy and to actual title to "UN Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment" that are major causes of disability.
- **Convention of the Elimination of all forms of Discrimination Against Women (1971):** The Convention provides the basis for realizing equality between women and men through ensuring women's equal access to, and equal opportunities in, political and public life -- including the right to vote and to stand for election -- as well as education, health and employment. States parties agree to take all appropriate measures, including legislation and temporary special measures, so that women can enjoy all their human rights and fundamental freedoms.
- **The UN Convention on Rights of the Child (1979):** Provides comprehensive rights of the child to education and health and prohibition to labor force.
- **African Charter on Human and Peoples Rights (1981):** This is also known as the Banjul Charter and it is an international human rights instrument that promotes and protects human rights and basic freedoms on the African continent.
- **The World Program of Action concerning Disabled Persons (1982):** This aims at promotion of effective measures for the prevention of disability, rehabilitation and the realization of equal opportunities for PWD.
- **The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993):** This is a set of objectives implying a strong political and moral commitment by the State to take action for the equalization of opportunities for PWD.
- **The UN Convention of the Rights of People with Disabilities (2007):** The Convention promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
- **UN Convention on Vocational Rehabilitation and Employment of Persons with Disabilities (1983):** The Convention prohibits discrimination on the basis of disability in all forms of employment, and calls on states to open up opportunities in mainstream workplaces to job seekers with disabilities. The Convention further promotes the access of disabled persons to freely chosen work, general technical and vocational guidance programmes, placement services and vocational and continuing training.

ANNEX 3: ESTIMATED PREVALENCE OF BOTH SEVERE AND MODERATE DISABILITY BY WHO REGION (WORLD REPORT ON DISABILITY, 2011)

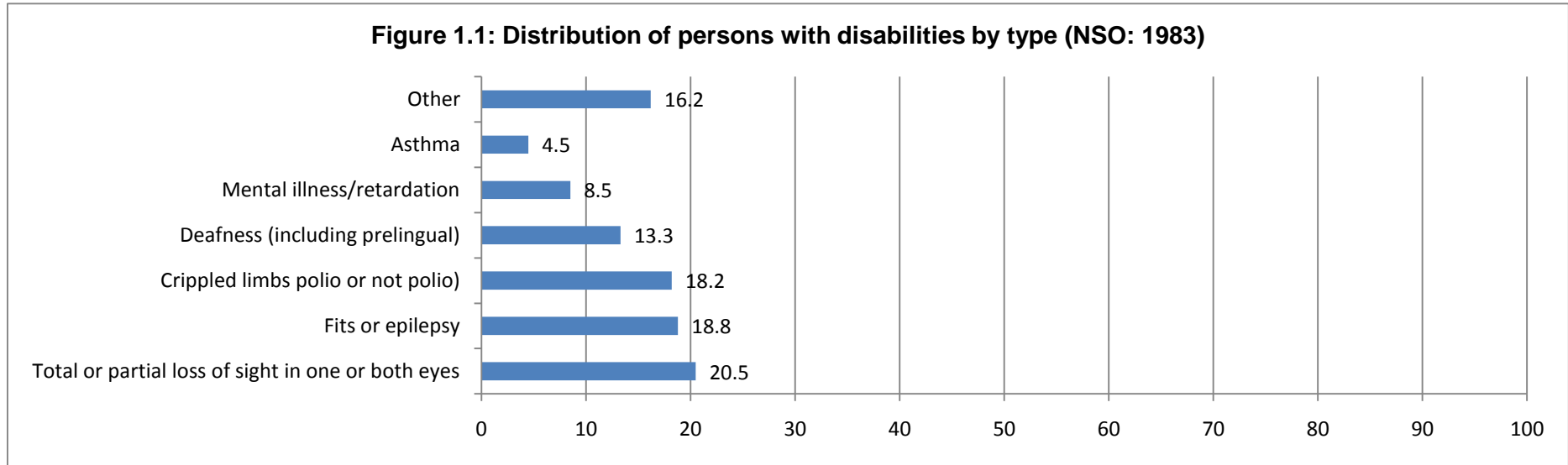
WHO REGION	DISABILITY PREVALENCE
High Income countries	15.4
Low income countries	
Africa	15.3
Americas	14.1
South East Asia	16.0
Europe	16.4
Eastern Mediterranean	14.0
Western Pacific	15.0
World	15.3

ANNEX 4: PREVALENCE OF DISABILITY IN SELECTED COUNTRIES

HIGH INCOME COUNTRIES			LOW INCOME COUNTRIES		
Country	Year	Percentage	Country	Year	Percentage
Canada	1991	14.7	Kenya	1989	0.7
Germany	1992	8.4	Namibia	1991	3.1
Italy	1994	5.0	Nigeria	1991	0.5
Netherlands	1986	11.6	Senegal	1988	1.1
Norway	1995	17.8	South Africa	1980	0.5
Sweden	1988	12.1	Zambia	1990	0.9
Spain	1986	15.0	Zimbabwe	1997	1.9
United Kingdom	1991	12.2	Mozambique	2009	
USA	1994	15.0	Malawi	2003	4.2

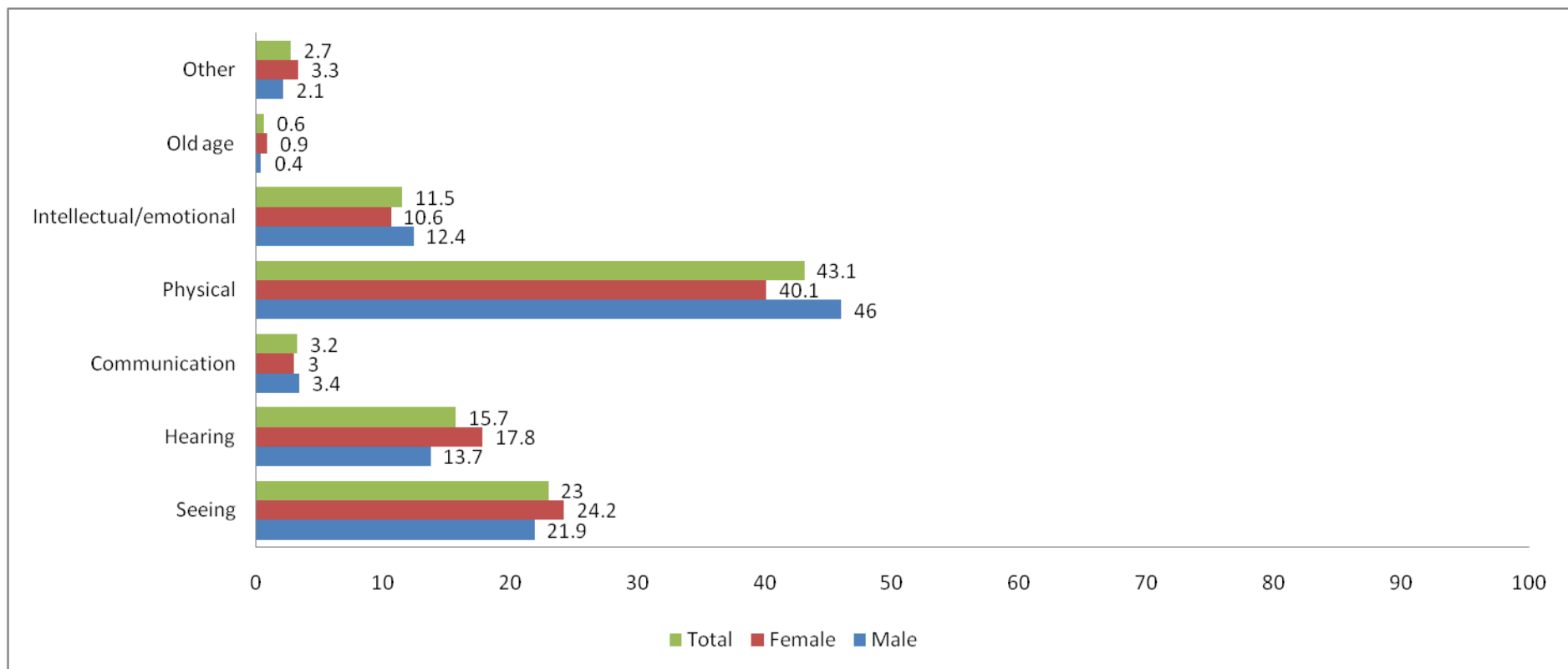
(Source: Loeb and Eide, 2004)

Annex 5: Distribution of persons with disabilities by type of disability



(Source: National Statistical Office, 1987)

Annex 6: Distribution of different types of disability by gender and type



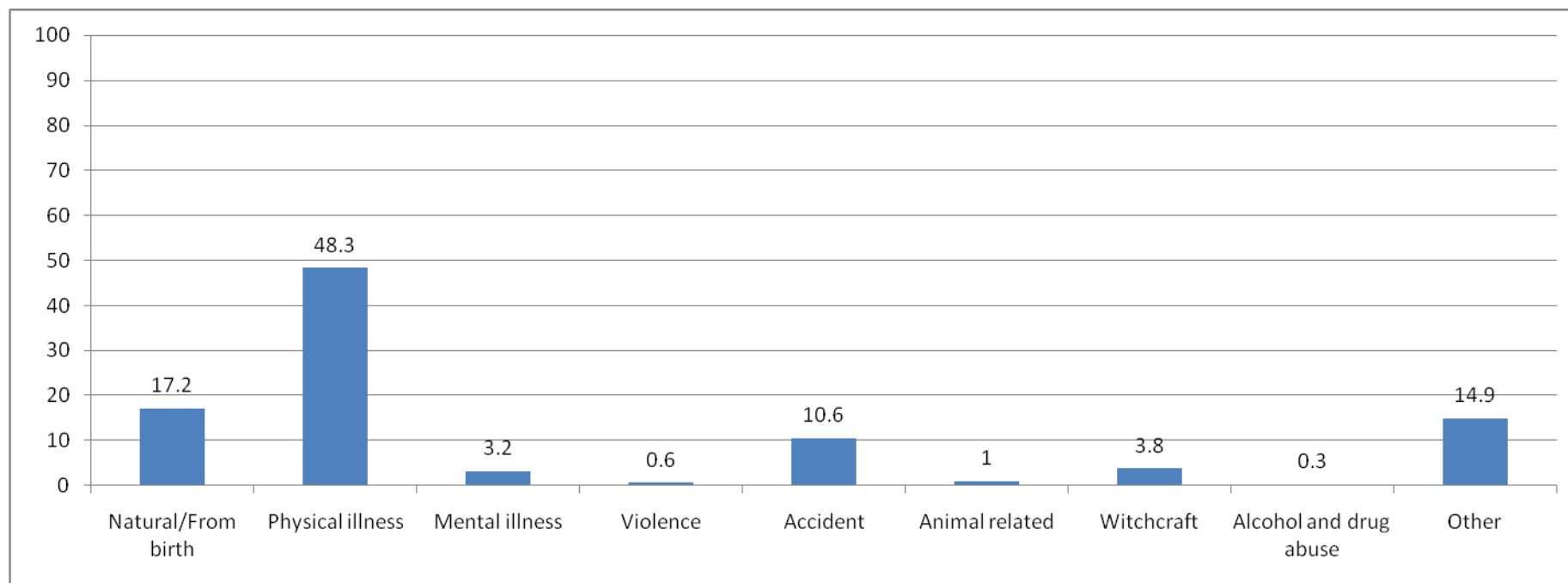
Source: Loeb and Eide, 2004)

ANNEX 7: DISTRIBUTION OF PERSONS WITH DISABILITIES BY TYPE OF DISABILITY

Area	Total Persons with Disabilities	Type of Disability				
		Seeing	Hearing	Speaking	Walking	Other
Malawi	498,122	133,273	6,462	3,291	9,712	11,225
Urban	45,379	14,689	6,462	3,291	9,712	11,225
Rural	452,743	118,584	75,718	26,907	99,158	132,376

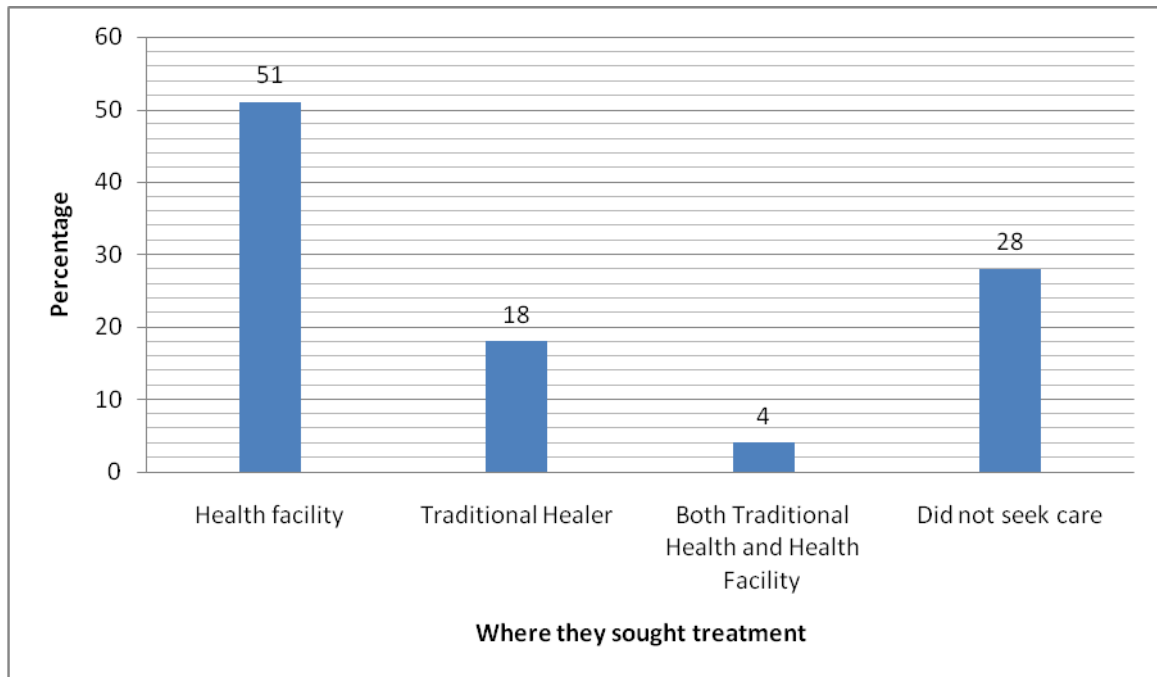
Source: 2008 Population and Housing Census Report

Annex 8: Causes of disability



Source: Loeb and Eide, 2004

Annex 9: Where people sought treatment for their disability

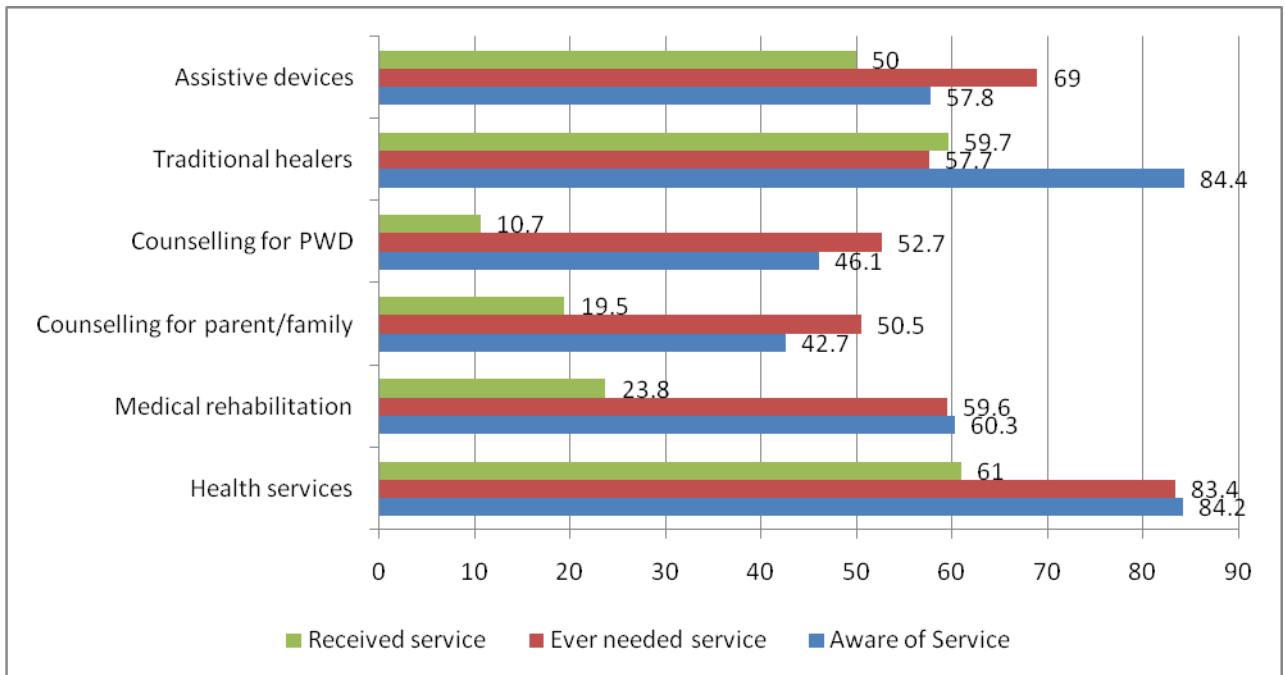


(McDonald, 1992)

Annex 10: Where PWDs and people without disabilities would seek treatment

Where they would seek treatment	Disease condition																			
	Epilepsy		Diarrhoea		HIV/AIDS		Malaria		Stroke		Tuberculosis		Physical Disability		Cancer		Mental/ intellectual disability			
	Non-PWD	PWD	Non-PWD	PWD	Non-PWD	PWD	Non-PWD	PWD	Non-PWD	PWD	Non-PWD	PWD	Non-PWD	PWD	Non-PWD	PWD	Non-PWD	PWD		
Hospital	79.5	76.6	98.6	97.6	98.6	97.2	99.1	96.6	98.4	96.0	99.1	98.4	98.6	97.2	99.1	98.4	96.2	86.9		
Traditional healer	19.1	21.4	0.9	1.6	1.2	1.2	0.9	1.6	1.6	2.8	0.9	1.2	1.4	2.0	0.9	0.4	7.4	12.7		
Don't seek treatment	0.7	0.8	0.5	0.4	0.0	0.4	0.0	0.4	0.0	0.4	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0		
Don't know	0.7	1.2	0.0	0.4	0.2	1.2	0.0	0.4	0.0	0.8	0.0	0.4	0.0	0.8	0.0	1.2	0.0	0.4		
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0		

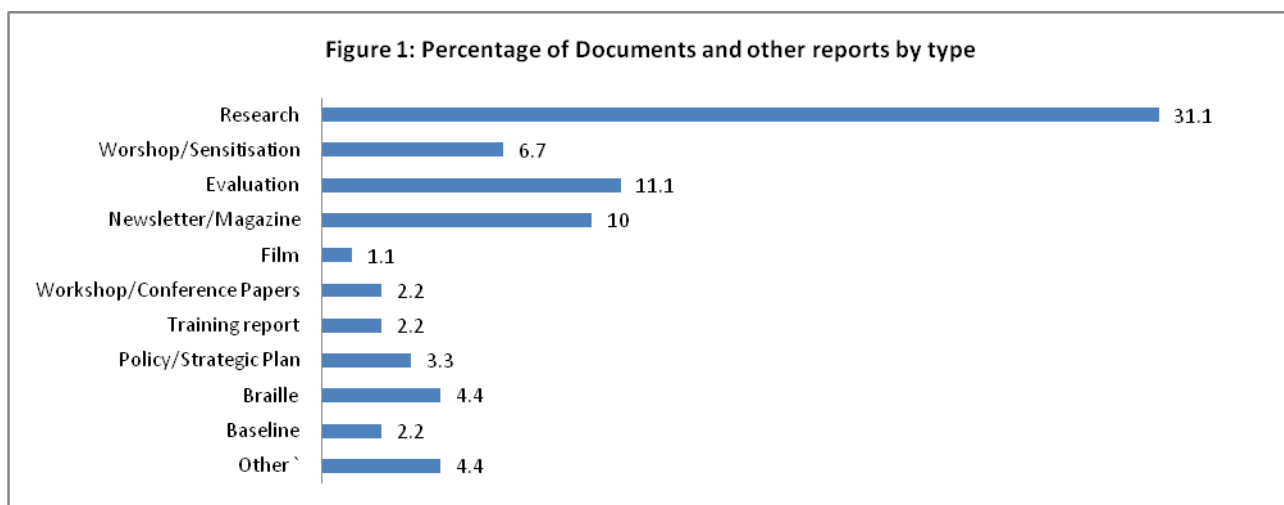
Annex 11: Health and related services PWDs are aware of, ever needed and ever received



Annex 12: Sources of information about HIV/AIDS

Source	Male	Female	Total
Health facilities	23.0	37.0	28.0
Teachers	9.6	5.0	7.9
Youth peer group	1.0	1.7	1.2
Party leaders	1.0	0.0	0.6
Religious/church leaders	6.2	5.0	5.8
Printed material	1.0	2.5	1.5
Parents	1.9	2.5	2.1
Friends	10.0	11.8	10.7
NGOs/FBOs	2.9	0.8	2.1
Radio	33.5	26.1	30.8
I saw my sister	0.0	1.7	0.6
Sign language	0.0	0.8	0.3
BLM	3.3	0.8	2.4
Other	6.2	4.2	5.5
Don't know	0.5	0.0	0.3
Total	100.0	100.0	100.0

Annex 13: Number of documents on CBR produced in Malawi by type

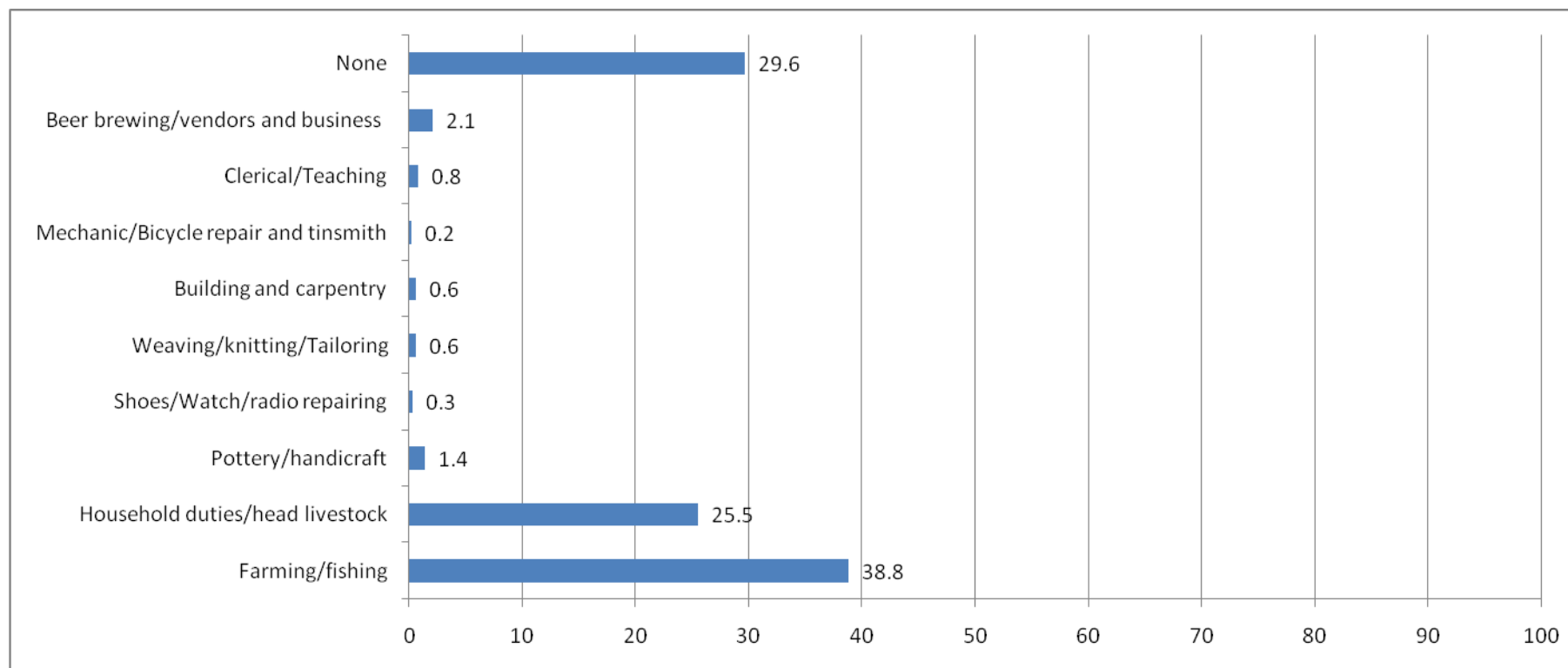


Source: Munthali and Kakhongwe, 2011

Annex 14: Number of pupils in primary and secondary schools by type of disability

Type of Disability	Number of children with special needs in primary school			Number of children with special needs in primary school		
	Boys	Girls	Total	Boys	Girls	Total
Blind	198	157	355	43	36	79
Deaf	1229	1047	2276	64	43	107
Hard of hearing	9563	9436	18999	237	205	442
Learning difficulties	18379	16567	34946	297	350	647
Low vision	9917	9157	19076	502	613	1115
Physical impairment	4520	3474	8014	230	160	390
	43806	39860	83666	1373	1407	2780

Annex 15: Percentage of disabled persons aged 5 years and over who usually do work by type of work



Annex 16: Main or primary sources of income

Main or primary source of income	Case Households	Control Households	Total
Wage/salary work	21.9	26.4	24.2
Remittances received	7.0	3.5	5.3
Cash cropping	21.1	20.8	20.9
Livestock sales	1.1	0.5	0.8
Subsistence farming	15.1	11.2	13.6
Formal business	1.4	1.6	1.5
Informal business	24.1	27.9	26.0
Private insurance/pension	0.7	0.2	0.5
Workman's compensation	0.1	0.3	0.2
Rent	0.9	0.7	0.8
Others	5.0	4.5	4.7
No income from any source	0.7	0.6	0.7
Not stated/refused	0.9	0.8	0.9
Total	100.0	100.0	100.0

Annex 17: ROLES AND RESPONSIBILITIES OF IMPLEMENTATION PARTNERS

The following are the roles and responsibilities of structures at macro and micro levels:

Ministry of Persons with Disabilities and the Elderly

- Coordinate programming of disability related activities.
- Coordinate implementation, monitoring and evaluation of NPA activities in all sectors.
- Represent government at all national and international fora on disability issues.
- Mobilise resources from both internal and external sources for NPA implementation and review processes.
- Mainstream disability issues in all sectors.
- Enhance advocacy to facilitate effective and efficient implementation of the disability activities.
- Strengthen capacity of Disabled Persons Organisations.

Ministry of Health

- Promote prevention and occurrence of disabilities.
- Provide early detection and early intervention services.
- Provide medical rehabilitation services.
- Provide specialised training in the area of disability.

Ministry of Education

- Ensure access by persons with disabilities to quality education and ample opportunities to develop their skills.
- Promote inclusive education and training programmes.
- Establish the Malawi Institute of Special Education.

Ministry of Labour and Vocational Training

- Promote equal access to open employment opportunities by people with disabilities.
- Increase access to technical, vocational and entrepreneurial training opportunities for persons with disabilities.

Office of the President and Cabinet

- Attain a barrier-free environment that will enable persons with disabilities to have access to public and private buildings and establishments.
- Improve representation of people with disabilities in leadership structures.
- Facilitate equal access to employment in public service opportunities by people with disabilities.
- Promote social support projects that target vulnerable groups, including persons with disabilities.

Ministry of Development, Planning and Corporation

- Promote economic empowerment of persons with disabilities by, *inter alia*, facilitating their access to loans and credit facilities for income generating activities.
- Include persons with disabilities in planning, monitoring and evaluation.
- Liaise with cooperating partners for financial and technical support.

Ministry of Finance

- Develop a sustainable micro-finance industry that provides credit, saving opportunities and other services to the poor including persons with disabilities.

Ministry of Lands, Housing and Survey

- Promote Access to land ownership, housing and property rights by persons with disabilities.
- Ensure non-discrimination of persons with disabilities in the allocation of houses for rent by the Malawi Housing Corporation.
- Ensure non-discrimination of civil servants with disabilities in the management of the Home Ownership Scheme.

Ministry of Transport and Public Works

- Provide access of persons with disabilities to public transport facilities; existing and new buildings; public information and communication, signs, symbols, and warning signals; appropriate public parking lots.
- Conduct public awareness campaigns among public transport operators on disability issues.

Ministry of Gender, Child and Community Development

- Provide access to social services and safety nets to persons with disabilities.
- Include persons with disabilities in social and community developmental programmes.

Ministry of Sports and Youth Development

- Include youths with disabilities in youth programmes.
- Facilitate accessibility of sports facilities and entertainment centres to persons with disabilities.

Ministry of Agriculture and Food Security

- Provide access to food security by persons with disabilities.
- Provide access to farm inputs.
- Provide extension services.

Ministry of Irrigation and Water Development

- Make water and sanitation services and facilities more inclusive and accessible for Persons with disabilities.

Ministry of Trade and Private Sector Development

- Promote the development of micro and small-scale enterprises by providing technical support to persons with disabilities.
- Promote the formation of clubs and cooperative societies among persons with disabilities to improve their business acumen and creditworthiness.

Ministry of Information and Civic Education

- Develop a comprehensive policy on access to public information by persons with disabilities in liaison with the public and private media organisations.

- Publicise and advocate for the disability cause and the implementation of the policy.
- Explore the use of Information and Communication Technology as an assistive device for persons with disabilities.

Ministry of Local Government-Local Assemblies

- Ensure user-friendliness of micro-building projects such as schools, hospitals, clinics, toilets to persons with disabilities.
- Incorporate special needs for persons with disabilities in Local Assemblies bye-laws.
- Maintain a data-base for all persons with disabilities in respective areas of jurisdiction.
- Integrate policy in district development plans in line with decentralisation programme.

National Statistical Office

- Develop disaggregated disability database.
- Timely provision of improved user-friendly and accessible socio-economic data.

Disabled Peoples Organisations

- Promote debate of legal and policy issues among respective members in their organisations.
- Promote consultative meetings with other stakeholders such as the State, employers and Trade Unions.
- Ensure that policy and legal recommendations are based on well-informed opinion.
- Undertake awareness campaigns and advocacy.
- Monitor and evaluate policy and legislation implementation.

Employers' Organisations

- Promote training and employment opportunities for disabled persons.
- Negotiate acceptable legal obligations.
- Negotiate of acceptable performance incentives.
- Sensitise employers on the rights based approach to training.

Workers' Organisations

- Lobby support for the employment of workers with disabilities, including new recruitment and job retention by those who acquire a disability while in employment.
- Sensitise members about the rights of persons with disabilities.

Service Providers

- Provide specialised services to people with disabilities such as training and rehabilitation as well as workplace services.
- Carry out research on disability issues.

Malawi Council on Disability Affairs (MACODA)

- Register NGOs dealing with disability issues.
- Regulate the work of disability organisations.
- Implement government policy on disability issues.

National Advisory and Coordination Committee on Disability Issues (NACCODI)

- Provide a forum for all stakeholders on disability issues through networking and resource mobilisation.
- Advise Government on all technical aspects of disability issues.
- Commission research and prepare technical documents required by Government.
- Provide Government with annual reports on progress with implementation of the National Policy on Equalisation of Opportunities for Persons with Disabilities.
- Assist Government in the execution of its functions directed towards the attainment of the goals of the policy.
- Provide policy guidance to the Ministry responsible for persons with disabilities.
- Ensure that disability is mainstreamed in all line Ministries and Departments and that the requisite funds are allocated in the respective budgets and utilised accordingly.
- Oversee the implementation, monitoring and evaluation of disability-related projects and programmes.

Research Institutions

- Undertake disability-related research in areas of political, social, cultural, and economic development as the bases for formulating realistic programmes for guiding policy implementation and review.

Parliamentary Committee on Social Welfare

- Advocate for the implementation of the Policy.
- Provide support and advice to the Ministry responsible for Persons with Disabilities on the implementation of the policy.
- Lobby for realistic budgetary allocation for implementation of disability programmes and activities.
- Lobby for review and enactment of policies, laws, and guidelines that will facilitate the implementation of this policy

NGOs and Civil Society

- Carry out, on a continuous basis, advocacy programmes and activities for the implementation of the policy.

Annex 18: Terms of Reference



**TERMS OF REFERENCE
DESK STUDY / SITUATION ANALYSIS
OF PERSONS WITH DISABILITIES IN MALAWI**

A. INTRODUCTION

The Ministry of Persons with Disabilities and the Elderly (MPWDE) has entered into partnership with CBM¹⁰, NAD¹¹ and SADPD¹² to develop a **National Disability Mainstreaming Plan** for the Government of Malawi, in collaboration with FEDOMA¹³. For background information on the stakeholders, please refer to Annex 1.

The **purpose** of a National Disability Mainstreaming Plan of the Government of Malawi will be to ensure that in the future (1.) people living with disability are considered and included in all development activities of the Government, that (2.) all existing government services are made accessible also to people with disabilities (e.g. education, livelihoods, health), and that (3.) Government is systematically developing additional, disability specific services, as required.

Consequently, the main **target group** of the National Disability Mainstreaming Plan will be sector ministries as well as relevant government institutions and statutory corporations at all levels¹⁴. In order to effectively institutionalize disability mainstreaming, capacity will have to be built within government entities how to mainstream disability in their respective strategies, projects and services, and regularly report on their progress and achievements. **Core function of the Ministry of Persons with Disabilities and the Elderly** (MPWDE) will be to:

1. Develop the National Disability Mainstreaming Plan in collaboration with all stakeholders;
2. Build capacity in relevant sector ministries, government institutions and statutory corporations at all levels to mainstream disability in their respective strategies, projects and services;
3. Monitor the implementation of the National Disability Mainstreaming Plan and efforts of all relevant sector ministries, government institutions and statutory corporations at all levels to mainstream disability;
4. Provide back-stopping and technical assistance to relevant sector ministries, government institutions and statutory corporations to effectively mainstream disability.

B. OBJECTIVES OF THE SITUATION ANALYSIS

For the development of a National Disability Mainstreaming Plan, **the existing situation with regards to disability and development in Malawi needs to be established to serve as a baseline** from which to commence further planning together with sector ministries, local partners and stakeholders. The situation analysis will be utilized for doing a GAP or SWOT¹⁵ analysis with local partners. It will also be useful when evaluating outcomes and impact at a national level after a few years when change can be tracked.

The Desk Study / Situation Analysis is being commissioned by SADPD, CBM and NAD. The contracting party to the Consultant / Company assigned to carry out the study is CBM.

¹⁰ International Organization for Disability and Development

¹¹ Norwegian Association of the Disabled

¹² Secretariat of the African Decade of Persons with Disabilities

¹³ Federation of Disability Organizations of Malawi

¹⁴ Note: to ensure availability of funding for the implementation of the Plan, also donors / development partners of the Government of Malawi will be targeted

¹⁵ Strength, Weaknesses, Opportunities and Threats

The **overall objective** of the desk study / situation analysis is to compile and comprehensively summarize information from a selection of existing studies and documents on the situation of Persons with Disabilities (PWDs) in Malawi.

The study should establish what the existing legislative and policy framework is (1.), availability and level of access to existing services (2.), who are the key stakeholders and what are the existing programmes and interventions (3.). Based on the findings, main gaps should be identified and recommendations should be provided (4.) on priority intervention areas for the Government of Malawi and its development partners in the remaining years of the African Decade (until 2019). Framework for structuring of the analysis / report on current interventions and gaps is the CBR matrix¹⁶.

C. SCOPE

Most information should be obtained from existing studies through **document review** of national plans, policies and legislation, available surveys, reports and other information. Key documents and studies will be made available to the Consultant at the commencement of the assignment. If required, additional documents will be identified by the Consultant via Internet research and through e-mail contact, or by obtaining physical copies of relevant documents from ministries and organisations involved with disability. To verify findings and recommendations, **interviews** will have to be carried out **with key informants** such as representatives of disabled people and CBR stakeholders as well as with Ministries and Government service providers.

D. EXPECTED RESULTS

The study should provide information and establish the baseline with regards to the following, expected results:

1. Documentation of disability related **policy and legislative framework** in Malawi, and disability specific **national plans** of the Government of Malawi;
2. **Availability of services** in the country with regards to the intervention areas of the CBR matrix, and **level of access** to those services by PwDs;
3. **Mapping of roles and responsibilities of key stakeholders** and institutions **versus their actual programmes and interventions** with focus on Government, but also including Civil Society, and National and International Organizations. Analysis of key stakeholders has to include the following Government Ministries:

- 3.1 Ministry of Health;
- 3.2 Ministry of Education;
- 3.3 Ministry of Labour;
- 3.4 Ministry of Agriculture;
- 3.5 Ministry of Youth, Sports and Culture;

¹⁶ WHO, UNESCO, ILO (2010): Community Based Rehabilitation (CBR) Guidelines

3.6 Ministry of Women, Child and Community Services;

Information should be displayed in form of tables, also providing information to what extent disability is already mainstreamed in the respective programmes and interventions.

For verification of findings, interviews need to be carried out with MACOHA HO as well as CBR Project staff from district level, FEDOMA, Sightsavers, MANAD¹⁷ and MUB¹⁸. A list of organizations to be interviewed has to be agreed between the Consultant and the contracting parties; for scheduling of the interviews, CBM and MPWDE will assist the Consultant.

Based on the findings, **main gaps** should be identified and **recommendations** should be provided on priority areas of intervention and action for the respective Ministries and Institutions of the Government of Malawi and its development partners in the remaining years of the African Decade (until 2019). **Framework** for structuring of the main gaps and recommendations should be the **CBR matrix, with focus on the sections 'Health', 'Education' and 'Livelihoods' (compare Annex 1)**;

E. EXPECTED DELIVERABLES

The consultant will be expected to deliver the following:

1. A detailed work plan for the assignment with clear time lines to be submitted for approval to CBM / NAD / MPwDE / SADPD / FEDOMA, incl. schedule for interviews to verify findings;
2. A draft and final report in English with results of the situational analysis as specified above. The draft report will be reviewed, and recommendations will be given for further improvement;
3. Any documents / reports received from ministries/service provider describing or assessing policies, programmes and services that have been or need to be developed to address the needs of disabled people;
4. A Power Point Presentation (1,5 hours) on main findings and recommendations;
5. Presentation of the final document / Power Point Presentation to the stakeholders involved (Government/NGOs/DPOs) during a half day workshop on 19th or 20th of July, 2011;

F. REPORT FORMAT

The report should follow the following format:

1. Executive Summary (max. 4 pages);
2. Introduction (objective of the study, methodology – max. 1 page);
3. Statistical country and disability information (demographic situation, disability situation, statistics, known/ estimated disability data) (max. 2-3 pages);
4. Main report detailing information (findings / recommendations) on each result area in separate chapters; it is expected that in addition to the narrative in the report, the Consultant will utilize data / information analysis - and presentation tools such as

¹⁷ Malawi National Association of the Deaf

¹⁸ Malawi Union of the Blind

tables; Note: the main report shall not exceed 25 pages, excluding executive summary, references, appendices and tables.

5. References (Bibliography);
6. Appendices for important, additional information, incl. Terms of Reference, Work plan, list of people met / interviewed, guiding questions for interviews;
7. For main report (1.-4.), font type and size is **Arial 11**; Paragraph line spacing: **Multiple, 1.15**;

G. REQUIRED PROFILE OF THE CONSULTANT

- ✓ Strong background in human rights and social sciences;
- ✓ Academic qualification at Masters Level in social sciences, education, law or related field and 5 years' experience in work with government and NGOs involved in advocacy and capacity building in Africa;
- ✓ Excellent writing and analytical skills; intuitive, thorough, creative, innovative, articulate and objective;
- ✓ Excellent interviewing and reporting skills;
- ✓ Excellent command of English, both written and oral;
- ✓ Excellent ability to develop data / information analysis - and presentation tools, such as tables;
- ✓ Ability to strictly adhere to timelines;
- ✓ Familiarity with the disability situation in Malawi will be an advantage;
- ✓ Experience in the field of disability and diversity management and familiarity with the Convention on the Rights of Persons with Disabilities (CRPD) will be an advantage;

H. TIME FRAME

- ✓ 18 working days;
- ✓ Commencement of consultancy assignment 09.05.2011;
- ✓ Draft report by 31st May 2011;
- ✓ Commenting period 31st May – 13th June 2011;
- ✓ submission of final report incl. Power Point Presentation; 20th June 2011