What is the effectiveness of community based rehabilitation in improving the well-being of adults with physical disabilities in Sub-Saharan Africa?

Policy recommendations for International Non-government Organizations
Community Based Rehabilitation:
What is the effectiveness of CBR strategy in improving the well-being for adults with disabilities in Sub-Saharan Africa?

Policy Recommendations for International Non-Government Organizations

Candidate number: 473180

Word count:
Executive Summary - 385
Policy report – 9,989
ACKNOWLEDGEMENTS

I would like to thank my tutor Karen Lock for her guidance with this policy report and throughout the year, and Judith Green for her research advice. Additionally, I am grateful to those individuals who gave up their time to be interviewed. Their information and expertise regarding CBR strategy and development was extremely valuable to my research.

I also want to give many thanks to my family and friends for their support throughout this year.
# Table of Contents

1. Abbreviations .................................................................................. 6
2. Executive Summary ......................................................................... 7
3. Introduction ...................................................................................... 9
   3.1. Disability in developing countries ............................................. 9
   3.2. International disability policies ............................................... 10
   3.3. Community based rehabilitation .............................................. 11
      3.3.1. Background .................................................................. 12
      3.3.2. CBR framework evolution .............................................. 12
      3.3.3. CBR Matrix .................................................................. 13
      3.3.4. Delivery structure .......................................................... 13
      3.3.5. Multi-sectoral support ..................................................... 14
      3.3.6. Present situation ............................................................. 15
4. Background in Sub-Saharan Africa ................................................... 16
   4.1. Disability prevalence .............................................................. 16
   4.2. CBR in SSA ........................................................................... 16
   4.3. Theoretical context ................................................................. 17
5. Aims and Objectives ........................................................................ 18
   5.1. Aims ...................................................................................... 18
   5.2. Objectives ............................................................................... 18
6. Methodology ..................................................................................... 19
   6.1. Literature Review I Search Strategy ....................................... 19
   6.2. Literature Review II Search Strategy ..................................... 20
   6.3. Stakeholder interviews ............................................................ 21
   6.4. Ethical approval and considerations ...................................... 22
7. Results ............................................................................................ 24
   7.1. CBR effectiveness in developing countries ............................. 24
      7.1.1. Description of literature ............................................... 24
      7.1.2. Discussion of results ..................................................... 24
   7.2. Effectiveness of CBR in SSA .................................................. 31
      7.2.1. Description of studies ................................................... 31
      7.2.2. Discussion of themes ..................................................... 32
   7.3. Stakeholder Interviews ............................................................ 41
      7.3.1. Description of interviews .............................................. 41
      7.3.2. Discussion of themes ..................................................... 41
8. Discussion ......................................................................................... 49
   8.1. Discussion of themes .............................................................. 49
   8.2. Report limitations: Literature reviews I & II ......................... 52
   8.3. Report limitations: Stakeholder interviews ............................. 53
9. SSA Recommendations ..................................................................... 54
   9.1. Community level ................................................................... 54
   9.2. National level ......................................................................... 54
   9.3. International level ................................................................. 55
10. Conclusion ....................................................................................... 56
11. References ...................................................................................... 57
Appendices
1. SSA countries practicing CBR .................................................. 61
2. CBR Matrix ............................................................................. 62
3. Literature search strategies ...................................................... 63
4. Table 2: Developing country literature reviews .................. 66
5. Table 3: SSA CBR Studies......................................................... 68
6. Table 5: Stakeholder Interview quotes .............................. 71
7. CBR Interview form ................................................................. 74
8. CBR Interview themes ............................................................. 76
9. Information and consent form ........................................... 77
10. Ethics Approval ............................................................................ 79
11. Project protocol ........................................................…………... 83
12. Risk Assessment ................................................................. 86
# 1. Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>AIFO</td>
<td>Associazione Italiana Amici di Raoul Follereau</td>
</tr>
<tr>
<td>CBM</td>
<td>Christian Blind Mission</td>
</tr>
<tr>
<td>CBR</td>
<td>Community Based Rehabilitation</td>
</tr>
<tr>
<td>CRW</td>
<td>Community Rehabilitation Worker (other terms??)</td>
</tr>
<tr>
<td>DAR</td>
<td>Disability and Rehabilitation team (at WHO)</td>
</tr>
<tr>
<td>DPI</td>
<td>Disabled People’s International</td>
</tr>
<tr>
<td>DPO</td>
<td>Disabled People’s Organization</td>
</tr>
<tr>
<td>EDF</td>
<td>European Disability Forum</td>
</tr>
<tr>
<td>HI</td>
<td>Handicap International</td>
</tr>
<tr>
<td>HFA</td>
<td>Health For All</td>
</tr>
<tr>
<td>IBR</td>
<td>Institution-Based Rehabilitation</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>IDDC</td>
<td>International Disability and Development Consortium</td>
</tr>
<tr>
<td>IGA</td>
<td>Income generating activity</td>
</tr>
<tr>
<td>ILO</td>
<td>International Labour Organisation</td>
</tr>
<tr>
<td>INGO</td>
<td>International Non-Government Organization</td>
</tr>
<tr>
<td>LCI</td>
<td>Leonard Cheshire International</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
</tr>
<tr>
<td>MDG</td>
<td>Millennium Development Goals</td>
</tr>
<tr>
<td>MIS</td>
<td>Management information systems</td>
</tr>
<tr>
<td>MIUSA</td>
<td>Mobility International USA</td>
</tr>
<tr>
<td>NAD</td>
<td>Norwegian Association of the Disabled</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
</tr>
<tr>
<td>PRSP</td>
<td>Poverty Reduction Strategy Paper</td>
</tr>
<tr>
<td>PWD</td>
<td>People with disabilities</td>
</tr>
<tr>
<td>RI</td>
<td>Rehabilitation International</td>
</tr>
<tr>
<td>SCF</td>
<td>Save the Children Fund</td>
</tr>
<tr>
<td>SIDA</td>
<td>Swedish International Development Authority</td>
</tr>
<tr>
<td>SSA</td>
<td>Sub-Saharan Africa</td>
</tr>
<tr>
<td>SSI</td>
<td>Sight Savers International</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organization</td>
</tr>
<tr>
<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
2. Executive Summary

There are an estimated 650 million people living with disabilities in the world. Due to poverty, cultural influences and scarcity of resources, the profile of disability in developing countries continues to remain low. Given that one in five of the world’s poorest are disabled, disability prevalence in the Sub-Saharan Africa regions is grossly underestimated at 36 million using figures from 1998.

Beginning in the 1980s through a WHO initiative, Community based rehabilitation (CBR) has evolved as a community development strategy focusing holistically upon social inclusion, poverty reduction strategies and the rights of people with disabilities through education, vocational training, social rehabilitation and prevention interventions. Despite a rise in programming, CBR services continue to remain inadequately covered in developing countries with only 2% of the world’s disabled population having access to CBR services. Presently there are 31 countries in Sub-Saharan Africa that implement CBR.

This policy report aims to examine the effectiveness of CBR in improving the well-being of people with disabilities in Sub-Saharan Africa and to make recommendations to INGOs for improving CBR strategy. This was achieved through two literature reviews and four stakeholder interviews. The first literature review was completed to examine the effectiveness of CBR in improving the well-
being of PWD in developing countries, while the second literature review examined CBR’s impact and application in Sub-Saharan Africa. Four stakeholder interviews were conducted to examine the successes and barriers in the design, development and implementation of CBR. Finally recommendations are suggested to INGOs for improving CBR strategy in Sub-Saharan Africa.

Though there is growing literature of CBR in the field, the literature reviews and the stakeholder interviews indicate that more research is needed to determine what key components of CBR are effective to enable wider evidence-based practice. CBR successes involve flexibility with programming, establishing local support systems and partnerships with agencies, improved training, provision of assistive devices, capacity building and decentralization of services. CBR recommendations include decentralized management information systems, enhanced socio-cultural awareness, increased local community involvement, improved CBR worker training and competencies, and empowerment strategies of self-help groups and disabled people’s organizations.

INGOs have a crucial role in the future of Sub-Saharan Africa CBR through supporting evidence-based programming and by furthering the development of national and international policies. Recommendations for their future involvement are provided at the community, national and international levels.
3. Introduction

This policy report examines the effectiveness of CBR strategy in improving the well-being of adults with physical disabilities in the Sub-Saharan Africa region and makes recommendations to NGOs for future policy design. A literature search is conducted to examine CBR’s effectiveness in developing countries, followed by a second literature review to analyze CBR’s impact and application in SSA. Four stakeholder interviews are conducted to gather current perspectives on the factors influencing SSA CBR design, development and implementation. Finally, recommendations are provided to INGOs for improving their CBR strategy in SSA. It is necessary to understand the complexities of disability, policy progress and CBR development in developing countries to obtain an introduction for this report.

3.1 Disability in developing countries

At least 7-10% of the world’s population suffer from various types of physical or mental disabilities, and most of the estimated 650 million people living with disabilities around the world lack access to appropriate medical care and rehabilitation services.\(^1\)\(^-\)\(^3\) However, these numbers are rough and incomplete underestimates given that systematic data on disability prevalence is not available, especially in developing countries.\(^3\) Initially, under the medical model, disability was viewed as an impairment, and medical rehabilitation services were emphasized through IBR approaches which
often compounded illicit discrimination and negative attitudes towards PWD.\textsuperscript{4} Under the current social model using WHA’s ICF 2001 framework, disability is defined as the impairments in body functions and structure, limitations in activities and restrictions in participation from both the individual and societal perspective.\textsuperscript{3, 5} Disability perceptions, conceptual frameworks and measurement tools differ worldwide which presents a challenge when developing international and national disability policies since what is considered ‘handicap’ in one cultural context may be considered normal in another context.\textsuperscript{3, 6}

Disability and poverty are intricately linked together in a malicious cycle of a cause/effect paradox, resulting in the majority of PWD in developing countries living in hardship.\textsuperscript{4} The most marginalized groups of people with disabilities include women and children with disabilities, people with severe and multiple disabilities, people with psychiatric conditions, people living with HIV, PWD who are poor, and their families.\textsuperscript{7, 8} Though the profile of disability in developing countries is improving, it still remains low due to the scarcity of resources, the failure to view disability as a development issue, and undeveloped political rights movements especially in rural and urban slum areas.\textsuperscript{4, 9}

\textbf{3.2 International policies}

International disability policies have evolved over the years through the collaboration efforts among UN agencies including the UN Enable, WHO, UNESCO and ILO.\textsuperscript{10} Regarding general disability, the UN General Assembly
adopted the “Standard Rules on the Equalization of Opportunities for Persons with Disabilities” in 1993 which stated preconditions for equal opportunity, equal participation and promoted implementation measures and monitoring mechanisms.\textsuperscript{11} In 1994, the Salamanca Statement was issued to account for the special education needs of children with disabilities, and CBR was initiated as an inclusive development strategy for people with disabilities in developing countries through the Joint Position Paper.\textsuperscript{8,12} In 2006 the UN agencies adopted the “Convention on the Rights of Persons with Disabilities” which ensured the promotion and protection of the rights and dignity of PWDs.\textsuperscript{13} The Convention and optional protocol opened for signature at UN Headquarters in 2007 and 130 countries have signed the declaration.\textsuperscript{10} Though disability was not directly mentioned in the MDGs or PRSP, disability continues to remain a strong presence within the international agencies’ agendas and poverty reduction strategies targeting the “poorest of the poor”.\textsuperscript{14-18} It is argued that the MDGs goals and indicators can only be reached if PWD are included.\textsuperscript{16}

3.3 Community Based Rehabilitation

\begin{quote}
"CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services."
\end{quote}

\textit{From the 2004 Joint Position Paper\textsuperscript{8}}
3.3.1 Background on CBR

Influenced by the principles of Alma Ata and HFA in 1978, WHO introduced the concept of CBR given the need for specialized medical rehabilitation services in the developing world. CBR programs eventually shifted from the medical model to a comprehensive social approach, focusing holistically upon the context of people’s lives living with a disability including education, vocational training, social rehabilitation and prevention interventions. The CBR strategy emphasizes “a society for all,” and the disability movement motto “nothing about us, without us” has emerged as the current focal point of CBR programming and policy. The long term goal of CBR is to support and empower PWD in their efforts to take control of their own lives, to be decisively active in the accessibility and creation of services, and to achieve social integration.

3.3.2 CBR framework evolution

Throughout the evolution of CBR framework since the early eighties, there is a consensus in the field about a need for international uniformity and standardization of CBR practice. Initially in 1989 WHO published the CBR Training Manual which assisted in the promotion of CBR in developing countries. In 1994 UN agencies issued a “Joint Position Paper on CBR” that promoted a common approach to the development of CBR programs. The Joint Position Paper was updated in 2004 to further support the strategy as a social model of disability development and poverty reduction.
agencies and civil societies including DPOs are expected to publish the first established international guidelines for CBR programs.19

3.3.3 CBR Matrix

The CBR framework is centred around a matrix that provides a visual representation of CBR.2 The matrix encompasses five component domains that make up the universe of well-being: health, education, livelihood, social and empowerment.19 Each domain includes five key elements, and the elements are then sub-divided into content headings (see Appendix 2). Practitioners can select any combination of components and elements for the framework of CBR programming, while it is essential that the other elements are coordinated by other key organizations.19

3.3.4 Delivery Structure

National policies and legislation guide the prioritization and planning of programs, as well as ensuring disability rights of equalization of opportunities, social inclusion and economic inclusion.8 CBR essentially functions at three country
specific levels: the National level, the Intermediate/District level and the Community level.\textsuperscript{7,8}

1. National level - coordination of CBR through policies, legislation, management structure, support and resource allocation including the MOH, PHC system and a national CBR coordinator

2. Intermediate/District level – coordination of community support by MOH and PHC team committees and CBR managers

3. Local community level – recognition of CBR needs and program implementation through community representative involvement and leadership including CRWs, family trainers, PWD and community members

\textbf{3.3.5 Multi-sectoral support}

Multi-sectoral collaboration is essential in the delivery of CBR. This involves collaboration among the country specific levels and the government ministries including the social sector, health sector, education sector and employment/labour sector.\textsuperscript{8} Finally, collaboration and coordination among non-government organizations and the private sector is imperative.

Based upon the international policies and the Joint Position Paper, INGO CBR CBR involvement is multi-faceted in developing countries. Some INGOs involved in disability advocacy and CBR development include AIPO, ADD, CBM, DPI, HI, MIUSA, NAD, RI, SCF, SSI and LCI. There are also international networks and umbrella organizations such as IDDC and EDF that aim for collaboration mainstreaming disability and CBR issues.\textsuperscript{15}
3.3.6 Present situation

In many developing countries, actual national disability policy development and implementation is hindered by the lack of resources and coordination. Only 2% of the world’s disabled population has access to CBR services, and the number of individual service providers has not been counted. Many PWD in developing countries still do not receive basic rehabilitation services and are not enabled to participate equally in education, training, work, recreation or other community and societal activities.
4. Background in Sub-Saharan Africa

4.1 Disability prevalence

Disability prevalence in the SSA region is grossly underestimated given that PWD account for one in five of the worlds poorest. In 1998, it was approximated that 36 million of the 524 million people in Africa south of the Sahara were disabled. It was predicted by Helander that the region will be populated by about 435 million handicapped people who need to be rehabilitated by the year 2025.

4.2 CBR in SSA

CBR was implemented in the Africa region in the early 1980s beginning the country of Botswana. Though WHO has been promoting CBR since the eighties, evidence-based research in the field remains limited, fragmented and incoherent. Governments and international aid agencies in SSA have been funding CBR programs for over 25 years without significant evidence of its effectiveness; therefore, SSA CBR programs are often based upon ideological conviction and are mostly confined to pilot projects in some areas using foreign funds limiting their sustainability. For the purposes of this policy report, the areas of Sub-Saharan Africa initially included 31 countries that are practicing CBR (Appendix 1).
4.3 Theoretical context

CBR embraces the Health Promotion approach of Community Mobilization. The foundation for this approach lies in Zimmerman and Rappaport’s Empowerment Theory where individuals with greater participation in groups had higher levels of empowerment, as well as embracing the Social Capital Theory where a sense of solidarity or equality in a community is determined by norms or trust, support and cooperation. The actual participation of community members relies upon the Theory of Reasoned Action where their decisions to engage in action fills the gap between attitudes and behaviour, and the Social Cognitive Theory where self-efficacy, defined as one’s belief in their ability to execute actions necessary to reach an outcome, has a modifying effect on attitudes and intentions.
5. Aim and Objectives

5.1 Aim

This policy report aims to examine the effectiveness of CBR strategy in improving the well-being of adults with physical disabilities in the Sub-Saharan Africa region and make recommendations to INGOs for future policy design.

5.2 Objectives

1. To examine the effectiveness of CBR in improving the well-being of PWD in developing countries.

2. To examine CBR’s impact and application in Sub-Saharan Africa.

3. To conduct stakeholder interviews examining successes and barriers in the design, development and implementation of CBR.

4. To provide recommendations to INGOs for improving CBR strategy in Sub-Saharan Africa.
6. Methodology
Two literature reviews were completed in this policy report. The first literature review was conducted to examine the effectiveness of CBR in improving the well-being for adults who have physical disabilities in developing countries. The second literature review was completed to examine the application of CBR in SSA evaluating the impact of policies and programs. Four stakeholder interviews were completed to gather current perspectives on CBR successes and barriers in the design, development and implementation of CBR.

6.1 Literature Review I Search Strategy
A literature review was conducted examining the effectiveness of CBR in improving the well-being for adults who have physical disabilities in developing countries. A search strategy for relevant published literature was developed for the following databases: Pub Med, Medline-Ovid and JStor. Databases specific to developing countries, African Healthline for published literature and Eldis for unpublished literature, were also searched. An internet search using the Google search engine and the Google scholar search engine was also completed. Search terms included combinations of “CBR,” “community based rehabilitation,” “disability,” “effectiveness,” “evaluation,” “impact,” “participation,” “rights” and “empowerment.” See Appendix 3 for detailed search terms for specific databases. WHO’s DAR disability website and UN’s ENABLE website were utilized for general disability and CBR policy information.
Only published and unpublished articles in English are included in this policy report. The time period of 1988-2008 was used as inclusion criteria given that the most relevant articles would be published within the past 20 years, especially after the publication of the Joint Position paper on CBR in 1994. Articles titles and abstracts were reviewed for relevance. Papers were considered if they were about CBR reviews, editorials, research and policy documents including adults, physical disabilities, and developing countries. The terms mental disabilities and/or mental handicap were included since it commonly refers to cognitive impairments associated with physical disabilities. Exclusion criteria included studies with only children or caregivers of children, developed countries, psychiatric disabilities and mental health. It is noted that alternate titles, including community rehabilitation services, community based vocational rehabilitation, community integration programs, community based support and socio-economic rehabilitation, were not included in this report. Though there is overlap, these programs either have more specific focuses or use alternate frameworks.

6.2 Literature Review II Search strategy
A second literature review was conducted to examine the application of CBR in SSA evaluating the impact of policies and programs. Literature searches were conducted on Pub Med and Africa Healthline, as well on the disability specific Independent living Institute and Source search engines. Reference lists of 3 systematic review literature articles found in the first literature search were searched by hand for studies relating to SSA. The findings from the literature
reviews were crossed referenced from the references of the published literature reviews for duplication. *Disability and Rehabilitation Journal* and *International Journal of Rehabilitation Research* were hand searched over the last five years for SSA relevant articles. A Google search was also done to locate books, government, INGO and NGO information relating to SSA CBR information. Search terms included combinations of “CBR,” “community based rehabilitation,” “disability,” “effectiveness,” “evaluation,” “impact,” “participation,” “empowerment,” “Africa,” “Sub-Saharan Africa,” and “Southern Africa.” See Appendix 3 for detailed search terms for specific databases.

Only published and unpublished articles in English are included in this policy report. The time period of 1988-2008 was used as inclusion criteria, with the one exception of a study published in 1987. Only papers that are about CBR specifically are included in this report. Alternate rehabilitation titles mentioned as above in Literature review I were excluded. Inclusion criteria included studies with adults, physical disabilities, CBR successes, CBR limitations and recommendations, INGO information and countries in SSA. Exclusion criteria included studies and reports only mentioning children, caregivers, psychiatric disabilities, mental health and countries in other parts of Africa.

### 6.3 Stakeholder Interviews

Stakeholder interviews were completed to gather perspectives on what are factors influencing successful CBR implementation or barriers in the design, development and implementation of CBR. The use of purposively sampled
stakeholder interviews was the most appropriate method for my policy report given time constraints and the interviewees available. Four key stakeholders were interviewed from different organizations, and the stakeholders’ opinions were gathered using the most practical manner according to schedule and time constraints (Table 1).

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>CBR Interview method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic researcher in communication and health involved in CBR research</td>
<td>In person interview recorded and transcribed</td>
</tr>
<tr>
<td>Employee at an international health agency organization</td>
<td>Telephone interview recorded and transcribed</td>
</tr>
<tr>
<td>Employee at INGO head office</td>
<td>In person interview with note taking</td>
</tr>
<tr>
<td>Employee at a local South African NGO who has a disability</td>
<td>Completed interview form via email with guidance dialogue</td>
</tr>
</tbody>
</table>

Table 1: Stakeholder Interviews

After completing the initial literature review to obtain CBR effectiveness information, it seemed most appropriate to use a more structured interview format to obtain stakeholder perspectives. The questions were asked according to Literature review theme areas, so a proper qualitative study of stakeholder views was not completed (Appendix 8). The 45-minute-1-hour interview was conducted to examine CBR framework, evidence-based practice in CBR, the key successes and challenges in CBR, policy perspectives and the domain of empowerment (Appendix 7). Recorded interviews were transcribed, and key themes were extracted which were reflective of Literature review themes.

6.4 Ethical Approval and considerations

Primary data was obtained so LSHTM ethics approval was required to conduct the stakeholder interviews with specialists in the field to supplement the literature search information. Ethical approval and risk assessment was granted by The
London School of Hygiene & Tropical Medicine on 7th of April 2008 (Appendices 10 & 12). All interviewees read the information sheet and either signed, faxed or emailed a consent form witnessed by a third party (Appendix 9). Their confidentiality was maintained throughout the interview and analysis process, and additional consent was obtained to use quotations in the body of this policy report.
7. Results
The results from Literature search I, Literature search II and the Stakeholder interviews are analyzed according to themes in 3 separate components respectively and then synthesized in the discussion section.

7.1 CBR in developing countries

7.1.1 Description of studies
24 articles published between 1988-2008 were reviewed that fit the inclusion and exclusion criteria examining effectiveness of CBR in developing countries. Articles and review-level evidence examining adults with physical disabilities were found in the following countries: Afghanistan, Bangladesh, Botswana, Brazil, China, Eritrea, Egypt, Guyana, Haiti, Hong Kong, India, Indonesia, Jamaica, Lebanon, Mongolia, Nigeria, Papua New Guinea, Pakistan, Vietnam, Zimbabwe and Southern Africa states. The majority of the studies reviewed took place in Asia and examined CBR strategy with adults who have leprosy.

7.1.2 Description of results
The studies indicated that the effectiveness of CBR is not established in the field regarding the leading components and the best way to address PWD and their community needs.\(^7,^{16,29-31}\) CBR is often unattractive to researchers, governments and non-government agencies given its broad holistic scope and limited funding resulting in restricted studies focusing on easy, measurable targets.\(^1,^{22,32}\) The lack of research creates concern for the future of this inclusive
development concept for policy makers, funding agencies, program implementers and user groups.\textsuperscript{28, 30}

Literature search I yielded only 7 published literature reviews of CBR articles and evaluation reports all using different methods of research, 3 of which discussed CBR successes and 2 of which were recently published in 2008 (Appendix 4). Kuipers et. al. used a proof-of-concept method examining 37 evaluations in 22 countries identifying 3 key theme recommendations of training, funding and collaborating organizations.\textsuperscript{31} Velema et. al. examined 29 reports from 22 countries and found benefits in CBR home based training, economic interventions and activities including enhanced family member coping skills, improved school attendance, increased income, enhanced social inclusion and advanced levels of PWD independence, mobility and communication skills.\textsuperscript{35} The authors conclude that CBR programs are most beneficial to PWD with mild disability and who can verbally communicate.\textsuperscript{35} The most comprehensive literature review was Finkenflugel et. al. systematic review examining 128 articles to assess the evidence base of CBR. The authors report that though there is an increase in research noted, the majority of the CBR articles are theory papers and future research is needed to determine key aspects for planning and policy development.\textsuperscript{29} This finding supports the noted trend to describe CBR practice in research rather than ascertain effectiveness resulting in evidence poor but data rich analysis.\textsuperscript{30, 32}
There is a need to formulate an evidence base for CBR using appropriate data, a systematic methodology and globally recognized criteria. Thomas and Thomas additionally suggest that research is needed to explore effective CBR for the most marginalized disabled populations including people with severe disabilities and the needs of women with disabilities. The following are themes mentioned in the literature as key important issues and recommendations for future CBR evaluation.

- **CBR coordination: organization, management and monitoring**

  Though only a few developing countries have integrated CBR into their national plans, it is essential that the planning, managing and monitoring of CBR programs be completed at the government, organizational, political and community levels. It is found that enhanced management of organizational, personnel and administrative infrastructure in CBR projects is critical at all levels of service delivery given that effective managerial changes reduce barriers of time and resources, improve decision making capabilities and further policy development. To measure the effectiveness and efficacy of programs, systematic information gathering is needed within the CBR program for baseline data collection, client information and continuous routine monitoring. Research has advocated that a nationally coordinated user-friendly CBR MIS is necessary to encourage participation, compliance and ownership with all stakeholders.
• **CBR indicator debate**

Sharma indicates that sets of indicators are needed to describe the context, content and direction of the project and to address program-specific aims.\(^{40}\) Though many studies have investigated possible sets of indicators, there is no consensus about which indicators are best to use in the field to measure effectiveness of programs.\(^{29, 30, 40}\) There is research that supports the need to develop uniform indicators and to incorporate their use in CBR evaluation to further evidence based practice.\(^{30, 40}\) However, due to the heterogeneity of CBR programs, Velema and Cornielje support that indicators should be derived from each program's own goals and objectives.\(^{38}\)

• **Enhancing cultural awareness in CBR Policy development**

Given the variation cross-culturally in CBR programs, there is a struggle among the need for international uniformity and the need for increased recognition of local cultural factors within CBR policy development.\(^{6, 9, 40}\) As Turmusrani et al. indicate, the danger in international uniformity is the potential mismatch of local and international rehabilitation ideas when western views are exported and mistakenly applied in a developing country context.\(^{4}\) Therefore, it is imperative that CBR policies use a bottom up, grassroots approach obtaining context dependent perspectives through community felt needs and resource assessments.\(^{6, 7, 9, 21}\) Failure to recognize local perspectives can perpetuate negative attitudes and practices towards PWDs compromising their involvement in CBR.\(^{4, 7, 26}\)
• **Inclusive community development strategy: A human rights based approach**

Due to poverty, corruption and resistance to bottom-up practices secondary to cultural passivity, active involvement of local heterogeneous communities is often limited hindering the sustainability of the CBR programming and operationalizing the decentralization of services. However, CBR efforts cannot be sustainable or effective without full community participation in needs based planning, decision making and evaluation. CBR services should aim to include PWD in mainstream development programs and strategies given that community participation advances the sense of empowerment, facilitates community inclusion, reduces social isolation, increases social contact and enhances confidence. To integrate CBR among community development strategies, community power structures must be acknowledged, and coordination of national services among governmental sectors and non-governmental services is needed.

• **CBR empowerment: Locus of power and control**

CBR contributes substantially to the social inclusion of PWD, increasing their self-reliance, self-esteem and redefining the role of PWD in society through initiating a social change process in remote and rural areas. Effective CBR empowerment requires that clients participate in all aspects of the process resulting in program ownership, greater sustainability, and affordable
and manageable solutions.\textsuperscript{9, 26} Additionally, CBR encourages and enables PWD to join social networks and participate in DPOs and local self-help groups.\textsuperscript{31, 35} This is in contrast to a previously noted PWD passive role where limited mobility, education and skills in PWD hindered their participation in development programs and further exclusion occurred due to poor motivation and expectations of charity.\textsuperscript{26, 36, 41} Effective rehabilitation programs need to allow PWD to have greater control in the nature of their rehabilitation program resulting in choice, respect, trust and equally distributed power with the CRW enabling change.\textsuperscript{4, 26, 38, 41}

- **CBR workers and their training**

In the context of poverty, it is often unrealistic to depend upon community and family volunteers for consistency of a workforce given other daily survival needs and their balance of time demands.\textsuperscript{21, 26, 36, 42} Though regarded by some as a cost-effective approach utilizing local resources, CBR becomes more expensive to the families of PWD given time commitments and expenses of medication and transport.\textsuperscript{1, 4, 7, 9, 42} Additionally, depending upon an unpaid workforce through use of incentives can lead to questionable exploitation, and in practice results in difficulties finding willing community workers, leads to high dropout rates and a lack of motivation among unpaid CBR workforce.\textsuperscript{21, 25, 36, 42} Research suggests that when CRWs and family trainers are paid and provided with educational activities there is a improved
sense of self-efficacy, incentive for retention, improved program sustainability and a reduction of time and resource barriers.\textsuperscript{16, 25} CRWs’ training, their supervision and availability of referral services needs attention for improved capacity building and increased self-efficacy.\textsuperscript{25, 31} Despite the various changing roles of rehabilitation workers of trainers and therapists, there is a need for the continued development of the mid-level worker who supports PWD at community level.\textsuperscript{7, 16} Future CBR curriculum should define and address required competencies, establish regular retraining sessions, develop convenient systematic steps for CRWs to gather program data and utilize locally available materials and technology.\textsuperscript{1, 16, 25, 41}

- **Contribution of INGOs**

NGOs and INGOs are crucial resources for CBR service delivery providing technical expertise, funding, and training in provider, collaborator, supervisor and advocate roles.\textsuperscript{31} Though cooperation is strived for, often INGO CBR programming works in isolation, has limited long-term sustainability and their project evaluation reports remain unpublished which hinders the evidence base of CBR.\textsuperscript{4, 30, 31, 43} Furthermore, INGO evaluations have limited research validity and reliability given the use of subjective methods to gather information including PWD, family and CRW perspectives.\textsuperscript{43} INGO networking among CBR programs should be encouraged since partnerships are found to be effective resulting in cost-effectiveness, significant increases
in empowerment and significant increase in the quality of life. Additionally, Turmusami et. al. encourages improved dissemination of INGO findings.

• CBR Funding

Due to the external support that is targeted to specific projects, groups and geographical areas, funding complications involve the risk of dependency, possible disempowerment of local communities and limited sustainability. Additionally, CRWs are forced to balance the rights and needs of their client with the demands of the funding source, resulting in PWD disempowerment, program inflexibility, restricted time and financial-based outcomes. To enable future policy change, Velema et. al indicate the need to highlight discrepancies between donor expectations and local realities. Kuipers et. al. indicate the need for CBR projects to actively collaborate across local organizations, government departments and INGOs to enhance skills, increase networks and to secure funding. To increase community ownership and sustainability, CBR practice needs to incorporate local capacity building and IGA, and to encourage community members to make contributions of resources such as labour, material and money.

7.2 Effectiveness of CBR in SSA

7.2.1 Description of studies

22 articles published between 1988-2008 were reviewed that fit the inclusion and exclusion criteria, inclusive of one study published in 1987. Articles were
included from the following countries: Botswana, Ethiopia, Ghana, Malawi, South Africa, Uganda and Zimbabwe. Primary study participants included adults 18 years or older from rural villages, however studies and reviews were included that involved infants to elderly (0-75+) given the combined study sample. SSA studies that solely focused upon socio-economic rehabilitation, children with disabilities and parents of children with disabilities were excluded from this report.

7.2.2 Description of themes

7.2.2.1 SSA CBR effectiveness: successes and limitations

There were 9 primary research studies measuring the impact of CBR programming in SSA with adults who had physical disabilities given this report’s inclusion and exclusion criteria (Appendix 5). CBR was highly effective for PWD in the community being trained at home in Zimbabwe for both children and adults, yielding 93% increases in ability scores. Additionally, CBR is shown to have a significant impact among economic and social facets of PWD lives including ADLs, school attendance, employment and social integration as well as quality of life. Furthermore, CBR appears to improve community and family attitude towards PWD. CBR successes appear to be partnerships with agencies, use of volunteers, establishing support systems, flexibility with programming, training programs with broad range of skills and education with culturally relevant disability resource materials. Additionally, timely follow-up, advice and support is essential with CBR programming, especially with
loan schemes where the aim is to transfer clients to micro-finance enterprises.47.

Details of SSA CBR study intervention areas are included in Table 4 below.

<table>
<thead>
<tr>
<th>SSA CBR Intervention Areas</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment activities46</td>
<td>Full of part-time jobs including farming, cattle tending, working in small shops or a petrol station</td>
</tr>
<tr>
<td>Rural ADLs46, 53</td>
<td>Feeding, getting up, washing oneself, visiting lavatory, dressing, fetching water, travelling to the local market, going to school or work and starting a fire</td>
</tr>
<tr>
<td>Community inclusion47, 49, 50</td>
<td>Improvement in social relationships, membership in funeral societies, establishment of village rehabilitation committees, increased respect and recognition among neighbours and family members, involvement in school committees, church organizations, DPOs</td>
</tr>
<tr>
<td>Economic activities47</td>
<td>Small loan scheme</td>
</tr>
</tbody>
</table>

More current research is needed to ascertain SSA CBR effectiveness to enable more evidence based practice.22 7 of the 9 studies were published before the year 2000. One of the studies was completed despite missing survey data, and most use varying techniques to select heterogeneous PWD sample sizes and do not describe what key aspects of the program were effective in impacting daily life.29, 46 Though the realities of performing research in SSA need to be acknowledged including difficulties in obtaining accurate and consistent data, it is essential that CBR evaluation is widely implemented, indicating goal and outcome fulfilment by initial epidemiological and baseline data monitored by continuous follow-up studies with measurable indicators.46, 48 This research will
provide stronger evidence-based practice, as well as providing motivation, support and encouragement for PWD, their families and SSA CBR workers.46

7.2.2.2 CBR organization and management

Many SSA CBR programs are run by people who lack a management background and training for CBR.22 Lundgren-Lindquist and Nordholm found that CBR requires a coordinated involvement of all levels of society, including community, intermediate and national to achieve the goal of representation and empowerment of PWD.46 There is a need to improve SSA CBR communication, coordination, planning and organizational capacity.54 Improved CBR information systems of baseline data are needed to increase the accuracy and consistency of planning, monitoring and evaluating programs.45, 48 Additionally, effective referral and network systems need to be established with health and social welfare services, education, and community-based organization or NGOs involved in community development.55

In SSA there is no national program where multi-sectoral CBR activities cover the whole country.22 In many developing countries governmental priorities may not emphasize the needs of PWD and there is often not a clear social policy.46, 47 South Africa, Uganda and Malawi are examples of SSA countries that have developed policies and documents to support the empowerment of PWD and the development of CBR.

to integrate PWD into the workforce and to provide grants for those unable to become financially independent. Currently, an ongoing need exists to monitor the situation of PWDS to determine whether the official policy is having an impact and to make information available to those who provide services to PWD.15 Uganda actively addresses the issues and needs of PWD. A 1999 study revealed that PWD may not be as stigmatized in Uganda as other countries despite the high prevalence of PWD. In Uganda, participation of PWD on all levels in Local councils is a legal requirement given that Uganda’s constitution reserves seats of the national parliament exclusively for PWD. This political organization of PWD raises awareness and empowers Ugandan citizens coping with a disability. Additionally, National Union of Disabled Peoples’ Organization is an active political organization of PWD raising awareness of disability and empowering PWD politically and economically.

In Malawi, CBR programs have been established since 1988 and the Malawi Council of Disability Affairs had programs running in 11 districts in 2004. The government has demonstrated an increased effort to develop and improve CBR programs, as illustrated by the Malawi Poverty Reduction Paper (MRSP) including a strategy for “Improving the quality of life of the most vulnerable.”

### 7.2.2.3 SSA CBR cultural disability policy development

Cultural beliefs about disability and value systems in SSA widely influence CBR implementation and the vulnerability of PWD. In areas of Botswana and other areas of SSA, the causes of mental or physical impairment are viewed as a
manifestation of misfortunes resulting from improper behaviour, witchcraft, sorcery, taboo, ancestor anger, spirits or pollution. PWD are sometimes shunned from public life, hidden, neglected and abused by family members and the community, while in other contexts PWD are considered holy. Additionally, a study by Lundgren-Lindquist & Nordholm found that disabled men were more satisfied with friends than disabled women. This is reflective of the cultural pattern in rural southern Africa where women do most of the work in fields and around the home, and men can often be found sitting around socializing with men. Therefore, when women are disabled, there is often increased marginalization resulting in isolation and exclusion from mainstream social and economic development including loss of cultural and family rituals such as marriage and employment.

As indicated by Whyte and Ingstad, SSA CBR often fails to respond to local realities and is more top down than grass-roots in orientation. SSA CBR must enlist and enhance cultural influences and value systems to avoid segregation and promote community integration. Therefore, CBR has the potential to fully embrace the cultural bias in SSA of the collective need and responsibility rather than the individual, viewing disability in a wider social and moral context as an issue for whole household units and communities. Once the value of CBR programs is established and demonstrated by enabling PWD to help their families, the cultural gap between the local perception of disability and the westernized rehabilitation needs of effort, training, independence and environmental adaptation is lessened through education and experience.
7.2.2.4 SSA CBR worker training

CBR programs in SSA tend to focus on the rehabilitation component, while doing little to address the equalization of opportunities or social integration of PWD and their family members. CBR must include not only rehabilitation but also the equalization of opportunities and social integration by meeting the physical, emotional and spiritual needs of clients. A SA study in 1995 highlights a successful 2 year CRW multi-purpose community-based training program involving the multiple dimensions of disability and handicap with more general psychological, social, functional, leisure and vocational areas, but also recognizes the difficulty in replicating this educational model. Kay et. al. explores the expansion of physiotherapy programs and indicates a need for intermediate level rehabilitation therapists to provide out-reach and educational programs at the SA local level while also achieving more independent roles in areas of management, assessment and treatment. A study in Botswana highlights the need to support their National Development Plan at the intermediate level to advise, train and supervise rehabilitation personnel. In Zimbabwe after a full-time course lasting 2 years, a CBR mid-level cadre establishes CBR programs with the help of a therapist at the provincial level, but the study found that the workers need more training to successfully include families and communities. Finally, as suggested in a SA CRW training study, it is imperative that continuing CBR education programs are established, preferably by capacity building though community based structures such as community
The impact of continuing education training for CRWs results not only in knowledge acquisition but also improvements in self-esteem and confidence. Therefore, there is a need for more educational training of volunteers and CRWs, including the use of practicals and training on the diversity of disability and rehabilitation, the inclusion of families and communities, the use of culturally relevant resource materials and continued support such as home visits. CRWs need skills to identify and mobilize community resources, to problem solve and strategically plan, to train and educate family and community members, and to advocate for PWD greater organizational development including support of DPOs.

7.2.2.5 Community development

Along with SSA CBR development, there must also be general community development to ensure opportunities for schooling, jobs and social services. There is a need for government resources to provide education for health personnel and to support CBR in village communities. Two studies indicated that the inclusion of non-disabled community members in CBR is essential to further facilitate the change in attitude towards PWD.

7.2.2.6 SSA CBR empowerment

Empowerment of PWD is essential for stigma management and the encouragement of the human rights movement. SSA CBR should be a consumer-focused model advocating the rights and inclusion of PWD in their
families, communities and society. Though the disabled people’s movement is relatively strong in Southern Africa, CBR implementers struggle with the balance between delivering quality services and empowering PWD and their families. However, when PWD and their family members are involved in the design and implementation of CBR, the program prioritizes education, employment and poverty alleviation, and CRWs assign tasks according to local abilities, priorities and interests instead of a previously planned list.

There is a need to further establish a coordinated working relationship among SSA CBR program implementers with local and national DPOs to encourage empowerment, capacity building, networking, sharing of resources and information dissemination. CBR programmes in Zanzibar and Mauritania were set up by national DPOs, but unfortunately these are isolated examples so it is essential that CBR programs in southern Africa partner with DPOs to avoid the mistakes of IBR. Examples of strong national DPOs and NGOs are established in Zimbabwe and South Africa. In Zimbabwe, SAFOD was established in 1986 as an umbrella organization for affiliation of DPOs. The aim of SAFOD is to support formation of local and national DPOs, to strengthen existing ones and to promote leadership training. In South Africa, Disabled People South Africa (DPSA) is a lead organization of the Disability Rights Movement in South Africa. This organization’s aim is to ensure the achievement of human rights and development in South Africa. They have helped set up an Office on the Status of Disabled People in the President’s Office, have PWD as Members of Parliament and have offices in the Premier’s Office in each of the nine provinces. Both of
these DPOs have provided a framework for the inclusion of disability issues into policy development and research.\textsuperscript{54} An example of an established SSA network NGO is Afri-CAN, CBR Africa Network. Afri-CAN was established in 2001 following a CBR Africa Regional Conference and is based at the Uganda National Institute of Special Education.\textsuperscript{22, 44} The aim of Afri-CAN is to further collaboration among SSA CBR initiatives and facilitate the sharing of information about CBR for PWD and their families in African countries.\textsuperscript{57} However the effectiveness of stigma management and empowerment by CBR programs is challenged in a Ghana study.\textsuperscript{27} In Muslim societies such as Ghana, Muslims have the right to give and accept alms without stigmatization according to the Koran so begging is accepted.\textsuperscript{27} Therefore PWD might prefer to seek economic independence and decreased stigmatization by begging in cities instead of joining CBR programmes in rural communities where CBR training is sometimes viewed to perpetuate stigma laden environments and roles.\textsuperscript{27}

\subsection*{7.2.2.7 Contribution of INGOs}

CBR is successful when there are partnerships established with agencies including INGOs, DPOs and local NGOs. The realities of SSA DPOs and local NGOs in the context of poverty result in many that lack the capacity to involve themselves in anything other than the development of their own organizations.\textsuperscript{20} Therefore INGOs have the unique ability to increase their involvement and support with local SSA NGOs and DPOs for CBR programming resulting in increased sustainability.\textsuperscript{15, 61}
7.3. Stakeholder Interviews

7.3.1 Description of interviews

Four stakeholder interviews were conducted to obtain different perspectives and information regarding CBR in the field. Interviewees included an academic researcher, an employee at an international health agency organization, an employee at an INGO head office and an employee at a local South African NGO who has a disability. Though common theme questions were asked, the four stakeholders had varying perceptions of current CBR issues. See Appendix 6 for a table of more extensive thematic quotations.

7.3.2 Discussion of themes

7.3.2.1 CBR effectiveness: successes and challenges

All 4 interviewees had been involved in CBR studies to evaluate the impact of programming on PWD, their families and the community. The local SA NGO employee noted that when people with physical impairments living remote areas are provided with access to assistive devices, their level of independence increases as well as their opportunities of employment, relationships and leisure activities. He also mentioned a current strategy being implemented by Afri-CAN in conducting writing workshops for capacity building of disability personnel and widening research about CBR. The INGO employee felt that decentralization was key for CBR success. He noted a CBR strategy in West Africa with physical rehabilitation at the community level and a volunteer at the village level with a
district clinic was successful given the collaboration with MOH, the provision of a
salary to the local NGO, and by providing CRW follow-up training. Therefore,
when states provide budgets close to the community worker, he noted that the
local authority provides information, services, training and outreach which
ensures greater CBR monitoring and follow up services. Without decentralization
of services, he noted that it leads to poor follow thru, monitoring and evaluation.

However, all stakeholders agreed that there needs to be more evidence-based
practice. The academic researcher identified a number of barriers to carrying out
effective evaluations of CBR, including the reality that CBR needs to be less
idealistic to be effective. Given that various complex interventions change for
every individual, some CBR effectiveness issues include the need for uniform
terminology, the variability involved in measuring quality of life, the need for
continued theory development, the need to establish outcome measures for
interventions and to further develop evaluative tools. Additionally, she
recognized that statistical power in studies is limited by the sample size’s
heterogeneity of disability, and that many CBR programs lack established
management systems including baseline data. She expressed the need for more
qualitative research given that both experimental and experiential evidence is
needed.

To enable more evidence-based practice, the international health agency
employee suggested the use of the future WHO/ILO/UNESCO CBR guidelines to
enable a more common language and an anticipated UN agency collaborative project to develop CBR evaluative tools. However, the stakeholder response's differed with regards to the expected use of the future CBR guidelines. Both the international health agency employee and the local SA NGO employee are hopeful that the guidelines will have a large impact in developing countries for poverty reduction and skill development at the local government level. The INGO employee discussed that the guidelines will be used as the basis for their INGO's CBR policy, and the academic researcher implied that it is the process of writing the guidelines that will impact the field, not the actual guidelines. The local SA NGO employee suggested the development of courses in CBR through SSA universities, as well as the development of an African Journal of Disability and CBR concluding that

"this would be an effective method through which one could really make CBR practice in Africa widely known. Why must all African research be published only in European journals?" Local SA NGO employee

7.3.2.2 CBR Indicator debate

The international health agency employee suggested the following indicators to measure CBR success: people’s visible participation in the program either as a passive receiver or an active participant, environment accessibility, and positive changes in people’s lives such as increased school attendance, livelihood, household income and marriage. The academic researcher acknowledged that measurable indicators need to be established and identified current indicators including: school attendance, levels of participation of both PWD and the community, quality of life, and social participation.
7.3.3.3 Multi-sectoral coordination of CBR

All stakeholders agreed that multi-sectoral coordination of CBR is essential at all levels. Despite SA’s Integrated National Disability Strategy, the local SA NGO employee acknowledges that CBR is only recognized by two government departments of health and social development limiting the multi-faceted entity of CBR by reinforcing a medical and charity model of disability. To overcome this challenge, he suggested that a multi-departmental commitment must be shown by government in the development and implementation of CBR across SSA. The international health agency employee stressed the need of CBR to work in partnership and not rivalry among government ministries, INGOs and international agencies with more horizontal programs. In Malawi, he described that the government has already embraced the five domain CBR matrix in their disability program with a health coordinator, a livelihood coordinator, education coordinator, social inclusion coordinator and a empowerment coordinator. The INGO employee acknowledged that strong interdepartmental links are essential within national CBR monitoring, follow though and evaluation through decentralization of services. He mentioned Togo’s successful link among sectors with local authority by providing information, services and outreach closer to the community worker. Additionally, Uganda’s successful inter-departmental collaboration and inclusive council policy advancement was highlighted by the academic researcher through a personal experience with a village disabled
representative who had devised a grassroots community solution with his limited funding to distribute a piglet to every PWD in his area. She concluded by stating:

“Uganda has this tremendously strong, tremendously powerful tool that they have nurtured. They have changed the lives of lot of people by doing that. There is no doubt about that. I have never seen that anywhere else in any of the other countries I have been to. It is quite unique I think.” Academic researcher

7.3.3.4 Inclusive community development strategy

All four stakeholders concluded that CBR is not solely about projects but a development approach since it focuses on community and grassroots village level involvement. The international health agency employee expressed that it is important to view disability in the broader community context, especially focusing on poverty alleviation to make CBR visible.

“The focus should be on poverty alleviation – if the economics change, there will be sustainable development. Disabled people and their families by remaining together and working together can make it possible.” International health agency employee

However, the INGO employee warned that if CBR focuses too broadly, it will remain at the surface components of disability.

7.3.3.5 Empowerment through self-help groups and DPOs

Three of the four stakeholders agreed on the development and mobilization of self-help groups and DPOs as successful CBR empowerment and community awareness strategies, and as a useful strategy in ensuring international policy implementation through highlighting personal experiences. Challenges identified to implementing CBR self-help groups involve time, communication, economic resources, sensitivity of the work force, limited competency levels, and dynamics in the community. Additionally, the academic researcher mentioned the need of
a participatory balance of all the stakeholders regarding the balance of the strength of having PWD involved and the limitation of only having PWD involved.

"Once the community sees the benefit, that it is not for just a few disabled people but the whole community is getting benefit of it then whole community participates which makes the CBR program more sustainable. Community ownership is the key to success of any CBR programme. The first step of starting any CBR is a formation and empowerment of self-help group." International health agency employee

7.3.3.6 CBR workers

All four stakeholders identified the need of CBR worker training given that it is currently underserved. The INGO employee noted that CRW competencies are more successful in an urban setting given the shorter distances and that training without professional instruction and follow-up training sessions can be harmful to communities. Given that CBR has evolved beyond the skill set of CRWs, he felt that is essential to limit the CRW role at the field level and encourage them to identify collaborators and build links for sustainability. Training was identified as the biggest limitation by the local NGO employee whose professional role is to train and educate mid-level rehabilitation workers throughout southern Africa. He acknowledged that these workers are usually from the local community who have potential to develop good rapport with local councils and traditional leaders. Therefore, as a priority for CBR in the future, proper guidelines in the training and retraining of mid-level rehabilitation workers need to be prioritized, and the establishment of academic CBR institutes.
7.3.3.7 Role of INGOs

The views of INGO involvement were similar among the 3 non-INGO stakeholders. The academic researcher and the local NGO employee viewed the INGO role as a 'silent partnership' where they have a vital role in helping local organizations develop their own skills and needs based decision making skills. The academic researcher indicated that there is little cohesion, conformity or cross learning among INGO programs. To rectify this limitation, she advocated for a plan to be developed by government officials to coordinate CBR programs in all areas and encourages the dissemination of their reports to be available in public domain. INGOS should share their knowledge and create platforms for information sharing with other INGOs, local NGOs, PWD and the academic fraternity. The local NGO employee recognized that it is essential for INGOs to encourage the networking among local organizations and to develop their advocacy and lobbying skills so that they themselves can influence local CBR policy given that …

“local organizations often have a better idea of local need than INGOs. If INGOs are involved in CBR it should definitely be a bottoms-up approach.” Local NGO employee

The international health agency employee agreed that the INGO role involves national policy development, capacity building of the CBR implementers and the sharing of knowledge and resources. He also indicated that INGOS need to invest in training on more evidence based practice and research.

“I feel that INGOs can play a large role to ensure that CBR strategies get implemented and to promote CBR as an inclusive community development strategy. This will ensure the benefits of any development initiatives reach to the majority.” International health agency employee
7.3.3.8 Funding and scaling up

Funding and lack of resources was noted by the employee at the international health agency to be one of the biggest barriers to CBR development and design. Funding was not mentioned by the other stakeholders as a biggest barrier. Scaling up was mentioned by the academic researcher as one of the biggest challenges to CBR development. Though there is evidence of people's lives changing in small pilot CBR projects, she stated that problems are encountered when the program is scaled up to a country wide reaction.
8. Discussion

8.1 Discussion of themes

Over the past 25 years, due to a lack of coordination, coherence and coverage in the research data, evidence is still needed to ascertain the effectiveness of CBR in SSA and developing countries. Both the literature reviews and the stakeholder interviews indicate that CBR is successful, however there is weak evidence examining what specific aspects of CBR are effective which limits the transferability of the findings. CBR successes involve flexibility with programming, establishing local support systems and partnerships with agencies, improved training, provision of assistive devices, improved capacity building and decentralization of services.

Future research is essential to improve the accountability of CBR projects and to strengthen positions of stakeholders. Governments and the INGOs working with CBR programs in developing countries need to operate with informed choices when spending money and allocating human resources in CBR programs. An initiative is needed to collect greater CBR information in SSA and to analyze these results to develop policies matching African interests based on the specific community context by government and INGO programming. The literature and interviewees suggest the increasing need for the establishment of CBR courses in SSA institutes. Additionally, an interviewee recommended the development of an African Disability and CBR Journal to gather and disseminate context specific evidence-based practice.
Though CBR is still evolving in SSA on a national scale, collaboration can be instrumental in the development of a multi-sectoral system enabling the delivery of essential CBR services from the national to the local levels.\textsuperscript{22} Using Uganda’s system as a model, similar context dependent legislative steps need to be encouraged in SSA to facilitate the rights of PWD and the delivery of CBR. Both the literature and the interviewees signify that it is imperative to develop a decentralized national plan for rehabilitation services, implemented and coordinated by government and non-government services. Additionally, the development of national MIS systems for CBR needs to be implemented and supported. MIS systems should be contextual, user friendly and evolve through a realistic collaborative stakeholder effort, including baseline data, sets of indicators, information monitoring, outcomes and feedback from PWD, their families and the community.

CBR workers are facilitators to enable change in PWD lives. They are in unique positions to provide a necessary link between the local and national issues by disseminating CBR information at the community level to the policy makers at the national level.\textsuperscript{20} Further clarity of their roles, competencies and wages are essential in SSA CBR delivery. Both the literature reviews and the interviews supported the prioritization of mid-level workers educational training and retraining, the use of practicals and culturally relevant resource materials, further training on the diversity of disability and rehabilitation, and the inclusion of
families and communities. Given the move to market economies in many developing countries, expectations of long-term free work is unrealistic so SSA CRWs need paid employment to survive, and incentives should be developed to encourage their motivation and retention. Equal partnerships among CRWs and PWD, their families and communities needs to be fostered to share the locus of power.

CBR needs are dynamic, viewing disease not in term of mortality or morbidity but looking at disability. Both research and the interviewees advocate that CBR needs to be less idealistic and more realistic incorporating an increased cultural awareness and integrating socio-cultural context. Through the acknowledgement of local cultural factors, CBR development can be an evolving, responsive, long term contextual process, not simply a universal model for developing country disability interventions. The cultural perception of disability must be established prior to SSA CBR implementation.

Empowerment strategies, specifically self-help groups and DPOs, are crucial socio-political constructs to CBR’s success and sustainability. DPOs in various regions of SSA have been critical in policy advancement, establishing national programs and furthering research. Though there was limited research regarding the establishment and benefits of self-help groups, the stakeholders advocated for this intervention modality illustrated through successful field experiences. The active inclusion of PWD and community needs and feedback is essential in CBR
to acknowledge PWD rights and decrease stigma. Through working with local organizations and communities at the grass roots level, CBR is more sustainable by facilitating PWD, their families and the community’s ideas and developing from their felt needs.

Both the literature and the stakeholders encourage INGOs to publish their CBR data to support the dissemination of knowledge and to further evidence-based research. INGOs need to be cognisant of potential funding dependency by supporting local capacity building and IGA activities to encourage financial development and sustainability. Through improved partnerships with local organizations, INGOs can support and incorporate the community’s needs and perspectives of disability in their CBR plan resulting in more sustainable change.

8.2 Report limitations: Literature searches I & II

There are a few issues that affected the feasibility of the literature reviews for this policy report. Despite increased recognition of CBR programming and a growing interest in the field, there still remains limited research information available. Though journal articles, books and grey literature about CBR in developing countries and in SSA were found, it is recognized in the field that there is a lack of CBR uniformity internationally and that there is a need for broader CBR evidence-based practice. Furthermore, the challenge of collecting and using grey literature is recognized. This information lacks strict editorial and bibliographic control which raises questions about authenticity and reliability.
Though this data was utilized in searching, analysis and conclusion, caution should be applied to the findings.

It was ambitious project given the scope and time allowed for this policy report. While conducting the literature searches I & II, some of the articles could not be obtained for the analysis within the time frame of this project given publication in inaccessible journals.

It is acknowledged there is great variability and heterogeneity between and within each country in SSA. This report aimed to highlight the documented CBR impact in this region and the need for continued evidence-based research to ascertain effectiveness. It is recognized that each national development of CBR must be culturally relevant and appropriate given existing infrastructure, political, and conflict situations, which is congruent with the report’s socio-cultural findings.

8.3 Report limitations: Stakeholder Interviews

Given the research question, the most appropriate analysis method was stakeholder perspectives. More interviews were planned and due to time constraints a proper qualitative study of stakeholder views was not completed. Therefore the process of analyzing and coding for themes was not done. The difficulties in scheduling and obtaining my stakeholder interview information are reflective of the flexibility required within CBR development in the field.
9. Recommendations for future INGO SSA CBR development

9.1 Community level

1. To focus on policy development at the local level, especially in SSA countries where there is little decentralization at MOH and district levels.

2. To enable inclusive local development by mobilizing local self help groups and DPOs and developing strategies and sustainable programming through partnerships with local NGOs, groups and organizations in SSA.

3. To consider the context and definition of disability at the community level prior to program design and implementation.

4. To encourage the gathering of baseline data and support MIS at all levels. This involves prioritizing baseline data collection, establishing clear objectives, targets and necessary indicators, and enabling ownership of the monitoring and evaluation system by both stakeholders and users to encourage participation and involvement.

5. To prioritize the training and support of CBR workers. Guidelines should be developed, especially for the mid-level worker, and training programs are key to maintaining competencies in the field with regular retraining sessions and wage incentives to increase retention of staff.

9.2 National level

1. To build links among the sectors, including the MOH, Ministry of Education, Ministry of Transportation and Ministry of Labour, for multi-
sectoral support and involvement in CBR to enable sustainable policy development.

2. To support the development of an appropriate national disability referral system of care within the health system

3. To support the position of a national rehabilitation position that can coordinate CBR and delegate specific areas to INGOs so that there is greater collaboration and coordination among CBR programming

4. To support the development of national CBR baseline, monitoring and information systems that are realistic to be completed by field workers, PWD and their families

9.3 International level

1. To continue involvement in the development of the guidelines and the next WHO anticipated project of developing indicators and evaluation protocols to further the evolution of CBR evidence based practice

2. To make their CBR evaluation reports available as appropriate to the public and especially the academic research field to enable further published analysis of CBR best practice and the critique of successes and challenges to implementation.

3. To strengthen the development of SSA network organizations within SSA enabling them to develop their own research bodies and journal publications.
10. Conclusion

Given the rise of HIV/AIDS and chronic diseases, increased African urbanization, growth of SSA DPOs, increasing donor fatigue and foreign pressure for tougher economic policies, it is imperative that the field of CBR becomes more established through evidence-based practice and policies.\textsuperscript{22} Though there is growing evidence of CBR delivery in the developing world and in SSA, more information and research is needed to determine effectiveness. INGOs are in positions to enable these changes through their support of SSA CBR evidence-based programming and by furthering the development of national and international policies. The nature of SSA CBR delivery needs to be enhanced through a coordinated, decentralized multi-sectoral service delivery at national, regional and local community levels with established MIS systems, including the gathering of baseline data and monitoring throughout. Community involvement, contextual understanding of disability, empowerment of PWD and further training of CBR workers are keys to successful CBR. Though paradoxes exist in CBR given its societal and multi-service delivery context, there is great potential for CBR programming to empower PWD and provide sustainable positive change.
11. References


Appendix 1 SSA countries practicing CBR

<table>
<thead>
<tr>
<th>SSA countries practicing CBR(^9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Algeria</td>
</tr>
<tr>
<td>Angola</td>
</tr>
<tr>
<td>Botswana</td>
</tr>
<tr>
<td>Burkina Faso</td>
</tr>
<tr>
<td>Cameroon, Congo</td>
</tr>
<tr>
<td>Cote d'Ivoire</td>
</tr>
<tr>
<td>Eritrea</td>
</tr>
<tr>
<td>Ethiopia</td>
</tr>
<tr>
<td>Gambia</td>
</tr>
<tr>
<td>Ghana</td>
</tr>
<tr>
<td>Kenya</td>
</tr>
<tr>
<td>Lesotho</td>
</tr>
<tr>
<td>Liberia</td>
</tr>
<tr>
<td>Malawi</td>
</tr>
<tr>
<td>Mali</td>
</tr>
<tr>
<td>Mauritania</td>
</tr>
<tr>
<td>Mauritius</td>
</tr>
<tr>
<td>Mozambique</td>
</tr>
<tr>
<td>Namibia</td>
</tr>
<tr>
<td>Niger</td>
</tr>
<tr>
<td>Nigeria</td>
</tr>
<tr>
<td>South Africa</td>
</tr>
<tr>
<td>Senegal</td>
</tr>
<tr>
<td>Sierra Leone</td>
</tr>
<tr>
<td>Sudan</td>
</tr>
<tr>
<td>Tanzania</td>
</tr>
<tr>
<td>Togo</td>
</tr>
<tr>
<td>Uganda</td>
</tr>
<tr>
<td>Zambia</td>
</tr>
<tr>
<td>Zanzibar</td>
</tr>
<tr>
<td>Zimbabwe</td>
</tr>
</tbody>
</table>

61
Appendix 2 CBR Matrix

GOAL: INCLUSIVE DEVELOPMENT ~ INCLUSIVE SOCIETY

COMMUNITY BASED REHABILITATION (CBR)

HEALTH
- PROMOTION
- PREVENTION
- MEDICAL CARE
- REHABILITATION
- ASSISTIVE DEVICES

EDUCATION
- EARLY CHILDHOOD DEVELOPMENT
- NON-FORMAL
- FORMAL INCLUDING PRIMARY
- SECONDARY AND HIGHER
- LIFE-LONG LEARNING

LIVELIHOOD
- SKILLS DEVELOPMENT
- SELF EMPLOYMENT
- WAGED EMPLOYMENT
- FINANCIAL SERVICES
- SOCIAL PROTECTION

SOCIAL
- PERSONAL ASSISTANCE
- RELATIONSHIP MARRIAGE & FAMILY
- CULTURE RELIGION & ARTS
- SPORTS RECREATION & LEISURE
- ACCESS TO JUSTICE

EMPOWERMENT
- SOCIAL MOBILISATION
- POLITICAL PARTICIPATION
- LANGUAGE & COMMUNICATION
- SELF-HELP GROUPS
- DISABLED PEOPLES ORGANIZATIONS
Appendix 3 Literature Search Strategies

Literature Search I

Pub Med
(CBR and community based rehabilitation) and developing countr*
(CBR and community based rehabilitation) and low income countr*
(CBR and community based rehabilitation) and disabilit*
(CBR and community based rehabilitation) and developing countr* and disabilit*
(CBR and community based rehabilitation) and evaluation
(CBR and community based rehabilitation) and developing countr* and evaluation
(CBR and community based rehabilitation) and effectiveness
(CBR and community based rehabilitation) and developing countr* and effectiveness
(CBR and community based rehabilitation) and participation
(CBR and community based rehabilitation) and developing countr* and participation
(CBR and community based rehabilitation) and impact
(CBR and community based rehabilitation) and developing countr* and impact
(CBR and community based rehabilitation) and rights
(CBR and community based rehabilitation) and developing countr* and rights
(CBR and community based rehabilitation) and empowerment
(CBR and community based rehabilitation) and developing countr* and empowerment

Medline – Ovid
(CBR and community based rehabilitation) and developing countr*
(CBR and community based rehabilitation) and middle income countr*
(CBR and community based rehabilitation) and low income countr*
(CBR and community based rehabilitation) and disabilit*
(CBR and community based rehabilitation) and developing countr* and disabilit*
(CBR and community based rehabilitation) and evaluation
(CBR and community based rehabilitation) and evaluation and developing countr*
(CBR and community based rehabilitation) and effectiveness
(CBR and community based rehabilitation) and effectiveness and developing countr*
(CBR and community based rehabilitation) and participation
(CBR and community based rehabilitation) and participation and developing countr*
(CBR and community based rehabilitation) and impact
(CBR and community based rehabilitation) and impact and developing countr*
(CBR and community based rehabilitation) and rights
(CBR and community based rehabilitation) and rights and developing countr*
(CBR and community based rehabilitation) and empowerment
(CBR and community based rehabilitation) and empowerment and developing countr*

The rest of the search terms were not used for Medline as the articles identified were duplicates

JStor
(CBR and community based rehabilitation) and developing countr*
(CBR and community based rehabilitation) and disabilit*
(CBR and community based rehabilitation) and disabilit* and developing countr*
(CBR and community based rehabilitation) and evaluation
(CBR and community based rehabilitation) and evaluation and developing countr*
(CBR and community based rehabilitation) and effectiveness
(CBR and community based rehabilitation) and effectiveness and developing countr*
(CBR and community based rehabilitation) and participation
(CBR and community based rehabilitation) and participation and developing countr*
(CBR and community based rehabilitation) and impact
(CBR and community based rehabilitation) and impact and developing countr*
(CBR and community based rehabilitation) and rights
(CBR and community based rehabilitation) and rights and developing countr*
(CBR and community based rehabilitation) and empowerment
(CBR and community based rehabilitation) and empowerment and developing countr*

Africa Healthline
(CBR and community based rehabilitation) and disabilit* and developing countr*
(CBR and community based rehabilitation) and evaluation and developing countr*
(CBR and community based rehabilitation) and effectiveness and developing countr*
(CBR and community based rehabilitation) and participation and developing countr*
(CBR and community based rehabilitation) and impact and developing countr*
(CBR and community based rehabilitation) and rights and developing countr*
(CBR and community based rehabilitation) and empowerment and developing countr*
Eldis
CBR and community based rehabilitation and evaluation and developing countr*
CBR and community based rehabilitation and effectiveness and developing countr*
CBR and community based rehabilitation and impact and developing countr*

WHO DAR Website
Search was conducted through navigating website

UN ENABLE website
Search was conducted through navigating website

Google search Engine
CBR and community based rehabilitation and developing country and effectiveness
CBR and community based rehabilitation and developing country and evaluation
CBR and community based rehabilitation and developing country and disability

Google Scholar
Search was completed using the authors Finkenflugel, Kuipers, Miles, Hartley, Helander, Sharma, Thomas and Velema.

Literature Search II

PubMed
(CBR and community based rehabilitation) and Africa
(CBR and community based rehabilitation) and (sub-saharan Africa or sub saharan Africa)
(CBR and community based rehabilitation) and southern Africa
(CBR and community based rehabilitation) and (sub-saharan Africa or sub saharan Africa or southern africa)
(CBR and community based rehabilitation) and disability (sub-saharan Africa or sub saharan Africa or southern africa)
(CBR and community based rehabilitation) and effectiveness (sub-saharan Africa or sub saharan Africa or southern africa)
(CBR and community based rehabilitation) and evaluation (sub-saharan Africa or sub saharan Africa or southern africa)
(CBR and community based rehabilitation) and impact (sub-saharan Africa or sub saharan Africa or southern africa)
(CBR and community based rehabilitation) and participation (sub-saharan Africa or sub saharan Africa or southern africa)
(CBR and community based rehabilitation) and empowerment (sub-saharan Africa or sub saharan Africa or southern africa)

Africa Healthline
(CBR and community based rehabilitation) and disability* and Africa
(CBR and community based rehabilitation) and evaluation and Africa
(CBR and community based rehabilitation) and effectiveness and Africa
(CBR and community based rehabilitation) and participation and Africa
(CBR and community based rehabilitation) and impact and Africa
(CBR and community based rehabilitation) and rights and Africa
(CBR and community based rehabilitation) and empowerment and Africa

Independent Living Institute
(CBR and community based rehabilitation) and disability and Africa
(CBR and community based rehabilitation) and evaluation and Africa
(CBR and community based rehabilitation) and effectiveness and Africa
(CBR and community based rehabilitation) and participation and Africa
(CBR and community based rehabilitation) and impact and Africa
(CBR and community based rehabilitation) and rights and Africa
(CBR and community based rehabilitation) and empowerment and Africa
Source
Key topic – community based rehabilitation
(CBR and community based rehabilitation) and disability and Africa
(CBR and community based rehabilitation) and evaluation and Africa
(CBR and community based rehabilitation) and participation and Africa
(CBR and community based rehabilitation) and rights and Africa

Hand searched reference list of 3 literature reviews
Duplicate of articles noted as well articles and/or reports unobtainable to researcher

Hand search in Disability and Rehabilitation and International Journal of Rehabilitation Research from 2003-2008
Duplicates of articles already found

Google Search Engine
CBR and community based rehabilitation and disability and evaluation and sub-saharan Africa
CBR and community based rehabilitation and disability and effectiveness and sub-saharan Africa
CBR and community based rehabilitation and disability and NGO and sub-saharan Africa
<table>
<thead>
<tr>
<th>STUDY DETAILS</th>
<th>METHOD OF RESEARCH</th>
<th>CBR SUCCESSES</th>
<th>CBR LIMITATIONS AND RECOMMENDATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kuipers et. al. (2008)</td>
<td>Examined 37 evaluation reports in 22 countries</td>
<td>Proof-of-Concept Study by computer assisted thematic qualitative analysis conducted on CBR project evaluation recommendation sections</td>
<td>Future policy frameworks and implementation strategies in CBR need to include stronger emphasis on technical, organizational, administrative and personnel aspects of management and strategic leadership</td>
</tr>
<tr>
<td>Velema et. al (2008)</td>
<td>Identified 29 reports from 22 countries in Asia, Africa and Central America from 1987-2007.</td>
<td>Outcome evaluation of rehabilitation-in-the-community program interventions including home visits by CRWs who taught PWD ADLs, encouraged disabled children to attend school, helped PWD find employment or IGA. Programs also influenced community attitudes towards disability and/or encouraged formation of self-help groups and DPOs</td>
<td>PWD did not become financially independent Coverage of CBR programs in countries is inadequate and should investigate needs of PWD who have more severe disabilities Need to invest further in evidence-based outcome and impact evaluations</td>
</tr>
<tr>
<td>Finkenflugel et al. (2005)</td>
<td>Reviewed 128 CBR articles from 1978-2002.</td>
<td>Systematic review to assess evidence base of CBR by type of articles and key elements of CBR including screening, knowledge, local resources, participation, implementation, stakeholders, project evaluation and other</td>
<td>Need to review already-published articles and make them available to researchers, project implementers, policy etc. Need to agree on a the use of a transparent, systematic, coordinated and relevant way of reporting on CBR programs Need to perform research studies on the key aspects within CBR programs to determine evidence on a particular aspect to facilitate planning and policy development and allocate resources accordingly</td>
</tr>
<tr>
<td>Wirz and Thomas (2002)</td>
<td>Examined the reports noting methods used in the evaluations, labelling used to describe programs activities and outcome and indicators to describe practice</td>
<td>Classified into 5 types of CBR studies: intervention studies, descriptive studies, case reports, review papers and theory papers</td>
<td>Need to field test indicators across different cultures Indicators need to be related to aims of program, be robust and be easy to use Indicators need to be sensitive to gender issues and data collected accordingly</td>
</tr>
<tr>
<td>Finkenflugel et al. (2008)</td>
<td>Reviews 16 CBR documents</td>
<td>Literature review to examine classification models and their usability</td>
<td>Models need to be made less complex Models need to focus on outcomes that are meaningful for people involved in evaluation as well as policymaker and researchers</td>
</tr>
</tbody>
</table>

**Methodology**

- **Proof-of-Concept Study** by computer assisted thematic qualitative analysis conducted on CBR project evaluation recommendation sections.
- **Outcome evaluation** of rehabilitation-in-the-community program interventions including home visits by CRWs who taught PWD ADLs, encouraged disabled children to attend school, helped PWD find employment or IGA. Programs also influenced community attitudes towards disability and/or encouraged formation of self-help groups and DPOs.

**Succesess**

- Home based training increased independence, mobility and communication skills of PWD
- Helped parents of disabled children cope better and increased school attendance of children with disabilities
- Economic interventions increased the income of PWD improving self-esteem and status in family and community
- CBR activities enable social processes that changed community perception of PWD, increased their level of acceptance and social inclusion and mobilized resources to meet needs

**Limitations and Recommendations**

- Future policy frameworks and implementation strategies in CBR need to include stronger emphasis on technical, organizational, administrative and personnel aspects of management and strategic leadership
- PWD did not become financially independent Coverage of CBR programs in countries is inadequate and should investigate needs of PWD who have more severe disabilities Need to invest further in evidence-based outcome and impact evaluations
- Need to review already-published articles and make them available to researchers, project implementers, policy etc. Need to agree on a the use of a transparent, systematic, coordinated and relevant way of reporting on CBR programs Need to perform research studies on the key aspects within CBR programs to determine evidence on a particular aspect to facilitate planning and policy development and allocate resources accordingly
- Need to field test indicators across different cultures Indicators need to be related to aims of program, be robust and be easy to use Indicators need to be sensitive to gender issues and data collected accordingly
- Models need to be made less complex Models need to focus on outcomes that are meaningful for people involved in evaluation as well as policymaker and researchers
<table>
<thead>
<tr>
<th>STUDY DETAILS</th>
<th>METHOD OF RESEARCH</th>
<th>CBR SUCCESSES</th>
<th>CBR LIMITATIONS AND RECOMMENDATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharma (2007) examined 22 CBR project evaluations</td>
<td>Qualitative analysis to determine the extent of community participation evaluation in CBR studies evaluated over the last 30 years</td>
<td>4 reports documented positive effects of participation</td>
<td>Only 6 of the 22 evaluation reports measured community participation. 2 showed community participation did not work or was inadequate to the project. Community participation has not been adequately measured by CBR programs. Need to develop valid and reliable measures of community participation to measure all dimensions including measurement of the number of persons reached, and the quantity and quality of resources generated as a result of community participation.</td>
</tr>
<tr>
<td>Evans et al. (2001) explores 20 methods and measures to evaluate medical rehabilitation in CBR projects India</td>
<td>Tracer method to assess CBR technical quality, interpersonal quality and management (structural) quality that was process oriented, as opposed to output oriented</td>
<td>Method was found to be a low-cost method that might prove useful to the objective evaluation of disability services throughout the developing world.</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 5 Table 3: SSA Research studies

<table>
<thead>
<tr>
<th>YEAR</th>
<th>COUNTRY</th>
<th>TARGET POPULATION</th>
<th>STUDY DESIGN AND METHOD</th>
<th>EVIDENCE OF IMPACT OR EFFECTIVENESS OF CBR</th>
<th>CBR PROGRAM RECOMMENDATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1987</td>
<td>Zimbabwe</td>
<td>136 participants in Zimbabwe with mentally handicaps (41% undiagnosed followed by 22% with cerebral palsy)</td>
<td>Post test only design using outcome measures of etiology, learning targets, ratings of clients progress and participants reactions to the program</td>
<td>16% showed outstanding progress with 79% steady progress, 5% showed little or no progress</td>
<td>Successes: Partnerships with agencies Training in mental handicap Culturally relevant resource materials</td>
</tr>
<tr>
<td>1992</td>
<td>Zimbabwe and Philippines</td>
<td>Matched sample of 100 and 106 recipients of CBR program activities respectively (53% male and 47% female ages 5 to 83 years old)</td>
<td>Pre-test Post-test design in home, school or workplaces assessing history, testing of ability in ADL and communication, and family discussion</td>
<td>Ability scores after CBR training increased by 78% in Philippines and 93% in Zimbabwe with encouraging rates of starting school or taking up occupation CBR is highly effective for disabled people in the community being trained at home for both children and adults, yielding similar results in different societies</td>
<td>Successes: Greatest achievements in ADL, social inclusion, diminishing severity of disability, schooling and employment Low cost by recruiting volunteers Mobilizes human resources in the community while promoting self-esteem Suitable occupations found for older people Increase in school attendance Limitations: Limited records of subjects initial assessments and baseline data Variations in medical diagnoses</td>
</tr>
<tr>
<td>1993</td>
<td>Botswana</td>
<td>132 PWD surveyed between the ages of 0-75+ involved in CBR programming; average family group 7</td>
<td>Door-to-door survey conducted in Moshupa village in 1990 to identify and describe PWD</td>
<td>1-4% PWD identified: 22% &lt;15 years old and 17%&gt;65 years old High proportion (30%) had parents that were related to each other Majority of PWD had difficulties with mobility (65%) and 21% had 2 or more disabilities 34% received treatment (predominantly modern medicine) with positive association between treatment and education</td>
<td>Successes: Epidemiological data on disability is important for the planning of CBR programs Positive association between treatment and education Awareness in the community increased about disability Limitations: Need all members of the community involved in CBR Need government resources to provide education for health personnel and to support CBR in villages Need realistic goals so CBR services are not overloaded</td>
</tr>
<tr>
<td>1994</td>
<td>South Africa</td>
<td>Random sample of 40 clients out of 383 involved in CBR programming</td>
<td>Post test design using quantitative monthly time sheet records and qualitative structured client and CRW interviews to determine if relatively long training and broad range of skills covered is effective and appropriate and to determine the match between the skills of the CRWs and the support and referral systems</td>
<td>CRWs had significant impact of reducing functional limitations of the client and improving their ADLs CRWs raised PWD self-esteem and integrated PWD into family and local community with effect on psychological environment and opportunities to go to school and hospital CRWs active in generating local organizational strength and encouraging PWD membership</td>
<td>Successes: Increase in ADL performance, mobility, coping with environment and access to resources Enhanced self-reliance and self-image Involvement in local organizations Successful training program with broad range of skills Limitations: Family attitudes determined by forces beyond CRW influence Difficult to replicate training program Difficult to establish if program coverage was adequate or insufficient CRW caseloads might not reflect disability prevalence in area Difficult to quantify increased integration, independence and self-actualization</td>
</tr>
<tr>
<td>YEAR</td>
<td>COUNTRY</td>
<td>TARGET POPULATION</td>
<td>STUDY DESIGN AND METHOD</td>
<td>EVIDENCE OF IMPACT OR EFFECTIVENESS OF CBR</td>
<td>CBR PROGRAM RECOMMENDATIONS</td>
</tr>
<tr>
<td>------</td>
<td>---------------</td>
<td>------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>1994</td>
<td>South Africa</td>
<td>8 CRWs, 5 supervisors, 45 PWD and their families (convenience sampling used)</td>
<td>Qualitative analysis of nominal group technique and focused group discussion with CRWs and supervisors to identify learning needs that should be addressed through continuing education; Qualitative analysis of focused group discussions to discover PWD and their families perspectives on skills that the CRWs needed</td>
<td>CRWs lack skills in social work, IGA, literacy training and skills to handle socioeconomic problems of PWD. Need to improve identification and mobilization of resources. Need to learn different techniques, problem solving skills and strategic planning. Need for more training to educate the family and community on mental health and illness. Need training in advocacy skills for PWD to enable organizational development.</td>
<td>Limitations: Need continuing education programs by capacity building though community based structures such as community colleges. Need to develop effective referral and network systems with health and social welfare services, education, and community-based organization or NGOs involved in community development.</td>
</tr>
<tr>
<td>1996</td>
<td>Botswana</td>
<td>77 PWD were interviewed of 132 PWD initially identified in a 1990 survey between the ages of 0-75+, average family group 7</td>
<td>Post-test design using interviews during a 5-week period to study the impact of CBR in the lives of PWD identified in 1990 survey – first follow-up study</td>
<td>Remarkably high percentage of elderly were still alive (17% were 65 and over). Most people had maintained a high levels of independence in ADL. 20% of adults were working 10 out of 14 children were in school. Life satisfaction was high and noted higher for younger people than for older ones. Significantly more younger people reported that life had been improved while elderly believed life to be worse now.</td>
<td>Successes: Greater satisfaction with younger life satisfaction. Greater proportion of men satisfied with friends. Limitations: Older population less satisfied with friends, self care and stated health.</td>
</tr>
<tr>
<td>1999</td>
<td>Botswana</td>
<td>Selected group sample of 20 clients, 2 CBR team members and 15 Red Cross volunteers</td>
<td>Second follow-up study on selected group sample: clients interviewed about the rehabilitation personnel, CBR team members interviewed and Red Cross volunteers interviewed with open questions about CBR training, use of CBR manual, visits to disabled persons, perceived strengths and weaknesses of CBR program and suggestions for improving the CBR program</td>
<td>CBR Strengths: Knowledge and information about rehabilitation had reached majority of PWD. Awareness about disability had increased. PWD had become more integrated into the families and community &amp; were no longer hidden. CBR Problem Areas: Unsatisfactory cooperation between the CBR team and Red Cross volunteers. Lack of transport. Lack of information about the work of the CBR team among health-post personnel and school teachers. Lack of knowledge among health-post personnel in being able to diagnose children with disability – as consequence referral to CBR team did not function well.</td>
<td>Successes: Use of volunteers who try to fulfill the goals of CBR to the best of their ability. Formation of village Rehabilitation Committee to address fundraising, empowerment and social integration of PWD. Limitations: Need for more training for volunteers. Clients need continued support such as home visits. Need to develop support structures for National Development Plan at the intermediate level to advise, train and supervise rehabilitation personnel.</td>
</tr>
<tr>
<td>2000</td>
<td>Ethiopia</td>
<td>Random sample of 36 beneficiaries from 168 total beneficiaries (22 men and 14 women)</td>
<td>Evaluation study of a CBR pilot small loan scheme using questionnaires, structured interviews, case studies, participation observation, quantitative notes and reports</td>
<td>Increase in employment. Improvements in economic and living conditions with savings, income, food intake, clothing and housing (nearly half of 22 clients with own &quot;house&quot; had improved by either renovating or reconstruction). Overall repayment rate was 78%: majority of 61% made regular repayments; 17% showed irregularities with payment schedule. 86% reported improvement in community and family.</td>
<td>Successes: Flexibility of staff on loan repayment collection/schedules along with regular staff visits and advice. Limitations: Some of the loans to finance IGAs were spent on non-IGAs like purchasing clothes and acquiring land from urban authorities for house construction. Financial assistance alone cannot bring change to PWD lives. Need to include community members to further.</td>
</tr>
<tr>
<td>YEAR</td>
<td>COUNTRY</td>
<td>TARGET POPULATION</td>
<td>STUDY DESIGN AND METHOD</td>
<td>EVIDENCE OF IMPACT OR EFFECTIVENESS OF CBR</td>
<td>CBR PROGRAM RECOMMENDATIONS</td>
</tr>
<tr>
<td>------</td>
<td>-------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>2003</td>
<td>South Africa</td>
<td>45 to eventually 180 women living in peri-urban areas of Khayelitsha and Nyanga between the ages 14-55 years old</td>
<td>Qualitative participatory action research involving story telling workshop for 2.5 years to identify barriers faced and strategies used for social and economic development facilitated by CBR workers</td>
<td>Qualitative analysis revealed key themes of struggles, sadness, strength and spirit for women with disabilities</td>
<td>Limitations: Need to meet physical, emotional and spiritual needs as means to social and economic development for women with disabilities by building emotional resourcefulness and support systems, nurturing children and families in disability issues and renewing spirituality in disability and development programs by integrating cultural influences and value systems. Need to improve communication, coordination and planning and organizational capacity of those responsible for the program.</td>
</tr>
</tbody>
</table>

facilitate changes in attitude
Need timely follow up and advice
<table>
<thead>
<tr>
<th>INTERVIEW THEME</th>
<th>QUOTES</th>
</tr>
</thead>
</table>
| **CBR effectiveness: need for evidence-based research** | “This is one of the weakest areas in implementation of CBR. There are two problems identified. One is that practitioners are so busy in day to day work that they don’t have the time or energy or culture for writing and documenting their work well. And the professionals who know it well are quite far from the reality. There is quite a big gap between practitioners and researchers. We have to do lots of work to ensure there is more culture of evidence based practice in CBR and that needs be done now.”  
*International health agency employee*  
“For the future, however I feel that the development of courses/electives in CBR through universities in southern Africa is another effective avenue through which to increase research and evaluation of CBR. Another vision I have had for awhile is the development of an African Journal of disability and CBR…this would be an effective method through which one could really make CBR practice in Africa widely known. Why must all African research be published only in European journals?”  
*Local SA NGO employee* |
| **CBR international uniformity** | “In developing countries the major problem is that disability is not a priority area. The other problem is the lack of resources, both human and financial resources. To depend only on the government to ensure everything to change, is practically impossible. What we are trying to do while developing CBR guidelines is that we are also strengthening partnership among UN organizations, Government organizations, and International Non-Governmental Organizations including Disabled Peoples Organizations. We have developed a common understanding and consensus (CBR Matrix) so together with support of the government, especially the local government, CBR can be implemented at the local level. This is the best possibility of long term sustainability and positive changes in the developing world. Though CBR is practice in developing world but it has a high relevance to the developed world, especially to those who are geographically big.”  
*International health agency employee*  
“I am quite sceptical about them because my experience tells me that guidelines are often not used and that they sit on peoples shelves not because the guidelines don’t tell you good and useful things and that they haven’t been written properly, but because people in developing countries tend not to use them. What I think has been good about these guidelines is the process of writing them has enabled people to get together and talk further their ideas just because they have been in contact and because they have had a focus to be in contact about. People all around the world involved in CBR have got to meet other people around the world involved in CBR because they have been involved in writing all of these chapters. I think that networking opportunity has been tremendously productive so it is not just the guidelines but the process that has been a really good one. BUT for as for whether people will use the guidelines I think not - it is ironical.”  
*Academic researcher* |
| **Indicator Debate** | “In many countries CBR programs are still being funded by many overseas NGOs or donor agencies. And once that finding is over, the CBR program goes downhill because the program could not manage to get support from the local or national government…In many countries, the professionals are there, the knowledge is there but majority can not access it because of distance, funding and lack of resources. The environment of globalisation and privatization is about survival of the fittest. So the invisible people, unorganised people, voiceless people have less opportunities.”  
*International health agency employee* |
| **Funding and scaling up** | “In Uganda they have also got a lot of participation of disabled people in parliamentary positions so the implementation of these documents is better there probably than anywhere else in the world. It is tremendously participatory. They have a system there where all the villages and sub counties and counties have a council like what we have here with local councils. There is an elected council right from the village up to the...”  
*International health agency employee* |
parliament. Each of these councils has one seat if you like for a person with a disability and this seat cannot be filled by someone who does not have a disability. So you can't have someone sitting there representing disabled people if they are not disabled themselves. So they actually have this system so it means that they have 47,000 disabled people who sit on councils throughout the country. That means that the capacity of disabled people throughout the country has been supported, their dignity is raised and they are on the council and someone who hasn't got a disability is not. That increases their status, the amount of respect they get, their opportunity to speak, and be heard. That makes a difference to what happens. I remember going to a small village once and asking to see the disabled representative and this old fellow came up and said he was the person. I mean I think he was disabled because he was elderly – he didn't have any obvious impairment that you would perhaps would associate with our concept of disability. But he was an old man and he couldn't walk very far but he could ride his bicycle. And I said to him, 'what can he do?' He said he was in charge of all the people who are disabled and so he thought if you are in charge of anything you have to know what it is you are in charge of. So he said he went on his bicycle and found them in his area. He said there was something like 300 people with disabilities in his area. I didn't say what was wrong with them, you know that was his interpretation. You have to remember that we have evidence now that shows that people's interpretation of what is a disability varies a lot. For instance in Kenya, we have a study that shows that children who are orphaned are considered to be disabled. You know, bearing that in mind, he considered that he was looking after 300 or so disabled people. And I said 'did he have a budget?' And he said yes he did, it was so many Ugandan shillings that would be equivalent to about 30 pounds. And I said so what do you do because 300 people and 30 pounds that is quite a challenge you see. And he said yes it was but he had bought 6 pigs with the money and he had persuaded the richest person in the village to look after these pigs as gift to the village. And every time one of these pigs had a litter, he would tuck one of the piglets under his arm and would cycle to one of the homesteads where a disabled person lived. So he had almost given every disabled person a pig which meant that they could in turn breed and so on. I thought, what is the best 30 quid worthy I can think of and I think this probably is.

### Inclusive community development strategy

“Disabled people are people - they are people first, then disabled. So their needs are the same as anybody else’s needs, -- basic needs are the same whether you are disabled or not. Disabled people, especially people who are poor, have the same food, healthcare, education, housing needs – these basic needs have to be met first. Surprisingly these basic needs first, then special needs. All disabled people do not require special needs. These special needs vary in relation to their impairment, and the environment they live in. According to newly developed CBR matrix, there are 5 components of CBR and out of 5, 4 are basic needs health, education, livelihood and social goal. The 5th component is Empowerment which is the process - you need to empower the disabled people and their families to ensure that they can access health, education, livelihood and social opportunities and defend it equally. So they can be included in the society and all social activities as an equal member. That way we can remove the stigmas and barriers that are really common in all parts of the world. If any CBR practice follow these basic components, I think there will be good changes to people’s lives and it will promote the concept of inclusive development.”

---

### Empowerment through self-help groups and DPOs

“One rehab worker set up a support group for those with a spinal injuries. After talking with the 13 members of the group about accessibility and barriers in the community, many of the members reported problems with using ATMs. All the ATM machines in the town were too high for wheelchair users to access and they often had to rely on others to withdraw money for them. This left many with a loss of independence and frequent abuse of family members stealing their cash. Firstly as a group they wrote a letter to the Councillor informing him of the situation. After that the rehab worker went to the bank along with members of the paraplegic group to speak to the bank manager. The meeting was very successful and as a result they now have an accessible ATM in the town for all wheelchair users!”

Local SA NGO employee

“In South Africa many of the rehab workers we’ve trained have helped develop differing DPOs. In one DPO group in KwaZulu Natal, after
receiving training in advocacy and lobbying decided to tackle the issue of local inaccessibility by holding a march through the community. As a result of that march, much has changed e.g. local shop keepers have improved physical access to their premises and have also employed people with disabilities.”

Local SA NGO employee

<table>
<thead>
<tr>
<th>CBR worker</th>
</tr>
</thead>
<tbody>
<tr>
<td>“The biggest limitation to the future design of the CBR strategy is with regards clarity surrounding the training of mid-level rehab workers. From my experience the CBR strategy gives no clear guidelines with regards their training which has meant in many countries mid-level workers are either not recognised or confusion abounds over their role within a multidisciplinary team setting. Furthermore, the strategy currently perceives mid-level rehab workers often to be volunteers or parents of children with disabilities. Given the current global economic climate i.e. increasing fuel and food costs, I feel its unrealistic to expect people to work for free…also its not good for personal self-esteem to train individuals then expect them to work for free!”</td>
</tr>
<tr>
<td>Local SA NGO employee</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Role of INGOs</th>
</tr>
</thead>
<tbody>
<tr>
<td>“To make people aware on both sides of the developing world and the developed world that CBR is a grassroots strategy where people can get their dues even in far off areas from the cities through CBR. In many developing worlds these international or even national policies remain on paper, they do not get implemented until there is a movement of people and their organizations within the country. INGOs can strengthen such activities to ensure disabled people and their organizations are empowered enough, united enough to enforce the laws and policies gets implemented and benefit reaches to the majority.”</td>
</tr>
<tr>
<td>International health agency employee</td>
</tr>
</tbody>
</table>
Appendix 7 CBR Interview Form

CBR Interview

Study Title: What is the effectiveness of Community Based Rehabilitation in improving the wellbeing of people with disabilities in Sub-Saharan Africa?

Investigator Name:

“Hello, My name is _________ and I will be conducting this interview regarding the topic of effectiveness of Community Based Rehabilitation (CBR) in Sub-Saharan Africa. If you have not already read the information form and signed the consent form please do so now. I want to remind you that all of your responses are confidential, and your name will not be used in my report. The interview should take up to 1 hour of your time. I will be recording our interview and later will transcribe the notes. Prior to using any quotes in my thesis, I will request your authorization. Please feel free to ask me questions throughout and/or request the interview to be stopped. Thank you again for consenting to meet with me and for providing your time towards my research.”

1. What is your professional title and role within the field of CBR?

“Though the World Health Organization introduced the concept of CBR in the early 1980s, there appears to be a consensus in the field about a need of international uniformity as evidenced by the Joint Position Statement.”

2. Why do you agree or disagree with this statement regarding the concept of CBR?

3. How do you anticipate the development of the future WHO/UNESCO/ILO CBR guidelines will impact CBR in the developing country field?

4. What are the greatest strengths and limitations to the future design of this international inclusive disability strategy?

“In addition to a need of uniformity, there seems to be a need to develop a broader CBR evidence-based practice in the field. The following set of questions will be about CBR strategy evaluation.”

5. Have you been involved in the evaluation of effectiveness of CBR? If yes, please describe in what capacity.

6. What can be done to enable a wider CBR evidence-based practice?

“Next, I will ask you specific questions examining the barriers and strengths of CBR design, development and implementation. Please provide the answers based up your specific experiences with CBR professionally in the field. If possible, please answer from experiences of CBR with adults who have physical disabilities in Sub-Saharan Africa.”
7. What are the indicators of successful CBR development and design? Please state with specific examples.

8. What are the greatest challenges in CBR development and design? Please state with specific examples.

9. What are the indicators of successful CBR delivery and implementation? Please state with specific examples.

10. What are the greatest challenges in CBR delivery and implementation? Please state with specific examples.

“The following questions will be about CBR policy support and development by countries and INGOs. If your CBR experiences are in Sub-Saharan Africa, please provide specifics about these regions.”

11. How is CBR supported by international and national policies (i.e., at Local, District, National levels)?

12. What is your view of the INGO role within CBR?

13. How can INGOs influence CBR policy development and delivery?

“The next questions will be about CBR as an inclusive development policy regarding empowerment, one of the five specific domains in the CBR Matrix. Under the domain of empowerment, there are five components listed: Social Mobilization, Political Participation, Communication, Self-help groups, and Disabled People’s Organizations (DPOs). Once again, if your CBR experiences are in Sub-Saharan Africa, please provide specifics about these regions.”

14. What are the key components of successful CBR empowerment strategies?

15. What are the challenges to CBR empowerment strategies?

Finally, I will conclude with a few general questions regarding your perspective of CBR in the next decade. Please feel free to ask me any questions following my two questions.

16. In the next decade, what do you envision as the key components for CBR strategy?

17. What is your hope for future CBR development over the next 10 years?

“Thank you very much for your participation in my research. I really appreciate your time and effort. If you have any answers that you want to amend, please let contact me either via email (______________) or via my UK mobile __________. I will contact you once I have reviewed the interview data regarding any possible quotations I might use in my thesis. Thank you again!”
### Appendix 8 CBR Interview themes

<table>
<thead>
<tr>
<th>THEME AREAS</th>
<th>QUESTIONS</th>
<th>PROBES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>What is your professional title and role within the field of disability?</td>
<td></td>
</tr>
<tr>
<td>CBR concept</td>
<td>Why do you agree or disagree with this statement regarding the concept of CBR?</td>
<td>What are the greatest strengths and limitations to the future design of this international inclusive disability strategy?</td>
</tr>
<tr>
<td></td>
<td>How do your anticipate the development of the future WHO/UNESCO/ILO CBR guidelines will impact CBR in the developing country field?</td>
<td></td>
</tr>
<tr>
<td>CBR evidence-based practice</td>
<td>How is the effectiveness of CBR measured?</td>
<td>What can be done to enable a wider CBR evidence-based practice?</td>
</tr>
<tr>
<td>Barriers and strengths of CBR design, development and implementation</td>
<td>What are the indicators of successful CBR development and design? Please state with specific examples.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What are the greatest challenges in CBR development and design? Please state with specific examples.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What are the indicators of successful CBR delivery and implementation? Please state with specific examples.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What are the greatest challenges in CBR delivery and implementation? Please state with specific examples.</td>
<td></td>
</tr>
<tr>
<td>CBR policy support and development by countries and INGOs</td>
<td>How is CBR supported by international and national policies? (ie: at Local, District, National levels)</td>
<td>How can INGOs influence CBR policy development and delivery?</td>
</tr>
<tr>
<td></td>
<td>What is your view of the INGO role within CBR?</td>
<td></td>
</tr>
<tr>
<td>Inclusive development policy regarding empowerment</td>
<td>What are the key components of successful CBR empowerment strategies?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What are the challenges to CBR empowerment strategies?</td>
<td></td>
</tr>
<tr>
<td>Future of CBR</td>
<td>What do you envision as the key components for CBR strategy?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What is your hope for future CBR development over the next 10 years?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 9 Information Sheet and Consent Form

Information Sheet

Study Title: What is the effectiveness of Community Based Rehabilitation in improving the wellbeing of people with disabilities in Sub-Saharan Africa?

Investigator Name: ____________________________

Contact Details: __________@lshtm.ac.uk
Mobile – ___________

My research is being undertaken as part of a Masters’ degree in Public Health (Health Promotion). The overall aim of my study is to examine the effectiveness of Community Based Rehabilitation (CBR) strategy in the Sub-Saharan Africa region for adults with disabilities and make recommendations to a NGO for future policy design. This is important given that most of the estimated 650 million people living with disabilities around the world lack access to appropriate medical care and rehabilitation services, especially those in low-income and middle-income countries. Without access to services, people with disabilities are unable to develop their abilities and learn compensatory strategies necessary to lead more independent and productive lives. Given that many NGOs use this strategy to implement disability programming, I want to examine the effectiveness of CBR as a strategy for improving the wellbeing of people with disabilities in SSA and make recommendations for future policy changes. I am requesting your cooperation as part of my research project given your knowledge of CBR strategy design, development and implementation.

Your participation in my research is entirely voluntary and withdrawal is possible at any time without having to give a reason. There will be no financial compensation for your time. Your information will only be used for my research project, and I will maintain your confidentiality throughout. Your name will remain anonymous throughout the final report. You will have an option in the consent form to indicate your preference of use for direct quotations. Quotes will only be included if you agree and authorize the quote prior to inclusion in the paper. I will be collecting your answers via note taking and tape recording. I am willing to work with your schedule and comfort level regarding the questions asked. Please inform me if you would like to skip or not answer a question during the interview. Additionally, you may contact me at any time after the interview to withdraw any of the information you provided. The LSHTM ethics committee has approved this study.
Consent Form

Study Title: What is the effectiveness of Community Based Rehabilitation in improving the wellbeing of people with disabilities in Sub-Saharan Africa?

Investigator Name: ________________________

Contact Details: ___________@lshtm.ac.uk
Mobile phone –
Fax - +44 (0)20 7436 5389
[please specify ____________ MSc PH]

"I have read the information sheet concerning this study [or have understood the verbal explanation], and I understand what will be required of me and what will happen to me if I take part in it. My questions concerning this study have been answered by __________. I understand that at any time I may withdraw my information from this study without giving a reason and without affecting my normal care, management and professional standing. I agree to take part in this study."

Please tick the appropriate box:
  o Do not use any direct quotes from my interview.
  o Any of my quotes need to be authorized by me prior to use in the research paper.

Signed ........................................... Date ...........................................

Witnessed by ................................. Date ...........................................
Appendix 10 Ethics Form

London School of Hygiene & Tropical Medicine

Ethics application form: MSc research project (MSC1)

<table>
<thead>
<tr>
<th>Name:</th>
<th>473180</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSc Course:</td>
<td>MSc Public Health (Health Promotion, Tutor Group 4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Email:</th>
<th>@lshtm.ac.uk</th>
</tr>
</thead>
</table>

Supervisor Approval:
The application must be approved, especially for local acceptability, by the supervisor before it is submitted to the Ethics Committee.

Name …Karen Lock……………………..
Email …Karen.Lock@lshtm.ac.uk……….

Signature of Supervisor
.................................................................

Note for students:
- Please read the Policy and Procedure document and guidance notes at [http://intra.lshtm.ac.uk/reference/ethicsstuds.html](http://intra.lshtm.ac.uk/reference/ethicsstuds.html) before completing this form. This will help avoid delays in processing your application.
- Forms must be typewritten. Handwritten forms will be returned.
- Please answer either Section 1 or Section 2. Ensure the box for use of Ethics Committee remains on the form.

Please answer either Section 1 or Section 2.
Typewritten forms only - handwritten forms will be returned.

<table>
<thead>
<tr>
<th>For use of Research Ethics Committee</th>
</tr>
</thead>
<tbody>
<tr>
<td>No ........................................</td>
</tr>
<tr>
<td>Approved by ............................</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall assessment of quality of ethical application</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Excellent ☐ Good ☐ Satisfactory</td>
</tr>
</tbody>
</table>

Comment by Ethics Committee .................................................................

Section 1 – If your project is going to use only data, biological samples or datasets already collected in another study.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Project title:</td>
</tr>
<tr>
<td>2.</td>
<td>Ethics Committee that approved that original study - and number if LSHTM.</td>
</tr>
<tr>
<td></td>
<td>(Expand box to answer)</td>
</tr>
<tr>
<td>3.</td>
<td>a) Will your analyses be for purposes not covered by the original application detailed above?</td>
</tr>
<tr>
<td></td>
<td>YES/NO</td>
</tr>
<tr>
<td></td>
<td>b) If YES, please indicate how you will obtain permission to use the data.</td>
</tr>
<tr>
<td>4.</td>
<td>Brief summary of purpose and methods of other study</td>
</tr>
<tr>
<td></td>
<td>(max 100 words)</td>
</tr>
<tr>
<td>5.</td>
<td>Brief summary of your project, giving purpose, methods, numbers of participants and procedures to be performed.</td>
</tr>
<tr>
<td></td>
<td>See Guidance notes at <a href="http://intra.lshtm.ac.uk/reference/ethicsstuds.html">http://intra.lshtm.ac.uk/reference/ethicsstuds.html</a></td>
</tr>
<tr>
<td></td>
<td>(max 200 words)</td>
</tr>
<tr>
<td>6.</td>
<td>Does project involve:</td>
</tr>
<tr>
<td></td>
<td>a) analysis of documentary data already collected</td>
</tr>
<tr>
<td></td>
<td>YES/NO If yes, specify analyses briefly</td>
</tr>
<tr>
<td></td>
<td>b) analysis of the results of tests on biological material already collected</td>
</tr>
<tr>
<td></td>
<td>YES/NO If yes, specify tests</td>
</tr>
<tr>
<td>7.</td>
<td>Specify how confidentiality will be maintained. When small numbers are involved, indicate how possible identification of individuals will be avoided.</td>
</tr>
<tr>
<td></td>
<td>Guidance notes at <a href="http://intra.lshtm.ac.uk/reference/ethicsstuds.html">http://intra.lshtm.ac.uk/reference/ethicsstuds.html</a></td>
</tr>
</tbody>
</table>
Section 2: If your project is completely new or is collecting any new data from a previous study:

### Project Title
What is the effectiveness of Community Based Rehabilitation in improving the wellbeing of people with disabilities in Sub-Saharan Africa?

### Give an outline of the proposed project. Sufficient detail must be given to allow the Committee to make an informed decision without reference to other documents.

Most of the estimated 650 million people living with disabilities around the world lack access to appropriate medical care and rehabilitation services, especially those in low-income and middle-income countries. Without access to services, people with disabilities are unable to develop their abilities and learn compensatory strategies necessary to lead more independent and productive lives. Community Based Rehabilitation (CBR) is a strategy that was promoted in the early eighties by World Health Organization (WHO) and other United Nation (UN) agencies. The aim initially was to improve access to rehabilitation services for people who have disabilities in developing countries. CBR programs eventually shifted from a more medical model to a more comprehensive approach, focusing holistically upon the context of people's lives living with a disability including education, vocational training, social rehabilitation and prevention interventions. This ensured increased community participation, opportunities, equalized rights and promoted social acceptance. INGOs implement CBR programming in various countries, including Sub-Saharan Africa (SSA). The aim of my project is to examine the effectiveness of CBR strategy in the Sub-Saharan Africa region for adults with disabilities and make recommendations to INGOs for future policy design. Initially, I will conduct two literature reviews for my research examining the effectiveness of CBR in developing countries and CBR's impact and application in Sub-Saharan Africa. Additionally, I plan to conduct key informant interviews examining successes and barriers in the design, development and implementation of CBR. Finally, after assimilating this information, I will provide recommendations to INGOs for improving CBR strategy in Sub-Saharan Africa.

### Is project a randomised trial?
YES/NO

### Will any biological samples be collected and if so specify which
5. Specify the number (with scientific justification for sample size), age, gender, source and method of recruiting subjects for the study.

3-5 Informant interviews will be conducted. One interview will be with a female professor. She has extensive publications and experience working for and with people with disabilities in many different African countries. Other interviews will include contacts at the head office of an INGO and a contact in Africa who implements NGO CBR programming. These interviews and others will be recruited by me via email and phone.

6. State the likely duration of the project, and where it will be undertaken.

Likely duration will be about 2 months from mid-late June until mid-late August. The literature review will be conducted in London. Informant interviews will be conducted via phone and potentially in France and in England.

7. State the potential distress, discomfort or hazards, and their likelihood, that research subjects may be exposed to (these may include physical, biological and/or psychological hazards). What precautions are being taken to control and modify these hazards?

There are no potential physical or biological hazards or danger involved in my informant interviews. The interviewees will only encounter psychological distress and discomfort if they have schedule constraints and/or are uncomfortable with the line of questioning. If this occurs, the interview can be rescheduled, and questions will be omitted at the request of the interviewee. If appropriate, alternate questions will be used.

8. Specify how confidentiality will be maintained. When small numbers are involved, indicate how possible identification of individuals will be avoided.

Confidentiality will be honoured and maintained throughout the interview. The interviewees will be anonymised in the final report but due to small numbers they will have the option for any direct quotations to be included or omitted in the report.

9. State the manner in which consent will be obtained and supply copies of the information sheet and consent form.

Written consent is normally required. Where not possible, explain why and confirm that a record of those giving verbal consent will be kept.
Where appropriate, please state if and how the information and consent form will be translated into local language(s).

See information and consent form attached. Consent will be obtained either in person or over the phone for the interviewees. Written consent will be obtained for the in person interviews, and electronic consent with printed email confirmation will be obtained for the phone interviews.

10. Local Ethical Approval. Give details of local approval to be obtained prior to the commencement of fieldwork. (If you cannot identify an Ethical Committee or if the study has been approved by several different organisations, eg. NGOs, give this information and show that as much as possible has been done to obtain approval.)

The only ethical approval I will require will be LSHTM ethics committee approval. Local ethical approval is not required for my informant interviews.
Appendix 11 Project Protocol

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE
MSc Public Health

Project Protocol 2007-2008

<table>
<thead>
<tr>
<th>CANDIDATE NAME: 473180</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSc Public Health</td>
</tr>
<tr>
<td>Stream: Health Promotion</td>
</tr>
</tbody>
</table>

If you are a Half-time student please indicate whether this is your 1st or 2nd year of study: N/A

<table>
<thead>
<tr>
<th>PROJECT TYPE: Health Policy Report</th>
</tr>
</thead>
<tbody>
<tr>
<td>TITLE OF PROJECT:</td>
</tr>
<tr>
<td>What is the effectiveness of Community Based Rehabilitation in improving the wellbeing of people with disabilities in Sub-Saharan Africa?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BACKGROUND:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of the estimated 650 million people living with disabilities around the world lack access to appropriate medical care and rehabilitation services, especially those in low-income and middle-income countries. 1 Without access to services, people with disabilities are unable to develop their abilities and learn compensatory strategies necessary to lead more independent and productive lives. 1 Community Based Rehabilitation (CBR) is a strategy that was promoted in the early eighties by World Health Organization (WHO) and other United Nation (UN) agencies. The aim initially was to improve access to rehabilitation services for people who have disabilities in developing countries. CBR programs eventually shifted from a more medical model to a more comprehensive approach, focusing holistically upon the context of people’s lives living with a disability including education, vocational training, social rehabilitation and prevention interventions. 2 This ensured increased community participation, opportunities, equalized rights and promoted social acceptance. 2 In 2008 WHO is expected to publish guidelines for CBR programs. 1</td>
</tr>
<tr>
<td>INGOs implement CBR programming in various countries, including Sub-Saharan Africa (SSA) with the aim to help people with disabilities worldwide. INGOs implement and support many CBR programs in developing countries dealing with health, prevention, rehabilitation, social and economic inclusion. 3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AIMS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>To examine the effectiveness of CBR strategy in the Sub-Saharan Africa region for adults with disabilities and make recommendations to an INGO for future policy design.</td>
</tr>
</tbody>
</table>
OBJECTIVES:
To conduct literature reviews on effectiveness of CBR in developing countries.
To examine CBR’s impact and application in Sub-Saharan Africa.
To conduct key informant interviews examining successes and barriers in the design,
development and implementation of CBR.
To provide recommendations to INGOs for improving CBR strategy in Sub-Saharan Africa.

METHODOLOGY:
I will utilize qualitative research methods of literature reviews and informant interviews to
gather necessary information. First, I will conduct a literature review examining the
effectiveness of CBR on improving quality of life for adults who have disabilities in
developing countries. I will utilize WHO’s disability website, UN disability policies,
*Disability and Rehabilitation Journal* and *International Journal of Rehabilitation Research*
over the last 3-5 years. I will use the articles and references of articles found on the databases
Pub Med, Medline, Athens and JStor. I also will use databases specific to developing
countries, including African Healthline, Eldis, EMBASE, Global health/global health
archives, Popline and Web of Science. In completing my pilot search, I used the terms
“rehabilitation,” “CBR,” “employment,” “social inclusion,” “rights,” “community
participation,” “disability,” and “developing countries.”

Additionally, I will conduct a second literature review examining the application of CBR in
SSA. In this descriptive literature review, I will examine the application of CBR in SSA
evaluating the impact of practical policies and programs. I will utilize books, the internet,
expert and NGO contacts, and literature reviews from the databases listed above using the
search terms “rehabilitation,” “CBR,” “employment,” “social inclusion,” “rights,”
“community participation,” “disability,” “programming,” “NGO,” and “Sub-Saharan Africa.”

Finally, I will conduct 3-5 informant interviews examining barriers and strengths of CBR
design, development and implementation. This will include information regarding national
disability policies, government healthcare versus NGO programming, and client engagement.
One interview will be with _____ a professor. She has extensive publications and experience
working for and with people with disabilities in many different African countries. Other
interviews will include a contact at the head office of an INGO and a contact in Africa who
implements NGO CBR programming.

ETHICAL CONSIDERATIONS:
I will be collecting primary data information by conducting informant interviews so will need
to submit for LSTHM ethics approval. My interviews will be conducted with specialists in
the field of CBR to obtain information surrounding CBR design, development and
implementation in Sub-Saharan Africa. I am submitting my LSHTM ethics approval form
with my final proposal in March. Additionally, I will be submitting the required risk
assessment. I hope to obtain approval by mid-June so that I can complete my interviews to
supplement literature review information. If approval is not obtained in time I will complete
my health policy report using literature reviews only.
FEASIBILITY ISSUES:
There are a few issues that will affect the feasibility of my summer project policy report. Though I have found a book and systematic reviews of CBR’s strategy, I recognize that there is limited information available due to growing interest in the field and increased recognition of CBR programming. WHO has been promoting CBR since the eighties, however qualitative evidence-based research in the field remains limited. Additionally, I recognize the challenge of collecting and using gray literature. This information lacks strict editorial and bibliographic control which raises questions about authenticity and reliability. While conducting my informant interviews, I will be subjected to ethics approval and my interviewee’s schedule constraints. I plan to conduct my interview with my NGO contact in Africa via phone, while I hope to conduct my interviews in person with the professor and my contact at the head office of an INGO. If my interviews are not conducted, I will complete my health policy report by literature review only.

REFERENCES:

IMPORTANT NOTES:
Draft Protocol
You should submit ONE electronic copy of the draft protocol to your Tutor Group Administrator. The deadline for this draft is no later than 12 noon Friday 22nd February 2008.

Final Protocol
You should submit TWO signed hard copies and ONE electronic copy of your final protocol to your Tutor Group Administrator. Both hard copies should be signed by you and your tutor. The deadline for this draft is no later than 12 noon Thursday 20th March 2008. You should retain an electronic copy of your final protocol as an anonymised version needs to be inserted as an appendix in your final project report. ALL projects require a Risk Assessment, and you must submit a signed Risk Assessment Form with your final protocol. You cannot start off-site work on your project until risk assessment has been signed off. The Risk Assessment Form can be downloaded from the LSHTM intranet http://intra.lshtm.ac.uk/safety/tcsform.doc Depending on the nature of your project you may also require Ethical Approval from LSHTM and elsewhere. If so, then you must submit a request for Ethical Approval. You are strongly advised to submit your ethics application as early as possible. One hard copy of the ethics form should be submitted to Gemma Howe (Room 11, 8 Bedford Square) by Friday 21st March 2008. An electronic version in MS-word format should also be sent to ethics@lshtm.ac.uk by the same deadline. This will help the Ethics Committee deal with the heavy workload due to MSc projects and will reduce the need for hurried, last minute applications, which can be particularly difficult. All ethics forms must be typed. http://intra.lshtm.ac.uk/reference/guides/msc1-sept07.doc

Signature of student…………………………………………………Date……………………………

Signature of tutor…………………………………………………….Date……………………………
Appenidix 12 Risk Assessment Form

TAUGHT COURSE STUDENT PROJECT RISK ASSESSMENT FORM

1. This summary and assessment must address all planned aspects of the student project.
2. The student, in conjunction with the project supervisor, must complete both pages of the assessment.
3. Sufficient detail should be provided so that the location of the project is clear. i.e. Give more detail than just “London” in answer as to where the project is to be carried out.
4. Projects involving biological, chemical and radiological hazards must be referred to the Departmental Safety Supervisor.
5. Itineraries and contact details for projects involving work overseas must be lodged with the Teaching Office before the work starts.
6. This summary must be completed and all signatures obtained before work is started.
7. A copy of the completed form must be held by the Course Organiser, and retained for two years.

Full Name of Student 473180
Course MSc Public Health (Health Promotion)
Project Supervisor Karen Lock
Project Title What is the effectiveness of Community Based Rehabilitation in improving the wellbeing of people with disabilities in Sub-Saharan Africa?
Summary of project aims To examine the effectiveness of CBR strategy in the Sub-Saharan Africa region for adults with disabilities and make recommendations to a NGO for future policy design.
Where will the project be carried out? London for literature reviews. Informant interviews via phone, email and in France and England.
Will the project involve work overseas? No
If yes, where?
Will the project involve significant work away from LSHTM sites? If yes, where? No
Does the project involve work with pathogenic organisms / human blood / radiochemicals? No

If the Project involves work overseas:

Will the project be based in an established field station / research institute? If yes, where?
Is ethical approval required for the project? If yes, has it been granted?
What supervision arrangements are proposed while away from LSHTM?
Give the contact details for the off-site supervisor where applicable
Will the project involve lone / isolated work? If yes, state how you can contacted while working.
Has appropriate travel insurance been arranged?

If the Project involves significant work within the U.K., away from the LSHTM sites in London:

Will the project be based in an established college / hospital etc? If yes, where?
Is ethical approval required for the project? If yes, has it been granted?
Will the project involve home / personal visits?
Will the project involve lone / isolated work?
<table>
<thead>
<tr>
<th>What supervision / contact arrangements are proposed while away from LSHTM?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>If Project Involves work with Pathogenic Organisms, Human Blood or Radiochemicals: (form to be signed by Departmental Safety Supervisor *)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Organism/s to be used</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential Routes of Infection</td>
<td></td>
</tr>
<tr>
<td>Radiochemical/s to be used</td>
<td></td>
</tr>
<tr>
<td>Laboratories where work with pathogens / radioisotopes will be carried out</td>
<td></td>
</tr>
<tr>
<td>Disinfectants/Disposal</td>
<td></td>
</tr>
<tr>
<td>Health Surveillance required</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Additional Information:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Are there any special needs, disability-related issues or other concerns that may need to be taken into account?</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do these need to be considered in planning arrangements?</td>
<td>No</td>
</tr>
<tr>
<td>Do these need to be considered in relation to the location of the project?</td>
<td>No</td>
</tr>
<tr>
<td>Do they impact on supervision arrangements?</td>
<td>No</td>
</tr>
<tr>
<td>Do arrangements for access to specialist medical treatment need to be considered?</td>
<td>No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Student Signature</th>
<th>.................................................................</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervisor Signature</td>
<td>.................................................................</td>
<td>Date</td>
</tr>
<tr>
<td>M.Sc. Course Organiser Signature</td>
<td>.................................................................</td>
<td>Date</td>
</tr>
<tr>
<td>Departmental Safety Supervisor (only required if project involves work with pathogens or radiochemicals)</td>
<td>.................................................................</td>
<td>Date</td>
</tr>
</tbody>
</table>

I agree to comply with the relevant safety requirements
I agree that this is a reasonable summary of the project
I agree that this project may proceed