

Acknowledgements

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EXECUTIVE SUMMARY

Empowerment is one of the five key components of the WHO/UNESCO/ILO Community-Based Rehabilitation (CBR) Matrix. It is a cross cutting theme which focuses on building the capacity of persons with disabilities, their family members and communities to be aware of disability rights, demand inclusion of disability across key development sectors of health, education, livelihood and social sectors and ensure that persons with disabilities are able to access their rights and entitlements. Key elements of the CBR empowerment component are: accessible and transparent communication (awareness-raising), social mobilization, political participation, and capacity building of self-help groups and Disabled People's Organizations.

The term empowerment has different meanings in different contexts. However, improved levels of participation, self-organisation and improved livelihoods can be indicators for empowerment at individual level.¹ Individually empowered persons with disabilities are able to access services and facilities and take advantage of available opportunities that can lead to improvements in their social and economic independence and self-reliance. Empowered persons with disabilities are able to mobilize and organize themselves and demand a life of dignity in an inclusive environment. In both cases, they are aware of their rights and recognize the exclusion and discrimination they are subjected to and take steps to change their status quo.

From the mid-2000s there have been a number of evaluations² and related studies that have provided some insights into efforts by the Community Based Rehabilitation as well as other interventions that have been made to build the capacity of Disabled People's Organisations (DPOs) and individual persons with disabilities. These have been aimed at assessing the extent to which DPOs have been effective in carrying out lobbying and advocacy initiatives as well as looking at existing major challenges they have encountered. Based on these evaluations and observations of the challenges that have come to light, this research study aims at exploring, from the perspective of persons with disabilities, the extent to which they feel that they are empowered and also to identify strategies both CBR and others that further promote their empowerment.

The study aims at assessing, based on information gathered from persons with disabilities and their DPOs, what their perception of empowerment is and to document strategies and interventions implemented through the CBR empowerment component as well as non CBR interventions and to comment on their effectiveness. The study attempts to give voice to the

¹Empowered to Differ: Stakeholders Influence in CBR. H. Finkenflugel (2004)

²Notable among these works are the following:

- Norwegian Association of Disabled (2009). As strong as the weakest link: An evaluation of the community based rehabilitation program of the Malawi Council for the Handicapped supported by Norwegian Association of Disabled.
- Bondevik, P. N. (2008). Inclusion: A key priority in Malawi Microfinance: A feasibility study
- Danish Council of Organisations of Persons with Disabilities (2007). Comparative Study of Political Approaches and Government Processes to Mainstream Disability into all Sectors of Society in Malawi.
- Danish Council of Organisations of Persons with Disabilities (2003). A study report on the capacity of disability organizations in Malawi
- Ministry of Persons with Disabilities and the Elderly, MACOHA and FEDOMA CBR strategic plans and reports for 2004-2010.

experiences of persons with disabilities with regard to their perceptions, views, and ideas regarding their empowerment.

Methodology

A qualitative data collection method was used in this study. Four data collection tools were used with different respondents at different levels, namely, Literature Review, Semi-Structured Interviews (SSI), Focus Group Discussions (FGD) and Observation. The principal data collection tool SSI was used widely with most of the respondents. Ten Research Assistants were deployed to collect data while two Researchers collected data mainly at district and national levels. Three districts³ were selected, where NAD supports CBR activities. In one of the districts namely, Mzimba data was also collected from non CBR areas. The study targeted persons with disabilities across the main disability types of Deaf, Visual, Physical, Deaf/Blind, Albinism, Epilepsy and developmental and multiple disabilities.

In total, interviews were held with 100 persons with disabilities the majority (30%), being those with physical disabilities followed by those with visual (17%) and hearing (14%) impairments respectively. Only 1% was made up of Deaf-blind respondents with the remaining 38% having other disabilities. An additional 43 respondents were interviewed representing CBR staff/volunteers, DPOs, CBOs and authorities.

Some of the limitations to the study included the difficulty of communicating with persons with intellectual disabilities and children, conducting the study during the cultivation period when most people were in the field, and very low prevalence rate of some disabilities, for instance, albinism and Deaf/Blindness.

Findings

The current CBR empowerment programme being implemented by FEDOMA/DPOs has placed its focus on three main areas

- Training in human rights.
- Confidence building meetings
- Formation and strengthening of DPOs

Although there have been some positive effects resulting from these in terms of visibility of PWDs at local levels, reduced discrimination, participation in family and community activities and improved quality life, there are some indications that these interventions are not enough to meet perceived empowerment needs of PWDs. According to this study, most PWDs have linked empowerment and self reliance to economic factors through programmes that raise individual or family income more especially skills training and loan schemes.

At different levels PWDs defined empowerment differently but overall, they associated it with independence, more especially economic independence. To some 75% of the women this also implied independence from male dependency while another 46% extended the definition to imply wellbeing of their families especially children.

According to PWDs, although their perception of empowerment is cross cutting they related it more to livelihoods with, economic factors featuring prominently. For them, programmes that raised individual or family income, especially those that enabled them to gain access to loans, contributed more to their empowerment and self sustenance

³Balaka and Machinga in the south and Mzimba in the north

Among children with disabilities the term was very difficult to define especially for children that are slow learners and persons with severe disabilities. The study used *Happiness*, as a proxy for empowerment, to explore the meaning of empowerment. Most children (70%) felt empowered if they were able to play with other children or do some sporting activities (participation and social inclusion). Some parents of children with disabilities defined an empowered child as one who is independent in terms of daily living activities (ADL) and is able to communicate his/her needs.

Some 38% of parents of children with disabilities mentioned entry into special needs schools as a factor that can contribute towards empowerment of their children, especially parents of children with physical impairment followed by parents of children with multiple disabilities. The same parents also noted that the current school environment is not enabling because of lack of accessibility and teachers' lack of skills to handle children with disabilities.

Self Help Groups acknowledged that the formation of the groups was empowering and felt stronger if they were generating money. An empowered self-help group was also defined as one which was able to access services for its targeted groups especially social services and income generating opportunities. According to them factors leading to empowerment were linked to programmes that raised individual or family income especially those that enabled them to access loans or linked them to microfinance institutions. Also deemed empowering were skills training of groups and awareness-raising that helped promote an inclusive social environment.

DPOs at district level considered skills acquisition in various trades empowering for PWDs especially if this enabled them get into income generation. They perceived development of skills prior to financial support a prerequisite for empowerment. Some DPOs associated empowerment with being educated, self-reliant, economic wellbeing and ability to advocate for their rights. Factors, contributing to empowerment ranged from awareness raising and skills development to rehabilitation and medical care.

At National level DPOs linked empowerment to ability to '*self-advocate*' and '*ability to access their rights as well as to be socially included*' and '*ability to engage authorities, influence policy, build capacity of its membership*'. However some Individual DPOs such as PODCAM felt empowered DPOs were those that achieved financial independence and were free from donor dependency.

The study has revealed that there are different sectors Sue Ryder Foundation, Small Holder Revolving Fund that also provide services to persons with disabilities and that these interventions are not formally linked to the CBR programme. The NAD supported CBR programme was not able to fill gaps covered by these sectors. Implementation of the CBR programme demands the development of partnerships and alliances with other sectors to ensure that PWDs and their family members are able to access the benefits of these sectors.

To support the empowerment of persons with disabilities, the CBR programme has tried to make priorities appropriate to the context instead of strictly following the key elements of empowerment as outlined in the WHO CBR guidelines. The most common measures have been:

- a. Awareness-raising of care givers and teachers as well as contribution to the cost of assistive devices, school fees and accessibility of buildings.
- b. Skills development initiatives, most of which have been demand driven have empowered PWDs to lead decent and independent lives. These have been either in inclusive environments through vocational training centres that have mainstreamed disabilities e.g.

government run Soche technical college, apprenticeship in the community with local artisans and vocational training centres that have targeted PWDs such as those run by MACOHA⁴.

- c. Provision of and referrals for assistive devices, training in ADL and physical rehabilitation (physiotherapy/surgeries) which have impacted positively on the functional independence and self-reliance of many children and adults with disabilities.
- d. The support to formation and training of SHGs and DPOs has helped to raise the voices of PWDs and in the process some people with disabilities have been targeted by service providers.

As a multi-sectoral strategy that addresses broader needs of PWDs, the CBR programme has also developed partnerships and alliances with other sectors and programmes, both mainstream and disability specific, in order to facilitate access to services and benefits which may lead to empowerment. Through involvement of CRWs and CROs as members of the area and district executive committees respectively the needs of PWDs are integrated into various interventions.

Challenges and Recommendations

Even with a number of stakeholders supplementing MACOHA's efforts, the CBR programme has not adequately responded to the empowerment needs of PWDs by gender, age, disability types, and degree of disability and different experiences of marginalization within different cultural and economic backgrounds. The coverage of the CBR programme in the districts studied range from 70% in Balaka to 8% in Mzimba– and the CBR programme is not yet present in all districts. The main challenges are:

a. Coordination and cooperation

Currently there is a piece meal approach to education, skills training, access to micro finance and recruitment and employment of persons with disabilities. Despite efforts by the CBR programme to mobilize the education, skills training and employment sectors, lack of commitment from district and national policy makers has led to disjointed efforts in these areas.

b. Economic empowerment

Without disability specific objectives and disaggregated monitoring indicators in the Malawi Growth and Development Strategy the latter being the overall empowerment/poverty reduction programmes of government, sustainable improvements in the economic empowerment of PWDs will be difficult to achieve.

There is need for CBR to invest more in training in viable vocational skills especially at community level using local artisans and farming experts who can provide formal and informal training to equip more women and men, boys and girls with disabilities with vocational, farming and entrepreneurship skills.

In order to promote access to business credit, there is need for CBR to raise awareness among the managers of government's Malawi Rural Development Fund (MARDEF) and the Youth Development Fund (YEDEF) on inclusive development. CBR should also lobby the two micro finance institutions to ring fence some funds for access by PWDs.

c. Education

⁴ Lilongwe Vocational Training Centre for the disabled, and Kamuzu Vocational Rehabilitation and Training centre

Currently the Ministry of Education has not provided for personnel for inclusive education except at national level. There is therefore need to have designated desk officers to monitor and supervise inclusive education practices at divisional, district as well as zone levels as their absence has led to poor targeting of learners with special needs and oversight of their educational needs. Similarly there is need for the Ministry of Education to set up structures for promoting inclusive education through establishment of designated positions at division, district and zone levels who would ensure compliance to the national inclusive education guidelines.

d. DPOs

Although efforts are being made through CBR to establish single as well cross disability DPO branches country wide, there still remain very few PWDs across DPOs that can effectively advocate and lobby on issues of disability rights and inclusive development, especially at district and community levels. This effort notwithstanding, the study found that self representation though critical, is not a priority amongst PWDs at village community level

Considering that self representation is central to realisation of rights for people with disabilities DPOs especially at national level should seek support for capacity building of training of Trainers who would in turn serve as role models and trainers at district and community levels.

LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
ADC	Area Development Committee
AEC	Area Executive Committee
CBCC	Community Based Child Centre
CBM	Christoffel Blindenmission
CBO	Community Based Organization
CBR	Community Based Rehabilitation
CBRCC	Community Based Rehabilitation Coordination Committee
CDO	Community Development Officer
CPW	Child Protection Worker
CRO	Community Rehabilitation Officer
CRV	Community Rehabilitation Volunteer
CRW	Community Rehabilitation Worker
CWD	Child With Disability
DDC	District Development Committee
CSO	Civil Society Organization
DA	District Assembly
DEC	District Executive Committee
DO	Desk Officer
DPO	Disabled People Organization
ECD	Early Child Development
ECDCC	Early Child Development Community Centre
FEDOMA	Federation of Disability Organizations in Malawi
FGD	Focus Group Discussion
FINCOP	Finance Corporative
GVH	Group Village Headman
IDDC	International Disability and Development Consortium
ILO	International Labour Organizations
IT	Itinerant Teacher
LD	Learning Difficulties
MACOHA	Malawi Council for the Handicapped
MANAD	Malawi National Association of the Deaf
MAP	Malawi Against Physical Disabilities
MARDEF	Malawi Rural Development fund
NAC	National Aids Commission
NACCOD	National Advisory Coordination Committee on Disability
NAD	Norwegian Association of Disabled
NGO	Non-Governmental Organization
NCRT	National (CBR) Resource Team
NCST	National (CBR) Steering Team
PODCAM	Parents of Disabled Children in Malawi
PPA	Priority Policy Area
PSG	Parent Support Group
PTA	Parents Teachers Association
PWD	People with Disabilities
QECH	Queen Elizabeth Central Hospital
RA	Research Assistant
SCG	Savings and Credit Group

SHG	Self Help Group
SSI	Semi Structured Interview
TA	Traditional Authority
TOR	Terms of Reference
UN	United Nations
UNDP	United Nations Development Programme
VDC	Village Development Committee
UNESCO	United Nations Education and Scientific organizations
VH	Village Headman
WHO	World Health Organization
YEDEF	Youth Development Fund

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1. INTRODUCTION AND BACKGROUND

1.1 Prevalence of Disability in Malawi

There is lack of reliable statistics on the nature and prevalence of disability in Malawi although three key studies have been undertaken in this area.

The first initiative to determine the prevalence of disability was undertaken in 1983 through a national disability survey. The survey estimated that 2.9% of Malawi's population (190, 000) comprised PWDs, of the total, 102,000 were men and 88,000 were women. The survey also revealed that 93% of them lived in rural areas with little or no access to rehabilitation services. About 11% of the households had at least one person with a disability; and 4% of the households were headed by PWDs. 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 developmental disabilities and mental health disabilities constituted 8.3% of the PWDs. A follow up disability survey of 1993⁵ showed the same national prevalence of disability.

A follow up study was conducted on *Living Conditions among People with Activity Limitations was conducted in 2003* (Loeb and Eide, 2004). It showed the prevalence of disability to be at 4.18% or 480,000 persons of whom 50.7% were females while 49% were males. The major forms of disabilities were physical (43%), seeing (23%), hearing (15.7%) while 11.5% had developmental disabilities. The study⁶ 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 (Refer to Annex 2 for statistical summary per disability)

In 2008, disability was for the first time integrated in the Malawi Population and Housing Census. The census report revealed that of the 13.1 million persons counted, 498,122 were PWDs (representing 4 % of the total population). Like in previous studies, the census revealed that there were more PWDs in rural areas compared to urban areas⁷ and that the most prevalent disability this time round was visual as opposed to physical impairments⁸ (National Statistical Office, 2010) (Refer to Table 1 for the number of PWDs by type and area of residence).

The 2003 *Living Conditions Survey and the 2008 Population and Housing Census* have helped Malawi to determine the prevalence of disability for purposes of informing policy and programming. Prior to these surveys, Malawi like other countries based their estimates of national population of PWDs on the 10% estimate as used by the World Health Organization (WHO). Considering that disability specific comprehensive baseline surveys have so far not been undertaken to determine the number of PWDs, most stakeholders estimate the population of PWDs in Malawi using the 2003 *Living conditions of people with activity limitation* study.

⁵ In the 2011 Situation Analysis there is mention of national disability survey in 1993 although the researcher was not able to find it

⁶ Referred to in this report as the Sintef Report

⁷ 45,379 PWDs in urban and 452,743 in rural areas

⁸ Previously there were more people with physical than with visual challenges. Could this be resulting from the elimination of polio in Malawi? Need for more research?

Table 1: Distribution of Persons with Disabilities by Type of Disability

Area	Total Persons with Disabilities	Type of Disability				
		Visual Impairment	Hearing Impairment	Deaf	Physical disability	Other
Malawi	498,122	133,273	82,180	30,198	108,870	143,601
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

Based on a thematic report on Disability and the Elderly produced as part of the Population and Housing Census of 2008, the following table reflects the prevalence of disability in the three districts sampled for this study, namely, Machinga, Balaka and Mzimba.

Table 2: Prevalence of Disability in the study districts

District	Total population	Proportion of national popn.	PWDs	Proportion of PWDs	Prevalence rate
Mzimba	718402	5.5	39293	7.9	5.4
Machinga	494835	3.8	16970	3.4	3.4
Balaka	316574	2.4	11395	2.3	3.6

Source: National Statistical Office (2010). Population and Housing Census 2008: Analytical Report: Volume 11 – Disability and the Elderly. Pp 6-7

Based on the prevalence rate, the following table compares number of persons with disabilities in each of the three districts against number of persons registered by the national CBR programme in the districts.

Table 3 Population of PWDs by nature of disability in the three districts

District	Population	PWDs	Registered by CBR	Visual Disability (Registered)	Hearing Impairment (Registered)	Deaf (Registered)	Physical Disability (Registered)	Other (Registered)
Machinga	494835	16970	7,357	455	87	272	1,321	5,222
Balaka	316574	11395	8,016	625	409	638	2,432	3,912
Mzimba	718402	39293	3,120	294	58	85	1,207	1,476
Totals	1,529811	67658	18,495	1,006	922	995	4,960	10,610

Source: National Statistical Office (2010). Population and Housing Census 2008: Analytical Report: Volume 11 – Disability and the Elderly & MACOHA (2012) CBR Statistics

These tables show that coverage of the CBR programme ranges from 70% in Balaka, 43% in Machinga and 8 % in Mzimba. It also shows that persons with physical disabilities are the most served, except in Machinga where “other” is a very large group. The reasons for the discrepancies between the prevalence and CBR support to various disability groups have not been established in this research.

The table also shows that the total population sampled for this study (the three districts) makes up around 13% of the total population of persons with disabilities in Malawi.

1.2 Legislation and Policies

The Malawi Republican Constitution through the Bill of Rights (Chapter IV) provides for non-discrimination on any basis including on the basis of disability. It also provides for the right of PWDs to development and enjoyment of economic, social, cultural and political development. Sections 13 and 30 of the Constitution specifically provide for consideration of the rights of PWDs through: greater access to public places, fair opportunities in employment and the fullest possible participation in all spheres of Malawian society.

Currently, there are two specific piece of disability legislation. The Handicapped Persons Act of 1971 provides for the implementation of rehabilitation programmes and services for the social and economic empowerment of persons with disabilities. It should be noted, however, that the Handicapped Persons Act was adopted at a time when disability was perceived through the medical model. Currently efforts are underway to review the Act so that is in tandem with the current social model/human rights and development orientation of disability

On the other hand, Parliament recently enacted the Malawi Disability Bill (2012) into law. The Malawi Government has domesticated the United Nations Convention on the Rights of Persons with Disabilities through the Disability Act of 2012. The Act is in tandem with current global human right trends in disability. Development of the Bill was necessitated by the need for government to enforce provisions of Malawi's National Policy on Equalisation of Opportunities for Persons with Disabilities of 2006.

The policy adopts a human rights and development perspective and provides strategies for promoting access to services in the priority areas of Disability Prevention, Early Identification and Intervention, Rehabilitation, Accessibility, Transport, Information and Communication, Education and Training, Economic Empowerment, Social Welfare and Social Protection, Self-Representation and Participation, Sports, Recreation and Entertainment, Housing, Research and Appropriate Technology.

The policy development process involved a cross section of stakeholders at community, district, regional and policy levels.

The effectiveness of the Policy in achieving equalization of opportunities for persons with disabilities is central, not only in terms of the economic rights, but also their broader social and political rights, which are closely linked to economic empowerment. There is optimism that there will be meaningful efforts to enforce implementation of the policy now that the Disability Bill has been enacted into law. It needs to be noted, however, that development of a comprehensive policy implementation plan which commenced in 2006 is yet to be finalised. Policy implementation has therefore largely been piecemeal, uncoordinated and has focussed on a few priority policy areas with participation largely of MACOHA, FEDOMA, the Ministries of Education and of Gender, Child and Community Development.

The Policy is now due for review.

1.3 Community Based Rehabilitation Programme (CBR)

Community Based Rehabilitation (CBR) is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. Started as a strategy for delivery of primary rehabilitation services to persons with

disabilities in their communities, CBR focuses on enhancing the quality of life for people with disabilities and their families, ensuring access to basic services, providing guidance and promoting social inclusion and participation.

CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services. It involves capacity building of PWDs and their families in the context of their communities and culture. Initiated in the mid-1980s, CBR has evolved from medical rehabilitation towards a more comprehensive multi-sectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health care, vocational training, income generation programmes and community participation and social inclusion. In a global consultation to review the state of CBR⁹ it was noted that there cannot be one model of CBR for the world since communities differ in socio-economic conditions, terrain, cultures and political systems.

The CBR Components

Following the evolution of CBR into a broader multi-sectoral development strategy, a matrix was launched by WHO and its global partners in 2010 to provide a common framework for CBR programmes¹⁰. The framework has five components (health, education, livelihood, social inclusions and empowerment) and each component has five elements. The first four components of the CBR matrix relate to key development sectors which reflect the multi-sectoral focus of CBR while the final component refers to the empowerment of PWDs, their families and communities.

The empowerment component is fundamental in ensuring access to each development sector and improving the quality of life and enjoyment of human rights for PWDs.¹¹ The design of the matrix is such that it allows programmes to select options which best meet their local needs, priorities and resources and not to necessarily implement every component and element of the matrix. It is a 'pick and mix' series of options, a set of components and elements from which the practitioner can select. Any one programme may choose to address only some of the components and elements. The matrix should not be seen as sequential.

CBR Strategy in Malawi

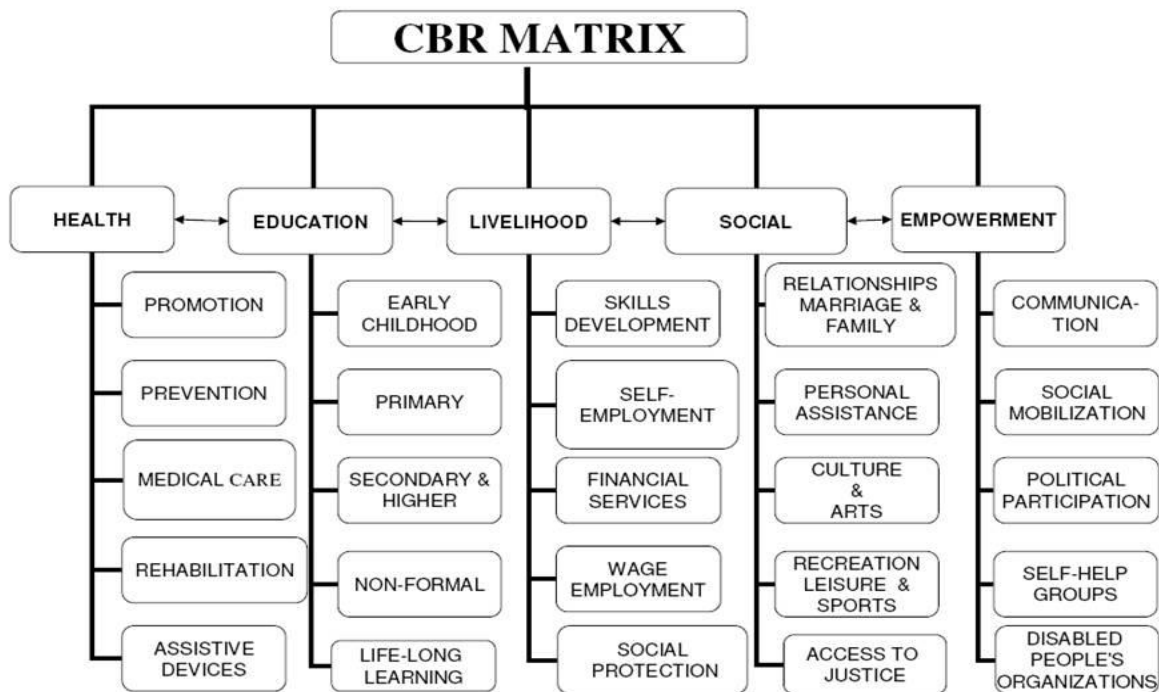
The CBR strategy was launched in Malawi on a pilot basis in 1987 with financial and technical support from the United Nations Development Programme (UNDP) and International Labour Organisation (ILO). Through CBR, considerable effort is being made to promote access to services for PWDs in 12 of the 28 districts countrywide. In four of these district namely Blantyre, Machinga, Balaka and Mzimba, the programme is comprehensive and modelled on the WHO CBR matrix; the programme has more of a medical orientation largely focusing on orthopaedic and visual appointment in six districts where it is supported by CBM namely Lilongwe, Nkhota-kota, Salima, Nkhata Bay, Dowa and parts of Ntchisi. In Karonga and Nsanje, where the emphasis is more on skills development and self employment the CBR programme is largely supported by government.

Fig.1

⁹CBR Global Review 2003

¹⁰See fig. in 1 next page

¹¹WHO, ILO, UNESCO, IDDC: CBR Guidelines: Towards Community Based Inclusive Development :



1.4 Principal Actors in Disability Activities

Several government and non-government organizations are involved in disability issues. The Malawi Council for the Handicapped (MACOHA) established in 1971 is the principal government agency responsible for championing disability mainstreaming across sectors. It carries out this task through direct implementation of rehabilitation activities largely through CBR in partnership with government ministries and agencies, disabled persons organisations, and NGOs.

The Federation of Disability Organizations in Malawi (FEDOMA) is the umbrella membership organization of associations of persons with disabilities which advocates for the rights based approaches to disability and development. Its agenda is to empower persons with disabilities to be actively engaged in decisions that affect their lives. FEDOMA affiliates¹² are involved in advocacy and lobbying activities as well as disability specific interventions in various parts of the country. Other principal actors include CBM International, Malawi Against Physical Disabilities (MAP); Feed the Children Malawi; Sue Ryder Foundation in Malawi; Sightsavers, the Ministry of Health and Population and the Ministry of Education. There are also some Non Governmental Organizations that target vulnerable groups and in the process include persons with disabilities. Among government sectors the Ministries of Social Welfare, Education¹³ and Community

¹²Association of the Physically Disabled in Malawi (APDM), Disabled Widows Orphans Organization in Malawi (DWOOM), Disabled Women in Development (DIWODE), Malawi National Association of the Deaf (MANAD), Malawi Disability Sports Association (MADISA), Parents of Disabled Children Association in Malawi (PODCAM), Malawi Union of the Blind (MUB), The Albino Association of Malawi (TAAM), Visual Hearing Membership Association (VIHEMA)

¹³ More specifically the Special Needs Education (SNE) sector

Development are amongst those that have made deliberate efforts to include persons with disabilities. They also have the formal responsibility to do so.

2. PURPOSE AND OBJECTIVES OF THE STUDY

2.1 Definition of the concept Empowerment

The definition of the term empowerment reflects both diversity and commonality with most definition focusing on issues of gaining power and control over decisions and resources that determine the quality of one's life. According to Bookman and Morgen (1984) empowerment is relevant at individual and collective level and can be economic, social, or political. The term can be used to characterize relations within households or between poor people and other actors at the global level. The United Nations Development Programme's Gender Empowerment Measure focuses on inequalities in economic and political participation and decision-making power and power over economic resources (UNDP 1995). Other writers such as Rowlands (1997) explore empowerment at different levels: personal, involving a sense of self confidence and capacity; relational, implying ability to negotiate and influence relationship and decisions; and collective. On the other hand the definition used by International Fund for Agricultural Development includes both access to productive resources and the capacity to participate in the decisions that affect the least privileged.

According to WHO CBR Guidelines (2010) empowerment, from the perspective of persons with disabilities, could be defined at two levels, namely, at individual and group level. At the individual level, empowerment is evident in increased level of independence/self-reliance, participation, and improved livelihoods. Empowered individuals increasingly participate in decisions that affect their day to day lives. They are able to access services and facilities and to utilize opportunities leading to improvements in their social and economic independence and self-reliance. At group level, on the other hand, empowerment refers to the ability of persons with disabilities to mobilize and organize themselves to demand a life of dignity in an inclusive environment. At both levels, empowered persons with disabilities, as individuals and collectively in disabled persons' organizations (DPOs) and self-help groups, are aware of their rights, recognize their unfavourable situation and take steps to change their status quo. The ultimate outcome is greater participation and ability to play a role in decision making, to harness more power and control that leads to positive action.

At intervention level, empowerment focuses on strategies to ensure that people with disabilities, their family members and communities have a say, are listened to, have capacity to make their own decisions, are able to gain further control, have independence, are capable of fighting for their rights (individually and collectively), are recognized and respected as equal citizens and human beings with a contribution to make. Empowerment as a process therefore aims at facilitating the inclusion of disability across sectors to ensure access to rights and entitlements by all. (WHO, UNESCO, ILO, IDDC CBR Guidelines: Empowerment Component).

Key elements of the CBR empowerment component include advocacy and communication, community mobilization, political participation, Self-Help Groups and DPOs¹⁴

¹⁴Refer to WHO/UNESCO/ILO/IDDC. (2010). CBR Guidelines: Empowerment component (pp: 5-7)

2.2 Initiatives to Promote Empowerment of PWDs

2.2.1 CBR pre 2002

In line with ILO's mandate, the CBR as launched in 1987 leaned more towards promoting access to vocational skills training and employment (largely self-employment). In the absence of an enabling policy framework to facilitate mainstreaming across sectors as well as absence of a viable DPO movement¹⁵, there was very little focus on building capacity of people with disabilities for self-representation and active participation.

Following the outcome of the evaluation of the pilot programme in 1992, the CBR programme was extended to five more districts, namely, Machinga in the southern region, Mzimba and Karonga in the northern region and Salima and Lilongwe in the central region¹⁶. Support from UNDP/ILO phased out, in 1992. From the mid-1990s to 2002, the programme, largely with financial support from Christoffel Blindenmission (now CBM), Action Aid International and Sightsavers, the programme further extended to Nsanje in the southern region, Nkhota-kota, Dowa and parts of Ntchisi in the central region and Nkhata-Bay in the northern region. During the cited extensions, emphasis continued to be on service delivery as opposed to enhancing mainstreaming of persons with disabilities in general development programmes across sectors.

2.2.2 CBR post 2002

In 2002, the Norwegian Association of Disabled (NAD) signed an agreement of cooperation with the Government of Malawi (the agreement has been renewed/extended several times with current extension to cover the period 2010 – 2014). The initial and subsequent agreements have laid down clear strategies on how the two partners could work together to promote inclusive development through CBR. Since the signing of the initial agreement, there has been increased focus by the CBR programme to implement interventions aimed at promoting empowerment of persons with disabilities. This has been done through support to awareness raising on disability rights, establishment and capacity building of self-help groups and DPOs, especially capacity building for effective advocacy.

The current Malawi CBR arrangement conforms to guidelines set by WHO, United Nations Education Scientific and Cultural organization (UNESCO), ILO and the International Disability and Development Consortium (IDDC). It is guided by five strategic objectives which focus on promoting equitable access by male and female persons with disabilities to; 1) health care and prevention, 2) education, 3) means of livelihood, 4) social inclusion (including persons with disabilities into the mainstream of family and community life and development programmes) and finally 5) empowerment (ensuring PWDs and family members confidently challenge negative attitudes and claim their right to equity, justice and inclusion).¹⁷.

FEDOMA receives financial support from NAD through MACOHA, for implementation of activities under the empowerment component of the CBR matrix. In 2011 FEDOMA was able to undertake the following activities.

¹⁵ The DPO movement emerged from the early 1990s.

¹⁶ Planning for extension of the CBR program between 1988 and 1992 benefitted greatly from the outcome of a baseline study which mapped existing services and facilities for implementation of the program (University of Malawi, Department of Demography: 1990)

¹⁷MACOHA. (2010). Five year CBR strategic plan for the NAD supported program, 2010-2014

2.2.3 Combined efforts – by DPOs and/through CBR

Since the mid-2000s, the Malawi CBR programme has incorporated a number of strategies to promote the active voice and participation of persons with disabilities. These include establishment of a national CBR resource team (NCRT) and the national CBR steering committee (NCST). FEDOMA is a member of both committees. The overall mandate of the NCRT is to champion disability rights and mainstreaming across the health, education, livelihoods, social and empowerment components by ensuring implementation of inclusive policies including allocation and utilization of requisite funds. FEDOMA champions the empowerment component on the NCRT.

On the other hand, the mandate of the NCST includes facilitating discussion towards harmonization of the Malawi CBR, mobilizing resources for CBR, CBR planning and implementation oversight and lobbying for visibility of disability including framework of the Malawi Growth and Development strategy at national level as well as at local government and community levels.

Persons with disabilities also comprise membership of District CBR Committees (DCC) at local assembly level¹⁸. The role of DCC is to ensure inclusion of disability in sectoral plans, and to develop and monitor implementation of CBR plans. At national level, involvement of persons with disabilities through the NCRT has served not only to build awareness on both felt and actual needs of persons with disabilities in CBR. It has also been instrumental in advocacy for DPO efforts to lobby for inclusive practices on the national development agenda. Similarly, participation of DPO in the NCSC has assisted stakeholders to focus more on outcomes as opposed to outputs and processes. At DCC level, the involvement of persons with disabilities has contributed to raising awareness among local assemblies not only to be inclusive in their development efforts but to implement provision of the Local Government Act, via self-representation by persons with disabilities.

2.3 Purpose and objectives of the study

The purpose of this study was to explore, from the perspective of persons with disabilities, the extent to which persons with disabilities feel that they are empowered and to identify CBR strategies and interventions to further promote their empowerment.

The following objectives guided the assessment. To:

- (a) Document from the perspective of persons with disabilities and or DPOs what constitutes empowerment as well as factors that have contributed to empowerment at individual as well as group level.
- (b) Document strategies and interventions /activities implemented through the CBR empowerment component. Based on the study's findings, comment on the effectiveness of the documented strategies and interventions. This will be accomplished through a desk study
- (c) Draw linkages between positive empowerment outcomes and interventions/empowerment activities including from CBR funded activities and collaboration with CBR

¹⁸Other members of DCC include heads of government departments and NGOs. MACOHA CBR Managers at district level serve as secretariat to the Committee.

- (d) From the perspective of persons with disabilities and their DPOs, identify key challenges to their empowerment
- (e) Provide key recommendations on how DPOs, government ministries, departments and agencies and other key stakeholders can work together to promote a rights based approach to development.

2.4 Key Research Questions

The study was guided by the following seven (7) research questions

- (a) What constitutes empowerment
- (b) Identify factors that have contributed to empowerment of persons with disabilities at individual as well as group level.
- (c) Identify strategies and interventions/activities that have been implemented through the CBR empowerment component.
- (d) Assess the effectiveness of strategies and interventions that have been implemented through the CBR empowerment component.
- (e) Demonstrate linkages between positive empowerment outcomes and interventions/empowerment activities including from CBR funded activities and collaboration with CBR.
- (f) What are the key challenges to empowerment of persons with disabilities at individual and group level?
- (g) What key recommendations would help DPOs, government ministries, departments and agencies and other key stakeholders to promote rights based approach to development.

3. RESEARCH METHODOLOGY

The consultants used mainly a qualitative approach both for data collection and analysis. The analysis used qualitative data gathered through interviews, focus group discussions and observation conducted from six villages in three districts. The study involved a number of steps and methodologies as described below. These included literature review, sampling of the three districts and villages within each for data collection and respondents, design and testing of interview guides for various groups of respondents, training of research assistants, data collection through interviews, focussed group discussions and observations and finally analysing the data.

3.1 Literature Review

According to Yin (1984) information gathered from documentation, helps to corroborate and augment evidence from other sources. Literature review involved a detailed desk study of key literature including research and evaluation studies as well as other background material on the subject. Current literature on community-based rehabilitation as well as internal documents of MACOHA and her partners were reviewed. These included previous evaluations on CBR programmes. Literature review was done to find an effective way of understanding PWDs' perceptions of empowerment and assessing the relevance of various CBR and non CBR empowerment initiatives.

Other documents reviewed included proposal documents, annual and monitoring reports, the latter were reviewed in order to assess, among other things, project design features, progress towards achieving set objectives and implementation challenges. Policy documents were reviewed in order to understand progress on government's initiatives regarding

disability issues. Various WHO/UNESCO/ILO/IDDC CBR Guidelines Documents including country reports on perceptions of PWDs were reviewed not only to increase breadth of knowledge of the subject area but also to put the current study into perspective and identify relevant information and ideas including methods. The list of documents reviewed form part of the references section of this report.

3.2 Data collection

Data was collected from respondents at village/community, district and national levels. Respondents at national level were DPOs and other stakeholders involved in disability related programmes. Respondents at district and village level were selected to be representative of the experiences of various regions of Malawi, various disability groups, ages and gender. The selection was done as follows:

3.2.1 Selection of districts, Traditional Authorities and Villages

Data was collected from three districts of Machinga and Balaka in the Southern region and Mzimba in the Northern region of the country. The research areas were selected to represent districts where NAD supports CBR as well as a non CBR area.

In Balaka and Machinga the CBR project was implemented in all the ten Traditional Authorities (TAs) of the districts while in Mzimba it was implemented only in three out of ten TAs. Two TAs were purposefully selected in each district and in each TA one village was identified. In Mzimba the pattern of selection was the same except that the study selected one non-CBR Traditional Authority for comparison purposes. The criteria for choice for the choice of study areas required that the setting should be rural, and the area accessibility considering that the research was being done during the rainy season when most roads are impassable.

Depending on the size of villages and the number of persons with disabilities identified in each, there was variation in terms of the number of villages that were covered by the CBR in a TA. There was no village specific data on population. However the CBR programme was introduced to the four districts of Mzimba and Machinga, Blantyre and Balaka between 1988 and 1992, with Balaka coming in closer to 1992 than earlier.

3.2.2 Selection of Individual Respondents with Disabilities

CBR supervisors and CBR volunteers identified PWDs to be interviewed from their registers. Identification of PWDs was based on fulfilment of the following criteria:

A total of ten (10) individuals to be selected for interviews from each of the two villages per district as follows: at least one person from each of the following disabilities: physical, blind/low vision, deaf/hard of hearing, epilepsy, Deaf-Blind, albinism and with a developmental disability Five of them (half) to be male and the other five female and four of the ten to be children between the ages of five and fourteen. In total it was expected that sixty (60) respondents would be interviewed country wide. These would comprise six (6) respondents per disability, thirty (30) of would be males and thirty (30) females. A total of twenty four (24) would be children between the ages of 5 - 14

From the analysis of the respondents interviewed¹⁹ a total of one hundred (100) respondents were interviewed of whom twenty two (22).were adult males and thirty one (31) adult females and forty seven (47) were children. Distribution per disability for both adults and children was as follows: Respondents with physical disabilities constituted the highest number (30%) more than

¹⁹Full table in the appendix

half of whom sixteen (16).were women (53%) and eleven (36%) were children of whom four (13%) were girls. The least number were Deaf-Blind, albinism and epilepsy due to the low prevalence rate of these disabilities Refer to Tables 4-5 below on respondents per disability sex and age.

Table 4: Summary of PWDs Interviewed per disability

SUMMARY	PWDs	Physical	Visual	Deaf	Epilepsy	Albinism	Deaf/blind	Developmental	Multiple	Totals
	Male	3	8	5	1			3	2	22
	Female	16	2	2	3	1	1	4	2	31
Totals for PWDs		19	10	7	4	1	1	7	4	53
	CWDs									
	Male	7	5	3		1		2	4	22
	Female	4	2	4	3	4		7	1	25
Totals for CWDs		11	7	7	3	5		9	5	47
Total Respondents		30	17	14	7	6	1	16	9	100

Table 5: Respondents with disabilities proportionate to population of PWDs and number of PWDs registered per district

District	No of PWDs	Registered by CBR	%	Respondents
Machinga	16970	7,357	43%	18
Balaka	11395	8,016	70%	37
Mzimba	39293	3,120	8%	45
Totals	67658	18,493	27%	100

3.2.3 Selection of DPO respondents and other Stakeholders

In addition to reaching individuals with disabilities, data was also collected from key DPOs at national and district levels. Both individual interviews and focus group discussions were held with DPOs. For example at National level the researchers conducted one focus group discussions with FEDOMA and other DPO representatives and two individual interviews with DPOs. At district level both focus group interviews as well as individual interviews were held with DPOs.

Other stakeholders such as relevant sectoral government departments were interviewed especially at district and community level because they are instrumental in addressing disability issues even where NAD is not implementing the CBR programme such as in part of Mzimba.

Stakeholders such as NGOs especially those working in the CBR project areas were interviewed since they also interact with PWDs and CWDs in their work. Mostly NGOs were interviewed individually at the district level. All PWDs and CWDs, except leadership of DPOs at district and national levels, were interviewed at community level.

3.3 Preparing research assistants

To manage the actual collection of data the researchers recruited research assistants (RAs). These were selected on the basis of previous research experience and knowledge of disability issues. A total of ten RAs were engaged. Two of them had physical disability, three had low vision and one had epilepsy. Three were persons with albinism and three had no disability. Four of the RAs were female while six were male. Two of the assistants with albinism had low vision.

The RAs were trained for two days. The training included topics in understanding CBR and empowerment and how to conduct interviews with PWDs. It also involved an appreciation and understanding of the questions in vernacular. There were practical sessions on data collection using a designed research tool through role plays. A practical field application was done in Blantyre in villages where CBR is being implemented. This also served as a piloting exercise. Discussions were held in plenary with the RAs after the pilot testing the tool and consequently the tool was adjusted accordingly before being taken to the field.

Data from individual PWDs and CWDs was collected by RAs while the researchers collected data from groups, organisations and institutions. Data collection tools are appended at the end of this report.

3.4 Development of Data Collection Tools

Multiple data collection methods were used as one way of gathering different views from different respondents regarding the interventions. Ample attention was paid to issues of validity and reliability in the choice of methodologies for data collection (Bowling 1997). Tools were developed for each targeted category of the sample.²⁰ The tools were piloted and adjusted before field work. It was important to be systematic in order to eliminate bias and to ensure that particular groups or individuals were not overlooked on account of their being less vocal or less visible.

A data collection guide was developed, discussing and adopted. A final checklist was developed by the consultants and was discussed thoroughly during training for research assistants. The following tools were identified and used for data collection:

3.4.1 Use of checklists/interview guides

The use of checklists for gathering information based on the research questions in the ToRs was meant to facilitate information gathering prior to meetings/discussions with stakeholders that were visited. The idea was to maintain consistency in information generation. Tools were developed for each targeted category of the sample.²¹ The tool for individuals with disabilities could be responded to by a close caretaker in case the PWDs had severe communication difficulties.

Children aged 5-14 years had a separate tool from adults. The children's tool included a section for parents or close caretakers. Caretakers interpreted for children with severe communication disabilities. Adults with developmental disabilities were administered the children's tool. The tools were adjusted before data collection in the field.

3.4.2 Semi structured interviews and focused group discussions

²⁰ Research Tools are put in the appendix

²¹ Research Tools are put in the appendix

Data collection was mainly done by semi-structured, individual interviews, based on the checklist. A total of 100 persons with disabilities or their guardians/careers were interviewed across disability groups of different age groups and gender lines. Most of the interviews of PWDs and CWDs were done at community level.

Apart from the sampled individuals with disabilities in villages, semi-structured interviews were also held with stakeholders who have particular interest, experience and knowledge in the project and are in some way directly or indirectly affected by it such as DPO representatives, government institutions and other NGOs. In total 43 persons in this group were interviewed.

The advantage of semi-structured interviews was that the method allowed points to be raised and followed up in detail during interviews (Robson, 1993). This was also a means of triangulating information provided through other tools.

In addition to interviews, focussed group discussions were held with Self-Help Groups and school children with disabilities at community level, representatives of DPOs at district level and DPOs at National level (see table 6 above).

3.4.3 Observations

Observation, according to Flick (1998) allows the integration of, not only visual perceptions, but also those based on hearing, feeling and smelling. In a study that aims at capturing respondents' perceptions and views, some of whom may have communication challenges, observation turned out to be an effective tool. In a number of cases, for example, research assistants reported observing inaccessible structures and amenities within the immediate environment of persons with physical disabilities.

In another environment the research assistant observed the number of people who came to entrust a PWD with their money for safe keeping – a clear sign of how much trust they had in him.²² Indeed observation is recommended for its directness since you do not need to ask about respondents' views, feelings and attitudes. Through observation the team also reported on issues pertaining to behaviour and relationships that would not be captured by interviews.

3.5 Data Management and Analysis

Quality of data collection was assured through daily evening meetings between the researchers and RAs. Forms were assessed for completeness, challenges discussed and solutions jointly sought.

Data analysis was carried out at two levels. The first was with RAs and the second level was by the researchers when scripts were coded and sorted into themes. Significant statements were extracted and these were summarized into findings. Data was analysed under themes based on the study objectives. Within each theme emerging sub-themes were identified and these formed the sub-section titles of the findings sections of the report.

As important information was being extracted it became clear that within each theme the source of information should be noted, as this would give meaning to the kind of responses that came out. Comparison by disability, sex, age and levels (community, district or national) was done. Collation and linkages between the themes was also done. The recommendations from the field discussions were used as raw data and analysed along with the rest of the data.

²²A PWD with physical challenge running a telephone bureau in Machinga

All statements made by individuals and groups were transcribed and organized into categories according to

- PWDs' definition of and factors leading to empowerment of disability groups
- Extent to which CBR strategies respond to empowerment factors
- Other factors/interventions that contribute to empowerment
- Impact of interventions on PWDs
- Extent of Cooperation with other Stakeholders

Statements from various disability groups and relevant stakeholders have been used as evidence in this study and form the basis for the conclusions drawn from the study. Conclusions have been made only when statements from communities in the three districts are the same regarding the definition and factors of empowerment.

3.6 Study limitations

These included the following:

- Being a qualitative research study the objective was to obtain respondents' views, ideas, opinions, perceptions and interpretations regarding the CBR empowerment component. These are subjective as they depend on individuals' experience and perceptions on the issues raised in the research questions. Through observations, the consistency of responses from different persons and other methods for triangulation, the team was able to confirm some of the phenomena or perceptions.
 - The difficulty of interviewing some disability types, especially those with communication difficulties and the deaf who depended on family gestures. These gestures were not developed enough to respond to the questionnaire. Caretakers or other family members were interviewed on their behalf.
 - The absence of population data at village level made it difficult for researchers to make meaningful comparison with set sample targets
 - Some disabilities such as albinism and Deaf-Blindness were of low prevalence and getting the required numbers was difficult. These were scattered and most of the field time was spent travelling to locate them. In one case telephone contact of the potential respondent (with albinism) was obtained and discussions were done through the phone.
 - The study took place when most communities were busy with work in the fields. In some cases the study team spent time waiting for respondents to come from the gardens. After first visits the researchers made arrangements for afternoon appointments.
- Developing methods to communicate directly with intellectually disabled persons and children was a challenge. Consequently in such cases the team had to deal with parents, guardians or care providers. Since we were dealing with an individual's perception about his or her own understanding of what constituted empowerment responses could not be deemed to be correct or incorrect. This means that we took into account the perceptions of respondents on behalf of PWDs themselves. It was therefore possible that their perceptions might have differed appreciably from the perceptions of the individual PWD. Again here observation as a tool facilitated the need to confirm whose perceptions were being considered.

4. STUDY FINDINGS

4.1 Overview of CBR Empowerment Component Programme

4.1.1 Introduction and Background

A study conducted in 2003 by MACOHA²³ and funded by NAD revealed the existence of significant constraints towards the mobilization of available resources for the empowerment and social economic integration of persons with disabilities. Specifically these included: poor coordination among service providers, inadequate human capacity, inadequate financial resources, and low levels of disability awareness at community and institutional levels and lack of basic equipment, materials and infrastructure.

The initial CBR proposal developed in 2003 marked the beginning of the NAD/MACOHA community rehabilitation programme whose purpose was to provide improved, equitable and comprehensive rehabilitation services for persons with disabilities. Project documents indicate that PWDs from different disability groups from the four districts were fully involved in the process of coming up with issues to be addressed in the current five year (2010-2014) phase. Since then MACOHA has been developing Strategic Plans²⁴ regularly based on the initial proposal²⁵. MACOHA coordinates implementation of the health, education, and livelihood components of the CBR matrix, while working with FEDOMA and other nongovernmental organizations, government ministries and disabled people's organizations to implement the social and empowerment components of the matrix.

4.2 Design of FEDOMA/DPOs CBR Empowerment Component

The CBR empowerment component is currently being championed by Federation of Disability Organizations in Malawi through a memorandum of understanding reached in 2007 between NAD, MACOHA and FEDOMA where NAD provides funding to the CBR programme through MACOHA. MACOHA's main role in this component has been in community mobilization and in some elements of awareness-raising. Annual work plans are developed jointly by MACOHA and FEDOMA.

According to FEDOMA/DPOs the CBR empowerment component aims at:

"Promoting the inclusion and participation of persons with disabilities in socio-political processes and leadership at national and local levels."

Objectives of the empowerment component include the following:

- Developing an integrated strategy for public awareness campaigns
- Raising awareness on the abilities, potential, aspirations and needs of persons with disabilities
- Ensuring adequate capacity among DPOs and other stakeholders

To achieve these objectives the project document lists three main focus areas:

- Training in human rights.
- Confidence building meetings
- Formation and strengthening of DPOs

In the 2003 proposal MACOHA mentions the absence of coordinated and sustained awareness-raising efforts as having contributed to the failure in changing both institutionalized and community negative attitudes towards the empowerment of persons with disabilities. The

²³ NAD (2003). Baseline study for the establishment of CBR in Malawi

²⁴ There have been two strategic plans developed since: 2007 and 2009. The last one covers the period 2009-2014

²⁵ The project initially run from 2003 to 2006 and was extended for a further three years from 2007 to 2009. It has been extended to 2014. A five year strategic plan is in place and this plan is derived from the strategic plan.

document also mentions low capacity of DPOs to launch effective advocacy and public awareness campaigns as having also contributed to this situation. The above focus areas are therefore a strategy to address these shortfalls.

CBR Empowerment Activities and Perceived Achievements

According to project reports the programme has been conducting *Training of Trainers* workshops in human rights involving male and female PWDs. Other activities are *confidence building meetings* with PWDs and *awareness meetings* with chiefs and civic leaders on the need to include PWDs in both political as well as community leadership processes. Awareness meetings with development organizations have centered on the need to mainstream disability issues in development programmes including poverty reduction strategy initiatives. Awareness-raising campaigns through the media and formation of DPOs and Self-Help Groups are some of the activities mentioned in the reports.

Achievements include numbers of PWDs trained as trainers through ToT and PWDs reached with human rights messages. Other achievements include the ability by PWDs to demand their rights and to stand up and speak for themselves and for others. Further successes mentioned are the inclusion/election of PWDs into various community structures such as the Village Development Committee (VDC) and Area Development Committees (ADC). In the 2010 annual report examples are given of Mzimba where 10 PWDs were elected into VDCs and ADCs of whom 2 were women and Machinga where 12 PWDs were elected into community structures 3 of whom were women. About 22 PWDs were reported to have managed to access bank loans as a result of being able to access information from development organizations.

Reports of achievements resulting from the formation and strengthening of DPOs and Self-Help Groups include; reduced discrimination of PWDs because of mainstreaming of disabilities in development programmes and improved quality of life for PWDs and their participation in community and family activities and decision making. Some PWDs are reported to have accessed bank loans.

4.3 Analysis of Empowerment Initiatives

Reports from literature review and from discussions with respondents illustrate some positive effects of the CBR programme while at the same time bringing forward concerns about whether these interventions are enough to meet perceived empowerment needs of PWDs.

4.3.1 Awareness-Raising

When asked to say whether they were treated better now than before the CBR programme 22 (65%) out of 34 respondents said they were treated better. Out of these 10 could not give examples to substantiate their responses however those who said were treated well were found to be economically independent: 5 were doing farming, 3 owned livestock while 6 were in trading. Two respondents said they felt they were treated better because they owned houses with iron sheets. Out of 13 respondents (38%) who said they were not treated well 4 had visual impairment (2 male 2 female), 4 had physical impairment (2 male and 2 female) 2 females were epileptic while another 2 females had multiple disabilities.

Awareness-raising has been perceived as an important and successful part of the empowerment component that has impacted on the quality of life of PWDs as it has contributed in eliminating stigma, increased people's knowledge of different disabilities and created an inclusive social environment. Other indicators of positive results mentioned have been an increasing number in the enrolment and retention of children with disability in schools and the provision of accessible structures within school environments.

4.3.2 Self Reliance

When asked to say whether they were better off now than before the CBR programme 28 respondents (72%) said they were. Out of these 13 respondents (33%) mentioned economic independence, 5 said they were better off now because their health had improved. Only 1 felt better off because she was not discriminated against. There were 11 respondents who indicated that they were not better off. Out of these 8 (72%) were female and from these 4 were with physical disabilities 4 (2 male and 2 female) were respondents with visual impairment and only 1 male had hearing impairment.

Confidence building meetings with PWDs have exposed some of the discriminatory practices that are still rampant in the country's service delivery systems, increased self-esteem and made PWDs visible. PWDs have been elected in various positions in the community and they have also shown that they (PWDs) can contribute to family life and in the community, irrespective of the type of disability. Resulting from confidence building more women with disabilities have gained confidence to lead major committees and local organizations in their communities.

4.3.3 Leadership

Respondents were asked whether they held any positions in the community. Out of 16 PWDs who said yes 12 said they were elected to their positions, 1 said he inherited while another one said the position was imposed on him. Of those who held positions in the community 8 (50%) were women all with physical disabilities, 3 were men with visual impairment. When those who did not have any positions were asked to give reasons 7 said they felt it was because of their disability while 1 said because he was not educated.

When PWDs were asked what the CBR programme should do to improve their lives 12 respondents (9 female and 9 respondents with physical disabilities) asked for financial assistance in terms of business loans, 5 respondents demanded skills training in various areas including farming, 4 (2 HI, 2 Multiple) prioritised communication skills and 3 demanded more awareness-raising.

4.3.4 Perceived Gaps

PWDs have demonstrated that at community level economic factors are the most prominent so that self-reliance and empowerment are linked to programmes that raise individual or family income more especially skills training and loan schemes. According to the PWDs income generation is the most appreciated CBR programme initiative by them.

This study has shown that the interventions as designed by FEDOMA/DPOs in the empowerment component are not enough to meet most of the perceived empowerment needs of PWDs. People with disabilities need a range of skills and knowledge to enable them to participate and contribute meaningfully to their families and communities. Gaining skills and knowledge can lead to increased confidence and self-esteem, which is an important part of the empowerment process. For example persons with hearing impairment prioritised communication skills in the above analysis since they depend on a sign language environment in order to be able to enjoy social inclusion. Sign language however is seldom accommodated in CBR projects. It is obvious therefore that CBR programmes need to be combined with other efforts and measures in society, integrated into mainstream community development programmes in order to bring about lasting and comprehensive improvements.

4.4 Perceptions on Empowerment by PWDs

4.4.1 Adults with Disabilities at Village/Community Level

When asked to define empowerment persons with disabilities both men and women generally associated it with independence especially economic independence. Of the 31 women 74% said that it also implied independence from male dependency. Both men and women were in agreement that ability to fend for oneself and the family is paramount in demonstrating that someone is empowered. These respondents considered an empowered individual one who is able to provide for the basic necessities of life, especially food and shelter for themselves and their families. A total of 14 women (46%) also extended the definition to the wellbeing of their families. If their children went to school, fed and slept well, that was part of being empowered.

Out of 38 adult respondents, (21 women and 17 men) who gave responses to this question, 26 adult respondents (68.4%) comprising 16 women and 10 men ((76.2% of female respondents and 58.8% of male respondents) defined empowerment in terms of being financially independent. They associated empowerment with provision of support to run a business or an income generation activity or any activity that brings financial benefits.

According to these respondents multiple and interlinked factors contributed to empowerment. Economic factors featured prominently in their explanation. They mentioned programmes that raised individual or family income as contributing to their empowerment. The most frequently mentioned programmes included those that enabled them to gain access to loans. Some respondents mentioned programmes by MACOHA that linked them to microfinance institutions. Others, for example in Machinga, mentioned the Rural Savings and Loan project being piloted by FEDOMA

Other than access to microfinance, PWDs generally appreciated access to skills training that preceded access to loans as empowering. Some of them revealed during discussions that they had come to this conclusion by observing the performance of some of the PWDs who had undergone such training and comparing them with those who had not. Out of 6 PWDs who said they valued training before business activity 4 were female. Of the 6, 3 had physical disabilities while 2 had visual impairment and one had multiple disabilities. Discussions with the PWDs demonstrated that economic intervention programmes bring in some positive aspects towards empowering PWDs.

When PWDs were asked to mention fellow PWDs they admire most and their reasons for doing so the following were the answers.

4.4.2 Children with Disabilities and their Guardians

Empowerment was very difficult to define and explore among children with disabilities, who included children with learning difficulties and persons with severe disabilities. *Happiness*, a proxy for empowerment, was used to explore the meaning of empowerment in this group. Out of 27 children who answered the question 19 (70.4%) reported that they were happy when *playing with other children or doing sporting activities*. Of these (19), 2 girls and 3 boys had physical disabilities, 3 boys and 1 girl had multiple disabilities while 2 boys and a girl had visual impairments. The remaining respondents were composed of children with epilepsy, cerebral palsy and learning difficulties.

In the same interview 38% of the parents of children with disabilities mentioned *entry into special needs schools* as a factor that can contribute towards empowerment of their children. This was a view expressed by 15 of the 18 (83.33%) respondents with 11 (61%) comprised of parents of children with physical impairment: This number was made up of an equal number of boys and girls.

The following are some of the answers parents of children with multiple disabilities gave when responding to the question: *"How best can your child be helped to be empowered?"*

Parents of children with disabilities also defined an empowered child as one who is independent in daily living activities and could communicate his/her needs. They further added that the roles of parent support groups were important for this to happen.

PWDs interviewed noted that education is an important right for children with disabilities. They however pointed out that the current school environment is not enabling because of lack of physical accessibility and teachers' lack of skills to manage children with disabilities. They further indicated that children with disabilities who complete primary education have no opportunities to go for secondary schools because of lack of fees since parents usually give priority to non-disabled children.

4.4.3 Self-Help Groups at Village/Community Level

At community level focus group discussions were held with two (2) self-help groups in Mzimba where one group was from the CBR area and another in a non CBR area, one (1) group was interviewed in Machinga. One of the groups in Mzimba comprised of PWDs and family members and had both male and female members while the other group comprised mothers of children with disabilities. The group in Machinga comprised parents and guardians.

In Mzimba the group that was composed of PWDs and family members acknowledged that the formation of these groups was empowering in itself, adding that there was strength in numbers since they were able to encourage each other to undertake tasks that could not be tackled individually. At community level groups also felt they were strong if they did not have quarrels and were generating money.

With this in mind, it was not surprising that the main purpose of groups at community level was to make money either through joint business ventures or through cyclic savings and credits schemes. One group defined an empowered self-help group as one which was able to access services for its targeted groups. They explained that this encompassed access to social

services and income generating opportunities. The following statements were in response to the question

'How do you define a strong Self-Help Group?'

The groups in which PWDs and parents of CWDs are involved are engaged in varied activities. The groups work as security for each other and secure loans in cash and kind. It was learnt that most of the PWDs who had prospered had started in a group. The groups that have more women than men were said to be more stable and successful than those with a stronger presence of men.

This finding supports the earlier view as expressed by adults with disabilities at village/ community level who perceived financial stability as an indicator of empowerment. This may need to be understood within the context that, financially stable households are better placed to provide for the basic needs of children and adults with disabilities, as well as to actively participate in rehabilitation programmes, e.g. Programmes that impart skills on basic physiotherapy, income generating activities etc.

The most successful groups that the team met were the groups that had both PWDs and parents of CWDs. Some parents revealed to the study that through these groups they had learnt how to take better care of and provide rehabilitation to their CWDs. The parents in these groups especially adults with disabilities also said they had become change agents²⁶ and sought out other parents who were ignorant of the potentials of CWDs.

Again factors leading to empowerment, according to the SHG members interviewed, were linked to programmes that raised individual or family income especially those that enabled them to access loans or linked them to microfinance institutions. Skills training of groups before disbursement of start-up capital as well as awareness-raising trainings that helped an inclusive social environment were also deemed empowering.

On the other hand raising voices for services or learning about the disability seemed secondary and in some instances considered a waste of time. In Balaka, one of the explanations given by Tigwirizane Disability Club for dropping out of members was the absence of financial benefits. When MACOHA mobilized the group, members thought they would be given grants and loans but instead they were taught about the 'independence' of disabled people and how parents could look after their disabled children. This was not well received.

4.4.4 DPOs at District Level

Amongst the DPOs at district level, and this was especially the case in Mzimba, skills training in various trades contributes to empowerment of PWDs especially training that has culminated in income generation. They perceived development of skills prior to financial support a prerequisite

²⁶ These had become inspiring role models

for empowerment adding that PWDs who are provided with working capital in the form of material and equipment after skills training are better prepared for business.

The chairman for the blind in Balaka decried the lenders who did not train blind people and said this was responsible for the increased default rate on loan repayment. In Mzimba the DPO representative for FEDOMA bemoaned institutions that trained community groups in particular skills but did not provide starting capital thereafter.

DPOs at this level also defined empowerment from a wider perspective ranging from self-reliance and economic wellbeing to ability to advocate. Terms such as “*economic independence, able to confidently express their needs, to talk on behalf of self and other PWDs, meet his own needs, articulate issues, provide for family, does not depend on others to get information*” defined empowerment. The following examples attest to this:

Factors contributing to empowerment were also varied as they ranged from awareness raising from perspective of DPOs at National level, skills development from the perspective of DPOs at District level to rehabilitation and medical care from the perspective of DPOs at Community level.

The chairperson of the blind in Balaka felt education was an empowering factor for both children and adults adding that adults with disabilities who had received education were more empowered than those with none. He added that low education level of PWDs in general affected the process of empowering. The following is what he said:

4.4.5 Leadership of DPOs at National Level

At National level researchers held both focus groups discussions as well as individual interviews with DPO leaders. From statements provided at focus group discussions the definition of empowerment was not strongly linked to economic wellbeing but to ability to ‘*self-advocate*’ and ‘*ability to access their rights as well as to be socially included, ability to engage authorities, influence policy, build capacity of its membership.*’

The source of empowerment at national level was the same like that mentioned at districts level for DPOs i.e. capacity building through skills training. Education, especially access to basic education and development of literacy skills were also considered empowering.

However, when some national DPOs were interviewed individually the study noted some deviation. Individually some felt empowered DPOs were those that achieved financial independence and were free from donor dependency. To the question “*How do you define a strong DPO?*” came the following replies:

The difference in defining an empowered DPO was apparent between the district and national level. The district level emphasized the importance of financial resources while the national emphasized a strong voice. This was demonstrated in the results of the pair wise ranking exercise whose results are shown below.

Table 6: Comparison between district and national DPO scores on the most important characteristic of empowerment

Characters of empowered DPO	Order of importance	
	District	National
Mobilizing new membership	4 rd	1 st
Influencing authorities	2 nd	2 nd
Assisting & supporting members	6 th	6 th
Attracting funding	1 st	5 th
Able to Change attitude	5 rd	3 rd
Practicing democracy	3 rd	4 th

The district level, just like the community, felt generating some income was the most important while the national level felt it was important to mobilize membership. The district chairperson of the blind in Balaka felt that money answers all things, he pointed out that mobilizing new members raises expectations because many PWDs still wait for hand-outs when mobilized. It is important to observe that both levels felt that the ability to influence authority was important.

Factors that contributed to empowerment were the same like those mentioned during focus group discussions.

4.5. How well the CBR programme Answers to the Empowerment Factors

The CBR programme has focused on factors it feels are positively impacting on the empowerment of its targeted beneficiaries. For example for the different sub-components under health, education, livelihood, social and empowerment there has been some degree of flexibility where the programme has made priorities appropriate to the context as explained below instead of following the CBR guidelines to the letter.

At the same time, the study has revealed that the CBR programme has not sufficiently listened to children, men and women with disabilities and their own definition of empowerment and adapted the support accordingly. During the study it was interesting to note that when service providers were asked what the needs of people with disabilities were, their responses were not as explicit as those reflected by persons with disability themselves and parents of children with disabilities- an indication that the service users know their needs better than the professionals. This was especially true with NGOs whose programmes were not target specific. By extension this could go to confirm that PWDs are better placed to define what empowerment is and to determine whether a particular initiative is empowering or not.

The study did not find evidence of a deliberate attempt by services providers to tailor make the design of their programmes to address particular needs of PWDs. There is a difference in priorities between FEDOMA and PWDs. In its CBR empowerment programme FEDOMA prioritises Training in Human Rights, Confidence Building and Formation of DPOs. All these are least valued by PWDs who consider economic empowerment, rehabilitation and mobility initial areas of priority.

In a NAD commissioned baseline survey of 2003 education, mobility and assistive devices were mentioned by most PWDs as some of their priorities. Poverty was also included as one of the concerns amongst PWDs. This study highlights the importance of economic empowerment as a key factor of empowerment.

Below is a summary of the empowerment efforts of the NAD CBR programme:

4.5.1 Education

CBR as a strategy to achieve inclusive development aims at facilitating the inclusion of children in neighbourhood schools and in age appropriate classes. The CBR programme in Malawi has given more attention to the elements of early childhood and primary education than to secondary, non-formal education and lifelong learning.

Activities such as providing accessibility to school infrastructure, raising awareness on inclusive education targeting children with and without disabilities, parents, guardians, families, teachers, Parents and Teachers Associations (PTAs) and community leaders have the potential to increase enrolment and improve retention of CWDs and in some cases, create a conducive learning environment for them.

Through Early Child Development centres the programme has also conducted early childhood identification assessment and intervention. Among parents of children with disabilities functional independence and education were considered the hallmark of empowerment in children. As explained above, if we take happiness as a proxy for empowerment some CWDs interviewed reported that they were happy:

“When I am chatting with friends and playing football.”

Another proxy question was what makes children sad and this was carried further to what action they take. In the focus group discussion with disabled school children in Balaka, two children informed the team that they hate it when they are teased about the disability. One boy informed the team that when he is called ‘*olumala*’ (disabled persons) he beats the children who tease him.

Through awareness-raising some children with disabilities have learnt to take action when teased about their disability. A standard two boy with albinism informed the study team how he reported such incidents to school authorities. He added that since then other students do not tease him. This confidence required to report demonstrates empowered children. The study observed that children who could communicate were confident and mixed freely with non disabled children unlike the deaf children who tended to drop out or the little child with CP who was confident only when the mother was around.

In Machinga, World Vision had identified two TAs where it was implementing a project aimed at making schools inclusive for the CWDs with a special focus for the deaf. The organisation selected 10 schools where it facilitated a two-week teacher in-service course on inclusive

education. At the time of the evaluation 90% of the teachers had been reached with this course. World Vision also carried out community based identification and assessment. Forty children who are hard of hearing had received hearing aids. Scholarships were given to pupils who needed to go to Montfort school for the blind and school for the deaf. The non disabled school children were sensitized on disability and this helped them to embrace those with disabilities. Parents were also sensitized and parents of deaf children were taught some sign language. The project, according to its coordinator was very successful and had comprehensively reached over 100 children with disabilities.

These are all indications that accessibility and awareness messages have, to a limited extent, facilitated inclusive education and that they have created a conducive learning environment.

The incidents narrated below further confirm this.

The team observed that the children who were confident in school were those with physical disabilities. Those in secondary school were students with mild or moderate disability. However despite increased enrolment in school reported by the CRW and CDOs, most schools remain inaccessible and the majority of teachers have not developed skills for addressing the learning needs of pupils and students with disabilities. Parents informed the team of children who had been asked to leave school because '*their teacher had been transferred*'. Others had not been accepted outright because the schools had no capacity to teach the children (as above example). The worst affected were the children with learning difficulties²⁷ and the deaf.

Indeed awareness raising, especially through social counselling with families, school children and teachers as well as school committees, information dissemination at community meetings and to some extent exposure of role models especially to school children, has been deemed an important part of the CBR programmes.

4.5.2 Skills Development and Financial Services

Adequate standard of living is a universal human right and a vital component of the CBR strategy. The goal of CBR in the livelihood component is for people with disabilities to gain a livelihood, have access to social protection measures, and be able to earn enough income to lead dignified lives and contribute economically to their families and communities.²⁸

The most focused livelihood elements in the Malawi CBR programme have been skills development and financial services. Some of the specific empowering activities include the training of persons with disabilities in a variety of appropriate skills to enable them to become productive citizens. Linking PWDs to micro-finance agencies and farm inputs and offering training in business management have been the other empowering elements on which the CBR programme has focused even though this has not been the case in all districts.

Skills acquisition has empowered PWDs to lead decent and independent lives. MACOHA has provided vocational skills, most of which have been demand driven, either in an inclusive environment through vocational training centres or through apprenticeship in the community

²⁷ Those with difficulties in reading and writing

²⁸ Community Based Rehabilitation: CBR Guidelines. WHO/UNESCO/ILO/IDDC (2010)

with local artisans. Through these initiatives PWDs have acquired various skills in tinsmithing, carpentry, sewing, knitting, tailoring and other such skills as are demanded by the communities. Skills development also has focused on training PWDs on '*gainful employment*' and '*home-based income generating activities*'. Business skills training has also been part of the curriculum of the vocational training.

In some cases, after skills training MACOHA has provided start-up capital either in cash or material form. In other cases FEDOMA and MACOHA have managed micro financing programmes with PWDs such as a business loan credit scheme, savings and credit schemes, including a pass-on scheme in animal husbandry.

Discussions with SHGs also revealed that they appreciated skills training initiatives as empowering. They specifically mentioned training that was accompanied by loans or starter packs.

The following case studies illustrate the positive aspects of these initiatives and how PWDs have found them empowering and improved their lives.

The generation of income, whether through a savings and credit scheme, production of goods and services has positively impacted on the empowerment of PWDs thereby having a bearing on their quality of life.

4.5.3 Rehabilitation and Assistive Devices

It was service providers and not the PWDs who identified rehabilitation and assistive devices among the factors that lead to empowerment. Although functional independence did not feature as an empowering factor at village community level, it was mentioned by persons with physical disabilities both male and female as a deterrent to economic empowerment in cases where a device had been lost or could not be used because it had broken down. Therefore among the limitations to empowerment is non availability of appropriate assistive devices (tailor-made) and delays in maintaining devices by service providers²⁹ when they break down.

Within the health component of the CBR programme elements of promotion, prevention and medical care receive less focus than rehabilitation and assistive devices. Activities taking central stage under assistive devices include the assessment and provision of assistive devices such as mobility devices, prostheses and hearing aids. This also includes training parents and volunteers in the production and maintenance of simple appliances. Rehabilitation services involve training SHGs, parents, guardians and community groups in rehabilitation techniques which have been used in caring for CWDs.

²⁹ MAP (due to financial constraints MAP no longer regularly runs clinics in the communities during which appliances would be taken for maintenance)

The provision of devices initially was not mentioned among the primary attributes of empowerment unless probed but the loss of a device such as a wheelchair was incapacitating. Lack of assistive aids was seen as a barrier for PWDs to participate in different activities most notable was that children could not attend schools if they are not able to move around. The parents also expressed the burden of carrying older children if they were not able to move. The programme was finding difficulties in providing assistive devices to those who needed them mainly because of the scaling down of MAP activities. Fortunately Sue Ryder had stepped in to fill the gap, but was only interested in children. The researchers also noted a dire gap in providing rehabilitative medicine to persons with epilepsy and to those with mental health challenges.

Distance to school was found to be a hindrance to enhance empowerment. Some of the children who are brought to school on a bicycle drop out if the bicycle breaks down. Others are pushed by mothers in wheel chairs. As the child grows older and difficult to push, the mother may give up and the child drops out of school. For example, a mother of a CWD in Balaka reported to the team that although CBR has helped her immensely in teaching her how to look after her child (who has developmental disability), CBR has not solved her issue regarding pushing the child to school every day. She has grown too heavy to push. In any case pushing her to school by 8 am and picking her at 12noon did not allow her enough time in the field, yet that is where food for the family comes from.

All in all, according to PWDs, provision of assistive devices as well as physical rehabilitation has impacted positively on the functional independence and self-reliance of many children and adults with disabilities.

4.5.4 Social Inclusion

In this component there is less priority given to specific elements of social inclusion as provided in the WHO Guidelines. However social inclusion is addressed in general terms through awareness-raising amongst communities and community leaders on the need to eliminate stigma and include PWDs in social and development activities.

The programme has put relatively high emphasis on creating awareness of CBR and related issues, through trainings and workshops for stakeholders involved on most levels. The following observation by a FEDOMA member at district level demonstrates the idea of empowerment being associated with ability to be self-reliant, to advocate for one-self and others, to integrate.

4.5.5. Formation and Training of SHGs and DPOs

Specific elements of empowerment in the CBR Guidelines receiving attention include facilitating the formation and training of SHGs and DPOs and linking SHGs to money lending institutions. Empowering these groups through capacity building in group dynamics, advocacy and business management contributes to improved accessibility of services, when they have become strong in advocacy and interaction with other stakeholders. As mentioned before, the formation of SHGs may also be empowering since it is seen as the crux for wealth creation.

The CBR programme has assisted in establishing Self-Help Groups and DPOs in both CBR project areas and non CBR project areas. The study visited one such area in Mzimba where Self-Help groups have been formed and one such group is FEDOMA Disability Network which at the time its members were undergoing an agricultural training workshop³⁰. The team learnt that there was successful mainstreaming of disability issues and that the groups were quite active. Unlike in the CBR project areas, here the rights based approach to development was happening earlier than in areas where the CBR project has been in operation and where elements of giver and receiver were initial approaches.

At National level FEDOMA said it had started many disability groups as part of its empowerment programme. These groups serve two purposes. They raised the voices of PWDs and are also conduits for delivery of development programmes. The CBR programme discourages single-disability groups due to difficulty in mobilizing members. This could also work against those disability groups that are unable to form their own groupings.

4.6 Extent of Coverage of CBR Programme

The structure for the CBR programme follows that of government. At district level a Community Rehabilitation Officer coordinates the activities while at TA level a Community Rehabilitation Worker is responsible for CBR activities³¹. A CBR volunteer is placed at Group Village Headman (GVH) level to coordinate activities in all villages falling under that GVH.

There are 8 Community Rehabilitation Workers in Machinga against 10 Traditional Authorities, 7 CRWs in Balaka against 5 Traditional Authorities; there are no CRWs in Mzimba. In Machinga the shortfalls in the number of CRWs mean a lot of work for the current CRWs. There are more CRWs in Balaka due to the vastness of the villages.

In a district the volunteers are responsible for identifying potential PWDs. They move from village to village identifying and making simple assessment of the PWDs before calling on CRWs to make a comprehensive assessment on the identified PWDs. In Mzimba the duties for the CRWs are performed by the CROs and due to the vastness of the area of coverage and the many volunteers across the CBR NAD project areas the CROs³² are unable to supervise them all and so they meet every three months at a central point to share and discuss progress on activities.

In summary it can be concluded that the CBR programme still has limited coverage and few resources to reach all districts and all persons with disabilities.

³⁰ Not one of FEDOMA's activity in the CBR empowerment programme through/with MACOHA

³¹ This arrangement is not available in Mzimba where we have the CRO and Volunteers without CRWs.

³² There are two CROs in Mzimba alone

4.7 Meeting different Empowerment Requirements

CBR has evolved into a multi-sectoral strategy that addresses the broader needs of PWDs. However, the CBR programme faces a number of challenges, one of them being the need to respond to the mainstreaming needs and poverty concerns of a wide clientele. These are of different gender, age, disability types, degree of disability, and different experiences of marginalisation within different cultural and economic settings. The ability of CBR to respond to specific or unique needs of PWDs is one of the major features that differentiate it from institution-based rehabilitation. The challenge has therefore been for the CBR programme to respond to the array of basic empowerment needs of PWDs, their families and communities.

At district level the CBR programme is organised in such a way that enables harmonisation of service delivery and most other interventions. The CRWs and CROs are well positioned to develop a reasonably good overview of relevant interventions, and it was evident that these are well aware and committed to best possible integration with other interventions in order to provide for the empowerment requirements of various disability groups. CRWs' participation in the Area Executive Committees at Traditional Authority level and CROs' participation in the Coordination Committee under District Executive Committee at District Assembly for example offers them an opportunity to learn about existing opportunities for empowerment of PWDs

During discussions community rehabilitation workers demonstrated clear knowledge of what organisations were operating in their areas including specific projects that they were implementing and who they were targeting. When asked further how the programme linked PWDs to relevant service providers in the area a Community Rehabilitation Officer in Mzimba gave the following reply.

In all the three districts TEVETA trains PWDs in various skills through vocational training. Indeed efforts by various collaborators have complemented those of MACOHA to respond to different needs of PWDs. For example, support is provided to persons with visually and physically impaired through referral services offered by MAP, CURE Hospital; Feed the children, SS, CBM and the Government health facilities. MAP provides medical rehabilitation and assistive devices for persons with physical disabilities in all the CBR districts, and deploys rehabilitation technicians at district level thereby bringing the service even closer to PWDs.

The provision of assistive devices has helped persons with disabilities to become more independent and encouraged them to break out of isolation. Supporting them to be self-confident and encouraging them to be integrated in community activities and to be volunteers and leaders in the CBR activities is another step forward.

The Ministry of health has also deployed orthopaedic officers and provided basic orthopaedic services to hospitals and health centres. Sightsavers on the other hand, apart from contributing to the prevention of blindness by promoting early identification and treatment of eye diseases, has been involved in rehabilitation of the blind through provision of financial and technical support to MACOHA, Ministry of Health and of education orientation and mobility training and supporting education for blind pupils.

There are unequal opportunities in service provision for people with disabilities and notable were the gaps for children with learning difficulties. It was also pointed out that in Machinga and Balaka only the visually impaired used to receive special services and reasons given were that there was only funding for that category of persons. The study team was informed that Sightsavers, which had been supporting the Machinga and Balaka project, only had a mandate to support those with visual impairment. They no longer are supporting CBR in these districts.

4.8 Cooperation/Collaboration

The CBR programme involves government and non-government actors in close collaboration. In all the four districts the CBR Programme aligns with the decentralised institutions. At District level a District Executive Committee is the technical advisory body composed of all government line ministries, statutory corporations and civil society organizations (CSO) working in the district. The MACOHA rehabilitation Officers belong to a CBR Coordinating Committee (CBRCC) a subcommittee of the DEC. At Traditional Authority level there is an Area Development Committee (ADC) which is responsible for mobilizing community resources and determining development interventions.

The CBR Community Rehabilitation Worker is a member of an Area Executive Committee a technical wing of the ADC which is also composed of extension workers of government and CSOs working in the area. The Village Development Committee is involved in development initiatives that include mobilizing community resources for popular participation in self-help initiatives.

Structures such as District Development Committees down to the Village development Committee have offered opportunities for stakeholders of the CBR programme to share information, discuss plans and implement CBR activities. Through these structures the programme has made alliances with various stakeholders for effective implementation of the CBR programme.

According to a programme manager at MACOHA, MAP has been providing medical rehabilitation, assistive devices, physiotherapy and occupational therapy as well as training rehabilitation technicians deploying them to bring the services closer to PWDs in all the four CBR districts. MAP has trained different groups of people, including community rehabilitation volunteers, in making simple assistive devices especially for people with mobility challenges. Generally these have taken place within the community's settings. This has contributed tremendously to the empowerment of persons with physical disabilities as observed by volunteers in three districts visited.

On the other hand NAD has supported the establishment of a wheelchair production workshop at Queen Elisabeth Central Hospital (QECH) Orthopaedic Centre in collaboration with Motivation Africa. Availability of wheelchairs has been one of the main limiting factors to mobility for people with physical disabilities. Notable was that children could not attend school if they are not able to move around. The parents also expressed the burden of carrying older children if they were not able to move. This notwithstanding it has to be noted that though the wheelchairs

are available and user friendly they were not for free and in some cases those who acquired them had difficulties in accessing spares.

The CBR programme has also managed to link with existing service providers. In order to respond to the challenges that PWDs face in engaging in economic activities because of their exclusion and lack of access to micro-financing opportunities FEDOMA introduced a microfinance project in Machinga and Balaka that took a savings and loan approach called FEDOMA Rural Savings and Loan Project. This was a means to economically uplift the lives of PWDs while at the same time to prove to the nation that PWDs are able to own pledges once trusted and given the opportunity.

In a similar economic empowerment drive of PWDs in both Machinga and Mzimba, World Vision Malawi and Malawi Rural Development Fund (MARDEF) have been distributing goats in a pass on scheme that has enabled to uplift the lives of the targeted beneficiaries as evidenced from the report from monthly activity report below.

Initiatives by other services providers include skills training in various skills through vocational training offered by TEVETA in Machinga and Balaka in which women have undergone training in sewing and are able to support their families. Other benefits from alliances with other institutions were reported in Machinga where some families have benefitted from Social Cash Transfer programme under Machinga district assembly. Beneficiaries to this scheme were identified by CBR volunteers through village development committee thanks to awareness-raising efforts conducted earlier. In the non CBR project area in Mzimba World Vision Malawi was carrying out a goat pass on scheme that involved PWDs as well; FEDOMA had set up a network with persons with disabilities in the same area.

In Balaka PODCAM has provided sunscreen lotion for Albinism group in order to protect their skin from sunrays. Previously at national level FEDOMA had been instrumental in establishing this service for people with albinism at health facilities. In an attempt to economically empower parents of children with disabilities PODCAM has in 2010 facilitated 12 groups of parents of children with disabilities to access loans to engage in various businesses through one of the micro-lending institution called Fincoop.

Even though basically facilitating and mobilizing groups from within the disability community has been part of MACOHA's work in Mzimba, the government Social Welfare Officer told the researcher that his department has been instrumental in the formation of SHGs and mainstreaming them into village loans and savings clubs and linking them with micro-financing institutions. He added that the focus has been more on getting access to credits than establishing independent savings and credit groups (SCG). This seemed to be more of a "linking-to-credit" approach than a SCG initiative.

5. DISCUSSIONS WITH STAKEHOLDERS FROM NON CBR LINKED INTERVENTIONS.

During the study it was revealed that different sectors are providing services to persons with disabilities. It was noted that some of these interventions were not formally linked to the CBR programme. These interventions were of two types: some, by design were targeting persons with disabilities; others whose prime targets were *vulnerable groups* ended up dealing with PWDs. Their efforts were neither linked to nor coordinated by the CBR programme.

In Balaka the study found that Sue Ryder Foundation, a charity organisation that provides health and social care services in local communities, provides medication for persons with

epilepsy in the district. During discussions the study learnt that the organisation does not have formal linkage to or collaborates with the CBR programme. Both the Rehabilitation Assistant and Rehabilitation Assistant of the Foundation admitted that they were not aware of the existence of the disability committee within the District Development structure and yet their work covers the whole of Balaka district and part of Ntcheu (Bwanje Valley).

In Mzimba an organisation called Every Child in Malawi works with vulnerable families and children especially orphans in which CWDs are part of the beneficiaries. During discussions the Project Coordinator explained that the project aims at building capacity for individual children through early childhood development programmes by providing fees, uniform and learning materials. It also does vocational skills training for out of school children, supports food security and village savings and loan projects emphasising on rights based approach.

In a another discussion with the Chairman of the Disability group in a non CBR area in Mzimba he expressed satisfaction at the rights based approach adopted by NGOs during sensitization and awareness raising adding that by putting people in groups to discuss their needs this had helped to create a good atmosphere for the community to address their needs and find solutions. During interview he gave the comment below.

Implementation of the CBR programme demands the development of partnerships and alliances with other sectors to ensure that PWDs and their family members are able to access the benefits of these sectors. Providing services to persons with all disability types has been the biggest challenge for the CBR programme. Some of the notable gaps include services to people with epilepsy, children with learning difficulties and interventions that will economically empower PWDs, their families and communities. The NAD/CBR programme is not able to fill the gaps covered by institutions mentioned in this section. In order to meet different empowerment requirements for the various disability groups, CBR needs to strive to work with various stakeholders some of whom have targeted specific disability groups while others have been more generally focused.

6. SUMMARY OF FINDINGS

This study has shown that at community level persons with disabilities are in a better position to define effective empowerment interventions than service providers and that programmes that raise individual or family income more especially skills training and loan schemes are more empowering. People with disabilities need a range of skills and knowledge to enable them to participate and contribute meaningfully to their families and communities. Education and functional independence are also considered indicators of being empowered.

For DPOs empowerment is being self-reliant and able to advocate and articulate issues. Skills development and awareness raising were mentioned as contributing to this kind of empowerment.

The development of the CBR programme in Malawi is mainly guided by WHO CBR Guidelines and is aligned with the five components of the guidelines. To empower PWDs the programme has tried to be flexible and adapt to priorities appropriate to the context for example:

- (a) Awareness raising targeting children with disabilities and non disabled parents, guardians, families, teachers, PTAs and community leaders and providing accessibility to school infrastructure. Despite the achievements most schools have remained inaccessible and teachers still lack the necessary skills to address learning needs of pupils with disabilities
- (b) Skills acquisition and linking PWDs to loans or financial institutions have empowered PWDs to lead decent and independent lives.
- (c) ADL training, rehabilitation and assistive devices have greatly contributed to the empowerment of PWDs by making them functionally independent, in some cases relieving parents of the burden of carrying their children around.
- (d) The formation and training of Self-Help Groups and DPOs has raised awareness on disability rights and improved on inclusion and access to business credit.

The CBR programme has to some extent managed to meet the different empowerment needs of various disability groups especially through its collaboration with a number of various stakeholders such as in rehabilitation and assistive devices. There is still a huge gap in coordination and cooperation between different initiatives.

7. CHALLENGES AND RECOMMENDATIONS

7.1 Promoting Financial Independence and Security

Economic empowerment and independence and security at household level featured highly as a key factor in the definition of empowerment among adult with disabilities at village and community level. This view was also highlighted by SHG at community level as well by DPOs at district and national level. Among some women with disabilities, financial security was articulated as being key to attainment of independence from male dominance.

The current piecemeal approach to education, skills training, access to micro finance and recruitment and employment of persons with disabilities is not conducive to promoting economic empowerment and independence. Notwithstanding efforts by the CBR to mobilize the education, skills training and employment sectors, lack of commitment has led to disjointed efforts in these areas. For instance, inclusive education although promoted at national level is not adequately supported in terms of human, financial and material resources to facilitate attainment of qualifications requisite for entry into more skilled training programmes, and subsequently, paid employment, entrepreneurship or farming.

Mainstreaming of skills development including access to business credit and/or start up tools and materials coupled with a systems approach to achieving equity in employment practices would go a long way to enhance and sustain financial independence for more persons with disabilities.

Absence of disability specific goals and disaggregated monitoring indicators in programmes and services of the Ministry of Labour, other government agencies and employers have negatively affected PWDs' advances in the livelihood sector

The following recommendations could be considered in efforts to address the existing challenges:

- 7.1.1 The design of the Malawi CBR programme needs to be reviewed to focus more on strategies that would promote economic empowerment and independence for women and men with disabilities. Such strategies would include but not be limited to mobilizing stakeholders in the areas of skills development at both community and institutional level, building capacity to influence equity and inclusiveness vis a vis access to opportunities for skills training, as well as for training in entrepreneurial skills and access to business credit and to paid employment etc.
- 7.1.2 In an effort to equip more people with vocational, farming and entrepreneurship skills, CBR should promote training in viable vocational skills at community level using local artisans through informal and non-formal training arrangements. Training models used by Technical Entrepreneurial and Vocational Educational Training Authority (TEVETA) could be adopted. TEVETA would need to prioritize PWDs directly or through SHG in its skills training programmes - PWDs being one of the organization's key target groups as per TEVETA Act.
- 7.1.3 The CBR programme needs to engage the Ministry of Labour as a policy holder in the area of skills training largely through public technical colleges. CBR stakeholders need to lobby the Ministry for the latter to eliminate barriers to skills training by among other things engaging in a programme to make the remaining 6 of the 7 public technical colleges in the country accessible to youth with disabilities thereby increasing intake of PWDs. In the same vein, equity issues need to be addressed through provision of scholarships to persons in need at college level.
- 7.1.4 To promote access to business credit, the CBR programme needs to raise awareness among the leadership of government's Malawi Rural Development Fund (MARDEF) and YEDEF on inclusive development. Further, CBR should lobby the two micro finance institutions to ring fence³³ some funds for access by PWDs. There is also need to build capacity of fund managers in inclusive and result based planning with specific indicators (both qualitative and quantitative) for persons with disabilities.
- 7.1.6 .At national level, CBR stakeholders need to influence the policy holder, namely, the Ministry of Labour to review its policy, programming and monitoring arrangements to include priority policy areas (PPA) which focus on economic empowerment. These are PPA 6 (Education and Training) and PPA 7 (Economic Empowerment) of the National Policy on Equalization of Opportunities for Persons with Disabilities. The objective of PPA 6 is to promote equal access and inclusion of persons with disabilities in education and training programmes while that of PPA 7 is to Increase access to technical, vocational and entrepreneurial training opportunities for persons with disabilities. Disability mainstreaming of the related strategies in the Labour policy would go a long way to promote access of persons with disabilities to vocational education, entrepreneurial skills, access to business credit as well as to employment.

7.2 Promoting Education for All

The perspective of children with disabilities through their parents and guardians on what constituted empowerment point to lack of an inclusive learning environment at primary school level. One gets the impression that children/learners with special educational needs are discriminated against as well as marginalized in the classroom as well as in recreation activities (play and sporting activities) not only at primary but at preschool level as well. This could be

³³ Protect

attributed to inadequate awareness among parents and guardians, family members, non-disabled pupils, teachers and preschool leaders on the value of education for learners with disabilities. The expressed desire by some of the respondents and or guardians to opt for enrolment in special schools may be an indication that children with disabilities are not benefitting much from the regular school environment.

In response to this finding, there is need to prioritize pre and primary school education in the design of interventions through the CBR. This entails focusing on specific actions that would promote a conducive learning environment at these levels.

The following specific recommendations may need to be considered in the design of education services within CBR and non CBR settings:

7.2.1 Stakeholders need to work closely with the local, district and zone educational officers to promote inclusive schools by supporting local schools to develop their own inclusive education guidelines (see 7.2.2 below). This would involve progressive enforcement of principles that would reduce discrimination and promote a supportive environment for learners with special needs. These would include, in service education for regular teachers, modification of the physical infrastructure to make schools more accessible (construction of ramps, wide doorways, modifications of water and sanitation facilities), promoting school awareness programmes to nurture positive attitudes among teachers, pupils and the general public towards learners with special needs. These activities will be championed by the Ministry of Education. Similarly, the Ministry of Gender would need to build capacity of pre-school leaders on how they could reasonably accommodate children with disabilities.

7.2.2 The CBR programme needs to engage the Ministry of Education for the latter to set up structures for promoting inclusive education at community level through establishment of positions of inclusive education desk officers at division, district and zone level and ensuring compliance to the national inclusive education guidelines. The absence of desk officers to monitor and supervise inclusive education practices at divisional, district as well as zone level has led to poor targeting of learners with special needs.

Similarly, the Civil Society Coalition for Basic Education needs to partner with CBR to ensure that inclusive education becomes an integral component of the former's awareness as well as monitoring drive.

7.2.3 As part of the strategy to promote enrolment of learners with special educational needs as well as their retention in regular schools, role modelling should be encouraged and promoted. PWDs who against all odds have succeeded in attaining higher levels of education and or gainful employment should participate in initiatives to motivate learners at primary and even higher levels.

7.2.4 A ring fenced fund should be availed to ensure ready availability of resources for school fees for needy and deserving students with disabilities especially at secondary and tertiary education levels.

7.3 Promoting Empowerment of DPOs

The paradigm shift from the medical to social model requires that PWDs be actively involved in decision making processes through self-representation. Effective self-representation, however, requires that DPOs should have cadres of PWDs that are knowledgeable in disability rights and

can effectively lobby and advocate for and demand their rights at village, district and higher levels. Although efforts are being made through CBR to establish single as well cross disability DPO branches country wide, there still remain very few PWDs in DPOs that can effectively advocate and lobby on issues of disability rights and inclusive development, especially at district and grassroots levels. It is therefore recommended that:

- (a) International development partners in disability should support efforts by DPOs in building capacity for self representation. This could be done through engaging qualified and experienced persons (preferably other persons with disability) to run comprehensive programmes for Trainer of Trainers (ToT) in effective lobbying and advocacy. The ToT would in turn train community and village level DPO representatives.
- (b) DPOs at district level should engage district level local assemblies for the latter to enforce a provision of the Local Government Act which calls for self representation of persons with disabilities as an interest group at Assembly level. In the same vein, there is need for DPOs to lobby government for increased representation by PWDs on Boards of government institutions. Such a development would help to raise the visibility of disability in development efforts at local assembly/district level.
- (c) There is need for FEDOMA to match its capacity (knowledge and skills) with its aspirations (program objectives and outcome indicators). This could be done through a critical assessment of the human capacity of FEDOMA and its affiliates to be followed by a relevant development program targeting existing potential within the organization and in its affiliates

7.4 Need for Improved Collaboration

The study has revealed there is unstructured collaboration of service providers in the area of disability especially at district and traditional authority levels that needs to be harnessed. If the role of the CBR programme is to facilitate cooperation and access to existing initiatives for the benefit of persons with disabilities, there is need for CBR to harness collaboration and deploy a more proactive approach.

7.5 Rehabilitative Medicine

There is need for the CBR programme to engage policy holders especially the Ministry of Health and the Ministry of Persons with Disabilities and Elderly Affairs to critically look into the apparent gap that exists in the provision of rehabilitative medicine to persons with epilepsy and to those with mental health disabilities.

8 APPENDICES

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TERMS of REFERENCE

NORWEGIAN ASSOCIATION OF DISABLED (NAD): DOCUMENTATION AND RESEARCH IN COMMUNITY BASED REHABILITATION (CBR) PROGRAMMES TERMS OF REFERENCE FOR A RESEARCH STUDY - MALAWI

RESEARCH TOPIC:

“AN ANALYSIS OF EMPOWERMENT FROM THE PERSPECTIVE OF PERSONS WITH DISABILITIES IN MALAWI: IMPLICATIONS FOR THE CBR PROGRAMME EMPOWERMENT COMPONENT”

1.0 PREAMBLE

1.1 Definition of the concept of empowerment

From the perspective of persons with disabilities, empowerment could be defined at two levels, namely, at individual and group level. At the individual level, empowerment is evident in increased level of participation, and improved livelihoods. Empowered individuals increasingly participate in decisions that affect their day to day lives. They are able, as a right, to progressively access services and facilities and to utilise opportunities leading to improvements in their social economic independence and self reliance. At group level, on the other hand, empowerment refers to the ability of persons with disabilities to mobilise and organise themselves to demand a life of dignity in an inclusive environment. At both levels, empowered persons with disabilities, as individuals or through their respective disabled persons' organisations (DPOs) and self help groups, are aware of their unfavourable situation, recognise and take steps to change their status quo. The ultimate outcome is greater participation and ability to play a key role in decision making, to harness more power and control that leads to positive action.

At intervention level, empowerment focuses on implementation of strategies to ensure that people with disabilities, their family members and communities have a say, are listened to, have capacity to make their own decisions, are able to gain further control, have independence, are capable of fighting for their rights (individually and collectively), are recognised and respected as equal citizens and human beings with a contribution to make. Empowerment as a process therefore aims at facilitating the mainstreaming of disability across sectors to ensure access to rights and entitlements by all. (WHO, UNESCO, ILO, IDDC CBR Guidelines: Empowerment Component).

The key concepts in empowerment are: disempowerment (rejection, discrimination, stigma and exclusion from community activities due to overprotection, negative attitudes and low self esteem among other factors);

empowerment and motivation (active participation emanating from overcoming attitudinal, institutional and physical barriers as a result of awareness raising, capacity building, encouraging participation etc); awareness (realisation of existing negative situations and of the need for positive change); information (on rights/entitlements, existing opportunities for change, access to services etc); capacity building (access to knowledge and skills to facilitate full participation and realisation of equal rights); peer support (sharing of information on common challenges and solutions through self help groups and DPOs), participation (social recognition that people with disabilities can and should be given roles to play at family, community, organisational as well as at national level) and alliances and partnerships (establishing networks to facilitate joint efforts with other groups and organisations that champion inclusion and development).

Finally, key elements of the empowerment component include advocacy and communication, community mobilisation, political participation, self help groups and DPOs³⁴

1.2 Disability statistics and initiatives to promote empowerment of persons with disabilities in Malawi

1.2.1 Disability statistics

A disability survey conducted by the National Statistical Office in 1983 revealed that there were 190,000 people with disabilities (or 2.9% of the total population) in Malawi. The survey further indicated that 93% of them lived in rural areas and 40% were in the 15 - 45-age group. A study on *Living Conditions among Persons with Activity Limitations* (FEDOMA, University of Malawi, SINTEF, 2004) indicated that the number of persons with disabilities had gone up to 480, 000 (4.18% of the population), 30% higher than in 1983. Recently, the National Population Census (2008) established that 4% of the population (about 500, 000) comprise persons with disabilities.

1.2.2 Initiatives to promote empowerment of persons with disabilities

CBR pre 2002

Based on results of the 1983 disability survey and other available data, a CBR programme was piloted in Blantyre district in 1987 with financial and technical support from the United Nations Development Programme (UNDP) and International Labour Organisation (ILO). In line with ILO's mandate, programme activities leaned more towards promoting access to vocational skills training and employment (largely self employment). In the absence of an enabling policy framework to facilitate mainstreaming across sectors as well as absence of a viable DPO movement³⁵, there was very little focus on building capacity of people with disabilities for self representation and active participation. Following the outcome of the evaluation of the pilot programme in 1988, the CBR programme was extended to five more districts, namely, Machinga in the southern region, Mzimba and Karonga in the northern region and Salima and Lilongwe in the central region³⁶. Support from UNDP/ILO phased out, in 1992. From the mid 1990s to 2002, the programme, largely with financial support from Christoffel Blindenmission (now CBM), Action Aid International and Sightsavers, the programme further extended to Nsanje in the southern region, Nkhota –kota, Dowa and parts of Ntchisi in the central region and Nkhata-Bay in the northern region. During the cited extensions, emphasis continued to be on programme delivery as opposed to among other things, setting up structures to enhance mainstreaming of persons with disabilities across sectors.

CBR post 2002

In 2002, the Norwegian Association of Disabled (NAD) signed an agreement of cooperation with the Government of Malawi (the agreement has been renewed/extended several times with current extension to cover the period 2010 – 2014). The initial and subsequent agreements have laid down clear strategies on how the two partners could work together to promote inclusive development through CBR. Since the signing of the initial agreement, there has been increased focus by the CBR programme to implement interventions aimed at promoting empowerment of persons with disabilities. This has been done through direct investment in

³⁴ Refer to WHO/UNESCO/ILO/IDDC. (2010). CBR Guidelines: Empowerment component (pp: 5-7)

³⁵The DPO movement emerged from the early 1990s.

³⁶ Planning for extension of the CBR program between 1988 and 1992 benefitted greatly from the outcome of a baseline study which mapped existing services and facilities for implementation of the program (University of Malawi, Department of Demography: 1990)

CBR programme development targeting DPOs with emphasis on awareness raising on disability rights, establishment of self help groups and DPOs and generally, capacity building for effective advocacy.

The current Malawi CBR arrangement conforms to guidelines set by WHO, United Nations Education Scientific and Cultural organization (UNESCO), ILO and the International Disability and Development Consortium (IDDC). It is guided by the following five strategic objectives:

- Provide access to quality, equitable and relevant education to male and female persons with disabilities.
- Improve livelihood for male and female persons with disabilities
- Promote an inclusive society at all levels
- Facilitate healthier life styles for male and female persons with disabilities through improved access to basic health services
- Engage people with disabilities into the mainstream of family and community life and development programmes

Through this arrangement, the Federation of Disability Organisations in Malawi (FEDOMA)³⁷ receives financial and technical support from NAD for its core business of building capacity for advocacy to promote active participation of people with disabilities in CBR and other development activities.

Combined efforts – by DPOs and/through CBR

Since the mid 2000s, the Malawi CBR programme has incorporated a number of strategies to promote the active voice and participation of persons with disabilities. These include establishment of a national CBR resource team (NCRT) and the national CBR steering committee (NCST). FEDOMA is a member of both committees. The overall mandate of the NCRT is to champion disability rights and mainstreaming across the health, education, livelihoods, social and empowerment components by ensuring implementation of inclusive policies including allocation and utilisation of requisite funds. FEDOMA champions the empowerment component on the NCRT.

On the other hand, the mandate of the NCST is to:

- Initiate discussions with development partners towards harmonisation of the CBR programme
- Broaden the funding base for the programme
- Work towards the development of national CBR plans
- Approve/vet annual CBR plans and reports including mid year reviews and reports
- Strategise on strengthening the CBR referral system as well as involvement of stakeholders
- Provide guidance towards improving access to quality and affordable assistive devices
- Lobby for the inclusion of disability in the Malawi Growth and Development Strategy (MGDS) from 2012
- Conduct awareness raising campaigns towards disability mainstreaming at ministry (central) and district (local assembly level) and in non-governmental organisations (NGOs)
- Oversee implementation, monitoring and evaluation of disability-related projects and programmes.

³⁷FEDOMA is the Umbrella organisation (secretariat) of all registered disability organisations in Malawi

- Provide training in CBR mainstreaming

Persons with disabilities also comprise membership of District CBR Committees (DCC) at local assembly level³⁸. The role of DCC is to ensure inclusion of disability in sectoral plans, and to develop and monitor implementation of CBR plans.

2.0 PROPOSED STUDY ON “ANALYSIS OF EMPOWERMENT FROM THE PERSPECTIVE OF PERSONS WITH DISABILITIES IN MALAWI: IMPLICATIONS FOR THE CBR PROGRAMME EMPOWERMENT COMPONENT”

2.1 Rationale and purpose of the study

People with disabilities, their families and communities have a key role to play in promoting a rights based approach to service delivery. A number of evaluations and related studies undertaken especially from the mid-2000s provide some insights into efforts that have been made to build DPO capacity by the CBR programme and through other interventions for more effective lobbying and advocacy, and on existing major challenges³⁹.

The purpose of this study is to explore, from the perspective of persons with disabilities, the extent to which persons with disabilities feel that they are empowered and to identify CBR strategies and interventions to further promote their empowerment. To accomplish this, the study will collect and analyze information on what 'being empowered' means for them. The study will aim to document factors that have facilitated /contributed to their feeling empowered. The study will ensure to include men and women, girls and boys with all kinds of disabilities in the targeted districts to see if there are differences of opinion depending on gender, age and disability.

The study will document and analyze current constraints to empowerment and propose key strategies to promote empowerment.

2.2 Study objectives

The following objectives will guide the assessment to:

³⁸Other members of DCC include heads of government departments and NGOs. MACOHA CBR Managers at district level serve as secretariat to the Committee.

³⁹Notable among these works are the following:

- Norwegian Association of Disabled (2009). As strong as the weakest link: An evaluation of the community based rehabilitation program of the Malawi Council for the Handicapped supported by Norwegian Association of Disabled.
- Bondevik, P. N. (2008). Inclusion: A key priority in Malawi Microfinance: A feasibility study
- Danish Council of Organisations of Persons with Disabilities (2007). Comparative Study of Political Approaches and Government Processes to Mainstream Disability into all Sectors of Society in Malawi.
- Danish Council of Organisations of Persons with Disabilities (2003). A study report on the capacity of disability organizations in Malawi
- Ministry of Persons with Disabilities and the Elderly, MACOHA and FEDOMA CBR strategic plans and reports for 2004-2010.

2.2.1 Document from the perspective of persons with disabilities and or DPOs what constitutes empowerment as well as factors that have contributed to empowerment at individual as well as group level.

2.2.2 Document strategies and interventions /activities implemented through the CBR empowerment component. Based on the study's findings, comment on the effectiveness of the documented strategies and interventions. This will be accomplished through a desk study

2.2.3 Draw linkages between positive empowerment outcomes and interventions/empowerment activities including from CBR funded activities and collaboration with CBR

2.2.4 From the perspective of persons with disabilities and their DPOs, identify key challenges to their empowerment

2.2.5 Provide key recommendations on how DPOs, government ministries, departments and agencies and other key stakeholders can work together to promote a rights based approach to development.

2.3 Key research question and guiding questions

The key research question will be to determine the extent to which persons with disabilities feel empowered to actively participate in improving their lives. The researchers' guiding questions shall cover but not be limited to the issues and questions below:

2.3.1 What constitutes empowerment?

2.3.2 Identify factors that have contributed to empowerment of persons with disabilities at individual as well as group level.

2.3.3 Identify strategies and interventions /activities that have been implemented through the CBR empowerment component.

2.3.4 Assess the effectiveness of strategies and intervention identified under 2.3.3 above

2.3.4 Demonstrate linkages between positive empowerment outcomes and interventions/empowerment activities including from CBR funded activities and collaboration with CBR

2.3.5 What are the key challenges to empowerment of persons with disabilities at individuals and group level?

2.3.6 What key recommendations would help DPOs, government ministries, departments and agencies and other key stakeholders to promoting a rights based approach to development?

2.4 Deliverables

A comprehensive report not exceeding 25 pages (excluding annexure) shall be submitted as per study schedule. The report shall highlight major study findings and recommendations in line with study objectives and in response to the key research and guiding questions. Key findings and recommendations will be summarized in an Executive Summary. Further, the report shall provide a summary of methodologies used for data collection and analysis. A summary of terms of reference for the study and a list of research participants shall be captured in the annexure.

2.5 Methodology

It is expected that the consultants will use a number of data collection and analysis tools to ensure triangulation of data and to draw conclusions that reflect the prevailing situation. Data collection tools to be used will include a review of relevant literature (plans, reports including baseline studies and project evaluation reports). It is expected that the consultants will study key literature on CBR/disability to develop an in-depth appreciation of the subject matter. Other data collection methodologies will include key informant interviews and focus group discussions. The main respondents will be persons with disabilities that participate in CBR programme areas.

A number of villages targeted by the CBR programme will be randomly selected. Persons with disabilities will be interviewed as individuals as well as in groups. Other respondents will include DPO representatives and CBR workers. The sampling methodology will be designed to ensure that responses will be obtained from both male and female persons with disabilities, of different ages and from a cross section of disabilities.

The assignment will be organised as follows:

A team leader (Local consultant) will be engaged to:

- Develop the tools and methodology together with an external advisor
- Contract and train research assistants
- Oversee data collection procedures
- Analyse responses and make follow up visits/questions
- Draft a report and get feedback from the external advisor
- Make revisions and possibly supplementary interviews

Finalise the report

An external advisor will be engaged to:

Provide input on development of an appropriate research methodology including data collection tools

Train data collectors

Involvement in pre testing of data collection tools

Ensure sound analysis of data

Critique the study report and provide relevant advice

It is expected that deliberate effort will be made (by the consultant to recruit male and female persons with disabilities as research assistants.

2.6 Period of engagement

The entire assignment including preparation, field work, data analysis and report writing shall be undertaken within a period of 35 working days to commence on the 9th of January 2012 as detailed in the table below:

QUESTION GUIDES

Interview guide for CRWs (Designed with enough space for recording the answers)

1. What is your educational background including training? (probe)
2. What are your roles as a CRW?
3. Out of this list which ones do you find difficult to perform and Why?
4. How do you define a strong DPO/branch?
5. How do you describe a strong (empowered) PWD?
6. Describe a strong (empowered) PWD whom you have been working with?
7. What factors/qualities made them different from other PWDs
8. What disability groups are the weakest?(are least empowered)(explore disability type, gender and age) Why are they so
9. Which disability type do you find most difficult to work with and why?
10. What has been your role in making DPOs/CBO of PWDs strong?
11. What CBR activities are you implementing in your operating areas?

12. What are the most important results of the CBR programme in communication, education, livelihoods, community mobilization, political participation of PWDs, formation of self help groups/DPOs?
13. How do you know that you are achieving what you set out to do?
14. Are there any groups of persons with disabilities (gender, age, type of disability) that are not reached by the CBR? Why?
15. What other activities targeting PWDs are taking place in your operating area and who is implementing them?
16. How do you cooperate with these other implementers?
17. How do you link PWDs or groups with other service providers or organizations in your area?
18. How have PWDs benefited from organizations/programme other than the CBR programme. Give specific examples.
19. How can community leaders help you to make disabled persons stronger?
20. How can community leaders help you to make disabled people's groups stronger?
21. How can community development workers help to make PWDs stronger?
22. How can the CBR programme make PWDs stronger?
23. Mention challenges (problems) you have faced related to implementation of specific empowerment interventions.
24. Any success stories to share regarding the CBR empowerment interventions?

Interview guide for DPOs at national and district level

Organisational level

1. How do you define a strong DPO/branch?
2. Based on your definition – how would you describe the performance your organisation/branch?
3. What assistance has your organisation/branch received?
 - a) How important is
 - b) Ability to mobilise new members
 - c) Ability to influence authorities and decisions
 - d) Ability to support and assist individual members
 - e) Ability to attract funding
 - f) Ability to influence attitudes
 - g) ability to practice democratic leadership
4. Criteria defined by the respondent in question 1 should also be listed here
5. (use pair-wise ranking to rank & stimulate discussion)
6. What disability groups are the weakest? (are least empowered)(explore disability type, gender and age) Why do you consider them the weakest?
7. What CBR activities are taking place in your operating areas?
8. How has the CBR interventions improved your performance as an organization/branch? Mention specific abilities/give examples. (Explore capacity e.g. skills, training & equipment)
9. Describe the relationship between your organisation and the CBR programme. (Explore the role of the DPO/branch in CBR, involvement and influence i.e. Do the implementers and leaders in the CBR programme listen to you? Do they respect your views)? Give specific examples
10. What else could the CBR do to involve and support DPOs/Branches?
11. Are there any disability groups that are not reached by the CBR?
12. Which?, Why?
13. What other activities targeting PWDs are taking place in your operating areas and Who is implementing them?

14. Describe your involvement as DPO in these activities?
15. What improvements have followed as a result of these activities for
16. Persons with disabilities?
17. DPOs/branches?
18. Are there linkages between other organizations that support PWDs and the CBR programme?
19. What skills or abilities does your DPO/branch still need?
20. Are there women/men/children with disabilities that are not supported by the CBR?
21. Who are they? and why aren't they supported?
22. What are the major challenges of your organisation/branch presently? (*probe for advocacy& lobbying, communication, governance, membership mobilisation, funding, capacity building, etc*)
23. How can these challenges be addressed?
24. How can community leaders help your organisation to be stronger?
25. How about you and your membership, how can you make the organisation stronger?
26. How can you help individual members to become stronger (empowerment)?
27. How can government (ask according to level) help to make organisations of PWDs stronger?

Interview Guide for Individuals with Disability

DATE TIME.....VILLAGE.....DISTRICT.....

USE THIS IN A CONVERSATION FORM

1. Which person with disability do you admire most?
2. Why do you admire them?
3. What do you wish to be in future
4. What do you need in order to get to achieve your dream of the future
5. , Are you better off now than three years ago?
6. In what way? Give specific examples.
7. What helped improve your situation?
8. Are you a member of a disability group/DPO branch?
9. If yes which
10. If no why not?
11. Are you a member of any other group?-a group of mixed disabled and non disabled such as a saving & credit group or choir etc
12. Do you hold a position of responsibility in the community?
13. If yes which?
14. How did you come to hold this position?
15. If no why?
16. Are you treated better now than before the CBR intervention? Give example
17. Do you have independence in your life now? Give example.
18. When you speak do people respect your opinion/wish/suggestion?
19. What is your role in the CBR programme?
20. If none, why?
21. What did the CBR programme do to improve the situation in your life? (*interventions*)
family?
In your community?
In your school?
In your work place?
22. What are you able to do now that you could not do before the CBR intervention?
(*outcome and impact*)
23. What else do you think the CBR programme should do to improve the lives of persons with disabilities?
24. Have you received support from any other programmes? yes ...no.....
25. If so which?
26. What did they do?
27. How did your life change as a result?
28. Has the CBR linked you to another institution or service or organisation in the community?
29. Which organisation?
30. What is your main challenge at the moment with regard to
31. What can be done about the challenges you have mentioned?
32. How much has CBR and other programmes helped you in the following (use an X in the relevant box)

	A lot	some	little	Not at all	Not applicable
ADL e.g. dressing, eating,					

toileting					
Movement e.g. leaving house to compound; home to school, well; to work, market, church					
Communicating					
Earning a living					
Decision making					
Self confidence					

IF THE BACK IS FULL OF NOTES USE EXTRA PAPER FROM NOTEBOOK AND STAPLE ON THE TOOL

TO BE USED BY RESEARCH ASSISTANTS WITH VISUAL IMPAIRMENT

QUESTIONNAIRE CHILDREN 5 TO 14 YEARS

DATE.....TIME.....VILLAGE.....DISTRICT.....

USE THIS IN A CONVERSATION FORM

This version should be used for children and persons with intellectual disabilities. The following open ended questions should be posed and the answers listed under each question:

1. What makes you happy?

2. What makes you sad?

3. What do you want to become in the future?
4. What do you do during a normal day?
 - at home
 - at school/work
 - in free time
5. What support did you get from CBR/MACOHA?
6. What support would you need?

The following questions can be used as a basis for the conversation. They may be rephrased if not understood. Put “X” in the relevant box

Is it true that...	yes	A little some- times	no	Don't know	Comments
1. You often go outside your home					
2. You feel lonely/isolated					
3. You feel happy					
4. You feel good about the future					
5. You play with neighbours/schoolmates					
6. You play with brothers & sisters/cousins					
7. You stay at home most of the time					
8. You can do many things (feeding, dressing, moving, playing) by yourself					
9. You often join community activities					
10. You can help in household activities (cooking, digging, washing, looking after animals, fetching water)					
11. You can move around at home without help					
12. children tease you					
13. Adults in the community treat you well					
14. Your family is proud of you Mother					
Father					
Brothers and sisters					
15. <i>(for speech and hearing impaired)</i> Your family use sign language when communicating with you <i>(even one member of the family)</i>					

Is it true that...	yes	A little some- times	no	Don't know	Comments
16. Your family asks for your opinion					
17. Your family understands what you need Mother Father Brothers and Sisters					
18. Your family helps you a lot Mother Father Brothers and Sisters					
19. Your family is protecting you too much					
20. Your family is taking decisions about your life without asking you					
21. You go to school/kindergarten					
22. Your teacher helps you when you have a problem because of your disability					
23. Your school mates care about you and invite you to play with them					
24. You have difficulties in school/kindergarten because of your disability					
25. You have problems walking to school					
26. You have problems in understanding/hearing/seeing what happens in class					
27. <i>(for speech and hearing impaired)</i> Your teachers use sign language when communicating with you <i>(even one teacher)</i>					
28. You know where to get help if you have a problem because of your disability					
29. You feel healthy					

Is it true that...	yes	A little some- times	no	Don't know	Comments
30. You get the medical treatment/rehabilitation you need					
31. You get the assistive devices you need					
32. You are able to communicate to people outside your family					
33. You are able to understanding what people outside your family say					

QUESTIONS TO PARENTS/CARETAKER

1. How are you related to the child/children with disabilities?
2. How long has your child been disabled
3. What are your main problems regarding your child/children with disabilities?
4. Who has helped you deal with these problems?
5. How long have they supported you?
- 6.
7. What help was offered?
8. What is the benefit of this support to the child/children with disability? (probe for specific examples)?
9. What is the benefit of this support to you?
10. What is the benefit of this support to the family?
11. How best can your child be helped to be stronger (empowered)

Interview Guide for Individuals with Disability

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48. Are you treated better now than before the CBR intervention? Give example
49. Do you have independence in your life now? Give example.
50. When you speak do people respect your opinion/wish/suggestion?

51. What is your role in the CBR programme?
52. If none, why?
53. What did the CBR programme do to improve the situation in your life? (*interventions*)
 family?
 In your community?
 In your school?
 In your work place?
54. What are you able to do now that you could not do before the CBR intervention?
 (*outcome and impact*)
55. What else do you think the CBR programme should do to improve the lives of persons with disabilities?
56. Have you received support from any other programmes? yes ...no.....
57. If so which?
58. What did they do?
59. How did your life change as a result?
60. Has the CBR linked you to another institution or service or organisation in the community?
61. Which organisation?
62. What is your main challenge at the moment with regard to
63. What can be done about the challenges you have mentioned?
64. How much has CBR and other programmes helped you in the following (use an X in the relevant box)

	A lot	some	little	Not at all	Not applicable
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Movement e.g. leaving house to compound;, home to school, well; to work, market, church					
Communicating					
Earning a living					
Decision making					
Self confidence					

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Tool for Government and NGO officials

1. What social welfare programmes is Government implementing in your district?
2. What poverty reduction programmes is government /NGO implementing?
3. Whom do these programmes target?
4. How are PWDs benefiting from these programmes?
5. How are PWDs reached?
6. How are PWDs linked to other programmes?

7. How audible is the demand voice of PWDs for services; either individually or as groups?
8. What recommendations do you give for raising their voices and for these voices to be respected?
9. What recommendations do you give for their increased participation in development programmes?

Tool for Primary School FGD

(Invite pupils with disabilities from form five to eight. If required separate girls and boys)

1. What do you like about this school?
2. What do you not like about this school?
3. Whom do you play with in school?
4. How do you cope in the classroom? (probe for special arrangement regarding vision, hearing, communication physical access)
5. How do you use the toilet?
6. Are there children with disabilities who used to come to school and they stopped? Why did they stop?
7. What extra curricula activities (activities outside lessons) do you participate in? Probe for clubs e.g. debating, dancing, scouting, sports etc. Probe for reasons for those who are not participating.
8. What leadership position(s) do you hold? Probe for reasons for those not in leadership positions.
9. How has the school made you are better/stronger person?
10. What activities do other children do which you do not participate in? Probe for reasons.
11. How can the school be improved so that it makes children with disabilities stronger/empowered.

Summary of PWDs Interviewed per district/per sample

District	Disability							
	PWDs	Physical	Visual	Deaf	Epilepsy	Albinism	Deaf/blind	Developmental
Machinga								
	Male		4					1
	Female					1		2
Total sampled adults per disability			4			1		3
	CWDs							
	Male	2	2			1		1
	Female	2			1			
Total sampled children per disability		4	2		1	1		1
Overall total respondents for Machinga per disability		4	6	0	1	2	0	4
Balaka	PWDs	Physical	Visual	Deaf	Epilepsy	Albinism	Deaf/blind	Developmental
	Male	2	3	2	1			3
	Female	9	1	2	1			2
Total sampled adults per disability		11	4	4	2			5
	CWDs							
	Male							2
	Female		1	1		2		3
Total sampled children per disability			1	1		2		5
Overall total respondents for Balaka per disability		11	5	5	2	2	0	10
Mzimba	PWDs	Physical	Visual	Deaf	Epilepsy	Albinism	Deaf/blind	Developmental
	Male	1	1	3				
	Female	7	1		2		1	

Total sampled adults per disability		8	2	3	2		1	
	CWDs							
	Male	5	3	3				
	Female	2	1	3	2	1		3
Total sampled children per disability		7	4	6	2	1		3
Overall total respondents for Mzimba per disability		15	6	9	4	1	1	3
Total Respondents for the study per disability		30	17	14	7	5	1	17