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# Barriers to education for youth with disabilities in Malawi:

## A qualitative study of policy and practice in urban and rural areas

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## A qualitative study of policy and practice in urban and rural areas

Master´s thesis
by Caroline Hagen
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Title Photo: Classroom, village in Zomba District (Photo: Caroline Hagen)

## **Declaration**

I, Caroline Hagen, declare that this thesis is a result of my research investigations and findings. Sources of information other than my own have been acknowledged and a reference list has been appended. This work has not been previously submitted to any other university for award of any type of academic degree.

Signature…………………………..

Date……………………………………

# Acknowledgements

## **Abstract**

Youth with disabilities in Malawi constitute a minority group that is particularly vulnerable to social exclusion and lack of education. The aim of this study is to carry out an in-depth exploration of barriers to education for youth with disabilities in Malawi. The objectives are: to identify relevant policies and actors at national, district and local level; to explore the situation in practice for youth with disabilities regarding education; and finally to explore possible differences between urban and rural areas. This research was conducted in two different geographical areas in Malawi: urban Lilongwe in the Central Region and rural Zomba in the Southern Region. Data collection was conducted between July and December 2015. The study offers a qualitative approach to the subject, being based on a series of in-depth, semi-structured interviews. To explore barriers and facilitators to education in the respective areas, ten youths with disabilities were interviewed as case studies, in addition to their families, service providers and contextual informants. Two different translators were used, one in each of the two geographical areas.

Findings reveal that although Malawi´s policies and legal framework towards disability and education are adequate, these are not implemented in practice. Barriers to education are many. These include the way special needs are organised in the respective areas; little or no attention from teachers; stigmatization; lack of support and knowledge from home and the community; physical obstacles; lack of human and material resources; and poverty. Although the urban and rural areas in this study differ in the way special needs are organised, the poor economic situation of Malawi results in few and inadequate resources for youth with special needs in both areas. Consequences of these barriers include early dropouts and/or continuous repeating of levels.

# List of Acronyms

| | |
|---|---|
| CAMFED: | Campaign for Female Education |
| CRPD: | the Convention on the Rights of Persons with Disabilities |
| CRC: | the Convention on the Rights of the Child |
| CSR: | Centre for Social Research |
| DEM: | District Education Managers |
| DFID: | the Department for International Development |
| DPO: | Disabled Peoples Organisation |
| EFA: | Education for All |
| FEDOMA: | Federation of Disabled Organisations in Malawi |
| FFO: | Norwegian Federation of Organisations of Disabled People |
| GDP: | Gross National Product |
| GNI: | Gross National Income |
| GVH: | Group Village Head |
| IMF: | International Monetary Fund |
| LIC: | Low-Income Country |
| LSE: | Leaving Certificate Examination |
| MACOHA: | Malawi Council for the Handicapped |
| MDG: | Millennium Development Goals |
| MANEB: | Malawi National Examinations Board |
| MGDS: | Malawi Growth and Development Strategy |
| MoEST: | Ministry of Education, Science and Technology |
| MSCE: | Malawi School Certificate of Education |
| NGO: | Non-Governmental Organisation |
| NMBU: | Norges Miljø-og Biovitenskapelige Universitet (Norwegian University of Life Sciences) |
| NSD: | Norwegian Centre for Research Data |
| NSO: | National Statistical Office |
| PEA: | Primary Education Advisor |
| SADC: | Southern African Development Community |
| SAFOD: | Southern Africa Federation of the Disabled |
| SDG: | Sustainable Development Goals |
| SEN: | Special Educational Needs |

| SNE: | Special Needs Education |
|------|------------------------|
| SINTEF | Stiftelsen for Industriell og Teknisk Forskning |
| SWAp | Sector Wide Approach |
| TA: | Traditional Authority |
| UNIMA: | University of Malawi |
| UN: | United Nations |
| WHO: | World Health Organisation |

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# Chapter 1: Introduction

People with disabilities are considered the world's largest minority (UN, 2006). People with disabilities are a part of every social category; men and women, children, different races and different cultures; among all social classes; wealthy and poor, highly educated people and those without education. According to the World Health Organisation, around 15 % of the worlds´ population have some sort of disability (WHO, 2011). These include all kinds of impairments; sensory impairment, (blindness/visual impairment, deaf/hard of hearing), physical impairments, psychosocial or developmental. Having a disability is, according to the United Nations, a combination of the actual impairment, such as being in a wheelchair, being blind or deaf) and the socially constructed obstacles the person with the impairment faces (UN, 2006).

Historically, many children with disabilities have been excluded from basic education (WHO, 2011), and to a large extent the education offered has been separate specialised schools, targeted at people with specific impairments, such as special schools for the blind or deaf (WHO, 2011). This makes people with disabilities particularly vulnerable to exclusion and stigmatisation later in life. Segregating children with disabilities from "non disabled children" using specialised schools creates a notion that this social group is different from children without disabilities very early in life (WHO, 2011). The same goes for excluding children with disabilities from education altogether. Segregation and exclusion promotes lack of knowledge and social stigmatisation towards children with disabilities. Along with exclusion from basic education comes exclusion from social interaction with peers. One consequence of this is that basic capabilities will be limited already as a young child, which can lead to lack of other capabilities and thus lower quality of life as an adult (DFID, 2000 p. 3). The term "capabilities" is a term developed by Amartya Sen, and is an approach to assess the quality of life, and theorize basic social justice (Nussbaum, 2011). The term will be thoroughly explained in chapter 3 of this thesis. Exclusion from basic education can limit the capability to obtain higher education and employment later in life, as well as limiting the capability to socially interact as equals with other human beings.

Around 80 % of people living with a disability live in a low-income country (LIC) (UN, 2015b). A low-income country is defined as a country with an economy with a gross national

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income (GNI) per capita of 1,045 USD or less (World Bank, 2016). In other words, most of the people living with a disability live in by definition less developed countries. Moreover, some 150 million young people in low-income country have a sensory, intellectual or physical disability. By definition, low-income countries have limited resources. People with disabilities are therefore, for a variety of reasons, rarely the focus of political and social policy priorities. Thus, youth with disabilities are among the worlds poorest and most marginalised of the world's young people (Groce, 2004). In LICs, children and youth with disabilities are more likely to be out of school than those in high-income countries (HIC´s) (WHO, 2011). This thesis uses several definitions of youth, among them the UNESCO definition of youth, which encompasses people between 15 and 24 years, and the Malawi Youth Policy definition, which is those between 10 and 35 years. Since the focus of this thesis is access to and learning in education, this thesis will limit its definition of youth to encompass those between 12 and 20 years old.

Ensuring quality education for youth with disabilities means that special needs are met (appropriate mode of teaching, a disability friendly environment) and that family, teachers and other service providers provide the same teaching and opportunities to students with disabilities as to those without (EFA, 2015). Malawi is an example of a low-income country where education is less likely to be obtained by children and youth with disabilities than those without (Braathen & Loeb, 2011). Being one of the poorest countries in the world with few available resources, little is known about the situation for youth with disabilities in education (Munthali, Tsoka, Milner, & Mvula, 2013). Although it has an adequate legal framework to ensure the rights and protection of children with disabilities (Braathen & Loeb, 2011), UNICEF (2013) reports that those with disabilities who are offered education in Malawi face a number of difficulties. These include both physical difficulties like lack of universal design (A design foundation for a more accessible and usable products and environments (Burgstahler, 2016)), and social stigmatisation. However, there is a need for further knowledge about the specific difficulties, and the reasons that lie behind these mechanisms.

An increase in knowledge about education and various disabilities at country level can increase knowledge of the issues facing people with disabilities further in the wider southern African region, and indeed provide applicable lessons to low-income countries in general. Thus, this study will focus on access to education and learning in school for youth with disabilities in Malawi. As this study focuses on access to education, this study will focus on

youth enrolled in school, but also youth that have previously been enrolled that have now dropped out. The specific case study for this research will thus be youth in, or previously in education in Malawi.

1.1 **Problem statement**: Youth with disabilities is a minority group that is particularly vulnerable to lack of education in Malawi. This study will explore access to education and learning for youth with disabilities in Malawi. Investigating and understanding the specific barriers to education for disabled youth is necessary in order to implement existing policies that can ensure that the equal right to education is achieved in practice.

## 1.2 Objectives

1.2.1   Identify relevant policies and actors at national, district and local level, and examine their ability to provide education to disabled youth in practice.

1.2.2   Explore the situation for youth with disabilities concerning education.

1.2.3   With respect to findings from the objectives above, explore differences between urban and rural areas in Malawi.

## 1.3 Research questions

1.3.1   What are the policies towards securing access to and learning in education for youth with disabilities at local and national level in Malawi? Who are the different actors involved?

1.3.2   What are the special needs of youth with different types of disabilities in school, and how are these special needs met (i.e: to what degree is education delivered in the appropriate mode?)

1.3.3   What are the specific barriers and facilitators to education?

1.3.4   Who is responsible for learning/lack of learning in education for youth with disabilities at community and school level?

1.3.5   What are the personal experiences of youth with disabilities regarding their situation in school?

This study is linked to a larger study regarding access to education for children and young people with disabilities. SINTEF Technology and Society and the University of Malawi (UNIMA) undertake the study, where the main objective was to carry out an in-depth exploration of barriers and facilitators for access to education and scholastic achievements

(Braathen & Munthali, 2016). While the study by SINTEF and UNIMA focuses mainly on access to education for children at primary level in a rural setting, the research done for this thesis is focused on access to education for youth in primary and secondary level in a rural *and* urban setting. The report of case studies (Braathen & Munthali, 2016) and this thesis has been written simultaneously and independently.

## Chapter 2: Thematic background

In this chapter, I will present background information and existing literature relevant to this study. Firstly, I will present how disability has taken its place on the international agenda. Secondly, some background information is offered on the link between disability, youth and education, background that will set the stage for an investigation of disability in low-income countries. Lastly, I will present some background information on the country in focus, Malawi, before reviewing existing policies and regulations on disability and education in Malawi.

### 2.1 Disability on the international agenda

The beginning of the 90s called for international attention towards disability. In 1994, the United Nations adopted the "Standard rules for the equalization of opportunities for persons with disabilities". The program provided international standards for laws and programs on disability for United Nations member states (Albrecht, Seelman, & Bury, 2001), and encouraged greater participation of people with disabilities across all sectors of society. Although member states that signed the program were not legally obliged to follow them, it enforced a strong moral commitment. Furthermore, it incorporated a human rights perspective towards disability that had emerged over the last decade (UN, 1994). In 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD). It had 82 signatories, and entered into force on May 3rd, 2008 (UN, 2006). The Convention is a human rights instrument with an explicit social development dimension (UN, 2006), and rejects the viewing of persons with disabilities as objects of charity, medical treatment and social protection. Instead, it promotes regarding people with disabilities as subjects of equal rights, who are capable of claiming these rights and of being active members of the society. The convention set the basis for a global paradigm shift in development cooperation (Norad, 2012). NGOs and development agencies are now working towards mainstreaming disability

into development. The idea is that development and poverty reduction strategies should mainstream disability, rather than pursuing specific programs and leaving focus on disability to NGOs that are strictly working for bettering the life of persons with disabilities. This a strategy adopted by many development actors, including Norwegian NGOs and Norad, who are heavily involved in development projects in Malawi (Norad, no date). However, an evaluation report from 2012 revealed that this strategy is not yet up and running among development agencies, and that the general trend among people, communities, NGOs and other stake-holders is still to regard disability as an individual, medical problem (Norad, 2012). The idea of mainstreaming disability in development cooperation is of particular importance in the context of Malawi; a country that is heavily dependent on financial aid and development cooperation.

## 2.2 Disability, youth and education

Youth with disabilities are among the poorest and most marginalised among of all the world's young people (Groce, 2004). According to the World Health Organization, there are between 93 million and 150 million children and young people living with disabilities worldwide (WHO, 2011). These youths face a number of challenges in poorer countries, according to Groce (2004). Some of these challenges are first and foremost the little knowledge that exists globally about this age group. Finding accurate numbers of youth with disabilities globally is a difficult task. Measurements of disability prevalence, in the World Report on Disability (WHO, 2011) divides the population into age groups of 0-18, 18-49 and so on. Youth therefore often fall under the umbrella of either children or adults. However, Groce (2004) argues, youth and adolescents are in transition between being a child and an adult, and are thus expected "acquire skills, go through physical and psychological maturation and assume a social identity"(Groce, 2004, p.18), leaving the social group of youth significantly different from children and adults (Groce, 2004).

The Department for International Development (DFID) in the United Kingdom states that disability affects people´s chances of going to school, for employment and for equal participation in everyday life (2000). Historically, many children and youth with disabilities have been excluded from the opportunity of education. The reasons for this are many. Often children with disabilities are regarded as a distraction to other students, are considered incapable of learning, or it is felt that they simply should not be put under the stress of

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schooling (Groce, 2004). By the time children with disabilities reach adolescence; they are far behind in terms of learning skills compared to their non-disabled peers.

Ensuring that children with disabilities receive quality education in an inclusive environment is an important part of the Convention on the Rights of People with Disabilities. The WHO has four reasons for disability inclusive education: 1.a contribution of human capital and thus general well-being, 2. The exclusion of children with disabilities in education and further employment has high social and economic costs. 3. The Education for All initiative and the Millennium Development Goal (MDG) 9. 4. Countries that have signed and ratified the Convention on the Rights of Persons with Disabilities cannot fulfil their obligations without disability inclusive education (WHO, 2011)

## 2.3 Disability in low-income countries

The World Report on Disability, published in 2011 by the World Health Organization estimates that around one billion people in the world live with a form of disability. On a general basis, the WHO suggests that people with disabilities have poorer health, lower education and fewer economic opportunities than people without disabilities. This is because of few resources available as well as numerous physical and social obstacles on a daily basis (WHO, 2011). A large proportion of people with disabilities live in low-income countries. There is a link between poverty and disability, indeed poverty is both a cause and a consequence of disability (DFID, 2000). Disability exacerbates poverty by increasing isolation of large groups and thereby sets economic strains within the community. The cycle of poverty and disability starts with economic poverty. Economic poverty leads to malnutrition and disease, which again leads to impairment and disability (Parnes et al., 2009). This in turns leads to lower levels of human development, and the cycle continues. Disability therefore has an impact on whole communities, and the cost of excluding people with disabilities is high. Thus, disability and the exclusion of this minority are not only a strain on the individual itself, but the lack of economic activity for this group can exacerbate to poverty for the whole community (DFID, 2000)

In 2012, the Open Society Initiative did a study on the status of disability rights in Southern Africa for Southern Africa (OSISA). The study reveals that people with disabilities are characterised by severe poverty and deprivation and low levels of education. Many Southern Africans with disabilities face obstacles when trying to obtain education and vocational

training, and a large portion of them do not know about the resources that are available to them (OSISA, 2012). Especially in rural areas, stigmatisation is attached to most forms of disabilities. Also in the educational system, those children and youth with disabilities that had access to education experienced bullying and social stigmatisation from their peers (OSISA, 2012). Therefore, there is some knowledge of the situation of people with disabilities in Southern Africa, but there is a lack of knowledge on the specific challenges and the reasons behind these.

## 2.4 Malawi

The Republic of Malawi is a landlocked country in the south central part of Africa. It borders Tanzania in the North, Mozambique in the East and South, and Zambia in the West, and is part of the Southern African Development Cooperation (SADC). Malawi is a multiparty democracy, and its current president is Prof. Peter Mutharika. Malawi is a densely populated area, with approximately 16 million people (BBC, 2015), with around 80% of its population living in rural areas. On the Human Development Index, Malawi is ranked the 15th poorest country in the world (UNDP, 2015). The economy of Malawi is predominantly agricultural, which accounts for one third of its national GDP (CIA, 2015). Moreover, Malawi´s economy is highly dependent on economic assistance from International Monetary Fund (IMF), the World Bank and individual donors.

Figure 1: Map of Malawi and neighbouring countries



(CDC, 2015)

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**2.5 Disability in Malawi**

Malawi has signed and ratified the Convention on the Rights of People with Disabilities and the Convention on the Rights of the Child (Munthali et al., 2013). UNICEF, in collaboration with the Government of Malawi published a report in 2013 on the situation of children with disabilities in Malawi (Munthali et al., 2013). The report reveals that in addition to signing and ratifying the convention, there is a legal framework on the national level promoting the rights of people with disabilities in Malawi. Nevertheless, the framework is not implemented fully. While there are various policies promoting the rights of people with disabilities, these policies are not always fully implemented.

Loeb and Eide published a report in 2004 on the living conditions among people with disabilities in Malawi, with the aim of providing an overview of the situation of people with disabilities in Malawi, as well as a comparison of the living conditions for those living with and without disabilities (Loeb & Eide, 2004). The study was an international cooperation between Southern Africa Federation of the Disabled (SAFOD), Federation of Disability Organisations in Malawi (FEDOMA), Norwegian Federation of Organisations of Disabled People (FFO), University of Malawi (Centre for Social Research) and SINTEF Health Research. The study was funded by Atlas Alliance, the umbrella organisation for the development work of Norwegian disabled people´s organisations (DPO) (IDDC, no date), on behalf of Norad. The main findings from the survey is that overall, people with disabilities are worse off in several of the indicators used in the study, compared to those without disabilities. These indicators include employment, education, and health. The study revealed, among others that households with disabled members had lower standard of living than those without. Regarding employment, though official employment records are not to be found, a higher proportion of people with disabilities were found "not to be working", compared to those without disabilities (Loeb & Eide, 2004). The study also revealed low levels of service provision among those with disabilities, including welfare services, vocational training and assistive device services. However, health services and traditional healers were found to be available for the majority of those with disabilities (Loeb & Eide, 2004). This comprehensive study provides a basis for future studies on disability in Malawi.

A number of studies have been undertaken on disability in Malawi since the study on living conditions. One of them is a study on albinism. This study revealed great lack of awareness towards disability, albinism and the causes and consequences of albinism. A study on living conditions for women with disabilities in Malawi was undertaken in 2006. The study revealed a mixed picture of the situation of Malawian disabled women. First of all, the women themselves stated that they had the impression that men with disabilities in Malawi were generally better off than women. In addition, they had all experienced negative attitudes towards them and their disability in their community. In spite of this, the women in this particular study felt that they had been taken good care of, and they were well educated (Braathen & Kvam, 2008). However, the women in this study were not representative of the average Malawian woman (Braathen & Kvam, 2008); they came from an urban setting with more available resources. For this reason, this study does not paint a clear picture of the situation of persons with disabilities in Malawi. A study on barriers for accessing health services among people in four African countries, including Malawi, was published in 2015, revealed that people with disabilities experience various barriers to health care, and that education reduces these barriers (Eide et al., 2015). The literature shows that people with disabilities in Malawi and Southern Africa experience lower access to health care, social stigma and that there is in general little knowledge on disability.

**2.6 Education in Malawi**

Malawi´s formal education system is divided into primary school (Standard 1-8), secondary school (Form 1-4) and tertiary education. The Constitution of Malawi, from 1994 states that it is determined to implement policies and legislation aiming at free and compulsory education for every citizen. As a result of this, primary education fees were abolished, which increased enrolment rates (UNICEF, 2009). However, there is a strain on resources in schools in Malawi due to the heavy influx of students that has followed the abolition of fees. Secondary schools charge tuition fees. They vary in physical size in size and spaces are invariably limited. A student is selected to attend a public secondary school based upon their results from the Leaving Certificate Examination at the end of Standard 8 (Banks & Zuurmond, 2015).

Education is described as the portal to better opportunities for those with disabilities (Munthali et al., 2013). Education provides self-esteem, integration to society and participation in political and social processes. A lack of either access to education or quality

in the education offered for youth with disabilities in Malawi can lead to a missed opportunity for higher education and employment, and/or further exclusion from the society (Munthali et al., 2013). This is supported by Loeb and Eide (2004), who found in their study that unemployment is higher among people with disabilities than those without, as well as a lower standard of living.

The same study also revealed that school attendance is clearly lower than for those without (Loeb & Eide, 2004). Among children aged 5 or older, 35% of those with disabilities had never attended school (Loeb & Eide, 2004). In the book chapter ""No disabled can go here.." How education affects disability and education in Malawi", Braathen and Loeb (2011) describes the link between poverty, disability and education. The main problem that results in a lack of education for those with disabilities are access, both physical and economic, and poor standards of education (teaching and teaching materials) (Braathen & Loeb, 2011).

The study by Braathen and Kvam on the situation of women with disabilities in Malawi gathered data from informants that all had some education (2008). However, most of them had faced difficulties in relation to their education because of their disabilities. There was also a strong will to be empowered through education and training (Braathen & Kvam, 2008). In a recent study, enablers and barriers to education were investigated in a district in Malawi. Among the barriers to education were poverty, the lack of ability to accommodate students with disabilities properly and discrimination and violence. In spite of this, the children studied were highly motivated and enthusiastic about education. The reasons were a love to learn and socializing with friends (Banks & Zuurmond, 2015). Regarding the inability to accommodate students with disability, the reasons for this were many. One is the inaccessible school environment for those with physical disabilities. Another is the lack of investment in resources for inclusive education, causing students to drop out of school.

The examples from Malawi and Southern Africa in general suggests that even if education is offered to children with disabilities, the physical and social environment within the school can render adequate education close to impossible. An understanding of the quality of education offered youth with disabilities is therefore an important part of further promoting the rights of persons with disabilities.

**2.7 Policy and legislation towards ensuring education for youth with disabilities**

There are several laws and policies within the Malawian law that are put in place to ensure the right to education for children and youth with disabilities. In 2012, the former President Joyce Banda passed the Disability Act 12 (Chilemba, 2012), a bill that had waited eight years to be passed. The Act states that the government is responsible for recognising the rights of persons with disabilities to education on the basis of equal opportunities (Government of Malawi, 2012). Furthermore, it aims to ensure an inclusive education system and lifelong learning, and states that persons with disabilities should be included in the education system at all levels: primary, secondary and tertiary. The Disability Act also takes into consideration the special requirements of persons with disabilities in the formulation of policies and programs. This will include provision of assistive devices such as teaching aids, braille or other special needs.

Moreover, the Act states that the government should provide financial assistance to less privileged students with disabilities who are pursuing secondary and tertiary education since primary education is free. The Disability Act also provides for the establishment of a trust fund that will provide resources to relevant support programmes and services (Munthali et al., 2013). Lastly, the Act prohibits any form of discrimination towards persons with disabilities in educational institutions. People who breaks the principles of non-discrimination can face a 100 000 MK (approx. 136 USD (OANDA, 2016)) fine or 12 months imprisonment. (Government of Malawi, 2012).

The National Policy on Equalisation of Opportunities for Persons with Disabilities from 2006 describes the challenges faced by people with disabilities in Malawi. The Policy is intended to meet these challenges (Ministry of Education, 2006). The National Policy on Equalisation of Opportunities for Persons with Disabilities promotes easy access to education for learners with special needs by: eliminating the imbalance between learners with special needs and those without, putting systems in place for early identification of disabilities, bringing awareness to the public and ensuring that learners with special needs receive adequate care and support services. By special needs, and special needs education, we are talking about the practice of educating students with special educational needs in the appropriate way, so that it addresses the individual needs of the student/learner (OECD, 2007)

In 2009, the Ministry of Education, Science and Technology (MoEST) developed a set of guidelines (the National Policy Guidelines on Special Needs Education) to promote the inclusion of learners with special educational needs (Ministry of Education, 2009). The

guidelines provide a framework for Special Needs Education (SNE) in Malawi. In the process of implementing the National Policy on Equalisation of Opportunities for Persons with Disabilities, the guidelines developed four priorities:

1. Early identification, assessment and intervention
2. Advocacy, care and support
3. Management, planning and financing
4. Access, quality, equity and relevance

The guiding principles required that SNE shall be implemented in the context of Education for All (EFA) and the Sector Wide Approach (SWAp) to financing educational programmes. The SWAp is an approach for foreign aid in which project funds are directly contributing to a specific sector, and are tied to a defined sector policy (for instance the National Policy on the Equalisation of Opportunities for People with Disabilities) (WHO, no date). Decision-making will be decentralized to local assemblies. The implementation of SNE should take into consideration the multiplicity of partners that are involved in the delivery of services, and there should be transparency, accountability and good governance in the provision of goods and services by all stakeholders. Moreover, learners with SEN (Special Educational Needs) shall not be discriminated against, and provision of education for children with SNE should be integrated and harmonized with other interventions (Ministry of Education, 2009).

Adding to this, the Malawian Constitution recognises the rights of persons with disabilities in line with international instruments, such as the Convention on the Rights of Persons with Disabilities and the Education for All movement (these instruments are explained further below). The Constitution guarantees all citizens their right to education (Munthali et al., 2013). Section 20 in the constitution ensures the right to not to be discriminated against, regardless of age, gender, colour, race, disability or political opinion (Government of Malawi, 1994). In section 25, the right to education is explicitly outlined. All persons have the right to education, and primary education should last at least five years.

The Malawi Growth and Development Strategy 2 is the second Poverty Reduction Strategy Paper of Malawi. In the Malawi Growth and Development Strategy, the importance of social development for economic growth is expressed, along with a plan to achieve universal primary education with an extra emphasis on gender equality and the empowerment of

women. However, under the sub-themes "education", child development and protection" and "youth development", people with disabilities are not mentioned. Under the theme "Social Support and Disaster Risk Management", under the sub-theme "supporting the vulnerable", people with disabilities are prioritised (IMF, 2012).

In the 2014/2015 state budget in Malawi, the allocations towards education were 127,9 billion, which makes 17,2% of the total budget (Ministry of Finance, 2014b). The education sector includes resources allocated to the MoEST Public Universities, District Councils and allocations to the Local Development Fund for the construction of primary schools and teacher´s houses (Ministry of Finance, 2014a). The state allocations to the Ministry of Disability and Elderly Affairs (MoDEA) (now Ministry of Gender, Children, Disability and Social Welfare) were around 0,7% of the budget (Munthali et al., 2013).

In addition to national policy and legislation towards disability and education, Malawi has committed itself to a number of international policies aimed at improving the lives of youth with disabilities. The United Nations (UN) Convention on the Rights of the Child was adopted in 1989, and ratified by Malawi in 1991 (UN, no date-a). The convention outlines the specific rights of children and young people worldwide. Article 2 is concerned with the right to non-discrimination on the basis of race, colour, abilities, religion or background. Article 28 and 29 points out the right to education; that all children have a right to primary education, that this should be free, and that every child should be encouraged to reach the highest level of education. Governments shall ensure that school administrations review their policies for disciplining their learners, and not conduct any form of discipline involving physical or mental abuse. Article 23 specifically spells out the rights of children with disabilities and explains that children with disabilities have the right to special care and support. Moreover, it underlines that the other rights in the convention includes those with disabilities (UN, no date-b).

The UN adopted the Convention on the Rights of Persons with Disabilities in 2006, ratified by Malawi in 2007. The general principles in the convention are non-discrimination, full participation in society and equality of opportunities. Various articles define these rights more specifically. Article 7 outlines the rights of children with disabilities; that state parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of full human rights. Article 9 has to do with accessibility; that all persons with disabilities should be

ensured access to the physical environment on an equal basis as others. Persons with disabilities shall also be guaranteed transportation, information and communication. Regarding education, article 24 highlights that states should ensure an inclusive education system at all levels and lifelong learning. Furthermore, they should ensure that persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others. Lastly, it is set out that states should ensure that persons with disabilities receive the support needed within the general education system to facilitate their education. This support includes visual aids, hearing aids, and learning of sign language, braille or alternative scripts. Furthermore, in order to realize these rights, appropriate measures shall be taken to employ teachers, including teachers with disabilities, who are qualified in special needs (UN, 2015a).

Malawi is also committed to the Education for All (EFA) movement (*Education for All: National Action Plan*, 2004). EFA is a global commitment to provide quality education for all by 2015 (EFA, 2015). Furthermore, Malawi is committed to the Sustainable Development Goals (SDGs). SDG 4 aims at ensuring inclusive and quality education for all (UNDP, 2016).

## 2.8 The organisation of education and special needs education in Malawi

At national level, special needs education (SEN) is organised and managed by the Ministry of Education, Science and Technology (MoEST). The Minister of Education manages the Ministry headquarters of Education. The Secretary for education is in charge of the various departments. There are 13 departments in MoEST headquarters, among them Department of Basic Education, Department of Secondary Education, Department for higher education, Department of Planning and the Department of Special Needs Education.

Below the various departments are the districts, and district offices. For each district, there are District Education Managers (DEMs). Politically, Malawi consists of 28 districts, divided into the three regions; Northern, Central, and Southern. However, there are 34 educational districts. The reason for this is the cities, where there are two offices: urban and rural. In Lilongwe, the capital, the city is divided between the city office, and rural east and west. One district is divided into school zones that are managed by the Primary Education Advisors (PEA). The number of school zones varies from district to district. In each zone, there are between ten and fifteen schools, each managed by a head teacher.

At district level, the responsibility of special needs is divided between the DEM and two special needs district co-ordinators in each district (one for rural and one for urban). The co-ordinators organise and coordinate all special needs programs in their districts. Under the DEM are the various special needs education teachers that work in the various schools in the district. Usually the special needs education teachers are responsible for one or two school zones. The special needs education teachers' work hand in hand with the PEA and the headmasters at the relevant schools.

Special needs in schools in Malawi are tackled in three different ways: resource centres, itinerant teachers and residential systems. In a resource centre system, a resource room is attached to the mainstream schools. There, one or two special needs teachers work hand in hand with the mainstream teacher, as well as teaching SEN learners at the resource centre. A residential system is what is known as special schools: where SEN learners are taught and live in schools specialised in the specific disability. There are schools for the visually impaired, for the hearing impaired, school for learners with learning and intellectual disabilities and so on. In an itinerant system, a special needs teacher is deployed at the zone and teacher development centre to work with the PEA and the various headmasters to identify and assist learners in the different schools at zone level. In an itinerant system, the special needs teacher travels to various schools and assists in identifying as well as teaching learners with special needs.

Special Educational Needs are divided into specific categories. These categories are hearing impaired, visually impaired, specific learning disabilities, intellectual disabilities, deaf-blind, physical and health impairment, emotional and behavioural difficulties (Ministry of Education, 2009). During the education of special needs teachers, they are all taught in all categories of disability during the first year. After this, the teachers specialize in one of the categories. Thus; the special needs teachers are usually qualified teachers in one of the categories.

## Chapter 3: Conceptual framework

### 3.1 The capabilities approach

As a theoretical framework for this thesis, the capabilities approach will be applied.

In the capability approach initiated by Amartya Sen, capabilities are the objects of value. The capability to do what we want, achieve particular states of being or to undertake particular activities is how individual well-being is measured (Burchardt, 2004). The capability approach puts a large emphasis on the social, economic and environmental barriers to equality. Central to the evaluation of quality of life for any individual is the surrounding society, and what barriers is therein that hinder the full capabilities of the individual. Relevant to the idea of capabilities is the concept of functioning. Functioning's are "states of being", that thus creates opportunities (Mitra, 2006).

To evaluate a person´s well-being or quality of life, the capability approach demands an examination of the capabilities that any person has to lead the kind of life she has reason to want to lead. This is instead of evaluating human well-being through income, or utilities (Sen, 2001). In order to do this, attention needs to be paid to personal characteristics as well as to income and other resources. Specifically for this particular research project, attention needs to be paid towards what the specific impairments are for the specific individual. As Burchardt (2004) argues; impairment is a condition of the body or mind, like lacking a limb or being partially sighted. The impairment thus becomes part of the characteristic of the individual. Moreover, in order to examine the capabilities one has, we need to evaluate what resources are available to the individual in regards to education. The combination of the specific impairment, thus functioning as well as the resources available makes up for the capability. Lack of quality in education for youth in Malawi will in this study be analysed as a capability deprivation.

Amartya Sen has initiated the capability approach, in which Martha Nussbaum has built upon with her theory relating to specific capabilities. Her argument is that in order to evaluate capabilities to examine one individual's quality of life, there is a need for specific goals (Nussbaum, 2003). The central human capabilities, according to Nussbaum are: 1. Life, 2 Bodily Health, 3 Bodily integrity, 4 Senses, imagination and thought, 5 Emotions, 6 Practical Reason, 7 Affiliation, 8 Other Species, 9 Play, 10 Control over One´s Environment. All of the bodily capabilities developed by Nussbaum are in one way or another relevant in regards to youth with disabilities. Collecting data and analysing each of them through all of the listed capabilities goes beyond the scope of this thesis. Instead, two of them have been chosen. This paper will mainly analyse through the capability of bodily integrity and the capability of

senses, imagination and thought (Nussbaum, 2003). The reason for choosing each of these is further discussed below.

The capability of bodily integrity is concerned with being able to move freely from place to place, and being secure against violent assault. While Nussbaum arguably developed these capabilities within a feminist framework, as she states herself, the list is open ended and subject to revision (Nussbaum, 2003). In this thesis, these capabilities will be analysed through a disability framework; however, a large portion of the same language used in a feminist framework can be integrated in discussions on disability. Previous research, as presented in the former part of this paper, has revealed physical obstacles to quality education, as well as psychological obstacles in the form of social stigmatisation. The capability of bodily integrity has both to do with the ability of an individual to move freely from place to place, and is free from assault in one way or the other (Nussbaum, 2003).

The capability of senses, imagination and thought has to do with being able to use one´s senses, thought and reason, informed and cultivated by an adequate education (Nussbaum, 2011). Access to, and also completion of education is therefore central to this capability. Being able to use one´s mind without hindrance of any sort is the goal of this capability, which requires literacy, basic mathematics and scientific training. The obtainment of being able to be creative, have control over one´s own mind and to be knowledgeable is therefore dependent on the amount of education provided, and the quality of this.

It is, however, important to note that there is a difference between (human) rights and capabilities. Many of the capabilities listed by Nussbaum have common motivations a human rights, but Sen argues that one concept should not be understood within the territory of the other (2005). As shown in the former part of this thesis, youth with disabilities have the legal right to obtain quality education, but are kept from quality education. Nussbaum argues that some political views hold that the right thing for a government to do is make people lead healthy lives, obtain education etc, which is closely linked to human rights. The capabilities approach denies this approach, and argues that it is the capability to obtain these things, not functioning's that measures welfare and quality of life. This is because there will then be room left for the freedom of choice (Nussbaum, 2011). The capability approach can therefore help identify, through the mentioned specific capabilities formulated by Nussbaum, the capability of disabled youth to obtain education on an equal basis with others.

**3.2 Disability**

What do we mean when we are talking about disability, and who does the category include? The term "disability" is a socially constructed term, and the way we define it has varied throughout different time periods, between cultures and between various fields of expertise. The way we define disability can have a huge impact on the outcome of research, in regards to the construction of research questions, methods of data collection and the overall results of the study. The concept of disability and its various approaches will therefore be discussed below. This is necessary in order to make apparent the choices made in regards to methods of data collection, and the results of the study.

Within the field, two main models have been used when defining and approaching the concept of disability (Llewellyn & Hogan, 1997). The use of models in social research enables us to represent information in a way that helps us understand an issue in a certain way (1997). Among the many models of disability, the medical model and the social model are the ones most widely utilised and discussed. The medical model views all disability as a result of a physical impairment due to some sort of bodily damage or disease. This is the root cause of any disadvantage experienced in society and daily life (Crow, 1996), and rejects other possible explanations for problems experienced (Oliver, 1992). Moreover, it is also the approach historically undertaken by researchers within the disability field. During the last 30 years, however, activists and researchers have worked towards a social model of disability (WHO, 2011). The social model of disability locates the problem in society, and sees the problems faced by a person with some sort of disability as social oppression by a society obsessed by the concept of normality (Llewellyn & Hogan, 1997). In the social model of disability, people experience "being disabled" as a cause of societal factors; not the individual characteristics. An example can be that most buildings have stairs and not ramps.

Burchardt (2004) argues that there is a complementarity between the capabilities approach and the social model of disability, and that the social model of disability provides an application of the capabilities framework in analysis. She argues further, that the social model of disability and the capabilities framework have common features. These include among others, inadequacy of income. By this, she is talking about the fact that individuals convert income and utilities into standard of living different ways according to personal circumstances.

However, this study approaches disability within a bio-psycho-social model, an approach developed during the last twenty years (Braathen, Munthali, & Grut, 2015). The bio-psycho-social approach understands disability as a dynamic interaction between health conditions and various contextual factors (WHO, 2011). The approach identifies disability as a combination of the impairment ("problems in bodily functions or alterations in body structure – for example paralysis or blindness" (WHO, 2011, p.6)) and environmental factors.

Figure 2: The bio-psycho-social model to disability as explained by WHO.



(WHO, 2002)
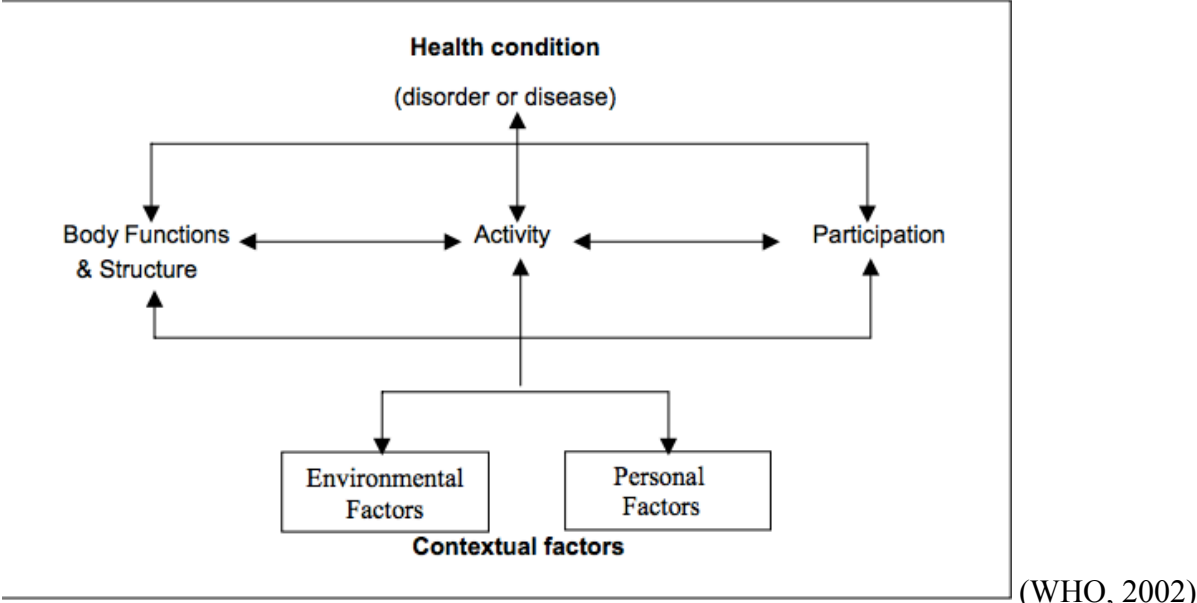
The approach recognises thus, as explained in the figure, that disability can be caused by the impairment itself, but also by contextual factors such as inaccessible environment in school, workplace or in society in general (WHO, 2011). Poverty and access to health care and sanitation facilities and climate influence these contextual factors, and play therefore a significant role in the bio-psycho-social approach to disability. This approach has set the basis for the "International Classification of Functioning, Disability and Health", more commonly known as ICF. The ICF is a classification of health and health related domains, and is the framework for measurement of disability at both individual and population level (WHO, 2001). The ICF is used as a framework for disability in the *World Report on Disability (*WHO, 2011*), and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006).

Nevertheless, the medical and social models of disability appear at various stages of this research. Systems of classification and categorization of disabilities are shaped by various factors, also including the intended use of classification (Florian et al., 2006). The intended use of categorization for this research is to explore access and barriers to learning for youth with various disabilities. For example, in the identification of sampling of informants, a medical model of disability has been conducted; because of the way informants have been chosen strictly on the basis of their impairments: visual impairment, hearing impairment, physical/intellectual impairment and learning difficulties. During interviews, however, the capabilities approach and the bio-psycho-social model have been frameworks for understanding barriers to learning. These issues will be further discussed in Chapter 5.

## 3.3 Urban and rural areas in Malawi

Urban areas in Malawi constitute an area that is within city boundaries, all district centres and all townships. (NSO, 2012; UNStats, 2005). Rural areas constitute all areas outside urban areas as defined. The rural population is approximately 14 million people (2014) out of a total population of approx. 16 million (UNdata, 2016).

## Chapter 4: Methods

## 4.1 Research strategy

The chosen research strategy for this thesis is qualitative methods. The reason for this is the choice to focus on the personal experiences, meanings and opinions regarding education and everyday life of my informants. Qualitative methods differ from quantitative methods. When doing social research, we as researchers can use qualitative methods, quantitative methods, or both. Quantitative methods seek produce statistical information about prevalence and population level patterns; while qualitative seeks to understand the reasons behind these patterns. The methods can be combined, using qualitative methods to research how people interact in a specific situation, and using quantitative methods to verify and generalize (Silverman, 2013). This study seeks to investigate reasons behind actions and patterns regarding disability and education. The purpose is to understand the nature of learning in the education offered youth with disabilities, and reasons for why the situation is the way it is. There is a need to understand youth with disabilities own understanding of their situation, as well as thoughts and perceptions of service providers, family members and decision-makers. Thus, qualitative methods are appropriate (Bryman, 2012).

**4.2 Research Design**

Research design is a framework for collection and analysis of data (Bryman, 2012). For this study, a case study design is applied, to explore access to education for youth with disabilities in Malawi. According to Yin (2003), one should use a case study method if the research aims at answering a descriptive question, like "what is happening", or an explanatory question, like "how or why is it happening". For this study, the focus was to explore what the situation of education is like in schools for disabled youth in Malawi, and why it is happening. The study also concentrates on how other factors in everyday life affects what is happening in schools. Thus, the cases in question are, for this study, disabled youth in school Malawi. Yin differs between different kinds of case studies; critical, extreme, representative, revelatory and longitudinal (Yin, 2009). This particular study uses a representative case, where the objective is to capture the circumstances and conditions of an everyday situation. This study seeks to explore the everyday situation of youth with disabilities in a particular context, namely school.

The case studies were carried out through fieldwork. Fieldwork involves going into the place of interest, "the field", where the field worker will immerse himself/herself in face-to-face relationships with the cases being researched. This is being done within a certain period of time (Amit, 2000). For my study, fieldwork was a crucial part of the research strategy in order to be able to capture the issues of concern. There was a need to observe, and interact with the informants to understand what the general patterns were. While some previous research has been done on education and disability, answering the research questions for this particular study would not have been possible without going into the field and engaging with informants.

**4.3 Data collection**

The term data collection refers to the process of preparation and gathering of information that is relevant to the case study. In qualitative research, there are several ways to collect data. Bryman (2012) argues that it is the flexibility of qualitative interviews that makes this the most widely used method for collection of qualitative data (2012). While participant observation can give valuable insight into everyday situations that otherwise will be left out of the research, participant observation is a process that takes time and resources that were not available for this fieldwork. For this study, I chose in-depth interviews as the main method of

data collection, as well as some focus group discussion and direct observation. The area of interest is the personal experiences of youth with disabilities and their families, studied through face-to-face contact with the informants. Thus, in-depth interviews were the most appropriate method of data collection for this study. However, some direct observation was done throughout the fieldwork in specific situations. These were passive observations; meaning that observations were made without me participating in the specific situation (Bryman, 2012). These observations were written down in the research diary and furthermore included in this research, providing information on the physical context in which the interviews were done.

All of the interviews undertaken were semi-structured. This means that I had an interview guide with a list of questions to be covered, but the conversation is shaped more or less by which direction the conversation takes (Bryman, 2012). It is a highly flexible process, where questions may not follow exactly as planned. This method allowed the informants to talk about issues important to them and shape the conversation the way they wanted. The interview guide used for this thesis is based on the interview guide developed by SINTEF for the main study (Braathen & Munthali, 2016).

All of the informants were interviewed separately, except for one youth with a hearing impairment. During the interview with him, one special needs teacher who knows sign language was present. All of the interviews were recorded using the recording application on a telephone, and the recording started after obtaining consent/assent. As many in Malawi only speak the local language Chichewa, many of the interviews were undertaken with an interpreter present. The interpreter used in the rural site is a master´s student at the University of Malawi, with experience from data collection and interpretation. The interpreter in the urban site is a secondary school teacher with experience from interpretation and research in her bachelor's studies. The interpretations happened in the way that I asked the questions, my interpreter translated the question to Chichewa, and then translated the answer.

## 4.4 Study sites

The fieldwork was conducted in two different geographical areas in Malawi. The purpose of this was to compare data between one urban and one rural area in Malawi. In July and August 2015, fieldwork was carried out in a rural village in Zomba district, in the Southern Region of Malawi. In the first part of the data collection from this particular area, I assisted in a larger

study (in which, as explained in the introduction chapter, this thesis is linked to) conducted by SINTEF Health Research and Centre for Social Research at the University of Malawi (Braathen & Munthali, 2016). The area was primarily chosen because it represents a typical rural area of Malawi. As Centre for Social Research is located in Zomba town, this particular study area was also chosen due to convenience: its short distance to some of the team member's homes. As the fieldwork in this area was undertaken during the months of school holiday, data collection was mainly conducted at the homes of the informants, inside empty classrooms or in schools 'outside area.

Between September and December 2015, data collection was conducted in an urban township in Lilongwe, Malawi´s capital city. Lilongwe is located in the Central Region of the country. The study area is densely populated, and poverty is high. The collection of data was conducted in one school within this area during school hours. Informants from only one school were selected in this area. This was done due to the schools large number of youth with disabilities, as the school has over 8000 learners.

Figure 2: Location of Lilongwe District            Figure 3: Location of Zomba District
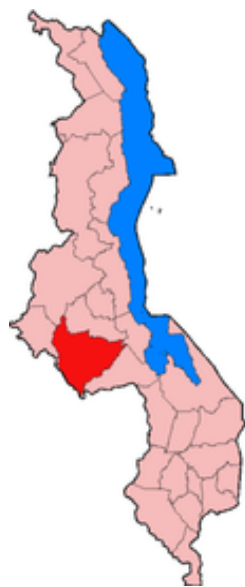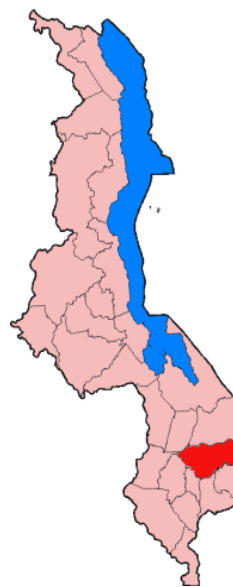


(Wikipedia, 2014a)                                   (Wikipedia, 2014b)

## 4.5 Sampling

Sampling in qualitative research refers to the "segment of the population that is selected for research" (Bryman, 2012, p.715). In qualitative methods, the importance of purposive

sampling is often emphasized (Bryman, 2012). Purposive sampling is a method in which the selection of units has a direct connection with the objectives and the research questions. The research questions indicate which units should be sampled in the study. More specifically, it means that one choses the people to interview according to their relevance to the study. This was also the method of sampling for this particular research; my units were selected due to their direct relevance to the research questions. My units were youth with disabilities that could share their experiences from school, as well as families and service providers. Furthermore, I used criterion sampling, meaning that all units should meet specific criteria (Bryman, 2012).

In the process of designing a research proposal, I created the specific criteria for sampling. I have three different groups of informants (1. Key informants – youth with disabilities, 2.Parents/guardians and/or other family members, 3. Contextual informants). The sampling criteria are different for the different groups of units. For the main group, youth with disabilities the criteria, initially, was to be a youth between 12 and 30 years old, to be enrolled at secondary level at a public, mainstream school, and have some sort of disability. However, these criteria had to change when I entered the field. Finding youth with disabilities that are enrolled in secondary education in Malawi is difficult, and those who are, are most likely to have a physical disability, or to be enrolled in a special school. At the same time, I observed that many learners above primary level are still enrolled in primary school, for various reasons. These reasons will be presented in the findings chapter and discussed in the discussion chapter. Thus, I changed the sample criteria early in the research process, widening the sampling to including learners enrolled in both primary and secondary school, as well as learners who have previously been enrolled, but dropped out. Furthermore, the youth were recruited in a way so that they represented each category of disability: visual, hearing, intellectual, learning and physical. This principle is called maximum variation (Onwuegbuzie & Leech, 2007). For the rest of the informants, these were chosen due to their relevance in the youth's education and everyday life, and their knowledge of the issue. For each of the youth, at least one parent was interviewed, or the person responsible for the youth. Both mainstream and special needs teachers were interviewed.

The sample size is 25 units all together. The sample size was not planned before entering the field. The reason for this number is the amount of informants I was able to gather in each area, as well as limitations due to the size limit of this paper. In rural Zomba, five youth with

disabilities were interviewed, as well as five parents. In urban Lilongwe, five youth were interviewed, as well as four parents, as one of the parents was mother of two of the informants. The case studies; the youth, were identified via snowball sampling. Snowball sampling is a method in which one or more informant suggests others to participate in the study (Bryman, 2012). In this case, they were identified via the special needs teachers in the respective areas. The ten youth interviewed presents the case studies, where the interviews with parents serve as additional informants within the case studies. The contextual informants consists of one district coordinator for special needs, two mainstream teachers, three special needs teachers, one teacher at a teacher training college, one member of a local disabled people´s organisation (DPO) and one government official from the Ministry of Education, Science and Technology (MoEST). Interviews with these informants are contextual informants, in which their purpose is to add information on disability in Malawi, policies, and the organisation of special needs. Most of these informants were identified through snowball sampling, where one informant (for example a special needs teacher) identified an additional informant. Others were identified through other people not participating in the study.

**4.6 Procedure**

As mentioned above, during my first two weeks in the field, I assisted in a research project conducted by SINTEF Technology and Society, Department of Health and the University of Malawi. The project was a qualitative study, seeking to map out barriers and facilitators to education for children and youth with disabilities in Malawi. My role in the project was mainly to observe, take field notes and learn during data collection. The sampling started when we arrived in the district. After selecting a geographical area and obtaining permits from local authorities, we reached out to the head teacher of one of the local schools in the area. He was asked to identify a number of children and youth with disabilities. After this, a number of these were selected for interviews. The special needs teacher in the area also helped identify some of the informants. The interviews took place at a local school and at some of the informants' homes. In addition to the relevant children and youth with disabilities and their family members, the special needs teacher in the area and the district coordinator for special needs in the district were interviewed.

After completion of the data collection for the research project, I continued my fieldwork in the same area for an additional two weeks. I worked closely with the special needs teacher, who helped me identify additional informants. Additional interviews with youth with various

disabilities and their families were conducted during this period, as well as an interview with a head teacher at a local secondary school.

After spending almost four weeks in the rural site (Zomba District) in the Southern Region, I continued my fieldwork in the urban site (Lilongwe) in the Central Region. In this site, purposive sampling was also used. Here, I contacted a DPO, who helped me identify a geographical area within the city where I could continue my data collection. I contacted the district coordinator for special needs in the area, who helped me identify and organise meetings for interviews for the rest of my fieldwork. I used the specific criteria as explained above when cooperating with her to find suitable informants. In this area, all of the interviews with cases and their families/caretakers were carried out within the school area where they are enrolled. In addition to these, I held focus groups with two special needs teachers at the school. This was done in order to discuss the patterns observed, and give them an opportunity to come with input and additional information in regards to the case studies. During a field trip with a Norwegian development worker, I had the chance to do an interview with a lecturer at a teacher training college. This was done in order to get contextual information about how teacher training is done in Malawi, with an emphasis on special needs teacher training. Moreover, a friend in the MoEST helped me locate an official in the special needs department within the ministry. Lastly, during a private visit to the southern region, where a local DPO is located, I interviewed one of their employees.

During the fieldwork process, I have kept a research diary. This diary has documented events that have happened through the course of the day, impressions, thoughts and plans for the next days. A research diary is used as a tool for reflection in the research process, and to keep track on what has been done and when, as well as report changes along the way in the research process (Nadin & Cassell, 2006). The diary has documented what and where it has been done through the day, as well as anything unusual observed. As months went by, personal reflections regarding everyday life in Malawi was also documented; also things that were unrelated to the research project. Moreover, the diary has documented progress reports (how far I have come, and what needs to be done in the future).

Transcriptions have been done after the interviews throughout the fieldwork process. Transcribing interviews is the process in which the interview recordings are written down, word for word, in as much detail as possible. This was done after each and every interview.

However, since many of the interviews have been done with a translator present, these words are the translator's words, and not the informant. The limitations this may present are presented in the "limitations" section of this chapter.

## 4.7 Data Analysis

Data analysis is the process in which the data, or raw material is managed (Bryman, 2012). Bryman explains that data analysis is about data reduction; reducing the large amount of data into categories or themes relevant to the study.

In the matter of analysing data, the method of coding has been conducted. Coding in qualitative research refers to the process whereby data is broken down into component parts and been given names (Bryman, 2012). During the research process, I have documented in the research diary what the special needs are for youth with disabilities and the different patterns that represent a barrier to the quality of education for youth with disabilities. These patterns were detected during fieldwork and by reading through transcripts after the interviews were done. Firstly, I conducted colour coding whereby each component/pattern was assigned a colour, where I marked the components in the transcription documents. These patterns were "little or no attention from teachers", "stigmatization", "lack of support and knowledge from home and the community", "physical obstacles", "lack of resources: specialist teachers and materials" and "poverty". Each of these themes were given a colour, and further marked in the transcripts with these colours. An example can be the reoccurring pattern of poverty as a barrier to quality education, in which was assigned the colour purple. This process was done for all the informants. Secondly, for the ten case studies (the youth), I created coding tables where each code was listed, and the youth relevant to the specific code was ticked off. The coding tables are found in table 1 and 2, page 45 and 46. For the family members and others relevant to the case studies and the contextual informants, summaries of the interviews (taken from the interview transcripts) were written. This way, the relevant information to the objectives and research questions was detected and furthermore included in the final paper.

## 4.8 Limitations

As in any study, there are limitations. Firstly there are limitations in regards to the chosen topic. The scope of problems facing youth and children with various disabilities in regards to education in Malawi is big. Issues vary according to age, gender, type of disability and

background. For a more in-depth elicitation of these, it might have been useful to restrict this research to one type of disability, or a smaller age group.

In qualitative methods, the quality of data is often measured through trustworthiness (Bryman, 2012). Credibility and transferability are two of the criteria for trustworthiness. Credibility has to do with whether or not the conclusions made by the researcher are supported by the data (Silverman, 2013). It means that the researcher has understood the data collected, and the information given in interviews. Transferability is about whether the findings could be found in some other context, or the same context in another time (Lincoln & Guba, 1986). Regarding credibility for this particular study, there are some limitations. During the data collection, most of the interviews were conducted using an interpreter. While the interpreters in this study are well educated and highly qualified interpreters, using an interpreter implies that the personal accounts of the informants does not come directly from them. This involved a risk that some information may "get lost in translation". However, the various informants 'accounts were discussed with the interpreter (and the research team) after each interview, ensuring that we all understood their stories the same way. In qualitative research, ensuring transferability usually has its limits (Bryman, 2012). Qualitative research usually involves researching a small population in a restricted area, as this study is. To obtain the same results in a different location or time is therefore difficult. Nevertheless, as is described in the background chapter, previous research has shown that youth with disabilities are, and have been, faced with various barriers to education in both Malawi and Southern Africa. Thus, one might argue that had the research been conducted in an alternative Malawi location, the same results would have been produced.

## 4.9 Ethical considerations

The study has followed ethical standards and guidelines as described by NMBU (UMB, 2009). Moreover, I obtained approval for the project from National Health Sciences Research Committee in Malawi (PROTOCOL NO. P.07/15/45), through the SINTEF and UNIMA project I participated in. Lastly, the project also has approval from Norwegian Centre for Research Data (NSD) (Project number: 43645).

To gain access to do fieldwork in the rural area in the Southern Region, I had to obtain consent and inform various gatekeepers at district, area and community level about the study. I, along with the rest of the research team from SINTEF and UNIMA met the District

Education Manager (DEM) for the rural areas, the Traditional Authority (TA), the Group Village Head (GVH) and two headmasters at the schools where the informants were recruited. We informed them about the study, and obtained permission to go forward with the research. In the urban site, the head master at the school was informed and approved the research project.

All participation in the study was on a voluntary basis, and the informants had the liberty of withdrawing any time and declining to answer any questions. This was the case for both study areas: rural and urban. The participants are kept anonymous, meaning that their real names, addresses and the like are not visible in any research outputs. In this thesis, key informants have been given pseudonyms. Nor is their personal information visible in any of the research documents, and the recordings of interviews were deleted shortly after transcribing. Recording was only done when the participants agreed to this. Before each interview, the participants were informed of the aim of the research and their rights, in order for them to make an informed decision to participate. Before each interview started, we obtained oral consent. For informants under legal age (18 years), one or both parents or caretaker gave us an additional consent, and the under-age informants themselves gave assent.

Throughout the research process, attention towards the informants' vulnerability was taken into consideration. Efforts were made to ensure that the daily lives of informants were not disrupted, financially or practically. This study is not only a study in a low-income country, meaning that the units being researched come from a different context both culturally and financially, it is also a study of "vulnerable groups". Silverman (2013) argues that ethical issues become more complicated when deciding to conduct a study on vulnerable groups such as children or people with disabilities. Given that this research involves both, particular care clearly had to be taken. People with disabilities are among the most vulnerable groups in any population, and many are exposed to discrimination (WHO, 2011). Therefore, words were chosen in a way that did not seem offensive, and interview objects were approached with understanding and kindness.

Another ethical issue regarding research on disability is the concept of "nothing about us, without us" (Yeo & Moore, 2003). The argument is that it is time that people with disabilities are included in development work and research, especially if the research involves them. Even though this study involves insider accounts of the lives of persons with disabilities, they

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are not included in the research process itself. A person with a disability him/herself have insider experience from living with a disability, and can therefore guide the shaping or objectives and research questions before the study. Moreover, it can create a safe interview environment for those being researched. An example of including insider experience is to, for example, use an interpreter with a disability him/herself. Thus, leaving people with disabilities out of the research process may be ethically questionable. However, due to limits in resources and the low level of education in Malawi, it is, unfortunately, difficult to find qualified interpreters with a disability. Nevertheless, the project is partly funded by FFO, a Norwegian DPO that works closely with DPO´s in Malawi and Southern Africa

## Chapter 5: Findings, Analysis and Discussion

In this chapter, findings will be presented and analysed and further discussed through a capabilities approach to development, as the one formulated by Martha Nussbaum. Firstly, findings of special needs and how they are met will be presented. Secondly, the stories of case studies, family members, policy makers and service providers will be presented and analysed. Their accounts and the categories of barriers to education will then will be discussed within the framework of the relevant capabilities, and within the framework of the concept of disability. The last part of this chapter will discuss the findings of secondary literature on disability and education in Malawi within a capabilities framework.

### 5.1 Special needs and how they are met
*Rural Malawi*
The following information is gathered from one special needs teacher, the District Co-ordinator for the relevant area, and a head teacher at secondary level and two mainstream teachers at primary level.

In the rural area where the first part of this research was undertaken, two primary and one secondary school were visited. The area is approximately a half hour drive from the nearest city, Zomba, where there is a central hospital and a specialist eye clinic. Most households in this area live from self-subsistence farming and some fishing. Poverty is prevalent. In the rural part of this district, they have identified 400 learners with special needs at primary level. It is however important to note that an accurate number of learners enrolled in schools is

difficult to find, so we don´t know what the 400 learner with special needs are in comparison with. The coordinator believes that there are far more learners with disabilities than that have not yet been identified:

*I think there are more, it´s like some learners come and some go, so the numbers do change. But I know that it´s about 400 now because I am using the records. That is for standard 1 to 8.*

The relevant schools visited for this study were mainstream schools. In this district, there are eight special needs teachers for learners with special needs. Six of these teachers are specialists in visual impairment, and two in learning difficulties. There are 17 zones in this district all together, and 12 of these have special needs teachers available. The five remaining school zones do not have a special needs teacher available. Thus, some of the special needs teachers are responsible for two school zones.

In this specific area, they use an itinerant system. The special needs teacher in this area was responsible for two school zones, 18 schools in total. In addition to primary schools, he assists secondary schools in his zones, as well as visits nursery schools in preparation for children with special needs for primary school. There is a resource centre in one of the schools in the area, where the special needs teacher teaches a class of learners with special needs a few days a week. These learners are otherwise in a mainstream class. Sometimes he teaches in mainstream classes, while the mainstream teacher is present, to demonstrate how to best teach in a class in which there are learners with disabilities present. Lastly, he also assists identifying learners with disabilities. The way this is done is through screening charts, where they detect potential disabilities. When this is done, learners are referred to either the central hospital, local clinic or to Montfort Special Needs Education College, where they have special equipment to detect various disabilities and provide assistance.

The special needs teacher for the two zones uses a bicycle as a means for transportation between schools. He described transportation as one of the main challenges he faces in his attempt to teach these learners.

*I have to visit maybe one school per day. If I arrange to go to school I have to leave early in the morning, maybe five o´clock, so that I reach there by maybe eight, and then I start*

*working. I train teachers on how to handle these learners with special educational needs, because it is difficult for me to travel maybe from one point to another because of the distance.. Some of the schools are maybe 20 kilometres from where I live, others 25 kilometres. So to say the truth, it's impossible to go there each and every time. So I have to trust the teachers and the head teachers.*

He further explains that one person is far from enough for the task he is given, which creates a bigger task for the mainstream teachers in the area. According to him, learners in mainstream classes are not given enough attention due to various factors. One is the large enrolment in classes:

*For example if the classroom has got 172 learners, against one learner with special educational needs within the class, and maybe one or two teachers, it is difficult to pay attention to this one (the special needs learner). The result is that they suffer. So, in my opinion, they are not given enough attention. The effort is there; the willing is there, but due to those pressures, as they teach against time, a period of maybe 35 minutes to teach 135 learners. (...) So to pay attention to that one may be difficult.*

The consequence of this, he explains, is in the worst cases, dropouts among learners with disabilities, or early marriage for young girls.

### Urban Malawi

In the urban area where the second part of this research was undertaken, I interviewed two special needs teachers, and one of them was also the district co-ordinator for the area. This was in addition to the youth and their families.

In this area, one school in an urban township in Lilongwe was visited continuously over a period of two months. The school is situated in an urban township in a highly populated area, and has between 8000 and 10 000 learners, divided between primary and secondary. In Lilongwe, there is a large central hospital, as well as both private and public medical clinics. The households in this area are mostly poor families, and live off local businesses, piecework and farming. Accurate numbers for children and young people with disabilities are difficult to find in this area. In 2013, quantitative data on learners with disabilities was gathered for a situation analysis before implementing a development project on education and disability.

Among 13 primary schools in this city, 418 learners with disabilities were documented (FEDOMA, 2013). However, these numbers are not accurate due to the fact that there are schools in this area that were not able to provide statistics. In addition to this, the numbers were retrieved three years ago. Moreover, though the data reveal numbers of children with disabilities in schools, the total number of children enrolled in schools was not found. However, it gives an indication of the number of children and young people with disabilities in this area.

The school researched in this area used a resource centre system, where two special needs teachers are teaching full-time. In this school zone, there are six special needs teachers available, for 13 schools. Two of them are employed full time at one school, and the rest are itinerant special needs teachers. The two special needs teachers working at the resource centre are specialized in learning disabilities and hearing impairment. In this specific school, there are 80 learners with special needs. 18 of these learners are taught full time in the resource room; the rest are enrolled in the mainstream classes. The resource room is a small room, with one desk, a blackboard and a few chairs. It is the learners with the most severe disabilities who are taught in the resource centre.

*Most of them are here at the resource room, most of them are severe, and they cannot be in the normal classroom. Due to the severity. We have tried to put the learners in the other classrooms for socialization, but the teachers are just complaining about the behaviour. "…." They are aggressive to their friends, that they disturb the classes. So we decided that we should just keep them in the resource room.*

The learners who are taught in the resource room have disabilities like hearing impairment, Downs's syndrome and other intellectual disabilities. In the resource room, they are also given speech therapy.

When one of the special needs teachers, who is also the district co-ordinator for the area, first started working at this school, there were five learners with disabilities enrolled in school. She discovered that there were many more in the same area who were hindered from obtaining education:

*The time I came, there were only five learners. But the others were still there, outside here, they were hiding, and the parents were blocking them. So I used the community, the chiefs, and did a total campaign with the chiefs. So we moved around, then after that the teachers called about a Parent Teacher Association meeting. We were there and then they gave me a chance to talk about special needs education. After that, there were lots of parents here, bringing their children.*

Thus, there are efforts to accommodate learners with special needs within this school. However, there are other schools in the same area of the city that are lacking the same efforts. The district co-ordinator describes big problems at other schools; schools that use an itinerant system. At these schools, some of the learners with special needs receive teaching once a week. When the special needs teacher is not there, these learners are left at the schools, walking around and playing among themselves:

*So when the time she is away, the learners are just left. I found them there, just moving around. So I said "these learners are learners with special needs, why are they outside when their friends are writing exams there?" They were saying because they have disabilities. They were labelling them.*

The reason why the school where this information is gathered from has two permanent special needs teachers is because of the resource centre. This resource centre used to be a storage room for a development project. When the project was over, the co-ordinator convinced them to leave the room as it is, so that they could use it to accommodate learners with special needs.

**5.2 The youth**
The youth that have provided information for this study, along with their families, are ten all together. They are:

*Rural*
-   Emanuel, age 15, hearing impairment
-   Thokozani, age 12, physical disability
-   Hamilton, age 16, visual impairment
-   Jumani, age 12, Downs Syndrome

- Sophie, age 16, intellectual disability

## *Urban*

- Rosemary, age 12, learning disability
- Chikondi, age 19, physical disability
- Jemima, age 18, hearing and visual impairment
- Christina, age 14, physical disability
- Esther, age 20, intellectual and learning disability

All these names are pseudonyms; a fictitious name to conceal his or her identity (Dictionary, no date). Among these ten case studies I have chosen four cases; two from urban and two from rural Malawi, for an in-depth exploration of the challenges of providing education for youth with disabilities in Malawi. These four informants are purposively chosen to represent various disabilities, and the various challenges and barriers these youths are faced with in education. The cases also present facilitators to education; what and who are important for these youths in respect to obtaining and completing education. The case studies represent the daily lives and life in school from their own point of view, as well as the point of view of their parents/caretakers, and teachers.

## *Rural*

### *Christina*

Christina is a 14-year-old girl who was born with a physical disability. Herself and her mother provided the information used in this case study. She lives in a house in rural Malawi with her parents, and shares the plot with her siblings. Her parents are both farmers, and they sell the harvested surplus at the local market. The children, Christina included, helps out with the farming. Two of her siblings are born with the same disability as her.

Christina´s legs are paralysed, and she is not able to walk. For her to move around, she is either carried, or she crawls. At the time of data collection, she was waiting to see if she has passed Form 2 and could proceed to Form 3. Christina was given a wheelchair by a local NGO when she was four. However, the chair is currently not working, and has not been for the past year. The mechanic lacks the spare parts that are needed for it to be fixed.

She was born with her legs wrapped around her neck, which was straightened out by doctors when she was a baby. She went back and forth to the hospital during her first years, and was offered an operation for her legs when she was younger. The operation involved an amputation of her legs, in which she would get prostheses instead. To this, her mother refused:

*Can somebody who has wooden legs go and fetch water? Right now she can even go and fetch water and then come back. But then with the prostheses I don´t think she would be able to do that*

Christina has progressed well in school. She has repeated one year, standard six. Her main issues in obtaining education have to do with mobility. She goes to a local secondary school, that she spends approximately 1,5 hours to get to each morning. She either crawls, her mother carries her, or she gets a ride from other youths going the same way on a bicycle:

*Sometimes I walk (crawl) until where you branched off over there (points), and I stay by the roadside to wait for my friends to pick me to go to school. These are no friends from within, but since it is the same road where there are school going children, the other boys and girls that use the same road from wherever they are staying to go to the same school.*

Thus, Christina sometimes gets a ride to school from children that are not her friends, but children in the neighbourhood that go to the same school and therefore uses the same road. For the mother, having three children with disabilities, education has been an important part of the children´s upbringing:

*I know that there are reasons why God gave me these children, so I wouldn´t even worry. When they were young, I would put one on my back, and one at the shoulders and carry the last one. So I would still get them to primary school through standard 8 and they all passed.*

The school areas visited for this study are all composed in a way that there are several school buildings divided throughout the plot, with a large schoolyard in the middle. The ground is brown, dry and sandy, and the terrain can sometimes be difficult to access. The toilet facilities are typical for most parts of Malawi; pit latrines, which are the cheapest and most basic form

of sanitation. When it comes to moving around within the school area, Christina gets help from friends.

*They help me, sometimes I go about myself, but they will follow me, just to see that I don´t have any problems. When I need to go to the toilet, they carry me.*

Her mobility issues sometimes cause her problems during break time, when she is dependent on someone to help her out of the classroom and into the schoolyard:

*There are sometimes some learners that mistreat me during breaks. Most of them are girls. I chat with them in class, but when break comes, they walk out and don´t take me. When that happens, I will just stay in class, reading my studies or something. Most times, I stay in class during breaks.*

Christina talked about this type of behaviour among fellow learners, but also among teachers in school. We talked about the subjects that she likes, which were physical science, biology and English, and the subjects she didn´t like, which were bible knowledge and geography.

*The teachers, some are good and some teachers are bad. Like cause, there are some teachers who when I didn´t understand something, they refuse to answer me. But then there are other students who ask the same question but they will answer them fine. They just ignore me. If they ask a question, or another student will ask a question, he will respond to the other one and not to her. So I have decided that if I have a question, I will ask a friend to ask it. And then the teacher will respond.*

When Christina passed her Primary School Certificate (PSC) and was selected to go to secondary school, her family was dependent on an NGO to support them financially, for them to be able to pay for school fees. This was the case for her siblings as well, her mother explains:

*For Christina, it is the Red Cross that have been paying for her, but for the other, ----, she is being paid for by a pastor, and for the boy ---, it was Malawi Against Polio that would pay for him. I worry a lot about these things, because I am like, I have these children, they are disabled, how am I going to help them. The Red Cross are moving out of here so they are*

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*stopping their interventions here in December. So I don´t know if they will continue to pay for Christina´s fees*

All in all, the barriers to Christina´s education include environmental barriers like long distance to school and insufficient toilet facilities, lack of mode of transportation, and social stigmatization from peers and teacher. Poverty may become a direct barrier to education, if the NGO pulls out of the area.

*Rosemary*

Rosemary is a 12-year-old girl with a learning disability. The information provided for this case study is from Rosemary herself, her father, and the special needs teacher responsible for her school. She lives in a rural area, with her parents and her five siblings. Rosemary´s father is a teacher at secondary level, and her mother is a housewife who sells tobwe, a non-alcoholic beer, at the local market every once in a while.

Rosemary is in standard 4, and has failed four times since she started primary school in standard 1. If she had progressed continuously, without repeating, she would have been in standard 8, the last grade in primary school before they move on to secondary education. Her father reports that she does not yet know how to read:

*I don´t know what has happened to her. But she doesn´t know how to write, and even know how to read. Up to now. I have tried my best teaching her at home and even been taking her to part time classes after normal classes end, but it doesn´t pay off.*

He further explains that the way she has been able to go through classes without the teacher picking up on her not knowing how to write, is that she copies.

*She is good at copying. But if she is to write, like "can you write boy?", she can´t.*

Rosemary herself explains it like this:

*It´s difficult to write because it´s hard to write down what I am supposed to write down. It´s not that I don´t know how to write, it´s just that I find it hard to write down those things.*

Thus; Rosemary has gone through eight years of primary schooling without learning how to read and write. When talking about teachers and others students reactions to her problems, she explains that sometimes, the teachers throw her out of class.

*Sometimes she sends me out of class, when I don´t know the answer to a question, or she just asks me to sit down. When this happens, my friends laugh at me, they say "look at her, she doesn´t know how to read and write". When that happens, it pains me.*

Thus, Rosemary has failed her exams four years in a row, without action been taken by the family, the school or the community. The reason why many years have passed without anyone noticing Rosemary´s problems, her father thinks, has to do with lack of knowledge and interest from teachers, and a lack of enough materials.

*They should have an interest to check on those who are failing, so that way they can follow up and help them, so that also they access education and so on. Yeah because some teachers they are there but are not interested in those who are failing. Some even take a lead in helping them, but they are failing to do that, because of learning and teaching resources, like enough books so that it is enough for everyone. That way they can go home and still have some time to actually practice more and be helped by their families.*

Furthermore, he explains that no special needs teacher has been in touch with her, up until three-four weeks before this interview took place. As previously explained, for this area, the special needs teacher is itinerant, and travels from school to school in the two zones every week. As a result, there are always possible learners with special needs that are not detected. The special needs teacher explains her situation like this:

*That is quite unusual, and that´s where the problem lies, because in special needs we don´t proceed to another activity if the child is not mastering this one. I think the problem is with assessment procedure with the teachers. That´s why I feel most of the job have to be done with the teachers. They should know how to handle these learners, how to handle assessment methods and procedures, so that the learners should be assisted accordingly. Because it´s surprising that how can this child proceed up to standard four when he or she doesn´t know how to read. There I think the class teacher did not bring me to her attention. Because sometimes I rely on the teachers. Because I tell them that if you see that there is a learner that*

*you suspect to have a special case, please inform me so that we should work hand in hand together. So I think we had a problem, yes.*

When speaking of Rosemary´s future, her father expresses a fear that she might drop out. Rosemary herself, has hopes for the future:

*I think they should help me how to read and write. When I grow up, I want to be a journalist. First, I need to learn so that I can be able to read.*

Thus; Rosemary´s problems in her education are firstly related to the lack of identification of her learning difficulties. Secondly, there is a lack of knowledge and attention from mainstream teachers on how to assist her to be able to proceed in school. Thirdly, there is a lack of human and material resources.

### Urban

*Emanuel*

Emanuel is 15 years old. He has a hearing impairment and is almost completely deaf. He lives in an urban township with his parents, brother and sister. His father works as a sign-writer in the area, and the mother is a housewife. The information gathered for this case is from Emanuel himself, with help from the special needs teacher at the primary school, the special needs teacher himself, and his father.

The father of Emanuel is not sure how the disability came about, but he thinks it is from birth:

*We never realised that he had this problem until maybe the time when kids are supposed to start talking, and we saw that that he couldn´t talk.*

Emanuel is currently enrolled in Form 1; the first year of secondary school. When he was little, he was enrolled at a special school for the hearing impaired, which was a boarding school. Here, he learned sign language and communicated well with friends, fellow learners and teachers.

*He really liked going to that school. Because he met people with the same problems and he could actually communicate with one another. So it was a great experience for him", his father tells me.*

However, even though there are no school fees at this school, the families have to pay for boarding, meals, and equipment. Due to lack of funding, Emanuel was taken out of school after a year. After this, he had two gap years where he did not attend school. The special needs teacher at the primary school where he was eventually enrolled found him and convinced the family to enrol him in a mainstream class:

*When he came here, he was not enrolled at any school. After he met me, on the ground there, I talked to him. I knew that he was deaf, so I went to see the parents. I asked them this: "why are you just not letting this one go to school?" And the parents said, "we don't have a school for the deaf". I said to the parents "go to school tomorrow, and find the head teacher there, and mention my name".*

Emanuel started in Standard 3 in a mainstream class, and, with assistance from this particular special needs teacher, who is specialised in hearing impairment, completed Standard 8 and proceeded to secondary school without failing.

In secondary school, he is also enrolled in a mainstream class. However, there are no special needs teachers available at secondary level. Thus, the main problem he has in inclusive education at his school is lack of communication. Emanuel is almost completely deaf, and therefore does not hear what is being said in class. Because of this, he is not learning. At the time when the interview took place (September 2015) he had only been enrolled in secondary school for a couple of weeks. Because he is not learning, due to lack of expertise from his teachers, he has applied to go to other secondary schools where they have special needs teachers.

Emanuel´s problems are therefore related to lack of knowledge and understanding from home and not being able to communicate in school; with friends or teachers. The secondary school he is enrolled in have no knowledge in teaching a learner with a hearing impairment, resulting in Emanuel not learning in school.

*Hamilton*

Hamilton is a 16-year-old boy with a visual impairment. He lives in an urban township with his grandmother, who is his guardian, grandfather and their children. Hamilton´s parents are both dead. His grandmother is the one who provides for the household income through business. The information provided for this case study is gathered from his grandmother, and Hamilton himself.

His grandmother tells us that Hamilton has had visual problems for many years, ever since he was little and had chicken pocks. Hamilton is, in addition to his visual impairment, HIV-positive. He therefore takes a lot of medicines, is regularly at the hospital, and is a part of a support group for youth diagnosed with HIV.

Hamilton is currently in Standard 8, after repeating standard 7 four times. The reason for this, is according to him, the materials they use in their exams. He cannot see the letters in the exam papers, and therefore fails.

*When I fail, the teachers just encourage me and say that since I have failed, they just tell me to work harder and perform better in the next term.*

He further explains that the teachers in the mainstream classes are aware of his visual problems. He has problems in reading and writing, and Hamilton himself says that his main issues in obtaining education are due to his placement in the classroom. Hamilton currently sits in the middle of the classroom, where he cannot see properly what is written on the blackboard.

Hamilton: *Even in class I experience problems, because I am not able to see clearly what´s on the board. I should be able to sit somewhere where I am able to see*
Interviewer: *What do you usually do when that happens?*
Hamilton: *I don´t inform them, I just continue to learn even though I cannot see anything. I don´t want to bother people.*

In Hamilton´s class, there are 200 fellow learners, and according to himself, he is the only with a visual impairment.

Even though there is a resource centre linked to the primary school, which is located next to his secondary school, he does not go there. He does, however, get a lot of help from a tenant at the house where he lives. He supports him after school in various subjects, especially in mathematics.

Stigmatisation is also an obstacle for Hamilton in terms of his education. His grandmother also reports that some of his friends and even his teachers shy away from him because of the way his eyes look:

*There was a problem whereby the teachers would stigmatise him based on his eye problems, because they were telling him that he should go home, as he would infect his friends. So we had to go to the hospital and make them write a letter, whereby they told them about the problem and it was not contagious.*

***General patterns observed among the ten case studies:***
In this part of the chapter, general patterns observed in the ten case studies in regards to barriers and facilitators to education will be explained. The relevant youths that experience the various patterns will be presented.

The coding tables used for analysing findings are presented below. Here, the categories of barriers have been coded in accordance with the relevant youth and their categories of disabilities.

Table 1: Coding table of informants and barriers to education in rural Zomba

| Code | Rosemary (Learning disability) | Jemima (Hearing and visual impairment) | Christina (Physical disability) | Esther (Intellectual and learning disability) | Chikondi (Physical disability) |
|---|---|---|---|---|---|
| Little or no attention from teachers | Rosemary | Jemima | | Esther | |
| Stigmatization | Rosemary | | Christina | Esther | |
| Lack of support and knowledge from home, | | Jemima | | Esther | |

| | | | | | |
|---|---|---|---|---|---|
| community | | | | | |
| Physical obstacles | | | Christina | | |
| Lack of resources: specialist teachers and materials | Rosemary | Jemima | | Esther | |
| Poverty | | Jemima | Christina | Esther | Chikondi |

Table 2: Coding table of informants and barriers to education in urban Lilongwe

| Code | Emanuel (Hearing impairment) | Thokozani (Physical disability) | Hamilton (Visual impairment) | Jumani (Down´s Syndrome) | Sophie (Intellectual disability) |
|---|---|---|---|---|---|
| Little or no attention from teachers | Emanuel | | Hamilton | | Sophie |
| Stigmatization | Emanuel | | | Jumani | Sophie |
| Lack of support and knowledge from home, community | Emanuel | Thokozani | Hamilton | Jumani | Sophie |
| Physical obstacles | | Thokozani | | | |
| Lack of resources: specialist teachers and materials | Emanuel | | Hamilton | Jumani | Sophie |
| Poverty | Emanuel | Thokozani | | Jumani | Sophie |

*Little or no attention from teachers*

As seen in the four case studies above, the youths are suffering from lack of attention from special needs teachers, but mostly mainstream teachers. For Emanuel, as described above, little attention from mainstream teachers is causing him to not learn anything in an inclusive environment. For Rosemary, the teachers have not been able to pick up on her learning difficulties, and she has not yet learned how to read and write by the age of 12. Little or no attention from teachers can be a destroying factor for a child with learning disabilities, explains the special needs teacher in rural Malawi:

*Those with learning difficulties are most likely to drop out. Sometimes those with learning difficulties they maybe drop out in standard 8, standard 7.*

Jemima is another girl living in rural Malawi, who has been experiencing problems in class. She is 18, and is enrolled in Standard 6. She has been repeating several levels. She has both a visual and hearing impairment, and does not yet know how to read and write. According to herself and her mother, the teachers have not been able to help her learn how to read and write, and she reports herself that she often does not understand anything of what is being taught in class.

Sophie is a 16-year-old girl with an intellectual and learning disability living in urban Malawi. She is currently in standard 6.  She divides her time in school between the mainstream class and attending to the resource room for learners with special needs. Her father explains that she repeated standard 1 and 2 twice, and that the reasons for this have to do with poverty, and also the student/teacher ratio. She is enrolled in a large class, with one teacher. There is thus simply not enough time for the one teacher to attend to her.

A mainstream teacher in rural Malawi also reports that many of her fellow teachers are not giving learners with various disabilities proper attention, when responding to the question of what the teachers do:

*Nothing, they just ignore him because he is a slow learner. They just take the paper without giving him extra time and in so doing that′s not better. That's bad. Some of them don't care about them (youth with special needs).*

She also explains that in her class, she has 190 learners, and 4 of them are learners with special needs. She explains that it is simply impossible to attend to every one of them. Moreover, as seen in the coding tables from the two areas, neither of the youths with physical disabilities are suffering from lack of attention from their teachers.

*Stigmatization*

As presented in the coding tables, three of the youth in the rural area and three in the urban area reported experiences of stigmatization in their schools. Jemima experiences fellow

learners laughing at her when there are things in class she does not understand. Jumani is a young man with an intellectual disability, downs syndrome, who is placed in the resource centre in the school in urban Malawi. Jumani has been in the resource room for 5-6 years, but has not yet started standard 1. The plan is, according to his mother, that he will start primary school "when he is ready". As explained previously in this chapter, every week the special needs teacher tries to place some of the special needs learners in the mainstream class. The mother explained that:

*When they go to the mainstream usually there is a reaction because most of the times they are surprised of why they are there at that side. So usually they call them names, mark people, saying "what are you doing here", sometimes they stone them, chase them away…*

Also Sophie is experiencing stigmatization and negative attitudes because of her intellectual disability:

Father of Sophie: *So she used to beat up her friends, or her friends would beat her up. That´s the way they were interacting. They were fighting*
Interviewer: *Do you think they teased her?*
Father of Sophie: *They were mocking her because of the way she is. And the previous place we were, the community was always playing tricks on her. Maybe she would take bathing water to the bathroom, they would remove the water from there.*

One of the mainstream teachers in rural Malawi shared experiences of stigmatization from parents to their disabled child.

*There are some parents that keep them indoors, not letting them go play with others because they are disabled. They are ashamed of them; they are ashamed of their children. They forget that it´s God will in them, that´s why I am saying that they need sensitization.*

*Lack of support and knowledge from home and school*
In one way or the other, almost all the informants had experienced a lack of knowledge from their families on what to do. Some of the parents/guardians had not spoken to special needs teachers, mainstream teachers or head teachers about their youth's problems in school. This was the case for three of the informants in the urban area. Others were not aware of the

medical services available in their community to make the situation better for their child. In the rural area, two youth experienced a lack of knowledge from home. Jemima has both visual and hearing impairments, but has not seen a doctor for an eye-check. The mother was not aware of the free local clinic where they do check-ups.

Esther is around 20 years old and lives in rural area with her family and daughter. She has an intellectual disability and suffers from epilepsy. She dropped out of school in standard 2. When speaking to her mother about her dropping out, she described Esther´s situation as hopeless:

Interviewer: *So why did she drop out of school in standard 2?*
Mother: *Because of this reason. She would go to school and not understand what the teacher is saying because her head is malfunctioning. She would not write when her friends were writing. She would just go out to chat. Because of her fits she would not get what you were saying and she was aggressive when you told her to go to school.*

As seen in the examples above, it is not a rarity that parents have little knowledge on how to best assist their child, which results in drop out as the only solution. When the district co-ordinator for the rural area in this study was interviewed, he shared experiences from his time as a mainstream teacher, before he entered into special needs.

*One time I picked a learner in my class who used to say "Sir, I can´t see what you are writing on the board." I was writing notes on the board and this boy stood up and said "I can´t see what you have written", and I said "What?" I grabbed his neck, found a stick and whipped him and said, "Do you want to joke with me?" But later I discovered that the boy had low vision. And come the following day, I found him specs. So it is now that I see that I did a lot of evil to those learners.*

This lack of knowledge is, according to him, not unusual among mainstream teachers in Malawi:

*The challenges are there especially for those teachers who are not trained in special needs, that you find most of the time these learners are left out and are not taken on board when teaching.*

*Physical obstacles*

The learners with physical disabilities are usually the ones who experience physical limitations as obstacles to inclusive education. As described previously in this chapter, Christina is one of the youth who are dependent on her guardian or friends to make sure she can get to school every day, and to and from the different classrooms.

Thokozani, age 12, is paralysed from the waist down and is in a wheelchair. He started four years late in school, because of lack of means of transportation to school, according to himself and his guardian. While he should have been in Standard 8, he is now in Standard 4. His friends push him to school on his wheelchair.

*I need my friends to push me around. Because one tyre got broke, my wheelchair does not work that well. Normally they don´t have to push me, but now that does not work. No teachers are helping me, it is my friends.*

Another problem he faces is accessing the toilets at his school. The toilet facilities at school are dark pit latrines, which often get very dirty.

*When he goes to the toilet, he has to walk with his hands and his knees. So he touches the urine that has been on the floor. Especially during the rainy season. He has no gloves, and no protective pads on his knees either. He is afraid the rainy water carries some disease and germs,* says his guardian.

Because Thokozani is infected with HIV, infection caused by soiled water and from crawling in the toilet areas happens frequently.

*Lack of resources: specialist teachers and materials*

All cases, except for the three with a physical disability, as shown in the coding tables are suffering from lack of resources; human and/or material. Moreover, all the schools visited for this study, urban and rural, had very limited resources available, both human and material. There was no braille, sign language interpretation or adapted exam materials available for students with special needs. This problem is persistent across the country, explains a lecturer at a teacher training college:

*There is a need of a lot of improvement. In terms of resources; class resources, material resources and human resources. There are not many special needs teachers who can assist learners with special needs.*

As explained above, it is not unusual that there is one teacher available for a class of around 200 students. With a general lack of special needs teachers overall, learners with special needs are easily forgotten. The reason for the lack of special needs teacher in Malawi is due to various reasons. Firstly, there is no training in special needs at general teacher training colleges in Malawi. If one wants to become a special needs teacher, there is one college in the country, which is located in the Southern Region. The lack of special needs teachers in the two areas is described previously in this chapter. Resources are particularly lacking at secondary level.

Firstly, for a learner with disabilities to be selected to secondary education is very difficult. It takes "collective efforts", according to the district co-ordinator in the rural area. To begin with, one has to get good results in the last exam in Standard 8, the Leaving Certificate Examination (LSE). Furthermore, one has to be selected, depending on the "catchment area", which is, according to a Head Teacher at a rural secondary school, depending on how many primary schools there are in the area around the secondary school. If the catchment area has a low number of primary schools, the likelihood of getting selected to secondary school is bigger, because there is less competition. Therefore, the likelihood of a learner with special needs of being selected is therefore low. Finally, the family of the youth has to be able to pay for secondary school. The tuition fees vary greatly between the different secondary schools across the country; from 3000 Malawian Kwacha (MK) (1000 MK = approx. 1,5 USD) per term, to 70 000 MK per term.

Secondly, the secondary school system is not designed to accommodate learners with special needs in an inclusive environment.

*We have no teachers with that experience; to take care of them in secondary school. In general, we have very few secondary schools taking care of the disabled children,* explains the Head Teacher at a local secondary school.

Graduates from special needs teacher training colleges are usually only qualified to work at primary school level (Banks & Zuurmond, 2015). Moreover, special needs resources are usually only channelled to primary level, leaving very few, and often no, resources available for special needs at mainstream secondary schools.

*Poverty*

The link between poverty and disability has previously been mentioned in this thesis. The district co-ordinator for the rural area also expressed concern around poverty and youth with disabilities:

*I don´t know what the connection is there.. I discovered that most of these children come from not well to do families. I don´t know what connection is there, but we would love if even the parents would be supported and in doing so, that they support their children.*

All the households participating in this study were poor households. For all the informants, poverty is directly related the ability to obtain education. For instance, Sophie has problems in performing in school due to the fact that she goes hungry, according to her father. Others, like Emanuel, cannot go to a secondary school that meets his special needs due to lack of funding.

Many of the youth in this study are dependent on individuals or NGO´s for them to pay for resources or their education. For Thokozani, his life in schools becomes hard due to a lack of protective pads on knees and gloves, especially when accessing toilets. They have enquired with local DPOs:

*I have tried to go to MACOHA* (Malawi Council for the Handicapped), *FEDOMA* (Federation of Disabled´s Organisations in Malawi), *and they promise they will help, but they just came to the house, checked out the toilets, checked out the houses and they said they would bring some change, but they never came.*

For other informants, NGOs and DPOs have been helpful in terms of equipment like wheelchairs and crutches.

Two of the learners who are currently enrolled in secondary school, Christina and Chikondi, are having their fees paid for by different NGOs. Chikondi is 19 years old, and is in Form 4.

She has a physical disability and is dependent on crutches. She goes to a secondary school, and the tuition is paid for by Campaign for Female Education (CAMFED). Moreover, for the sake of easier access to school, and lack of resources from home, Chikondi lives in a convent. Here, the nuns living with her provide her with food and shelter.

*My future is bright, because of CAMFED. They told me if I pass my MSCE (Malawi School Certificate of Education), and get selected to college, they will ensure that I get through college and they will support me all the way. I am very excited; I know that there is a lot of support for me.*

### 5.3 Capabilities and the youth

In this part of the chapter, the capability to obtain education for youth with disabilities will be discussed. This will be done with respect to their individual characteristics and their various disabilities.

For the informants with a physical disability; Thokozani, Chikondi and Christina, mobility was one of the main issues that were interfering with their capability to access education. For those with a physical disability, being able to move from one place to another with the help from another was a determining factor of whether or not they could go to school. The capability of bodily integrity is concerned with, among other things, being able to move freely from place to place (Nussbaum, 2011). For the three informants with mobility problems, to obtain this capability was dependent on people in their family and community.

Christina, the 14-year-old girl living in rural Malawi, who was born without functioning legs, reported that she was highly encouraged by her family, more specifically her mother, and most of her teachers in school. Her mother was determined to get her three disabled children to school, and thus carried them every day.

Thokozani, age 12, living in urban Malawi, also has a severe physical disability. He is being taken care of by a neighbour, because in his opinion, Thokozani´s aunt, who is his guardian, is not able to take care of him. His neighbour gathered funds in order for Thokozani to get a wheelchair that takes him to school every day.

The last informant with a physical disability is Chikondi, who was dependent on crutches. For her, the initiative of the nuns at the convent located close to her secondary school was determining in her ability to access school.

For all three informants with a physical disability, facilitators to access to education were key people in their communities. Even though for many of them the distance was to school far, friends, parents or other community members made sure they made their way to school.

For two out of the three physically disabled informants, however, accessing the toilet facilities at the school was difficult, and required help from their fellow learners. The capability of bodily integrity can, as well as being able to move freely from one place to another, be understood as being able to access sanitary facilities without exposing their bodies. For Thokozani, accessing the toilets presented a health risk: he is HIV positive and going to the toilet involved being exposed to bacterias that could make him ill.

The youth with physical disabilities interviewed for this study were all enrolled in school; one in primary and two in secondary. However, they were all dependent on 1: key people in their lives who could take them to school and help them to the toilet, and 2: people or NGOs to pay for their school fees. Other people therefore facilitated their capability to access education. Though the youth with a physical disability were successful in terms of education, relatively speaking, one might argue that not all learners in their situation are able to access education. Christina and Chikondi were both able to reach secondary level because of initiatives to pay for school fees by NGOs, which is not the case for many youth in Malawi, whether he/she has some kind of disability or not.

Four youths, as seen previously in the chapter, had various intellectual and learning disabilities. Due to lack of knowledge about their different intellectual challenges these youth has, the school and the community had difficulties in meeting their special needs. One of them, Jumani, age 12, has Downs Syndrome, and because of his condition, not yet started Standard 1. In his case, there are various factors that present as barriers to obtaining education. As described previously, it is explained that Jumani and his fellow learners are being discriminated against in the mainstream setting, because of their disabilities. Jumani does not read or write, and has difficulties speaking. His mother explained that she did not have high hopes for his future:

*I do not have hopes that he will be independent, because of the way he is. I don´t think he is going to make it, to be an independent person.*

The authors of *Inclusive Education in Low-Income Countries: A Resource for Teacher Educators, Parent Trainers and Community Development Workers (Mariga, McConkey, & Myezwa, 2014)* argue that inclusive education cannot come about without the cooperation of families. The expectations of parents, family members and service providers for the future of disabled youth can arguably have an effect of the educational outcomes of the child. Parents and family members can serve as both a facilitator, and also barriers to education. For Esther, a 20-year-old girl with an intellectual impairment and epilepsy, motivation from the family and community to complete education, or lack thereof, presents as a capability barrier to education. Her mother explained the reason for Esther dropping out of school like this:

*She would go to school and not understand what the teacher is saying because her head was malfunctioning. She would not write what her friends were writing; she would just go out to chat. Because of her fits she would not get what you were saying and she was aggressive when you told her to go to school. She is like the mad people who walk about the markets; the only difference is that she remembers to return home.*

In other words, parent's attitudes and perceptions on what is right for their child with a disability can serve as both a capability barrier, and a facilitator to educational achievement. In the case of Jumani and Esther, their parents do not think they are "fit" to get an education, due to their intellectual disabilities. Thus, Esther dropping out seemed like the only option for her and her family. For Jumani, one might argue that school, or the resource room where he learns, serves as more an arena to socialize than to learn. In the case of Emanuel, his parents did not think he could be in school unless it was a special school, which they could not afford. He therefore started late, until a special needs teacher intervened and convinced them that he could be enrolled in a mainstream class.

Another main finding in this study was the lack of resources; human and material. Each and every one of the youth in the study was lacking books, writing materials, and enough teachers. As stated previously in this thesis, the students were in classes with up to 200 fellow learners, with one or two teachers. These are issues that affect the quality of education for all youth

enrolled in school, not only those with various disabilities. However, arguably, the combination of student/teacher ratios, along with lack of materials and small, dark classrooms affect youth with disabilities more critically. As mentioned previously, Malawi has had free enrolment to primary school since 1994. This resulted in a dramatic increase in enrolment in school in the following years (Kadzamira & Rose, 2003). High level of enrolment demands an increase of capacity in schools. However, for various reasons, the state of educational quality in Malawi is very low (UNICEF, 2016). These reasons are linked to the broader financial difficulties that Malawi is facing, which is evident in the high reliance some of the youth have in the aid from international and local NGOs to pay for school fees at secondary level, wheelchairs and other special equipment.

An observation made during the first days of my fieldwork was that the amount of youth with disabilities enrolled in secondary school was low, so low that it would have been difficult to gather enough informants. Additionally, as seen during this study, the youth that are enrolled in secondary school for this study are almost all physically disabled. This is because their main challenge is linked to mobility issues – if they can get to and around the school area, they can learn within the same educational environment as their fellow learners. The reason for this, as discussed above, is linked to how children and youths special needs are met in primary school. Many of them tend to stay and repeat levels in primary school, like Rosemary, Sophie, Hamilton, Jumani, and many of them drop out before reaching secondary school, like Esther.

**5.4 Capabilities, disability and inclusive education**
Nussbaum´s capability of senses, imagination and though has to do with being able to use senses, thought and reason, cultivated by an adequate education (Nussbaum, 2011). For many of the youths in this study, the inability to read and write is a consequence and a barrier of obtaining education. This, in turn, arguably, limits the capability to choose their future. As many of the youths said in the interviews, they had high hopes for their future; they had hopes of higher education and hopes of getting a future job. As Nussbaum (2011) argues, people who are literate and are therefore able to communicate with other people who face the same problems are no longer isolated. Thus, being able to read and write enhances other capabilities; the capability to get a job, the capability to interact well with other people and the capability to participate effectively in a political system. Illiteracy, Nussbaum argues, is an "enduring disability" (Nussbaum, 2011, p.154). By this, she means, that the inability to read

and write will limit the abilities for this individual for rest of their lives. Thus, youth with disabilities who are deprived from the opportunity to being able to read and write, are, arguably, double disabled.

The capability of senses, imagine and thought is cultivated by an adequate education (Nussbaum, 2011). Thus, an adequate education is a fundamental part of being able to think, reason and make choices. In light of obtaining an "adequate education" for youth with disabilities, a discussion on the idea of inclusive education in the context of Malawi is necessary, based on the findings of this thesis.

This study has been conducted in the context of mainstream schools in an inclusive system, where learners with disabilities learn mostly in mainstream classrooms. Inclusive education is established as the main policy regarding special needs education, which is influenced by a stronger influence of disabled people´s movements (Terzi, 2010). The idea is that access to mainstream schools is a fundamental process for equalisation of opportunities for people with disabilities (2010). The theoretical basis for the idea of inclusive education is the social model of disability; that existing structures in the school environment should be changed in order to meet everyone´s needs (Geoff, 2003). The way in which this should be done in practice has been documented in a range of guidance for governments and organizations, as seen previously.

In the rural area where this research was conducted, they used an itinerant system of Special Educational Needs (SEN). The organisation of SEN in this area, one might argue, is a barrier in itself for the capability to obtain education for youth with special needs. How special needs are met varies greatly according to what type of disability the youth has. This is because: 1.various types of disabilities demands different kind of special needs materials and equipment 2.special needs teachers are specialized in different types of disabilities, thus many of the youth have disabilities in which the special needs teachers available are not specialised in.

For example, Rosemary has a learning disability that had not yet been detected; either by mainstream or the itinerant special needs teacher in the area. Thus; the way special needs are organised in this area thus became a barrier in itself for Rosemary´s chances of accessing quality education. Lorella Terzi (2005) is a scholar within the field of education, and is one of

those who argue for a capabilities perspective regarding disability issues. She argues that conceptualizing differences between children demands not only a definition of a person's diversity, but also a definition of the factors that are causing the difficulties experienced by some children throughout their school career (2005). For Rosemary´s sake, to use an example, factors that cause her difficulties are linked to the way special needs are organised and how they are met. One might argue that if special needs were organised differently, and more human resources were allocated to this rural area, she would be able to read and write, and thus succeed in her exams in primary school. As Terzi (2005) argue, when the educational environment is appropriately designed to address the learning techniques of an individual with learning difficulties, the restrictions in functioning's may not become a disability. This is closely linked to the social model of disability; for Rosemary´s sake, her individual circumstances become a disability as a result of societal structures.

For Emanuel, the capability to obtain education is, among others hindered by the way Special Needs Education (SNE) is organised. Emanuel has a hearing impairment, and is an example of a youth with special needs that has been selected to secondary school. However, his school is unable to meet his special needs, which primarily requires a person who knows sign language to teach him, as well as hearing aids. Emanuel progressed well when he was enrolled in primary school, where there was a special needs teacher with a specialization in hearing impairment available to him at the resource centre attached to the primary school. Thus, the primary school was structured in a way that made him progress well and learn in school. The secondary school that he is enrolled in now, however, is structured in a way that enforces his inability to learn in school. Considering Emanuel from a medical perspective, his impairment in the form of lack of hearing is the barrier to learning in school. Lack of being able to listen and communicate restricts being able to learn. However, considering Emanuel from a capabilities perspective, with the right possibilities to turn capabilities into functioning in education, he is able to learn along with his peers who communicate through vocal languages (Terzi, 2005).

An equalisation of capabilities in education is determined on equality of resources. However, in the debate on disability and special needs, this is not unproblematic. Equality of resources, understood as equal distribution of goods, overlooks the differences and diversity between people. People have different ways and opportunities to convert their resources into well-being, and the capability to convert resources into opportunities varies in relation to the

design of the "environment they inhabit", argues Terzi (2010). The capability to convert resources into functioning's depends highly on the circumstances of each and every youth.

The examples mentioned are examples of structural barriers to quality of education; the way special needs education is organised in the respective areas is unable to meet the various challenges the different youth are experiencing. The capability of senses, imagination and thought is thus hindered by how the system meets special needs in an inclusive system. Furthermore, the two geographical areas researched for this study, one urban and one rural, have two different ways of organising special needs. In a society of equals, social and institutional arrangements should be designed to show equal consideration and respect for all (Terzi, 2010). Terzi further argues that once these institutional arrangements are made, changes can be made within the society. Malawi has different arrangements for special needs, depending on the resources available. In some areas, like the rural area in Southern Malawi where half of the research for this study was undertaken, resources for special needs are almost non-existent. There are various reasons for this. One is environment; it is difficult to make the few special needs teachers available in the country to move to a rural area and work as a special needs teacher. Furthermore, there are not many houses available for those who choose to move to a rural area and work there. Teachers are given rural hardship allowances as an incentive to increase the number of teachers. However, this is the same for all teachers in rural area, although there are different types of rural areas; some of them are moderate rural, some of them are extreme rural. It is therefore still difficult to find teachers for the extreme rural areas. The differences between the urban and rural site will be further discussed later in this chapter.

Thus, a successful implementation of inclusive education demands available resources, materials and adequate funding for this. The main goal for education is, arguably, learning. Findings of this study have revealed that education in an inclusive system in Malawi confronts the youth with various disabilities with the challenges outlined above. The findings reveal major problems in learning in mainstream schools for youth with various disabilities, concerning lack of resources, the physical environment and attitudinal problems of educators and fellow learners. One might argue that from a learning perspective in Malawi, learners like Emanuel, who has a hearing impairment, learns more in a special school for hearing impaired. He went to a special school during the beginning of his education, was taught in sign language and communicated with peers through sign language. From a social model of

disability perspective, the inclusive education system observed in the rural and urban areas plays, arguably, a part in "disabling" the youth. In the case of Rosemary, who has a learning disability, the way special needs are organised at her school enforces her inability to read and write. For Emanuel, who has a visual impairment, the classroom structure, where he sits in the classroom and mode of examination enforces his visual impairment. One might argue that, strictly from a learning perspective, the inclusive system serves more as a barrier rather than facilitator for learning in the areas studied for this research.

Nevertheless, Special education is closely linked to the medical model of disability, where the impairment itself is in focus, and ignoring environmental factors (Geoff, 2003). It is argued that specialized institutions are questionable from a human rights perspective; that they promote segregation and discrimination (Terzi, 2010). Critics of the Medical models applied to education argue that the exclusion of children and youth from mainstream schooling illustrates that these children are categorized as educationally abnormal and uneducable. (Terzi, 2010). As stated in the "World Report on Disability", ensuring quality education in an inclusive society should be a priority for all countries (WHO, 2011). Moreover, Barton argues that working towards inclusive education is not only about access to mainstream schools for children and youth with disabilities, but it is a means to an end: which is establishing an inclusive society (Barton, 1998). Therefore, efforts need to made towards strengthening an inclusive education system.

## 5.5 Capabilities and poverty
One of the main barriers to access to education and learning is poverty. The issues discussed in this chapter are all linked, to some degree, to poverty. Firstly, Malawi is, as explained, one of the poorest countries in the world. The government lacks necessary financial means for each and every school in the country, and therefore also lack the ability to meet the special needs of youth with disabilities. International aid plays a major role in Malawi, in education as in many other sectors. Wheelchairs for those in need were provided by NGOs. Moreover, two out of three youth enrolled in secondary school had their tuition fees paid for by NGOs. The heavy reliance of NGOs in the youth´s special needs education can be understood in light of the country´s inability to follow through on its policies.

Sen has argued that poverty is, in fact a capability failure. It is not just a shortage of commodities, income or wealth, but also involved heterogeneous failures of opportunities

(Nussbaum, 2011). Socially excluded people, Nussbaum argues, may have difficulties in converting income or opportunities to actual capabilities. This can be understood as the failure to convert the access to education (because of free primary education) to actual quality of education for those with disabilities. Therefore, the opportunity to enrol in school is a means, not an end. The quality and completion of education is thus an end. The reason for Malawi´s poverty and low level of education is therefore understood as a capability failure. Because most of Malawians are disadvantaged, most of them fail to convert opportunities into capabilities.

Wolff and De-Shalit (2013) has built upon Nussbaum´s capability approach and discussed the issue of disadvantage further. They argue, firstly, that security plays a big role in the debate on poverty and capabilities. People need not to have a capability today, they argue, but a secure knowledge that capability will be there tomorrow as well. For the youths participating in this study, this was not the case. Two of the youth's school tuitions were paid for by a certain NGO, but whether or not the NGO would pull out of the area and stop their support was an uncertainty. Furthermore, Wollf and de-Shalit argue that one disadvantage often leads to another; or one capability deprivation leading to another capability deprivation. As explained, these youths are not disadvantaged only because of their disability, but the disability opens up space for other capability deprivations, or the other way around. For example, those who have challenges hearing or seeing have a capability deprivation that thus can lead to another capability deprivation, which is, for example, not being able to read or write. Or, the lack of adequate human and material resources in schools (for everyone), leads to other disadvantages, like a learning disability. This is, arguably, the case of Rosemary in the rural area, Sophie in the urban area.

**5.6 Urban/rural differences**

One of the objectives of this study was to explore differences between urban and rural areas of Malawi. Firstly, access to education for youth with disabilities between urban and rural differ structurally and environmentally.

The rural and urban sites visited for this thesis differ in the way Special Needs Education (SEN) is structured. In the rural area, there were only resources available for an itinerant special needs teacher. This system did, arguably, not meet the special needs of youth with

various disabilities. The reason for the organisation of SNE in rural areas is, as discussed above, a combination of difficulty to find incentives to make it attractive for a special needs teacher to work in a rural area and lack of funding for resources in the rural areas. The rural development fund gets money from the government in order to develop more teacher's houses, more classrooms and resources for classrooms. However, as the official in the special needs department points out; money allocated to the Rural Development Fund is inadequate.

Moreover, as pointed out by the district coordinator for rural Zomba; some school zones did not have special needs education at all. The result of this is that youth and children with disabilities are not identified, or they may be identified but not given adequate follow up. When it comes to the organisation of special needs in the urban site, it was organised in a way that it had better chances of meeting various special needs. As pointed out, the resource room at the school where research was conducted had two special needs teachers available full-time. Here, children and youth with special needs were accommodated. However, these two were primarily employed at the primary school, not secondary, leaving the secondary school without special needs education.

Another difference between the rural and urban site concerns the environmental barriers. Schools situated in a rural area means longer distances between home and school. Roads are almost always dirt roads, where the terrain can be difficult. In the rural areas, it could take up to 1,5 hours to get to and from school on dirt roads, according to the special needs teacher and one of the youth with a physical disability.

Nevertheless, it must be noted the personal stories of the youth and their families were similar in terms of barriers to education. The case studies from both sites; urban and rural, shared stories on inadequate access to learning and education. Even though the school in the urban site had a resource room to accommodate youth with disabilities, this room was firstly, in theory only for primary school students, and secondly not sufficient in terms of capacity to accommodate everyone. An example is Jumani, age 12 with Down´s syndrome, who spends his days in the resource room, without having started Standard 1 yet´. There is no knowledge among SNE staff on how to teach him. Another example is Hamilton, who has a visual impairment, and is taught in a mainstream setting. In his case, neither the mainstream teacher nor the special needs teachers have the knowledge on how best to accommodate him. Thus, though there are structural and environmental differences, the youth shared the same barriers

to education in both areas. These stem from inadequate resources, which again stems from the poor economic situation of the government.

**5.7 Policies and legislation towards disability and education in Malawi**

As seen in the background chapter, there are a great deal of policies and legislation towards securing access to education for youth with disabilities in Malawi. Policies regarding disability and education in Malawi constitute the Disability Act of 2012 and the National Policy on Equalisation of Opportunities for People with Disabilities. Relevant regulations described in the background chapter are Section 20 and Section 25 in the Constitution. These regulations and policies are there to set the basis for and justify changes made to promote equal access to education for youth with disabilities.

The most recent regulation regarding people with disabilities in Malawi is the Disability Act of 2012. As described earlier, the Act states that the government should be responsible for ensuring the rights of people with disabilities to education on the equal basis as everyone else. It also aims to ensure an inclusive education system. Recognition of rights of people with disabilities and access to an inclusive education system can be argued to be a typical functioning; an end in which several capabilities has to be fulfilled to be able to achieve. As Nussbaum argues; "to promote capabilities is to promote areas of freedom, and this is not the same as making people function in a certain way" (e.g. make people open up for access to inclusive education for youth with disabilities (Nussbaum, 2011, p. 25).

As the Disability Act of 2012, so does the Malawian Constitution guarantee all persons their right to both education and development. Furthermore, the constitution states that no one should be discriminated against on the basis of age, race, gender, colour, political opinion or disability. This again, is a state of functioning, which requires policy changes to achieve. As presented in the previous chapter, Malawi has taken action and promoted policies to promote access to quality of education for youth with disabilities, like for instance The National Policy on Equalisation of Opportunities for Persons with Disabilities. By developing four specific priorities in the process of implementation, the MoEST demonstrates, arguably, an understanding that certain capabilities need to be fulfilled in order to achieve education.

However, as stated earlier, these measures in promoting education for youth with disabilities are ends, not means to achieve a goal. Implementing policies and adopting regulations that

speak up for the voices of youth with disabilities does not increase specific individuals capabilities. There are many aspects that interfere in a person's capability to achieve a certain goal; as seen so far in this thesis. However, Nussbaum argues that nations are both a starting place for increasing capabilities, and they are of moral importance (Nussbaum, 2011). Nations therefore sets the standards for people´s aim to achieve these capabilities. Promoting rules, regulations and policies that promote quality of education for youth with disabilities gives importance in people´s freedom to pursue these capabilities.

Nevertheless, Nussbaum admits, not all nations are equipped to secure these rights for their citizens. Malawi is such a nation, even though as she says "most democratic nations, wisely and efficiently administered, can do pretty well in securing for their people the capabilities on the list" (p. 114). Different nations have different life chances to start with, for various reasons. There are numerous factors that influences the population of Malawi´s basic life chances, and chances of implementing policies that secure access to quality of education. These are, to name a few, health obstacles, like malaria or HIV/AIDS, nutrition, draught, and poverty.

Nussbaum argues that if justice means that a person´s (or nation´s) entitlements should not be influenced by reasons that are out of one´s hands, this inequality is reason enough to do something about it, from an international perspective. In the findings chapter, Malawi´s commitment to international efforts is outlined. These include human rights obligations such as the Convention the Rights of Persons with Disabilities and the Convention on the Rights of the Child. Moreover, Malawi is committed to the Education for All Initiative.

As we have seen in the other parts of this chapter, a commitment to these international initiatives does not mean that each and every signatory country will fulfil the initiatives. Nevertheless, it sets the basis for policy changes. These are changes that promote the various capabilities that can enhance the chances of obtaining education for youth with disabilities

## Chapter 7: Conclusion

The aim of this thesis has been to explore the barriers to education for youth with disabilities in Malawi in urban and rural areas. Malawi has taken several policy initiatives in promoting

the rights of people with disabilities. Moreover, Malawi has signed and ratified the Convention on the Rights of Persons with Disabilities, Convention on the Rights of the Child, and is dedicated to the Sustainable Development Goals (SDGs) and the Education for All (EFA) Initiative.

Nevertheless, there are several barriers that hinder youth with disabilities to access learning and education. These barriers are many and complex. For some youth, the lack of attention, and the knowledge on how to teach youth with disabilities in mainstream schools is a barrier, resulting in many youth not learning how to read and write, which again causes youth to repeat standards for many years, or dropping out. Another barrier is the lack of resources; books, writing materials, special equipment like braille or hearing aids, sign language and special needs teachers. The lack of special needs teachers available for youth with disabilities is linked to different factors, involving lack of funding for special needs teachers as well as the way special needs are organised in different areas. The study has shown that in some cases, resources are there without the parents or guardians being aware of them. Thus, there are several actors that are involved in determining and influencing access to education for youth with disabilities. These actors include special needs teachers as well as mainstream teachers and their dedication, the parents and guardians. Moreover, national and international NGOs play a key role in breaking economic barriers to quality of education.

Malawi´s overall economic challenges are the main link between the barriers, and a main reason behind the patterns observed. Because of poverty, there are few material resources available for youth with disabilities, and few human resources in terms of special needs teachers and specialists. Moreover, all the families participating in the study were from poor households. For this reason, many of them struggled to pay for school fees (for secondary education), special education and necessary equipment, for example wheelchairs.

The study proved differences in the quality of education between urban and rural areas for youth with disabilities. Though the quality of education is relatively low and challenging for all the key informants, rural areas in Malawi are lacking crucial human and material resources in a higher degree than urban areas. Moreover, rural areas can have larger physical barriers to education, because of its large distances between home and school, and between schools for itinerate special needs teachers.

Obtaining education for youth with disabilities in Malawi takes collective efforts. Motivation from parents/guardians, attention and proper teaching from special needs and mainstream teachers and adequate funding can give youth with disabilities a chance to access education, which again can increase the chances of higher education and employment opportunities. Unfortunately, despite good policies, there seems to be a "policy evaporation" regarding disability and education: policies are good on the national level, but evaporates along the way and does not reach those the policies are intended for, in practice.

**Recommendations**

In order for policies to be implemented in practice, there is a need for more funding towards all categories of actors in this study. Teaching facilities as well as human and material resources should be a priority. As explained, the way special needs is organised does not meet the special needs of youth with various disabilities. Therefore, focus on education and financing more special needs teachers all over Malawi is a crucial part of a successful inclusive education system. In addition to this, focus on training for mainstream teachers on teaching youth with disabilities in an inclusive setting should be a priority for policy makers and international NGOs conducting development projects within the field of disability and member with a disability.

**Recommendations for further research**

All the barriers to education observed in this study could all be a theme for more in-depth research in itself. An example is teachers attitudes towards learners with special needs, and how these serve as barriers/facilitators to inclusive education. Another is poverty, and how lack of money for food and school materials is a direct barrier to learning. More in-depth knowledge on the specific disabilities in the context of inclusive education is also necessary. Examples can be how best to accommodate youth with learning disabilities in an inclusive system, or access to learning for youth with intellectual disabilities. As mentioned, lack of quality education often results in early dropouts among youth with disabilities, which can result in early marriages for girls. Research on the reasons behind these dropouts, and what these youth do after dropping out, is a necessary tool in order to gain understanding of barriers to education. There is also a need for research on interventions that can increase the quality of education for youth with disabilities. Lastly, there is need for more research regarding health services and disability, and the link this has to the lack of education.

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**Appendix 1: Interview guide**

Introduction:
- Introduce yourself and give the formal information about the study
- Informed consent (make sure informant understands his/her rights and responsibilities, before he/she consents)

About the informant:
- Gender/Age/Marital status/Children (own/foster care/adopted)
- Educational level (formal/informal)
- Work status (formal/informal)
- Area of residence
- Household composition
- Household income (from all household members): Does it sustain the family?
- Activities of daily life of household members (division of labour in the household)

About the disability:
- Ask the informant to tell about the reason for the disability, as well as the reason for the onset of the disability
- Please tell or explain to me about your impairment. What happened, when and how? Why do you think this happened to you?
- How does your disability affect your life; in the pat/as a child? Today? In the future?

About activities of daily life:
- Invite the informant to tell about his/her daily activities. When asking the informant tell about activities, one has to adjust questions to the informant´s age, sex, family position/role etc. Encourage the informant to be specific and to illustrate by examples:
- Participation in household activities
- Self-care activities such as hygiene, going to the toilet, dressing etc
- Need for and access to health care and health services
- Participation in social activities
- Relate the activities above to the bodily and/or mental functioning of the informant:

- Describe how the disability affects access to and performance of the activities
- Describe assistance given and by whom the assistance is given
- If the person does not participate in some of the activities: Ask the person to reflect on why he/she does or does not participate in the activities
- Ask the person to describe what others (non-disabled) in the same situation do with regard to the activities mentioned

About participation of educational activities:
- What is the informant´s understanding of and experience with income-generating activities (formal and informal)?
- Own experience with participation in these activities; past and present
- How has their learning and educational activities prepared them for/not prepared them for participation in income-generating activities?
- Relate the activities above to the bodily and/or mental functioning of the informant:
- Describe how the disability affects participation in income-generating activities
- Describe assistance given and by whom the assistance is given
- If the person does not participate in some of the activities: Ask the person to reflect on why he/she does or does not participate in these activities. I n their opinion, is denied access related to the disability? How? Why? What can be done to ensure better access?
- Ask the person to describe what others (non-disabled) in the same situation do with regard to the activities mentioned

About participation in income-generating activities (formal/informal, past/present)
- What is the informant´s understanding of and experience with income-generating activities (formal and informal)?
- Own experience with participation in these activities; past and present
- How has their learning and educational activities prepared them for/not prepared them for participation in income-generating activities
- Relate the activities above to the bodily and/or mental functioning of the informant:
- Describe how the disability affects participation in income-generating activities
- Describe assistance given and by whom the assistance is given
- If the person does not participate in income generating activities: Ask the person to reflect on why he/she does or does not participate in the activities
- In their opinion, is the lack of participation related to their disability? How? Why? What can be done to ensure better access?

- Ask the person to describe what others (non-disabled) in the same situation do with regard to the income-generating activities mentioned

Closing the interview:

- Ask about the informant´s hopes for the future in regards to education/employment etc
- Ask if the informant has anything else she/he would like to share, or any questions
- Acknowledge of the informant´s cooperation, time spent and information shared.