

**A BASELINE STUDY TO MAP EXISTING
DOCUMENTATION RELATED TO CBR PROGRAMS
IN MALAWI**

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March 2011

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ABBREVIATIONS

CBR	Community Based Rehabilitation
CP	Cerebral Palsy
CRO	Community Rehabilitation Officer
CRW	Community Rehabilitation Worker
CSR	Centre for Social Research
DHO	District Health Office
DPO	Disabled Peoples' Organisation
D and R	Documentation and Research Project
DSWO	District Social Welfare Office
FEDOMA	Federation of Disability Organisations in Malawi
HSA	Health Surveillance Assistant
HTC	HIV Testing and Counselling
ICF	International Classification of Functioning, Disability and Health
ILO	International Labour Organisation
MACOHA	Malawi Council for the Handicapped
MACRO	Malawi AIDS Counselling and Resource Organisation
MAP	Malawi Against Physical Disabilities
NAD	Norwegian Association of Disabled
NSO	National Statistical Office
OUA	Organisation of African Unity (now African Union)
PSI	Population Services International
PWD	Persons with Disabilities
SRH	Sexual and Reproductive Health
SSI	Sightsavers International
STI	Sexually Transmitted infection
TEVET	Technical, Entrepreneurial Vocational and Educational and Training
TRL	Transport Research Laboratories
VRV	Village Rehabilitation Volunteers

EXECUTIVE SUMMARY

I: ABOUT THE DOCUMENTATION AND RESEARCH PROJECT

The Documentation and Research Project: The Documentation and Research (D&R) Project, being supported by NORAD and the Atlas Alliance through the Norwegian Association of the Disabled (NAD), aims at making documentation and research an integral part of community-based rehabilitation (CBR). The overall objective of the project is to promote effective documentation of CBR processes and outcomes and to facilitate sharing of knowledge, experiences and best practices among CBR programs. Specifically, the D & R project aims at addressing the need for evidence based justification for investment in CBR programs as an effective strategy for bringing about positive changes in the lives of disabled people, their families and the wider community. The project will also bring about positive changes in government development policy regarding CBR programming. Through the D & R project, NAD will also support and contribute to an evidence-based advocacy strategy, continuously assess the relevance of CBR as an approach and strategy in its different contexts, and establish a foundation of data that can be used for documenting the added value in using CBR as an approach and strategy in disability programming. The D & R project has two components: (i) The documentation component aims to improve the ability of CBR partners to document processes, progress and results of CBR interventions and ensure that such information is accessible; (ii) The research component builds upon existing CBR and other relevant documentation, as well as the activities and outcomes of the documentation component of this project. A baseline survey was therefore required for the project.

II: PURPOSE, OBJECTIVES AND METHODOLOGY FOR THE BASELINE

Purpose and objectives of the baseline study: The aim of the baseline study was to map, analyze and provide recommendations on existing CBR program documentation. This involved mapping of existing CBR documents including evidence based research documents, as well as current CBR program monitoring and documentation tools, systems and practices. The specific objectives of the baseline study were as follows: (i) to make available a comprehensive list of CBR documentation produced in Malawi since the program's inception; (ii) to establish a baseline for documentation and research activities to be undertaken through NAD's D&R project; and (iii) to identify gaps in CBR documentation practices and to make recommendations to address these.

Methodology: A number of institutions were visited in order to collect CBR documents and these included FEDOMA, MACOHA (Lilongwe and Blantyre), Feed the Children Malawi, Sue Ryder Foundation, Malawi Against Physical Disabilities, National Library Service, Beit Cure International, Centre for Social Research, Chancellor College and the Ministry of People with Disabilities and the Elderly. In addition to visiting institutions internet searches were also done to identify documents on the Malawi CBR program. During these visits interviews were also held with some key stakeholders in order to collect information about monitoring and evaluation, participation in documentation and research, and the recommendation on how documentation and research can be improved in CBR programs. The review mainly looked at various forms of documentation on CBR since the inception of the program. Such CBR documents included documentation commissioned by the CBR program and carried out by external consultants as well as internal CBR program studies/evaluations. The review did not include routine reports (e.g. semi- annual and annual reports) annual plans, funding applications, and training materials prepared by the CBR program or its partners).

II. RESULTS

Available Documentation and Research on CBR: There were 64 documents that were collected during the 15 day fieldwork. In 2010 NAD also identified 26 other documents which were not seen during the baseline study by the authors. In total, there were 90 documents on the CBR program in Malawi. These documents have been divided into the following categories: research reports; workshop and sensitisation reports; baseline reports; evaluation reports; booklets, pamphlets and brochures; newsletters and magazines; training reports; policy and strategic plans; Braille materials; and films. Nearly a third (31.1%) of the documents reviewed were research reports and this was followed by booklets, pamphlets and brochures at 20%; evaluation reports (11.1%); and then newsletters and magazines (10%). The rest of the types of documents reviewed were less than 10%. There was only one firm produced.

Year of publication and language: Nearly two thirds of the documents were produced between 2000 and 2010 and this was followed by the 1990s and very few documents were produced in the 1980s. The 2000s coincide with the period when the disability movement has been quite active in Malawi. About 16% of the documents did not have a year of publication and these were mostly brochures, pamphlets and booklets. Most of the documents that have no date of publication most likely were also produced between 2000 and 2010. Most of the documents have been written in English which makes access to these documents by people with disabilities a major barrier. Only about 9 documents have been written in local languages namely Chichewa, Chitumbuka and Chiyao. A few documents have been published in Braille.

Research: The CBR matrix covers five themes namely: health, education, livelihoods, social and empowerment. Most of the research done on CBR has been crosscutting mainly covering three themes namely health, education and empowerment. Most of the research on CBR has been basic with much fewer baseline surveys compared to evaluation studies. Studies on the theme of *health* have looked at prevalence of disability, causes of disability and barriers to health seeking behaviour among people with disabilities. The CBR program has helped to increase access to health services by people with disabilities. With regard to AIDS, knowledge is quite high; condom use is low; packaging of information especially for the visually impaired and the deaf is not appropriate; and the proportion of people with disabilities who have gone for an HIV test is also low. Research on access to ART and PMTCT services by people with disabilities in Malawi is however rare.

Studies have also shown that with regard to *education*, access by people with disabilities and ensuring that they remain in school is still a major challenge. School attendance is lower among the disabled household members compared to those members without disabilities. Some parents have withdrawn their children from school because of disability. Children with disabilities may fail to attend school because they do not have a wheel chair and that some schools are not accessible to them. Visually impaired children may discontinue school because of lack of Braille materials. A number of CBR programs have been implemented in Malawi aimed at improving access to education by people with disabilities.

The major source of *livelihood* for people with disabilities is farming. The CBR program has provided people with disabilities vocational skills (such as tailoring, weaving, agriculture, carpentry and home economics) in order for them to earn a decent living. People with disabilities generally find vocational skills acquired useful in finding work or in ensuring that

they are self employed. In addition to providing vocational skills some CBR programs have also provided loans to people with disabilities. Some of the loan schemes have been quite successful as some recipients have been able to build better houses, others bought livestock, paid school fees for their children and their homes became food secure. Hence, this demonstrates that the provision of loans to people with disabilities if properly managed can help to better transform the lives of people with disabilities but such opportunities are however limited.

Not many studies have been done on the theme *social*. Some studies have demonstrated that it is difficult for people with disabilities to get into sexual relationships including marriage; and that disabled women, after being impregnated can be abandoned by men because of their disability. Disabled women sometimes find difficulties getting into intimate relationships because they cannot fulfil the obligations of married women in families such as carrying water, cooking and lifting heavy things because of their disability. Cases of disabled women being sexually abused have been reported. Some disabled children have been abandoned by their fathers. People with disabilities in most cases do not get involved in decision making at household and community level even when it comes to decisions that will affect them. This theme has not really been studied much.

On *empowerment* not many studies have been done. As part of empowerment, disability issues have been included in the Constitution of the Republic of Malawi; and that Malawi is a signatory to the Convention on the Rights of Persons with Disabilities. In 2006 the National Policy on Equalisation of Opportunities for People with Disabilities was launched in order to promote the rights of people with disabilities. Over the last decade DPOs have conducted a lot of meetings aimed at sensitizing the wider community on the rights of people with disabilities. The Policy Investment Framework (2001) has placed a lot of emphasis on special needs education. The CBR program aims at improving the lives of people with disabilities as well as ensuring that Malawians are aware of the disabled people's rights. As part of the empowerment process, a directory of disabled people's organisations that was produced in 2006 that lists the different DPOs and other service providers in Malawi including the services that they offer. The CBR programs have also empowered people with disabilities with training and disbursement of loans in order to economically empower them. Such an approach has been carried out because in most cases people with disabilities are often discriminated against in programs that offer cash or in kind benefits such as public works programs. This discussion generally shows that research on empowerment of people with disabilities is limited; hence the need to do more on this theme.

CBR documentation: The study found that in most cases the documentation process is either not available for the CBR program and stakeholders or when available it is not detailed enough. A number of stakeholders are involved in documentation but the major problem is that sharing of documentation (including annual reports) is somehow limited and the documentation process itself is inadequate. The skills for documentation among the stakeholders are also lacking as they do not really explain the context in which the person with a disability lives. As part of documentation CBR programs rely on field reports which are in most cases sent late or in some cases not available. The failure to effectively document CBR programs comes about because the workload of CBR staff is very heavy; lack of computers and unavailability of internet and email services; lack of financial resources; lack of documentation skills and that the development of an CBR Information Management System is yet to be completed. As part of documentation, mid-term and end term evaluations are done. Some of the evaluation reports however lack details on the impact of the

interventions i.e. how the interventions have changed the lives of people with disabilities. Some reports on evaluations of CBR programmes have not been professionally done. While CBR programs attempt to document processes, there are challenges that need to be addressed.

Participation of DPOs in CBR Research: Most studies commissioned on CBR have been done by research institutions. The involvement of people with disabilities in research only started in the early 2000s mainly during the *Living conditions study* when DPOs including the Ministry of Persons with Disabilities and the Elderly participated in the design of the study: DPOs participated in the finalisation of the questionnaires for the study and half of the enumerators and supervisors (with disabilities) who participated in the study were recruited by FEDOMA. In a series of studies conducted by CSR and SINTED attempts have been made to involve people with disabilities as enumerators. Within FEDOMA and affiliate DPOs some persons with disabilities have participated in research and there is some capacity to collect data. At regional level, SAFOD is also working with FEDOMA and training people with disabilities in the conduct of research. However, some of FEDOMA affiliate DPOs have not been involved in research. While there are such attempts, there is generally lack of capacity within disability organisations to fully utilise the findings from studies and that there is a general lack of professional researchers who can be able to conduct research.

Accessibility and use of available documents by CBR cadres and other stakeholders: CBR stakeholders have produced a number of documents. Most of the documents are not accessible: even institutions that produced some of these documents do not have copies. The sharing of documentation on CBR is rather limited. Dissemination of research results is mainly done at national level where reports are distributed. Research reports and other documentation on CBR are also disseminated during sensitisation meetings. Others are sent to stakeholders or left at the reception for visitors. Some DPOs have resource centres and websites where documents are posted. Accessing documents on websites is also a challenge as many stakeholders do not have access to internet. Other challenges with regard to accessing documents include people not knowing what documents are available; documents being in English and hence not accessible to most people with disabilities; and unavailability of documents in Braille for the visually impaired;

Using the research and evaluation results: Results have been used for the development of CBR interventions and this is especially applicable to baseline surveys, midterm reviews and final evaluations. These reports are used to monitor the progress which has been made to achieve the objectives of the project. A number of studies have also been done to inform the development of policies e.g. the 2003 *Living conditions study* was used to develop the National Policy on Equalisation of Opportunities for Persons with Disabilities and the Disability Bill. The results of some of the studies that have been done have been used as a tool for advocacy as well as for mobilisation of resources.

Monitoring and evaluation tools: In addition to field reports, as part of monitoring and evaluation, staff at headquarters of organisations (e.g. MAP) should visit offices at regional and district level but the lack of funds make this activity impossible; hence reliance on monthly reports from districts and regions. Baseline studies are in most cases not done because of lack of resources and lack of capacity for CBR staff to conduct such studies. In addition to using baseline and final evaluations, MACOHA also uses the *most significant change tool* which measures the qualitative outcomes of interventions on an individual with a disability. This is written in form of a story and a series of questions are addressed to the individual with a disability. This tool is therefore important as CBR programs can use it for

monitoring the impact of interventions. However there is a need to get more information on people with disabilities such as their families, including the support they get from them before and after the interventions, the role of the wider community and the availability of institutions around the community to help people with disabilities.

IV. CONCLUSIONS AND RECOMMENDATIONS

This study has found that there are 90 documents that have been produced on CBR **and most** of these documents were written in 2000s. Most of these documents are either research or evaluations. While there has been involvement of DPOs in research, this has been limited. The documentation of the CBR program is however affected by a number of factors including: (i) lack of documentation skills among staff of CBR programs and volunteers; (ii) lack of financial resources; (iii) shortage of human resources to effectively carry out documentation; and (iv) lack of computers and associated skills. The study has also found out that there is limited dissemination of documents among CBR stakeholders. While there are these shortfalls, the results from studies have however been used in the development of intervention and policies and acts affecting people with disabilities in Malawi. The following recommendations are therefore being made based on this study:

- Since most of the studies done have been in the area of health and education there is a need to prioritise research on other CBR themes especially social and empowerment.
- Stakeholders should be oriented in documentation so that they are able to show the results of their interventions clearly.
- Qualitative tools should be designed for evaluating the impact of programs such as *the most significant change tool* that is being used by MACOHA.
- The documents that have been collected as part of this baseline should be used as a basis for establishing a comprehensive database of CBR documentation.
- In order to ensure availability of CBR documents, the documents that have been collected as part of this study should be scanned and made available to stakeholders.
- CBR stakeholders networking should be encouraged and that sharing of documentation on CBR should be established as a norm among stakeholders.
- There is a need to establish and operationalise an electronic Disability Management Information System similar to Health Management Information System in the health sector.
- An effective referral system for cases identified at community level should be established and sustained.
- The CBR matrix (with the 5 themes) is quite new; hence there is a need to orient people on these themes.
- The D and R project stakeholders should critically look at what research has been done and propose topics that should be researched or further researched.
- FEDOMA and MACOHA should continue encouraging the participation of people with disabilities in disability studies.
- Important CBR Documents should be translated into major Malawian languages and that a provision should also be made to produce these documents in Braille.

1. INTRODUCTION

1.1 The NAD supported documentation and research project

The Documentation and Research (D&R) Project, being supported by NORAD and the Atlas Alliance through the Norwegian Association of the Disabled (NAD), aims at making documentation and research an integral part of the community based rehabilitation (CBR) programs in 4 NAD supported program countries in Africa, namely, Malawi, Uganda, Lesotho and Zambia. The overall objective of the project is to promote effective documentation of CBR processes and outcomes and to facilitate sharing of knowledge, experiences and best practices among CBR programs. Specifically, the D & R project will address the need for evidence based justification for investment in CBR programs as an effective strategy for bringing about positive changes in the lives of disabled people, their families and the wider community. The Project will also serve to bring about positive changes in government development policy regarding CBR programming. Through the D & R project, NAD will also support and contribute to an evidence-based advocacy strategy, continuously assess the relevance of CBR as an approach and strategy in its different contexts, and establish a foundation of data that can be used for documenting the added value in using CBR as an approach and strategy in disability programming. The project has two components:

(i) The documentation component aims to improve the ability of CBR partners to document processes, progress and not least results of their CBR interventions within particular themes, for example, in key areas such as health, education, social inclusion, livelihood and empowerment, ensure that this information is accessible for analysis, reporting, research, publication and other purposes, and enable comparisons across countries. Documentation will include the following activities:

- Mapping of existing monitoring tools/systems and documentation practices of the CBR programs in the project countries.
- Identification of themes of specific interest to be targeted for documentation purposes in cooperation with CBR stakeholders and disabled people's organizations (DPOs).
- Development of definitions of relevant terms/concepts, indicators and other monitoring tools/systems to strengthen the CBR documentation process
- Collaboration with the CBR program(s) and relevant departments/offices (e.g. National Statistical Office and other data information systems) to improve the storage and availability of CBR program documentation
- Development of effective monitoring systems.
- Training of CBR, DPO and relevant government cadres in areas such as monitoring, data collection, reporting, and the use of qualitative information in documentation of best practices and most significant changes of the lives of people with disabilities brought about by the CBR programs.

(ii) The research component builds upon existing CBR and other relevant documentation, as well as the activities and outcomes of the documentation component of this project. Activities of the research component will include:

- Mapping of existing evidence-based research documents related to the CBR programs.

- Undertaking studies across CBR programs on themes derived from or identified during the project. Studies will be undertaken by professional researchers (with the active participation of disabled persons).
- Production/publication of research papers.
- Presentation of research papers in both national and international fora.

1.2. MACOHA AND the CBR program in Malawi

The Malawi Council for the Handicapped (MACOHA) is a government agency responsible for championing disability mainstreaming in Malawi. It was established in 1971 by an act of parliament, the Handicapped Persons Act of 1971. MACOHA operates under the direction of the Ministry of Persons with Disabilities and the Elderly on technical and operational issues and the Department of Statutory Corporations on finance, personnel and other management issues. The organization has adopted a human rights, development and multi sectoral approach to disability mainstreaming across sectors. MACOHA works in partnership with a number of stakeholders including the Federation of Disability Organizations in Malawi (FEDOMA) and its affiliates, government ministries and departments and non-governmental organizations (NGOs) responsible for education, health, livelihood, social inclusion and empowerment of persons with disabilities. In addition, MACOHA works in close collaboration with international development agencies such as the Norwegian Association of Disabled (NAD), CBM and Sightsavers.

MACOHA runs four programs, namely, the CBR program, institutional based vocational training program, production units and extension services. Through these programs, MACOHA serves a total of 500,000 persons with disabilities¹. MACOHA's major program, the CBR program, aims at promoting access by persons with disabilities to education and health (at all levels), livelihoods (through skills acquisition, access to business credit employment) and services available through various social inclusion programs being implemented mostly by Government, parastatal organizations (such as MACOHA) and NGOs. MACOHA's CBR program also promotes the empowerment of persons with disabilities for active participation in development work through self representation. Planning and implementation of the CBR program in 2 of the 12 CBR program areas, namely, Karonga and Nsanje is supported by the government and modeled on the ILO's vocational skills training and employment model. On the other hand, the programs in Blantyre, Balaka, Machinga and Mzimba are supported by NAD and modeled on the World Health Organization's CBR Matrix. Finally, the program is supported by CBM in the other districts of Salima, Nkhota-kota, Lilongwe, Nkhata-Bay, Dowa and most recently Ntchisi. Until recently, the main focus of the program in the CBM supported areas was ability of restoring surgery through cataract and orthopedic surgery. There are ongoing efforts to harmonize the three CBR program models. Malawi has made efforts to document CBR approaches and outcomes, but there has been no deliberate effort to prioritize documentation and to use the outcomes to share best practices and/or to inform practice. Most of the available documentation is related to mid-term and annual plans and reports, baseline studies, assessment and evaluation reports and brochures.

1.3. Purpose and objectives of the baseline study

¹ See SINTEF, CSR and FEDOMA. (2004). *Living conditions among people with activity limitations in Malawi*. Oslo: SINTEF.

The aim of the baseline study was to map, analyze and provide recommendations on existing CBR program documentation. This involved mapping of existing CBR documents including evidence based research documents, as well as current CBR program monitoring and documentation tools, systems and practices. The specific objectives of the baseline study included the following:

- to make available a comprehensive list of CBR documentation produced in Malawi since the program's inception
- to establish a baseline for documentation and research activities to be undertaken through NAD's D&R project
- to identify gaps in CBR documentation practices and to make recommendations to address these

The following activities were conducted as part of the baseline survey:

- Prepare information (in table format) on existing documentation to highlight the following information:
 - Title of the document.
 - Type of document (e.g. brochure, guidebook, evaluation/research report, assessment report, follow up study, newsletter, CBR update, other).
 - Year prepared/published.
 - Authorship.
 - Purpose (Explain briefly why the document or study was prepared/undertaken).
 - Methodology used to collect data/information (qualitative, quantitative, participatory, review of existing documentation, in-depth interviews with stakeholders).
 - Geographical coverage (national, regional, specific CBR districts or program, other).
 - Language (in which it is available e.g. English, Chichewa, Tumbuka).
 - Size of the document (number of pages).
- Summarize (in table format) existing research documentation on CBR by theme (i.e. by CBR Guidelines matrix component: education, health, livelihood, social and empowerment), nature of research (baseline study, action research), objectives and major research outcomes.
- Identify and describe current CBR program monitoring and documentation tools, systems and practices.
- Assess the extent to which existing documents have been disseminated (e.g. locally and internationally through publication, seminar presentation, e mail discussion lists, review meetings).
- Describe how documents have been used by MACOHA/the CBR program, CBR partners or other actors (e.g. to further develop / change / introduce new interventions, etc.).
- Identify stakeholder's strengths and challenges in terms of their capacity to document and carry out research on CBR related topics.

- Sum up reflections, observations and recommendations based on the study.

2.0 METHODOLOGY

A number of institutions were visited in order to collect CBR documents and these included FEDOMA, MACOHA (Lilongwe and Blantyre), Feed the Children Malawi, Sue Ryder Foundation, Malawi Against Physical Disabilities, National Library Service, Beit Cure International, Centre for Social Research, Chancellor College and the Ministry of People with Disabilities and the Elderly. In addition to visiting institutions internet searches were also done. During these visits interviews were also held with stakeholders in order to collect information about monitoring and evaluation, participation in documentation and research, and the recommendation on how documentation and research can be improved in CBR programs. The review mainly looked at various forms of documentation on CBR since the inception of the program. Such CBR documents included documentation commissioned by the CBR program and carried out by external consultants as well as internal CBR program studies/evaluations. The review did not include routine reports (e.g. semi- annual and annual reports) annual plans, funding applications, and training materials prepared by the CBR program or its partners).

3. RESULTS

Since the Community Based Rehabilitation (CBR) Program started in Malawi, there has been a significant growth in the number of documentation on CBR and on disability issues in general. CBR literature embraces a wide range of publications: research reports, policy documents, journal articles, directories, guides, workshop, conference and seminar reports, training modules, handbooks, theses, evaluation reports, magazines, newsletters and book chapters. Unfortunately, these materials are scattered in different institutions, libraries and documentation centres across the country. In the absence of a guide to these materials, it has been difficult to know what literature is available. As such, their utilization to inform policy and programming has been limited. There was, therefore, a need to compile a list of available documentation on CBR.

The purpose of this exercise was to identify and document information about literature on CBR programs in Malawi. Visits were made to various stakeholders and libraries in order to identify available documents on CBR. In addition, internet searches were also conducted. Sections 3.1 and 3.2 aim at broadening our knowledge of available literature on CBR in Malawi. These sections are intended for all those who work in institutions dealing with or are interested in disability issues. It is hoped that the two lists will facilitate the sharing of information and learning from each other; thus avoiding the unnecessary and costly duplication of efforts. The materials reviewed cover the period 1981-2010. For the first time, this exercise has enabled the compilation of all documents on CBR² in Malawi.

3.1 Chronological list of available Documentation and Research on CBR

Annex 1 shows a chronological list of documents including research reports on CBR in Malawi that have been collected as part of the NAD funded D & R project. This exercise was a continuation of the exercise started by NAD in mid 2010: NAD had collected and compiled

² This list of documents on CBR is not exhaustive. There are very few documents that might be missing from this list.

a number of documents on CBR but the list was incomplete. There were some documents that NAD had accessed but were not found during visits made to stakeholders by the researcher. Annex 1 shows a list of documents that were accessed and reviewed. Annex 2 contains documents that were accessed by NAD but not by the researchers who carried out this exercise. All the documents that were in the original list of documents compiled by NAD and also accessed by the researchers were removed and added to Annex 1. The majority of these documents were written by individuals on behalf of CBR organisations and research institutions they were affiliated to.

Annex 1 shows that there were 64 documents that were collected during the 15 day fieldwork. In Annex 2 there were 26 documents (No. 65-90) that were found by NAD but not seen by the researcher. In total, therefore, there were 90 documents including research reports on the CBR program in Malawi. These documents have been divided into the following categories: research reports; workshop and sensitisation reports; baseline reports; evaluation reports; booklets, pamphlets and brochures; newsletters and magazines; training reports; policy and strategic plans; Braille materials; and films. Figure 1 below shows the number of documents on CBR in Malawi reviewed by type:

Nearly a third (31.1%) of the documents and other reports reviewed were research reports and this was followed by booklets, pamphlets and brochures at 20%; evaluation reports (11.1%); and then newsletters and magazines (10%). The rest of the types of documents reviewed were less than 10%. There was actually only one firm produced. This demonstrates that quite a number of studies have been done on CBR in Malawi but this will be discussed in detail later. These studies have been done in order to better understand the challenges that people with disabilities experience. There were very few policy or strategic planning documents reviewed. It should be mentioned that there was no policy governing disability in Malawi until 2006 when the National Policy on Equalisation of Opportunities for People with Disabilities was published.

The newsletters and magazines are produced by stakeholders such as MACOHA, Sue Ryder Foundation and Malawi Against Physical Disabilities (MAPD). These newsletters depict activities including news about people with disabilities in Malawi that are being implemented by the producers of the newsletters and in most cases the articles are written by staff members. For example MACOHA CBR Update is a newsletter that contains articles written by MACOHA staff and it gives updates on the CBR program being implemented by MACOHA. Some of the newsletters also contain adverts for conferences on CBR – for example in 2004

the Disability World Newsletter contained a call for people working on CBR in Africa to submit papers for presentation during a CBR Africa Network conference that was held in Lilongwe, Malawi. The problem, however, is that in some cases these newsletters are not produced regularly mostly, according to some stakeholders, because of lack of funding.

A number of projects have been conducted by MACOHA and other CBR stakeholders and yet very few baselines have been done. The number of evaluation reports reviewed in this exercise was much more than baseline surveys that have been reviewed. This is an indication that possibly not all baseline reports have been kept by stakeholders or that the baselines were not done. Some stakeholders did mention that while they implement programs and they would like to conduct baselines in order to assess the achievements at the end of the projects, in some cases baselines are not done because of lack of resources and capacity of institutions to conduct such evaluations. Poor maintenance of records is one of the major challenges that organisations working on CBR in Malawi experience. CBR involves a lot of sensitisation of the people, both disabled and non-disabled, and workshops have been conducted by MACOHA and other organisations. Training of stakeholders has also been done. Either reports on these activities are not written or if they are compiled then they are not being kept properly as the research team managed to access very few of these documents.

3.2 Year of publication and language

Figure 2 below shows the proportion of CBR documents produced by year:

It is evident that nearly two thirds of the documents were produced in the 2000s and this was followed by the 1990s and then very few documents were produced in the 1980s. The 2000s coincide with the period when the disability movement has been quite active in Malawi. However, 15.6% of the documents did not have a year of publication (noted as ND on Figure 2) and these were mostly brochures, pamphlets and booklets. Most of the documents that have no date of publication most likely were also produced between 2000 and 2010. Figure 3 below shows the number of documents produced by year for the period 2000-2010.

As has been said earlier, it is over this period that most of the documents were produced. Most of the documents have been studies to inform the development of interventions as well as the development of the disability policy and bill. In 2009 alone 10 documents were produced followed by the year 2003 and 2006 when 9 and 8 documents were produced, respectively. The production of many documents on disability in Malawi coincides with the African Decade for the Disabled People (2000-2009) which was officially proclaimed in 2000 by the OAU in Lome.

In terms of language, most of the documents have been written in English with an exception of about 9 documents which have been written in local languages namely Chichewa, Chitumbuka and Chiyao. A few documents have been published in Braille. The major problem is that a significant proportion of Malawi's population including people with disabilities is illiterate hence unable to read and write. Since the majority of the publications are in English, a good proportion of Malawians will not be able to read these documents hence the need for translation. While most of the documents have been produced for the national level, some of the documents have been produced for specific geographical location to inform the development of interventions, for example the 2003 "*Baseline study for CBR Programs in Machinga and Blantyre Districts*" authored by Kangere,

3.3 Research

3.3.1 Most studies on CBR are crosscutting

Annex 3 is a list of studies on CBR that have been done in Malawi by theme: health, education, empowerment and social. It provides details on the title of research, year of publication, the type of research, objectives and major research outcomes. It should be mentioned that while there are these five themes, most of the studies that have been done have really been crosscutting in nature: one study could cover a wide range of themes for example, a study done by Kvam and Braathen in 2006 investigated the forms of abuse, violence and discrimination against women with disabilities in Blantyre. The study used in-depth interviews and focus group discussions with the target groups in order to collect data. The study provided information on health: that women access health care through public facilities and that they have no problems with health professionals with an exception of women with hearing impairment who experience communication problems as health professionals do not know sign language. Women with disabilities also consult traditional healers as they believe that they have been bewitched. The study also covers the theme of education: it highlights the problems that people with disabilities are experiencing as far as accessing education is concerned, namely, lack of financial resources, mobility problems, some schools not being accessible for various reasons, lack of Braille materials, lack of knowledge among teachers to

use sign language and the lack of teachers of special education. It also highlights the problems that disabled girls especially and albinos experience. Finally, the study also looks at the theme of social: highlighting the problems for example, that women with disabilities experience in creating relationships and the sexual abuse that they experience in these relationships for example pregnant women with disabilities being abandoned by men responsible for the pregnancy³. While the five themes are being examined, there is a need to also bear in mind that most of the studies were cross cutting as has been exemplified by the study above.

3.3.2 CBR research by theme

Although the studies done on CBR were cross-cutting we also looked at the number of studies covering each theme. Figure 4 below shows the number of studies that have been done by theme:

Figure 4 above generally shows that there have not been many studies on two themes namely social and empowerment as only 7 and 5 studies have been done, respectively. Most of the studies done in Malawi on CBR have covered health, education and livelihoods as can be seen in Figure 4 above. Research on CBR that has been done in Malawi was further classified into several categories namely:

- Basic research mostly done for academic or theoretical reasons (but may have policy and program design implications);
- Evaluation studies to determine the impact of a particular project; baseline to determine the situation before starting implementation of interventions;
- Action research aimed at designing interventions or informing policy development.

Annex 3 shows the type of studies that have been done. There are 20 studies that can be classified as basic research but they have had policy and program implications. As was highlighted earlier the number of baseline surveys that have been done is much less compared to evaluations.

3.3.3 Theme I: Health

This theme covers issues such as health promotion, prevention, primary and secondary care, tertiary care and rehabilitation and assistive devices. This section discusses prevalence of disability in Malawi, the causes of disability, health seeking behaviour by people with

³ Kvam, M.H. and S.H. Braathen. (2006). *Violence and abuse against women with disabilities in Malawi*. Oslo: SINTEF Health Research.

disabilities, HIV and AIDS and sexual and reproductive health issues including the challenges that people with disabilities experience as they seek treatment.

3.3.3.1 Disability prevalence

A number of studies have been done to determine the prevalence of disability in Malawi. In 1983 the first study was done by National Statistical Office (NSO) to determine the prevalence of handicapped persons in Malawi. This study estimated that about 3% of the population of Malawi consisted of handicapped persons and the majority of handicapped persons (93%) were in rural areas with only 7% in the urban areas. At the time there were three major forms of disability namely fits/epilepsy (18.8%), crippled limbs (18.2%) and deafness (13.3%)⁴. More than 90% of the people surveyed suffered from more than one form of disability. Another national survey was done in 1993 and the prevalence of disability was just the same as that found in 1983⁵. A more comprehensive survey, *Living conditions of people with activity limitations in Malawi*, was carried out to determine the prevalence of disability in Malawi was conducted in 2003 by SINTEF, CSR and FEDOMA. This survey found a national prevalence of 4.18% which was higher than earlier surveys. The major forms of disabilities as determined by this survey were physical disabilities (43%), sensory impairments (42%) and 11% other forms of disabilities. The *Living conditions* study 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.

In addition to the large nationwide surveys there have also been small-scale geographical location specific studies that have also looked at prevalence of disability. For example, in 1992 MacDonald did a small survey in Balala Ward in Ntchisi District where he found that there were 206 disabled persons in the 35 villages in this ward. She says that this was below 2.9% disability prevalence at national as estimated in the 1983 survey. In this study physical disabilities were as well the most common⁶. A 2009 baseline study in Chikwawa District reported that in 2003 there were 1065 registered persons with disabilities in the district and the types of disabilities prevalent in the community included visual, physical, hearing, epilepsy among others⁷. These were just estimations.

When designing interventions in most cases baseline surveys are not undertaken to determine the number of people with disabilities: stakeholders look at the prevalence of disability as estimated at national level and then determine the number of people with disabilities they would like to target. As far as prevalence surveys among people with disabilities is concerned, it seems that there is reliable data from the 2003 *Living conditions of people with activity limitation* study. It is necessary to conduct another living conditions survey to determine if there are any changes in the living conditions of people with disabilities including access to education and health.

3.3.3.2 Causes of disability

⁴ National Statistical Office. *A survey of handicapped persons in Malawi*. Zomba: National Statistical Office.

⁵ Researcher did not access this report.

⁶ MacDonald, P. (1992). *Report on the disabled within the Bawala Ward: Ntchisi Strategy for Assistance*. [Publisher not known]

⁷ Ministry of People with Disabilities and the Elderly. (2009). *Baseline survey report on the socio-economic situation of people with disabilities in Chikwawa district*. Lilongwe: Ministry of People with Disabilities and the Elderly

Knowing what people perceive to be causes of disability is important as it is an important determinant of where people will seek treatment. A number of studies have looked at causes of disabilities. For example in 1992 McDonald in his study in a Bawala Ward in Ntchisi found that people mentioned the following as causes of disability: diseases such as polio, accidents, burns and witchcraft among others⁸. The 2003 *Living condition study* also showed that the most common causes of disability in Malawi were physical illness, from birth (natural/congenital) and accidents⁹. There also exist beliefs that children born from disabled persons will also be disabled¹⁰.

Some specific studies have been done looking at particular forms of disabilities. For example, Kvan and Braathen found that albinism is caused by *mwanamphepo* or if a pregnant woman looks at an albino she may also deliver an albino as well and this is why some people spit on the ground when they see an albino. In some cases albinism is looked upon as God's will and this implies that this condition is natural. The study further points out the different problems that albinos experience as far as health is concerned, namely, skin problems, vision and many of them have never used sunscreen before because of poverty¹¹. There have been situations when FEDOMA has helped people with albinism with sunscreen¹².

Another specific disease that some studies have looked at is cerebral palsy which is also a major problem among children in Malawi. A number of studies have also been done looking at what people believe are the causes of this condition. Some respondents knew that cerebral palsy (CP) was a medical condition resulting from brain damage from different causes but some did not know. Most of the participants knew what caused the condition of their children e.g. malaria, meningitis and jaundice. Others demonstrated lack of knowledge about the condition, especially those who did not know what CP is. Even though the majority of the people believed that witchcraft was not involved in the causation of CP in children, others believed that it was involved due to some events preceding the condition¹³. It can be concluded therefore that in most cases people attribute disability to biomedical causes and while this is the case there are also others who believe that witchcraft and other supernatural forces are involved.

3.3.3.3 Improving access to treatment for people with disabilities

A number of studies have generally demonstrated that people with disabilities have problems in terms of accessing health services. The 2003 *Living conditions study* showed that the majority of people with disabilities were aware of the services available and that a significant proportion of the people with disabilities needed the services. However, a considerably lower proportion of people with disabilities actually received the services they needed. For example the study revealed that 84% of the respondents were aware of the health services available, 83% required these services but only 64% received the services. This demonstrates that there exist gaps between what services people with disabilities need and what they receive¹⁴.

⁸ McDonald, P. (1992). *Report on the disabled within the Bawala Ward: Ntchisi Strategy for Assistance*. [Publisher unknown]

⁹ SINTEF, CSR and FEDOMA. (2004). *Living conditions of people with activity limitations in Malawi*. Oslo: SINTEF.

¹⁰ A report on HIV/AIDS and reproductive health care amongst people with disabilities. (nd).

¹¹ Braathen, S. (2006). *Albinism in Malawi: a qualitative study on attitudes and beliefs*. MA in Medical Anthropology Thesis, University of Oslo.

¹² Kvam, M.H. and S.H. Braathen. (2006). *Violence and abuse against women with disabilities in Malawi*. Oslo: SINTEF.

¹³ Mwafulirwa, S.K. (2008). *Mothers/guardians' perception on rehabilitation of cerebral palsy children at Feed the Children Malawi, Blantyre campus*.

¹⁴ SINTEF, CSR and FEDOMA. (2004). *Living conditions among people with activity limitations in Malawi*. Oslo: SINTEF

CBR programs being implemented in Malawi, among other activities, also aim at improving access to health services by people with disabilities. These programs register persons with disabilities and they are provided home-based treatment and taught about home-based treatment the family can implement or referred to hospitals or other service providers such as Sightsavers supported initiatives such as ophthalmic services for further treatment. An example can be given of the Msakambewa Community Based Rehabilitation Program which registered 1,658 persons with disabilities over a period of three years. The program assisted 238 persons with disabilities with physiotherapy while 526 were referred to hospitals, 95 to Sight Savers and 49 to institutions for the visually impaired while 74 were referred to MAP. Some persons with visual impairment regained sight and those with hearing impairments their situation improved and for people with epilepsy their seizures improved due to treatment and advice¹⁵. In 2010 a quality of life assessment tool study also gave an example of a parent whose child had club foot and after an operation and physiotherapy the life of the child and his family changed: initially the child could not walk but after being treated he started walking and leading an independent life¹⁶. The evaluation of the Blantyre Cheshire Homes CBR project (1998-2001) also found that during the period of the project a total of 1158 clients were assisted and 138 of these were children among whom the most common identified problem was cerebral palsy, learning difficulties and communication problems. Most of the children who were going to Blantyre Cheshire Homes presented either for physiotherapy or occupational therapy and others went there for special needs education or vocational skills. The project also offered 243 pieces of equipment to children and the most common pieces of equipment provided to children were the CP chairs, corner seats and standing frames. Over the period of the project there was an increase of 318% in the number of children receiving treatment¹⁷. Therefore, studies have demonstrated that it is evident that the CBR programs help to increase access to treatment and other services.

A 2007 study looking at children with CP revealed that in most cases children with this problem attended therapy with their mothers or grandmothers. Most of the caregivers did not have anyone to help them take the children with CP to rehabilitation centres. The main problem that prevented some mothers from attending therapy with their children was that they were at work¹⁸. Knowledge about CP among mothers with children with CP was found generally low: in 2008 67% of the mothers had no or little knowledge about CP¹⁹. The major problems caregivers of children with CP experienced were gossiping among community members, lack of transport money to get to the clinic, that the child was dependent and hence caregivers were spending too much time seeking care instead of doing productive work and that some community members have bad feelings towards children with CP²⁰.

Some parents or guardians with children who had cerebral palsy reported getting family support especially in terms of showing love and helping in caring for the child and provision of resources while others did not get any such support. The same thing applied to community

¹⁵ Makoko, A.J.L. (2002). *Final evaluation of Msakambewa Community Based Rehabilitation Program*. Blantyre: MACOHA.

¹⁶ Massa. (2010). *Quality of life assessment tool and impact analysis in the framework of P1919*.

¹⁷ Nieuwenhuizen, R. (2001). *Blantyre Cheshire Home Community Based Rehabilitation Project Project dates: April 1998-March 2001*. Blantyre: Blantyre Cheshire Home.

¹⁸ Alfazema, E.J.M. (2007). *A descriptive study identifying the caregivers attending treatment with C.P. children at Feed the Child Malawi, Blantyre Campus from 30th April to 5th May 2007*.

¹⁹ Mwafulirwa, S.K. (2008). *Mothers/guardians' perception on rehabilitation of cerebral palsy children at Feed the Children Malawi, Blantyre campus*.

²⁰ Alfazema, E.J.M. (2007). *A descriptive study identifying the caregivers attending treatment with C.P. children at Feed the Child Malawi, Blantyre Campus from 30th April to 5th May 2007*.

support²¹. Even though in places such as Feed the Children Malawi, treatment including rehabilitation services is given to children with CP, nearly half of the mothers do not know whether this was helpful or not. Because some people believe that CP is sometimes caused by witchcraft they consult traditional healers but stop consulting them after seeing the benefits of the treatment they were getting at for example Feed the Children Malawi²². In order to improve care for children with cerebral palsy a number of suggestions were made for example:

- No segregation by health workers in other hospitals.
- Provision of free equipment for physiotherapy at home.
- Availability of funds for parents to start business.
- Showing love to the child.
- Provision of educational opportunities.
- Putting more effort on physiotherapy by parents²³.

In some CBR programs the number of people with disabilities assisted is much less than desired: for example in an evaluation of a CBR program for the visually impaired persons conducted in Blantyre it was found that only 9% of the visually impaired were identified and of these only 3% were assisted. In this program the quality of services was considered low mainly because the CROs and VRVs were responsible for very large areas and there were many disabled persons in the areas they were responsible for. The other problem was that there was lack of understanding among VRVs about the prevention of further loss of vision²⁴.

The theme of health also includes the provision of assistive devices. One nationwide study found that 17% of the respondents used assistive devices. There were more men (25%) who used assistive devices compared to women (14%). Seventy percent (70%) of the respondents who were using assistive devices used personal mobility devices such as wheelchairs, crutches and walking sticks etc. Some used more than one assistive device. Thirty four percent of those using devices acquired them privately, 19% from government and 9% through NGOs and the rest through other sources²⁵.

In terms of accessing health care, some studies have demonstrated that people with disabilities have good experiences with health professionals. The majority seem not to be discriminated against when they go for services at the health facility²⁶. In some cases however people with disabilities are mistreated at the health facilities: e.g. Mji et al report that disabled women are mistreated at antenatal clinics, during delivery and post natal services as if they are not supposed to conceive and give birth²⁷. As well, people with hearing impairment experience communication difficulties because of lack of knowledge about sign language among health professionals.

²¹ Chimowa, T. (2007). *Perceptions of parents/guardians' of children with cerebral palsy*.

²² Mwafulirwa, S.K. (2008). *Mothers/guardians' perception on rehabilitation of cerebral palsy children at Feed the Children Malawi, Blantyre campus*.

²³ Chimowa, T. (2007). *Perceptions of parents/guardians' of children with cerebral palsy*.

²⁴ Fagan, T; G. Nyaga and I.L. Campbell. (1990). *Evaluation of services for the visually impaired within a CBR program*. Blantyre: MACOHA

²⁵ SINTEF, CSR and FEDOMA. (2004). *Living conditions among people with activity limitations in Malawi*. Oslo: SINTEF.

²⁶ Ministry of People with Disabilities and the Elderly. (2009). *Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District*. Lilongwe: Ministry of People with Disabilities and the Elderly.

²⁷ Gubela M., S. Gcaza, M. Wazakili and D. Skinner (nd). *A report on HIV/AIDS and reproductive health care amongst people with disabilities*. Capetown: Stellenbosch University.

In most cases people with disabilities will seek treatment for their disability from health facilities but some do go to traditional healers because of the belief that they have been bewitched. In a study conducted in Ntchisi in 1992 it was found that 51% of the disabled sought medical help from facilities, 18% from traditional healers while 4% sought both medical and traditional treatment, and 28% did not seek treatment. It was also found that it was mainly those with epilepsy who sought help from traditional healers as they thought that this disease was caused by witchcraft. In terms of seeking care, mobility is one of the major problems that people with disabilities experience²⁸. Another study revealed that some people with disabilities live very far from health facilities, which affects access to health care²⁹. It is evident that while there are different sources of treatment, most people with disabilities seek treatment from modern health facilities and that the majority of health workers treat people with disabilities well. However there are other problems that people with disabilities experience when accessing care with inaccessibility of facilities and long distances being two of them.

3.3.3.4 HIV/AIDS and sexual and reproductive health among people with disabilities

Studies generally reveal that there are no differences in sexuality between people with and without disabilities. People with disabilities are equally sexually active: a 2004 study showed that three quarters of respondents reported having had sex and of those who had had sex 17% reported that they were forced. In 2004 28% of the respondents with disabilities also reported that they were using family planning methods. In 2004 the majority of people with disabilities knew about condoms: only 42% of those who knew about condoms reported knowing how to use condoms and 27% of those who knew about condoms reported having ever used condoms. A number of reasons were given for non-use of condoms, for example never having had sexual intercourse, not liking the condoms, not being promiscuous i.e. being faithful. Some reported having difficulties in using condoms because of disability, hence they need for them to be assisted by their partners³⁰.

In terms of HIV and AIDS in 2004 90% of the respondents had heard about HIV and 94% had heard about AIDS³¹. Even though some studies (such as the one done by Munthali et al in 2004) have shown that all people with disabilities are aware about how HIV is transmitted and how it can be prevented, there are others who are not aware of this^{32,33}. One study has shown that learners with disabilities have little knowledge about AIDS especially the deaf-blind³⁴. The major sources of HIV information for people with disabilities include the radio, health facilities and friends. Only one person talked about sign language as a source of information on HIV and AIDS. There are quite a number of problems that people with disabilities experience in accessing information on HIV/AIDS and these include lack of radios, lack of outreach programs, lack of materials, long distances to health facilities and mobility problems.

²⁸ McDonald, P. (1992). *Report on the disabled within the Bawala Ward: Ntchisi Strategy for Assistance*.

²⁹ Ministry of People with Disabilities and the Elderly. (2009). *Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District*. Lilongwe: Ministry of People with Disabilities and the Elderly.

³⁰ Munthali, A., P. Mvula and S. Ali. (2004). *Effective HIV/AIDS and reproductive health information to people with disabilities*. Blantyre: FEDOMA.

³¹ Munthali, A., P. Mvula and S. Ali. (2004). *Effective HIV/AIDS and reproductive health information to people with disabilities*. Blantyre: FEDOMA.

³² Gubela M., S. Gcaza, M. Wazakili and D. Skinner (nd). *A report on HIV/AIDS and reproductive health care amongst people with disabilities*. Capetown: Stellenbosch University.

³³ Munthali, A., P. Mvula and S. Ali. (2004). *Effective HIV/AIDS and reproductive health information to people with disabilities*. Blantyre: FEDOMA.

³⁴ A baseline study of steps taken towards inclusive education in Blantyre, Balaka and Machinga Districts in Malawi

In addition to HIV and AIDS most people with disabilities were aware of STIs and 3% admitted to having ever had an STI and the majority of those who reported this sought treatment from facilities³⁵.

People with disabilities are vulnerable to HIV infection because among other reasons they lack information on HIV/AIDS. One of the major barriers is that the information on HIV/AIDS is not properly packaged so as to effectively reach people with different forms of disabilities such as the visually impaired and the deaf³⁶. People with disabilities are also vulnerable because there is a belief that a disabled person is a cleanser of HIV/AIDS meaning that if an HIV+ person has sex with a disabled person the disease will be cured. Other negative attitudes towards people with disabilities is that having sex with them would increase one's wealth³⁷. Knowing that HIV/AIDS is also a problem among people with disabilities, a total of 22,330 condoms were distributed to people with disabilities and staff. These condoms were sourced from PSI, MACRO, DHOs and other service providers. These condoms were left in the washrooms for people to pick and the rate of condom replenishment was higher in male washrooms compared to ladies' washrooms. The major problems with this HIV/AIDS project was that it was a one off activity and no follow up was done and that most of the youths with disabilities were not given attention³⁸.

In terms of HIV testing and counselling a 2004 study showed that 70% of the people with disabilities were aware of HIV testing and counselling (HTC) but only 10% reported having been tested³⁹. An evaluation of one CBR program showed that nearly half of the target number of people went for HTC⁴⁰. Mji et al also report that not many people with disabilities have been tested for HIV. Issues of confidentiality are important and Mji et al further report that among people with disabilities who cannot talk and need a sign language interpreter there may not be confidentiality with regard to HIV testing and counselling. Other challenges include lack of a guide to take the visually impaired for example to HTC sites and long distances to HTC sites⁴¹. Other reasons which deter people with disabilities from going for HTC include the thinking that they are okay and the fear that blood will be pumped from their bodies⁴². Research on access to ART and PMTCT services by people with disabilities in Malawi is however rare.

3.3.3.5 Capacity building

Some of the projects e.g. the Blantyre Cheshire Homes CBR project (1998-2001) were involved in capacity building for example by training health personnel (such as HSAs, nurses, medical assistants, CBR volunteers) including parents in the management of disability.

³⁵ Munthali, A., P. Mvula and S. Ali. (2004). Effective HIV/AIDS and reproductive health information to people with disabilities. Blantyre: FEDOMA.

³⁶ Munthali, A., P. Mvula and S. Ali. (2004). Effective HIV/AIDS and reproductive health information to people with disabilities. Blantyre: FEDOMA.

³⁷ Mji, G., S. Gcaza, M. Wazakili and D. Skinner (nd). *A report on HIV/AIDS and reproductive health care amongst people with disabilities*. Capetown: Stellenbosch University.

³⁸ Makoko, A.J.L (2007). *HIV/AIDS Awareness, Behavioural and Attitude Change Towards Persons with Disabilities program (April 2005 – March 2006)*. Blantyre: MACOHA.

³⁹ Munthali, A., P. Mvula and S. Ali. (2004). Effective HIV/AIDS and reproductive health information to people with disabilities. Blantyre: FEDOMA.

⁴⁰ Makoko, A.J.L (2007). *HIV/AIDS Awareness, Behavioural and Attitude Change Towards Persons with Disabilities program (April 2005 – March 2006)*. Blantyre: MACOHA.

⁴¹ Mji, G., S. Gcaza, M. Wazakili and D. Skinner (nd). *A report on HIV/AIDS and reproductive health care amongst people with disabilities*. Capetown: Stellenbosch University.

⁴² Munthali, A., P. Mvula and S. Ali. (2004). Effective HIV/AIDS and reproductive health information to people with disabilities. Blantyre: FEDOMA.

Access to information on health and health care for example about HIV/AIDS among people with disabilities is one of the major concerns affecting people with disabilities. The HIV/AIDS awareness, behavioural and attitude change towards persons with disabilities program (2005-2006) was aimed at bringing awareness about HIV/AIDS and disability. In this program the dissemination of information on HIV/AIDS to people with disabilities included the production and dissemination of HIV/AIDS messages through Braille and the use of large print for those who were visually impaired, the airing of programs on TV and radio for those with hearing and speech problems and the production of various IEC materials. As part of this program participants from various organisations dealing with HIV/AIDS were trained in sign language so that they are able to communicate with people who have hearing and speech impairments. An evaluation of this program showed that nearly half of the target number of people went for HTC⁴³. In the case of cerebral palsy all mothers and guardians of children with cerebral palsy were being taught how to do physiotherapy⁴⁴. It is evident therefore that capacity building programs for people with disabilities especially in the area of health have been limited and it seems they are one off activities.

3.3.4 Theme II: Education

A number of studies have been done on disability and education. Accessing education and ensuring that people with disabilities remain in school is a major challenge experienced by people with disabilities and their families. For example in 1983 among handicapped persons aged 5+ only 42% ever attended school, 96% of these went up to primary school and only 4% went to secondary school or higher⁴⁵. A study conducted in 1992 in one ward in Ntchisi District showed that only 19% of those aged 6+ years were attending school at the time of the survey and that 52% of the disabled had never been to school⁴⁶. Even when people with disabilities attend school, in most cases they are behind compared to other disabled children⁴⁷. A more recent study conducted in 2003 showed that school attendance is lower among the disabled members of the households compared to those members without disabilities: 34.8% of households with disabled members had ever attended school compared with 17.7% among the non-disabled⁴⁸. In some cases parents have also withdrawn their children from school because of disability and this has resulted into low enrolment of among children with disabilities⁴⁹. Some parents with children with disabilities do not send their children to school due to poverty and lack of interest⁵⁰. Earlier on in 1992 one of the primary reasons for children with disabilities not to attend school was lack of school fees and others included severity of disability, schools being too far and having walking problems⁵¹.

One of the major problems that people with disabilities experience with regard to education is that they quit school mainly because they lack financial resources. Children with physical disabilities experience mobility problems e.g. as much as they would like to attend school some do not have a wheel chair to get to school and some schools are not accessible to people with disabilities hence they end up withdrawing from school. Albinos are afraid of going to

⁴³ Makoko, A.J.L (2007). *HIV/AIDS Awareness, Behavioural and Attitude Change Towards Persons with Disabilities program (April 2005 – March 2006)*. Blantyre: MACOHA.

⁴⁴ Chimowa, T. (2007). *Perceptions of parents/guardians' of children with cerebral palsy.*

⁴⁵ National Statistical Office. (1983). *Survey of handicapped persons in Malawi*. Zomba: National Statistical Office.

⁴⁶ McDonald, P. (1992). *Report on the disabled within Bawala Ward*. Dowa: Publisher Unknown.

⁴⁷ Kaliwa, G. (2006). *Visually impaired children's experiences with special segregated schools in Malawi: the case of Chilanga School for the Blind*. MA Thesis, University of Oslo, Norway.

⁴⁸ SINTEF, CSR and FEDOMA. (2004). *Living conditions among people with activity limitations in Malawi*. Oslo: SINTEF.

⁴⁹ Kvam and Braathen. (2006). *Violence and abuse against women with disabilities*. Oslo: SINTEF.

⁵⁰ Ministry of Persons with Disabilities and the Elderly. (2009). *Baseline survey report on socio-economic situation of people with disabilities in Chikhwawa District*. Lilongwe: Ministry of Persons with Disabilities and the Elderly.

⁵¹ McDonald, P. (1992). *Report on the disabled within Bawala Ward*. Dowa: ???

and from school in sunshine; they also experience problems reading books and hence this affects their performance⁵².

There are external factors that make visually impaired children quit school. However there are certain factors within the school environment that can also make children with disabilities leave school. Suka in her study conducted with visually impaired school girls outline the forms of violence that are perpetrated against visually impaired girls in school and these include threats and actual sexual abuse from for example specialist teachers; verbal abuse such as belittling them, saying that no one would be interested in having an affair with them; and extensive teasing such as leading them to wrong classrooms among other factors. Suka argues that there are high dropout rates among visually impaired girls because of girls' lack of interest in school and violence perpetrated against them in school. As a result of these experiences very few visually impaired girls make it to secondary school⁵³. Chavuta has also highlighted the problems that girls with special educational needs experience such as inappropriate school facilities, long distances and poverty⁵⁴.

In some schools especially the mainstream schools there is a general lack of Braille materials for the visually impaired. This is also complicated by the lack of knowledge among teachers about sign language; hence people with hearing impairments experience communication problems. Sign language has now been incorporated into in service training for teachers and sign language interpreters are being trained, There is also a lack of teachers of special education^{55,56} and some itinerant teachers, while based at one school, also visit other schools to teach children with special needs. Recognising the challenges faced by people who are visually impaired the Government of Malawi has established special schools to cater for visually impaired. Most of the children in speciality schools such as the Schools for the Blind (e.g. Chilanga School for the Blind in Kasungu) started in other schools but because of lack of facilities for the visually impaired the pupils had to be transferred to special schools. The visually impaired pupils liked being in these special schools because teachers were available who knew Braille, unlike teachers in mainstream schools. For people who are visually impaired the biggest challenge is lack of resources and they suggested that secondary school education should be free as their parents cannot afford to pay school fees⁵⁷.

Learners with special needs are identified mostly by teachers, parents and the community. The teachers of special needs education conduct advocacy work but their impact is limited because their numbers are few. On the other hand regular teachers and the community lack knowledge and skills on how to identify learners with special needs. Delivering special needs education is hampered by unfavourable working conditions and insufficient teaching and learning materials⁵⁸. In addition to this, classes in mainstream schools are usually large and learners with disabilities do not receive adequate support especially the deaf. There seems to be more awareness about special needs education than in education. The demand for special needs education is high in Malawi but it seems this demand is not being met⁵⁹.

⁵² Kvam and Hellium Braathen. (2006). *Violence and abuse against women with disabilities*. Oslo: SINTEF.

⁵³ Suka, A. (2006). *Violence against girls who are blind and visually impaired in schools in Malawi*. Lilongwe: SSI.

⁵⁴ Ministry of Education. (2009). *An investigation on the effectiveness of special needs education service delivery in Malawi primary schools*. Lilongwe: Ministry of Education.

⁵⁵ Kvam and Hellium Braathen. (2006). *Violence and abuse against women with disabilities*. Oslo: SINTEF.

⁵⁶ A baseline study of steps taken towards inclusive education in Blantyre, Balaka and Machinga Districts in Malawi

⁵⁷ Kaliwa, G. (2006). *Visually impaired children's experiences with special segregated schools in Malawi: the case of Chilanga School for the Blind*. MA Thesis, University of Oslo, Norway.

⁵⁸ Ministry of Education. (2009). *An investigation on the effectiveness of special needs education service delivery in Malawi primary schools*. Lilongwe: Ministry of Education.

⁵⁹ A baseline study of steps taken towards inclusive education in Blantyre, Balaka and Machinga Districts in Malawi

Because of the problems that people with disabilities experience, there are a number of CBR projects that have been implemented in order to ensure that children with disabilities stay in school. For example the Msakambewa CBR program integrated disabled children into regular or special schools and trained teachers in special education. This training of teachers reduced the problem of the shortage of teachers of special education in the catchment area of the project. In addition to this, the project also paid school fees for some students who were in secondary schools. As part of the project CRWs were also visiting the children integrated in schools to observe how they were doing and offer support⁶⁰. Another project which initially targeted visually impaired children in Balaka district, as a way of improving access to education for visually impaired children, had two Montfort trained teachers deployed to the area and Braille textbooks were also made available to the visually impaired. Massa has also given an example of a parent who appreciated the impact of the CBR interventions as her child was able to go to school without being escorted⁶¹.

3.3.5 Theme III: Livelihoods

In a number of studies, people with disabilities have been asked about their sources of livelihoods. As is the case with the general population in Malawi a number of studies have shown that the major source of livelihood for people with disabilities is farming both subsistence and commercial^{62,63}. For example a baseline study done in Chikhwawa District in 2009 has shown that people with disabilities grow crops such as maize, millet and sorghum but they also engage in small scale business. The *Living conditions study* found that 58% of the people with disabilities were not working at the time of the survey compared to 53% among the non disabled. This emphasises the high unemployment rate in Malawi⁶⁴.

The CBR program in Malawi has also aimed at addressing livelihood challenges that people with disabilities are experiencing. People with disabilities for example have been provided with vocational skills in order to earn a living and the trainees are in most cases identified by Ministry of Persons with Disabilities and the Elderly, CROs, DSWO, MACOHA and DPOs. A slightly higher proportion of people with disabilities (41.2%) had acquired some skills compared to 38.7% of people without disabilities⁶⁵. In 2007 one study found that 48% of the survey population had attended some skills training and 50% of those who attended some skills training were in employment. Most of the people with disabilities had acquired skills at training centres of MACOHA and TEVET or at primary schools where handcrafts were provided. The most common vocational skills acquired by people with disabilities were tailoring, weaving, agriculture, carpentry and home economics and women were more likely to be trained in home economics and weaving compared to men who were most trained in agriculture and tailoring⁶⁶. A more recent study conducted in 2010 has shown that after being equipped with vocational skills people with disabilities are recognised by society and have

⁶⁰ Kvam and Hellium Braathen. (2006). *Violence and abuse against women with disabilities*. Oslo: SINTEF.

⁶¹ Massa, B. (2010). *Quality of life assessment tool and impact analysis in the framework of P1919*.

⁶² Mji, G., S. Gcaza, M. Wazakili and D. Skinner (nd). *A report on HIV/AIDS and reproductive health care amongst people with disabilities*. Capetown: Stellenbosch University..

⁶³ McDonald, P. (1992). *Report on the disabled within Bawala Ward, Ntchisi Strategy for Assistance*. [Publisher not specified].

⁶⁴ SINTEF, CSR and FEDOMA. (2004). *Living conditions of people with activity limitations in Malawi*. Oslo: SINTEF.

⁶⁵ SINTEF, CSR and FEDOMA. (2004). *Living conditions of people with activity limitations in Malawi*. Oslo: SINTEF.

⁶⁶ International Labour Organisation. (2007). *Strategies for skills acquisition and work for persons with disabilities in Southern Africa – Malawi*. Geneva: International Labour Organisation.

been able to take up jobs⁶⁷. The majority of the respondents found the vocational skills they had acquired useful in finding work.

While some people with disabilities would want to attend vocational training there were some barriers to attending such trainings: some cannot afford training fees; there is no opportunity of taking time off because of family responsibilities; transport challenges of getting to and from training centres; and communication difficulties among people with disabilities; unwillingness of trainers to train people with disabilities with others being sent back home because of disability; lack of training materials in Braille among other factors⁶⁸.

In addition to TEVETA and MACOHA training centres as has been mentioned above, people with disabilities also acquired vocational skills from local artisans as was the case in the Msakambewa CBR program. In this program people with disabilities acquired skills in carpentry, knitting, tailoring and tinsmithing. MACOHA paid the training fees because, as has been mentioned earlier, there were problems in terms of people with disabilities being able to pay such fees. After the training people with disabilities in the Msakambewa CBR program were given loans to purchase tools and start operating on their own. While the Msakambewa CBR program aimed at training 150 PWDs only 79 were trained because of lack of local artisans in the area⁶⁹.

In terms of employment, people with disabilities are either employed or in self employment utilising the skills they had acquired. For example a study conducted in 2007 found that a good proportion of people with disabilities were in self employment engaging in trades such as bicycle and radio repairing; selling foods; and tailoring. Others were in formal employment: they either found their jobs through the training centres where they got vocational skills or on their own, help from friends and relatives. This study also looked at the barriers for people with disabilities in finding work and these included lack of skills training that could empower people with disabilities, lack of jobs, mobility challenges, lack of access to credit for small scale businesses and lack of awareness among employers about the rights of people with disabilities⁷⁰. In addition to these problems albinos also experience other problems: they have problems in finding employment as it is believed that they die young and some of them have been rejected in training institutions⁷¹. Respondents also said that skills training and availability of support services such as access to loans or any form of financial assistance would help them find work or improve at work⁷².

In order to improve living conditions of people with disabilities there have been a number of CBR programs that have disbursed loans to people with disabilities. For example:

- An evaluation of a CBR program targeting visually impaired persons in 1990 found that a good proportion of people with disabilities who were given loans had paid back

⁶⁷ Massa.(2010), *Quality of life assessment tool and impact analysis in the framework of 2010*.

⁶⁸ International Labour Organisation. (2007). *Strategies for skills acquisition and work for persons with disabilities in Southern Africa – Malawi*. Geneva: International Labour Organisation.

⁶⁹ Makoko, A.J.L (2002). *Final evaluation of Msakambewa Community based Rehabilitation program*. Blantyre: MACOHA.

⁷⁰ International Labour Organisation. (2007). *Strategies for skills acquisition and work for persons with disabilities in Southern Africa – Malawi*. Geneva: International Labour Organisation. Also see Ministry of Persons with Disabilities and the Elderly. (2009). *Baseline survey on the socio-economic situation of people with disabilities in Chikhwawa District*. Lilongwe: Ministry of Persons with Disabilities and the Elderly.

⁷¹ Braathen, S.H. (2006). *Albinism in Malawi: a qualitative study on attitudes and beliefs*. MA in Medical anthropology Thesis. Oslo: University of Oslo.

⁷² International Labour Organisation. (2007). *Strategies for skills acquisition and work for persons with disabilities in Southern Africa – Malawi*. Geneva: International Labour Organisation.

the loans because of the business they were engaged in but some people who got loans were unable to do anything meaningful with the money because the price of equipment they planned to purchase had gone up and the amount of the loan was inadequate to do the business they had wanted⁷³.

- In 2002 a final evaluation of the Msakambewa CBR program showed that 183 people with disabilities were given loans up to MK10,000 and that most people who got these loans were paying back and unlike in the past the majority of those who got loans were able to support their families. The people who got loans were able to successfully engage in activities such as farming, carpentry bakery, beer brewing among others⁷⁴.

An earlier study also identifies quite a number of problems that people with disabilities faced in running businesses such as lack of business administration skills, business location, market limitations and understaffing at MACOHA⁷⁵. This explains why in most cases people with disabilities who were given loans had to be trained before they started running their business as was the case in the Balaka/Machinga Comprehensive eye care services loan scheme. While some cases in this project were hopeless and could not even return the loan, others were quite successful in that they managed to build better houses, others bought livestock, paid school fees for their children and their homes became food secure⁷⁶. Hence, this demonstrates that the provision of loans to people with disabilities if properly managed can help to better transform the lives of people with disabilities but such opportunities are however limited.

3.3.6 Theme IV: Social

This theme looks at legal protection; culture and arts; sports, recreation and leisure; relationships, marriage and family and personal assistance. Not many studies have been done in this area. In terms of forming relationships some studies have shown that some women with disabilities would want to get married and have children but they do not have boyfriends or husbands and it is the disability itself that makes these women less attractive. One of the issues that has come from studies that have been conducted is that in some cases women with disabilities report that they have been dumped by their husbands because of the disability they have and some are even tricked into having sex with men and once they are pregnant they are abandoned by these men⁷⁷. It has been argued that poverty makes disabled women accept men who in some cases will just sexually abuse them and abandon them. In some cases when a disabled man falls in love with a disabled women it is family members who discourage him from such a marriage because of the belief that such a couple will bear children with disabilities⁷⁸. It is not only disabled women who experience problems in forming relationships with the opposite sex, men too have problems as they are in some cases rejected by the women they propose to. Both men and women with disabilities may have difficulties entering into intimate relationships due to stigma and difficulties in mobility as it decreases the

⁷³ Fagan, T; G. Nyaga and I.L. Campbell. (1990). *Evaluation of services for the visually impaired within a CBR program*. Blantyre: MACOHA.

⁷⁴ Makoko, A.J.L (2002). *Final evaluation of Msakambewa Community based Rehabilitation program*. Blantyre: MACOHA.

⁷⁵ Manda, J. (1989). *Evaluation of the SEDOM -MACOHA Revolving Loan Fund for the Malawi Council for the Handicapped*. Blantyre: MACOHA

⁷⁶ Manda, J. (1989). *Evaluation of the SEDOM -MACOHA Revolving Loan Fund for the Malawi Council for the Handicapped*. Blantyre: MACOHA.

⁷⁷ Kvam and Braathen, (2006). *Violence and abuse against women with disabilities*. Oslo: SINTEF. Gubela M., S. Gcaza, M. Wazakili and D. Skinner (nd). *A report on HIV/AIDS and reproductive health care amongst people with disabilities*. Capetown: Stellenbosch University.

⁷⁸ Gubela M., S. Gcaza, M. Wazakili and D. Skinner (nd). *A report on HIV/AIDS and reproductive health care amongst people with disabilities*. Capetown: Stellenbosch University.

opportunity of meeting new people⁷⁹. While women with disabilities may have problems forming relationships, a significant proportion of men and women with disabilities get married.

It is not only women with disabilities who are abandoned by husbands, in some cases fathers of disabled children for example albino children also abandon such children and marry other women as they think that such children are not theirs. While mothers of albinos love their children, reactions from other members of the community are sometimes not good and such children also experience discrimination especially with strangers⁸⁰. Women also have a duty in the home such as carrying water on their heads, cooking, lifting heavy things and women with disabilities sometimes cannot fulfil these duties effectively hence their chances of getting married or being in relationships is further reduced⁸¹. The *Living conditions study* also showed that about 15% of the people with disabilities are not involved in family life and that nearly a fifth are not consulted about making household decisions even those decisions that have an impact on their lives⁸². Most of the people with disabilities are excluded deliberately in community benefits and trainings yet they participate in other community development activities⁸³. It is evident that most of the aspects of this theme have not really been studied.

3.3.7 Theme V: Empowerment

This theme covers issues such as self help groups, disabled peoples organisations, social mobilisation, political lobbying and language and communication. As has been said earlier, not many documents including research reports were found on this theme. As a result of political lobbying, disability issues have been included in the Constitution of the Republic of Malawi and the country is a signatory to the Convention on the Rights of Persons with Disabilities. In addition to this, in 2006 the National Policy on Equalisation of Opportunities for People with Disabilities was launched in order to promote the rights of people with disabilities. Even though documentation on meetings and sensitisation of Malawians on the rights of people with disabilities is scarce, over the last decade DPOs have conducted a lot of meetings aimed at sensitizing the wider community on the rights of people with disabilities. Because of the problems that people with disabilities are experiencing in terms of accessing education, the Policy Investment Framework (2001) has placed a lot of emphasis on special needs education. In addition to this the CBR program has been running in Malawi since the 1980s, and it aims at improving the lives of people with disabilities as well as ensuring that Malawians are aware of the disabled people's rights.

In 2003, funded by DFID, Transport Research Laboratory (TRL)⁸⁴ and the Centre for Social Research conducted a study in Blantyre aimed at exploring the problems that people with disabilities experience. This study was aimed at exploring how accessibility for people with disabilities can be enhanced in an urban area. A small scale demonstration project was therefore implemented around Queen Elizabeth Central Hospital along Masauko Chipembere Highway. This road is a busy road and people with disabilities had problems crossing the road and getting into the premises of the central hospital. Hence an exploratory study showed that

⁷⁹ Munthali et al. (2005).

⁸⁰ Kvam and Braathen, (2006). *Violence and abuse against women with disabilities*. Oslo: SINTEF.

⁸¹ Kvam and Braathen, (2006). *Violence and abuse against women with disabilities*. Oslo: SINTEF.

⁸² See SINTEF, CSR and FEDOMA. (2004). *Living conditions among people with disabilities*. Oslo: SINTEF

⁸³ Ministry of Persons with disabilities and the Elderly. (2009). *Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District*. Lilongwe: Ministry of Persons with disabilities and the Elderly.

⁸⁴ TRL is British firm which is globally recognised for its research and testing work in the development of innovative transport products and systems for customers.

in order to improve access by people with disabilities into the hospital there was a need to widen the pathway into the hospital, making the pathway concrete, installing disabled friendly traffic lights etc. These were done and the purpose was to demonstrate to the wider community that with small investments accessibility to facilities by people with disabilities can be enhanced and that through this small demonstration project other stakeholders, especially the business community, can work with DPOs to implement small-scale projects targeting people with disabilities⁸⁵.

One of the most valuable resources on empowerment is the directory of disabled people's organisations that was produced by Marko Kerac in 2006 that lists the different DPOs and other service providers in Malawi including the services that they offer⁸⁶. Earlier on Msiska also produced a list of resources and facilities that are available for people with disabilities⁸⁷. As has also been mentioned earlier there have been quite a number of CBR programs that have empowered people with disabilities with training and disbursement of loans in order to economically empower them. Such an approach has been carried out because in most cases people with disabilities are often discriminated against in programs that offer cash or in kind benefits such as public works programs – there are very isolated cases where family members have offered to do the work on behalf of the disabled. It has been found that people with disabilities are in most cases integrated in programs that do not come along with any monetary benefits such as building school blocks or clearing the graveyard⁸⁸. This discussion generally shows that research on empowerment of people with disabilities is limited; hence the need to do more on this theme.

3.4 Level of DPO participation in documentation and research assignments

3.4.1 CBR documentation

As far as CBR documentation is concerned, stakeholders are supposed to document in a logical manner the interventions that are being implemented, especially the processes that are followed and the results and whether the interventions have been done well or not. This documentation should also explain the context (socio-economic context) in which the people with disabilities live or are found at the time of identification and before implementing any interventions to improve their lives. In short, there is a need to document the processes of identification, referral and type of interventions and whether these interventions are working. In most cases however the documentation process is either not available for the CBR program and stakeholders or when available it is not detailed enough e.g. MACOHA identifies people with disabilities at community level who need CBR services and refers them to appropriate agencies such as MAP or Ministry of Health but sometimes such cases are not referred back to MACOHA to facilitate update of records and or for further rehabilitation; hence MACOHA does not know what happens to some of the persons that it refers to service providers. A number of stakeholders (e.g. MACOHA, FEDOMA, Ministry of Persons with Disabilities and the Elderly) are involved in documentation but the major problem is that sharing of documentation (including annual reports) is somehow limited and the documentation process itself is inadequate. The skills for documentation among the stakeholders are also lacking.

⁸⁵ Munthali, A. (2003). *Enhanced accessibility for people with disabilities in urban areas: a small scale demonstration project in Blantyre, Malawi*. Zomba: Centre for Social Research.

⁸⁶ Kerac, M. (2006). *The Malawi Directory of Disability Organisations*. [Publisher not specified].

⁸⁷ Msiska, A.W.C. (1990). *A guide to community resources/facilities available for the rehabilitation of disabled persons in Malawi*. Zomba: Chancellor College.

⁸⁸ Ministry of Persons with disabilities and the Elderly. (2009). *Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District*. Lilongwe: Ministry of Persons with disabilities and the Elderly.

Within the CBR program there are also standard forms that are supposed to be filled. These forms do not explain much about the person with a disability. Most of the reports from the field show that as far as people with disabilities are concerned, there is nothing much that is being done to help these individuals. Volunteers and other staff members from CBR programs will identify someone with a disability: they take the name of the person with a disability and the type of disability he or she is suffering from and location. Unfortunately, this type of information is not very helpful as it does not say much about what is happening in the community: there is a need for complete information on the family, the type of support he or she gets from family members; and the availability or absence of other stakeholders within the community who are providing support to the disabled. This information is in most cases not collected by CBR programs. Currently Form One which is used for identification of clients has been completed but Form Two which will be used for recording more detailed information about the client and changes in status following receipt of various interventions is yet to be finalised. In addition to the forms, CRWs and village level volunteers need to be provided with a standard format for recording client information, interventions, as well as the social economic environment and support that clients receive.

Most of the CBR programs rely on reports from the field. These reports are supposed to be submitted monthly and are then used to compile quarterly reports. The major challenge, however, is that in some cases these reports are submitted quite late. Most of the CBR programs have not been able to do proper documentation; yet evidence of progress is required. Problems with documentation that were mentioned by CBR stakeholders included the following:

- The workload of CBR staff is too great to do proper documentation. Monitoring and evaluation of CBR programs are important but this may not be realised in situations where monitoring and evaluation officers are not available.
- CBR programs in some cases do not have adequate computers and some do not have reliable internet and email services. Most of the documentation is therefore done manually and this impacts on timeliness of reporting.
- Lack of financial resources to implement specific programs for example special studies. This also impacts on the carrying out of baseline surveys: in some cases these may not be done to properly monitor programming.
- People lack skills in documentation.
- Most of the work on CBR monitoring and evaluation is paper based. The development of an CBR Information Management System is yet to be completed

As part of documentation, mid-term and end term evaluations are done. This gives an opportunity for external evaluators to properly document CBR program processes in order to understand the impact of the interventions on persons with disabilities. Some of the evaluation reports lack details on the impact of the interventions i.e. how the interventions have changed the lives of people with disabilities. For example, evaluations of loan schemes for people with disabilities are supposed to demonstrate vividly how these have impacted on the lives of people with disabilities and their families. In some evaluations such details are lacking. Some reports on evaluations of CBR programmes have not been professionally done. While CBR programs attempt to document processes, there are challenges that need to be addressed.

3.4.2 CBR Research

Most of the studies that have been commissioned on CBR have been done by research institutions both in and outside Malawi. The involvement of people with disabilities in

research only started in the early 2000s mainly during the *Living conditions study* when DPOs including the Ministry of Persons with Disabilities and the Elderly participated in the design of the study: DPOs participated in the finalisation of the questionnaires for the study and half of the enumerators and supervisors (with disabilities) who participated in the study were recruited by FEDOMA. In another study conducted in 2005 on sexual and reproductive health (SRH) issues a similar arrangement occurred when half of the supervisors and enumerators were again persons with disabilities. In a series of studies conducted by CSR and SINTED attempts have been made to involve people with disabilities as enumerators⁸⁹.

With regard to research FEDOMA has been advocating for the involvement of people with disabilities in doing research among people with disabilities and this is yielding positive results as can be seen from the active participation of people with disabilities in quite a number of studies. Within FEDOMA and affiliate DPOs some persons with disabilities have participated in research and there is some capacity to collect data. At regional level, SAFOD is also working with FEDOMA and training people with disabilities in the conduct of research. A number of people have been trained in this way. However, some of FEDOMA affiliate DPOs have not been involved in research.

While there has been some involvement of people with disabilities in research and capacity building among people with disabilities is going on in this area, there are also some weaknesses. In an interview with stakeholders one thing that came out was that there is generally lack of capacity within disability organisations to fully utilise the findings from studies such as the *Living conditions study*. There is too much information and the capacity to use this is not there. The other problem is that most of the people with disabilities who have been involved in research have done so as Research Assistants/Enumerators. There is a general lack of professional researchers who can be able to conduct research.

3.5 Accessibility and use of available documents by CBR cadres and other stakeholders

A number of documents have been produced on CBR over the years. These documents have been produced by MACOHA, Ministry of Persons with Disabilities and the Elderly, Sue Ryder Foundation, research institutions (such as CSR and the College of Medicine) and other NGOs. Some of these documents have also been produced by international stakeholders e.g. SINTEF and the International Labour Organisation. Annex 1 details the reasons why certain documents were produced; namely the use of the documents produced for example:

- A number of baseline surveys have been done on CBR in Malawi. Before implementing interventions it is important to determine the situation of people with disabilities so that at the end of the program implementers should know the impact of the program.
- Midterm and end term evaluations are done and reports produced. These reports are important because they inform the program implementers the progress they have made in addressing the problems that people with disabilities are experiencing.
- A number of prevalence surveys have been done in order to determine the prevalence of disability in Malawi e.g. the 1993 *Survey of handicapped persons in Malawi* and the 2003 *Living conditions survey*. Some of these documents have been used in the development of policies and interventions e.g. the 2003 Living conditions study was used extensively in the development of the Disability Bill.

⁸⁹ These studies have included *Living conditions of persons with activity limitation in Malawi*; the *Global Health Study*; the *Equitable Study* among others.

- Newsletters such as CBR update, MACOHA's Quaterly Disability Forum, Magazine and MAP newsletter especially are produced in order to inform CBR stakeholders about what is happening in the CBR programs for example the MAP newsletter gives some figures on the number of people that have been reached with interventions.

Annex 1 therefore provides the reasons for the production of documents. While over 90 documents on CBR have been produced since the program started⁹⁰, most of the documents are not accessible: even institutions that produced some of these documents do not have copies. One of the reasons advanced by stakeholders was that some of the reports were produced a long time ago and they do not have copies. Electronic copies are also in some cases not available. The sharing of documentation on CBR is rather limited.

In most cases in terms of dissemination this is done at national level e.g. national workshops where people will get some copies of reports, while dissemination at district and community levels is very limited e.g. the report on *Living conditions study* was mainly disseminated at national level and not at district and lower levels. Research reports and other documentation on CBR are also disseminated during workshops and sensitisation meetings. Others are sent to stakeholders or left at the reception for visitors. Some DPOs (e.g. FEDOMA) have resource centres where documents are kept. Some of the reports are printed outside Malawi (for example 2003 *Living conditions study*) and availability of hard copies to CBR stakeholders is therefore problematic.

Some stakeholders such as FEDOMA have websites where reports, newsletters and other documents are posted. This is mainly accessed by CBR staff who have access to internet. Such people as well experience problems as internet accessibility is still a challenge among many CBR stakeholders in Malawi. Lower cadres of CBR workers, especially at district and community levels, have a lot of problems accessing documentation of all types namely hard and electronic copies. It is therefore difficult for such documents to be used by such cadres. Availability of CBR documents is a major challenge as in most cases people do not know what is available. At international level, MACOHA and DPOs depend on international partners in terms of disseminating information on CBR where for example papers on CBR are presented but also research reports are posted on websites.

The other problem with CBR documents is language. Most of the documents that have been listed in Annex 1 are in English. Stakeholders also mentioned that most of these documents have not been translated into local languages. For people who are visually impaired, it is also difficult to access such documents as they are not written in Braille. A number of DPOs expressed the need for their staff to be trained in documentation (including language, formatting and appropriate computer packages) so that at the end of the day they are able to document CBR processes properly.

In terms of using the research and evaluation results, it was mentioned that these have been used for the development of CBR interventions and this is especially applicable to baseline surveys and midterm reviews. It can also be observed that Annexes 1 and 2 also contain midterm and final project evaluations. The reports from these studies are used to monitor the progress which has been made to achieve the objectives of the project. There are also a number of studies that have been done and have been used to inform the development of policies. Examples were given of the 2003 *Living conditions study* which was extensively

⁹⁰ There might be more.

used to develop the National Policy on Equalisation of Opportunities for Persons with Disabilities. FEDOMA also reported that the results were used to influence the development of the Disability Bill which is currently with Cabinet. The results of some of the studies that have been done have been used as a tool for advocacy as well as for mobilisation of resources.

3.6 Monitoring and evaluation tools

As far as CBR documentation is concerned stakeholders rely on reports from the field. These reports are supposed to be submitted monthly which are then used to compile annual reports. These reports in some cases, as mentioned by MAP, are submitted late; hence if there are urgent issues that need to be addressed there are delays in rectifying such issues. As far as monitoring and evaluation is concerned there is also a need for staff at headquarters of organisations concerned (for example MAP) to visit offices at regional and district level but the lack of funds make this activity impossible; hence reliance on monthly reports from districts and regions. Therefore the follow up of cases is hampered by lack of funds on the part of CBR implementers.

While some CBR programs have done baseline surveys in most cases it seems that this is not done because of lack of resources as well as the capacity of CBR programs to conduct such surveys. FEDOMA mentioned that while it might be able to conduct baseline and end line surveys there is a need to identify tools for monitoring qualitative aspects of CBR programmes for example looking at how the lives of people with disabilities have changed because of the interventions.

In addition to using baseline and final evaluations, MACOHA also uses the *most significant change tool* which measures the qualitative outcomes of interventions on an individual. This is written in form of a story and a series of questions are addressed to the individual with a disability as can be seen from the two examples below⁹¹:

(a) Most Significant Change (MSC) Story I

Do you (the storyteller):

Want to have your name on the story (tick one)?	Yes X	No o
Consent to us using your story for publication (tick one)?	Yes X	No o

Contact Details:

Name of person recording story (CRW ⁹²): Edgar Thom	District: Nkhota-kota
Name of storyteller: Andrew Matoliro	TA/village: Kanyenda/ Mkomandolo
Age and sex of story teller: 60 ⁹³ / male	Date of recording: 17 th April, 2009

Title of story? **LIFE WORTHY IT**

1. Tell me how you (the storyteller) first became involved with MACOHA CBR, and what your current involvement is:

I had been a well-known farmer in my home village before my illness. Most of the people in the village were supplied with fresh food from my garden, I was really doing well. As I was in my garden some years past I suddenly felt drowsed and fell down in convulsion. I was carried home by my wife and later to hospital, still in seizure state.

⁹¹ These two stories were sourced from MACOHA Lilongwe CBR program.

⁹² Community Rehabilitation Worker

⁹³ Age to be re-verified

Afterwards the fit happened frequently; in some days I had four convulsions. My health deteriorated as I was badly affected, and I concluded in my thought that I had been bewitched by disgruntled village men. I had been to several traditional healers for herbal concoction but to no avail.

In 2004 I heard that MACOHA helps people suffering from epilepsy, I made every effort to meet them. When I visited Msenjere Health Centre in a bid to seek for medical care, I heard that MACOHA will be at the hospital the next day; so I came to hospital to meet them, I explained my problem to the medical assistant who prescribed to me drugs (Phenorbarbitone) for me. Since then I have been taking 3 tablets per day.

2. From your point of view, describe the most significant change that has resulted from your involvement with MACOHA CBR:

Since then I could have zero or only one fit in three months; with the medication I receive from MACOHA I have been able to restore confidence in my family and relatives by going back to my farming business. My family members are also able to do chores other than spending time in looking after me. I have also been able to change the mind set of other people suffering from epilepsy in my community to receive medication from MACOHA.

3. Why is this significant to you?

I was rejected and taken as a mad person in my neighborhood due to my illness but after having medication from MACOHA CBR I am again living a happy and healthy life and a life worth living.

(b) Most Significant Change (MSC) Story II

Do you (the storyteller):

Want to have your name on the story (tick one)?	Yes X	No o
Consent to us using your story for publication (tick one)?	Yes X	No o

Contact Details:

Name of person recording story (CRW ⁹⁴): Kondwani Banda	District: Nkhata-Bay
Name of storyteller: Bechu Chirwa	TA and village: Bwereka/ TA Mkumbira
Age and sex of story teller: 60 / ADULT	Date of recording: 23 rd May, 2009.

Title of story? **GREAT CHANGE IN MY LIFE** When did it happen? 2006.

1. Tell me how you (the storyteller) first became involved with MACOHA CBR, and what your current involvement is:

I became involved with this program through mobilization and sensitization which was done by a MACOHA field worker who came by bicycle to our village. Our group village Headman had told the whole village about the upcoming meeting. People with eye problems including myself were gathering to hear what MACOHA CBR brought to us. I took it as a very important meeting because I was hoping that – being blind - I possibly could benefit from MACOHA's services.

2. From your point of view, describe the most significant change that has resulted from your involvement with MACOHA CBR:

I could not see anything! I was blind - until the time this CRW came to our village. I had been blind for 14 years, and although I had visited many hospitals before they failed to heal me. That is why at one point I started to take it for granted or simply my destiny - until the time when the MACOHA fieldworker visited our village, screened me and organized for an assessment by a medical assistant of MACOHA. Afterwards, I was referred to Chintheche Rural Hospital to see a Doctor who was dealing with eye problems, and who operated me. It was a miracle to gain back my sight. I started doing all the things I was not able to do like walking long distance, reading, farming and looking after myself. I am so glad to be back to life.

⁹⁴ Community Rehabilitation Worker

3. Why is this significant to you?

This is significant to me because I gained back my sight which I lost 14 years ago! It is significant because now I can stay with my sight until I die. I am very happy and grateful for this. MACOHA has really changed my life. I was in great trouble when I had no sight, since it affected deeply my daily living conditions. But now I can see.

These two stories highlight the importance of the CBR interventions. This tool is therefore important as CBR programs can use it for monitoring the impact of interventions. However there is a need to get more information on people with disabilities such as their families, including the support they get from them before and after the interventions, the role of the wider community and the availability of institutions around the community to help people with disabilities.

4. CONCLUSIONS AND RECOMMENDATIONS

4.1 Some conclusions: fulfilling the ToR

One of the objectives of assignment was to make a comprehensive list of CBR documentation in Malawi since the start of the CBR program. Annexes 1 and 2 contain 90 documents on CBR in Malawi and these documents are scattered and can be found in different institutions. In accordance with the ToRs the list of documents on CBR has been arranged by Title; Type of Document; Year of Publication; Author; Purpose; Methodology; Geographical Coverage; Language; and the size of the document in terms of number of pages. Most of these documents were written in 2000s and most of these documents are either research or evaluations. Documentation of the CBR program is however affected by a number of factors including:

- Lack of documentation skills among staff of CBR programs and volunteers.
- Lack of financial resources.
- Lack of sharing of CBR best practices among stakeholders.
- Shortage of human resources to effectively carry out documentation.
- Lack of computers and associated skills.

Secondly, the ToR also required to summarise (in table format) existing research documentation on CBR by theme, nature of research, objectives and major research outcomes. Annex 3 is a table that summaries the studies that have been done on CBR in Malawi. The review shows that most of the studies that have been done in Malawi on CBR are cross cutting covering several CBR themes. Most of the studies are on health and very little research has been done on two themes namely social and empowerment.

Thirdly, CBR programs have systems and tools for monitoring and evaluation. CBR programs have the desire to conduct baseline surveys and mid-term and final evaluation in order to monitor the impact of programs. This review has shown that in most cases the baseline surveys are not done and hence monitoring the impact of interventions can be difficult. The lack of financial resources is a major constraint in the conduct of such surveys. While program implementers would want to visit the field where interventions are being carried out, the lack of funds limits such undertakings. The most significant change tool is an important tool for monitoring but it has its own shortfalls which need to be addressed. One of the major problems is the lack of skills among volunteers and other CBR staff on effectively recording information on cases identified and how the interventions have impacted on the lives of people with disabilities and their families; hence the need for capacitating these personnel in documentation.

Fourthly, the dissemination of documents is limited. One thing that came out from this study is the lack of sharing of documentation among CBR stakeholders. For those organisations that have been able to disseminate documents, a number of channels have been used such as websites, seminar presentations, during meetings/workshops etc. Accessing websites and email is a major problem among DPOs. Normally CBR documents are shared largely among the three organisations namely MACOHA, FEDOMA and the MoPWD&E. Most of the dissemination is done at national level and very limited dissemination at district and lower levels.

Fifthly, CBR programs use documents for program development and evaluation as has been mentioned earlier on. Some research has been used for development of policies and the disability bill, as well as for advocacy and resource mobilisation. The utilisation of CBR documentation is hampered by the lack of sharing of documentation among CBR stakeholders.

4.2 Recommendations

Based on the findings of this study the following recommendations are made:

- Currently documentation is being done but stakeholders lack skills to properly document CBR processes. There is a need to train stakeholders in documentation so that they are able to show the results of their interventions clearly. This will also help CBR stakeholders to document everything they are engaged in. Training should also target CRVs and CRWs.
- Quantitative evaluations on the impact of the CBR programs on the lives of disabled people are important. There is however a need to devise qualitative tools for evaluating the impact of programs such as *the most significant change tool* that is being used by MACOHA.
- Most of the research that has been done on CBR has been on health, education and livelihoods. There is a need to encourage researchers and DPOs to commission studies on the two other themes namely social and empowerment.
- Currently there is no one place where stakeholders can easily access documents on CBR. The documents that have been collected as part of the baseline survey should be kept by MACOHA where a database will be established and it should be updated accordingly. It is also recommended that these documents should be scanned (with permission from authors) so that electronic copies can be available and circulated widely among CBR stakeholders.
- Some stakeholders expressed lack of knowledge on some of the studies that have been done in Malawi on CBR. Sharing of documentation among stakeholders is limited; hence it is recommended that networking among CBR stakeholders should be encouraged and that sharing of documentation on CBR should be established as a norm among stakeholders.
- Currently the bulk of CBR monitoring and evaluation work is paper based and this affects timeliness of submission of data from community levels to national level. The completion, establishment and operationalisation of an effective Disability Management Information System similar to Health Management Information System in the health sector would help

address some of the problems. While the system will be paper based at point of source of data i.e. community level, at district level this can be entered into a computer and transmitted electronically.

- It has been mentioned that it is important to follow up cases that have been identified and referred. Current feedback from referral institutions is limited. An effective referral system is currently not available; hence a need for establishment of an effective system for referrals. Adequate funds should also be allocated to following up of cases.
- The CBR matrix with its 5 themes is quite new. In terms of documentation, it is also important that stakeholders at national, district and community level are oriented on these themes so that the themes constitute part of the documentation process.
- This study has highlighted the types of studies that have been done on CBR in Malawi. Under each theme we have highlighted the studies that have been done. It is important that as part of the D and R project stakeholders should critically look at what research has been done and propose topics that should be researched or further researched. FEDOMA and MACOHA should continue encouraging the participation of people with disabilities in these studies.
- Most of the documentation is in English and this makes it difficult for people with disabilities who are illiterate to access. People who are visually impaired will also not be able to access these documents. It is suggested that as part of this project CBR documents should be made accessible to people with disabilities.

Annex 1: List of documents produced by the Malawi MACOHA CBR Program

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
1	National program of activities for the international year of the disabled persons		1981	Government of Malawi Ministry of Social Welfare	Presents activities for the international year of the disabled	-	National	English	11
2	A survey of handicapped persons in Malawi	Research Report	1983	National Statistical Office	It was aimed at estimating the incidence of disability and establish the demographic and socio-economic characteristics of the handicapped persons by type and severity of disability	Administration of a questionnaire	National	English	68
3	Workshop of organizations for disabled persons	Workshop report	1988	Ministry of Community Services and MACOHA	This paper discusses systems and institutions that need to be put in place in order to address the needs of people with disabilities	-	National	English	8
4	Evaluation of the SEDOM -MACOHA Revolving Loan Fund for the Malawi Council for the Handicapped	Evaluation report	1989	James W. Manda	To examine the present policies, procedures and operations of the UNDP/ILO project of the Ministry of Community Services SEDOM (Small Enterprise Development Organisation of Malawi) - MACOHA (Revolving Loan Fund) and to provide recommendations	Review and analysis of the revolving fund's present status, operational procedures, loan financing procedures, monitoring, extension support services, and staffing. Involved consultation with MACOHA management and ILO Chief Technical Advisor, visit to SEDOM (administering institution), discussions with Ministry staff (Senior Social Welfare Officer), CROs, DSWO, commercial banks and other institutions, and visiting	National with a focus on disabled graduates of KVRTC (located in Magomero, Chiradzulu District)	English	37 pp.

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
						entrepreneurs.			
5	A guide to community resources/facilities available for the rehabilitation of disabled persons in Malawi	Research Report	1990	Augustine W.C. Msiska	Identified and documented resources/facilities that are available for people with disabilities.	Questionnaire administration and telephone interviews	Malawi	English	21
6	Community Based Rehabilitation (CBR) Program for the Disabled Persons in Malawi	Booklet	1990	MACOHA / ILO Chief Technical Advisor Mr. K. Kumar	To give information on the techniques and methodology followed in the implementation of the CBR program in Malawi, its present status and future strategy. The booklet was published during the initial phase of implementation of the CBR program in Malawi as a guide on CBR as well as a public awareness/information document.	The document is prepared as a handbook.		English	32 pp.
7	Evaluation of Services for the Visually Impaired within a CBR Program	Evaluation report	1990	T. Fagan, G. Nyaga, I.L. Campbell	To determine the success of the CBR program to date, including the soundness, effectiveness, impact and sustainability of the CBR program with particular reference to its services for the visually impaired, and to make appropriate	Five mainstream schools in which visually impaired children have been integrated were visited and meetings with headmasters and deputies of these schools held; visited 10 visually impaired and 1 physically disabled client;	Blantyre District	English	69 pp. Plus appendices

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
					recommendations arising from the findings.	meetings with 10 village rehabilitation volunteers and other village stakeholders, as well as MACOHA staff held. Visited KVRTC Magomero.			
8	MACOHA Newsletter	Newsletter	1990 to 1999	MACOHA staff	Provides news about persons with disabilities	Short articles by MACOHA and FEDOMA staff highlighting the situation of disabled people in Malawi, including featured individual stories. Published several times a year.	National	English	Approx. 9-18 pp. per issue
9	MAP Feedback	Newsletter	1992	Malawi Against polio	Gives reports on MAP activities	Articles by staff	National	English	8
10	Report on the Disabled within the Bawala Ward: Ntchisi Strategy for Assistance	Research report	1992	Peggy MacDonald	Identifies people with disabilities, their demographic details, their involvement in village activities, causes of the disabilities and major problems they experience among other issues	Survey, interviews	Ntchisi	English	20
11	Report on Oxfam funded MAP seminar held at Kudya Discovery Lodge in Machinga District - Malawi from 27 to 29 August 1992	Workshop Report	1992	Malawi Against Polio	Presents the findings of an evaluation research	Paper presentations and discussions	National	English	58

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
12	A Study on the Effect of the Community-Based Rehabilitation Program on the Socio-Economic Status of the Disabled Women in Malawi with Reference to Lilongwe District (Future Implementation Strategy)	Study report	1994	Lewis J.M. Msasa	To increase community awareness and the awareness of planners in various developmental sectors on the plight of disabled women so that programs address women's needs and strengthen their capabilities. Objectives: to profile disabled women, develop strategies for future support and participation by women in the program, identify existing community facilities, and assess the effect of the CBR program on women's survival strategies.	Cross-sectional, exploratory study using 3 main instruments: structured questionnaire (pre-tested and validated) using systematic random sampling (51 disabled women responded); open-ended interviews of 40 persons (community stakeholders and service providers); and non-participatory observation. Case studies were also reviewed.	Rural areas of Lilongwe district (Central region)	English	20+
13	Needs study for rehabilitation training in Malawi	Research Report	1998	Ann-Marie Brouder	Explores whether there is a need for a rehabilitation training in Malawi	FGDs, Interviews, key informant interviews	National	English	113
14	MACOHA CBR Update	Newsletter	2000, 2001 and 2003	MACOHA Staff	An update on CBR activities being conducted by MACOHA	Articles written up by MACOHA Staff	National	English	4
15	Rights of People with Disabilities in Malawi	Paper	2000	Shenard Mazengera, Legal officer	To discuss human rights standards relating to people with disabilities at international and national levels as a step in protecting and safeguarding the rights of people with disabilities	Discusses various international and national instruments that safeguard the rights of persons with disabilities		English	10 pp.

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
16	Blantyre Cheshire Home Community Based Rehabilitation Project dates: April 1998-March 2001	Evaluation	2001	Rodney Nieuwenhuizen and David Geyer	Discusses the impact of the project in Blantyre i.e. awareness among communities and health professionals and the number of children who have been assisted by the project	Analysis of registers, various types of questionnaires, community clinic survey, meeting with project committee and review of literature	Blantyre	English	45
17	Final Evaluation of Msakambewa Community Based Rehabilitation Program	Evaluation report	2002	AJL Makoko	To examine the relevance of the aims and objectives of the pilot CBR program proposal and the extent to which the major objectives have been achieved in terms of positive impact on program beneficiaries, and to identify which objectives have not been achieved. Recommendations were made for the way forward.	Semi-structured interviews, focus group discussions, review of relevant documents.	Msakambe-wa Rural Development Area, Dowa District	English	35 pp.
18	CBR Update	Newsletter	2003	MACOHA	Disseminates news/information on rehabilitation activities	Articles submitted by MACOHA	National	English	4p
19	Enhanced accessibility for people with disabilities living in urban areas: a small scale demonstration project	Research Report	2003	Alister Munthali	The project was aimed at enhancing access into Queen Elizabeth Central Hospital particularly for people with disabilities through the construction of a pathway, the installation of a disabled friendly pedestrian crossing close to the hospital entrance, the renovation of a bus stand and the construction of a handrail close to the road to avoid minibuses using	Observations, in-depth interviews	Blantyre	English	23

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
					footpaths as passenger pick up and dropping points				
20	Disability Forum	Magazine	2003 - 2006	Published by MACOHA quarterly	Forum for presentation / discussion of disability issues in Malawi.	Short articles by MACOHA staff and others on disability-related issues included rights and empowerment. .	National	English	20 pp.
21	Community based rehabilitation (CBR)- the experience of the Sue Ryder Foundation in Malawi	Workshop Paper	2004	Levi Mhowa	Discusses Sue Ryder Foundation's experience with CBR, sources of funding and the dependence on volunteers to run the program	Personal experiences	Balaka and Ntcheu	English	12
22	Living conditions among people with disabilities in Malawi:	Research Report	2004	FEDOMA, University of Malawi and SINTEF	A representative national survey on the living conditions among PWD in Malawi so as to provide data for policy influence and planning.	Questionnaire administration to people with and without disabilities	National	English	179
23	Effective HIV/AIDS and reproductive health information to people with disabilities	Research Report	2004	Alister Munthali, Peter Mvula and Sandra Ali	Explores and discusses the sexual and reproductive health needs and experiences of people with disabilities, their perceptions about HIV/AIDS and how best information on HIV/AIDS can be communicated to people with disabilities	Questionnaire administration, FGDs	National	English	116

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
24	Disability World-A bi-monthly web-zine of international disability news and views	Newsletter	2004	CBR Africa Network	A call for people working on CBR in Africa to submit papers	Call was placed on a website of the Disability World newsletter	Africa	English	4
25	Households with disabled people have lower standards of living than others	Newsletter (Disability Frontline newsletter)	2004	SAFOD	Discusses living conditions of people with disabilities in three countries namely Malawi, Zimbabwe and Namibia	SAFOD writers	Malawi, Zimbabwe and Namibia	English	6
26	Multinational capacity building for disability rehabilitation: national workshop on community based rehabilitation (CBR)	Workshop report	2004	MACOHA	Building the capacity of stakeholders in CBR as a preferred approach in the planning and implementation of rehabilitation programs for persons with disabilities	Brief lectures, group discussions and plenary sessions	National workshop	English	33
27	Albinism in Malawi	Research Report	2005	Stine Helium Braathen	To examine attitudes and beliefs related to people with albinism, and assess implications of these on the lives of people born with albinism as well as for their closest network of family and friends.	Literature review, individual in-depth interviews and participant observation	Blantyre and Mangochi	English	31
28	Stakeholders' influences in CBR projects in Southern Africa	Case study of CBR projects in Southern Africa including Malawi	2005	Harry Flunkenflugel	Explores and analyses the characteristics of the different stakeholders and their roles in influencing and achieving the objectives of CBR projects	Review of literature	Southern Africa including Malawi	English	24

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
29	Report for Training of the Malawi National CBR Resource Team at Anne's Lodge, Zomba 16 th to 26 th January 2006 (included because of comments under purpose)	Training report	2006	Basil Kandyomunda, Alice Nganwa, Steven Msowoya	Course curriculum on CBR as a poverty reduction strategy for a training held for technical officers who will form the National Resource Team tasked with facilitation of similar courses at district level. The WHO CBR guidelines served as the framework for the training, and thus the training provides a learning experience for Malawi and the rest of the world.	Participatory training process using adult learning facilitation. Included presentations, group discussions, buzzes, and quizzes.		English	147 pp. including appendices, annexes
30	Violence and abuse against women with disabilities in Malawi	Research Report	2006	Marit Hoem Kvam and Stine Hellum Braathen	Investigates the forms of abuse, violence and discrimination against women with disabilities in Blantyre	FGDs and key informant interviews	Blantyre	English	64
31	Violence against girls who are blind and visually impaired in schools in Malawi	Research Report	2006	Abigail Suka	Discusses perceptions about violence against girls in schools and factors that make girls with visual impairment vulnerable to violence and why violence against such girls should be addressed	Review of CSR study on violence against girls in schools and other studies; key informant interviews	Not specified	English	7
32	National Policy on Equalization of opportunities for persons with disabilities	Policy document	2006	Ministry of Persons with Disabilities and the Elderly	Promotes the rights of people with disabilities to enable them play a full and participatory role in society	Policy developed through review of literature and participation of stakeholders	National	English	28
33	The Malawi Directory of Disability Organizations	Directory	2006	Marko Kerac	Brings together all the organizations, groups and services specifically working on disability issues in Malawi	Snowballing was used to identify organizations	National	English	3

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
34	Perceptions of parents/Guardians of children with cerebral palsy	Research report	2007	Takondwa Chimowa	Explores perceptions of parents/guardians of children with cerebral palsy especially their knowledge, beliefs and practices, treatment given to their children and the support they get from families and communities	In-depth interviews	Blantyre	English	52
35	Visually impaired children's experiences with special segregated schools in Malawi: a case of Chilanga School for the Blind	Research Report	2007	Gillian Louisa Kaliwa	Discusses how disabled children view their condition and how it impacts on their daily life and aspirations for the future.	FGDs	Kasungu	English	55
36	HIV/AIDS Awareness, Behavioural and Attitude Change Towards Persons with Disabilities program (April 2005 – March 2006)	Evaluation report	2007	Inter nos Consult: AJL Makoko	To evaluate the HIV/AIDS program to review its progress and realign the activities to meet the program goals; to provide an opportunity to take stock of what had happened to staff and persons with disabilities in terms of awareness, behavioral and attitude change; to assess strengths and weaknesses of MACOHA as the implementing agency, examine effectiveness of the project with an eye to its replication to other districts; to provide information and recommendations for future planning of the HIFV/AIDS awareness initiatives.	Gathered different views from different respondents regarding the HIV/AIDS program. Principal data collection tool was semi-structured interviews; supplementary tools included review of documents, focus group discussions and direct observation.	4 pilot districts: Blantyre, Balaka, Salima, Mzimba	English	38 pp.

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
37	Strategies for skills acquisition and work for persons with disabilities in southern Africa: MALAWI	Research report	2007	ILO	Identifies effective strategies for vocational skills acquisition by persons with disabilities leading to productive work	Questionnaire administration and case studies	Blantyre, Machinga, Mzimba, Nkhota Kota and Salima	English	40
38	A descriptive study identifying the caregivers attending treatment with C.P. children at Feed the Child Malawi, Blantyre Campus from 30 th April to 5 th May 2007	Research Report	2007	Elijah Julius M. Alfazema	Gives insight into perceptions of medical practitioners and all staff involved in dealing with the welfare of C.P. children and caregivers	Self administered questionnaire and literature review	Blantyre	English	42p
39	Evaluation Report on Balaka/Machinga Comprehensive Eye Services Loan Scheme Project	Evaluation report	2007	Inter nos Consult: AJL Makoko	Review progress of the Balaka/Machinga loan scheme project with an eye to realigning its activities to meet its goals: to find out if loans given are making a positive impact on beneficiaries; to explore whether success in loan repayment depends on the type of business; determine the appropriateness of loan sizes for the respective enterprises; assess challenges and opportunities affecting sustainability.	Semi-structured interviews, review of documents, direct observation; random selection of respondents, ensuring that particular groups were not overlooked (18 out of 73 beneficiaries were visited in the two districts).	Balaka Machinga	English	17 pp.

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
40	Mothers/guardians perception on rehabilitation of cerebral palsy children at the Feed the Children Malawi, Blantyre Campus	Research Report	2008	Sneed Kakutu Mwafulirwa	Identifies mothers' and guardians' perceptions about rehabilitation of children with cerebral palsy at Feed the Children, Blantyre campus	Personal interviews with mothers/guardians who had children with cerebral palsy	Blantyre	English	24
41	Disability policy audit in Namibia, Swaziland, Malawi and Mozambique	Research report	2008	Raymond Lang	To provide an analysis of disability policy and practice in four Southern African countries, namely, Malawi, Mozambique, Namibia and Swaziland	literature review, Focus Group Discussions and Key Informant Interviews	National	English	16
42	Report on the advocacy training workshop for women with disabilities in Mzimba	Workshop report	2009	Disabled Women in Development	Assist participants to identify and discuss challenges faced by women with disabilities and equip them with skills that would assist them to influence decision makers in their areas to address the situation	Presentations and discussions	Mzimba District	English	7
43	Implementation guidelines for the National Policy on Special Needs Education	Policy Document	2009	Ministry of Education	Provides guidelines for implementing special needs education in Malawi	Guidelines developed with participation of stakeholders and a comprehensive review of literature was done	National	English	15
44	An investigation on the effectiveness of special needs education service delivery in Malawi primary schools	Research Report	2009	Ministry of Education	Discusses the effectiveness of the special needs education service delivery in primary schools in Malawi. It was aimed at gathering information which reflects the current situation in schools in Malawi and find ways through which both management and educators	Questionnaire administration, review of literature	National	English	45

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
					can alleviate any experienced challenges.				
45	Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District	Research report	2009	Ministry of Persons with Disabilities and the Elderly	Analyses the socio-economic situation of people with disabilities before implementing the CBR program in Chikhwawa	Key informant interviews FGDs, Observations	Chikhwawa	English	19
46	Kukhala m'chiyembekezo ndi HIV ndi matenda a EDZI	Braille material	2009	MACOHA	Braille material on HIV/AIDS for people who are visually impaired	Translated by MACOHA	National	Chichewa	
47	Kuba muchirindizga na HIV na matenda ya EDZI	Braille material	2009	National AIDS Commission	Braille material on HIV/AIDS for people who are visually impaired	-	National	Chitumbuka	-
48	Kupokera umphungu nakupimiska ndopa kwambula kuchichizgika	Braille material	2009	National AIDS Commission	Braille material on HIV testing and counseling for people who are visually impaired	-	National	Chitumbuka	-
49	Kulandira uphungu ndi kuyezetsa magazi mosakakamizidwa	Braille material	2009	National AIDS Commission	Braille material on HIV testing and counseling for people who are visually impaired	-	National	Chichewa	-

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
50	Quality of life assessment tool and impact analysis in the framework of P1919	Research Report	2010	Boniface Ophiyah Massa	Analyses the impact of MACOHA-CBM CBR program for people with disabilities using the Quality of Life Assessment Tool	Key informant interviews, FGDs, Critical Incidents Technique and nominal group technique	Nkhota Kota, Dowa and Lilongwe	English	32
51	Baseline survey report on inclusive education conducted in Phalombe, Thyolo, Machinga, Mangochi and Blantyre Rural Districts in Malawi	Research Report	2010	Alick Chavuta	A situation analysis of the current mainstream education with a view to establishing needs, challenges, opportunities and approaches for the successful implementation of inclusive education in target districts	Questionnaire administration, key informant interviews, FGDs and observations	Phalombe, Thyolo, Machinga, Mangochi and Blantyre	English	63
52	Report on the sensitization of ADCs and identification of CBR volunteers for Chikhwawa CBR project from 20 th to 30 th September 2010	Sensitization report	2010	Ministry of Persons with disabilities and the elderly	Report on sensitization meeting	-	Chikhwawa	English	4
53	Report on training of Chikhwawa CBR project volunteers	Training report	2010	Ministry of Persons with Disabilities and the Elderly	Presents the training of volunteers working with the Chikhwawa CBR program. This training was aimed at equipping trainees with knowledge on disability issues, CBR concepts and also equipping them with skills on how to carry out their duties	Presentations and discussions	Chikhwawa	English	15p +attachments
54	Sue Ryder foundation newsletter	Newsletter	2010	Sue Ryder Foundation	Used to disseminate Sue Ryder activities and programs in Malawi	Articles scoured from staff	National	English	4

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
55	A report on HIV/AIDS and reproductive health care amongst disabled people	Research report	ND	Gubela Mji, Siphokazi Gcaza, Margret Wazakili and Donald Skinner	To establish HIV/AIDS and sexual and reproductive health needs among people with disabilities	FGDs, Face to face interviews and review of literature	Blantyre	English	22
56	The language of disability	Guide	ND	Malawi Council of for the Handicapped	Discusses the language that people should use when communicating or talking about people with disabilities	-	National	English	4
57	Report on the media workshop	Workshop report	ND	FEDOMA	Build a solid relationship with the media leadership of the DPOs and equip them to be proactive towards passage of the disability bill	Presentations and discussions	National	English	10
58	Advocacy strategy	Strategic plan	ND	FEDOMA	Discusses key advocacy issues and action plan and the methodology used to develop the plan	Workshop	National	English	23
59	UNDP/ILO Project Ministry of Community Services The Community and Disabled Persons	Brochure	ND	MACOHA	To provide members of the community with information about the situation of people with disabilities in Malawi; and how they can support rehabilitation programs, help disabled persons in their own areas or fields, and help educate the community on preventing disabilities	Letter to 'Reader' in brochure format		English	8 pp.
60	Malawi: Mtundu wa anthu onse – Tidziwitsane za kulumala	Brochure	ND	FEDOMA	Information leaflet on disability	-	National	Chichewa	6

NO	TITLE	TYPE	YEAR	AUTHORS	PURPOSE	METHODOLOGY	GEOGRAPHIC COVERAGE	LANGUAGE	PAGINATION
61	Guidelines on disability terms	Booklet	ND	FEDOMA	Presents terms which are disability friendly	-	National	English	5
62	Fighting for rights of people with disabilities in Malawi	Article	ND	Lameck Masina	Discusses the story of Mussa Chiwaula, the Executive Director of FEDOMA	Interview	Blantyre	English	3
63	Rehabilitation technician students' training in community based rehabilitation in Malawi	Article	ND	Mzota Robert Kabibwa	Discusses how the rehabilitation students' training can be improved	-	National	English	4
64	MACOHA Services offered	Pamphlet	ND	MACOHA	Discusses the different services offered by MACOHA	-	National	English	6

Annex 2: List of documents not seen or found by researcher

No	Title	Type	Year	Authors	Purpose	Methodology	Geographic coverage	Language	Pagination
65	In-Depth Study of Malawi Council for the Handicapped	Study report	1997	Dr. DMC Nyirenda, Malawi Institute of Education	To focus on the analysis of the Council (MACOHA) in terms of its activities, describing the Council, its organization and management structure, and sustainability; to assess what the Council does to ensure the welfare and training of disabled persons; to describe lessons learned.	Data collection, including the use of official documents, a structured questionnaire and interviews with 13 officers. Respondent validation used to authenticate the results.	National	English	59 pp. including appendices (7 pp.)
66	Disability in Malawi – A situational analysis	Situational analysis report	2001 May	NAD: Svein Brodtkorb, Dr. Mohammad Kisubi	Rapid situational analysis	Field visit.		English	
67	2001 White Cane Day 15 October – Changing What it Means to be Blind	Pamphlet	2001	Sight Savers International (SSI)	Briefly presents the situation of blind people in Malawi, the reason for observing White Cane Day, and how one can help the blind.			English	
68	Report on co-operation with the Disability Sector in Malawi	Report from field visit	2001 Sept.	NAD: Svein Brodtkorb, Dr. Mohammad Kisubi	To consider possible long-term cooperation by NAD with the Malawi Disability Sector, implementation issues and actions needed to be taken prior to start of support from NAD.	Field visit		English	

No	Title	Type	Year	Authors	Purpose	Methodology	Geographic coverage	Language	Pagination
69	Language Guide on Disability	Pamphlet	2003	MACOHA	Introduces examples of appropriate and inappropriate usage of language in relation to disability)			English	
70	Baseline study for CBR Programs in Machinga and Blantyre Districts	Baseline study	2003	Maria Kangere	To explore perceptions of stakeholders on the Machinga and Blantyre CBR programs implemented by MACOHA; examine strengths, weaknesses, threats and opportunities in service delivery including processes and infrastructure; identify strategies for sustainability of CBR in the two districts; and draw recommendations for improving service delivery.	Participatory methodology where a team of 10 people collected data from different sources; triangulation of information using key informants; focus, group discussions, documents review and observations. A total of 37 interviews of key informant and focus group discussions were carried out, seeking information on perceptions of different stakeholders in CBR and other disability issues; stakeholders included DPOs, parents of children with disabilities; NGOs, Government line Ministries and department staff, service providers/collaborators at traditional authority level; local leaders; and volunteers.	Machinga Blantyre	English	72 pp.
71	TIGAWANE The Newsletter of VSO Malawi	Newsletter	2003	VSO Malawi	Issue (Vol. 14, Dec. 2003) focuses on disability as a human right and developmental issue	Articles by different authors on the topic of disability		English	9 pp.

No	Title	Type	Year	Authors	Purpose	Methodology	Geographic coverage	Language	Pagination
72	Language Guide on Disability	Pamphlet	2003	MACOHA	Introduces examples of appropriate and inappropriate usage of language in relation to disability)			English	
73	Saving Sight – Changing Lives	Documentary film (funded by SSI)	2003	MACOHA	The film aims to publicize MACOHA’s project for visually impaired persons in the Balaka / Machinga CBR project.	The film documents achievements of the project, for example positive results achieved through training of visually impaired persons in various skills, as well as inform about cataract operations, eye camps and mobility training.	Balaka / Machinga CBR project	Chichewa	33 min.
74	Vocational Skills Development for Youth with Disabilities (mentioned as a reference in a report but the report was not available at MACOHA)	The study was commissioned by the African Rehabilitation Institute – Southern Africa Regional Office	2005	John Mataya and Steven Msowoya	To assess the impact of vocational skills training at institutional level on the lives of former trainees (persons with disabilities) The study followed up some of the graduates and assessed the extent to which the skills/training contributed towards self reliance on the part of the graduates	Both quantitative and qualitative tracer study	countrywide	English	30pp
75	Evaluation of the Community Based Rehabilitation Program in Malawi (a mid-term evaluation of the NAD supported CBR Project)	Evaluation report	2006	Nordic Consulting Group (NCG): Jens Claussen, Basil Kandyomunda, Stein Erik Kruise, Jack Makoko	The study was commissioned by NAD to assess to what extent the CBR program will achieve intended objectives, make recommendations for strengthening the program, consider CBR in the 3 districts as a	Assessed the extent to which the CBR program has addressed gaps identified in 2003 (baseline study), strengths and weaknesses with emphasis on the program’s organization, management and financial arrangements and sustainability. Involved document review, interviews,	Machinga Blantyre Balaka	English	64 pp. plus annexes

No	Title	Type	Year	Authors	Purpose	Methodology	Geographic coverage	Language	Pagination
					model for expansion, and assess the capacity of DPOs, including the outcome of the project to support FEDOMA.	and field visit.			
76	(Review of OD)	Evaluation report	2006	Nordic Consulting Group (NCG): Jens Claussen, Basil Kandyomunda, Stein Erik Kruuse, Jack Makoko	To review three projects targeting youth with disabilities support with Operation Day's Work (ODW) funding: two components involving institutional support to youth with disabilities and one component within the CBR program targeting youth at community level		Machinga Blantyre Balaka	English	
77	Report on MACOHA Community Based Rehabilitation Information Systems project	Project report	2007	Anthony Muyepa	To summarize progress to date in the first four phases of the CBR information systems project.	Narrative documentation of action already taken, constraints, action remaining and developing costs		English	3 pp. plus CBR reporting forms
78	Malawi Country Report on a Comparative Study of Political Approaches to Securing Equal Opportunities, Equal Participation, and	Comparative research study	2007	Msoyoya Steven	erate rate research based evidence of the impact of the two approaches used and the "road of good men") which have been used by peoples organizations to influence design and implementation; to share national experiences with key stakeholders in Africa and Denmark of persons with disabilities	Focus group discussions, open ended interviews, document review; e-mail questionnaire and discussion group	Part of a larger comparative study which was carried out simultaneously in Denmark, Kenya,	English	59 pp.

No	Title	Type	Year	Authors	Purpose	Methodology	Geographic coverage	Language	Pagination
	Equal Rights in the Context of the United Nations Convention on the Rights of Persons with Disabilities				eam society. (full text below)		Uganda, South Africa and Malawi		
79	Baseline Study Report on the Status of Special Needs Education in Malawi	Study report	2007	Inter nos Consult: AJL Makoko, Patrick Chimutu	Commissioned by the Catholic University of Malawi to conduct a situational analysis of Special Needs Education (SNE) in Malawi in order for SNE stakeholders to devise programs and projects for possible interventions for the improvement of the sector in the country.	Baseline survey involving: literature review, visits to SNE Centers (special schools, resource centers), government ministries, and relevant academic institutions (including NGOs), and discussions/interviews with a cross section of stakeholders (e.g. education officials in government and universities, students and staff in SNE institutions, and parents/guardians.	National	English	50 pp.
80	Assessment and Training of CBR Personnel in Malawi	Report on capacity building in CBR	2008	Padmani Mendis	To teach the CBR National Resource Team and MACOHA staff (to prepare participants to carry out the role of National CBR Trainers); to assess the Malawian CBR training arrangements (for CBR cadres within MACOHA) and organizational aspects (e.g. identification of training needs, curriculum,	Qualitative information was gathered through interviews and discussions with MACOHA staff, randomly selected CBR workers and volunteers, the National Resource Team and other relevant stakeholders. Training of CBR Trainers course (for MACOHA staff and National Resource Team) held in May 2008.	Balaka Blantyre Machinga Mzimba	English	49 pp.

No	Title	Type	Year	Authors	Purpose	Methodology	Geographic coverage	Language	Pagination
					capacity of resource team, cost efficiency and quality), and make recommendations for MACOHA and NAD.				
81	As Strong as the Weakest Link	Evaluation report	2009	NUPI: Øyvind Eggen, Alice Nganwa, Abigail Suka	To assess the relevance, efficiency and coherence of the CBR program in Malawi supported by NAD and provide recommendations for strengthening the program's response to the needs of persons with disabilities and for improved approaches in the next long-term period (2010-2014).	Review of program documents, semi-structured stakeholder interviews, focus group discussions, demonstrations of actual practice in management and service delivery, and consultations with science based literature.	Blantyre Machinga Balaka Mzimba	English	58 pp.
82	Information on HIV from the National AIDS Commission in Braille	Leaflet	2009	National Aids Commission (Montfort College Braille Press, Malawi)	To disseminate information about HIV in the local language	Braille document		Chichewa Braille	
83	The Kamuzu Vocational Rehabilitation and Training Centre	Pamphlet	Reviewed and reproduced from time to time	MACOHA	To inform about the 8 training programs offered at the KVRTC.	Pamphlet format briefly describing the center's historical background, capacity and training programs.		English	
84	Youth Enterprise Development Fund (YEDF)	Pamphlet	2010		To present information on YEDF and its objective, which is to provide youth with sustainable technical, entrepreneurial and	Pamphlet format describing YEDF's background; coverage and target group; types of businesses; lending methodology; types of loans and loan conditions;			

No	Title	Type	Year	Authors	Purpose	Methodology	Geographic coverage	Language	Pagination
					financial skills that promote business ingenuity	conditions for the group; loan application forms; appraisal and approval process; and training.			
85	FEDOMA	Pamphlet	ND	FEDOMA	To provide an introduction to FEDOMA	Pamphlet format describing FEDOMA's mission, objectives, activities, research, advocacy, capacity building and membership		English	
86	Malawi: Mtundu Wa Anthu Onse, Tidziwitsane Za Kulumala	Pamphlet	ND	FEDOMA	To provide an introduction to FEDOMA and to lobby for a rights based approach to development work			Chichewa	
87	MACOHA Bangwe Factory Specialists in: Handicrafts Weaving Screen Printing Tie & Dye Batik Tailoring	Brochure	ND	MACOHA	To introduce the story of the Bangwe Factory, a production unit of MACOHA established in Limbe in 1975	Brochure format briefly describing the various handicrafts of the Bangwe Factory		English	
88	Federation of Disability Organizations in Malawi (FEDOMA) Guidelines on Disability Terms	Brochure	ND	FEDOMA	Provide a set of clear guidelines about preferred disability terminology and offer suggestions for appropriate ways to describe people with disabilities	Brochure format giving appropriate terminology and describing portrayal issues		English	5 pp.

No	Title	Type	Year	Authors	Purpose	Methodology	Geographic coverage	Language	Pagination
89	Various newspaper articles on people with disabilities, FEDOMA, rights of people with disabilities, and disability issues		ND					English Chichewa	
90	Malawi Council for the Handicapped	Pamphlet	Reviewed and reproduced from time to time	MACOHA	Briefly introduces the role of MACOHA and vocational rehabilitation with instructions on who can apply, when to apply and who should be contacted to apply for services.			English	

Annex 3: Existing research documentation on CBR by theme

(i.e. by CBR Guidelines matrix component: education, health, livelihood, social and empowerment), nature of research (baseline study, action research), objectives and major research outcomes.

THEME	TITLE OF RESEARCH	YEA R		OBJECTIVES	MAJOR RESEARCH OUTCOMES
	Violence and abuse against women with disabilities	2006	Basic research	<ul style="list-style-type: none"> To improve the living conditions of women with disabilities in Malawi by disclosing and describing the nature of abuse, neglect, violence and discrimination against this vulnerable group. 	<ul style="list-style-type: none"> Most women access health care through public facilities but for some the cost of medication was more than what they could afford. In general people with disabilities had good experiences with health professionals but for people with hearing impairment, the lack of knowledge of sign language by health professionals such as nurses can be a barrier. Because of the belief that they had been bewitched some did not go to health facilities for treatment but traditional healers or through prayer. An example was given by a woman who said that traditional medicine did not help cure her disability. FEDOMA helps people with albinism with sunscreen lotion.
HEALTH	Final evaluation of Msakambewa Community Based Rehabilitation Program	2002	Evaluation	<ul style="list-style-type: none"> To examine the relevance of aims and objectives of the original project proposal. To examine the extent to which each of the major objectives has been achieved in terms of having a positive impact on the project beneficiaries. To identify which objectives have not been achieved. 	<ul style="list-style-type: none"> Social services such as education and health and most development activities such as access to loans for IGAs have sidelined people with disabilities. These problems have been compounded by the general belief that disabled persons are helpless and dependent. The CBR project was therefore relevant as it addressed specific problems that people with disabilities were experiencing. A total of 1658 persons with disabilities were registered in the 3 year program: 305 had visual impairments, 18% deaf or hearing impairment, 22 physical disabilities, 24.5% epilepsy and 5.5% mental retardation/psychological disorders /albino. The number of people with disability was considered higher than 3% national average. For ear infections the outreach program screened 716 people with disabilities, treated 6628 and assisted 1182; on the other hand 4280 people with disabilities were treated suffering from ear infections. For physiotherapy 238 were assisted while 151 were supported or cared for. There were quite a number of people with disabilities who were referred: 526 were referred to hospitals, 95 to Sight Savers and

Evaluation of services for the visually impaired within a CBR program	1990	Evaluation	<ul style="list-style-type: none"> ○ To determine the soundness, effectiveness, impact and sustainability of the CBR program with particular reference to its services for the visually impaired and to make appropriate recommendations arising from the findings. 	<p>49 to Institutions for the blind while 74 were referred to MAP⁹⁵.</p> <ul style="list-style-type: none"> ○ The program also sensitized people about the rights and abilities of people with disabilities. ○ CRWs led by physiotherapists conducted clinics where a number of people with ear and eye problems were screened. Simple treatment was offered but more serious ones were referred. Some of these regained sight or their hearing improved. The CRWs followed up cases. ○ Due to treatment and advice offered, the frequency of epileptic seizures decreased. <p>In 1990 there was one CRO in each district and 371 volunteers nationally. Blantyre alone had 63 volunteers.</p> <ul style="list-style-type: none"> ○ The report outlines the roles of women and children program officers, CROs and volunteers. ○ Informal or spontaneous community help to the disabled is limited. This may be because the communities have low income and hence have nothing to spare. There was no evidence of substantial change of attitude towards people with visual impairment in 1st 3 years of the program. ○ Volunteers were enthusiastic and committed to their work. They did not ask for payment but recognition, identity and incentives. ○ The needs of the visually impaired are inadequately provided for at village level. ○ The Village Rehabilitation Volunteers are important and they are committed and a valuable resource. The use of VRVs was found sustainable. Their workload seemed too high within the context of lack of transport and their limited availability. The VRV service could be improved by providing incentives. ○ Volunteers' trainers are chosen by VRVs from the village. As at the time of evaluation 191 clients had received some form of training under the program. However it was difficult to recruit trainers ○ As of 1990 the CBR program in Blantyre had reached 17% of the estimated 8000 people with disabilities in the district. ○ In 1990 9% of the visually impaired in Blantyre had been identified and the proportion assisted is estimated at 3%. The number identified is considered low. The quality of services for the visually impaired was considered of low quality partly because the CROs and
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⁹⁵ The statistics from the report do not add up.

				<p>VRVs are responsible for very large areas and too many disabled persons to be able to spend adequate time with clients.</p> <ul style="list-style-type: none"> ○ At VRV level there was a serious lack of understanding concerning the prevention of further loss of vision.
Report on the disabled within the Bawala Ward. Ntchisi Strategy for Assistance	1992	Action Research	<ul style="list-style-type: none"> ○ To identify disabled persons within the Bawala Ward. ○ To identify disabilities and assess them by age, sex and type of disability. ○ To state the number of disabled individuals who have been treated for their disabilities. ○ To identify available services within the area and state those utilized by the disabled. ○ To state educational levels of the disabled. ○ To state the number of disabled individuals who are involved in village activities. ○ To state cultural/traditional beliefs that may affect disabled individuals acceptance within the community. ○ To identify types of employment disabled individuals are engaged in. ○ To identify major problems faced by the disabled. 	<ul style="list-style-type: none"> ○ There were 206 disable individuals in the 35 villages surveyed and this was below the expected 2.9% of the population. There are more males with disabilities compared to females. Over 2/3 of the disabled persons are aged above 17 years. ○ Physical disabilities are the most common but other forms of disabilities included behavoooural, hearing/speaking, seeing, retardation and fits. ○ A number of causes of disability were mentioned: diseases such as polio, TB, measles, malaria; accidents, burns and witchcraft among others. ○ 51% of the disabled sought medical help, 18% sought traditional assistance and 4% sought both medical and traditional while 28% did not seek help. ○ Most of those seeking traditional help were those with fits which people believed was caused by witchcraft. ○ In the past the disabled were feared and misunderstood hence were not readily accepted in community. They were not encouraged to hold office. ○ Common problems faced by people with disabilities: <ul style="list-style-type: none"> ○ No money. ○ Mobility problems. ○ Difficulty with farming. ○ No schooling. ○ No social life. ○ Food insecurity. ○ 44% reported having no problems.
Albinism in Malawi: A qualitative study on attitudes and beliefs	2005	Basic Research	<ul style="list-style-type: none"> ○ Explore attitudes on marriage in regards to people with albinism. ○ Explore events in the lives of people with albinism and how people think these events have influenced their lives. ○ Explore people's knowledge about albinism. 	<ul style="list-style-type: none"> ○ There are quite a number of beliefs about albinism: that the disease is caused by mwanamphepo; that if a pregnant woman looks at an albino she may deliver an albino child as well; that albinos are not people, they are ghosts and they do not die. ○ In most cases participants said that being an albino was god's will. ○ People with albinism are called a number of names: mzungu (white man), yellow man, Geoffrey Zigona or napwere. The report explains why they are called these names.

			<ul style="list-style-type: none"> ○ Determine if there is a difference between people with albinism in rural and urban areas and between males and females with albinism. ○ To explore the effect of poor eye sight and skin problems and if at all they get any help. 	<ul style="list-style-type: none"> ○ Problems experienced by albinos <ul style="list-style-type: none"> ○ Skin problems due to the sun. ○ Vision. ○ School insisting that they put on short sleeved shirts despite health personnel advising them to put on long sleeved shirts. ○ Many of them have not used sunscreen because of poverty.
Blantyre Cheshire Home Community Based rehabilitation project – project dates: April 1998-march 2001 – Evaluation paper	2001	Evaluation of program	<ul style="list-style-type: none"> ○ To determine <ul style="list-style-type: none"> ○ number of children assisted, number of children identified from target group. ○ number of children referred to other services from the project. ○ number of caregivers trained.. ○ number of community clinics identified. ○ Community views. ○ Cheshire homes staff views. ○ Impact of volunteers. ○ To make recommendations. 	<ul style="list-style-type: none"> ○ A total of 1158 clients were assisted between 1st April 1998 and 31st March 2001. 138 of these were children. Most of these children come from Blantyre area. ○ 53% were males while the rest were females. ○ Common problems identified in children were cerebral palsy, learning difficulties, communication disorders (such as hearing impairment or speech impairment). ○ Primary health workers did not provide children with rehabilitation during the period. their role is to identify a problem and refer child to appropriate service. ○ The majority of children attending BCH present for either physiotherapy or occupational therapy. The others go there for special needs education or vocational skills.. ○ 243 pieces of equipment were issued to disabled children and the most common pieces of equipment issued were CP chairs, corner seats and standing frames. ○ The total number of children identified from the target group was 1656 by the project. These were identified by Cheshire Homes and MAP. ○ Over the project period there was an increase of 318% in the number of children receiving treatment i.e. from 232 to 738 children. Of the newly admitted children 74% were presented with CP. Most of the new clients were referred by friends and guardians of clients ○ 788 children were admitted to BCH: 374 were females while 414 were males. ○ 14 community clinics were opened during the course of the project. Some of these had proper structures while in some cases services were provided under a tree. ○ A total of 362 participants were trained during the project but this does not include parents trained in disability management. About 900 parents were trained in some form. The people trained included HSAs, Nurses, medical assistants, teachers, community leaders and

CBR volunteers.

HIV/AIDS awareness, behavioral and attitude change towards persons with disabilities program (April 2005-March 2006)	2007	Program Evaluation	<ul style="list-style-type: none">○ To assess the extent to which the project has addressed the gaps outlined in the proposal document.○ To assess the strengths and weaknesses of MACOHA as the implementing agency of the project.○ To examine the effectiveness of the project in the four districts with a view to determine prospects for replication to other districts.○ To make recommendations for strengthening and sustainability of the project.	<ul style="list-style-type: none">○ The program was on target in bringing awareness about HIV/AIDS and disability issues to target groups.○ HIV/AIDS Message dissemination included Braille messages and large print for those with visual impairment, television and radio messages for those with speech and hearing problems.○ Twenty two participants from various organizations dealing with HIV/AIDS were trained in sign language and training was facilitated by MANAD. The aim was to equip participants with skills in communicating with the hearing and speech impaired.○ The project also trained community structures through support groups and peer educators.○ IEC materials were obtained from various organizations for selection, adaptation, reproduction and distribution to target groups. Over 27000 IEC materials were acquired.○ Because of awareness programs, 593 people out of a target of 1230 went for HTC. Among these 95 were members of staff while eth others were people with disabilities.○ 22330 condoms were distributed to people with disabilities and staff. These condoms were sourced from PSI, MACRO, DHOs and other service providers. Condoms were left in most cases in the washrooms for people to pick. The rate of condom replenishment was higher in male washrooms compared to female washrooms. Condoms were also distributed during meetings.○ 152 people were on ARVs while 198 patients were receiving HBC support. A total of 353 orphans were being given nutritional and psychological support.○ Each MACOHA Unit had an HIV/AIDS institutional committee. These had regular meetings.○ Shortfalls of the program:<ul style="list-style-type: none">○ Most of the training of support groups was a one off activity and there was no follow up○ In the messages factors that influence change in behavior were not given adequate attention.○ In most campaigns youths with disabilities were not given
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				<ul style="list-style-type: none"> ○ much attention. ○ Support for economic activities was absent. ○ Some items were not budgeted for.
A descriptive study identifying the caregivers attending treatment with the CP children at Feed the Children Malawi, Blantyre Campus from 30 April to 05 May 2007	2007	Basic research	<ul style="list-style-type: none"> ○ To identify which position of the children in the family commonly suffer from CP. ○ To establish the common problem the caregivers faced in the process of rehabilitation of the child. ○ To identify how the community say about the CP child and their caregivers. 	<ul style="list-style-type: none"> ○ In most cases children with CP attended therapy with their mothers followed by grandmothers. The main reason some mothers do not attend therapy with their children is that they were at work. Fathers do not normally attend the centres with CP children: they are either at home or at work. Most of the caregivers are business persons; near a quarter are working and just more than a fifth are farmers. ○ 80% of the caregivers had no one to help them take the child to the rehabilitation centre. This is seen as the duty of the mother. ○ Most of the children with CP are aged less than 5 years. ○ 50% of the children with CP are first borns in their families. Nearly a fifth of caregivers experienced no problem during the rehabilitation of the child. Others experienced problems such as gossiping, giving more time to the child than other activities, the child being dependent; transport costs; sickness of the child and lack of resources. ○ Just over 51% of the CP children attended therapy for less than 1 year. ○ Some community members have bad feelings towards children with CP and their caregivers while others have good feelings.
Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District	2009	Baseline Study	<ul style="list-style-type: none"> ○ To estimate the population of persons with disabilities in Chikhwawa District. ○ To identify the types of disabilities prevalent in Chikhwawa district. ○ To determine socio-economic characteristics of persons with disabilities in the district. ○ To analyse stakeholders interventions on rehabilitation services for persons with disabilities. ○ To determine the availability of appropriate health, education, vocational training and other social services for persons with disabilities in Malawi. 	<ul style="list-style-type: none"> ○ In 2003 there were 1065 registered persons with disabilities in Chikhwawa District. ○ Types of disabilities prevalent in communities: visual, physical, hearing, epilepsy, albinism, multiple disabilities and mental retardation. ○ Some PWDs live very far from health facilities while others are very close. ○ PWDs are not discriminated against when they go for services at health facilities. ○ Challenges experienced by people with disabilities include: lack of food; poor shelter; lack of assistive devices; lack of access to information; poor access to health services. ○ Some PWDs are hard working: gave examples of PWDs who are doing well in agriculture. ○ Other people with disabilities undermined themselves as useless. ○ In Chikhwawa District Shire Valley Initiative for Persons with Disabilities and Malawi Union for the Blind were identified as the

only service providers that have programs targeting PWDs.

A report on HIV/AIDS and reproductive health care amongst people with disabilities	ND	Basic Research	<ul style="list-style-type: none"> ○ To explore perceptions, knowledge, attitudes and practices of sexuality and HIV/AIDS among people with disabilities. ○ To identify the contexts and extent of sexual abuse of women and children with disabilities. ○ To assess the extent to which disabled people access sexual and reproductive health services including HIV/AIDS ○ To gain an understanding of the constraints and opportunities that disabled people experience when trying to access sexual and reproductive health services. ○ To mitigate the inclusion of disabled people in HIV/AIDS policy formulation and strategies to combat HIV/AIDS. ○ To explore the role of families and community supports for persons with disabilities who have HIV/AIDS; produce outputs that will be applicable in a community based rehabilitation (CBR) context (this will make the project sustainable overtime). 	<ul style="list-style-type: none"> ○ Some believe that children from persons with disabilities are also disabled. ○ Others think a disabled person is a cleanser of AIDS – if an HIV+ person has sex with a disabled person the disease will be cured. ○ Other beliefs include: disabled persons as beggars; white canes are stolen for use in juju; having sex with a disabled person increases once wealth; disabled persons are sinners hence should not give offerings but be given etc. ○ There are no differences in terms of sexuality between people with and without disabilities. People with disabilities are equally sexually active. ○ In some cases disabled women are mistreated at antenatal clinics, during delivery and post natal services as if they are not supposed to conceive and give birth. ○ Disabled women interviewed said they have never attended health education programs but they need such services. ○ Most disabled women are able to access birth control pills just as is the case with other women. ○ Almost all disabled people are aware about how HIV is transmitted and how this can be prevented. Some students not sure about how HIV is transmitted. ○ Not many of those interviewed have been tested. Those who cannot talk and need sign language interpreter felt there is no confidentiality in their case with regard to HIV testing. Other challenges included lack of a guide to take the visually impaired for example to HTC sites and long distances to HTC.
Quality of life assessment tool and impact analysis in the framework of P1919	2010	Basic research	<ul style="list-style-type: none"> ○ To examine and gather information on quality of life of the target group before and after a specific programs intervention on the individual, family and community. ○ To understand the meaning of 	<ul style="list-style-type: none"> ○ In health this should result in ensuring that people with disabilities live a better life and that they are able to access rehabilitation and other health services. ○ Gives an example of a parent whose child had club foot and after an operation and physiotherapy the life of the child and his family changed: initially the child could not walk but after being treated he

			<p>quality of life in the context and content of Malawi.</p> <ul style="list-style-type: none"> ○ To develop a ranking mechanism that allows to measure to what extent quality of life for people with disabilities has been improved through intervention of the program. ○ To assess the most significant program interventions that have contributed to quality of life of people with disabilities. 	started walking and lead an independent life
Mothers'/guardians' perception on rehabilitation of cerebral palsy children at Feed the Children Malawi, Blantyre Campus	2008	Basic research	<ul style="list-style-type: none"> ○ To identify the length of rehabilitation services given to the child. ○ To identify the age at which the child started receiving rehabilitation services. ○ To identify the treatment of management used. ○ To identify the effectiveness of the treatment given. ○ To make recommendations according to the findings and literature review. 	<ul style="list-style-type: none"> ○ 33% of the mothers had moderate knowledge of causes of CP while 67% had no or little knowledge. ○ 93% of the mothers had moderate knowledge about rehabilitation of their children while the rest had little or no knowledge about this. ○ Just more than half of the parents said that the treatment given to children with CP was effective, 37% did not know whether it was helpful or not while the rest thought it was not useful. ○ Most of the children in this study had been receiving rehabilitation services for less than 12 months and about two thirds received both exercises and appliances for their children. ○ Nearly half of the children started receiving rehabilitation services at age 7-12 months.
Perceptions of parents/guardians of children with cerebral palsy	2007	Basic research	<ul style="list-style-type: none"> ○ To determine parents/guardians knowledge of the condition. ○ Explore parents'/guardians' attitudes and beliefs about cerebral palsy. ○ To determine the parents'/guardians' understanding of the treatment process offered. ○ To explore the support parents/guardians get from their families and communities. 	<ul style="list-style-type: none"> ○ Some respondents knew that cerebral palsy was a medical condition caused resulting from brain damage from different causes but some did not know. ○ Most of the participants knew what caused the condition of their children e.g. cerebral malaria, meningitis and jaundice. Others demonstrated lack of knowledge about the condition especially those who did not know what CP is. ○ Some people stay with the condition for the rest of their lives while others do get better and live a normal life as is the case with other people: the condition improves with physiotherapy. ○ The majority were satisfied with the information given to them about CP. Others however were not satisfied as they were just told that the child has CP without investigations. ○ Even though most respondents were satisfied with information given

- they would have loved to have some additional information.
- Participants had positive attitudes towards children with CP. Some participants felt that such children are not happy since they seemed as if they admired their friends who are normal; some felt that such children have deficiency in intelligence and cannot compete with their normal friends if they attend same schools.
 - While the majority believed that witchcraft was not involved in the causation of CP in children, others believed that it was involved due to some events preceding the condition. Some parents go to witchdoctors because of the pressure elders and community members. While others consulted witchdoctors, they stopped after seeing the benefits of treatment they received at Feed the Children.
 - In terms of treatment, the main one was physiotherapy and other treatments included nutritional support, medical consultations and counseling. All the respondents were involved in the treatment process: they were attending the clinics and being taught how to do physiotherapy etc.
 - The expectation from the treatment process included: the child would get better and live normally; they would give him the drugs and he would get better, ; child would be able to pick an item, crawl and do other things.
 - Interventions to help improving care:
 - No segregation by health workers in other hospitals.
 - Provision of free equipment for physiotherapy at home.
 - Availability of funds for parents to start business.
 - Showing love to the child.
 - Provision of educational opportunities.
 - Putting more effort on physiotherapy by parents.
 - Participants felt HBC should be introduced in management of their children
 - Support from families and communities.
 - Family support in form of love, help in caring, provision of resources, encouragement, help in doing physiotherapy etc. others lacked support. Those who were getting family support were satisfied with support given.
 - Support from community included encouragement, sympathy, help in caring for the child, love, pieces of advice, members of the community allowing their children to play with children with CP. Others felt the community

was not helpful. Some community members make very bad comments about CP children. In some cases such children are segregated.

Survey of handicapped persons in Malawi	1983	Basic Research	<ul style="list-style-type: none"> ○ To estimate the incidence of disability. ○ To establish the demographic and socio-economic characteristics of the handicapped persons by type and severity of disability. 	<ul style="list-style-type: none"> ○ The survey found that there were 190,000 handicapped persons in Malawi: 102,000 were males and 88,000 females.; and 7% of these were in urban areas while 93% were in rural areas. Three percent of the people in Malawi were estimated to be handicapped. ○ 11% of the household had at least one handicapped person. ○ 32% of the disabled persons were head of households, 17.8% were daughters and 22.7% were sons. ○ 90% of the handicapped suffer from one form of disability, 9% from two forms of disabilities while the rest from three or more forms. There were three major forms of disabilities: fits/epilepsy (18.8%), crippled limbs (18.2%) and deafness (13,3%). 8.5% of the handicapped persons had mental illness. ○ 29% of the disabled persons aged 5+ had mobility problems i.e. could not move around unless carried, could only move with assistive devices or moved around with difficulties,.
Living conditions among people with activity limitations in Malawi: a national representative survey	2004	Action Research	<ul style="list-style-type: none"> ○ To carry out a representative National Survey on the living conditions of people with disabilities in Malawi so as to provided much needed data for policy influence and planning. 	<ul style="list-style-type: none"> ○ The prevalence of disability in Malawi was at 4.18% as opposed to earlier estimates of 10%. ○ 43% had physical disabilities; 42% had sensory impairments; 115 other forms of disabilities. There were no gender differences. ○ The most common causes of disabilities were physical illness, from birth (natural), and accidents. ○ The majority of the people with disabilities interviewed were aware of the services available, a significant proportion needed the services but considerably lower proportions received services e.g. 84% of the respondents were aware of the health services available; 835 needed the services but only 61% were able to receive the services. This demonstrates that there exists a gap between what services people with disabilities need and what they receive. ○ 17% of the respondents used assistive devices. There were more men (25%) who used assistive devices compared to women (14%). 70% of the respondents who were using assistive devices used personal mobility devices such as wheelchairs, crutches and walking sticks etc. Some used more than one assistive device. 34% of those using devices acquired them privately, 19% from government and 9%

through NGOs and the rest through other sources.

Effective HIV/AIDS and reproductive health information to people with disabilities	2004	Action Research	<ul style="list-style-type: none"> ○ To describe the major forms of disabilities existing among the sampled population. ○ To explore how people with disabilities communicate with other people and amongst themselves. ○ To determine knowledge about HIV/AIDS among people with disabilities. ○ To describe perceptions of people with disabilities about the transmission and prevention of HIV. ○ To determine knowledge and perceptions of people with disabilities regarding family planning, condoms and condom use. ○ To explore experiences of people with disabilities regarding sexual and reproductive health issues. ○ To make recommendations on how best information can be communicated to people with disabilities. 	<ul style="list-style-type: none"> ○ A third of the respondents had paralyzed legs; nearly a fifth were visually impaired; and 10% had epilepsy; 9% had paralyzed arms. The rest had various forms of disabilities. ○ The majority of respondents communicated through speech; 1.8% used sign language because they had hearing and speech problems. ○ Just over three quarters of respondents reported having had sex; of those who had sex 17% were forced. ○ Nearly 90% of the respondents had heard about HIV. 94% had heard about AIDS. ○ Respondents were also aware of the different ways through which HIV is transmitted. ○ Major sources of information on HIV: radio, health facilities and friends. Only one person talked about sign language as a source of AIDS information. ○ Problems experienced by people with disabilities in accessing HIV information: lack of radios, lack of outreach programs, lack of materials, long distances to health facilities and mobility problems. ○ 70% of respondents were aware of HTC but only 10% reported having been tested. Reasons for not going for HTC included: thinking they are okay; fearing blood will be pumped from their bodies, mobility problems to reach HTC sites and lack of transport. ○ Only 42% of those who knew condoms reported knowing how to use condoms. 27% of those who knew condoms had ever used condoms. The majority knew where to buy condoms. Low condom use is due to never having had sex before, not liking the condoms, not promiscuous and always being with spouse. Some reported having difficulties using condoms because of disability. ○ Most were aware of STIs: 3% admitted to have contracted an STI and the majority sought treatment. ○ 28% reported using family planning methods. ○ The major recommendations were that people with disabilities should be involved in SRH activities and that a variety of techniques should be used in order to effectively reach people with disabilities.
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EDUCATION

Violence and abuse against women with disabilities	2006	Basic research	<ul style="list-style-type: none"> ○ To improve the living conditions of women with disabilities in Malawi by disclosing and describing the nature of abuse, neglect, violence and discrimination against this vulnerable group. 	<ul style="list-style-type: none"> ○ In some cases people with disabilities are not encouraged to work hard in school and get good marks. ○ Some people with disabilities quit school because of lack of financial resources. ○ The higher the educational level of parents the more likely they are to give their children a good education. ○ Children with physical disabilities experienced mobility problems e.g. as much as they would have liked to attend school they did not have a wheel chair for example to get to school. ○ Some schools are not accessible to people with disabilities. ○ Children with albinism were afraid of walking to and from school in sunshine and experienced problems with reading books. ○ There was a lack of Braille materials for the visually impaired. ○ Lack of knowledge among teachers to use sign language; hence people with hearing impairment experience communication problems. ○ The lack of teachers of special education. ○ Teasing of people with disabilities in school is not uncommon in Malawi. ○ Girls are less likely to go to school than boys. Disabled girls are double blowed.
Final evaluation of Msakambewa Community Based Rehabilitation Program	2002	Evaluation	<ul style="list-style-type: none"> ○ To examine the relevance of aims and objectives of the original project proposal. ○ To examine the extent to which each of the major objectives has been achieved in terms of having a positive impact on the project beneficiaries. ○ To identify which objectives have not been achieved. 	<ul style="list-style-type: none"> ○ This project also registered disability cases, rendered assistance to children with disabilities, integrated disabled children into regular or special schools and trained teachers in special education. ○ Over the period of the project 64 children were integrated into schools: 55 into regular schools, 2 at Mua School for the Deaf and 7 at Chilanga School for the Blind. Most of these had visual or hearing impairments ○ 5 students at secondary schools were being supported with school fees, one of them also with clothes and accommodation. CRWs were also visiting pupils integrated into different schools to observe how they were coping and offer support. ○ In some cases teachers lacked basic teaching and learning materials. ○ Some parents were also withdrawing their children from schools because of their disability. Regular teachers also attended special education training workshops to learn effective skills for them to support learners with special education needs. 41 teachers from 7 schools in Msakambewa were trained.

Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District	2009	Baseline Study	<ul style="list-style-type: none"> ○ To estimate the population of persons with disabilities in Chikhwawa District. ○ To identify the types of disabilities prevalent in Chikhwawa district. ○ To determine socio-economic characteristics of persons with disabilities in the district. ○ To analyse stakeholders interventions on rehabilitation services for persons with disabilities. ○ To determine the availability of appropriate health, education, vocational training and other social services for persons with disabilities in Malawi. 	<ul style="list-style-type: none"> ○ Most parents with children with disabilities do not send their children to school due to poverty and lack of interest. ○ One of the challenges PWDs experience is lack of necessary learning materials for special needs pupils in primary school which has resulted into low enrolment among children with disabilities. There are also insufficient teachers and materials for special needs pupils. There is also lack of support services for children with disabilities to attend school.
Evaluation of services for the visually impaired within a CBR program	1990	Evaluation	<ul style="list-style-type: none"> ○ To determine the soundness, effectiveness, impact and sustainability of the CBR program with particular reference to its services for the visually impaired and to make appropriate recommendations arising from the findings. 	<ul style="list-style-type: none"> ○ Two teachers at trained at Montfort College were deployed to the CBR program. Braille textbook was available for visually impaired pupils. The evaluation spells out the duties of itinerant teachers,
Violence against girls who are blind and visually impaired in schools in Malawi	2006	Basic Research	<ul style="list-style-type: none"> ○ To establish how the girl who is blind is affected by violence. 	<ul style="list-style-type: none"> ○ Forms of violence perpetrated against girls who are blind or visually impaired include: <ul style="list-style-type: none"> ○ Threats and actual sexual abuse from specialist teachers, class room (contact) teachers and blind boys. ○ Promises to marry from blind adults in leadership positions in the organisations for the blind. ○ Extensive teasing such as leading them to wrong classrooms, hiding their white cane and their writing materials (primary education park) ○ Not escorting them to the toilet. ○ Name calling: for girls with albinism and low vision they face ridiculing names such as Zigoma after the name of a singer with albinism or mzungu or whitey. ○ Verbal abuse: belittling them suggesting no one would be

Report on the disabled within the Bawala Ward. Ntchisi Strategy for Assistance	1992	Action Research	<ul style="list-style-type: none"> ○ To identify disabled persons within the Bawala Ward. ○ To identify disabilities and assess them by age, sex and type of disability. ○ To state the number of disabled individuals who have been treated for their disabilities. ○ To identify available services within the area and state those utilized by the disabled. ○ To state educational levels of the disabled. ○ To state the number of disabled individuals who are involved in village activities. ○ To state cultural/traditional beliefs that may affect disabled individuals acceptance within the community. ○ To identify types of employment 	<ul style="list-style-type: none"> ○ interested in an affair with a blind girl. ○ Low enrolment of visually impaired girls in school despite that there are more women who are visually impaired compared to males. ○ There are high dropout rates of visually impaired girls from school because of lack of interest and violence against visually impaired girls . Violence against these girls in schools may be the major cause of lack of interest in school. Girls stop going to school because of lack of a safe school environment. Only a few visually impaired girls in primary school make it to secondary school and even fewer are able to complete secondary school education. ○ For many such girls abuses start from their homes and extend to their trusted mentors such as specialist teachers. Such abuses are in most cases also not reported. ○ The paper also gives reasons why there is a need to address violence against visually impaired girls and makes recommendations on what needs to be done to address these problems. ○ Of individuals aged 6+ some experienced sexual abuse from specialist teachers, classroom (contact) teachers and blind boys. ○ years, 19% were attending school; 52% of the disabled had never been to school ○ Disability does hinder a child from receiving an education. The primary reason for non-attendance of school is school fees. Other reasons were severity of disability, schools being too far, having walking difficulties.
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			disabled individuals are engaged in.	
			<ul style="list-style-type: none"> ○ To identify major problems faced by the disabled. 	
Visually impaired children's experiences with special segregated schools in Malawi: the case of Chilanga School for the Blind	2007	Basic Research	<ul style="list-style-type: none"> ○ To describe the importance of education and access to it for disabled people in Malawi. ○ To determine barriers and opportunities for persons with disabilities present in the education system. ○ To explore the advantages and disadvantages of being in a special school and whether this is preferable to being in the mainstream schools. ○ To explore the perceptions of communities around them with regards to their condition. ○ To explore views about the future of people with disabilities in Malawi. ○ To explore what should be done to improve their social conditions. 	<ul style="list-style-type: none"> ○ Young people who are blind miss the pleasures of childhood: collecting plastic bags and making your own ball, collecting clay from dambo and making things out of it, playing on muddy ground etc). ○ Chilanga school has 87 children and 26 do not have any impairment. Most of the children are behind in school compared to other non-disabled children. Most of these pupils come from rural and poor families. ○ Some of the children at the school started school at other schools but because these schools did not have facilities for visually impaired persons the pupils had to be transferred. ○ All the children liked being in the school and teachers were trained to teach Braille which is not the case in other mainstream schools. Teachers are also aware of the handicap children have and they take special account of that when teaching. ○ The school only had visually impaired pupils but other non-disabled pupils were introduced later. Some blind pupils did not like this accusing them of benefiting from their resources – others however were happy with the new arrangement. ○ Just like any boy and girl, visually impaired pupils also have dreams of having a brighter future after school. Some of them would like to become doctors, teachers, radio presenters, traffic officers, musicians, catholic nuns etc and they all gave reasons why they wanted to be in that profession. ○ The biggest challenge they experience is lack of resources. In order to address this problem and ensure they achieve their dreams they said that secondary school education should be free as their parents cannot afford to pay fees. ○ In order to improve their social condition, a number of suggestions were made: they should work hard in school, they would like to see more investment in the education of people with visual and other forms of impairment, government should make secondary school education free

An investigation on the effectiveness of special needs education service delivery in Malawi primary schools	2009	Action Research	<ul style="list-style-type: none"> ○ To explore the effectiveness of special needs education service delivery in primary schools in Malawi. ○ To gather relevant information which reflects the current situation in schools in Malawi. ○ To find ways through which both management and educators can alleviate any experienced challenges in order to strengthen special needs education service delivery system in Malawi. 	<ul style="list-style-type: none"> ○ Learners with special educational needs are identified mostly by teachers followed by parents and then the community. ○ Learners with special needs should be educated in order for them to be self reliant in future; it is their rights and for them to contribute to national development. ○ The performance of learners with special needs is affected by factors such as attitude, poverty, and accessibility of infrastructure and lack of knowledge on special needs issues among other issues. ○ Special needs teachers conduct a lot of advocacy for learners with special needs but their impact is small because they are few in number. ○ The community is mainly involved in provision of support services to the schools and mobilization of resources. It does not help much in the identification of learners with special needs. ○ Challenges experienced by girls with special educational needs in their education include negative attitudes, inappropriate school facilities, long distances and poverty. These challenges can be dealt with through sensitization, use of guidance and counseling and provision of support by parents and communities. ○ Guidance and counseling is the most appropriate means of dealing with HIV and AIDS stereotypes that affect learners with special needs in the community and this is followed by sensitization and the practice of inclusion. ○ Regular teachers and the community lack knowledge and skills in how to identify learners with special needs. ○ Schools get teaching and learning materials for learners with special needs from TALULAR, government and civil society. ○ Infrastructure for learners with special needs is generally unfriendly ○ Availability of support structures and the practice of inclusive education would make regular schools friendly to learners with special needs education. ○ Parents and guardians play an important role in promoting the education of learners with special educational needs by providing support services. The community at large and the civic and political leaders mainly provide support services, advocacy and guidance and counseling. Traditional leaders seem not to be involved in this. Organizations of persons with disabilities are mainly involved in provision of support services and advocacy for SNE. ○ When teaching ordinary learners and learners with special
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				<p>educational needs, regular teachers experience challenges such as teaching methods, teaching and learning materials and time.</p> <ul style="list-style-type: none"> ○ The two major challenges faced in delivering special needs education services are unfavourable working conditions and insufficient teaching and learning materials. These problems can be dealt with by training more specialist teachers and provision of more training and learning materials.
<p>A baseline study of steps taken towards inclusive education in Blantyre, Balaka and Machinga Districts in Malawi</p>	<p>2006</p>	<p>Baseline Survey</p>	<ul style="list-style-type: none"> ○ To describe the situation of inclusive education in Malawi with emphasis on the districts of Blantyre, Machinga and Balaka. ○ To give recommendations on how to strengthen the input from CBR program to improve accessibility and quality. 	<ul style="list-style-type: none"> ○ FEDOMA promotes mainstreaming inclusion with SNE teachers and resource centres covering 6-7 schools and this is seen as complimentary to existing special schools. It also promotes sign language as the teaching language for the deaf. ○ There is more awareness of inclusive education in CBR than in education. However education shows a more pragmatic approach when it comes to inclusive education. ○ Data available in the CBR program is not consistent with surveys: fewer numbers of people with disabilities are identified and even less are attended to ○ Identification and attention are paid to children with disabilities despite all the difficulties that are prevalent. ○ Deaf children are considered most difficult to integrate in mainstream schools due to lack of knowledge on how to communicate. ○ Sign language is has been incorporated into in-service training program for teachers and also members of DPOs, MACOHA and Ministry. Sign language interpreters are also being trained. ○ Teachers in primary and secondary schools have limited training in special needs education. ○ There are some itinerant special needs education teachers who, while based at one school, also visit other schools. ○ In some schools visited pupils with disabilities are integrated into mainstream schools. ○ The SNE support given by the SNE teachers is to teach Braille to the visually impaired and help the teachers with translations to Braille. ○ The teacher of deaf pupils at one school had no means to communicate with the pupil which makes it hard for pupils to learn. Some physically disabled children were physically carried to schools because of lack of wheelchairs. ○ At one primary school the suppliers of school books are CIDA while MACOHA and MAP supplies wheelchairs.

			<ul style="list-style-type: none"> ○ Where there are no facilities disabled children are referred to secondary schools or vocational training centres for the disabled to complete secondary school or vocational training. Public technical colleges now accept people with disabilities as students and over the period 2003-2005, a total of 42 students with various forms of disabilities were enrolled. ○ There is generally a big demand for special needs education in Malawi which is not being met. 	
Quality of life assessment tool and impact analysis in the framework of P1919	2010	Basic research	<ul style="list-style-type: none"> ○ To examine and gather information on quality of life of the target group before and after a specific programs intervention on the individual, family and community. ○ To understand the meaning of quality of life in the context and content of Malawi. ○ To develop a ranking mechanism that allows to measure to what extent quality of life for people with disabilities has been improved through intervention of the program. ○ To assess the most significant program interventions that have contributed to quality of life of people with disabilities. 	<ul style="list-style-type: none"> ○ Parents give anecdotal evidence about the impact of the interventions e.g. children being able to go to school without being accompanied.
Baseline survey report on inclusive education conducted in Phalombe, Thyolo, Machinga, Mangochi and Blantyre Rural Districts in Malawi	2010	Action Research	<ul style="list-style-type: none"> ○ To identify compliment stakeholders of the project in targeted districts. ○ To identify other initiatives on education that exist targeting youths with disabilities in the targeted districts. ○ To identify the level of understanding on the HIV/AIDS pandemic among the youths with disabilities including those who are dead-blind. ○ Identify the level of understanding 	<ul style="list-style-type: none"> ○ Knowledge about disability among principals of Technical Colleges, CPEAs, primary and secondary school teachers was low except among special needs teachers. ○ All respondents in this study except the SMCs and VDCs were knowledgeable about inclusive education. ○ The inclusion of learners in schools and colleges was acceptable and this was the practice. However one school insisted that learners with disabilities should have their own schools. ○ Challenges experienced by learners in schools: <ul style="list-style-type: none"> ○ Inadequate instructional materials. ○ Classes are usually large and learners with disabilities do not receive adequate support especially the deaf. ○ Physical infrastructure not disability learners friendly.

			<ul style="list-style-type: none"> on disability issues in the targeted districts. ○ To identify the most suitable approaches on the implementation of the project. ○ To collect data based on sex and gender of youth benefiting from the existing formal/informal education and vocational training. 	<ul style="list-style-type: none"> ○ Challenges faced by secondary school teachers <ul style="list-style-type: none"> ○ Lack of knowledge and skills in providing additional learning support to learners with disabilities ○ Lack of communication skills especially with learners with hearing impairment. ○ Teachers lack skills in Braille and their knowledge about assistive devices that learners use is also lacking. ○ Crowded classrooms. ○ Absenteeism among learners on market days. ○ Learners with disabilities have little knowledge about AIDS especially among the deaf-blind. ○ Major reasons for learners dropping out of school <ul style="list-style-type: none"> ○ Attitude towards school. ○ Illness. ○ Poverty. ○ Orphanhood. ○ Early marriages. ○ Teenage pregnancies ○ Physical disabilities ○ Stakeholders for implementation of inclusive education <ul style="list-style-type: none"> ○ NGOs provide different social services which can facilitate the development of inclusive education. They provide health services, construction of schools, food security, HIV/AIDS etc. ○ Government extension workers who provide a wide range of services to parents and people with disabilities ○ Community leaders and community structures at various levels (e.g. VDCs). ○
Survey of handicapped persons in Malawi	1983	Basic Research	<ul style="list-style-type: none"> ○ To estimate the incidence of disability. ○ To establish the demographic and socio-economic characteristics of the handicapped persons by type and severity of disability. 	<ul style="list-style-type: none"> ○ Among handicapped persons aged 5+, 42% ever attended school; 96% of these went up to primary school and only 4% went to secondary school level or higher.

Living conditions among people with activity limitations in Malawi: a national representative survey	2004	Action Research	<ul style="list-style-type: none"> ○ To carry out a representative National Survey on the living conditions of people with disabilities in Malawi so as to provide much needed data for policy influence and planning. 	<ul style="list-style-type: none"> ○ School attendance is lower among the disabled members of the households compared to those members without a disability: 34.8% of the disabled members had never attended school compared with 17.7% among the non-disabled and that 18.8% of the disabled were still attending school compared to 41.1% among the non-disabled. ○ 41% of the disabled females and 29% of the disabled males never attended school compared to 21% of the non-disabled females and 14% of the non-disabled males.
Strategies for skills acquisition and work for persons with disabilities in Southern Africa	2007	Action Research	<ul style="list-style-type: none"> ○ To identify effective strategies for vocational skills acquisition by persons with disabilities leading to productive work. ○ To promote policies and effective methods of training and employment services delivery for individuals with different types of disabilities, particularly in mainstream training institutions. 	<ul style="list-style-type: none"> ○ 48% of the survey population (118) had attended some skills training. ○ 50% of those who had attended some skills training were employed. ○ Most of the respondents acquired skills at training centres of MACPHATEVET centres or at primary schools where training in handicrafts was provided. ○ Of those who had acquired skills, the following were the major skills acquired: tailoring (23%), weaving (25%), agriculture (15%), carpentry (11%), home economics (11%) and other skills (17%). ○ Women were more likely to be trained in weaving and home economics while men were more likely to be trained in agriculture and tailoring. ○ 55% of respondents with visual impairment had acquired skills in agriculture, 33% with physical disabilities acquired skills in tailoring and carpentry was common among those with hearing impairment (38%). ○ 11% reported they did not have any problems relating to training. 82% of the respondents encountered barriers in their efforts to attend training as follows: <ul style="list-style-type: none"> ○ 31% could not afford the training fees. ○ 18% could not access the training centres they wished to attend. ○ About 10% could not take time off to attend the training because of family responsibilities. ○ 7% experienced problems in getting to and from the training centres due to lack of transport ○ Other challenges: communication difficulties among people with hearing impairments; unwilling of the trainer to train people with disabilities with others being sent home because of disability; lack of information about training courses; lack of training materials in Braille.

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				<ul style="list-style-type: none"> ○ The majority of the respondents with skills and employed found the skills acquired quite useful in finding work and such skills were also being used. ○ Skills training was viewed as beneficial by respondents. ○ About 40% of respondents were in employment and this was whether they had attended training or not.\ ○ 36% of respondents were self employed (engaging for example in bicycle or radio repairing, selling food, tailoring etc); 18% were working in formal employment; ○ 13% of the respondents who had previously worked but were at the time of survey not working said they lost their job because of economic problems experienced by their employer. ○ The majority of those employed found the job on their own; some through the training centre or with help from friends or relatives. ○ Barriers in finding work among people with disabilities included the following: lack of skills training; lack of jobs; lack of access to credit to start business; lack of awareness among employers about rights of people with disabilities and mobility problem. ○ What people with disabilities say would help to find work or improve at work: <ul style="list-style-type: none"> ○ Skill straining. ○ Availability of support services such as access to loans or any form of financial assistance.
Evaluation of services for the visually impaired within a CBR program	1990	Evaluation	<ul style="list-style-type: none"> ○ To determine the soundness, effectiveness, impact and sustainability of the CBR program with particular reference to its services for the visually impaired and to make appropriate recommendations arising from the findings. 	<ul style="list-style-type: none"> ○ By 1990 a total of 162 loans were disbursed. On average each person got MK450. ○ Repayments of MK13,762 had been made but MK27,571 was in arrears. As at the time of the evaluation 725 of the loanees were in arrears in terms of repaying their loans. Fundamental problems included: the forms being inappropriate and complex; the period between application of loan and the time one gets it is long , sometimes cheques expiring before being cashed and because the period was too long the price of equipment had increased – hence the amount given is inadequate for intended purposes etc.
Final evaluation of Msakambewa Community Based Rehabilitation Program	2002	Evaluation	<ul style="list-style-type: none"> ○ To examine the relevance of aims and objectives of the original project proposal. ○ To examine the extent to which each of the major objectives has been achieved in terms of having a 	<ul style="list-style-type: none"> ○ Vocational skill straining was one of the activities of the project. This was done through local artisans or through formal training. They acquired skill sin carpentry, knitting tailoring and tinsmith. MACOHA paid school fees. After the training, the PWDs were supported with a loan to purchase tools and start operating on their own.

			<p>positive impact on the project beneficiaries.</p> <ul style="list-style-type: none"> ○ To identify which objectives have not been achieved. 	<ul style="list-style-type: none"> ○ The project trained 20 in carpentry, 17 in tinsmithing, 39 in knitting and 3 in tailoring. A total of 79 people with disabilities were trained. The objective of training 150 PWDs failed because of lack of adequate artisans in the project area. ○ The project also had a credit revolving fund for people with disabilities to engage in income generating activities or improve their food production. This loan attracted 5% interest. Between 1998 and 2001 183 people with disabilities benefited from this facility over this period. A total of MK343,464 was disbursed. Initially people received as little as MK200 as loan but people ended up using this money for pressing needs. Later PWDs were given MK10000 loans and beneficiaries started engaging in activities such as farming, bakery, beer brewing, hawker, livestock farming, carpentry among others. Most of the people who got these loans were paying back as at the time of the evaluation a total of MK91,020 had been repaid representing a 27% recovery rate. Fifty eight percent of the loanees were also adequately providing for their own needs.
<p>A report on HIV/AIDS and reproductive health care amongst people with disabilities</p>	<p>ND</p>	<ul style="list-style-type: none"> ○ Basic Research 	<ul style="list-style-type: none"> ○ To explore perceptions, knowledge, attitudes and practices of sexuality and HIV/AIDS among people with disabilities. ○ To identify the contexts and extent of sexual abuse of women and children with disabilities. ○ To assess the extent to which disabled people access sexual and reproductive health services including HIV/AIDS ○ To gain an understanding of the constraints and opportunities that disabled people experience when trying to access sexual and reproductive health services. ○ To mitigate the inclusion of disabled people in HIV/AIDS policy formulation and strategies to combat HIV/AIDS. ○ To explore the role of families and community supports for persons 	<ul style="list-style-type: none"> ○ Most people with disabilities (except students) earn their living through working or doing businesses or both. Salaried workers would also want to do business as salary not adequate.

				with disabilities who have HIV/AIDS; produce outputs that will be applicable in a community based rehabilitation (CBR) context (this will make the project sustainable overtime).	
Final evaluation of Msakambewa Community Based Rehabilitation Program	2002	Evaluation	<ul style="list-style-type: none"> ○ To examine the relevance of aims and objectives of the original project proposal. ○ To examine the extent to which each of the major objectives has been achieved in terms of having a positive impact on the project beneficiaries. ○ To identify which objectives have not been achieved. 	<ul style="list-style-type: none"> ○ The project also offered vocational training to persons with disabilities so that they can lead an independent and sustainable life. After this training they were able to engage in business. 	
Report on the disabled within the Bawala Ward. Ntchisi Strategy for Assistance	1992	Action Research	<ul style="list-style-type: none"> ○ To identify disabled persons within the Bawala Ward. ○ To identify disabilities and assess them by age, sex and type of disability. ○ To state the number of disabled individuals who have been treated for their disabilities. ○ To identify available services within the area and state those utilized by the disabled. ○ To state educational levels of the disabled. ○ To state the number of disabled individuals who are involved in village activities. ○ To state cultural/traditional beliefs that may affect disabled individuals acceptance within the community. ○ To identify types of employment disabled individuals are engaged in. 	<ul style="list-style-type: none"> ○ For people with disabilities, subsistence farming is the number one form of employment with cash cropping as the second. ○ Few had vocational training: 8 of those aged 17+ years had received training from a vocational centre. 	

			<ul style="list-style-type: none"> ○ To identify major problems faced by the disabled. 	
Albinism in Malawi: A qualitative study on attitudes and beliefs	2005	Basic Research	<ul style="list-style-type: none"> ○ Explore attitudes on marriage in regards to people with albinism. ○ Explore events in the lives of people with albinism and how people think these events have influenced their lives. ○ Explore people's knowledge about albinism. ○ Determine if there is a difference between people with albinism in rural and urban areas and between males and females with albinism. ○ To explore the effect of poor eye sight and skin problems and if at all they get any help. 	<ul style="list-style-type: none"> ○ Albinos experience a lot o problems getting employment: it is believed they die young; some have also been rejected in training institutions.
Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District	2009	Baseline Study	<ul style="list-style-type: none"> ○ To estimate the population of persons with disabilities in Chikhwawa District. ○ To identify the types of disabilities prevalent in Chikhwawa district. ○ To determine socio-economic characteristics of persons with disabilities in the district. ○ To analyse stakeholders interventions on rehabilitation services for persons with disabilities. ○ To determine the availability of appropriate health, education, vocational training and other social services for persons with disabilities in Malawi. 	<ul style="list-style-type: none"> ○ Agriculture is the main source of livelihood for people with disabilities. They grow crops such as maize, millet and sorghum ○ They engage in small scale business such as baking, handcrafting; doing piece work for others; tinsmithing; and participating in cash for work programs.

Living conditions among people with activity limitations in Malawi: a national representative survey	2004	Action Research	<ul style="list-style-type: none"> ○ To carry out a representative National Survey on the living conditions of people with disabilities in Malawi so as to provide much needed data for policy influence and planning. 	<ul style="list-style-type: none"> ○ Unemployment is high in Malawi estimated at 54%. ○ A significantly higher proportion of people with disabilities (57.7%) was at the time of the survey not working compared to 53.2% among people without disabilities. ○ 28% of disabled persons aged 15+ were at the time of the study working. ○ A slightly higher proportion of people with disabilities (41.2%) had acquired some skills compared to 38.7% among people without disabilities.
Survey of handicapped persons in Malawi	1983	Basic Research	<ul style="list-style-type: none"> ○ To estimate the incidence of disability. ○ To establish the demographic and socio-economic characteristics of the handicapped persons by type and severity of disability. 	<ul style="list-style-type: none"> ○ 12% of the handicapped persons worked for pay or profit. ○ 20% worked occasionally and 67% never worked.
Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District	2009	Baseline Study	<ul style="list-style-type: none"> ○ To estimate the population of persons with disabilities in Chikhwawa District. ○ To identify the types of disabilities prevalent in Chikhwawa district. ○ To determine socio-economic characteristics of persons with disabilities in the district. ○ To analyse stakeholders interventions on rehabilitation services for persons with disabilities. ○ To determine the availability of appropriate health, education, vocational training and other social services for persons with disabilities in Malawi. 	<ul style="list-style-type: none"> ○ Challenges experienced by people with disabilities include lack of startup capital and lack of vocational training that could empower PWDs with skills to assist them lead an independent life. There is also lack of employment among PWDs.
Quality of life assessment tool and impact analysis in the framework of P1919	2010	Basic research	<ul style="list-style-type: none"> ○ To examine and gather information on quality of life of the target group before and after a specific program intervention on the individual, family and community. ○ To understand the meaning of quality of life in the context and 	<ul style="list-style-type: none"> ○ Examples have been given in which after training, people with disabilities are recognized by members of the society and able to earn a living e.g. one woman was trained in accounts and became an accountant for the local church; others were trained in agriculture and tailoring and are doing well as they have the requisite skills.

			<ul style="list-style-type: none"> ○ content of Malawi. ○ To develop a ranking mechanism that allows to measure to what extent quality of life for people with disabilities has been improved through intervention of the program. ○ To assess the most significant program interventions that have contributed to quality of life of people with disabilities.
Evaluation of the SEDOM-MACOHA revolving loan fund for the Malawi Council for the Handicapped	1989	Action research	<ul style="list-style-type: none"> ○ To review and analyse the revolving fund's present status and operational procedures in respect of lending conditions, lending target group selection mechanism and loan pay back constraints and capabilities. ○ To critically review loan financing procedures. ○ To review adequacy of financed projects operations monitoring and extension support services. ○ To assess adequacy of staffing in servicing the revolving fund.

- A grant of US\$25,000 was given by UNCDF to MACOHA to provide credit to disabled Malawian entrepreneurs for setting up and operating viable enterprises. The fund was administered by SEDOM.
- Conditions for getting loans: business should be viable; no other sources of funding for the borrower; borrower's income should be low; borrower should contribute 5% towards business venture; business should be run by borrower; and the business should provide primary source of income for the borrower.
- Terms and conditions of loans were also specified: 5% interest rate; period of repayment depended on amount; 1.5% of loan amount to be paid by borrower as commission and processing fee and an application fee of MK0.50.
- Accepted securities were also specified.
- The roles of MACOHA, SEDOM, DEMATT; ADD and Ministry of Community Services were also spelt out.
- The beneficiaries are identified by CROs and DSWOs and register with MACOHA. KVRTC trains those who express the need for training.
- As at the time of evaluation 90% of the funds had been disbursed and 8.7% was the loan recovery rate. There were chances that the fund could succeed.
- Problems observed in running businesses: lack of business administration skills; business location; market limitations and understaffing at MACOHA.

Balaka/Machinga Comprehensive eye services loan scheme	2007	Evaluation Research	<ul style="list-style-type: none"> ○ To find out if loans given to the beneficiaries are making a positive impact on the beneficiaries. ○ To explore whether success in loan repayment depends on the type of business one is undertaking. ○ To look at the various loan sizes for the respective enterprises and determine their appropriateness. ○ To assess any challenges and opportunities that would affect sustainability of the project. 	<ul style="list-style-type: none"> ○ A revolving loan fund of MK1,000,000.00 was introduced for people with disabilities in Balaka and Machinga. The loan was given by Opportunity Banking but guaranteed by Sight Savers International. ○ 73 persons with disabilities benefited from the loan scheme. ○ A total of MK958,200 was disbursed. Beneficiaries received between MK5,000 and MK25,000 loans. No criteria was used to decide amount of loans beneficiaries applied for. ○ Some beneficiaries took loans to start a certain business but changed their minds and started a different one. ○ All of these were trained in business management. ○ Beneficiaries chose business they wanted to be involved in and program managers had no role in these decisions. ○ Business that people with disabilities were involved in included fishing, selling fish, repairing bicycles, selling bicycle parts, baking, tinsmithing; running groceries. ○ Some cases were hopeless and could not pay back the loan. The repayment rate was at 65%. ○ The project has positive impact: some clients built better houses; others bought livestock; others were able to pay school fees for their children; still others became food secure. ○ Even though successful, this seemed to be a one off activity as MACOHA could not raise enough money to sustain this program.
Violence and abuse against women with disabilities	2006	Basic research	<ul style="list-style-type: none"> ○ To improve the living conditions of women with disabilities in Malawi by disclosing and describing the nature of abuse, neglect, violence and discrimination against this vulnerable group. 	<ul style="list-style-type: none"> ○ The majority of the informants did not know why they had become disabled: they held about it from parents and relatives. ○ Some parents become ashamed if their parents become disabled and examples have been given of some respondents who were abandoned and grew up with relatives. In most cases relatives are very supportive of children with disabilities ○ While diseases can lead to disability, supernatural means e.g. witchcraft has been cited as a major cause of disability; hence the resort to traditional healers during seeking care. ○ Women with disabilities interviewed said they had not been victims of sexual abuse. Some knew of adult women with disabilities who had been victims of sexual abuse. ○ Some people with disabilities would want to get married and have children but did not have a boyfriend or husband. The disability makes them less attractive; hence they might have a smaller expectation and make smaller demands on the personality of the husband.

				<ul style="list-style-type: none"> ○ Some women with disabilities claimed their husbands left /divorced them because of the disability. ○ Women with physical disabilities experience problems such as carrying water on their heads, cooking, lifting heavy things etc; hence cannot fulfill their duties as women. ○ Many women felt discriminated because of their gender and disability. ○ Some women with disabilities are tricked by men to have sex but are abandoned the moment they get pregnant. 	
	Living conditions among people with activity limitations in Malawi: a national representative survey	2004	Action Research	<ul style="list-style-type: none"> ○ To carry out a representative National Survey on the living conditions of people with disabilities in Malawi so as to provided much needed data for policy influence and planning. 	<ul style="list-style-type: none"> ○ In terms of involvement in family life, 15% of people with disabilities are not involved; 11% are not involved in conversations and 2% do not feel part of the family. ○ For those aged 15+, 16% are not consulted about making household decisions; and 30% are not part of the decision making process concerning their lives. ○ Significantly more men are married or in a relationship compared to women.
SOCIAL	Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District	2009	Baseline Study	<ul style="list-style-type: none"> ○ To estimate the population of persons with disabilities in Chikhwawa District. ○ To identify the types of disabilities prevalent in Chikhwawa district. ○ To determine socio-economic characteristics of persons with disabilities in the district. ○ To analyse stakeholders interventions on rehabilitation services for persons with disabilities. ○ To determine the availability of appropriate health, education, vocational training and other social services for persons with disabilities in Malawi. 	<ul style="list-style-type: none"> ○ Most of the PWDs are excluded deliberately in community benefits and trainings yet they participate in other community development activities. Few cases of land grabbing were reported.

Albinism in Malawi: A qualitative study on attitudes and beliefs	2005	Basic Research	<ul style="list-style-type: none"> ○ Explore attitudes on marriage in regards to people with albinism. ○ Explore events in the lives of people with albinism and how people think these events have influenced their lives. ○ Explore people's knowledge about albinism. ○ Determine if there is a difference between people with albinism in rural and urban areas and between males and females with albinism. ○ To explore the effect of poor eye sight and skin problems and if at all they get any help. 	<ul style="list-style-type: none"> ○ All the mothers loved their albino children but reactions from people in the community in some cases were not good/discouraging: albinos sometimes experience discrimination especially with strangers. ○ In some cases the fathers of these children abandoned them and married other women. They did not think that those children were theirs.
A report on HIV/AIDS and reproductive health care amongst people with disabilities	ND	Basic Research	<ul style="list-style-type: none"> ○ To explore perceptions, knowledge, attitudes and practices of sexuality and HIV/AIDS among people with disabilities. ○ To identify the contexts and extent of sexual abuse of women and children with disabilities. ○ To assess the extent to which disabled people access sexual and reproductive health services including HIV/AIDS ○ To gain an understanding of the constraints and opportunities that disabled people experience when trying to access sexual and reproductive health services. ○ To mitigate the inclusion of disabled people in HIV/AIDS policy formulation and strategies to combat HIV/AIDS. ○ To explore the role of families and community supports for persons with disabilities who have HIV/AIDS; produce outputs that 	<ul style="list-style-type: none"> ○ Most participants in this study are married except for a few who are students. ○ People with disabilities are equally sexually active and they marry and have children but women with disabilities experience challenges and men just have sex with them and are left with children to look after while men abandon them. ○ Disabled women are often abused: because of poverty disabled women will accept a man but she will just be sexually abused and abandoned. ○ Sometimes when a disabled man falls in love with a disabled woman, family members are the ones who destroy the relationship as sometimes they think that children from such a marriage will also be disabled. ○ In some cases men also experience problems in having relationships as women deny their proposals. ○ Women who are physically disabled cannot run and those who are visually impaired and those who are speech impaired (cannot shout for help); hence vulnerable to sexual abuse.

will be applicable in a community based rehabilitation (CBR) context (this will make the project sustainable overtime).

Survey of handicapped persons in Malawi	1983	Basic Research	<ul style="list-style-type: none"> ○ To estimate the incidence of disability. ○ To establish the demographic and socio-economic characteristics of the handicapped persons by type and severity of disability. 	<ul style="list-style-type: none"> ○ Only 3% of the handicapped persons received some form of help (wheel chairs, shoes/calipers, crutches, scholarships, spectacles, clothes, cash or some kind of gift)
Effective HIV/AIDS and reproductive health information to people with disabilities	2004	Action Research	<ul style="list-style-type: none"> ○ To describe the major forms of disabilities existing among the sampled population. ○ To explore how people with disabilities communicate with other people and amongst themselves. ○ To determine knowledge about HIV/AIDS among people with disabilities. ○ To describe perceptions of people with disabilities about the transmission and prevention of HIV. ○ To determine knowledge and perceptions of people with disabilities regarding family planning, condoms and condom use. ○ To explore experiences of people with disabilities regarding sexual and reproductive health issues. ○ To make recommendations on how best information can be 	<ul style="list-style-type: none"> ○ While a number of respondents said that they had relationships, some people with disabilities said that they had difficulties entering into an intimate relationship due to stigma and difficulties in mobility as it decreased the opportunity to meet new people.

				communicated to people with disabilities.	
EMPOWERMENT	Enhanced accessibility for people with disabilities in urban areas: a small scale demonstration project in Blantyre, Malawi	2003	Action Research	<ul style="list-style-type: none"> ○ To enhance access into Queen Elizabeth Central Hospital in Blantyre particularly for people with disabilities. 	<ul style="list-style-type: none"> ○ The hospital pathway was frequently used by people with and without disabilities. The major problems experienced in using the pathway were as follows: <ul style="list-style-type: none"> ○ Congestion on the pathway. ○ Slippery and dirty surface during the rainy season. ○ Uneven surface made people stumble. ○ Pathway was narrow. ○ Suggestion to improve the pathway included: widening the pathway, removing vendors, making the pathway concrete, installing security lights. ○ A pathway (with tactile blocks) into Queen Elizabeth Central Hospital, a disabled friendly bus shelter and disabled friendly traffic lights were constructed around ginnery corner in Blantyre. People generally appreciated the construction of these structures.
	Final evaluation of Msakambewa Community Based Rehabilitation Program	2002	Evaluation	<ul style="list-style-type: none"> ○ To examine the relevance of aims and objectives of the original project proposal. ○ To examine the extent to which each of the major objectives has been achieved in terms of having a positive impact on the project beneficiaries. ○ To identify which objectives have not been achieved. 	<ul style="list-style-type: none"> ○
	Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District	2009	Baseline Study	<ul style="list-style-type: none"> ○ To estimate the population of persons with disabilities in Chikhwawa District. ○ To identify the types of disabilities prevalent in Chikhwawa district. ○ To determine socio-economic characteristics of persons with disabilities in the district. ○ To analyse stakeholders interventions on rehabilitation 	<ul style="list-style-type: none"> ○ People with disabilities are often discriminated in activities that offer cash or in kind benefits such as public works programs. ○ In a few cases PWDs reported that family members or relatives could do the work on their behalf. ○ PWDs are integrated in development activities that do not come along with cash or in kind benefits e.g. building school blocks, clearing the graveyard etc.

			<p>services for persons with disabilities.</p> <ul style="list-style-type: none"> ○ To determine the availability of appropriate health, education, vocational training and other social services for persons with disabilities in Malawi. 	
Baseline survey report on the socio-economic situation of people with disabilities in Chikhwawa District	2009	Baseline Study	<ul style="list-style-type: none"> ○ To estimate the population of persons with disabilities in Chikhwawa District. ○ To identify the types of disabilities prevalent in Chikhwawa district. ○ To determine socio-economic characteristics of persons with disabilities in the district. ○ To analyse stakeholders interventions on rehabilitation services for persons with disabilities. ○ To determine the availability of appropriate health, education, vocational training and other social services for persons with disabilities in Malawi. 	<ul style="list-style-type: none"> ○ Participants were asked about the resources and opportunities available in the district that can be utilized by PWDs to improve their lives and the following were mentioned: <ul style="list-style-type: none"> ○ Locally available skills (carpentry, bicycle repairing, tailoring etc) in the communities. ○ Presence of service providers such as NGOs and government departments. ○ Land and water resources. ○ Availability of livestock that can be distributed to PWDs. ○ Community support.
Disability policy audit in Namibia, Swaziland, Malawi and Mozambique			<ul style="list-style-type: none"> ○ To undertake a review of existing disability policy and practice in the four countries. ○ To assess the extent to which each country's policy and practice were in alignment with the principles of the UN convention on the rights of persons with disabilities. ○ To assess to what extent disability policy had been mainstreamed in 	<ul style="list-style-type: none"> ○ Disability issues are included in the 1994 constitution of the Republic of Malawi. ○ Malawi is a signatory of the Convention on the Rights of Persons with Disabilities. ○ The report claims there are no reliable statistics on disability in Malawi⁹⁶. ○ The key government department responsible for disability issues is the ministry of Social Development and People with Disabilities.⁹⁷ ○ The national policy on equalization of opportunities for people with disabilities was launched in 2006.

⁹⁶ This report is erroneous as disability statistics exist in Malawi. The authors cite the SINTEF, CSR and FEDOMA study on living conditions but they say no reliable statistics.

⁹⁷ There has been no such Ministry.

each of the four designated countries; and

- To provide an assessment of to what extent disabled people's organizations have been effective and been engaged in the policy making process with regard to disability issues.

- The Policy Investment Framework 2001 of the Ministry of education puts a lot of emphasis on special needs education.

- A CBR program is being run by MACOHA since the late 1980s.

- FEDOMA is the national umbrella body for disabled people's organizations with six affiliate members. FEDOMA plays an important role in the development of policies.