



# Barriers and enablers to inclusion in education for children with disabilities in Malawi

A CASE STUDY FROM NTCHEU DISTRICT

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*All photos in which individuals can be identified that appear in this report were taken with written consent of the caregivers and assent of the child.*

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Photographs and case studies have been obtained with informed consent and permission to use in this publication.

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## Executive Summary

“I would like to go back to school. I admire my friends who go to school... It hurts me [that I was asked to drop out] because if I had continued to go to school, I would’ve been independent.”

Girl, 16, who has a profound visual impairment and who was asked to drop out of primary school when her vision began to deteriorate.

Access to a quality education has long been recognised as both a fundamental human right and as essential for reducing poverty, inequality and achieving other development goals. However, many of the 150 million children living with disabilities – about one in twenty children – are being excluded from the promise of education.

Although it is widely acknowledged that children with disabilities are less likely to access and progress through school, more research is needed to better understand *why* these disparities exist. Consequently, the following study was conducted to identify the barriers and enablers to inclusion in education for children with disabilities, using Ntcheu district in Malawi as a case study.

For this study, in-depth interviews were conducted with 23 families (23 caregivers, 17 children). Children had a range of reported disabilities and 14 were currently enrolled in school, 5 had dropped out and 4 had never been enrolled. Additionally, 13 teachers of children in the sample and 9 key informant interviews were conducted for further context.

### Main findings

A number of individual, family, school and society factors impacted access to and experience in school for children with disabilities in Malawi. Often, the range of challenges which led to children dropping out of school were the same as those experienced by children with disabilities who were still managing to stay in school.

**Attitudes towards education for children with disabilities** played an important role in decisions about school – from attendance, academic performance and overall experience.

- Many children were highly **motivated and enthusiastic** about going to school, even in extremely difficult circumstances. Major reasons children wanted to attend was a love for learning and a desire to be with peers.
- The belief that education could lead to a better future was a major reason for attending, for both caregivers and children.
- Some caregivers, however, were reluctant to send their children to school if they feared they wouldn’t receive adequate **care and protection**.
- Some caregivers and teachers also questioned whether children with disabilities could receive a **meaningful education in a mainstream school**.

Additionally, **poverty** was also a dominant theme throughout all interviews and served as a main reason for not being in school, missing classes or having difficulties with learning. Although economic challenges are a universal barrier to accessing education, there is an argument to be made that households with children with disabilities are particularly vulnerable to poverty.

Furthermore, almost half of the children in the sample had **ongoing health issues** – such as untreated epilepsy or progressively worsening visual or hearing impairments – that had implications for their education and reduced families' often limited resources, highlighting the need to address the linkages between health, education and poverty.

Even when children did attend school, however, **schools were frequently ill-equipped to accommodate students with disabilities.**

- Almost three-quarters of children who had ever been to school had **repeated a grade** and there was also evidence that children with disabilities were being **upgraded to higher grades without passing**. On average, children with disabilities were almost three grades behind the official national standard for their age. While siblings without disabilities were also behind in their schooling - indicating the influence of non-disability related factors in education outcomes or perhaps spill-over impacts of disability on others in the family – difference in age for grade between children with disabilities and their siblings was still more than a full year.
- **Physical access** to schools was a major barrier. Classroom and toilet facilities were often inaccessible and almost half of families reported challenges getting to school due to long distances, lack of transport and unmet assistive device or other support needs.
- Most schools have very limited physical and human **resources available for inclusive education. Large class sizes** and **lack of teacher training** on inclusive education were particularly challenging.

Finally, children with disabilities faced numerous forms of **discrimination, violence and social exclusion** inside and outside of school. These experiences, in some cases lead to expressed feelings of low self-esteem and isolation among many of the children interviewed and could have impacts on their learning and social experience while at school. **Sexual violence and other serious child protection issues** also emerged as an issue requiring further attention.

Addressing these barriers that are affecting access to a quality education and school experience brings benefits for all children – with and without disabilities. Investing in and engaging with families, schools and communities so that they can better provide a meaningful education and positive, inclusive school experiences for all children is essential to fulfilling the promises of universal education.

# 1 Introduction

That every child should have access to a quality education has been recognised as both a fundamental human right and as essential reducing poverty, inequality and achieving other development goals. However, for the 150 million children living with disabilities<sup>1</sup> – about one in twenty children – the promise of universal education remains out of reach.

Children with disabilities face pervasive barriers that limit their participation in education.<sup>2</sup> While there has been recent efforts to improve inclusion of children with disabilities, exclusion is still persistent, particularly in low and middle income countries. Compared to their peers without disabilities, children with disabilities are less likely to start school, have lower levels of school attendance and lower transition rates to higher levels of education.<sup>3</sup>

A variety of challenges – at the individual, family, school, community and national level – may prevent children with disabilities from attending and progressing through school. It is important to understand how these barriers are limiting participation in order to identify ways to promote greater inclusion of children with disabilities in education.

The overall aim of this study was to explore barriers and enablers to inclusion in education for children with disabilities in Malawi, with a focus on the perspectives of children and their caregivers.

This research was commissioned by the Norwegian Association of Disabled (NAD) as part of its Documentation and Research in Community-Based Rehabilitation (CBR) project.<sup>4</sup> It was conducted in collaboration with the Malawi Council for the Handicapped (MACOHA), a parastatal organization that runs community-based rehabilitation programmes across the country and advocates for the rights of people with disabilities. MACOHA follows a multidimensional approach to community-based rehabilitation, supporting interventions across the key areas of health, education, livelihoods, social life and empowerment.

Specific objectives of the research included:

- To identify the main barriers and enablers to accessing and progressing through school.
- To explore the academic and social experience of children with disabilities while at school.
- To identify any particular challenges experienced around the transition from primary to secondary school.

Findings from the research were in turn used to form recommendations towards overcoming barriers to inclusion in education for children with disabilities.

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<sup>1</sup> UNICEF. (2013). *Children and Young People with Disabilities*. New York.

<sup>2</sup> World Health Organization & World Bank. (2011). *World Report on Disability*. WHO Press, Geneva available at [http://www.who.int/disabilities/world\\_report/2011/en/index.html](http://www.who.int/disabilities/world_report/2011/en/index.html)

<sup>3</sup> Ibid

<sup>4</sup> AfriCAN (2015). *Norwegian Association of Disabled (NAD) Documentation and Research in CBR Project*. Available from: <http://www.afri-can.org/D&R%20CBR%20Project.html>

## 2 Background

### 2.1 Policy and provision of education for children with disabilities in Malawi

Malawi has signed and ratified several international conventions that enshrine the rights of children with disabilities to education. These include the United Nations (UN) Convention on the Rights of the Child, which protects the right of all children to education and the UN Convention on the Rights of Persons with Disabilities (CRPD), which explicitly focuses on the right of children with disabilities to education.<sup>5</sup> The latter also obliges states to create an inclusive education system.

The principles of these conventions are further codified within Malawian national laws and policies. The Disability Act (2012) defines inclusive education as “a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities and reducing exclusion from and within education.” The National Policy Guidelines on Special Needs Education (2007), the National Education Strategic Plan 2008-2017 and the National Policy on the Equalization of Opportunities for Persons’ with Disabilities (2006) reaffirm a commitment towards equal access and inclusion in education for children with disabilities.

Resource centres are the main model for inclusive education. Resource centres are special education units within some mainstream schools where children with disabilities can receive specialized instruction and extra resources to support their learning. Typically, children with disabilities are still taught in a general class alongside learners without disabilities and receive this additional instruction outside of normal class hours. Currently there are 126 resource centres (16 residential and 110 day schools) across 130 out of Malawi’s 447 educational zones.<sup>6</sup>

Special schools also provide disability-specific instruction, primarily for the hearing and visually impaired; however there are only six special schools in all of Malawi – all of which are residential – as others have been converted into resource centres to reflect a shift in directive towards inclusive rather than segregated education.<sup>7</sup> Given the limited availability of resource centres and special schools, many children with disabilities attend standard mainstream schools.<sup>8</sup>

To improve the capacity of mainstream schools to offer an inclusive education, an itinerant teaching programme was started by the Ministry of Education in collaboration with Sightsavers. With this programme, specialist teachers provide basic training to teachers in mainstream schools on how to improve inclusion in the classroom. Additionally, itinerant teachers provide some direct support to children with profound visual impairments in

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<sup>5</sup> Research for Inclusive Education in International Cooperation. (2015). *Country Studies: Malawi*. Hanover, Germany.

<sup>6</sup> *ibid*

<sup>7</sup> *ibid*

<sup>8</sup> Research for Inclusive Education in International Cooperation. (2015). *Country Studies: Malawi*. Hanover, Germany.



mainstream schools within their catchment area. Although scaling up, this programme currently operates in 11 of the 34 educational districts.<sup>9</sup>

Malawi's formal education system is divided into primary (grades 1-8), secondary (grades 9-12) and tertiary education. The Constitution of Malawi (1994) states that it will progressively adopt and implement policies and legislation aimed at achieving the goal of free and compulsory primary education for all citizens. With the enactment of the Constitution, primary school fees were abolished, leading to dramatic surges in enrolment; however, the lack of capacity building so that schools could accommodate the influx of additional students led to strains on resources that have continued to the present.<sup>10</sup>

Unlike primary school, secondary schools charge tuition fees and spaces are limited. Children are thus selected to attend public secondary schools based on their performance on the Primary School Leaving Certificate Examination at the end of grade 8. However, there is affirmative action for children with disabilities, whereby they only must earn a pass on these exams to be awarded a seat.<sup>11</sup>

The Ministry of Education, Science and Technology (MoEST) is responsible for the overall development and provision of formal education. Implementation and oversight falls to the District Education Offices in each of Malawi's 34 educational districts. The Special Needs Education Directorate within the MoEST is responsible for national coordination of inclusive education; however, there is no designated office or position dedicated to overseeing the implementation inclusive education at the district level.<sup>12</sup>

## 2.2 Children with disabilities and education in Malawi: current state of knowledge

The National Statistics Office of Malawi estimates a prevalence of childhood (<18 years) disability of 2.4%.<sup>13</sup> However, these figures are believed to be low, as the definition of disability used in the census is not in line with the World Health Organization's International Classification of Functioning, Disability and Health.<sup>i</sup><sup>14</sup> By these estimates, the most common type of disability was listed as hearing impairment (23%), followed by visual impairment (16.9%), reduced mobility (15.8%) and speaking difficulties (9.3%); however most disabilities were classified as 'other' (35%).<sup>15</sup> Disability was more prevalent in rural areas – which also

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<sup>9</sup> *ibid*

<sup>10</sup> Government of Malawi. (1994). Constitution of the Republic of Malawi. Lilongwe.

World Bank & UNICEF. *Abolishing School Fees in Africa: Lessons from Ethiopia, Ghana, Kenya, Malawi, and Mozambique*. Washington, DC.

<sup>11</sup> David Njaidi, Deputy Director of Special Needs Education. (2015). [Personal Communication].

<sup>12</sup> Greystone Alindiamao, Deputy Director of District Education Office Ntcheu. (2015). [Personal Communication].

<sup>13</sup> National Statistics Office. (2010). *Population and Housing Census 2008: Disability and the Elderly*. Zomba, Malawi: Government of Malawi.

<sup>14</sup> National Statistics Office. (2010). *Population and Housing Census 2008: Disability and the Elderly*. Zomba, Malawi: Government of Malawi; Ngomwa, P. (2014). *Article 24 of the United Nations Convention on the Rights of Persons with Disabilities and Realization of Access to Primary Education by Children with Disabilities through Community-Based Rehabilitation Support*. (Degree of Masters of Law), National University of Ireland, Galway.

<sup>15</sup> National Statistics Office. (2010). *Population and Housing Census 2008: Thematic report on Disability and the Elderly*. Zomba, Malawi: Government of Malawi.

have higher levels of poverty and lower access to social services – compared to urban areas (4.1% vs 2.5%).<sup>16</sup>

Data on the school attendance of children with disabilities is lacking. Although the Ministry of Education, Science and Technology collects information on the number of students with disabilities attending school each year, the figures are provided by teachers, the vast majority of whom have never received training or guidelines for identifying children with disabilities.<sup>17</sup> By these methods, it was estimated that there were approximately 90,000 learners with special needs attending school in 2012-2013.<sup>18</sup> However little is known about the number of children with disabilities out of school.

### 3 Methods

#### 3.1 Selection of participants

The sample was drawn from a previous study conducted by LSHTM called the Key Informant Child Disability Project (see Box 1).

#### **Box 1. The Key Informant Child Disability Project<sup>19</sup>**

The Key Informant Method (KIM) is a novel method for generating data on the prevalence and causes of childhood disability, which are lacking in most low and middle income countries. As this information is needed for informing policies, services and advocacy, improving the collection of robust data is essential. KIM offers an alternative to population-based surveys of disability, which can be costly and time consuming.

With KIM, community-based volunteers are trained to identify children in their area who may have disabilities. These children are then invited to screening camps, where they are assessed by medical professionals and referred for appropriate health and rehabilitation services.

The KIM Project in Malawi identified 2,788 children with disabilities across two districts in Malawi (Ntcheu and Thyolo). Nearly three-quarters of the children with disabilities of school-age (6-18 years) were attending school. However, attendance varied by impairment type and was lowest among children with multiple impairments (38%).

Ntcheu was selected as the site for this study, given the logistical advantages of MACOHA's links with the district. Furthermore, an analysis of KIM data found no significant differences between Ntcheu and Thyolo in terms of school enrolment or disability prevalence. Ntcheu is a rural district in the Central Region of Malawi and is located midway between Lilongwe and

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<sup>16</sup> *ibid*

<sup>17</sup> Greystone Alindiamao, Deputy Director of District Education Office Ntcheu. (2015). [Personal Communication].

<sup>18</sup> Research for Inclusive Education in International Cooperation. (2015). *Country Studies: Malawi*. Hannover.

<sup>19</sup> Tataryn, M., Chokocho, L., Mulwafu, W., Kayange, P., Polack, S., Lavy, C., & Kuper, H. (2013). *The Malawi Key Informant Child Disability Project - Summary Report*. ICED Research Report. London: International Centre for Evidence in Disability.

Blantyre, the capital and largest cities. Ntcheu has 236 schools, 3 of which have resource centres (2 primary, 1 secondary) and no special schools.

A purposeful selection of children was drawn from the KIM survey data in Ntcheu district. Children ages 12-18 were selected to provide a sample of children that have had several years of school experience and perspectives on transitioning to secondary school. Furthermore, the sample was selected to ensure representativeness by impairment type/condition (physical, intellectual, hearing, visual, epilepsy), gender, and school status (in vs. out of school). The selection was carried out by researchers from LSHTM using datasheets with basic demographic information from the original KIM study.

Where possible, teachers of the children in the sample were also interviewed to gain this additional perspective of the children's experience in school. Other key informant interviews included government officials, members of Disabled Peoples' Organisations (DPOs) and NGOs and academics in inclusive education.

### 3.2 Ethical considerations

Ethical approval for this study was received from LSHTM's Research Ethics Committee and the University of Malawi's College of Medicine Research and Ethics Committee in January and March 2015, respectively.

Before the start of each interview, informed written consent was received from key informants, caregivers and older children. For younger children and children with communication/intellectual impairments, a simplified oral consent was sought, and pictorial child-friendly information sheets were developed. All names of children have been changed in order to maintain confidentiality.

If a child protection issue arose, MACOHA was notified of the situation and additional supports for the family and child were made available.

### 3.3 Data collection

Children and caregivers were interviewed separately. However, if a child was unable to communicate independently or requested the presence of his/her caregiver, caregivers were invited to join the interview. Interviews were conducted in Chichewa, with the support of a translator.

A semi-structured interview guide was used to guide discussions (see appendix for guides). Key topics covered in the caregiver interviews included: (1) family background; (2) child's impairment, abilities, and general health, including access to health/rehabilitative services; and (3) child's education, including social and academic experience in school and/or reasons for non-attendance.

For child interviews, a visual tool was also used to prompt discussions (see figure 1). Children were provided with emotion cards (faces with “Happy”, “Sad”, and “Angry” expressions) and asked about the experiences/activities/people that made them feel those emotions at each of the following places: home, on the way to school, in the classroom, in the playground and in using the toilet facilities.



Figure 1: Visual aid used in child interviews

For key informants, questions were tailored to each individual’s area of expertise, but broadly focused on family/community, school and policy barriers and facilitators to education for children with disabilities. For teachers, questions focused on their student from the sample’s experience in school, as well as their experience teaching children with disabilities. Most key informant and teacher interviews were conducted in English, with some in Chichewa.

All child and caregiver interviews were recorded and transcribed. Detailed notes were taken of key informant interviews, and where necessary, the notes and quotes were cross-checked against the recordings.

### 3.4 Data Analysis

A thematic approach was used to analyse findings, and comparisons and inter-relationships between themes and different categories were explored throughout the analysis. After each day of fieldwork, interview notes were reviewed by the lead LSHTM field researcher and the local research assistant. This helped to identify any gaps in the interview schedule that needed to be addressed and also provided some emergent themes. On the completion of field work, these emergent themes were shared and verified with the reference group<sup>ii</sup> of key informants. Additionally, a second researcher at LSHTM reviewed the interviews, and a fuller framework of themes and sub-themes was developed, with additional sub-themes added during the data analysis process. Data was coded using NVivo 10, a specialist software for qualitative data analysis.

## 4 Description of the Sample

In total, information on 23 children was gathered through 23 caregiver and 17 child interviews (see table 1 for characteristics of the study sample). In the six cases where no child was interviewed, all had communication difficulties related to their impairments. All six had profound intellectual impairments that limited their understanding and two also had profound hearing loss with no sign language knowledge. Sign language interpretation was available for children with profound hearing impairment, but no children in the sample had knowledge of sign language.

The sample was evenly divided between girls (n=11) and boys (n=12). Ages ranged from 12-18 years, with an average of 14.7 years. By impairment types and conditions, the following breakdown was reported: visual (n=4), hearing (n=7), intellectual (n=9), physical (n=9), epilepsy (n=3) and albinism (n=1). Seven children had multiple impairments/conditions. Illness was reported in over two thirds of cases (n=15) as the cause of impairment. Most illnesses were infectious in nature, with severe malaria implicated in a third of all cases. Impairments arising at birth were cited in an additional eight cases and accident was the source of one.

Most caregiver interviews involved the child's mother or grandmother. Of note, almost half of children were living with relatives (typically a grandmother) or in single parent households.

Of the 23 children, 14 were currently attending school.

Of the nine not in school, five had dropped out and four had never been formally enrolled. Three children were currently attending schools with resource centres and two children had briefly attended special schools for the hearing impaired in the past. All were government-run schools, except for the two special schools.

The caregiver and child perspectives were complemented with 13 interviews with teachers of 11 of the children in the sample. All were teachers of children currently in school. Additionally, four schools were visited to observe the school environment and resources available to students with disabilities. Finally nine key informants were interviewed for context on the policy and provision of education for children with disabilities in Malawi. The backgrounds of the key informants were as follows: government officials (n=3), NGO staff (n=2) and members of DPOs (n=4).

Characteristic	#
<i>Gender</i>	
Boys	12
Girls	11
<i>School status</i>	
In	14
Out of school	9
- Dropped out	5
- Never enrolled	4
<i>Impairment type/condition</i>	
Physical	9
Intellectual	9
Hearing	7
Visual	4
Epilepsy	3
Albinism	1
<i>Cause of impairment</i>	
Illness	15
- Malaria	8
Birth	8
Accident	1
<i>Relationship of primary caregiver interviewed</i>	
Mother	11
Grandmother	8
Father	6
Aunt	2
Sibling	1
Stepfather	1

Table 1: characteristics of study sample

## 5 Findings

The factors which affect children with disabilities' access to and experience in school are complex: as seen through this study, often a combination of individual, family, school and societal level factors are at play, with different weightings for every child. The additional influences of gender, poverty and other elements frequently interact with impairment-related factors to compound or mitigate exclusion.

Below, we discuss the factors that impacted access to and experience in school for children with disabilities in Malawi. Often, the range of challenges which led to children dropping out of school were the same as those experienced by children with disabilities who were still managing to stay in school. Typically, these same factors led to decreased attendance, difficulties with learning and negative experiences at school.

### 5.1 Attitudes towards education for children with disabilities

Attitudes of children, caregivers and teachers played an important role in decisions about school – from attendance, academic performance and overall experience. Below some of the attitudes that both enabled and deterred access to education are discussed.

#### 5.1.1 Motivators for going to school

Many of the children were highly motivated and enthusiastic about going to school. Despite challenges such as being bullied, facing physically difficult journeys to school, repeating grades and having difficulties understanding and communicating with teachers, the vast majority of children wanted to attend. Similarly, most caregivers wanted their children to go to school and were trying their best to support them in pursuing an education.

Major reasons children wanted to attend school included a love for learning and a desire to be with peers. The desire to be included with peers continually reoccurred a powerful influence for wanting to attend school: in several cases, children self-enrolled after seeing their peers go to class.



Young boy with a hearing impairment who is motivated to learn.

He started [school] on his own, he would admire his friends. He followed his friends to school, then he demanded that we buy a notebook for him....He just wants to learn... When he was at home he would scribble on the floor. You could see that if he was alright he could have been educated.

Mother discussing why her son (age 15, who has epilepsy, profound hearing and intellectual impairments and is not in school), wants to go to school (case 101)

Additionally, for both caregivers and children, the belief that education could lead to a better future was a primary motivator. Many caregivers attributed their current socioeconomic problems to their own lack of education and children and caregivers alike

viewed school as a route out of poverty. Caregivers and children frequently mentioned their hope that school would lead to 'an independent life'. Caregivers also hoped their educated children could support them as they aged.

*[Why do you think education is important for her?] It is good for her everyday life because education is good...I didn't go further with education, that's why we are having problems. If she gets educated, she will get a good job and she will be able to help us...I want her to go to a secondary school and get a job so that she can help me because I stopped schooling because of lack of school fees.*

Mother discussing her motivation for sending her daughter (age 12, who has a physical impairment and is in grade 5), to school (case 107).

Additionally, for some impairment types, caregivers recognized that traditional livelihoods such as farming or manual labour would not be an option and so hoped that education could provide a stable alternative. This was particularly true for children with physical impairments and mobility limitations.

*[What is your hope for Chifundo's future? Why do you send him to school?] He can't do jobs that require him to work in the sun because of his condition but we send him to school so that he gets a job that will enable him to work inside a building...we also want him not to have problems in his family. [If he stops school, do you think all this that you want will happen?] No it can't.*

Father discussing the reasons why his son (age 17, in secondary school, grade 10), who due albinism develops sores and eye problems if in sunlight, should continue with his education (case 110).

Even when caregivers doubted that their children could receive a formal education, they still hoped their children could learn some helpful skills at school. For example, in a few cases caregivers reported sending their children to school in the hopes that the socialization process could improve their child's behaviour and abilities.

The case study with Chisomo below illustrates the resilience and determination to go to school and get an education – despite seemingly overwhelming challenges – seen in many of the children interviewed.

## Voices of children: motivation and determination

Chisomo is a 15 year old girl who is in Grade 8, her final year of primary school. Chisomo lives with her grandmother, an arrangement that came into place to escape an abusive stepfather.

Chisomo has had continuous eye infections for the last five years and the lack of access to treatment has caused her vision to progressively worsen. Chisomo relates that she struggles in class because “I can’t see what’s on the board and I also miss classes when [my eyes] swell.” She is also worried about being teased because of her eye problems: although usually social, her teacher explains that “when the [eye] problems come, she isolates herself. Then she’ll tell me she’s going home because of her eyes.”

Poverty is also a problem for Chisomo. Her teacher explains that she sometimes cannot afford learning materials such as notebooks and pens. He notes that “she lacks her basic needs – food, soap, face wash – her face is often dirty – it shows she’s having money problems.” Chisomo even comes to school in the evenings to study, although she cannot afford a torch and the school has no electricity.

Despite these challenges Chisomo has excelled at school. She is studying for her Primary School Leaving Examination. She recently took mock exams, where she placed fifth – the top spot for a girl – among all schools in her zone. Chisomo points to the importance of small accommodations that help her to learn, such as having a front seat and asking the teacher to use bigger font when writing on the blackboard. Her teacher and grandmother credit her motivation and determination, as her grandmother explains:

*[What do you think makes her do well in class?] She is hard working and she is passionate about education. She doesn’t want to stay idle, she likes studying...one time when I told her to escort me to the farm [instead of going to school], she told me she doesn’t want to be poor like me... she wants to have a bright future...and to be independent.*

Chisomo is excited about the prospect of going to secondary school – although paying tuition will be an issue – and hopes to be a nurse in the future.

*Case 115: all names have been changed*

### 5.1.2 Care and protection

In a few cases involving children with high support needs, caregivers did not send their children to school for fear that they would not be adequately cared for. This fear was also cited as a reason why caregivers were hesitant to send their children to special or schools with resource centres if they needed to board away from home.

*[Who made the decision to stop him from going to school?] It was me and the grandmother because we were afraid of him getting lost if he continued going...his cousins would follow him and take him back home. He was sometimes beating them and his friends so that why we had to stop him.*

Mother, talking about why her son (age 13, who has an intellectual impairment), stopped school (case 118).



Additionally, given the limited availability of secondary schools, many children who attend either board away from home or else travelled long distances to reach school. Safety of children – particularly girls – was a common concern. For those who board, options included either school-provided facilities, which have limited placements, or ‘self-boarding’, where children rented rooms close to school. The first option was greatly preferred by caregivers interviewed, as it afforded a level of supervision and protection. Key informants explained that fears for girls’ safety in attending secondary school has been noted to be a major reason for the disparity in school progression between girls and boys – with and without disabilities – and that the government has begun to construct additional school-provided boarding facilities for girls to address this concern.

For some of these schools, students do self-boarding - the owners are not concerned with the welfare of the students, it doesn’t concern them whether they are engaging in bad behaviour or not. Whereas in a boarding school, students are more secure since there are girls only...[with self-boarding] there is no security at such schools.

Grandmother discussing her concerns with boarding for secondary school for her granddaughter (age 15, who has a visual impairment and is in her final year of primary school) (case 115).

Furthermore, some caregivers felt that association with boys could derail their girls’ future and so sought to limit interactions.

[My relatives] say I should not be playing around with boys. [*What do they say is the reason you should not be playing with boys?*] So that I can continue with my education and have an independent bright future.

Girl (age 13 who has a hearing impairment and is in grade 5) on why her relatives do not want her associating with boys (case 113).

It should be noted that early marriage and pregnancy are major reasons for drop-outs for all girls nationally. Two of the girls in the sample were in relationships and one reported being sexually active and was not using protection.

### 5.1.3 *Place of children in mainstream schools*

Caregivers and teachers often questioned whether children with disabilities could receive a meaningful education in a mainstream school. Consequently, some caregivers did not see the utility of sending their children to school or the need for regular attendance and diligence in studies, while teachers were reluctant to invest energy into teaching students with disabilities.

Teachers and caregivers sometimes did not believe children with disabilities should be included in mainstream schools. This attitude was particularly pronounced for children with behavioural problems. Tellingly, the majority of children not in school exhibited behavioural challenges. In many of these cases, the school suggested or explicitly requested the child not be sent to school. However, in several cases caregivers made the decision to keep their child out of school for fear that their inclusion would burden teachers.

Had it been that he acted the same way his friends are acting there wouldn't have been any problem. But he chases his friends when they are busy writing. As a result we stop him from going to school. *[Who decided that the boy should drop out of school because he disturbs his friends?]* His teachers...they told us that there is a special school for learners with disabilities. That's what we were told. So what could we have done? How would we send him as if we know where the school is?...They said there is a special school for children like him and people from the government will come pick to pick him up. So we are just waiting for them to come get him.... Otherwise in the mainstream school he does not interact well with his peers.

Mother talking about the teacher's response when she tried to enrol her son, age 15 who has epilepsy, profound hearing impairment and an intellectual impairment, in a mainstream school (case 101).

Teachers frequently indicated that they believed children with disabilities should be taught outside of the mainstream system, instead recommending caregivers send their children to a special school. In a few cases, this recommendation was made even when the child had a minor impairment and was performing at or above average. Similarly, caregivers often reported that they hoped to send their child to a special school, but lacked enough information to follow-up.

#### *5.1.4 Involvement of caregivers in schooling decisions*

Children appeared to have significant control in the decision to attend: there were frequent reports of children either enrolling themselves, going despite caregivers' wishes, as well as dropping out or skipping class at their discretion.

While some caregivers were actively engaged in their child's schooling – for example, going to school to talk to teachers about their child's condition and need for accommodations – many others had a more hands-off approach. When probed, caregivers indicated that they did not have the time for follow-up or were weary of being a burden to teachers. Some key informants also suggested that caregivers' own lack of schooling made them inexperienced at knowing how best to help with their child's education or navigate the school system.

*[What is her performance at school?]* She doesn't do very well...I think it's because there are many pupils so it's possible that she doesn't understand that's why she doesn't do well. *[Have you ever talked to them about giving her a front seat]* I haven't *[Why not?]* Because I would look like I am troubling them by telling them what to do.

Mother discussing her daughter's (age 13, who has a hearing impairment) difficulties in primary school (case 113).

## 5.2 Economic Challenges

Poverty was a dominant theme throughout all interviews and served as a main reason for not being in school, missing classes or having difficulties with learning. Key informants noted that throughout Malawi, financial challenges were the main barrier for all children – with and without disabilities – in attending and succeeding at school. Although economic challenges are a universal barrier to accessing education, there’s an argument to be made that households with children with disabilities are particularly vulnerable to poverty. For example, caregivers reported spending on items such as health services to try to treat their child’s disability or taking time away from work to care for children with disabilities – all of which reduce available household resources. Additionally, as almost half of children were living with other relatives or in single parent households, these families have fewer breadwinners and so poverty may be more severe than local standards.



Even the cost of notebooks and pens could be difficult for families to afford.

### 5.2.1 School-related costs

Although primary school is free under Malawi law, families frequently still have to pay small fees for items such as “school development funds”, registration, uniforms and school supplies. Given the high level of poverty, many families found these small fees were difficult to manage. Without supplies as basic as a pen and notebook, children found it difficult to learn. Additionally, some children who were particularly poor were embarrassed by their lack of means.

*[What would make you go back to school?] If I had somewhere to write, a pen and a pencil. [When you were going to school, didn't you have those materials?] I didn't have any...we were writing on the floor. [What else would make you go to school?] A uniform and a dress [Do the other kids at school also wear uniforms?] Yes... [What do your friends say about you not going to school?] They tell me to go to school. [And what do you say?] I tell them I don't have clothes to wear to school...Other kids would be laughing at me when I wore dirty clothes.*

Girl, age 12 who has a hearing impairment, talking about why she decided to stop going to primary school (case 111).

While government-run primary schools are not allowed to charge tuition fees, secondary schools do not have the same exemption: to attend, fees were cited at US\$ 40 per year in tuition alone. Additionally, given the limited availability of secondary schools, most children would have to board away from home in order to attend, leading to further costs for accommodations and travel. Given that most families interviewed survive on subsistence

farming, these fees are prohibitive. Of the two children in our sample who had transitioned to secondary school, one had dropped out over fees, while the other was struggling to make payments on time.

Almost all families highlighted this financial barrier as the main reason their children – with and without disabilities – may not progress with their education beyond primary school. Without outside assistance, the majority of families indicated that they would not be able to pay the tuition fees. For those who managed to send their child to secondary school, maintaining the payments was a struggle and exhausted household resources. Failure to make payments on time could also lead to prolonged absences that interrupted schooling.

It is a problem, sometimes he is sent away from school [when his fees are overdue]. Then his brother borrows some money from somewhere to finish paying when this happens. [How long does he stay without going to school?] A week passes...he even fails to eat when that happens...because he feels he is losing out on what his friends are learning from school. [Because it is difficult to find work] we don't even know if he will finish his education.

Mother and father discussing difficulties in making payments for secondary school fees their son, age 17 who has albinism and a visual impairment (case 110).

Additionally, perceived cost (of both boarding and school fees) was cited as the main reason for not sending children to special schools. Even when expressing an interest in sending children to special schools, caregivers stated that they had not researched these alternative options for schools as they believed they would be too costly.

### 5.2.2 Work

Almost a third of children in the sample had missed school in order to work. Work was most often around the house or in the fields and served to help the family meet basic subsistence needs. In a few cases, children took on short-term paid work outside of the house in order to help with school-related costs.

*[What makes you angry at home?] If my mother tells me not to go to school...I want to go to school. [Why does she tell you not to go to school?] She says I should look after the baby when she goes to the fields.*

Boy, age 13 who has epilepsy and is in grade 3, talking about reasons for missing school (case 119).

Children without disabilities seemed at least as likely to be missing school in order to work. For the most part, caregivers were open in revealing that their children miss school in order to work, although in a few cases, the disclosure only came from the child. In these cases, caregivers had requested the child take time out of school in order to work and may have been reluctant to disclose this information for fear that it reflected poorly on their parenting.

### 5.3 Ability of schools to accommodate students with disabilities

From interviews with key informants and observations from school visits – as well as from the experiences of children in the sample - schools are frequently ill-equipped to accommodate students with disabilities. Inaccessible facilities made getting to and around school difficult for many students with disabilities while the lack of investment in resources for inclusive education excluded many from the learning process.

#### 5.3.1 Repeating and upgrading without passing

Although some children in the sample were excelling at school despite numerous challenges, many more were struggling. Almost three-quarters of children who had ever been to school had repeated a grade, with many repeating multiple times. On average, children with disabilities were almost three grades behind the official national standard for their age.<sup>20</sup> Siblings without disabilities similarly had a high rate of grade repetition and were also behind in their schooling – indicating the influence of non-disability related factors in education outcomes or perhaps spill-over impacts of disability on others in the family. Still, the difference in age for grade between children with disabilities and their siblings was more than a full year.

Additionally, in several cases, there was evidence that children with disabilities were being upgraded to higher grades even if they were not passing:

When she was in standard 2, they said they will just be shifting her to the next class even if she doesn't do well. [*Why did they say she will not be repeating?*] It's because they said she is growing up and she can't be remaining in the same class, they just have to allow her to move to other classes.

Mother discussing why her daughter, age 12 who has a hearing impairment and recently dropped out of primary school, was being upgraded without passing (case 111).

Both high repetition rates and upgrading without passing indicate exclusion of children with disabilities in the learning process. Furthermore, constant grade repetition, difficulties keeping pace with the rest of the class and being older than classmates appeared in some cases, not surprisingly, to result in low self-esteem, potentially discouraging some from continuing on with school.

[*Why did you repeat?*] I was not intelligent enough...I didn't know how to read and write. [*When you repeated, how did you feel about that?*] I felt bad because repeating a class means you've taken a step backwards in education. [*Did your other friends repeat too?*] No.

Girl (age 13 who has a hearing impairment who is in grade 5), talking about how she felt when she repeated grades (case 113).

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<sup>20</sup> World Bank. (2015). Primary school starting age (years). *World Development Indicators*. Available from: <http://data.worldbank.org/indicator/SE.PRM.AGES>

### 5.3.2 Physical access

It was clear from observation of all the schools visited that they were not well equipped to accommodate students with disabilities. Even at schools with resource centres, accessibility was poor. For example, in the images on the right, although attempts were clearly made to improve accessibility, poor planning was evident: ramps were too steep, in disrepair and access to adjoining doorways was still not step-free. Accessibility in and around buildings was also poor: toilet facilities were also not step-free and terrain to reach them was uneven, while the stalls were narrow and frequently unclean. Key informants verified that this situation was common across schools in Malawi.

Within this sample, a more common barrier to physically accessing schools was travel. Almost half of families reported challenges in getting to school. These difficulties resulted in absenteeism, lateness to class and in two cases, dropouts. Two children required the assistance or supervision of a family member to get to school, which was not always regularly available and had opportunity costs for the family.



Figure 2: ramps at resource centre (1) and mainstream (2) schools

This year the school is close by, it is in the village. I could have been in standard 8 or form 1 but in the previous years it was difficult to get to school because the school is very far from the village. So now I am in standard 6. *[How far is the former school? If you start off at 6 am when do you get there?]* I could get there at around past 8 in the morning. I would find people already in class, sometimes I could get there at around past 9... when I walk for a distance I need to sit down [because of pain in my legs and back] and my friends leave me behind.

Boy (age 15 who has a physical impairment) talking about difficulties getting to his primary school (case 102).

For secondary schools, the distances were a particular issue. Availability of secondary schools is low, with typically only 1-2 per district; if commuting, travel times can be substantial. Children and caregivers and key informants alike spoke of the long distances to secondary schools as a barrier to progressing onwards with education. Similarly, special schools tend to be far from the communities in which children live. Although boarding is available, and often free, transport to and from school during breaks can be too costly for some: in one case, while all other expenses were covered, a student had to drop out of a special school for the hearing impaired due to the cost of transport (about US\$3.50, paid three times per year). While schools with resource centres also are limited in their availability, most children only attend if that happens to be their neighbourhood school.

### 5.3.3 Resources for inclusive education

Most schools have very limited physical and human resources available for inclusive education. Key informants explained that typically only resource centres or special schools have any sort of specialist resources, but even these are minimal. In mainstream schools, the availability of resources such as Braille, sign language interpretation, adapted curricula is virtually non-existent.

Furthermore, few teachers had received any sort of training on disability or inclusive education either at their teaching colleges or on the job. Even for those who had received some training, the teachings were general and focused more on the need to include children with disabilities in the classroom without providing any practical tools for inclusion. For schools with resource centres, key informants noted the transfer of specialised skills to teachers in the general classrooms was limited, which was confirmed in our school observations and the experience of some children in the sample:

The teachers [in the general class] do not give special attention to these special learners...There is time allocated to them that they should meet the special teachers but the time is not enough...most of the times they are in the general class.

It is difficult for us teachers to understand the methods these students use to learn when they come to the general classes...David's performance is below average. It might be due to communication that he can't perform to his potential.

Mother and teacher discussing challenges at the resource primary school where a boy in the sample (age 15, grade 7, who has a profound hearing impairment) attends (case 120).

Additionally, a major challenge highlighted by all teachers across all types of schools was class size, which meant that they often lacked the capacity to provide any individual attention to students. Although the maximum class size under Malawi educational policy is 60 students per teacher, almost all teachers had well over 100 children in a single class.

I have 139 children [in my class] – it's too much to notice each one. The class is too much, there's other students with disabilities too but it's so hard to help them, each and every one – to give personal attention to individual students.

Teacher discussing the challenges of providing support to students with disabilities.

Consequently, few children with disabilities were receiving the support they needed in the classroom. In several cases, teachers were unaware before our interview that the child we were discussing even had a disability. Identification of children with disabilities and understanding their support needs is important for developing strategies to promote their inclusion. Furthermore, affirmative action is used to promote the selection of children with disabilities for limited secondary school spots. Since the classification of children is done by teachers – who lack training and time to make accurate assessments – key informants noted that many children eligible for this policy are not benefitting.

Combined with large class sizes, key informants noted that turnover of teachers is high, particularly in rural areas. Most teachers interviewed had only been at this position for less than a year and many of the children had had multiple teachers in a single academic year.

Therefore, any rapport or strategies established with one teacher appears to be often lost with the changeover, as illustrated in the case below of a young 13 year old girl with a hearing impairment.

Because the teachers keep changing, they don't really get used to her condition so it is hard for them to keep their attention on her. They do not get accustomed to her because the teachers keep on being transferred...I have [talked to the teachers about her condition] before but because the teachers keep on changing, it is difficult because it means I need to be talking to every teacher that comes.

Mother talking about the difficulties in establishing strategies for inclusion of her daughter (age 13, who has a hearing impairment and is in grade 5), in a mainstream classroom (case 113).

However, there were several examples of teachers providing support and small, but helpful interventions: putting children with hearing and visual impairments at the front of the class, letting children take down notes after class, following up with children and their caregivers if they missed class or were performing poorly. Children and caregivers alike frequently noted the importance of these accommodations in helping with learning.

Key informants noted that resources for inclusive education were particularly lacking at the secondary school level. Of note was the shortage of secondary school teachers with inclusive education training. To teach at the secondary school level, teachers must go through a longer degree programme to gain expertise in specific subject area (e.g. chemistry, algebra). However, the training colleges in Malawi that specialize in inclusive education confer diplomas which largely restrict teachers to the primary school level. While diploma holders can qualify to teach secondary school, in these rare cases, they are only able to teach Chichewa as they do not have the subject specific qualifications. Furthermore, the limited funds that are available for specialist resources and accessibility are mostly funnelled into primary schools: even if a child with a disability makes it to secondary school, the lack of resources and adaptations to support their learning hinders continued success.

#### 5.4 Discrimination, violence and social exclusion

Children with disabilities faced numerous forms of discrimination, violence and social exclusion inside and outside of school. These experiences, in some cases lead to expressed feelings of low self-esteem and isolation among many of the children interviewed.

##### 5.4.1 *Discrimination, stigma and abuse*

Discrimination, stigma and abuse were pervasive themes across both child and caregiver interviews: virtually all children had experienced these harmful behaviours, either at school, in the community or at home. Unsurprisingly, the persistence of stigmatizing and derogatory comments, bullying and violence led to social exclusion and in many cases children reported on how it impacted upon their self-esteem and confidence. Caregivers reported their children with disabilities were more likely to be targeted than siblings without disabilities, and this was confirmed by the children themselves:



When I haven't done the right thing [my mother] gets angry and teases me that I can't see. *[How do you feel when she says that?]* I feel hurt...I didn't choose to be blind.

Girl, (age 16, who has a profound visual impairment and dropped out), talking about her mother (case 109).

I just stay at home. I do not like going to other people's homes...They talk about my short leg...they say that I am disabled and they don't want to look at me. *[How do you feel when they are saying this?]* It hurts me because it's not my fault that I have an impairment.

Girl (age 15 who has a physical impairment and goes to a resource primary school), talking about discriminatory attitudes in the community (case 103).

I just hear from her friends that Mphatso did something bad [at school] but I know that it's because the others are not used to her... they have problems communicating...because of her mental status, she sometimes annoys her friends and they beat her...[and] make fun of her arm condition and her dumb condition...It affects her...sometimes she just stays quiet thinking about it.

Mother talking about bullying of her daughter (age 13, grade 3, who has an intellectual and physical impairment (case 112).

Children across all types of impairments faced bullying, discrimination and violence; however, children with impairments that affected communication appear more vulnerable, as they tended to be less able to defend themselves or explain their situation.

Nearly three quarters of all children had experienced bullying or violence in school. Classmates were the most common perpetrators of the abuse, although in a few cases, teachers were also implicated. The constant bullying and abuse could discourage children with disabilities from wanting to attend school:

[His classmates] tease him that he is disabled, they also beat him...and steal his food...In the past he used to run away from school...he would sometimes say he will stop school but I encourage him.

Mother talking about the bullying experienced by her son (age 14, grade 4 who has a physical impairment and an intellectual impairment) (case 108).

Most teachers appeared to be unaware of the abuse and violence directed towards their students with disabilities in schools: when probed, only one of the teachers interviewed reported any difficulties in a specific child's relationship with peers and a few more indicated that in general children with disabilities were more likely to be bullied. Most of the reported events took place outside of the teacher's presence, typically on the playground or on the journey to school. Furthermore, some teachers expressed that fighting was common among school children and so may have not recognized the additional vulnerability of children with disabilities to violence and abuse from peers.

Similarly, in almost half of cases where a child had been bullied by classmates, this information came from child interviews alone, suggesting caregivers were possibly unaware of the situation. When probed, several children indicated that they didn't disclose bullying to their caregivers, while caregivers often reported learning of bullying and abuse from other children.

It is important to note the role of individual supporters who mitigated the social exclusion from persistent bullying and stigmatization. Caregivers and some teachers would intervene on behalf of some children to stop bullying and abuse. Additionally, both at school and in the community, children and caregivers often spoke of peers – typically a relative, friends or others who 'understood their condition' - who defended them against aggressors. Children noted the importance of these friends in making them feel less isolated and included:

I love my friends. They don't gossip about me, and aren't violent. But there are other learners who keep saying that they can't be friends with me because of the way I walk... [My friends] just tell me to leave them alone, and that maybe their whole family does not have people with disabilities...[so] I just tell [the kids who tease me] that God should bless them, I just walk with the ones that like me...

Boy (age 16, grade 6), who has a physical impairment, talking about the importance of friends (case 102).



Importance of individual supporters: young boy with his mother.

### Sexual violence and other serious child protection issues

A real concern was the emergence of serious child protection issues faced by children with disabilities. Of particular worry was the threat of sexual violence against children – particularly girls – with disabilities. One girl in the sample was reported to have been recently raped; however, as her impairments make it difficult for her to communicate her experience, her rapist has not been identified (see case study below). Another case involving a 17 year old girl with an intellectual disability who is engaging in unprotected sex is being followed up for potential sexual exploitation. As the topic of sexual abuse wasn't probed during interviews, it is possible that it is underreported. Key informants also reaffirmed the heightened risk of girls with disabilities to sexual violence.

### **Voices of Children: Sexual Violence**

Madalitso is a 17 year old girl with an intellectual impairment. She has difficulties in communication and is only able to say a few words. Madalitso lives with her grandmother and mother; she has not seen her father since her parents divorced six years ago.

Last year, Madalitso was raped one day while walking alone. Although the police were involved, there is very little evidence to go off of as this child is unable to speak and tell who the perpetrator was. They only discovered she had been raped when she did not come home one day and was found alone, in pain and with blood on her clothes and wounds on her body. Consequently, her rapist has never been identified and brought to justice.

Her mother and grandmother are understandably worried about Madalitso's future:

The girl has already had problems growing up due to her condition and now people are coming up and raping her. I don't know why these things are happening... we are worried that the raping has started when she is very young, what will happen when she grows up?

Madalitso is an active child and likes to explore her community. This adventurousness spirit led her to self-enrol in primary school after seeing her friends going. Although she has remained in grade 1 for the past 3 years, her teacher notes that she has made some improvements: she can recite her vowels and has started to say a few sentences.

However, because of the recent rape, Madalitso's mother and grandmother are wary of allowing her continue to roam unattended. Since both work long days in the field, it is difficult to watch over her though. They would feel much more at ease if they could find supervision for Madalitso so that she can continue to go to school, play with friends and explore while they work.

*Case 117: Interviews with caregivers and teacher. All names have been changed.*

Additionally, a growing problem in Malawi and surrounding countries is the abduction and butchering of people with albinism so that their body parts can be used by witchdoctors.<sup>21</sup> Children, who are less able to physically resist attackers and whose 'innocence' is believed to bring additional potency to rituals, are particularly vulnerable.<sup>22</sup> Although only one child in the sample had albinism, this gruesome practice was also highlighted frequently by key informants as a serious concern throughout Malawi, particularly in rural districts more heavily affected by poverty, where the high price paid for body parts creates incentives that drive its continuation.

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<sup>21</sup> United Nations. (2013). *Persons with albinism: Report of the Office of the United Nations High Commissioner for Human Rights A/HRC/24/57*.

<sup>22</sup> *ibid*

There was one child [with albinism] that was sold by his stepfather. Traders came around and told him that he was sitting on a pile of gold so he sold him and no one can find him now...People with albinism are getting kidnapped and murdered or their arms, legs cut off so these parts can be used in traditional medicine practices because it's believed to cure diseases.

Key informant, DPO representative

We hear that people are killing [children with albinism] to produce cures for diseases. There is a fear because God gave us this child and he cannot be used for charms by other people, [but] we don't know how to protect him. But we just accept whatever happens.

Father talking about the dangers facing his son (age 17, secondary school), who has albinism and visual impairment (case 110).

While the government and other stakeholders are beginning to put in place strategies and protections for addressing the issue, children and adults with albinism are still facing serious threats to their safety.

#### *5.4.2 Social exclusion and isolation*

Children with disabilities also experienced other forms of social exclusion. Of particular concern were challenges with communication, particularly for children with profound hearing or certain intellectual impairments. Children with impairments that limited communication faced barriers to inclusion in the learning process at school as well as social participation both in and out of school.

Other kids are nice to him – they are interested in his signs...I try to teach them some [home-made] signs...but they don't really communicate with him...At [the school with a resource centre that they both attend], there's a special teacher for children with hearing problems, but he just provides extra attention...sometimes the teacher also asks me to help explain things to my brother.

Brother of a boy (age 16, in final year of primary at a resource centre school) with a hearing impairment discussing challenges of communication (case 104).

While families had devised ways of communicating with children – such as by developing their own forms of sign language – they were only able to convey very basic information: in attempting interviews with children with profound hearing impairments with interpretation by family members, only very limited conversations were possible and the frustration felt by children and their interpreters in trying to communicate was evident.

Additionally, even when special and resource centre schools had strategies to improve communication – such as the provision of a hearing aid or some limited sign language instruction - these strategies were often not shared with families. Consequently, any benefits from increased inclusion were not spread to families and communities:

[When he was using his hearing aid at his former special school] he could show some signs that he is hearing what the people are saying...but now [without a hearing aid] he is not able to hear what people say, he does not hear anything. We use sign language [that we made up at home]...I think he uses hearing aids at [the resource centre] and they leave it there when coming home. But I am not sure if he is still using them.

Mother discussing challenges of communication with her son (age 15, grade 7), who has a hearing impairment (case 120).

Finally, children with all types of impairments were often excluded from social activities, either on the playground or in the community. In addition to exclusion due to discrimination, several children were unable to participate in certain activities due to limitations from their impairments – for example, children with physical impairments not being able to play popular games like football or children with albinism or certain eye conditions unable to stay in sunlight for long periods of time. Being excluded from these activities – even if unintentional – led some children to feel isolated:

Sometimes my friends run to school instead of walking which makes it difficult for me because I can't see properly. It makes me feel sad for myself...Sometimes they don't want me to participate in the game because they are worried they'll hurt my eyes. That frustrates me.

Girl (age 15, in final year of primary school), who has a visual impairment, talking about exclusion from social activities (case 115).

#### 5.4.3 *The lives of children not in school*

Besides potentially limiting some of the economic and social benefits linked with education, this research has shed light on some of the negative psychosocial aspects of not being in school. Children not at school have fewer opportunities to be with peers or engage in stimulating activities. Caregivers and children alike spoke of boredom, frustration and feelings of isolation and social exclusion:

I would like to go back to school. I admire my friends who go to school...when they carry their note books and are going to school...[*How do you feel about not going to school?*] It hurts me because if I had continued to school I would've been independent.

Girl, (age 16, who has a profound visual impairment and dropped out), talking about wanting to return to school (case 109).

Furthermore, for children who had been excelling at school and were eager to continue, some felt robbed of their dreams for the future, as illustrated by the case of the boy below who dropped out of secondary school because of fees:

He [wanted] to do well in school so that he can have a bright future. He said for one to get a good job, you have to go to school...[when he dropped out] he cried the whole day. I also cried...I think [now that he has dropped out] his future will be difficult. Education is the only key to a successful future.

Mother talking about her son (age 18, who has hearing impairment), who dropped out of secondary school (case 106).

### 5.5 *Poor health and need for health and rehabilitation services*

Almost half of children – particularly those with epilepsy, visual or hearing impairments - in the sample had ongoing health issues that had implications for their education. Poor health and the need for treatment was a major source of absenteeism, difficulties learning, grade repetition and in a few cases, reasons for not attending.

Epilepsy attacks him often. He was also having fits [at school] and I would be called often. I just thought that he should just stop school.

Mother relating why her son (age 14), who has epilepsy and an intellectual impairment, does not attend school (case 114).

Often, health issues were related to their impairment. Many children in the sample had impairments that fluctuated in severity. For example, multiple children had visual or hearing impairments from unresolved eye and ear infections. These infections that had remained untreated for years on end, not only slowly eroded their hearing or vision, but frequent flare ups also caused pain and aggravated their impairment:

I sometimes fail in class because I can't see what's on the board and I also miss classes when I have the swellings while my friends are learning. *[How often is it that you can't see the board even when you sit at the front?]* It's not all days, it's only when my eyes are itchy and tears come out that I can't see what's written on the board and that is why I fail. *[How often does that happen in a month?]* Three days a month...It happens when my medication is finished.

Girl (age 15, in grade 8) who has a visual impairment, discussing the impact of poor health on her education (case 115).

Additionally, seeking care and treatment could lead to frequent absences. Health facilities were often far and repeated visits were needed. Medication stock outs, frequent referrals, conflicting advice and seeking out traditional medicine also led to delays and more absences.

*[Why did you repeat?]* I was mostly absent from school because I was going to the hospital to get treatment for my eyes.

Boy (age 15, grade 6) who has visual and hearing impairments, discussing reasons for repeating grades (case 116).

Furthermore, four children started school markedly late – or did not attend at all – as caregivers hoped for a ‘cure’ in order to enrol them. In these cases, caregivers either did not think their child could be educated without the resolution of their impairment or else were actively seeking out different treatment options that conflicted with school time.

In addition to the direct effects on education, poor health and the need for health and rehabilitation services also had broader impacts on the entire family, which in turn could indirectly affect schooling decisions. For example, some caregivers reported paying for medications at private clinics when public dispensaries were out of stock or for transportation to reach distant hospitals as well as having to take time out from work to care for a sick child, pick up medications or accompany them for healthcare visits. These costs further reduce families’ often limited financial resources, aggravating poverty-related barriers to education, potentially for all children in the family.

The involvement of community-based organizations and groups – such as the parastatal MACOHA – was helpful for some families in accessing needed health and rehabilitation services. For example, one family was provided with transportation to take their daughter who has intellectual and physical impairments to Lilongwe for physiotherapy and fitting with an assistive device, which led to a marked improvement in her functioning and reduced their caregiving burden. Improving access to similar supports and services can therefore play an important role in not just health but education and other areas of family life.



Young girl with an intellectual and physical impairment who has received support in accessing health services

## Voices of children – how health impacts my education

Foster is an 18 year boy who dropped out of secondary school two years ago. He lives with his mother and siblings and has not seen his father since he abandoned the family 12 years ago. Foster has had to take over from his father as a primary breadwinner, taking short-term work to support his family.

Foster has a hearing impairment due to unresolved ear infections – since he was 3 years old, he has had pus coming out of his ears for two weeks every month. Though treatable, he has been unable to access appropriate medications. His hearing has progressively worsened and is especially poor during the times when he has pus coming out.

His ongoing ear infections led to challenges at school. His hearing impairment made it difficult to understand the teacher, especially in overcrowded and noisy classrooms. The weeks where he had pus are especially difficult, as ‘I could not get what they were teaching.’ The discharge of pus from his ears also was stigmatizing, as other children ‘would run away from me and find somewhere else to sit.’ Foster also relates that dealing with the pus created disruptions:

I would go out of the class and start wiping my ears using my shirt. Then I could get back to the class and if I have pus again I would get out of the class again. Teachers would wonder as to why I was getting out of the class so often...they were worried because I was disrupting the class.

Foster’s teachers recommended that he seek treatment for his ear infections. Although he has taken medications in the past, the effectiveness has been limited. Keeping up with refills was difficult as the hospital where he got his medications was ‘far away and I was missing whatever my friends were learning... [when I returned], my friends had covered a lot of work in my absence.’

Still, Foster’s passion for education and some important accommodations helped him succeed at school despite these challenges. He was top of his class in primary school and was accepted into secondary school. Foster’s explains his strategy: ‘I study, wherever I was going I would carry my notebooks.’ His mother confirms his dedication ‘After school, he wouldn’t go to play but he would stay at home to study.’ Foster’s mother also requested that he have a front seat to better hear the lessons. Furthermore, Foster explains that ‘teachers would stand closer to where I was sitting and tell me what we learnt a day before and also what and where to read from the books.’

Ultimately, Foster dropped out of secondary school as he wasn’t able to afford his school fees. He hopes desperately to return to school, studying his old notes to ‘remind myself what I learned in class because I might be lucky and go back to school.’ He also hopes if he is able to return that he’ll be able to board closer to a hospital so he could keep up with his medications.



## 6 Limitations

In interpreting the findings of this study some limitations should be taken into account.

- As the sample from this study was only drawn from the Ntcheu district, the situation of children with disabilities in this area may be different from children in other districts. For example, Ntcheu has a higher number of schools with resource centres and the District Education Office is the only one in the country with an inclusive education expert.<sup>23</sup> Furthermore, although Ntcheu is predominately rural, it has transportation links to Lilongwe and Blantyre – major urban centres where specialized care can be sought.
- Some children with intellectual impairments in the sample were not interviewed because of the severity of the challenges around understanding and communication, and in these instances information was generally provided by the caregiver alone. In the future, further approaches need to be identified to conduct research with children with intellectual and communication impairments.
- The strength of the evidence is dependent on respondents' willingness to truthfully disclose information. In some instances, caregivers may not have been willing to share certain information if they felt it reflected poorly on them. Similarly, although efforts were made to interview children alone, if the caregivers' presence was requested by the child or needed to help with interpretation, children may have been reluctant to disclose certain details about life at home and in school around them. However, the combination of interviews with caregiver, child and teacher brought multiple perspectives that enriches the data.

## 7 Discussion

Understanding the barriers – and subsequent enablers – that affect access to a quality education for children with disabilities is essential for Malawi and other countries to fulfil their commitment to the right of all children to an education. Although data, when available, continually points to disparities in educational outcomes for children with disabilities, this case study from the district of Ntcheu has provided some explanation as to *why* those differences might exist.

The reasons why children with disabilities are not accessing or progressing with their education or facing difficulties that impact on their social and learning experience while at school are complex, involving a mixture of individual, family, school, community and policy level factors. Barriers vary in weight depending on the individual circumstances of each child. Furthermore, different impairment types may experience different challenges to inclusion: children with communication impairments, including children who have hearing impairments and with an intellectual disability or cerebral palsy, can be particularly vulnerable. Interventions to improve access to education must take into account their differing needs.

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<sup>23</sup> Alindiamao, G. (2015). [Personal Communication].

Many barriers that emerged from this research affect access to education for all children. For example, **poverty-related causes** are the most common reason for drop outs nationally and fees for secondary school are a major driver of failure to progress to secondary school for all children.<sup>24</sup> Similarly, large class sizes and overworked teachers affect all learners. Still, children with disabilities arguably are more vulnerable to exclusion from these barriers: for instance, extra costs associated with disability – such as the need for ongoing health and rehabilitation services – can exacerbate poverty,<sup>25</sup> while our research highlights that children with disabilities are more likely to be overlooked and not receive interventions that are essential to promote their learning in oversized classes. The increased risk of poverty resulting for disability-related costs may also have impacts on the entire family, including on the educational outcomes of siblings.

Challenges with **transitioning from primary to secondary school** emerged across several themes. Affordability was a dominant concern, as tuition along with boarding costs was prohibitive for most. Additionally, although affirmative action is in place to promote the selection of children with disabilities for limited secondary school seats, identification of children eligible for this policy is poor: classification is done by teachers, who are not provided with any training. Furthermore, resources for inclusive education are more limited than at primary. The lack of certification in inclusive education training and other less formal trainings for secondary school teachers is a particular problem.

Similarly, another cross-cutting issue was the apparent heightened **vulnerability of girls** to exclusion. A major concern that needs to be further explored is the risk of sexual violence directed against girls with disabilities. In addition to the devastating toll on girls affected by abuse, the fear for girls' safety was a barrier to accessing education, particularly if they had to travel long distances or board away from home in order to attend school. Furthermore, the documented exclusion of girls with disabilities from sexual and reproductive health services,<sup>26</sup> combined with the universal issue for girls of early marriage and pregnancy,<sup>27</sup> could impact education plans for girls with disabilities.

This study also highlighted some areas in need of further research and attention from programmes and policy makers. For example, there is a need to address the linkages between health, education and poverty. This study has shed light on the potential direct and indirect impacts from poor health and the need for ongoing treatment and rehabilitation on education, livelihood sustainability and other outcomes for children with disabilities and their families. Community-based rehabilitation programmes – such as MACOHA – that take a multidimensional approach for increasing participation of children and adults with disabilities can play an important role in coordinating responses between sectors.

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<sup>24</sup> Research for Inclusive Education in International Cooperation. (2015). "Country Studies: Malawi." Hannover, Germany.

<sup>25</sup> World Health Organization & World Bank. (2011). "World Report on Disability." WHO Press: Geneva available at [http://www.who.int/disabilities/world\\_report/2011/en/index.html](http://www.who.int/disabilities/world_report/2011/en/index.html)

<sup>26</sup> Groce, N. E. (2005). "HIV/AIDS and individuals with disability". *Health and Human Rights: an international journal*, 8(2), 215-224

<sup>27</sup> Research for Inclusive Education in International Cooperation. (2015). "Country Studies: Malawi." Hannover, Germany.

Furthermore, interventions to improve educational outcomes and inclusion for children with disabilities need to look at the whole school environment – on issues such as bullying and social exclusion in addition to classroom learning.

This research also highlights the importance of including input from children with disabilities themselves in research. Certain topics, such as bullying, came out mostly from child interviews and this valuable information may not have been explored in as great a detail without their perspectives. Including feedback from young people with disabilities in all programmes and policies is needed to ensure they are inclusive and that children with disabilities are having their needs and rights met.

Addressing these barriers that are affecting access to a quality education and school experience brings benefits for all children – with and without disabilities. Investing in and engaging with families, schools and communities so that they can better provide a meaningful education and positive, inclusive school experiences for all children is essential to fulfil the promises of universal education.

## 8 Recommendations

The recommendations outlined below are the product of collaboration between members of the advisory group of key stakeholders in Malawi, the Norwegian Association of Disabled and the London School of Hygiene and Tropical Medicine.

### 8.1 *Recommendations for families and communities*

- Raise awareness at the family and community level on the rights of children with disabilities to an education so as to address many of the attitudinal barriers preventing access.
- Empower families and children with disabilities to advocate for themselves so they can push for interventions and strategies that will best promote their inclusion.
- Increase caregivers' understanding of the health and support needs of their children with disabilities and find ways to overcome barriers to accessing health and rehabilitation services.
- Combat stigma, violence and abuse perpetrated against children with disabilities in the community.
- Review all existing child protection mechanisms and ensure they are disability-inclusive and develop strategies to address the particular vulnerability of children with disabilities to abuse.
- Work with schools and families when children are at pre-school stage to improve timely enrolment at school.
- Increase provision of community-based educational opportunities for children with disabilities who have dropped out of school.
- Ensure all community-based programmes are inclusive of children and adults with disabilities. Seek input from adults and children with disabilities in the design, implementation and evaluation of any new programmes.

## 8.2 *Recommendations for schools*

- Train teachers and principals to identify children with disabilities and develop strategies – with input from the students with a disability and their caregivers – to support their inclusion in the classroom. Ensure these strategies are shared during any changeover of teachers.
- Raise awareness among school staff on the vulnerability of children with disabilities to bullying and violence in and around schools and put in place measures to curtail these damaging behaviours.
- Put in place mechanisms to improve the inclusion of children with disabilities in all school activities, both inside and outside of the classroom.
- Promote the inclusion of caregivers of children with disabilities in parent-teacher associations to equally prioritise issues that affect children with disabilities in schools.

## 8.3 *Recommendations for policy and advocacy*

- Advocate for improved budgetary allocation and monitoring of existing laws and policies on inclusive education.
- Ensure proper supervision, planning, monitoring and evaluation of inclusive education at all levels of government, including district and sub-district levels.
- Strengthen the capacity of all schools to provide an inclusive education by improving accessibility of school facilities and availability of specialist resources. Provide training to all teachers in methods for promoting inclusive teaching and for working with children with different disabilities.
- Introduce a mandatory course on inclusive education as part of the curriculum at all teacher training colleges. Expand certifications on inclusive education to include secondary school teachers and increase the number of teachers with sign language proficiency.
- Engage families with a child with a disability in economically empowering activities to reduce the impact of poverty on access to education and health services. For example, ensure social protection programmes are inclusive and sensitive to the particular needs of families with a child with a disability.
- Address universal barriers to receiving a quality education, such as reducing class sizes and ensuring that poverty does not prevent access to or continuation with education, particularly in transitioning to secondary school.
- Strengthen child protection mechanisms and ensure they are disability-inclusive to combat violence and abuse perpetrated against children with disabilities.
- Increase access to health and rehabilitative services, including provision of assistive devices, to prevent impairments from worsening and improve overall well-being and independence of children with disabilities.

## 8.4 *Recommendations for research*

- Ensure that all research includes appropriate methods and adequate budgetary support for involving children with disabilities.

- Explore further the role of poor health and the impact of health and rehabilitation services on educational outcomes for children with disabilities.
- Explore further the issue of violence against children with disabilities, including sexual violence.
- Identify and evaluate interventions that could increase access to and success at school for children with disabilities, including in transitioning from primary to secondary. Other interventions to explore could include: ways to increase uptake of health and rehabilitation services and decrease discrimination, abuse and violence for children with disabilities.

## 9 Appendices

### Interview guidelines for Children with Disabilities

#### Materials:

Prepared flipchart, coloured pens, emotion cards

Adapt for children who are not in school. If they have dropped out then the questions will be related to their past experience of going to school.

If they have never been to school, or only been in school for a short period, then the focus is more on their home life. Where they spend their day. How they feel about dropping out of school.

For children with intellectual disability I suggest that you ONLY use the happy/sad card to keep the discussion simpler.

#### Introduction:

- In advance of the interview to have checked what their levels of communication and understanding are.
- Remind children of the purpose of the interview. How they can stop at any time, and they don't need to answer anything that they don't want to.
- Show them the different emotion cards – Happy, Sad, Frustration, very happy. Show them the picture.
- Ask them to write their name on the top of the picture if they can- if not then write it for them. (Issue of confidentiality here? I wonder if we should explain that we will not be putting their name on the picture – ask them at the end- and remind them that we will not be putting their name on any report).
- Test that they understand how to use the cards e.g. when it's their birthday how do they feel? Which card? Why? (or another suitable relevant question)
- Have the drawing pre-drawn to save time – although may be helpful to test out drawing it with them and talking it through what you are drawing with them. You may want to ask them to draw the journey to school – ask questions as they are drawing – is it far? How long does it take to get there. In piloting need to check how long this takes
- For children with an intellectual disability, where you are unclear whether they fully understand the question an/or if communication is a real issue then also check opportunistically with 1) siblings and 2) friends (if around) 3) teachers to help triangulate the information,
- Consider how this works with older young people. Propose that still use the pictorial image to break up the access to school into different components for discussion and still give them the emotion cards
- For children who are blind use the same questions and prompts but without the pictures
- As they discuss things – can ask them to draw on the paper, you can make notes on the paper if useful.

## Home

Show the picture with a house and a stick picture of them and ask them what they did yesterday when they were at home.

- Who are the important people in your life? (Prompt – siblings, parents, grandparents, friends)
- Can you tell me how you spend your days? For example, tell me what you did yesterday?
- What kind of things make you happy at home? Unhappy? Frustrated? About being at home. How do you feel about not being at school? Why?
- What are the things and/or people that make you happy at home?
  - Prompts: Playing with friends/siblings, helping in the house, particular members of the family who help you?
- What kind of things, if any, make you sad at home?
- What kind of things, if any, make you angry?

## Journey to school

Look at the journey to school – explore how they get there, who goes with them. Ask them to pick out the relevant emotion card. Explore why

## At school – in the classroom

We want to talk about being in the classroom. We would like to understand more about your time in school

- What kind of things and/or people that make you happy/really enjoy at school? Why? Give an example?
- Are there any things which make/made you sad? That you don't like? Why? Give an example- explore
- Are there any things that make/made you angry? Why? Give an example

Progression through school/Learning in the classroom

- If they didn't move up to the next class with the rest of their peers, explore why, what do they think were the main reasons for this? How do they feel about this?

Transition from primary to secondary

- Any particular issues in the transition from primary to secondary?

If they are not going to school, or have stopped going to school how does that make them feel?

## At school – in the playground.

- How do you feel in the playground? What kind of things make you happy (Happy emotion card). Are there any things which make you unhappy/sad? Are there any things which make you feel frustrated?
- At school – using the toilet facilities. What are the toilets like? Emotion cards

Thank you and shared drawing

We have talked about many things today. Is there anything else important that we haven't discussed that you think is important about your experience of school.

## Interview guide: Caregivers

### Introduction:

Good morning and thank you for your time. I am \_\_\_\_\_ from ..... . I am here today to as part of the research study we discussed before and which you kindly agreed to take part in. Remind parents of the full information sheet that they received about the study. Remind them of the issue of confidentiality which is fully explained in the info sheet.

You can stop me at any time if something is unclear. If there us anything that you do not want to answer then you do not need to.

### Code:

### Interviewee:

### Relationship to the child:

### Gender:

### Child at school: yes/No

### Type of school: primary, lower secondary, upper secondary, special school

### Interviewer:

### Date:

### Location:

### General observations (where interview conducted, who was present, anything which impacts upon how the interview conducted):

### About your Family

*Please tell me about your family* (Prompts: Who lives in the house, no of children, are children going to school, who is working in the house)

Note: at the end of the in-depth interview more detailed data on all children will be collected for later comparisons: age, attending school (if yes, what grade; if dropped out, highest grade achieved), repetition of grades, late starts/gaps in schooling

### About the child's condition

- Please tell me about your son/daughter who has difficulties with X (e.g. walking/seeing/understanding)
- How does this condition affect your child on a day to day basis?
- What is she/he able to do?
- What things does she/he find more difficult or not possible for your child to do, that other children of the same age can do? Please tell me about his/her day – does she go to school/is able to help around the house?



- About your child's health
- Please tell me about your child's general health?
- Prompts? Frequently ill? Explore any recent illnesses and treatment sought?
- How does this compare to other children in the family?
- Does this impact on school? In what way?

### **Treatment-seeking behaviour**

This section will be to determine if child went for the services that were referred to them in a past project (children attended a one-day screening camp to have their condition assessed by experts and then for children with a diagnosis, some were referred for further follow-up services, including CBR)

(Interviewer Note: This is NOT about checking up on them for not going to referred services—emphasise about learning from their experience)

### **Check if there has been a diagnosis of the child's condition**

- Do they recall the 'camp' – refer to camp location for each child- which they attended ~ 1.5 years ago (August /Sept 2013; show picture of stamp they would have received in health passport). Were they given a diagnosis then? Do they recall what it was?
- We would like to learn more about your experience from this camp and any follow up services you may have sought:
- Understanding about the diagnosis and understanding of opportunities for treatment
- Recall any follow up/referral form or advice (find out if they were given a referral slip)?
- If yes – what did they do? (If they didn't go to referred services): Explore main barriers for up-taking referrals (Prompt only if necessary: transport- what are the distances – how long to get there, lack of information about what was being offered)
- If multiple reasons listed, explore the MAIN reason for no uptake

### **About your child's education**

(Interviewer Note: clarify if the child is currently going to school, and if not, if they have ever been to school)

*If the child is going to school*

- Please tell me about your child's experience of school/education :
  - Prompts: where do they go to school? (government school, mission school, private school, community day school; mainstream, special/resource centre school; primary/secondary). Do they access any other type of informal education? Is this the same school as their other children?
- Is the child happy in school? Are you happy with their education – why/why not?
- Explore why the child may not have progressed as planned through the school – what do they think are the main reasons for this?
- If the child has stopped going to school, when did they stop, why? Whose decision was that?
- Are there any difficulties that you have noticed with their experience of school?
  - Prompts: What class are they in? Is that the right class for their age why/why not?
- Do they miss school – if so how often? Why? Compared with other children in your family? Any difficulties in getting to/from school? Other reasons they miss school such as illness?

*Transition issues:*

- From primary to lower secondary or from lower secondary to upper secondary?
- From special to mainstream?

*Enablers*

- What do you think helps your child the most in school? Teachers? If so, in what way?  
Support from other children?
- Are there any suggestions that you have for improving your child's experience of school?  
Explore why these will lead to improvements

*If the child is not going to school or has stopped going to school*

- Please tell me what the main reasons are for your child not going to school? Are these reasons the same/different for other children in the family?
  - If there are a number of reasons, ask parents to rank the main reasons explaining why they have ranked them in that way
- Are there any suggestions that you have for how some of these obstacles could be addressed?
  - Look at the different reasons given and how parent proposes these challenges could be addressed

*Hope for their child for the future /expectations from school*

- What is the hope for your child in sending them to school (if going to school)
  - Prompt- main reason for sending them- is this different from other children?
- Please tell me what you hope for your child in the future? (for all parents)
  - (Prompts, only if necessary- Education, getting married, work)

Anything else that we haven't covered about that you would like to add?

Thank you for your time. We will be providing feedback through the MACOHA office. This will be in 2-3 months time, once we've had time to look at all the information from the parents and children.

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<sup>i</sup> The 2008 census classified disability into five types: 'seeing', 'hearing', 'speaking', 'walking' and 'other'

<sup>ii</sup> Reference group included representatives from MACOHA, FEDOMA, Disabled People International, the Office of Special Needs Education in the Ministry of Education and the Ministry of Gender, Children, Disability and Social Welfare