



FROM EXCLUSION TO INCLUSION
PROMOTING THE RIGHTS OF CHILDREN
WITH DISABILITIES IN MALAWI



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of Malawi

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FROM EXCLUSION TO INCLUSION

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“Disability is not inability therefore they should not regard us as failures because we can do anything”

Female secondary school student,
focus group discussion participant



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FOREWORD

“As a democratic society, Malawi has a moral obligation to ensure that each and every injustice, whether through acts of commission or mission, is met with deliberate and tangible action. An inclusionary approach is essential to sustainable development, which must be development for all.”

These words from Her Excellency Dr Joyce Banda’s address at the Global Development Summit in Korea in January 2013, aptly sums up the moral duty we all have to address the needs and rights of children with disabilities in Malawi.

As we launch this report, “From Exclusion to Inclusion: Promoting the Rights of Children with Disabilities”, both the Ministry of Disability and Elderly Affairs and UNICEF Malawi are building on a vision of inclusion, but also recognising that as duty bearers we have much work to do.

We are proud to be launching this situation analysis together, for in doing so we aim to draw attention to the important information and recommendations contained inside. We hope that all those reading this report will recognize that children with disabilities and their families are too often invisible in statistics, policies and our society. We hope it will encourage all those involved in data gathering to ensure they are including people with disabilities in their surveys and questionnaires, and designing those tools appropriately. By counting all of our citizens, especially the most vulnerable, and hearing their voices we can begin to build truly inclusive societies.

Equally true, whilst the analysis commends the strong legal framework in the form of the landmark Disability Act, much more needs to be done to implement these bold legal instruments and ensure inclusion is not just a word, but a reality for children and families with disabilities.

We recognise that many of the recommendations contained here cannot be realised in the short term, but we hope that this report marks a starting point for renewed energy and a clear roadmap of actions, that can pave the way to improving the lives of children with disabilities, and as a result improving society as a whole.

The words of the UNICEF Executive Director, Tony Lake, sum up the vision for all of us involved with children and protection of rights for those with disabilities.

“Is there not a child who does not dream of being counted and having her or his gifts and talents recognized? No. All children have hopes and dreams – including children with disabilities. And all children deserve a fair chance to make their dreams real.”

Hon. Reen Kachere (MP)
Minister for Disabilities and Elderly Affairs

Mr. Mahimbo Mdoe
Representative, UNICEF Malawi

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ACRONYMS AND ABBREVIATIONS

| | |
|---------|--|
| APDM | Association for the Physically Disabled in Malawi |
| CBCC | Community-based childcare centre |
| CBR | Community-based rehabilitation |
| CRC | Convention on the Rights of the Child |
| CRPD | Convention on the Rights of Persons with Disabilities |
| CSR | Centre for Social Research |
| DPO | Disabled People's Organization |
| DSWO | District Social Welfare Officer |
| ECD | Early childhood development |
| FEDOMA | Federation of Disability Organizations in Malawi |
| GoM | Government of Malawi |
| ICF | International classification of functioning, disability and health |
| ICT | Information and communication technology |
| MACOHA | Malawi Council for the Handicapped |
| MADISA | Malawi Disabled Sports Association |
| MANAD | Malawi National Association for the Deaf |
| MAP | Malawi Against Physical Disabilities |
| MGDS | Malawi Growth and Development Strategy |
| MoEST | Ministry of Education, Science and Technology |
| MoGCSW | Ministry of Gender, Children and Social Welfare |
| MoDEA | Ministry of Disability and Elderly Affairs |
| MoH | Ministry of Health |
| MoYS | Ministry of Youth and Sports |
| MUB | Malawi Union for the Blind |
| NACCODI | National Coordinating Committee on Disability Issues |
| NAD | Norwegian Association for the Disabled |
| NESP | National Education Strategic Plan |
| NGO | Non-governmental organization |
| NSO | National Statistical Office |
| OPC | Office of the President and Cabinet |
| OSISA | Open Society Initiative for Southern Africa |
| PODCAM | Parents of Disabled Children Association in Malawi |
| SNE | Special needs education |
| SRF | Sue Ryder Foundation |
| TAAM | The Albino Association of Malawi |
| ToR | Terms of reference |
| UNICEF | United Nations Children's Fund |
| WHO | World Health Organization |
| WHS | World Health Survey |



EXECUTIVE SUMMARY

Why a study on children with disabilities?

While general disability studies have been done in Malawi, little is known specifically about children with disabilities. This study examined (i) the availability of data on children with disabilities; (ii) the challenges facing children with disabilities and their caretakers; (iii) interventions to address these challenges; and (iv) the extent to which existing policies and legislation incorporate issues relevant to children with disabilities. Results of this study will inform policy and programming.

Methodology

The study was done in Balaka, Karonga, Lilongwe and Nsanje Districts. Existing studies, policies and legislation were reviewed. The following focus group discussions and in-depth interviews were then conducted: 78 key informant interviews at national, district and community levels; in-depth interviews with 24 boys and 19 girls with different types of disabilities; in-depth interviews with 40 parents who had children with disabilities and 40 parents who themselves had disabilities; in-depth interviews with 39 children of parents with disabilities; and 14 focus group discussions with children with disabilities. The group discussions were done at community level and in institutions. At community-level the discussions were held separately for males and females while in institutions they were mixed.

Results

Legislative and policy framework for children with disabilities

Malawi has signed and ratified both the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Rights of the Child (CRC). At national level, the relevant legislation relating to children with disabilities are the Constitution (1995), the Child Care, Protection and Justice Act (2010) and the Disability Act (2012). Together these provide an adequate legal framework for the care, protection and development of children with disabilities. The Disability Act in particular incorporates provisions of the CRC and the CRPD. However, the legislation is not being implemented fully. There is outdated legislation in the form of the 1971 Handicapped Persons Act, but this is charity-based and is not aligned with current rights-based approaches. Despite the generally good legal environment, government funding for the disability sector is low: the Ministry of Disability and Elderly Affairs (MoDEA) receives only about 0.07% of the national budget.

An analysis of policies

Disability issues are not seen as high priority – for instance, children with disabilities are mentioned only once in the current Malawi Growth and Development Strategy (MGDS II). While the National Policy on Equalisation of Opportunities for Persons with Disabilities is good, it does not identify strategies to deal with the particular challenges experienced by children with disabilities, and the policy itself needs review. The National Education Strategic Plan (NESP) and other education policies promote an enabling environment for children with disabilities in conventional schools. The National Policy on Early Childhood Development does not specifically mention children with disabilities. There are other relevant policies in place, such as the National Policy on Orphans and Other Vulnerable Children (although this does not consider children with disabilities as vulnerable), the National Sports Policy (which promotes the participation of all people in sport regardless of disability) and the National Youth Policy (which encourages the provision of sports facilities to young people with disabilities). However, lack of implementation of all these policies is a major challenge.

Data on children with disabilities

The 2008 Malawi Housing and Population Census found that the prevalence of disability among children was lower at 2.4% (159,878) than among the general population at 3.8% (498,122). Prevalence was slightly higher among males at 2.5% (84,721) than females at 2.2% (75,157). The most common form of disability was hearing loss (23%) followed by visual impairment (17%), mobility problems (16%) and communication difficulties (9%). All other forms of disability were classified as 'other' and they constituted 35% of children with disabilities. The Northern Region had the highest prevalence of disability among children (3.3%), followed by Central (2.5%) and Southern (2.0%). Most forms of disability found in this study were either present at birth or were caused by illness.

Common challenges faced by children with disabilities

Healthcare

For various reasons, it is difficult for children with disabilities to access health services. There is a lack of appropriate transport for those with restricted mobility, and health workers may discriminate against such children. Children with impaired hearing find it hard to communicate with health workers. This situation may be aggravated by the absence of guardians and poor access to health education messages in appropriate formats, such as braille for the visually impaired. The gross shortage of drugs, especially for diseases such as epilepsy, makes the situation worse. Some parents are negligent and do not seek healthcare for their children with disabilities when they are ill. Access to sanitation for children with disabilities is often a challenge, especially for those with restricted mobility and those who cannot bathe on their own.

The government in theory provides assistive devices and healthcare to all Malawians, including children with disabilities, but in practice children with disabilities cannot access all the support they need.



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Education

Most children with disabilities, especially girls, are likely to be out of school, as preference is given to boys. Those in school face a number of difficulties. Most school environments are not 'disability-friendly' (for example poor access to sanitation facilities, especially for those using wheelchairs and the visually impaired), and there is a critical shortage of specialist teachers. Many parents cannot afford to pay for school fees and learning materials. There is a lack of assistive devices and assistants for children with mobility disabilities, and examination systems are unfair and discriminatory. While parents and relatives do their best to ensure that their children are in school, they often simply lack the time and resources to do this.

There are many initiatives aiming to make the school environment conducive to effective learning by children with disabilities. They include free education, training special education teachers, providing special-needs education and establishing resource centres in conventional schools. There is now a Directorate of Special Needs Education within the Ministry of Education, Science and Technology (MoEST), and a directive that all schools should be disability-friendly. The Malawi Council for the Handicapped (MACOHA) has a community-based rehabilitation programme that has improved access to education. However, efforts by both parents and the government do not yet meet all the needs of children with disabilities.

Access to skills development and employment

Major challenges in skills development include inadequate capacity for vocational training, a lack of awareness of these training programmes, and the fact that most children with disabilities do not meet the entry requirements. These challenges are exacerbated by the lack of resources. Some employment opportunities are not open to some types of disabilities. If children with disabilities are employed, they are at risk of economic exploitation (although child labour is prohibited in Malawi, many children are informally employed).

The government supports skills development for persons with disabilities but more needs to be done.

Socio-cultural challenges

Children with disabilities are usually treated differently from other children, both at home and in the wider community. They tend to be either neglected or over-protected; the situation is worse if they live with guardians or step-parents rather than their biological parents. Children whose parents are disabled face different problems – they work harder and play less than their peers, as they have to care for their parents. They are also more likely to drop out of school. Children with disabilities are often hidden for various reasons: in some cases they are viewed as ‘not children’, because parents think there is nothing they can do or they feel ashamed by them. Another challenge is that children with disabilities are often more or less abandoned after being sent to a special needs education (SNE) institution: parents do not send pocket money or transport money at the end of the term. Depending on the type of disability, children with disabilities may fail to find suitors. Those with hearing impairment and mobility problems find it hard to form relationships.

There is little response to these social challenges. Households respond to these challenges but many others remain.

Challenges faced by parents

Parents of children with disabilities generally take good care of their children. However, in some cases parents lock their children in the house in order to do productive work. Some children may require so much care that the parents are unable to work.

Disabled parents are often unable to provide for their household because their disability prevents them working or because employers discriminate against them. Low levels of education among persons with disabilities also reduce their opportunities of employment.

Institutional analysis

A number of institutions provide services to persons with disabilities. They include government ministries - the Ministry of Gender, Children and Social Welfare (MoGCSW) and the Ministry of Disability and Elderly Affairs (MoDEA) - and departments, including state-sponsored service providers (e.g. the Malawi Council for the Handicapped (MACOHA) and Malawi Against Physical Difficulties (MAP)). Relevant NGOs include the Sue Ryder Foundation and disabled people’s organizations such as the Federation of Disability Organizations in Malawi (FEDOMA) and its affiliates. Services can be categorised as (i) policy formulation, (ii) advocacy, (iii) coordination, (iv) monitoring and evaluation and (v) service-provision.

Overall, children with disabilities find it difficult to access services. Some national institutions, such as the Ministry of Disability, the Ministry of Education and the Malawi Council for the Handicapped are supposed to provide services throughout the country, but poor capacity means that coverage is limited.

Reporting on disability issues

There is no national mechanism to coordinate reporting on disability. At district level, disability issues are dealt with by the district social welfare officers (DSWOs) in the MoGCSW. Although the MoDEA is the line ministry for disability issues, social welfare officers report only to the MoGCSW and reports are not copied to the MoDEA. A similar situation exists in other sectors such as education, with officers from the education ministry reporting only to their own ministry. Stakeholders such as NGOs and organizations of disabled people do not have an obligation to report the disability ministry either. To coordinate activities, the National Coordinating Committee on Disability Issues (NACCODI) needs to be brought into operation as a forum through which stakeholders can share reports. Many stakeholders expressed support for the operationalization of NACCODI. Government-sponsored organizations, such as MACOHA and MAP, report directly to their respective ministries (MoDEA and the Ministry of Health). At district level the disability ministry is invisible, as all disability issues are dealt with by social welfare officers. The disability ministry is also constrained in carrying out its responsibilities because of shortage of staff and low budget allocation. Some stakeholders have the view that having a specific disability ministry is not in the interest of mainstreaming. Others suggested that it should not design and implement programmes but restrict itself to analysing programmes and lobbying on behalf of persons with disabilities.



Recommendations

The recommendations arising from this study have been grouped into short, medium and long-term recommendations.

Short-term Recommendations

Institutional

1. Implement the Disability Act and thereby bring the national coordinating committee (NACCODI) into operation. (MoDEA and stakeholders)
2. Replicate the NACCODI model at district level to help improve disability mainstreaming. (MoDEA)

Legislation and Policy

3. Initiate discussions with the Law Commission to review the 1971 Handicapped Persons Act. (MoDEA and MACOHA)
4. Review all disability-related policies to ensure that the specific needs of children with disabilities are addressed. (MoDEA and stakeholders)
5. Lobby for an increase in budgetary allocation for disability issues. (MoDEA, FEDOMA and MACOHA)
6. Lobby for the inclusion of disability issues in the post-2015 Global Agenda (successor to the Millennium Development Goals). (MoDEA and all stakeholders)

Data and Information

7. Undertake a needs assessment by type of disability to ensure that children with disabilities receive the particular care they need. (MoDEA)
8. Establish a meaningful monitoring system for all resource centres, rehabilitation facilities and skills training programmes. This would provide government with quality data for planning and budgeting purposes. (MoDEA, MACOHA, FEDOMA and its affiliates)
9. Conduct a countrywide survey of disabled people to collect disaggregated data on disability issues. (MoDEA, FEDOMA and MACOHA)
10. Carry out a comprehensive study on children with learning difficulties in order to design effective interventions. (MoEST)
11. Lobby for questions on disability to be included in national surveys. (MoDEA)

Awareness

12. Mount a sustained public awareness campaign on disability issues. (MoDEA, FEDOMA and its affiliates, and MACOHA)

Expansion of Services

13. Expand coverage of resource centres countrywide. (MoEST, through the Directorate of Special Needs Education)
14. Rehabilitate resource centres, SNE institutions and skills training institutions. (MoEST)
15. Train more specialist education teachers to meet the needs of the country. (MoEST)
16. Promote the establishment of community-based childcare centres (CBCCs) to ensure that children with special needs are properly cared for. (MoGCSW)
17. Train CBCC caregivers to understand the needs of children with disabilities and to make early diagnosis of disabilities. (MoGCSW)
18. Provide adequate funding to the MAP and other stakeholders so that they can provide assistive devices to children who need them. (Ministry of Finance)

Medium-term Recommendations

1. Review relevant policies and legislation to ensure that disability issues are understood and addressed. This would include providing disaggregated objectives and strategies for children with disabilities.
2. Establish a Disability Trust Fund.
3. Conduct a functional review of the MoDEA to reinforce the notion that disability issues are cross-cutting and require central coordination.
4. Integrate disability into health policies and plans.
5. Conduct a functional review of MACOHA and review the Handicapped Persons Act.
6. Run aggressive public-awareness campaigns based on proven Communication for Development methodology.
7. Conduct a study to analyse the budgetary allocation for the disability sector in Malawi.

Long-term Recommendations

1. Incorporate disability issues in overarching government policy and strategy documents, particularly the Malawi Growth and Development Strategy.
2. Mainstream disability issues to ensure that every service-provider considers children or people with disabilities.
3. Mount public awareness campaigns to remind people of the need to view children with disability in a positive light.
4. Expand skills and vocational training programmes to accommodate more children with disabilities.



1. INTRODUCTION

1.1 Rationale for the study

There are several international and regional instruments on the rights of children. The most comprehensive (and internationally important) is the Convention on the Rights of the Child (CRC) - Malawi is among the countries that have signed and ratified it. The Convention contains 54 articles that define universal rights, principles and norms for children. It also calls on member states to ensure that children with any kind of disability have access to care and support to live full and independent lives. It calls for activities to strengthen families and communities, including giving them skills to plan and manage the support that will enable orphans and other vulnerable children (including those with disabilities) to achieve their rights. The Convention advocates the protection of children's rights by setting standards in healthcare, and in educational, legal, civil and social services. These standards are benchmarks against which progress in the protection of children's rights can be assessed. There are a number of factors, however, that compromise children's rights in Malawi, including rampant poverty, the HIV and AIDS epidemic, and disability. Malawi has submitted two reports (in 2003 and 2010) on its progress in addressing CRC issues.

Malawi's Constitution states that the provision of social services should not discriminate on the basis of disability or other factors.¹ However, children with disabilities are often less likely to be in school, may face barriers in accessing health care and may be more vulnerable to violence, abuse, neglect and exploitation.² Children with visual and hearing impairments find it difficult to access mainstream schools and health facilities.³ Because of difficulties experienced at home as well as in school, many children become institutionalised, despite policy recommendations that putting children into care should be a last resort. A 2011 survey found 104 childcare institutions in Malawi, at which more than 5,800 children (55% of them boys) were registered.⁴

Few studies in Malawi have looked at access to education and health among people (including children) with disabilities.⁵ Many issues about children with disabilities are not known, although the community-based rehabilitation (CBR) matrix serves as a framework to analyse relevant issues under five themes (education, health, empowerment, social and livelihood). A study⁶ conducted in 2011 also looked at access to services by persons with disabilities based on the CBR themes. It showed that while Malawi was making progress in addressing challenges experienced by disabled people and that there was an appropriate legal and policy environment, challenges remained. A number of recommendations were made but they were not specific to children with disabilities.

1 GoM (1994). The Constitution of the Republic of Malawi (as amended). Lilongwe: GoM.

2 See ToRs as well as UNICEF Malawi Child Protection Strategy 2012-2016.

3 MoGCSW and UNICEF (2011). Child care institutions in Malawi. Lilongwe: UNICEF.

4 MoGCSW and UNICEF (2011). Ibid.

5 Loeb, M. and A.H. Eide (2004). Living conditions of people with activity limitations in Malawi. Oslo: SINTEF.

6 Munthali, A.C. (2011). A situation analysis of people with disabilities in Malawi. Oslo: NAD; Pretoria: Secretariat for the African Decade for people with Disabilities and Lilongwe: CBM.

INTRODUCTION

In Malawi several organizations, including government ministries and departments, implement disability programmes. They include the Department of Disability Programmes in the Ministry of Disability and Elderly Affairs (MoDEA); the Ministry of Education, Science and Technology (MoEST); the Ministry of Health (MoH); the Ministry of Gender, Children and Social Welfare (MoGCSW); the Malawi Council for the Handicapped (MACOHA); Montfort College; the Sue Ryder Foundation; Feed the Children Malawi; the Federation of Disability Organizations in Malawi (FEDOMA) and its affiliates; and Malawi Against Physical Disabilities (MAP). However, the types of services provided by different stakeholders and their geographical coverage are not well known. There was therefore a need to assess how well they respond to the needs of the children and their carers, discover their geographical coverage and degree of coordination, and highlight the achievements and challenges.

Given this background, a situation analysis of children with disabilities in Malawi was required to inform the development of effective and relevant programmes and interventions for such children. This situation analysis reviewed existing policies and legislation in order to identify gaps that need to be addressed. The study also explored the challenges that children with disabilities and their caretakers experience in terms of access to social and other services. There has also been a lack of knowledge regarding the problems faced by children (with or without disabilities) growing up in households with disabled parents. The identification of challenges experienced by children with disabled parents is critical, if such children are to realise and fully enjoy their rights. Accurate identification of issues will lead to targeted interventions that can ensure that all children, including those with disabilities, have opportunities for improved health, nutrition, education and a protective environment.

1.2 Objectives

The aim of this study was to conduct a situation analysis of children with disabilities in Malawi and make recommendations on how challenges experienced by these children can best be addressed. The specific objectives of this study were:

- i. To provide concrete information on the type of data that has been collected in the census, and in national and small-scale surveys on children with disabilities in Malawi;
- ii. To establish the existing legislative and policy framework for children with disabilities;
- iii. To determine the availability of and level of access to existing services for children with disabilities;
- iv. To map out organizations that offer services to children with disabilities and their caretakers, and their relevant programmes and interventions;
- v. To determine the needs and challenges experienced by children with disabilities and their caretakers from their own perspective and also determine service gaps based on some matching between the needs and services offered by various organizations;
- vi. To identify needs and challenges faced by children living with a parent or caretaker with a disability in order to determine the extent of enjoyment of child rights for such children; and
- vii. Based on the findings, make recommendations on priority intervention areas for the Government of Malawi and its development partners to implement in order to improve the lives of children with disabilities or those living with parents or caretakers with disabilities.

1.3 Methodology

This study was qualitative in nature. The team conducted key informant interviews (KIIs), focus group discussions (FGDs) and in-depth interviews (IDIs). A comprehensive review of literature was also conducted. This section describes in detail the data collection methods.

1.3.1 Data collection

1.3.1.1 Document review

A review of relevant literature was undertaken to complement primary data collection. The review looked at what is known about children with disabilities, the organizations that deal with and have programmes targeting such children. It also examined the implementation challenges face by organizations and noted any recommendations. In addition to research reports, the review also covered international conventions and instruments, and national laws, policies and strategies related to children with disabilities.

1.3.1.2 Key informant interviews

Key informant interviews were also conducted with key staff in both government and non-governmental organizations (NGOs) whose work is related to children with disabilities at national and sub-national levels. The interviews focussed on (i) the policy and legislative environment required for children with disabilities to fully enjoy their rights as children; (ii) services offered to children with disabilities in terms of spatial distribution, operational period and the identification of children in need of such services; (iii) the challenges in providing these services; and (iv) how such challenges are being or could be addressed.

1.3.1.3 In-depth interviews

To identify the needs and challenges faced by children with disabilities and their caretakers, two types of children were interviewed: (i) children who have a disability and (ii) children whose parents have a disability. The parents of children with disabilities were also interviewed.

1.3.1.4 Focus group discussions

The in-depth interviews with children with disabilities were supplemented by focus group discussions with these children at community level and in institutions. Community discussions were conducted separately for female and male children, covering the same issues as the in-depth interviews described above. The discussions with institution-based children with disabilities included male and female children together. They also looked at their experience (both positive and negative) of staying in institutions compared to living at home and how the challenges they experienced could be addressed.

1.3.2 Sampling of districts, informants and focus group discussion participants

This study was conducted in four districts: Karonga in Northern Region, Lilongwe in Central Region, and Balaka and Nsanje in Southern Region. Purposive sampling was used to choose these districts. The decision to go to the sampled districts was made jointly by the disability ministry (MoDEA), the Centre for Social Research (CSR) and UNICEF. A list of key informants at national and district levels was drawn up after consultations with the MoDEA and UNICEF. Traditional leaders and disability frontline officers from government and NGOs helped identify children with disabilities for interviews and discussions. Managers of institutions for children with disabilities helped identify participants for group discussions.

1.3.3 Data collection

Interviews with national-level key informants were conducted by researchers from the CSR. Key informants at district and community levels were interviewed by research team supervisors. In-depth interviews and focus group discussions with children (with and without disabilities) and their parents were carried out by research assistants. The CSR and the disability ministry together provided one week of training (for supervisors and research assistants) before data collection began. Data collection tools were developed jointly by ministry officials and UNICEF. During data collection, the ministry officials and CSR researchers made supervisory field visits. They also oversaw the data analysis, with the involvement of ministry officials being part of capacity-building within the MoDEA.



1.4 The CBR matrix as an analytical framework for children with disabilities issues

Community-based rehabilitation (CBR) is a strategy designed to eliminate barriers to development by enhancing the quality of life of disabled people and their families. It involves ensuring that their basic needs are met and that they can participate in all development activities. It is a multi-sectoral strategy that empowers people with disabilities to access and benefit from education, employment, health and other social services. Above all, the CBR approach stresses rehabilitation, equal opportunities, poverty reduction and social inclusion for all people with disabilities. As well as seeking certain end results, CBR (like other community-based development initiatives) embodies the process of empowering and including the disempowered and the excluded. It aims to break down and transform societal and systematic barriers to genuine participation; build respect for diversity; and recognise mutual interdependence.⁷

The major objectives of CBR are two-fold: to ensure that people with disabilities are able to maximise their physical and mental abilities by having access to regular services; and to activate communities to promote and protect the human rights of people with disabilities through changes within the community (such as by removing barriers to participation).⁸ CBR builds on the social model of disability, which emphasises that people are disabled not only by their impairment but also by societal barriers. Thus CBR deals with the person's impairment and society's 'impairment' using programmes that 'serve to eliminate or diminish the effects of the person's impairment and to address the causes of the impairment', on one hand, and promote social change at individual and community levels by changing attitudes of people towards disability or impairment. The social change strategies first target disabled people and their families so that they are empowered to work with others to eliminate or reduce various barriers (for example environmental, cultural and attitudinal) that exclude people with disabilities from enjoying their rights.⁹

7 ILO, UNESCO and WHO (2004). CBR: A Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities. Geneva: WHO.

8 ILO, UNESCO and WHO (2004). Ibid.

9 Munthali, A.C. (2011). Ibid.

There are five principles of community-based rehabilitation:

- *Inclusion*: Include people with disabilities in all community activities, services and institutions.
- *Participation*: Enable the participation of people with disabilities (and their families), in partnership with the community, to fully participate in deciding, planning, implementing, managing and evaluating programmes, particularly those targeting them.
- *Self-advocacy*: Lobby for the rights of persons with disabilities and to demand better access to information.
- *Accessibility*: Eliminate all barriers (physical, attitudinal, and communication) that prevent access to services.
- *Sustainability*: Coordinate efforts among all stakeholders, with disabled people's organizations (DPOs) playing a central role.

The CBR matrix has five components:

(a) Health: Every person, whether or not they have a disability, has a right to health. The World Health Organization (WHO) defines health as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity'. CBR in health covers 'the promotion of well-being, prevention of causes of impairment, delivery of affordable medical and rehabilitation interventions and the provision of affordable assistive devices'.

(b) Education: According to the Convention on the Rights of the Child, every child has a right to education. CBR therefore promotes inclusive development and education, and age-appropriate classes. By including children with disabilities in mainstream education, CBR aims to eliminate barriers that later deprive these children of choices and opportunities. CBR further discourages stand-alone special education and supports special education only as a supplement to mainstream classroom education.

(c) Livelihood: This is a universal basic need and right, and CBR promotes access to work for people with disabilities by (i) providing skills training; (ii) facilitating self- and open employment; (iii) facilitating access to lending institutions; (iv) mounting advocacy campaigns to change attitudes of employers and fellow workers; and (v) implementing social protection projects.

(d) Empowerment: Becoming empowered is a right for everyone. CBR promotes the right to equity, justice and inclusion in society by ensuring that everyone can access processes (including joining disability organizations) that enable people to empower themselves. People with disabilities can lobby for social change and for better life for all via their organizations.

(e) Social: Since participation of all persons in development activities or programmes is a human right, CBR supports actions which ensure that the social needs of children with disabilities are met. These include supporting participation in society (as members of a family, neighbourhood and community, as well as forming close relations with chosen loved ones and friends), using personal assistants and setting up procedures to ensure social justice.

Figure 1.1 below shows the various components of the CBR matrix.

Figure 1.1: CBR Matrix¹⁰



Each of the five components of the CBR matrix has five sub-themes. The CBR has been used in this study as a framework for the situation analysis of children with disabilities, and four of the five sub-themes are discussed in turn.

¹⁰ http://www.who.int/disabilities/cbr/cbr_matrix_11.10.pdf (accessed 15 December 2012)



2. RESULTS



2.1 Description of the key informants, interviewees and focus group participants

This section presents some characteristics of the key informants by sex and level. For children with disabilities the presentation is by sex, age and type of disability. A total of 78 key informants were interviewed (See Table 2.1) and 81% of these were men. At district level 21% of the informants were women. Most key informant interviews were done at community and national level. A list of the national level key informants is in Annex 1; Annex 2 is a list of district key informants.

Table 2.1: Number and sex of key informants interviewed by level

| Level | Female | Male | Total | % |
|--------------------------|--------|------|-------|-------|
| National key informants | 3 | 22 | 25 | 32.1 |
| District key informants | 3 | 13 | 16 | 20.5 |
| Community key informants | 3 | 34 | 37 | 47.4 |
| All levels | 9 | 63 | 78 | 100.0 |

Table 2.2 on the following page summarises Annex 3. In-depth interviews were conducted with 24 boys and 19 girls, of whom 42% had physical disabilities.¹¹ As the combination of children with hearing and speech impairment was common, this category was separated from those with different combinations of disabilities.

¹¹ In this study a physical disability is any impairment which limits the physical function of one or more limbs or gross motor ability.

Table 2.2: Children interviewed by disability and sex

| Disability | Female | Male | Total | % |
|-----------------------------|--------|------|-------|-------|
| Physical disability | 9 | 9 | 18 | 41.9 |
| Multiple disabilities | 3 | 6 | 9 | 20.9 |
| Hearing impairment | 1 | 4 | 5 | 11.6 |
| Hearing & speech impairment | 3 | 2 | 5 | 11.6 |
| Speech impairment | 2 | 0 | 2 | 4.7 |
| Albinism | 0 | 1 | 1 | 2.3 |
| Visual impairment | 0 | 1 | 1 | 2.3 |
| Epilepsy | 0 | 1 | 1 | 2.3 |
| Learning difficulties | 1 | 0 | 1 | 2.3 |
| All | 19 | 24 | 43 | 100.0 |

While the research team targeted all forms of disabilities, it was sometimes difficult to find particular types of disability (such as children with learning difficulties, epilepsy, visual impairment or albinism) in the communities. Since the research team used snowballing (a sampling technique that relies on members of a target population knowing the location of other similar targets), the difficulty in finding certain types of disability might suggest that the general population does not view these conditions as forms of disability. Table 2.3 below shows a breakdown of the other in-depth interviews that were conducted. Fifty-five per cent of the parents of children with disabilities were women. Among children of disabled parents, 51% were girls.

Table 2.3: In-depth interviews conducted at community level

| Other ID interviewees | Female (No. and %) | Male (No. and %) | Total (No. and %) |
|---------------------------------------|-----------------------|---------------------|----------------------|
| Parents of children with disabilities | 22 (55) | 18 (45) | 40 (100) |
| Parents with disabilities | 18 (45) | 22 (55) | 40 (100) |
| Children of parents with disabilities | 20 (51) | 19 (49) | 39 (100) |

Fourteen focus group discussions were conducted in the districts and childcare institutions. A total of 126 children participated, of whom 46% were girls. Fifty-six per cent of the children were aged 15-17 years; 43% were below 15 years of age, as detailed in Table 2.4 below.

Table 2.4: Number and sex of FGD participants by age group

| Focus group participants | Female | Male | Total | % |
|--------------------------|--------|------|-------|-------|
| Less than 15 years | 26 | 28 | 54 | 42.9 |
| 15-17 years | 30 | 40 | 70 | 55.6 |
| Unknown | 2 | 0 | 2 | 1.6 |
| Total | 58 | 68 | 126 | 100.0 |

2.2 Legislative and policy framework for children with disabilities

2.2.1 An analysis of legislation

The most relevant pieces of legislation in Malawi relating to children with disabilities are the Constitution of the Republic of Malawi (1995), the Disability Act (2012) and the Child Care, Protection and Justice Act (2010). This section also looks at budgetary allocation to the disability ministry (MoDEA) and other government institutions such as the Malawi Council for the Handicapped (MACOHA), Montfort College and Kachere Rehabilitation Centre.

2.2.1.1 The Malawi Constitution

Malawi's Constitution recognises the rights of persons with disabilities in line with international instruments. Section 20 explicitly guarantees the protection of children with disabilities from discrimination. These children are also implicitly catered for in Section 13(g), which requires that persons with disabilities be supported through promoting greater access to public places; offering equal opportunities for employment; and ensuring the fullest possible participation in all spheres of Malawi society. The Constitution guarantees all persons their right to education (Section 26); and all persons and peoples their right to development (and therefore to the enjoyment of economic, social, cultural and political development). Women, children and the disabled in particular are given special consideration in the application of this right (Section 30). Malawi's Constitution thus adequately provides for persons with disabilities, including children.

2.2.1.2 The Disability Act

The Disability Act, a major milestone in ensuring that the rights of persons with disabilities are guaranteed, came into force in May 2012. It guarantees the right of access for persons with disabilities, including children with disabilities, to at least 22 services. The major services cover health; health and rehabilitation; premises and services or amenities; education and training (including the relevant institutions); social protection; social services; cultural, sporting and recreational activities; and information and communication technologies. The Act is in line with international instruments such as the UN Convention on the Rights of Persons with Disabilities (CRPD) and the CRC. The Act further provides for the National Coordinating Committee on Disability Issues (NACCODI) to be established and brought into operation. NACCODI will provide a forum for all key disability stakeholders. It will allow them to review reports on disability mainstreaming, make recommendations to government on best practice; and oversee the implementation, monitoring and evaluation of relevant programmes. The National Policy on Equalisation of Opportunities for Persons with Disabilities provided for the establishment of NACCODI in 2006, but it has not yet become active.

The Disability Act also provides for the establishment of a Disability Trust Fund that will provide extra resources to support relevant programmes and services. Although there is no prior example of operational trust funds in Malawi, the ministry and other stakeholders will define how the fund is to operate.

2.2.1.3 The Handicapped Persons Act (1971)

Unlike the Convention on the Rights of Persons with Disabilities and the Disability Act, this Act is charity-based and does not promote or protect the rights of persons with disabilities. It is therefore not aligned with current international instruments. However, the Handicapped Persons Act provided for the establishment of the Malawi Council for the Handicapped (MACOHA), is a parastatal funded by the government to promote the welfare of persons with disabilities. MACOHA also provides rehabilitation services and manages vocational and special training centres for persons with disabilities. Parliament is currently considering legislation to replace this outdated Act, in the form of the Malawi Council for Disability Affairs Bill.

2.2.1.4 The Child Care, Protection and Justice Act

This Act was passed in 2010 to replace the Children and Young Persons Act. Among other provisions, the Act calls for district councils *'to keep a register of children with disabilities within its area of jurisdiction and give assistance to them whenever possible in order to enable those children grow up with dignity among other children and to develop their potential and self-reliance'*. However, it does not specify what type of assistance the district councils should provide to such children. While the Act provides for all children, including those with disabilities, to fully enjoy their rights, implementation is incomplete. District councils do not yet keep registers of children with disabilities. Worse still, district councils are not fully constituted to effectively deliver services. Special interest groups (such as persons with disabilities) are not fully represented in these councils, because local elections have not been conducted since May 2005.

2.2.1.5 Budgetary allocations to ministries and government-funded organizations

The level of government funding allocated to ministries and departments indicates the extent to which these are prioritized - stakeholders are concerned that the funds allocated to the ministries and departments dealing with disability are insufficient. The second Malawi Growth and Development Strategy (MGDS II), which defines the national development agenda, does not prioritise persons (including children) with disabilities. The budgetary allocation to the MoDEA has been low (MK293 million or about US\$733,000), representing only a tiny fraction (0.07%) of the total government budget (MK406 billion, roughly US\$1 billion) in 2012/13.¹² Over the last three years the government has allocated MK132 million (US\$330,000) per year for implementation of special needs education (SNE) at district level. The Directorate of Special Needs Education in the MoEST gets about MK30 million (US\$75,000) per year while Montfort College gets about MK94 million (US\$235,000). In 2012/2013 MK223 million (US\$558,000) was allocated to the Malawi Council for the Handicapped. Unless the budgetary allocation improves, it will be difficult to effectively implement disability issues.

¹² The exchange rate in 2013 is about US\$1 = MK400.

2.2.1.6 UN Conventions

The relevant UN conventions include the Convention on the Rights of Persons with Disabilities (CRPD), which Malawi signed in 2007 and ratified in 2009. Malawi also signed and ratified the Convention on the Rights of the Child (CRC) in 1990. Both conventions are comprehensive, providing for the rights of children with disabilities and prohibiting any form of discrimination against these children. The two conventions accord children with disabilities all the rights enjoyed by other children and provide for special services to enable them to enjoy their rights fully. State parties, such as Malawi, are required to ensure that these rights are enjoyed and are required to report to the UN on progress made to implement both conventions. So far, Malawi has produced two reports on the CRC but has not yet reported on the CRPD. The 2009 CRC report acknowledged the existence of constitutional and policy provisions promoting the rights of children with disabilities and mentioned the various programmes being implemented by government. However the report highlighted challenges too, including (i) the lack of comprehensive data on disabilities, especially disaggregated data, which makes it difficult to track the impacts of interventions; (ii) inadequate financial resources allocated to the disability ministry, and resources not being specific to children; (iii) too few childcare institutions and high levels of poverty, making it impossible for households to send children with disabilities to special needs schools located far away; and (iv) a shortage of special needs teachers. The CRC and the CRPD have since been domesticated in most of the legislation in Malawi, including in the Disability Act.

2.2.2 Stakeholders' understanding of legislation and conventions

More than 80% of key informants at district level, including civil servants, were unable to name key legislation related to children with disabilities in Malawi. Some categorically said there is none while others said frankly they did not know. Most of those who were able to answer positively mentioned the CRC and Malawi Constitution. A few, mainly at ministry headquarters, mentioned the Disability Act. Only one district-level key informant knew that the Disability Act had been passed. Although he had not yet seen or read it, he had a good idea of its main provisions. Only one key informant mentioned the Child Care, Protection and Justice Act. Those in the disability sector mentioned the (outdated) Handicapped Persons Act but quickly pointed out that it needs to be reviewed. Some stakeholders mentioned that the Handicapped Persons Act was being reviewed.

The CRPD was not well known among key informants either - only one person at district level mentioned it. Even at national level, very few mentioned the CRPD. One district-level informant bemoaned the lack public-awareness activities covering conventions and legislation on the rights of children with disabilities. According to this informant, disability issues are mostly known only by the disability sector, and policies and legislation are just dumped on the shelves at headquarters. These responses suggested that most stakeholders lacked knowledge about legislation mainly because the dissemination of information from national to districts and lower levels is limited. The successful implementation of these pieces of legislation also rests with officials at district level.

2.2.3 An analysis of policies

This section presents an analysis of relevant policies, focusing on whether the provisions take into account the needs of children with disabilities. The main policies are the second Malawi Growth and Development Strategy (MGDS II), the National Policy on Equalisation of Opportunities for Persons with Disabilities, the National Education Strategic Plan (NESP), the National Policy on Special Needs Education, the Early Childhood Development Policy, the National Sports Policy and the National Youth Policy.

2.2.3.1 Malawi Growth and Development Strategy 2011-2016

The MGDS II is an overarching government development strategy that informs all other policies and strategies for 2011-2016. Apart from covering all sectors and subsectors, the MGDS II also sets priority areas and strategies. A sector or sub-sector in the priority list is prioritised in resource allocation. By implication, unlisted sectors or sub-sectors receive lower priority. An analysis of MGDS II shows that disability and children with disabilities are not seen as high-priority issues. Providing for the needs of children with disabilities would fall under social development or social support, but children with disabilities are not mentioned at all. For example, under social development children are discussed under Child Development and Protection. Orphans and girls are the only two specific groups considered worthy of special consideration, and no strategies have been proposed for their development and protection. Children with disabilities are not considered to be a special group of children even though they clearly need special strategies for development and protection from abuse, violence, neglect, exploitation, malnutrition and harmful cultural practices.

Persons with disabilities are mentioned only once, under the sub-theme Social Support, but there is no specific strategy related to them. The context (Supporting the Most Vulnerable), implies that disability of the household head is a vulnerability that ought to be taken into consideration when assessing the eligibility of households for the Social Cash Transfer Programme. Beneficiaries for social support are identified by community groups, which use poverty as a major criterion, so a disabled person can only be a beneficiary if he or she fulfils this criterion. There are a number of people with disabilities who have benefited from the cash transfer programme. In 2010 a total of 28,138 households benefitted but this decreased to 27,925 households in 2011. It is estimated that 2% of the beneficiaries are persons with disabilities.¹³ It is not known what proportion of these beneficiaries are children with disabilities.

Within the MGDS II, children with disabilities are only mentioned once - under Education. The education of children with special needs is mentioned alongside girls: *'promoting a conducive environment for girls and students with special education needs'*. There is no elaboration in the MGDS II as to what a 'conducive environment' might be, but the education and related policies provide some explanation.

One key informant said that the near-absence of disability issues in the MGDS II is almost a tragedy for the disability sector, as it demonstrates the lack of priority given by government to children with disabilities. It is not surprising therefore that so far there has been little funding for disability issues.

2.2.3.2 National Policy on Equalisation of Opportunities for Persons with Disabilities

Cabinet approved this policy in July 2006 and the MoDEA is the line ministry charged with overseeing its implementation. Its purpose is to promote the rights of persons with disabilities to enable them to play a full role in society. It aims to ensure that concrete steps are taken for disabled people to access the same fundamental rights and responsibilities as any other person in Malawi. The policy recognises that to achieve these there is need to (i) integrate disability issues into all government development strategies, plans and programmes; (ii) integrate and coordinate management systems of planning, implementation and monitoring at all levels; and (iii) build capacity of all disability actors and mount nationwide public education and awareness campaigns about disability. The policy outlines strategies that will ensure that the rights of persons with disabilities are upheld.

¹³ Routine data from the MoGCSW, 2011. The data as presented looks at percentage of beneficiaries who have disabilities.

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A number of stakeholders said that the policy should be reviewed to take account of issues that have emerged during the seven years since the policy was approved. A review is also necessary in order to align the policy with the Disability Act and to domesticate the CRPD. Most of the actions contained in the policy, such as bringing the national coordinating committee, NACCODI, into operation have not been implemented. The government could also use a review to focus some of the generic objectives and strategies specifically towards children with disabilities, as their particular needs may be different from those pertaining to disabled adults. This would avoid the need to develop a separate policy specific to children with disabilities.

The policy acknowledges that children with disabilities have specific concerns: they are severely disadvantaged as they depend on the goodwill of their parents and guardians to access early interventions and rehabilitation services. However, although the policy identified these problems, it did not devise strategies to address them. If there had been a focus on children with disabilities, strategies on prevention (in the form of early detection, for example) could have linked these children to primary healthcare, early childhood development, primary school education and community-based rehabilitation activities. It might also have helped spot gaps such as educating out-of-school children and the needs of the elderly with disabilities, since each of these have specific needs. This type of analysis could be extended to other areas such as sports participation, access to health care and dealing with negative social attitudes.

2.2.3.3 Health Sector Strategic Plan

The Constitution of the Republic of Malawi guarantees equality to all people in Malawi and prohibits discrimination (Section 20, Malawi Constitution). With regard to health, the Constitution further says that the state is obliged *'To provide adequate health care, commensurate with the health needs of Malawian society and international standards of health care'*. People with disabilities are therefore guaranteed protection under the Constitution of the Republic of Malawi. Malawi does not currently have a national health policy but a Health Sector Strategic Plan was developed in 2011 to cover the period 2011-2016. This Plan assures all Malawians that they shall have access to health services without distinction by ethnicity, gender, disability, religion, political belief, economic and social condition or geographical location. The Plan also states that the rights of healthcare users and their families, providers, and support staff shall be respected and protected. It encourages the involvement of civil society organizations in issues of health rights and raising awareness about disease prevention and disability. While the Plan guarantees all people in Malawi access to health care, the current study found that persons with disabilities experience many challenges in accessing these services. A review of health policies has also demonstrated that most of the health policies in Malawi do not address the needs of persons with disabilities.¹⁴

¹⁴ Munthali, A.C., C.M. Makupe and C. Chilimampungu (2010). *Report on analysis of health and related policies in Malawi for the equitable project*. Zomba: Centre for Social Research.

2.2.3.4 National Education Strategic Plan (NESP) 2008-2017 and Policy Investment Framework

The NESP emphasises that learners with special educational needs should be supported through a range of strategies. These include improving the supply of teaching and learning materials for both special needs education (SNE) and other adults, and mainstreaming SNE at all levels, among both out-of-school and in-school youth. Increased enrolment of special needs pupils and greater numbers of specialised teachers are also highlighted. The NESP, therefore, addresses most of the problems relating to educating children with special needs.

Government commitment to SNE is also elaborated in the Policy Investment Framework (PIF). Previous government policy was to promote the establishment of special schools for children with disabilities. The PIF, on the other hand, aims to provide an enabling environment for children with special educational needs within the conventional school system. The PIF also calls for SNE to be a priority, with the aim of increasing the number of pupils with special needs completing primary education. The government is also committed to having enough teachers qualified to work with children with special needs, and ensuring that the physical design and construction of schools takes into account the needs of such children. The government also promotes the community-based rehabilitation strategy for pre-school children. This has the objective of helping families cater for children with special needs, so elder female siblings can be released to attend school. The Ministry of Education, Science and Technology is the line ministry responsible for implementing the PIF and the NESP, and these two documents address issues at all levels of the education system.



UNICEF/MALAWI/2012/Chagara

2.2.3.5 National Policy on Special Needs Education

The policy, developed by the MoEST and stakeholders in 2007, aims to develop the personal, social and academic competencies of learners with special needs. Several barriers to the implementation of special needs education were identified, and the policy document outlines strategies to overcome them. The barriers include (i) inadequate funding; (ii) inadequate teaching and learning materials; (iii) inaccessible infrastructure; (iv) long distances to facilities; and (v) shortage of specialist teachers.¹⁵ The policy covers three priority areas: access and equity, quality and relevance, and governance and management. The policy is comprehensive, as it covers advocacy, early identification, assessment and interventions for learners; the provision of appropriate education; and the provision of a supportive institutional framework for special needs education. The policy recognises the imbalances between learners with special education needs and those without. Imbalances are being addressed through (i) constructing and maintaining resource centres and special schools throughout the country; (ii) equipping SNE units with adequate staff and assistive devices, including a mandatory SNE component in the primary and secondary teacher-training courses; and (iii) establishing educational assessment and resource service centres.

However, although the policy itself is good, most of the contents have not been fully implemented. Specific strategies on how to increase specialist teachers and teacher aides are not mentioned in the policy. There is still a shortage of specialist teachers in Malawi and an acute lack of teaching materials (such as braille and other teaching aids). Furthermore, the policy recognises the need for Malawi to compile a databank on children with disabilities to inform service-provision. This survey should be conducted not only for children with disabilities but also for all persons with disabilities.

The education situation of children with disabilities has not improved since this policy was put into place. In 2012, experts on SNE mentioned the same needs and challenges as clearly outlined in this 2007 policy. The field teams and stakeholders who visited resource centres and special-needs schools reported facilities in a state of disrepair, non-functioning water taps and children with disabilities who rely on the goodwill of teachers to access health care.

¹⁵ Ministry of Education and Vocational Training. (2007). *The National Policy on Special Needs Education*. Lilongwe: Ministry of Education and Vocational Training.

2.2.3.6 National Policy on Early Childhood Development

The National Policy on Early Childhood Development (ECD), approved in 2006, was developed by the Ministry of Gender, Children and Social Welfare (MoGCSW) and stakeholders. The policy has a number of guiding principles, one of which is that *'Every child has the right to develop to his/her full potential.'* This is inclusive enough. Another principle is that *'No child shall be discriminated or abused on the basis of age, sex, race, tribe, health status, economic status, religious or political affiliation in the provision of ECD services by any organization.'* This is also inclusive but 'disability' is not one of the criteria listed. This is not a small 'slip of the tongue' or an innocent 'silence' because early childhood development practitioners play a crucial role in the early detection of disability and the inclusive development of children with disabilities.

The ECD Policy misses an opportunity to point out that community-based childcare centres and primary schools are currently the primary disability-detecting channels in Malawi. As early detection is the key to optimum treatment and rehabilitation, this is important in terms of improving the quality of life for children with disabilities. Any review of this policy should ensure that this point is made clearly. It is estimated that there are more than 771,000 children who access community-based childcare centres (for children aged 3-5 years) while 187,500 children access children's corners (for children aged 6-18).¹⁶ It is estimated that 4% of the children enrolled in such centres nationally are children with special needs.¹⁷

Out of the 12 policy objectives, only two touch on disability, albeit indirectly: *'Promote the protection of children against any forms of abuse and discrimination'* and *'Strengthen the protection and safeguarding of children in difficult circumstances'* (pp. 17-18). The related strategies under the former do not specifically include children with disabilities. However, examples of children in difficult circumstances under the latter include children with disabilities, orphans, children on the street, and abused and exploited children. Despite this, there are no specific strategies for the different groups of children identified as being in difficult circumstances. Strategies need to be disaggregated where the problems being addressed are unique to each group of children; this will help in monitoring and evaluation of activities. Currently, it is difficult to evaluate the extent to which the ECD Policy has helped address the particular needs of children with disabilities.

The Child Care, Protection and Justice Act provides penalties for persons or organizations that contravene the rights of the child. One of the major challenges, as mentioned by key informants in this study, is that the line ministry faces serious capacity and resource constraints, which result in poor coordination and inadequate resource allocation for ECD activities.

16 UNICEF (2011). *Vulnerability and Child Protection in the Face of HIV - MALAWI*. Lilongwe: UNICEF.
17 Munthali, A., P. Mvula and L. Silo (2008). *An Inventory of CBCCs in Malawi*. Lilongwe: UNICEF.

2.2.3.7 National Policy on Orphans and Other Vulnerable Children

Children with disabilities are certainly vulnerable, and this 2003 policy was supposed to take them into account. However, the definition in the policy does not include disability: a vulnerable child is said to be one *'who has no able parents and guardians, staying alone or with elderly grandparents or lives in a sibling headed household or has no fixed place of abode and lacks access to health care, material and psychological care, education and has no shelter'*.¹⁸ This definition includes a child without a disability but living in a household headed by a disabled person, but it excludes a child who has a disability. Children with disabilities are not listed in the policy as vulnerable and there are no strategies related to them. These children too are generally abandoned, malnourished and abused, so their needs should have been highlighted. Results of this study, as demonstrated later, suggest that children with disabilities are just as vulnerable as children of disabled parents. The National Policy on Orphans and other Vulnerable Children should have included children with disabilities.¹⁹

2.2.3.8 National Sports Policy

The National Sports Policy was launched in 2007 by the Ministry of Youth and Sports (MoYS). The policy recognises that sport can be for competition or recreation, and that the participation of children with disabilities is based on motivation to join in sporting activities. Participation makes them feel part of the community and improves their health. The policy therefore considers vulnerable and disadvantaged groups as a cross-cutting issue. For example, the policy states that *'Government will, therefore, ensure that sport is accessible to all people regardless of age, sex, language, religion, nationality, disability, birth or other status'* [and that] *'Every individual shall therefore have the right to participate in sports for recreation or for competition'* (pp. 5 & 7).

The consideration of disability issues is clear under the policy area 'Sustainable Sports Development'. The third objective here is *'To provide and promote access to sports for persons with disabilities, the aged, women and children'* (p. 9). Some of the strategies related to persons with disabilities include (i) developing sports programmes for persons with disabilities and the aged; (ii) modifying the existing sports infrastructure to make it disability-friendly; (iii) adapting and improving sports programmes to cater for persons with disabilities, the aged, women and children; and (iv) increasing public awareness and the profile of sports among persons with disabilities.

¹⁸ MoGSW. (2010). *A Plan of Action for Orphans and Other Vulnerable Children 2010-2011*. Lilongwe: MoGSW.

¹⁹ The National Plan of Action on OVC expired in 2011 so was not reviewed in this study.

The policy commits the MoYS to *'ensure that all youth of Malawi have equal opportunity to participate in sports for personal and/or community benefit'* (p. 21). It also commits the MoDEA, in collaboration with the MoYS, to *'ensure that all sports facilities are user friendly and adaptable; facilitate the provision of sports equipment for persons with disabilities; ensure equal sports opportunities to persons with disabilities; and arrange for the appropriate expertise in sports for persons with disabilities'* (pp. 22-23). The policy further commits the education ministry to provide the youth with appropriate physical education and sports programmes for their enjoyment and health.

For all practical purposes, the National Sports Policy sufficiently provides for children with disabilities. The major challenge, as with most strategic plans and policies, is lack of implementation. Stakeholders complained of insufficient resources allocated to sporting activities in schools or youth centres. Further, there is no strategy to deal with the low priority accorded to sporting activities for children, despite commitment to ensure equal participation by all youth.

2.2.3.9 National Youth Policy

This policy is currently under review by the government. One of its core principles is *'non-discrimination based on age, sex, marital status, disability and vulnerability'*, and one of the rights promulgated in the policy is that every youth has the *'right to protection from ... neglect'* (page 4). Under 'Social Services, Recreation and Culture', the policy encourages disabled people's organizations (DPOs) to participate in the provision of sports and recreation facilities. Under 'Implementation', youth with disabilities constitute one of the priority target groups. Although only the sports ministry and the Malawi National Council of Sports are given roles and responsibilities, the implementation plan also includes DPOs. However, the disability ministry is not included as a duty-bearer. And, despite including disability issues in the policy document, few indicators in the implementation plan pertain to children with disabilities. The absence of indicators specific to children with disabilities makes it difficult to evaluate what this policy has achieved in addressing the needs of such children.

2.2.4 Concluding remarks on policies

Most of the policies reviewed include provisions, either explicit or implicit, for children with disabilities. However, most of the policies related to children with disabilities do not sufficiently disaggregate the needs of different groups. A case in point is the policy aiming to equalise opportunities between people with and without disabilities. Without proper disaggregation of groups and their needs, the proposed strategies are merely generic and not sufficiently targeted for maximum impact. The government should look at all the relevant policies and undertake a needs assessment by type of disability. This would ensure that children with disabilities are properly positioned to benefit from the developed strategies.

RESULTS

Even though there are few policies related specifically to children with disabilities, such children would be in a position to fully enjoy their rights if they were all implemented. The biggest concern is that the National Policy on the Equalisation of People with Disabilities (the major policy intended to prioritise disability issues) has lapsed without being fully implemented. This demonstrates the lack of priority given to disability issues.

2.3 Data on children with disabilities

Several studies looking at the prevalence of disability and living conditions of persons with disabilities have been conducted in Malawi, but none are recent. Some of these studies (such as *A survey of handicapped persons in Malawi* by the National Statistical Office (NSO) in 1983 and another by NSO in 1993) are more than 20 years old. The *Living conditions of persons with activity limitations in Malawi* (2003) is now ten years old and there is a need for a national survey to determine the prevalence of disability. In this section we will therefore only present the 2008 data from the Malawi Housing and Population Census.

According to the 2008 Housing and Population Census, 3.8% (or almost half a million people) of the Malawi population as a whole were persons with disabilities. The prevalence of disability is slightly lower (at about 2.4% or 160,000 individuals) among those aged less than 18 years.

The census classified disability into five types: referred to on the census form as 'seeing', 'hearing', 'speaking', 'walking' and 'other'. It should be noted that the population and housing census of 2008 did not use the World Health Organization's International Classification of Functioning, Disability and Health (ICF) model to identify persons with disabilities (see Annex 4). Table 2.5 below shows the proportion of each type of disability by gender.

Table 2.5: Proportion of types of disabilities in the under-18 population by gender

| Type of disability | No. of males | No. of females | Total | % |
|--------------------|--------------|----------------|---------|--------|
| Hearing | 19,036 | 17,705 | 36,741 | 23.0 |
| Seeing | 13,840 | 13,181 | 27,021 | 16.9 |
| Walking | 13,450 | 11,890 | 25,340 | 15.8 |
| Speaking | 8,806 | 6,016 | 14,822 | 9.3 |
| Other | 29,589 | 26,365 | 55,954 | 35.0 |
| Total | 89,721 | 75,157 | 159,878 | 100.00 |

The most common form of disability is hearing loss, followed by visual impairment, reduced mobility and speaking difficulties. All other forms of disability were classified as 'other' - this category constituted 35% of the different forms of disability.

Table 2.6 on the following page shows the numbers and prevalence of disability by region and district. The Northern Region has the highest prevalence of disability among children at 3.3%, followed by Central Region at 2.5% and Southern Region at 2.0%. In terms of absolute numbers there are more children with disabilities in the south, followed by the centre and the north has the smallest number of children with disabilities. With the exception of Likoma Island, in all the districts the prevalence of disability was higher among males than among females.

This data can still be used for developing interventions, but there is an urgent need to determine prevalence of disability as defined by the ICF in Malawi.



Table 2.6: Numbers and prevalence of children with disabilities (aged <18) by region and district

| Location | Total population aged <18 | No. of males aged <18 | No. of males with disabilities aged <18 | Prevalence of disability among males (%) aged <18 | No. of females aged <18 | No. of females with disabilities aged <18 | Prevalence of disability among females (%) aged <18 | Overall prevalence (%) aged <18 |
|------------------------|---------------------------|-----------------------|---|---|-------------------------|---|---|---------------------------------|
| Malawi | 6,750,186 | 3,343,459 | 84,721 | 2.5 | 3,406,727 | 75,157 | 2.2 | 2.4 |
| Northern Region | 882,479 | 438,302 | 15,247 | 3.5 | 444,177 | 13,545 | 3.1 | 3.3 |
| Chitipa | 96,460 | 47,840 | 1,574 | 3.3 | 48,620 | 1,376 | 2.8 | |
| Karonga | 141,280 | 70,246 | 2,378 | 3.4 | 71,034 | 2,241 | 3.2 | 3.2 |
| Nkhata Bay | 113,135 | 56,645 | 2,152 | 3.8 | 56,490 | 1,839 | 3.3 | 3.5 |
| Rumphi | 87,175 | 43,580 | 1,382 | 3.2 | 43,595 | 1,251 | 2.9 | 3.0 |
| Mzimba | 377,818 | 187,572 | 6,698 | 3.6 | 190,246 | 5,922 | 3.1 | 3.3 |
| Likoma | 637 | 303 | 7 | 2.3 | 334 | 10 | 3.0 | 2.7 |
| Mzuzu City | 61,263 | 29,830 | 929 | 3.1 | 31,433 | 796 | 2.5 | 2.8 |
| Central Region | 2,851,318 | 1,414,788 | 38,321 | 2.7 | 1,436,530 | 33,949 | 2.4 | 2.5 |
| Kasungu | 332,412 | 165,215 | 3,994 | 2.4 | 167,197 | 3,564 | 2.1 | 2.3 |
| Nkhota Kota | 160,160 | 80,077 | 2,185 | 2.7 | 80,083 | 1,797 | 2.2 | 2.5 |
| Ntchisi | 117,097 | 57,764 | 2,065 | 3.8 | 59,333 | 1,802 | 3.0 | 3.3 |
| Dowa | 287,969 | 142,579 | 5,453 | 3.8 | 145,390 | 5,053 | 3.5 | 3.7 |
| Salima | 179,531 | 89,323 | 3,516 | 3.9 | 90,208 | 3,158 | 3.5 | 3.7 |
| Lilongwe | 643,665 | 319,875 | 8,654 | 2.7 | 323,790 | 7,630 | 2.4 | 2.5 |
| Mchinji | 244,493 | 122,351 | 4,106 | 3.4 | 122,142 | 3,571 | 2.9 | 3.1 |
| Dedza | 326,177 | 161,998 | 3,222 | 2.0 | 164,179 | 2,836 | 1.7 | 1.9 |
| Ntcheu | 243,907 | 121,765 | 2,377 | 2.0 | 122,142 | 1,987 | 1.6 | 1.8 |
| Lilongwe City | 315,907 | 153,841 | 2,749 | 1.8 | 162,066 | 2,551 | 1.6 | 1.7 |
| Southern Region | 3,016,389 | 1,490,369 | 31,153 | 2.1 | 1,526,020 | 27,663 | 1.8 | 2.0 |
| Mangochi | 424,182 | 210,251 | 4,164 | 2.0 | 213,931 | 3,636 | 1.7 | 1.9 |
| Machinga | 265,077 | 130,555 | 3,106 | 2.4 | 134,522 | 2,758 | 2.1 | 2.2 |
| Zomba | 301,370 | 148,629 | 2,223 | 1.5 | 152,741 | 1,909 | 1.2 | 1.4 |
| Chiradzulu | 145,382 | 71,985 | 2,571 | 3.6 | 73,397 | 2,384 | 3.2 | 3.4 |
| Blantyre | 173,113 | 85,436 | 2,087 | 2.4 | 87,677 | 1,858 | 2.1 | 2.3 |
| Mwanza | 48,800 | 23,968 | 640 | 2.7 | 24,832 | 591 | 2.4 | 2.5 |
| Thyolo | 304,834 | 150,036 | 3,991 | 2.7 | 154,798 | 3,744 | 2.4 | 2.5 |
| Mulanje | 268,179 | 132,082 | 2,039 | 1.5 | 136,097 | 1,774 | 1.3 | 1.4 |
| Phalombe | 167,408 | 82,558 | 1,622 | 2.0 | 84,850 | 1,535 | 1.8 | 1.9 |
| Chikwawa | 228,085 | 114,559 | 2,693 | 2.4 | 113,526 | 2,203 | 1.9 | 2.2 |
| Nsanje | 126,817 | 63,930 | 962 | 1.5 | 62,887 | 819 | 1.3 | 1.4 |
| Balaka | 167,918 | 83,942 | 1,913 | 2.3 | 83,976 | 1,543 | 1.8 | 2.1 |
| Neno | 58,159 | 28,749 | 804 | 2.8 | 29,410 | 720 | 2.4 | 2.3 |
| Zomba City | 38,921 | 18,696 | 290 | 1.5 | 20,225 | 314 | 1.6 | 1.6 |
| Blantyre City | 298,144 | 144,993 | 2,048 | 1.4 | 153,151 | 1,875 | 1.2 | 1.3 |

(Source: NSO, 2008 Population and Housing Census)

2.4 Causes of disability

In this study, children with disabilities (and their parents/carers) were asked about the causes of their disability. Biomedical explanatory causes were not universally accepted or known, either by key informants or by children with disabilities and their parents.

Of the 43 children interviewed, only five did not know the cause of their disability. There were two main causes of disability - birth defect or illness - representing 74% of all causes mentioned (see table 2.7 below). Witchcraft as a cause of disability was only mentioned once. The most common forms of disability were physical disabilities, and hearing and visual impairments. The physical disabilities mainly affected the limbs and affected mobility.

Table 2.7: Perceived causes of disability in 43 children interviewed individually

| Standard Disability Classification | Disability type | Birth | Illness | Un-known | Acci-dent | Birth /ill-ness ²⁰ | Snake bite | Witch-craft | Total |
|------------------------------------|-------------------------------------|-----------|-----------|----------|-----------|-------------------------------|------------|-------------|-----------|
| Physical | Physical disability | 9 | 4 | 1 | 2 | 0 | 1 | 1 | 18 |
| Multiple | Multiple disabilities ²¹ | 5 | 1 | 1 | 0 | 2 | 0 | 0 | 9 |
| Sensory | Hearing | 0 | 5 | 0 | 0 | 0 | 0 | 0 | 5 |
| Sensory | Hearing & speech | 1 | 3 | 1 | 0 | 0 | 0 | 0 | 5 |
| Learning | Speech | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 2 |
| Developmental | Epilepsy | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| Albinism | Albinism | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Sensory | Visual | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Learning | Learning difficulties | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 1 |
| | All | 18 | 14 | 5 | 2 | 2 | 1 | 1 | 43 |

²⁰ This represents those who mentioned that their disability was due to both birth and illness.

²¹ There were a number of children who had multiple disabilities that were difficult to classify.

2.5 Common challenges faced by children with disabilities

Key informants, together with children and adults who had direct experience of disability were asked about the challenges (in school and the wider community) facing children with disabilities. Some key informants (such as mainstream and special needs education teachers) had first-hand information of these children from working closely with them. Although children with disabilities have positive experiences as well as challenges, this report presents only the challenges. These challenges are not ranked in any way, as this was a qualitative study and because every child with a disability is unique. The study instead presents a combination of what the children themselves, their parents and key informants reported. Key informants could report general challenges, but the children and their parents were more specific. The fact that the challenges have now been identified means that programming can address them. The challenges are presented following themes in the community-based rehabilitation matrix discussed above - health (and sanitation), education, livelihoods and social issues.

It is perhaps worth noting that a public opinion survey conducted in June 2012 asked 2,400 people whether persons with disabilities were treated unequally under the law, by courts, traditional leaders, employers and the police. Most respondents felt that these institutions were said to treat persons with disabilities equally.²² This study, however, suggests that the reality in society is rather different.

²² Tsoka, M.G. (2012). Afrobarometer Round 5 Summary of Results. Zomba: CSR

2.5.1 Challenges in access to healthcare

Some of the access challenges related to healthcare are also relevant to education (see below). For instance, lack of appropriate transport means that if a child with limited mobility falls sick, someone has to carry him or her to the health facility, regardless of the weight and age of the child. Other challenges experienced by children with disabilities when accessing health services are shown in Table 2.11. All of the challenges are experienced by male and female children alike.

Table 2.11: Challenges related to access to healthcare

| Challenge | Type of disability |
|--|---|
| Lack of appropriate transport to health facilities | Physical disability, especially those with reduced mobility and visual impairment |
| The need to be carried to, from and around the health facility | Physical disability, especially those with severe mobility challenges |
| Lack of guardians to take a sick child with a disability to a health facility | Physical disability, especially those with severe mobility challenges, very young children and those with visual impairment |
| Use of over-the-counter medication due to inaccessible health care | All types of disabilities |
| Lack of resources (vehicles and/or cash) to transport sick children to health facilities from both households and SNE institutions | All types of disabilities |
| Poor and discriminatory treatment by health workers | All types of disabilities |
| Failure to communicate with health workers unless escorted by a carer who can help | Children with hearing and/or speech impairment |
| Health education messages not provided in accessible formats | Children with visual impairment, albinos and hearing impairment |

Source: Primary data collection reports

RESULTS

In cases where there was no one to take the sick child to a health facility, he or she did not receive treatment. If the family could afford it, the child might instead be given home remedies including over-the-counter medication and traditional medicine. Children with disabilities and some key informants talked of discriminatory treatment by health workers, especially within health facilities. One village headman in Lilongwe said that children with disabilities were always the last ones to receive treatment at the hospital. Participants in a focus group discussion with children with disabilities in Lilongwe said that instead of treating such children, some health workers would not even enquire into the nature of the health problem. The health workers would say, *'ingopitani ku central akakuthandizani ife palibe chomwe tingakuthandizeni,'* telling them to go to the central hospital, as there was nothing that could be done to help. Communication problems between a sick disabled child and health workers might be aggravated if there was no guardian or interpreter. Communication problems were mainly mentioned with regard to children with hearing impairments.

There is a lack of health education messages in formats accessible to children with visual impairments. A special education teacher in Chiradzulu said most of the information on HIV and AIDS, for example, is in print form and not accessible to children with poor vision. There is very little health information available in braille. Another special education teacher said that children with visual impairment might not be able to see health-related posters and pamphlets. Health education messages are important and relevant to children with disabilities, so they need to be translated into appropriate formats such as large print or braille.

Some forms of disability presented unique challenges. For example, children with epilepsy need a constant supply of drugs. Informants reported a recent lack of epilepsy drugs at local health facilities, so that children with this condition and their parents or guardians had to travel long distances to obtain the drugs. If they could do this they experienced more frequent attacks of epilepsy. More rarely, some children with disabilities are simply not taken to a clinic when they are ill. A focus group discussion with children with disabilities in Balaka said that other families in the area did not care when a disabled child was sick and that some families would simply lock up such a child at home. Participants said that this happened when a child had suffered a long illness. Those with albinism had unique challenges too. Many parents did not know the proper treatment for their children's skin and eye problems. Even if they did know, they might lack money transport or to buy sunblock lotions, sunglasses and hats.

2.5.2 Challenges in accessing sanitation facilities

Children with disabilities also experience challenges that relate to sanitation. Those needing assistance to bathe were likely to have fewer baths than other children. Likewise, those who needed someone to wash their clothes were likely to wear dirtier clothes than their counterparts. Boys were said to be more neglected than girls in terms of being given a bath or having their clothes washed or changed. Children with disabilities who had problems using toilets were also likely to soil themselves, as help might not be available when needed. A related challenge is the design of toilets, even for those who are able to help themselves. In most cases access to sanitation facilities was problematic, the worst case being public toilets in schools and health facilities. Toilets in schools constituted a health hazard to the visually impaired or those who use wheelchairs or use both hands and feet when moving from one place to another. A special education teacher at one school in Lilongwe said that children who used both hands and feet ended up touching the stools or urine in the toilets. Children with visual impairment also had problems in using toilets that are not clean, for example stepping on stools and urine. It was suggested that there should be special toilets for them. For children with mental illness, it was pointed out that they might not know how to handle themselves in the toilets. Many of them soiled themselves and attracted negative comments from fellow students. If toilets became messy, it was difficult for other children with disabilities to use them. Even though mentioned by only a few children with disabilities, it is likely that other children with similar disabilities would face exactly the same challenges, and that inadequate provision of accessible sanitation is an important factor causing such children to withdraw from school.

2.5.3 Challenges related to access to education

In 2003 a national survey of persons with activity limitations in Malawi found that only 18.8% of the persons with disabilities (of school age) were attending school. More than twice as many of the same age group without disabilities (41.1%) attended school.²³ Respondents in the current study said that most children with disabilities were likely to be out of school. For children with disabilities in school, the most common challenge was that the environment was not disability-friendly. Table 2.10 presents the common challenges that children with disabilities experience when accessing education.

²³ Loeb, M. and A. Eide. (2004). Ibid.

Table 2.10: Challenges related to access to education

| Challenge | Sex | Type of disability |
|---|----------------|--|
| Children not sent to school for various reasons: household poverty, overprotection, lack of proper care in school and education being deemed irrelevant to children with disabilities | Both/ girls | All |
| Unfriendly education system: lack of specialist teachers and SNE-oriented teachers, specific teaching and learning materials, and unfair examination system | Both | Hearing impairment, visual impairment and those with learning difficulties |
| Unfriendly school environment: long distance from home, inaccessible classrooms, playgrounds and toilets, poorly lit classrooms and presence of bullies | Both | Physical disability, albinos and all types of disabilities for bullying |
| The need to be carried to, from and around school | Both | Physical disability, especially those with mobility challenges |
| Lack of assistive devices, guides or assistants due to household poverty and lack of national prioritisation of disability issues | Both | Hearing impairment, visual impairment, physical disability |
| Voluntary withdrawal due to self-pity, poor performance, inadequate care for certain disabilities, or being bullied or harassed | Both | All types of disabilities |
| Lack of school fees or transport money and related costs for regular or recommended SNE special schools due to poverty or household neglect | Both | All types of disabilities |
| Lack of accommodation in SNE institutions | Both | All types of disabilities but especially those with hearing impairment, visual impairment, learning difficulties |
| Voluntary withdrawal from school due to the need to take care of parents with disabilities | Both/ girls | Children of disabled parents |
| Withdrawal from school due to the failure by parents with disabilities to provide school needs such as writing materials and clean clothes, among others | Both | Children with or without disabilities but with disabled parents |

Source: Primary data collection reports

As shown in table 2.10, a major challenge is the lack of specialist teachers, particularly for children with learning difficulties and those with hearing or visual impairment. The lack of specialist teachers was mentioned by the teachers themselves, by children with disabilities and by their parents. There are few special needs education schools and resource centres, and hostel accommodation for children with disabilities is limited. A number of key informants mentioned that girls with disabilities are less likely to be in school, but no statistics were provided. A 2003 survey showed that 41% of girls with disabilities and 29% of boys with disabilities had never attended school.²⁴ One reason why some girls with disabilities do not attend school is over-protection: a 14-year-old girl with epilepsy in Karonga was not in school because she frequently collapsed and her parents thought it dangerous for her to be in school. The school was near a river and the parents worried she might drown if she had a seizure near the water. Some parents felt that there was no one at the school who could adequately care for their children with disabilities and that they would be better off at home. Some girls with disabilities are not in school simply because, as key informants mentioned, boys are more likely to be sent to school than girls.

Children with disabilities and their parents said that they dropped out of school because of lack of school fees and learning materials. A parent of a 15-year-old disabled child in Balaka could not afford notebooks and other school requirements - she foresaw that when her son went to secondary school she would not be able to pay school fees. The lack of assistive devices, guides and assistants also reduce access to education. One 12-year-old girl who was physically impaired reported that she attended school but had to be carried by her younger sister to get there. Other children with disabilities wanted to go to school but said that their siblings sometimes refused to escort them, which forced them to stay at home. Children with disabilities sometimes dropped out of school because of the lack of a guide.

The examination system is perceived as unfair by many children with disabilities, especially those with hearing or visual impairment and those with learning difficulties. This issue was only mentioned by children, not by parents. In some cases teachers treated children with disabilities unfairly. A 16-year-old boy who was physically disabled and visually impaired said that his school environment was poor - there were no desks and his teachers did not 'wish him well' - so he was not able to pass examinations. He explained that his teachers seemed to have low expectations of a person with disability. This attitude was exacerbated by the lack of specialist teachers at his school. Failure and the requirement to repeat an academic year discourage children with special needs and they tend to voluntarily drop out of school. Children reported that it is especially painful to children with disabilities when they know that their failure is due to their disability and not inability. Most drop out after trying for many years, with some children still in primary school at the age of 17.

²⁴ Loeb, M. and A. Eide (2004). Ibid

RESULTS

The challenges to accessing education for children with disabilities relate to home (lack of appropriate transport, clothing, school needs because of poverty and negligence) as well as to school (infrastructure, teachers and peers). Some of these challenges can be dealt with through public awareness campaigns.

2.5.4 Challenges in access to skills development and employment

Table 2.12 presents some of the common challenges in accessing skills development programmes and employment. All challenges are relevant to both male and female children.

Table 2.12: Challenges in accessing skills development and employment opportunities

| Access to skills development | Age |
|--|----------|
| Too few places for vocational training for children with disabilities | All ages |
| Inadequate knowledge of vocational training opportunities for children with disabilities | All ages |
| Lack of qualifications | All ages |
| Access to employment and livelihoods | |
| Some types of disability restrict the type of employment | > 14 yrs |
| Places for regular short-term training are limited and almost closed to children with disabilities | > 14 yrs |
| Employers generally discriminate against children with disabilities | > 14 yrs |

Source: Primary data collection reports

With regard to skills development, the most critical challenge was the mismatch between demand and supply of training. There are too few places on vocational training courses, and many children with disabilities and their parents did not what type of courses were on offer. Current vocational training curricula are not responsive to the demands of children with disabilities or to changes in the service market. A number of focus group discussions and in-depth interview participants said that information and communication technology (ICT) should be introduced into the curriculum so that children with disabilities could learn how to repair cell phones, computers and other electronic devices.

Lack of qualifications is a major barrier, because enrolment on a training course requires minimum qualifications. One man with an epileptic son in Balaka said that he had never made an effort to find a training course for his son because he did not have secondary school education and he thought that he could not be enrolled in a vocational training school. A specialist teacher in Chiradzulu added that most children with disabilities did not meet minimum requirements for skills training. Some children with disabilities who sought admission to colleges were denied the opportunity, dropped out or were directed to areas that were not of interest to them. This limited their chances of employment or progression in later life. The shortage of vocational training schools, especially at community level, and a lack of awareness about such schools limit access to vocational training for children with disabilities.

2.5.5 Access to employment opportunities for children with disabilities

Some employment opportunities are not open to all types of disability. During a focus group discussion with disabled girls at a secondary school in Lilongwe, participants claimed that visually impaired persons were the most victimised in terms of employment, as employers felt that there was nothing they could do. Those with hearing impairments were said to be better off - when they wanted to do some *ganyu* (piecework), someone might negotiate wages on their behalf and they could perform manual jobs. However, employers generally found it difficult to employ children (and other persons) with disabilities mainly because they doubted their ability to work.²⁵ Children with disabilities who manage to find employment may be exploited - a specialist teacher mentioned a boy with learning difficulties in his community who was hired to fetch water for moulding bricks and was given only food leftovers or MK20 (a mere US\$0.05) for a day's work.

2.5.6 Socio-cultural challenges

This study found three types of social challenges experienced by children with disabilities. The first two are faced at home and in the wider community, while the third is specific to forming relationships. Table 2.8 presents the challenges faced at home and in the community.

²⁵ While the Employment Act (2000) does not allow the employment of children below the age of 14, in practice they are employed. The employment of children aged less than 15 years, as provided for in the ILO Convention No. 138 on minimum age for employment, is prohibited.

Table 2.8: Social challenges at home and in the community

| Home and community challenges for children with disabilities | Sex |
|---|------------|
| Such children less favoured at home due to limited resources or prejudice | Both |
| Those not living with their biological parents ill-treated and discriminated against by step-parents or guardians | Both |
| Children with disabilities, especially those with a speech impairment, beaten up by peers | Both |
| Not being understood by peers (sometimes leading to aggressive behaviour) | Both |
| Children with disabilities rarely cared for by the community | Both/boys |
| Mocked and given derogatory names in relation to their disability | Both/boys |
| Children with disabilities (especially with speech impairment and/or mental disability) sexually abused | Both/girls |
| Boys less protected and girls over-protected due to risk of sexual abuse | Girls |
| Raped and impregnated disabled girls suffer trauma and have no support | Girls |
| Children with mental disability exploited due to limited reasoning capacity | Both |
| Home and community challenges for children with disabled parents | |
| Children living with disabled parents work more and play less than their peers to support parents | Both |
| Children whose parents have problems experience mistreatment due to lack of parental support | Both |

Source: Primary data collection reports

The main challenge facing children with disabilities is that *they are rarely treated equally with other children*, either at home or the wider community. They tend to be either neglected or over-protected, both of which are to their disadvantage. Although both boys and girls face this challenge, boys are more neglected than girls and girls are more over-protected than boys. Disabled children (both girls and boys) living with step-parents or guardians face even worse general neglect at home. A 38-year-old man in Lilongwe said he was the father of five children and was also caring for two other children, including a girl who had a physical disability. He ran a business but did not make much money. All his children went to school except the girl with a disability. He said that he could not pay school fees for her as he did not earn enough, although all his own children were in school.

Children whose parents have disabilities face different challenges at home. Most such children are forced to work hard and play less than their peers because society expects them to take care of their parents. A 15-year-old girl in Lilongwe whose father had a disability reported that she and her siblings washed clothes for their father and give him water to bath every day, which other children did not have to do. Another 15-year-old girl in Lilongwe said that she sometimes could not play with her friends because she had to push her mother's wheelchair to town to sell commodities. Friends have to wait for such children to do their work before they can join them in play. Because of the burden of domestic responsibilities, children who live with disabled parents are also more likely to drop out of school. In child rights terms, such children are denied the right to play and get an education.

The social challenges faced by children with disabilities in the community stem from prejudice and lack of consideration. It seems society does not castigate anyone (parent or otherwise) who mistreats or neglects children with disabilities. And children whose parents had disabilities cited cases in which they were beaten by their peers. These peers knew that the parents of the children they beat could not retaliate. Such children suffer exploitation too: a 17-year-old boy whose guardian had a disability and mobility problems said that the person who hired him to mould bricks did not give him the money they had agreed upon. He was told, *'This is enough for you and your disabled father.'* The economic exploitation of children with disabilities or children whose parents had disabilities was frequently reported. The mistreatment of children with disabilities is quite common at community-level, which gives the impression that society condones this behaviour. While parents may protect their children, society as a whole should also protect its members, regardless of disability, sex or age.

Although not commonly reported, some parents were said to hide their disabled children. A special education teacher in Lilongwe mentioned a boy with visual impairment who was locked up at home for several years while his parents were busy with their life. Relatives of the boy stoned the teacher and his colleagues when they tried to persuade the parents to send the boy to school. A number of participants mentioned that some parents hid children with disabilities because they regarded such children as *'not children'*. This was said to be because the parents believed that they could do nothing to help the children, or because they felt ashamed by them.

Another challenge is that children with disabilities are often practically abandoned by parents once they are sent to a special needs education institution. Headmasters and special-needs teachers reported that most parents did not take care of their children once they had put them in boarding schools: they did not send pocket money or transport money at the end of the term for their children to travel back home. Most of them did not visit their children in boarding school regularly. In some cases it was reported that children in institutions might wait up to two weeks after the end of term before being collected by their parents.

RESULTS

Turning to the third broad social challenge, forming relationships can be problematic. Some children with disabilities, especially when young (and depending on the type of disability), are able to bond and play. However, as they grow older some have problems finding suitors for marriage as can be seen in Table 2.9 below.

Table 2.9: Social challenges in forming relationships

| Challenges in forming relationships | Sex | Age |
|---|-------|----------|
| Not approached by suitors | Girls | >14 yrs |
| Not accepted after proposing | Boys | >14 yrs |
| Isolated/discriminated against therefore difficult to bond | Both | >14 yrs |
| Some disabilities (such as hearing impairments or mobility problems) make it hard to form relationships | Both | All ages |

Source: Primary data collection reports

The type and severity of disability may affect the degree to which people with disabilities will have difficulties in attracting the suitors. Some boys reported that it was hard for them to find a girl because their disability made it difficult for them to work and support a partner. Some girls with disabilities (in focus group discussions in Lilongwe and Ntcheu) reported that they had never been approached by boys. Some women with disabilities reported being abandoned by their husbands: one woman with a disability had been married but said that her husband run away after a few months, leaving her with a child. This woman uses a wheelchair and takes care of eight children.

Another challenge is that in some cases the peers of children with disabilities do not want to play with them. At a focus group discussion conducted at Malingunde School for the Blind, participants said that other children sometimes dispersed when children with disabilities approached them. It was suggested that this happened because children feared they might be infected with disability or that the children with disabilities might ask for help.

2.5.7 Challenges faced by parents

Table 2.13 details the challenges faced by persons with disabilities who are parents themselves and by the parents or carers of children with disabilities.

Table 2.13: Challenges faced by parents

| Challenges facing parents of children with disabilities |
|--|
| Limited time for income-generating activities because child requires extra care |
| Prospect of taking care of a child for life (children without disabilities are able to help with errands when young, and would expect to care for their parents later in life) |
| Challenges facing parents who have disabilities themselves |
| Abandonment by spouse |
| Failure to provide basic necessities, including good shelter to family, due to lack of income-generating activities or spouse who can take responsibility |
| Some disabilities restrict the type of employment |
| Employers generally discriminate against people with disabilities |
| Mobility challenges tend to reduce profit on business as some activities have to be delegated |
| Low levels of education limits the possibilities of formal employment |
| Failure to take advantage of common cash income sources such as casual labour (ganyu) |

Even though many parents of children with disabilities try to take care of their children, it is not easy to balance the full-time care needed by children with severe disabilities and other household duties. One response, mentioned by a few informants, was for parents to lock up such children so that they could carry out productive activities. Other parents found that the time devoted to children with disabilities meant that their business ventures fail to prosper. A 43-year-old father of a child using a tricycle said that it was difficult for him to work because his child needed so much attention that he spent too little time on farming and tailoring - hence he did not make enough money for the household. Parents caring for children who have severely impaired mobility must mind their child constantly in case the child needs to be moved. This challenge sometimes led parents, even with good intentions, to lock their children up.

Parents who themselves have a disability may suffer serious psychological challenges when they are unable to provide adequately for their household. Having a disability may prevent them earning commonly available sources of income such as 'ganyu'. The section on employment above discussed in more detail why persons with disabilities have few employment opportunities. Having children when they are unable to generate enough income to meet food, shelter and education needs makes them feel inadequate. Some divorced or separated women with disabilities said that their husbands had abandoned them because they (the wives) were unable to carry out all the expected household and childcare tasks.

RESULTS

The challenge of psychological trauma was rarely mentioned by parents. Nor was it mentioned much by children with disabilities themselves. However, many children wondered why they were different from their peers and why other people (including family members in some cases) treated them differently. In some cases this psychological trauma forced children with disabilities to withdraw from school and other activities. For parents with children whose disability was likely to make them dependent for the rest of their lives, the trauma of imagining life for their children without them was severe. Such parents also faced the prospect that their children with disabilities would not be able to care for them as they grew older - even in youth such children cannot be sent on errands. Parents who became disabled later in life have the psychological trauma of remembering how they used to be able to take care of their children. This suffering affects how they relate to their children and can be detrimental to the children who support them. The management of psychological challenges affecting children with disabilities, other persons with disabilities or carers of children with disabilities is not commonly available in Malawi.

2.6 Responses to the various challenges

Information from children, parents and key informants revealed that there is little external response to the challenges experienced by children with disabilities. Individual households have naturally responded to some of the challenges but many others remain. A summary of key responses to the major challenges is presented below.

2.6.1 Dealing with health-related challenges

Some access challenges, such as a lack of assistive devices and transport, are common to those related to education. Some parents are unable to transport their children with disabilities to clinics or hospital when necessary, and few can afford assistive devices. In a few cases, government has provided devices, but there are many more children who would benefit from a wheelchair or tricycle, which would ease their access to health care services.

The challenge of poor attitudes shown by health workers and the lack of drugs are not unique problems to children with disabilities. However, considering the effort parents and guardians make to take their children to health facilities, the absence of drugs and unresponsive health workers amplifies the negative effects of these challenges. Carers of children with disabilities often resort to over-the-counter drugs and traditional medicine, only going to a health facility when a child is seriously ill. A child with a hearing impairment in Lilongwe said that the last time he was ill (two months before the interview) his parents took him to the clinic for treatment but the nurses were on strike and he had to be taken to traditional healers for further treatment.

Health care for children in special needs institutions tends to be dealt with pragmatically by school administrators. Institutions can divert other resources (such as for food and other boarding expenses) towards health treatment. A special needs teacher at Montfort Demonstration School said that children with disabilities generally failed to pay their medical bills at the nearby Nguludi Mission Hospital. (Nguludi is a Christian Health Association in Malawi (CHAM) facility and all patients pay to access services.) The nearest public facility is far away. Since most parents did not send pocket money to their children, the school shouldered most of the medical expenses and in some cases used funds meant for boarding. The head teacher occasionally asked teachers to contribute to students' medical bills. The schools also requested parents to contribute to a 'health care fund', but this was said to be inadequate to cover costs. None of these provides a sustainable solution to the problem. Lack of transport in these institutions is also major problem. This challenge could be dealt with by the state, given that there are very few schools catering for children with disabilities. In some cases health workers actually visit the institutions and provide services to children with disabilities who are not feeling well.

In this study it was not ascertained whether the lack of health education messages in appropriate formats is currently being addressed. However, this activity could be carried out by the Ministry of Health's Health Education Unit. Currently, the most critical health education messages concern HIV and AIDS. The National AIDS Commission is one of the duty-bearers here and could take useful action, as disabled children would otherwise access such information by hearsay only.



2.6.2 Addressing education-related challenges

Providing appropriate education to children of different abilities and conditions is the duty of the state, as stipulated in the Constitution. The state is responsible for providing appropriate education in an environment that is conducive to learning. Parents are also responsible for ensuring that their children, regardless of disability, are available and equipped with material for learning. Most challenges in education concern the capability of these two duty-bearers. Household poverty means that most parents or guardians of children with disabilities cannot provide school needs such as school fees. However, parents with children with disabilities do their best to ensure that their children are in school. Many children with severe mobility challenges are carried to and from school by parents and siblings. Within the school premises friends carry them around. Parents and guardians also provide their children with pens and exercise books. However, many parents fail to provide what their children require to learn comfortably, so they drop out of school.

One of the credits due to government is that primary education is now free. This is important, as many studies have demonstrated that households with children with disabilities constitute some of the poorest households. However, primary education is not compulsory, so children may drop out of school (or their parents may withdraw them) at any time before they reach adulthood at 18 years of age.

The government supports special needs education by providing specialist teachers, and teaching and learning materials in schools. The government has also established resource centres in mainstream schools to improve the education offered to children with disabilities. In 2011 there were 100 resource centres in mainstream primary schools and 22 centres in secondary schools. The Ministry of Education reports that it needs 12,000 special needs teachers but so far there are only 1,000.²⁶ The lack is being addressed by Montfort College in Chiradzulu, which trains such teachers to diploma level.²⁷ However the lack of particular incentives for special needs teachers means that some migrate out of SNE teaching or teaching altogether.

There is a Directorate of Special Needs Education (under the Ministry of Education), which is responsible for making sure that schools provide an environment where learners with special needs can access education unhindered. The government is also aiming to re-orient regular teachers so that they are aware of the particular needs of children with disabilities. However, progress is slow - most teachers have not yet been oriented. It should also be noted that the number of places in special schools is limited. Most of the schools were built by faith-based organizations and they have not expanded to meet the growing demand from children requiring such facilities. Existing schools are not being expanded, nor are new ones being built. Efforts made by both parents and the state fall short of requirements.

²⁶ Munthali, A. (2011). A Situation Analysis of Persons with Disabilities in Malawi. Lilongwe: CBM and MoDEA.

²⁷ Munthali, A. (2011). Ibid.

To improve the accessibility of buildings for children with disabilities, the Ministry of Education has issued a circular directing that all new schools should be disability-friendly. New schools such as the new Teachers' Training College in Machinga are following to this directive.²⁸ There is also a school improvement programme that allows the community to choose the type of improvements to implement. If communities choose to prioritise disability issues, this should improve the environment for children with disabilities.

Given the prevailing levels of household poverty, the challenge of lack of assistive devices such as wheelchairs will continue unless government can provide them. Currently, the government (through the organization Malawi Against Physical Disabilities (MAP)²⁹ provides most of these devices. Other NGOs also provide such devices, but demand far outstrips supply. A few statistics give an idea of the scale of the problem: a study in 2004 found that 17% of respondents with disabilities used assistive devices. More men (25%) used assistive devices than women (14%). Seventy per cent of respondents who used assistive devices used personal devices such as wheelchairs, crutches and walking sticks. Some used more than one device. Thirty-four per cent of those using devices acquired them privately, 19% obtained them from government, 9% through NGOs and the rest (38%) through other sources.³⁰

Another challenge is the lack of transport to a special needs education school once a child has been assessed to go there. The government used to support parents and the child with transport to the institution, but the burden is now borne by the parents. As a result, many parents cannot afford to send their children to such schools.

The Malawi Council for the Handicapped is implementing a number of community-based rehabilitation projects to ensure that children with disabilities stay in school. The projects encourage children with disabilities to enrol in mainstream schools, with some being referred to special schools. Special needs education teachers are also being trained to lessen the acute shortage of such teachers. The projects sometimes pay secondary school fees for students with special needs.³¹ Despite these interventions, the demand for special needs education is far from being fully met.

28 Munthali, A. (2011). Ibid.

29 MAP is under the MoH and is responsible for the early identification of impairments or disabilities, support and training for parents of children with disabilities, providing rehabilitation services and creating awareness about disability.

30 Loeb, M. and A. Eide (2004). Ibid.

31 Munthali, A. (2011). Ibid.

2.6.3 Challenges and progress in skills development

As with education, the government is the main duty-bearer providing skills-development programmes to persons with disabilities. This is mainly done at training institutions owned by the Malawi Council for the Handicapped in Lilongwe and Chiradzulu. All children with disabilities who have the required educational qualifications are free to apply. However, as discussed above, few children with disabilities have these qualifications. Also, space in these colleges is limited and the curriculum is out of date. As a result, many children are denied the opportunity to learn skills that would help them join the labour market (whether as employees or self-employed). There are in any case limited employment opportunities for people with disabilities, and discrimination against such people is widespread. The number of training places needs to be increased, and the curriculum should be reviewed and expanded to include disability-friendly courses such as ICT maintenance.

2.6.4 Slow progress with social challenges

Most of the social challenges faced by children with disabilities could be dealt with through public awareness campaigns. Messages could target the guardians and parents of children with disabilities, communities and all regular schools as well as other institutions. However, there have so far been no widespread, consistent and targeted public awareness campaigns. A particular challenge is that there is no sanction or punishment for people who mistreat or abuse children with disabilities.

One of the coping mechanisms adopted by children with disabilities is simply to withdraw, rarely venturing out to play with other children. Some even drop out of school. Some parents withdraw their children with disabilities from the public eye when they perceive they are being mistreated. As discussed earlier, some parents actually lock up children with mental and other disabilities.

2.7 Institutional Analysis

With the objective of presenting actors and the type of services offered (including geographical coverage), this section presents the supply-side of disability services. It complements the demand-side implicitly discussed earlier (the challenges faced by children with disabilities and their parents or guardians). Of all the stakeholders visited, a total of 16 institutions were considered to have direct links with children with disabilities and were therefore included in the analysis. The analysis included their mandates, services offered, coverage of their services and challenges faced in offering these services. The analysis did not cover institutions offering special needs education, because they were not systematically visited. Their role is covered by the Ministry of Education, which underwrites their services. Organizations that fund disability-related activities were also excluded.

2.7.1 Types of actors and services offered

Institutions dealing with disability can be categorised into government, member organizations and service-providers. Government institutions include ministries, departments and state-sponsored service-providers. Member organizations include disabled people's associations. Service-providers are non-state organizations that offer services to children with disabilities. There is some blurring of these distinctions - some government institutions and member organizations also offer services, while non-state actors do not necessarily offer services directly to children with disabilities. Based on institutional mandates and discussions with officials, services were grouped into different categories. Table 2.14 on the following page presents this information by service provider and type of institution.

Table 2.14: Type of services provided to children with disabilities

| Type of service | Institution | Type of institution |
|--|-----------------------------------|---------------------|
| Policy/programme formulation | MoDEA | Government |
| Coordination | MoDEA | Government |
| | MACOHA | Government |
| | FEDOMA | DPO |
| Advocacy | MoDEA | Government |
| | FEDOMA | DPO |
| | APDM | DPO |
| | MANAD | DPO |
| | TAAM | DPO |
| | PODCAM | DPO |
| | Christoffel Blinden Mission (CBM) | Service-provider |
| Material support to children with disabilities | MoGCSW | Government |
| | MACOHA | Government |
| | Malawi Union for the Blind (MUB) | DPO |
| | FEDOMA | DPO |
| Education/skills training | MoEST | Government |
| | MoGCSW | Government |
| | MACOHA | Government |
| | MADISA | DPO |
| | Feed the Children | Service-provider |
| Mobility assistive devices | MACOHA | Government |
| | MAP | Government |
| | Sue Ryder | Service-provider |
| Physical therapy | MACOHA | Government |
| | MAP | Government |
| | Cheshire Homes | Service-provider |
| | Sue Ryder | Service-provider |
| | SOS Villages | Service-provider |
| Occupational therapy | MAP | Government |
| | Cheshire Homes | Service provider |
| Corrective/orthopedic surgery | MAP | Government |
| Monitoring and evaluation | MoDEA | Government |
| | MACOHA | Government |
| | FEDOMA | DPO |

The accessibility of these services was not assessed, as this would be difficult to do in a qualitative study. However some of the general challenges were discussed above, and it appeared that a large proportion of children with disabilities experienced serious challenges when trying to access services.

Table 2.15 below shows the coverage given by each of the institutions visited. However, despite the fact that some of the service-providers are supposed to provide services nationwide, this is not necessarily the case in practice.

Table 2.15: Coverage of services for children with disabilities

| Institution | Services | Coverage | Specifics |
|----------------|--|--------------|--|
| MoDEA | All | Countrywide | All districts |
| MoGCSW | All | Countrywide | All districts |
| MoEST | All | Countrywide | All districts |
| FEDOMA | Coordination | Countrywide | Membership not given |
| | Advocacy | 4 districts | Machinga, Salima, Lilongwe & Mchinji |
| APDM | Advocacy | Countrywide | 480 members |
| MANAD | Advocacy | Countrywide | Membership not given |
| TAAM | Advocacy | 7 districts | 703 members in Zomba, Nkhota Kota, Mchinji, Balaka, Mzimba, Dedza & Ntchisi |
| MUB | Advocacy | Countrywide | 9,373 members |
| PODCAM | Advocacy | 21 districts | 13,250 beneficiaries |
| MADISA | Sports training for people with disabilities | 4 districts | Blantyre, Zomba, Machinga & Mulanje |
| MACOHA | CBR | 16 districts | Karonga, Mzimba, Nkhata Bay, Nkhota Kota, Salima, Lilongwe, Balaka, Machinga, Neno, Blantyre, Chikwawa Nsanje, Mwanza, Rumphu, Chiradzulu & Thyolo |
| MAP | All | 1 district | Blantyre |
| Cheshire Homes | All | 2 districts | Blantyre & Lilongwe |
| Sue Ryder | All | 2 districts | Balaka & Ntcheu |
| SOS Villages | Rehab services | 2 districts | Blantyre & Lilongwe |

RESULTS

Although government agencies can claim to have countrywide coverage, their resources are so thin that very little trickles down to the users of their services. Our district and community stakeholders (key informants, community leaders, parents of children with disabilities, disabled parents and children with disabilities themselves) rarely mentioned having *'felt the presence of these services'*. Even district officials, as already mentioned, complained that they lacked information on the relevant policies and laws. Service-providers who concentrated on one or a few districts were little better. Their resources were said to be so thin that only a small proportion of their target group knew about or benefited from their services. In other words, the coverage is theoretical only, as resources allocated are too little (according to the participants in this study) to be effective.

2.7.2 Reporting on disability issues

Stakeholder discussions revealed that there was no coordinated mechanism for reporting on disability issues. Each ministry compiled its own reports, and reporting depended entirely on the level of importance that each ministry or department attached to the subject. At district level, district social welfare offices (DSWO) of the MoGCSW deals with disability. But DSWO reports are not copied to the MoDEA even though this is the line ministry responsible for disability issues. Even reports from the MoGCSW to the Office of the President and Cabinet (OPC) are not copied to the MoDEA. A similar lack of coordination is found in education. As the sponsoring ministry of special needs education, all reports related to education of children with disabilities goes through the MoEST to the OPC (together with other education issues). But Education is not obliged to share the reports with Disability. Thus even within government there is no coordination of disability issues.

Ideally all disability issues would be coordinated by the MoDEA before being reported to the OPC every quarter. By extension all stakeholders (including ministries and government-sponsored service-providers and special schools) in the disability 'sector' would submit their quarterly reports to the MoDEA for compilation into a single document. The best mechanism for this would be meetings of the national disability coordinating committee (NACCODI). However, as noted above, this committee is not yet in place so effective coordination is difficult.

Reporting channels for government-sponsored organizations are straightforward, although not necessarily coordinated. The Malawi Council for the Handicapped (MACOHA) reports to the MoDEA, while Malawi Against Physical Disabilities (MAP) reports to the Ministry of Health. Even though disabled people's organizations work directly with the disability ministry, they are not obliged to provide reports. Some, depending on the nature of their activities, have their own 'parent' ministry. For example, the Malawi Disabled Sports Association (MADISA) works more with the Ministry of Youth and Sports. MACOHA, which provides social services to people with disabilities, works closely with the MoGCSW as well as reporting to the MoDEA .

The situation is worse at district level, especially for service-providers. Service-providers have worked with the MoGCSW (rather than the MoDEA) for a long time, and district social welfare officers are competent to deal with disability issues by training and practice. At district level the MoDEA is effectively invisible. Given this long-established scenario, it is difficult for service-providers to relate with the MoDEA at national level when at grassroots level they deal with the MoGCSW. And it is difficult for the MoDEA to coordinate activities when such activities are implemented at a level where it does not exist.

The solution could be working together. In discussions, these ministries mentioned that they worked with each other, although the mechanism for doing this was not clear. They apparently invite each other when formulating sector policies and when developing programmes and plans. However, such meetings are merely consultative. Disability officials invited to a meeting on programming for special needs education by the education ministry, for instance, would not expect to have strong influence because SNE does not fall under their remit. Proper coordination could only come about with a committee mechanism such as the NACCODI, which is perhaps why many stakeholders expressed support for bringing the committee into operation.

Stakeholders expressed various other concerns regarding the institutional framework for disability. Some saw the establishment of a specific MoDEA with clear objectives in 1998 as an indication of government seriousness towards disability issues. But they lamented the fact that the Ministry had not yet allocated enough resources to achieve its objectives. The Department of Disability Programmes, which deals with disability issues, has only seven officers. While this may not be a binding constraint, the limited financial resources certainly are binding. If the current staff were motivated and given sufficient resources, they could mount credible advocacy campaigns, develop meaningful policies and develop and implement programmes that would benefit people with disabilities.



RESULTS

Some stakeholders, however, believed that the creation of a ministry specifically responsible for disability issues had simply diverted resources that would otherwise be used to provide services to disabled people. Others took the view that the creation of the MoDEA was not in the interest of mainstreaming. They argued that for the mainstreaming agenda to move forward, it needed an institutional set-up that embraced inclusiveness. Just as special schools for children with disabilities are not always the best option for a disabled child, they argued that having a ministry for disabled people was not the best way forward. While it might be justifiable to have a ministry to champion the cause of disabled people, it was not necessarily beneficial when that 'champion' acted like a line ministry. Negative attitudes towards the 'champion' could arise when it agitated to have own officers at grassroots levels or worked to design and implement its own programmes and projects. Understandably, this agitation arose from frustration, especially when the MoDEA saw that actors did not mainstream or prioritise disability issues. Some government officials, especially at district level, gave low priority to disability issues due to lack of understanding of mainstreaming. They supposed that the MoDEA was fully resourced to deal with disability issues. Many people with disabilities also shared this supposition.

Seeing the mandate of the disability ministry and the size of the public purse, others recommend that, regardless of the status of the mainstreaming agenda, the MoDEA should not design intervention programmes but instead analyse programmes and lobby for the inclusion of disabled people (and the elderly) wherever possible. For example, if disability and age were considered to be vulnerabilities and used as criteria for inclusion in programmes, the Ministry should analyse the beneficiaries to check whether they are included fairly. In other words, the MoDEA should ride on existing programmes rather than creating parallel structures. To do so, it would need to build a strong monitoring and evaluation team.

Turning aside from questions over the existence and current form of the MoDEA, others recognised that progress on disability issues could only come if district councils mainstreamed disability. The first proposal was that instead of (or above) a champion ministry, there should be a 'disability' champion position similar to the District AIDS Coordinator. The Disability Coordinator (for lack of a better term) would not be attached to any line ministry and would report to the District Commissioner. At community level it was suggested that child protection workers could be retrained to be responsible for orphans, disability and other issues. These, like the MACOHA community-based rehabilitation experts (community rehabilitation workers and volunteers), would deal with both primary and secondary disability issues (being involved in the prevention of disabilities as well as rehabilitation of those with disabilities). By following this course, MACOHA would not need to expand to all districts. Another proposal was that all district councils should have a MACOHA community-based rehabilitation type of system. With this system, the community rehabilitation officer would become the district disability coordinator, while the community-level government officials would be retrained to take on the role of the community rehabilitation workers and MACOHA volunteers.

Regardless of any district-level reform, many stakeholders felt that MACOHA would benefit from a functional review. The first step would be to revise the Disability Act that established it as a council. Those involved in the initial stages of developing the Disability Bill stated that the early version of the draft bill established a Malawi Council for Disability Affairs (MACODA) to replace MACOHA. There is also an urgent need to review the 1971 Handicapped Persons Act to take on board the disability issues that have emerged over the years. Stakeholders argued that MACOHA's training component should be diversified to incorporate courses such as information and communication technology for disabled children who have completed secondary education. They said that MACOHA should also consider establishing rural polytechnics to train disabled people in trades such as farming or horticulture. A twenty-first century MACODA could also go into partnership with researchers to design inexpensive but functional assistive devices such as tricycles and wheelchairs.



3. RECOMMENDATIONS

The recommendations arising from this study have been grouped into short, medium and long-term recommendations.

Short-term Recommendations

Institutional

1. Implement the Disability Act and thereby bring the national coordinating committee (NACCODI) into operation. (MoDEA and stakeholders)
2. Replicate the NACCODI model at district level to help improve disability mainstreaming. (MoDEA)

Legislation and Policy

3. Initiate discussions with the Law Commission to review the 1971 Handicapped Persons Act. (MoDEA and MACOHA)
4. Review all disability-related policies to ensure that the specific needs of children with disabilities are addressed. (MoDEA and stakeholders)
5. Lobby for an increase in budgetary allocation for disability issues. (MoDEA, FEDOMA and MACOHA)
6. Lobby for the inclusion of disability issues in the post-2015 Global Agenda (successor to the Millennium Development Goals). (MoDEA and all stakeholders)

Data and Information

7. Undertake a needs assessment by type of disability to ensure that children with disabilities receive the particular care they need. (MoDEA)
8. Establish a meaningful monitoring system for all resource centres, rehabilitation facilities and skills training programmes. This would provide government with quality data for planning and budgeting purposes. (MoDEA, MACOHA, FEDOMA and its affiliates)
9. Conduct a countrywide survey of disabled people to collect disaggregated data on disability issues. (MoDEA, FEDOMA and MACOHA)
10. Carry out a comprehensive study on children with learning difficulties in order to design effective interventions. (MoEST)
11. Lobby for questions on disability to be included in national surveys. (MoDEA)

Awareness

12. Mount a sustained public awareness campaign on disability issues. (MoDEA, FEDOMA and its affiliates, and MACOHA)

Expansion of Services

13. Expand coverage of resource centres countrywide. (MoEST, through the Directorate of Special Needs Education)
14. Rehabilitate resource centres, SNE institutions and skills training institutions. (MoEST)
15. Train more specialist education teachers to meet the needs of the country. (MoEST)
16. Promote the establishment of community-based childcare centres (CBCCs) to ensure that children with special needs are properly cared for. (MoGCSW)
17. Train CBCC caregivers to understand the needs of children with disabilities and to make early diagnosis of disabilities. (MoGCSW)
18. Provide adequate funding to the MAP and other stakeholders so that they can provide assistive devices to children who need them. (Ministry of Finance)

Medium-term Recommendations

1. Review relevant policies and legislation to ensure that disability issues are understood and addressed. This would include providing disaggregated objectives and strategies for children with disabilities.
2. Establish a Disability Trust Fund.
3. Conduct a functional review of the MoDEA to reinforce the notion that disability issues are cross-cutting and require central coordination.
4. Integrate disability into health policies and plans.
5. Conduct a functional review of MACOHA and review the Handicapped Persons Act.
6. Run aggressive public-awareness campaigns based on proven Communication for Development methodology.
7. Conduct a study to analyse the budgetary allocation for the disability sector in Malawi.

Long-term Recommendations

1. Incorporate disability issues in overarching government policy and strategy documents, particularly the Malawi Growth and Development Strategy.
2. Mainstream disability issues to ensure that every service-provider considers children or people with disabilities.
3. Mount public awareness campaigns to remind people of the need to view children with disability in a positive light.
4. Expand skills and vocational training programmes to accommodate more children with disabilities.



4. ANNEXES

Annex 1: List of national-level key informants

| Name | Position/Organization | Sex |
|-----------------------|---|-----|
| Mr Manjolo | MoGCSW | M |
| Mr Bonongwe | MoGCSW | M |
| Mr Harry Mwamlima | Ministry of Economic Planning and Development | M |
| Mr Ngulama | Directorate of Special Needs Education, MoEST | M |
| Mr Noel Mwango | Ministry of Education | M |
| Mr Smart Namagonya | SOS | M |
| Mr Stefan Dofel | CBM | M |
| Mr Chiluzi | Ministry of Youth and Sports | M |
| Mr Mazaza | Ministry of Youth and Sports | M |
| Mr Penston Kilembe | MoDEA | M |
| Mr Felix Sapala | MoDEA | M |
| Mr Max Nyirenda | MoDEA | M |
| Mrs Jessie Chiyamwaka | MoDEA | F |
| Mr Joshua Mkwehiwa | MoDEA | M |
| Mr Mussa Chiwaula | FEDOMA | M |
| Mr Lynot Masumbu | Feed the Children Malawi | M |
| Mr AHP Chavuta | MACOHA | M |
| Mr Anthony Chilenga | MACOHA | M |
| Mr Boniface Massah | TAAM | M |
| Mr Hopson Kadewere | APDM | M |
| Mr Charles Khaula | APDM | M |
| Mr Ezekiel Kumwenda | Malawi Union for the Blind | M |
| Mr Alex Dzikambani | MAP | M |
| Mrs Mirriam Namanja | PODCAM | F |
| Mrs Julian Mwase | MANAD | F |

Annex 2: List of district-level key informants

| District | Name | Position/Organization | Sex |
|----------|-----------------------|---|-----|
| Nsanje | Ms Helen Simwaka | Acting DSWO | F |
| Lilongwe | Mr Phiri | DSWO | M |
| Lilongwe | Mr Mtandika | Rural West District Education Manager (DEM) | M |
| Lilongwe | Mr Chikankha | LL Rural East District SNE Coordinator | M |
| Lilongwe | Mrs Sezerine Misomali | Urban DEM | F |
| Karonga | Mr A Jaji | DSWO | M |
| Balaka | Mr Charles Salamu | DSWO | M |
| Balaka | Mrs Mercy Chamoto | Medical Rehabilitation Technician | F |
| Balaka | Mr Boniface Massah | District Rehabilitation Officer | M |
| Karonga | Hopekings Ngonga | Chairperson, District PODCAM | M |
| Karonga | Mr Charles Chipembere | District Community Rehabilitation Officer | M |
| Karonga | Mr J Nyondo | District Desk Officer, DEM | M |
| Nsanje | Mr Frederick Mazoko | District Community Rehabilitation Officer | M |
| Nsanje | Mr Mc Lean Sosono | Executive Director, Friends of AIDS Support Trust | M |
| Nsanje | Mr Enock Ali | DEM | M |
| Nsanje | Ms Joyce Kalikokha | Programmes & Finance Assistant, NICE | F |

Annex 3: Children interviewed by disability, district and age

| | District | Sex | Age | Type of disability | Cause of disability |
|----|----------|-----|-----|--|--|
| 1 | LILONGWE | M | 19 | Albinism | From birth |
| 2 | BALAKA | M | 17 | Epileptic | Not known, started when he was 4 years old |
| 3 | LILONGWE | M | 14 | Hearing impairment | After an illness |
| 4 | NSANJE | F | 16 | Partial hearing impairment | Illness - cerebral malaria |
| 5 | LILONGWE | M | 12 | Profound hearing loss | Illness - meningitis |
| 6 | LILONGWE | M | 17 | Hearing impairment | Illness - meningitis |
| 7 | NSANJE | M | 17 | Hearing impairment | Painful ears and puss comes out. Hears a little after the puss comes out (otitis media) |
| 8 | KARONGA | F | 15 | Hearing and speech impairment | From birth |
| 9 | KARONGA | F | 13 | Hearing and speech impairment | Long illness from age 3 |
| 10 | BALAKA | F | 12 | Hearing and speech impairment | Illness - malaria |
| 11 | LILONGWE | M | 15 | Hearing impairment, speech impairment and mental disability | Illness - malaria when he was in Standard 1 |
| 12 | LILONGWE | M | 12 | Hearing and speech impairment | Not known |
| 13 | NSANJE | F | 14 | Learning difficulty - mental disability | Not known |
| 14 | KARONGA | F | 13 | Physical and speech impairment - deformed foot and shorter arm | From birth |
| 15 | LILONGWE | M | 17 | Physical, epilepsy and learning difficulty, speech impairment | From birth |
| 16 | BALAKA | M | 16 | Physical and visual impairment | Physical disability from birth, became visually impaired after malaria |
| 17 | KARONGA | M | 14 | Physical and mental disability | From birth |
| 18 | KARONGA | M | 12 | Physical and speech impairment - short and small legs | From birth (and believes it is God's wish) |
| 19 | NSANJE | M | 17 | Low vision and hearing impairment | From young age following an ear infection. Pus was removed at the hospital, after which he has low hearing |
| 20 | NSANJE | M | 13 | Low vision and hearing impairment | From two or three years following an ear infection. At the same time eyes developed fast, which affected his sight |

| | District | Sex | Age | Type of disability | Cause of disability |
|----|----------|-----|-----|---|---|
| 21 | KARONGA | F | 14 | Physical - paralysed leg and epileptic | Long illness when she was a year old |
| 22 | NSANJE | F | 14 | Mental disability and visual impairment | Not known |
| 23 | KARONGA | F | 16 | Physical - leg does not properly function | Leg broke when her grandma tried to heal her with a hot cloth |
| 24 | BALAKA | M | 15 | Physical - arm and leg | Accident - fell from tree |
| 25 | LILONGWE | F | 17 | Physical | From birth |
| 26 | LILONGWE | F | 12 | Physical - can not walk nor crawl | From birth |
| 27 | BALAKA | F | 17 | Physical - one leg only | From birth |
| 28 | KARONGA | F | 17 | Physical - deformed foot and shorter leg | From birth |
| 29 | NSANJE | F | 16 | Physical - without legs | From birth |
| 30 | NSANJE | F | 13 | Physical - bent left hand | From birth |
| 31 | BALAKA | M | 12 | Physical - feet and legs cannot support the body to sit upright | From birth |
| 32 | BALAKA | M | 13 | Physical - both legs | From birth |
| 33 | BALAKA | M | 17 | Weak right leg and right arm | From birth |
| 34 | KARONGA | F | 16 | Physical - one leg is shorter | From age 3 as she grows the leg did not grow and is painful |
| 35 | LILONGWE | M | 12 | Physical - unable to walk | Since he was 8. At the hospital he was told that he could not walk any more |
| 36 | NSANJE | M | 19 | Physical disability - legs | Paralysed legs when he was 13 years old |
| 37 | BALAKA | M | 15 | Physical - one leg amputated | Amputated due to cancer |
| 38 | KARONGA | F | 16 | Physical - deformed leg and without a toe | Snake bite |
| 39 | NSANJE | M | 14 | Physical - ankles hurt after walking long distances or playing football | Not known but started when he was 5 years old |
| 40 | LILONGWE | M | 12 | Physical | Illness and "witchcraft related" |
| 41 | NSANJE | F | 16 | Cleft palate | From birth |
| 42 | BALAKA | F | 12 | Speech impairment | Not known - from young age |
| 43 | LILONGWE | M | 18 | Low vision | From birth |

Annex 4: The WHO International Classification of Functioning, Disability and Health (ICF)

The ICF model poses eight to screen for disability:

- Does (NAME) have problem performing tasks that are expected of people of their age?
- Does (NAME) have a problem with nerves, sadness or depression?
- Using the usual language, does (NAME) have difficulty communicating for example understanding or being understood?
- Does (NAME) have difficulty with self-care such as washing all over or dressing?
- Does (NAME) have any difficulty remembering or concentrating?
- Does (NAME) have difficulty walking or climbing steps?
- Does (NAME) have difficulty hearing, even if using a hearing aid?
- Does (NAME) have difficulty seeing, even if wearing glasses?

A “Yes” answer to any of these questions implies some level of disability.

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