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## **Disabled education?**

**A study concerning young adults with physical disabilities  
and their experiences with school in Livingstone, Zambia**

**Oslo and Akershus University College of Applied Sciences,  
Faculty of Social Sciences**

Oslo 2013



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Thesis submitted for the master's degree in  
International Social Welfare and Health Policy

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## **Abstract**

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There are about one billion people living with a disability in the world today. In Zambia, this number might be closer to two million. People with disabilities in the global South are almost always less likely to be in school, less likely to be employed, and more likely to be subject to economic hardship. The standing national education policy has failed in its aim to secure education for all, especially for children and youths with disabilities. Disability scholars have argued for a more comprehensive inclusion of grassroots perspectives on disability issues, as there is limited research on people's lived experiences, and the voices of disabled people are not being included in policies and planning. Therefore, this study aims to identify how people with disabilities experience schooling, how they have been included, and how they experience and explain the apparent lack of schooling. To this end, I pose the following research question: "What barriers do young adults with physical disabilities experience in relation to education?" This study investigates these barriers through the framework of critical disability theory, sensitized to the context of Livingstone.

This qualitative study relies on interviews with 17 young adults with physical disabilities from Livingstone. Purposive sampling was used to invite informants to participate. Their perspectives on education were examined to determine the barriers to education that they have confronted. Content analysis was chosen for systematically analyzing and making inferences from the transcribed interview material.

The main findings indicate that the barriers to education for young adults with physical disabilities in Livingstone are related to inadequate infrastructure, long distances to school, mobility to reach school, inaccessible school buildings, inadequate learning materials, and limited adaptations for them. Further, these barriers are related to negative attitudes or stigmatization from people in the community, school, or family, and instances of violence or abuse. These findings are presented in a table, and interrelated concerns between physical and socio-cultural barriers are addressed. Such interrelations are mainly represented by powerlessness and poverty.

**Keywords:** Disability, Education and Disability, Educational Barriers, Zambia



## **Acknowledgements**

First and foremost, I would like to thank the informants who so generously shared their stories, thoughts, and experiences with me. Your answers were worth seeking out; this study would have been worthless without your invaluable contributions.

To Evelyn Kazoka, my assistant researcher and friend, thank you for your valuable insights and translations, not only in terms of vernaculars but also in terms of culture. Our discussions provided me with new perspectives on disability in Livingstone.

Mr. Alick Nyirenda and the rest in the CBR (Community-Based Rehabilitation) Zambia Support Program in Livingstone, thank you for welcoming me to Livingstone, including me in workshops and discussions, assisting this study by addressing every matter of concern, and allowing me to contact your network of community workers, stakeholders, and researchers.

To the organizations and stakeholders working with disability and CBR in Livingstone, I wish to express a big thank you for your help in recruiting the informants for this study.

A big appreciation goes to NAD (the Norwegian Association of Disabled) and NFU (The Norwegian Association for Persons with Developmental Disabilities) for contributing with partial funding to this study.

Winnie and Jane, thank you both so much for accompanying me in Livingstone. Your support and company were precious, and I look forward to seeing you again.

My dear family spread throughout Norway, thank you for keeping me up and supporting me during this process. You are great! To my sister Kristine, I offer a special thanks for your patience, encouragement, and valuable feedback.

A big thanks also goes to all my friends and classmates from MIS 2011, for sharing your frustrations, insights, and laughs. Thanks to Ida, Rhaula, Siri, Heidi, Saskia, Hawa, and Aastha. Ingunn and Anne-Kathe: thank you for your valuable feedback!

Last, but not least, I would like to thank my supervisor, Erika Gubrium. Thank you for sharing your expertise and for guiding me through the process of developing this thesis!





## **Abbreviations**

CBR	-	Community-Based Rehabilitation
CDT	-	Critical Disability Theory
CRPD	-	Convention of the Rights of Persons with Disabilities
DPO	-	Disabled People's Organization
GDP	-	Gross Domestic Product
GRZ	-	the Government of Republic of Zambia
HIV/AIDS	-	Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrom
IE	-	Inclusive Education
ICF	-	the International Classification of Functioning, Disability and Health
MoE	-	Ministry of Education
SNDP	-	Sixth National Development Plan
UN	-	United Nations
UNDP	-	United Nations Development Program
UNESCO	-	The United Nations Educational, Scientific and Cultural Organization
UNZA	-	University of Zambia
WHO	-	World Health Organization



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**Attachment 1 – 6**

## 1. INTRODUCTION

*This is the story of “Agatha.” She is a young woman living in a compound outside Livingstone in southern Zambia. Agatha is the third born in the family. She lives with her younger siblings, her mother, and an aunt in a brick house without water or electricity. She stays close to the house every day. Agatha was born with a walking limitation that allows her to walk only for a few meters without assistance. She has never used any assistive devices such as crutches or a wheelchair. The family cannot afford them, and it is not sure that it would have been of any use because of the bad roads in the compound. When Agatha turned seven years old, she and her mother went to the community school nearby to request her enrollment. To reach the school, Agatha’s mother carried her on her back. The headmaster, who met them in the schoolyard told them to leave, as this was not a school for the disabled. The mother refused; Agatha is a bright girl who simply could not walk there by herself, but who was eager to learn to read. Again, the headmaster told them to leave; he made up a story that he would be arrested if the authorities found a disabled child in his school. Agatha and her mother returned home. Sometime later, the Agatha’s mother took her to another school, farther away from home. Again they were turned away; no disabled children could go to that school either. Even the mother’s explanation that she would carry Agatha every day, to and from school fell on deaf ears. Some years later, Agatha’s mother sought assistance from an office of the governmental district authorities in town. She had heard that they could help. However, she left disappointed and had to deliver the sad news to Agatha: the district authorities could only help children under the age of ten. Therefore, Agatha was too old to obtain assistance. The mother was not sure if that was true.*

*When I met Agatha, she sat outside the house watching her younger brothers and sisters. She seemed a bit shy, but she humbly explained that her dream was to learn how to read and write, and then perhaps get a job, so that she could buy clothes and other necessities herself and her siblings.*

This master’s thesis will take a closer look at disability in Livingstone, Zambia. As the above narrative elucidates, this thesis focuses on disabled young adults’ experiences with education and the challenges or barriers they that they face.

## **1.1 Background**

Today, about one billion of the world's population lives with a disability. Disability is a complex matter, and its measures vary. The prevalence of childhood disability varies from 0.4 to 12.7 percent depending on the measure (WHO and The World Bank 2011, 29, 36). United Nations (UN) estimates have suggested that around 80 percent of people with disabilities live in the majority world, the global South. Scholars have argued that inequitable economic resources and political development in today's world result in unrighteous living conditions for the majority of disabled people in the global South (Banda-Chalwe, Nitz, and de Jonge 2012; Priestley 2001a; WHO and The World Bank 2011). Studies carried out in countries in the global South, have shown that persons with disabilities are subject to substantial poverty, limited health services and lower education rates. The United Nations Educational, Scientific and Cultural Organization (UNESCO) published figures suggesting that more than 90 percent of children with disabilities in the global South do not attend school (UNESCO undated). Policies, regulations, and legislation are too seldom in accordance with the needs of people with disabilities. Environments are developed to suit the mainstream masses, and children exposed to poverty, malnutrition, or stunting have significantly higher risks of disability than those who are not exposed to the same (WHO and The World Bank 2011, 36–41, 169–195).

Over the past thirty years, the disability agenda has changed. Since the first Declaration on the Rights of Disabled Persons was made in 1975, disability has never been more of a mainstream issue than it is today. While it is currently an important matter on the international human rights agenda, a lot of work must still be done. The UN Convention on the Rights of Persons with Disabilities (CRPD) adopted in 2006 represents one of several means developed to target these important issues, and even though it had been ratified by 127 states as of 2012, its implementation is lagging behind (UN enable 2012; WHO and The World Bank 2011).

Similar to disability on the human rights agenda, studies on disability represent a relatively new field of research, especially in the global South. The existing academic literature on disability represents mostly the views and research from the global North. In those cases where the research originates from the South, it rarely covers the lived experiences of disabled people themselves. In addition, scholars argue, the research tends to be framed by definitions or social scientific traditions developed in

the global North. Furthermore, the researchers are generally non-disabled people, who state their findings in universal terms and attempt to apply them to conclusions globally. Thus, scholars and activists have argued about applicability to local contexts, such as in the global South (Grech 2009; Ingstad and Whyte 2007; Meekosha 2011; Priestley 2001a).

### *1.1.1 Zambia*

The Republic of Zambia is a peaceful, landlocked country in southern Africa with a population of 14.2 million in 2013 (CIA 2013). Since 1964, Zambia has been independent from the United Kingdom, and since 1991, it has been a democracy. It is a country rich in minerals, especially copper for which fluctuating revenues have affected the country's economy. The World Bank (2013) rates Zambia as a lower middle-income country with a gross domestic product (GDP) of 19.21 billion US\$ in 2011. Despite its growing economy, the income gap is widening, and this is especially affecting vulnerable children and youth in rural areas (CIA 2013; The World Bank 2013). Urbanization has left rural communities lagging behind in development, as these areas seldom receive sufficient prioritization. Peri-urban areas, such as those surrounding Livingstone, are also lagging behind, resulting in lower funding for government schools and health clinics. The HIV/AIDS epidemic together with other communicable diseases has affected the adult population, leaving Zambia with more than 6 million inhabitants between 0 and 14 years of age (CIA 2013). The under-five mortality rate in 2010 was 111, while life expectancy at birth was an average of 48 for both sexes (WHO 2013).<sup>1</sup> According to UNDP (2011), Zambia ranked 164<sup>th</sup> on the Human Development Index in 2011.

Livingstone is both a city and a district located in the Southern Province. The district area is 672 km<sup>2</sup> and houses a population close to 140,000. The city is characterized by its relatively small and urban center, as well as by the outstretched surrounding peri-urban compounds. Livingstone is further known as the tourist capital of Zambia, catering to thousands of tourists who visit every year to gaze at the mighty Victoria

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<sup>1</sup> Two indexes indicating life and health conditions and general development in a country (Lindstrand et al. 2007).

Falls or experience the stunning wildlife on safaris. Tourism is an important source of income here; thus Livingstone attracts many Zambians looking for work. However, the tourism industry does not offer work for everyone, and the expanding compounds surrounding peri-urban Livingstone house thousands of workers within the informal sector. Opportunities for education cannot be taken for granted either, particularly for those who have some kind of disability.

According to an estimate from the WHO (2011, 276), 14.8 percent of Zambians have some kind of disability. Zambia's National Census Report from 2000 estimated clearly different numbers, suggesting that 2.7 percent of the population was living with disabilities (CSO 2000). The diverging numbers are a result of the methods of measuring and defining disability. Persons with disabilities belong to a vulnerable group facing challenges with limited opportunities to participate in everyday life, and they are among Zambia's least empowered and most exposed individuals (WHO 2010a). To promote and protect the rights of persons with disabilities, the Government of the Republic of Zambia (GRZ) has implemented a number of laws and policies. Despite this wide range of pro-disability policies and laws, most have not been effectively implemented (Lewis 2007).

### *1.1.2 The education system in Zambia*

Ministry of Education (MoE) in Zambia introduced free basic education in 2002. However, attendance is not compulsory. Although the GRZ has steadily worked toward universal coverage of free, basic education school fees still prevail under the guise of Parent-Teacher Association fees, uniforms, books and others. That being said, net enrollment rates have increased substantially since 2002. Statistics from UNESCO (2012, 66–67) show that the net intake rate for first grade in Zambia has increased the last decade, and 97 out of 100 children are enrolled. These numbers account for all children in Zambia. However, only 76 out of 100 of children in the poorest population complete the last grade of primary school. Of the children who do attend school, recent statistics show that only 20 percent make it through grade 4 with an achieved minimum level of knowledge and skills. Thus, increased accessibility does not necessarily correspond with increased acquired minimum level of learning (UNESCO 2012, 124–125).



The formal school system has a 9-3-4 structure. It is divided into nine years of basic school, three years of high school and four years of university to obtain a bachelor degree. The age for entrance to basic school is seven years (although children often start school at a younger age). From grade 7, students must pass examinations each school year in order to proceed (MoE 1996, 9–13). However, the linking of grades 7 and 8 is a challenge since only two-thirds of the students make it into grade 8 (UNESCO 2012, 233).

Zambia has a combination of public, private, faith-based and community schools. Community schools are significant contributors to the increased enrollment in basic education for children and adolescents, and they are common around Livingstone. Since the 1990s, communities, often in collaboration with private or faith-based organizations, have opened their own schools to respond to the lack of schools or cumbersome fees. The GRZ positively responded to the local initiatives, and community schools have been registered with the MoE since 1998 (DeStefano 2006). The GRZ is responsible for grants and providing teachers and materials to the community schools. Although the provisions to community schools appear to be irregular in terms of support and supervision, the schools represent an important step toward universal basic education in Zambia. The lack of provisions nevertheless materializes in high pupil – teacher ratios, inadequate school buildings, insufficient hours of teaching, and low transition rates into upper basic school (EPDC 2008; Robson and Kanyanta 2007, 425). This affects all students in general, but even more so children with disabilities.

### *1.1.3 Education and disability in Zambia*

According to a household survey conducted by Deon Filmer (2008, 155), children with disabilities in Zambia are almost always considerably less likely to participate in education than other children. They are also less likely to start school. Scholars have supported Filmer in his suggestion that particular effort should be invested in getting children with disabilities into school, and keeping them from dropping out (Banda-Chalwe, Nitz, and de Jonge 2012; Filmer 2008; Kandyomunda and Nyirenda 2010; Serpell and Jere-Folotiya 2011). A national representative study on the living conditions of disabled people in Zambia revealed that almost 24 percent of the

children with disabilities above 5 years of age have never attended school. The same number for non-disabled children is close to 9 percent (Eide and Loeb 2006, 99).

There are private and public special schools and special units in schools throughout Zambia for children with disabilities. Some are parallel to the mainstream schools, but with capacities that are far too limited. Traditionally, and based on the standing national education policy, disabilities are understood in line with a medical model (elaborated in the framework in chapter 2), and disabled children are thus regarded as being in need of specialized education services (MoE 1996; Miles 2009). As such, in terms of aiming for education for *all*, Zambia is lagging behind. That being said, children with disabilities are not necessarily in need of specialized services. Susie Miles (2009) reported in a study from northern Zambia that mainstream teachers often feel that they lack the competence to teach children with disabilities, while at the same time feeling as though they are stepping into a field “belonging” to special teachers. Many teachers regard inclusive education<sup>2</sup> as an extension of special education. As a consequence, efforts to make mainstream schools more accessible to children with disabilities have often failed. However, teachers in mainstream schools are sufficiently competent to tackle challenging circumstances. They already overcome challenges such as large groups of students, gender discrimination, teenage pregnancy, a lack of teaching materials, unsatisfactory teaching environments, and so on. Miles (2009, 615–616) argued that mainstream teachers often lack confidence, not competence.

#### *1.1.4 Poverty, development and disability: interlinked?*

Since Zambia is a developing country, there is an arguable link between poverty and disability. Thus, it is apt to provide an introduction to this relation. The WHO and The World Bank (2011) established in the first and only *World report on disability* that disability is a development issue. Scholars in the fields of poverty, development, and disability have argued that impairments may exacerbate poverty in both a monetary

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<sup>2</sup> Inclusive education (IE) aims for education for *all*, and thus is not a strategy for disabled people only. IE aims to change the school system, not to change or label the children so that they fit into the system. IE regards education as something broader than just schooling; it is also part of the wider aim to create a genuine, inclusive society (Miles 2009; Stubbs 2002).

sense and a wider socio-economic sense (Chataika et al. 2012; Filmer 2008; Stone 2001; Trani and Loeb 2012; WHO and The World Bank 2011). This applies to most developing countries in the global South including Zambia. Children with disabilities are less likely to attend school when they are young. As such, they are also less likely to be engaged in employment and generate income when they grow older. Medical, transport and other disability-related costs are also likely to negatively impact households with already limited assets (Chataika et al. 2012; WHO and The World Bank 2011). Turning it the other way around, poverty may also cause disability. People living in poverty are likely to be subject to worse health conditions than those who have greater wealth (Helman 2007; Lindstrand et al. 2007), and those living with certain health conditions can acquire impairments or disabilities (WHO and The World Bank 2011).

## **1.2 Rationale for the study**

My previous six years of experience from working as an occupational therapist influenced my choice of the topic for this master's thesis. I had the opportunity to work in Zambia for 13 months in 2009 – 2010, after working in an upper secondary school in Norway with youths who were experiencing social or physical activity limitations. My work in Norway and Zambia challenged my perceptions of disability and activity limitations. In my work at health clinics in Livingstone and Kazungula (a rural district outside of Livingstone), I rarely saw children with disabilities; I met most of them through outreach programs. I was also left with the notion that young people with physical or intellectual disabilities somehow were restricted from school enrollment. This resulted in me wanting a more comprehensive understanding of how these young people were included in school, and if so, how they experienced it. That led to the following research question:

- What barriers do young adults with physical disabilities experience in relation to education?

There is limited academic literature and research on the experiences of schooling of people with disabilities in Zambia and the global South in general. The existing research has tended to focus on large-scale quantitative data sets. Critical scholars have argued for the inclusion of perspectives from grassroots level, as the existing

research has rarely included first-hand experiences (Filmer 2008; Ingstad and Whyte 2007; Miles 2009; Priestley 2001b; Robson and Kanyanta 2007; Singal 2010). Ian Kaplan et al. (2007) referred to other scholars in their search for more substantial research on the matter: "...very little social science research addresses children's and young people's own accounts of their daily experiences of schooling in any way that really taps into the richness of insight and detail of which they are capable of" (Kaplan, Lewis, and Mumba 2007, 24). As an attempt to account for some of these missing perspectives, this thesis aims to provide knowledge about how young adults experience their education and how they deal with it (or the lack thereof) when they have a physical disability. The current constitution in Zambia is not including the right to education, but according to Zambian national policies and the latest bills on disability and on education, basic education is a right for *all* (GRZ 2011; MoE 1996; Parliament of Zambia 2011; Parliament of Zambia 2012; RtEP 2012). However, this may not correspond with the grassroots experiences. The aim of this thesis is thus to identify the barriers that the young adults face in relation to education, through an analysis of interviews. I use critical disability theory, sensitized to the local context of Livingstone, as my approach to investigating and analyzing the interviews.

### **1.3 Education and disability in Zambia: policy and planning**

Zambian education policies aim to provide education to *all*, and thus should account for disabled people as well. A brief account of the standing national education policy and the latest national development plan is presented below, with a focus on the inclusion of disabled people and how the GRZ intends to secure educational rights for persons with disabilities. This is followed- up with a comment in the conclusion chapter that compares the findings from the interviews.

The standing national education policy *Educating Our Future*, states clearly that *every individual* in Zambia has a right to education, underlining access, participation, and benefit to all according to their individual needs, abilities, or (poor) financial situation. Further, it states that no individual should be denied her or his rights on any discriminatory basis (MoE 1996, 1, 4, 63, 72). The courageous policy also takes on the task of reaching students who are unable to attend school in the same way as the mainstream, to rehabilitate infrastructure and school buildings, and to provide

adequate school materials to meet the needs of students with physical disabilities. This is in addition to the policy aims for universal basic education, together with seven years of quality schooling. The policy addresses the MoE and the GRZ's deficiency in mainstreaming an education system that caters to *all* children including those with special educational needs, which is a primary aim (MoE 1996). It also refers to disabled children using expressions that can easily be perceived as degrading or suggesting their inferiority.

The Sixth National Development Plan 2011-2015 (SNDP) identifies mainstreaming disability issues (together with other areas) as critical in order to achieve the overall goal of “sustained economic growth and poverty reduction” (GRZ 2011, xii). This mainstreaming is planned to be performed with a basis in the CRPD<sup>3</sup>. The SNDP refers to the last decade's improvements in accessibility and enrollment of students with disabilities, but offers little information about learning outcomes or completion rates. One objective of the SNDP (GRZ 2011, 35–36) is “to enable persons with disabilities [to] participate fully in all aspects of life,” whereas related strategies (just a couple mentioned here) are to take responsibility for identifying and eliminating environmental barriers, and providing adequate education facilities and learning materials. The SNDP further describes a number of strategies to increase access, efficiency, equity and quality in education for disabled students (GRZ 2011, 91–100). However, these strategies appear rather unspecific and quite immeasurable.

#### **1.4 Structure of the thesis**

Chapter 2 of this thesis presents the conceptual and theoretical framework, starting with the definition of disability. Next, chapter 3 presents the methods employed to carry out this study. Chapter 4 presents the findings corresponding to four main categories, portrayed in a table. Thereafter, chapter 5 discusses the findings in relation to the conceptual and theoretical framework. The final chapter, chapter 6, presents the conclusion and discusses further implications.

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<sup>3</sup> Zambia ratified the UN CRPD in February 2010 (UNTC 2013).

## 2. CONCEPTUAL FRAMEWORK

### 2.1 Defining disability

In recent decades, the definition of disability has changed; what was previously a medical understanding has become a social understanding. The social model has challenged the medical model that has traditionally defined disability according to individual handicaps and bodily impairments. Furthermore, the social model represents the notion that societal and cultural structures disable (or enable) participation. More so, the social model incorporates complex processes in society that are barriers that contribute to disability, in addition to any impairment (Ingstad and Whyte 2007; WHO and The World Bank 2011).

Defining disability is a complex matter, and there are several other definitions and perceptions besides those belonging to the two models mentioned above. The varying definitions result in disability prevalence with significant disparities. Prevalence estimates vary, amongst others, according to the census-taking method and the definition of disability, and the disparities reflect this (Banda-Chalwe, Nitz, and de Jonge 2012; Loeb, Eide, and Mont 2008). The socio-cultural perceptions of disability will always vary according to the context, and this should be accounted for. At the same time, there is a need for universal definitions when doing research or when developing policies and legislation to secure the rights of disabled people. Today, the International Classification of Functioning, Disability and Health (ICF) offers the most widely accepted definition of disability, although it has been criticized for not being cross-culturally applicable “enough” (Banda-Chalwe, Nitz, and de Jonge 2012; Ingstad and Whyte 2007; McColl et al. 2006). According to the ICF, disability is an umbrella term that refers to difficulties within any of three interconnected areas: *impairments* refers to limitations in body functions or body structures, *activity limitations* refers to problems with activity execution, and *participation restriction* refers to challenges with being involved in any area of life (WHO and The World Bank 2011, 5).

In this thesis, disability is carefully defined, according to the ICF, as referring to functioning in any of the above-mentioned areas. The social model will be used, together with the contextual applicability to Zambia, as elaborated in section 2.2

describing the theoretical framework. That being said, disability must be understood in a broad sense, as definitions may lead to an understanding of disability that is not in line with an individual's own perceptions. Impairments, limitations, and restrictions will be experienced and pronounced differently according to each individual, and thus one disability cannot be equated with another.

Disability activists have argued about the apt wording when referring to people with disabilities. Some have emphasized the importance of a "people- first" language; as such "people with disabilities" would be most appropriate. Others have claimed that using the term "disabled people" is stigmatizing: the attribute of a disability is mentioned first and the person second (Pothier and Devlin 2006, 3–4). Terms like "activity limitation" or "impairment" are also prevalent. The common feature here is avoiding the use of terms with negative connotations that might offend or hurt. Language is not neutral, and with the lack of any "better" terms, the above-mentioned ones will be used interchangeably in this thesis. None of them are in any way intended to be discriminatory; here, it is simply a matter of using terms that cover a broad group of people with different activity functions. The members of this group are a kind of "different-able," not less worthy, less able, or less normal.

## **2.2 Theoretical framework – critical disability theory**

Critical disability theory (CDT) investigates the tension between the social and medical models of disability mentioned above. It incorporates factors from both models when explaining disability; the involvement of the impairment, the personal responses to that impairment and the social environments' barriers to the concept of disability (Hosking 2008). Conceptualizing disability this way means that the disability is not an inherent characteristic of the individual but a socially generated barrier hindering the individual's full opportunity to participate in everyday life. CDT contests the "dis" in disability and the impairment's responsibility for disability and emphasizes the need for change in political, environmental and other societal structures.

CDT, as a part of critical theory, challenges the dominant liberalist assumptions that society's structures are based on unavoidable able-bodied norms, that language is a relatively neutral means of communication, and that the individual's value is

determined by her or his productivity. CDT also tries to avoid an essentialist pitfall, where disability is understood as being an inherent characteristic of a person. Nevertheless, CDT states that there is a need for a somehow “general” conception of disability for the purpose of research and common understanding, but without being caught “universalizing” it (Goodley 2010; Pothier and Devlin 2006).

Historically, persons with disabilities have been defined as impaired - a misfortune that should be prevented, rehabilitated, or cured. They have, in a paternalistic way, been subject to charity and pity, rather than rights and empowerment (Goodley 2010; Pothier and Devlin 2006). Disability as a term has often had negative social connotations, and persons with disabilities have traditionally faced oppression, powerlessness, and discrimination, as opposed to being valued for their diversity. CDT challenges these negative and paternalistic connotations, and approaches disability in explanatory and normative ways - ways that challenge and break down mainstream society’s environmental barriers, allowing persons with disabilities to genuinely belong to society (Hosking 2008; Pothier and Devlin 2006).

Even though disability is part of being human, and almost every human being during life will experience some degree and length of a disability, disability is itself a major cause of discrimination worldwide. Persons with disabilities diverge from the able-bodied norms of what it means to be so-called normal. Societies impose barriers that restrict the full, genuine participation and inclusion of persons with disabilities. CDT calls for this marginalization and oppression to be confronted and eradicated, as persons with disabilities are to be valued and their voices heard. Political, social, and environmental conditions are contributors to disability and must be changed in order to enable genuine participation for all (Pothier and Devlin 2006).

CDT challenges mainstream society’s “unwillingness to adapt, transform and abandon its ‘normal’ way of doing things” (Pothier and Devlin 2006, 13). To confront this “normal” way of doing things, CDT values the context in which real experiences are found (McColl et al. 2006; Pothier and Devlin 2006). An understanding of context is valued, as it aims to genuinely incorporate the lived experiences from bottom-up perspectives. It acknowledges the stories of persons with disabilities, allowing their perspectives, and their voices to emerge.



### *2.2.1 Critical disability theory and beyond; whose reality counts?*

Scholars researching disability have criticized the over-representation of scholars and thinkers from the (global) North. They have argued that due to the continued dominance of Northern perspectives, these perspectives have shaped the disability research frameworks implemented in the (global) South (Grech 2009; Ingstad 2007; Meekosha 2011). Important geopolitical and contextual sensitivity has been lacking in the research; in addition, the uneven power relations between the North and the South, particularly caused by former (and some will say still existing) colonization, should be confronted (Grech 2009; Meekosha 2011). CDT surely represents Northern perspectives and caution is highly necessary in this study as well, so as to not analyze the interviews on the basis of assumptions that are not valid in the context of Livingstone. Thus, understanding disability in Livingstone from a CDT perspective requires the inclusion of the local concerns of persons with disabilities. That being said, Shaun Grech (2009) and Dan Goodley (2010) argued that disability studies and development studies must be connected in order to fully understand the ambitions and needs of persons with disabilities in developing countries. What this requires, then, in the peri-urban areas comprising Livingstone is to allow for interconnected concerns, such as poverty, infrastructure, and environmental issues. A lack of basic prevention and treatment of communicable diseases is also a relevant concern, together with the fact that primary health care not necessarily is accessible. In addition it is necessary to account for the roles of extended family and community, and the fact that disability is a matter of shared rather than individual responsibility (Ingstad and Whyte 2007, 24). Evidently, a social model alone is insufficient in this context, as it is based on concerns from the Northern, middle class, white, educated persons with disabilities (Grech 2009, 772). However, this does not mean that the return to the medical model is necessary (as feared in CDT).

Another argument for why the social model alone may be insufficient was given by Nidhi Singal (2010, 422). She argued that the social model of disability has a firm connection to emancipatory research and individual responsibility and thus is not suitable for all countries. Emancipatory research is more appropriate to contexts in which disability rights and movements are in place. In a context such as peri-urban Livingstone it is clearly less relevant, as life here more often concerns survival than emancipation. Individual responsibility is also less relevant in this context, where

families and kinship have primary responsibilities (Ingstad and Whyte 2007; Singal 2010).

Evidently, laws and policies must also be in place to secure rights for people with disabilities in Zambia, as peculiar as this seems, since many people with disabilities cannot afford or manage to contact or visit a government office to seek advice or claim their rights. They may not even be familiar with the existence of their rights (Grech 2009, 778). Another contextual concern is the above-mentioned North-domination and how it influences the making of policies and rights. When Zambian policymakers work, it is more often than not based on universal guidelines, conventions, or definitions from the UN, World Bank, or other multilateral institutions. In relation to context, then, this is not just a question about attainability; but it is just as much about applicability. As Benedicte Ingstad (2007, 252) aptly argued, "...The issue is not necessarily about what desirable goals are attainable but *which goals are desirable, in whose eyes, and in accordance with what ideology*" (emphasis in original).

CDT suggests changes in political, environmental, and other societal structures. However, some experts in disability studies have criticized the amount of focus that these structures receive and have called for more attention to the voices of disabled people (Johnstone 2001). In countries like Zambia, the voices of disabled people represented in research tend to be of those with more resources, who are able to attend meetings, take places in disabled people's organizations (DPOs), or are used to speaking in public. Allowing narratives from disabled people outside this sphere is a way to account for these voices, as is attempted in this study. In this study, thus, the personal experiences and voices are given more weight than a structural focus.

It is necessary to address that having a physical disability in Livingstone, in many ways, is intrinsically different from having a physical disability in the North - not necessarily different in biomedical terms, but from social, economic, structural, and cultural understandings (Ingstad 2007, 250). Education as a right plays a central role in CDT, and it is commonly agreed that education is an important cornerstone in society. In addition, it is also recognized that education not only is related to formal learning, but to the development of important social skills and play. Thus, school is an arena that potentially facilitates social inclusion and informal learning as well (WHO

2010b). However, education as formal learning is not unconditionally a necessity in all contexts per se, neither is it unconditionally a universal need. It is recognized as a right, although it may be unconditionally adopted *on behalf* of disabled people (Ingstad 2007, 252). Let me give one example from the interviews. A young woman from the Livingstone area has an activity limitation. One day, she was abused on her way to school. After this incident, due to concerns about her safety, her family withdrew her from school. Owing to both her impairment and the incident, she needs additional attention in school, as compared to her so-called ordinary peers. She does not receive this. The classroom has 50 students, sometimes even more, and the teacher(s) (do)es not have the capacity to follow- up with her. No adequate adaptations are available and the government school lacks resources to cater to her needs. The family cares for her from home, she has chores for which she is responsible of, and she perceives herself as an important resource at home. Neither she nor her family considers education to be a solution for her in the future. This example illustrates that education is not unconditionally seen as the most pressing need, although (Northern) policies and theories may claim the opposite. There is no structural reality that allows for education to be realized as the most pressing need, as other things must be addressed. This example requires the recognition that education is broader than just schooling. In addition, as in this example, complex issues such as poverty and development are paramount; thus educational rights seem more Utopian than applicable (Grech 2009, 777; Ingstad 2007). The example also illustrates how vulnerable persons with disabilities may be to violence or abuse (Ingstad 2007; Kvam and Braathen 2006), and that participation in education may be restricted because of this.

In many countries in the North the disabled body is viewed as something in need of technology, enabled by assistive devices (Goodley 2010). It is naïve to impose this view on a context such as Livingstone, with less technological development and, even more so, less adequate infrastructure available for such devices. In Livingstone, a wheelchair can most definitely enable participation, but it might also cause further isolation. A wheelchair may increase inclusion in a Northern context, but in one such as Livingstone, a wheelchair will not unconditionally help with transport purposes, given the lack of sufficient road constructions. These constructions must be tackled first; however, they are not likely to be prioritized in budgets, considering the number

of other fundamental challenges that Zambia faces today. As Grech (2009, 777) suggested, what is intended as an empowering service provision to a disabled person may, in turn, lead to exclusion, as she or he is suddenly defined as a “special case” in need of help. Grech (2009) exemplified this by depicting a person with dyslexia living in an illiterate community: it is not a problem until the “solution” arrives. Hence, incorporating CDT as a theoretical framework in the context of Livingstone is worth nothing unless it is accompanied by local perceptions.

In short, this chapter can be summed up by confirming that while the Northern-centric CDT has several arguments of relevance, it is not sufficient alone when doing a study on disability in the context of Livingstone. There is a need to go beyond it and describe the challenges according to the physical, social, economic, and cultural issues provided by other scholars or - most valid - the informants themselves.

### **3. METHODS**

This chapter will begin with an account of how the literature was chosen and accessed, before moving on to how the study proceeded in terms of design, sampling, data collection, analysis, study limitations, and reflexivity.

#### **3.1 Finding and choosing literature**

I retrieved most of the literature that I consulted to prepare for this study and the literature that I cite in this thesis, by using the search tools Taylor & Francis Online and BIBSYS. The keywords that I used for my literature search were as follows: *disability, disabled, impairments, special needs, vulnerable children, Zambia, Livingstone, global South, developing country, developing (development), critical disability studies, critical disability theory, inclusive education, educational inclusion, education, school, education(al) rights, education policy(policies), physical barriers, infrastructure, and disability and infrastructure*. These terms were composited in various combinations during searching. Another method that I used for identifying literature was by browsing reference lists from identified research documents or books concerning disability research in Zambia or neighboring countries.

The aim of the literature searches was to retrieve literature originating from Zambia, as the framework for this thesis prioritizes context sensitive literature. As such, I prioritized locally generated literature over Northern-based perspectives. First, I searched for literature written by authors from Zambia or neighboring countries. As a second option, I searched for literature concentrating on the Zambian context or the contexts in neighboring countries, and Northern authors had to be familiar with disability issues in Zambia. The goal was consistently to find literature that was contextually relevant to Zambia, addressing issues such as personal challenges and experiences concerning disability and education or barriers to disability in the social environment (cf. framework). Eighteen studies, articles, and books relevant to the Zambian context were selected for utilization in this study, on the basis of the aforementioned issues and search criteria.

In addition, the governmental Consultancy in Livingstone (introduced in section 3.3) was another source of information, together with several Community-Based Rehabilitation (CBR) – workshops in which I was invited to participate. Stakeholders and researchers working with disability issues attended these workshops. They were important resources, as they provided unpublished documents, and they were also open to discussing disability issues with me. However, most of the unpublished documents accessed here were not academically developed and are not included in this study. For instance, some of these documents did not have proper citations or reference lists, and hence reliability could not be established. Nevertheless, both discussions and documents contributed to a more comprehensive understanding that was beneficial, for example in my formulation of the interview guide. Three reliable articles were relevant and are utilized in this study.

### **3.2 Study design**

Qualitative studies are typically designed to capture previously unstudied lives and experiences of people. The researcher explores participants' experiences to gain deeper glances of how people act in certain life events, and why they do so (Chambliss and Schutt 2010). It is immensely important to shed light on the situations of vulnerable groups in a society through qualitative research (Dalen 2011). The perceptions of disability and education are dynamic, depending on individual as well as socio-cultural and physical aspects of life. As mentioned in the rationale for this study, there is a lack of research on this field in Zambia. People with disabilities own experiences and perceptions are valuable for gaining increased insight into how they live with a disability. For this reason, I selected a qualitative method in an attempt to achieve a comprehensive understanding of the challenges and barriers that disabled people in Livingstone have faced in relation to education. The qualitative method consisted of individual semi-structured interviews conducted with physically disabled young adults. Through these interviews, I attempted to understand the world of experiences on the basis of the informants' voices, thus avoiding understanding disability on the basis of "abstract and universal principles" (Kvale and Brinkmann 2009, 67). The informants' perspectives and understandings were then subject to analysis with the aim of achieving a contextual understanding through thick descriptions of their reality.

### 3.3 Access

Three different approvals were necessary in order to obtain ethical clearance for this study. The study was approved by the Norwegian Social Science Data Services<sup>4</sup>, the Directorate of Research and Graduate Studies' Ethics Committee at the University of Zambia (UNZA)<sup>5</sup>, and Permanent Secretary, Ministry of Health in Lusaka<sup>6</sup>. The study was supported by the CBR – Zambia Support Program in Livingstone, a governmental Consultancy in close collaboration with the Ministries of Community Development, Education, and Health. The consultancy provided practical assistance and formally introduced the study and researcher to relevant District Officers. During this whole study, all efforts were made to follow the guidelines on confidentiality, anonymity, and safe data storage, according to the above-mentioned approvals.

The Consultancy assisted in identifying a qualified assistant researcher for the study. The assistant researcher played a key role in enabling this study, just as much in discussions and debriefing interviews as an interpreter during interviews. She holds a degree in special education, had worked with disability related issues for ten years, and had experience in conducting research, interviews, and field work within the field of disability. The Consultancy further presented the study and initiated contact with stakeholders working with disability- related issues in Livingstone (the research site). Following a verbal agreement of collaboration, the stakeholders were crucial in identifying individuals who could participate as informants for this study. The stakeholders either had registers of people with disabilities or worked directly with community workers, community volunteers, or Community Development Officers (hereafter referred to as community workers). The community workers had sound knowledge of disability- related issues within their respective areas of work and responsibility; thus, they were valid sources for identifying potential informants for the study. Upon contacting the informants, all efforts were made to adhere to ethical considerations.

Within the areas where the assistant researcher and I (hereby referred to as the research team) carried out the interviews, we had to use a combination of driving and

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<sup>4</sup> See attachment 1 entitled *Tilbakemelding på melding om behandling av personopplysninger*

<sup>5</sup> See attachment 2 entitled *Re: Exemption from full ethical clearance*

<sup>6</sup> See attachment 3 entitled *Re: Request for Authority to Conduct Research*

walking. In most cases, one or more community workers escorted the research team. This provided valuable insights in the perspectives of the community workers, and it allowed the research team to observe and experience the community and local conditions in which the informants lived and moved around. Further, it allowed room for discussions and the debriefing of observations encountered during the day. The community worker remained with the informants' family members so as to give privacy to the informant while the research team conducted the interview.

### **3.4 Selection of informants**

The criteria for inclusion in the study were based on the informants' unique position to provide information linked to the purpose of the study. This is referred to as purposive sampling (Chambliss and Schutt 2010). Using purposive sampling means that this study does not contain a sample that is representative of a larger population, neither was it the aim of the study to find such a sample. The sampling could, however, be what was needed in order to cater to some of the views and experiences of the young adults living with disabilities in Livingstone. Nevertheless, the generalizability of the findings from the interviews is not known.

The criteria for inclusion in the study were that the informant had some kind of physical disability or activity limitation during school age, was above the age of majority, able to provide informed consent, and open to talking to the research team. As the scope was to collect experiences from young adults who had been of schooling age the recent years, the upper age limit was set at 24 years. In addition, the informant had to live within peri-urban Livingstone and be able to reflect upon her or his own experiences in relation to education - or the lack thereof. The study included informants who had been to school, had dropped out, were still in school, had repeated a class, or had never been to school. A final criterion was that the assistant researcher was confident in translating the informant's fluent vernacular.

The number of informants in this study was determined as the interviews proceeded. The aim was to continue conducting interviews until a saturation point was reached - a point where new informants seemed to provide little new information as compared to what had already been collected (Chambliss and Schutt 2010). We reached saturation at 17 informants.



The research team met the informants once, and the length of each interview varied from 30 to 90 minutes. In this study, 17 of 25 performed interviews are included. Of the eight excluded interviews, two presented potential challenges with anonymity, risking the recognition of the informants in the study, and the information provided in the remaining six interviews evinced that those were outside of the criteria presented above.

### **3.5 Interviews**

Informed consent<sup>7</sup> was a prerequisite for conducting the interviews, and it was obtained from all informants. The informed consent was cross- connected with an information sheet<sup>8</sup>. These were translated into the informants' vernaculars. Individual semi-structured interviews were then conducted. This was done to gain a deeper understanding of the young adults' experiences and perceptions of living with a physical disability, and their barriers to education. A semi-structured interview guide was used, as it was thought to allow flexibility during the interview, while still having some sense of a focused approach. At the same time, the main focus was to make use of open-ended questions to allow the informants to reply on the basis of their own, individual choices. Their reflections should have been based as little as possible on the researchers' preferences. It should, as much as possible, have been up to the informant to determine what kind of information she or he provided and how it was presented. By the end of each interview, the main findings were summarized and clarified.

In order to ensure accuracy, the research team debriefed the interviews every day. When necessary, tape recordings were re-played. This was particularly important, since all interviews except one had to be conducted in the vernaculars, with the assistant researcher interpreting. It was possible that there were statements made during the interviews that were misinterpreted by one or both members of the research team. The informant could also perceive questions differently than what was intended; this could lead to misunderstandings of the interpretation in relation to what

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<sup>7</sup> See attachment 4 entitled *Consent form*

<sup>8</sup> See attachment 5 entitled *Participant information sheet*

was really said and how it was intended to be perceived (Dalen 2011; Kapborg and Berterö 2002; Murray and Wynne 2001).

### *3.5.1 The interview sites*

The interviews were conducted in each informant's home or in the garden outside, as per the informant's choice. Visiting the home environment of the informant was of high priority. The aim was to utilize a familiar and relaxed environment for conducting the interviews, to promote the informant's well-being and nurture the feeling of security. Another argument for the home setting was that the informant should be spared any costs related to travel and should avoid challenging and unreasonable distances in order to participate in the study. In addition, conducting the interviews in this setting would take up less of the informant's time. Finally, going to the informant's home would also allow the research team to observe the environment.

On the other hand, visiting the home environment also created challenges. Keeping the anonymity of the visit itself was impossible. The research team walking or driving around, often accompanied by one or more community workers, aroused curiosity among the people we met on the way. Sometimes, we had to stop and ask for directions; this made people curious, and thus they enquired as to why we were. The research team or community worker then explained that we were part of a project looking into issues of disability, and the explanation was respected. Only in one case were we followed. This informant's responses were excluded from the thesis, as confidentiality could not be preserved.

### *3.5.2 The interview guide*

A semi-structured interview guide<sup>9</sup> was used. According to CDT, the barriers hindering participation in everyday life activities, such as school, must be identified by disabled people themselves. For the interview guide, this implied examining closely the barriers that the informants had met in relation to school. More specifically, the interview guide was framed around the current and general life

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<sup>9</sup> See attachment 6 entitled *Interview guide*

situation, school history, experiences and challenges with school, and the support of family and others with regard to schooling. The purpose of creating the interview guide was to have a tool of support and structure containing initial brief and simple open-ended questions. The questions that followed were based on the informants' responses to these initial questions (Kvale and Brinkmann 2009). Here, the main focus was to allow the informant to lead the direction of the interview.

### **3.6 Transcription of the interviews**

The 17 interviews included in this thesis were transcribed verbatim from the oral interview to the written (Kvale and Brinkmann 2009). In this case, it meant transcribing the assistant researcher's translation (the English parts of each interview). This was as close as I could get to a precise transcription of the material; however, it is likely that some valuable information got lost in this process. Ideally, the assistant researcher should have transcribed the vernaculars, but time limitations denied this opportunity, and I did the transcription after leaving Zambia.

### **3.7 Data analysis**

The overall aim of the data analysis in this study was to discover the meanings as the informants experienced them. As such, I chose a content analysis. This is a strategy for systematically analyzing and making inferences from textual material (Chambliss and Schutt 2010). In this study, that meant reading and analyzing the transcribed interviews to search for descriptive themes. I started out with a broad scope. The purpose of having a broader scope was to become thoroughly acquainted with the interview content, and thus enabling certain themes to emerge. I then wrote down these themes and categorized them as findings. Primarily, the research question formed the basis together with issues from CDT. More specifically, this obliged me to analyze the interviews according to the socio-cultural and physical barriers to education, while looking for everyday experiences and challenges as explained by the informants. Enhancing and substantiating the particular local realities in peri-urban Livingstone was a further focus of the analyses, and thereby incorporating issues related to poverty and development. Such issues are rarely considered in Northern-

based disability research, and this underlines the importance of illuminating the locally generated concerns, as stated within the framework above.

After performing the categorization, I read and re-read and re-analyzed the interviews to ensure accuracy in the presentation of the findings. From these findings, I could present descriptive statements or short cases from the interviews in order to substantiate the meanings and voices of the informants. However, it was not always self-evident or easy to distinguish between the categories, as they manifested, in many cases, as interwoven. Thus, I present my findings within categories with a notification of overlapping themes. Further, I present these findings briefly in a table in chapter 4, to make them highly accessible to the reader.

### **3.8 Study limitations and challenges**

The criteria for including informants in this study exclude a broad “group” of disabilities. The criteria were set so as to narrow the scope of the study, but it would have allowed broader and probably different perspectives and barriers if, for example, young adults with intellectual disabilities or hearing impairments had been included. The age of the informants was another limitation. Interviewing children who are in school today could have enabled a more in-depth understanding of the present day situation. That being said, young adults were interviewed because they could, by virtue of their age, provide in-depth reflections about their experiences.

The time and resources available undoubtedly enabled (and affected) this study. However, the timescale of processing an ethical clearance from UNZA took more time than initially planned (and promised). The time remaining for conducting interviews was therefore short and, as a consequence, the research team could only meet informants once.

During the interviews, I examined whether the informants understood the questions as I intended them to. Yet, I did this only in situations where I perceived a lack of clarity. As such, there may have been questions that the informants perceived as unclear, and in such instances, it was my understanding that should have been examined.

It would have strengthened the reliability of the interpretations if a second interpreter could have verified the accuracy of the interpretations by going through the recorded interviews (Murray and Wynne 2001). This was not feasible within the limitations of this study, neither was it clarified with the informants. It would also have strengthened the study if the informants had been met more than once. This was initially planned, but it could not be achieved within the limitations of time and resources. Consequently, the research team did not get to follow- up or clarify issues that arose later on, after the interviews.

The informants' understanding of the term disability could have been investigated more deeply. Their perception of the term, although translated into their vernacular, could have affected what kind of information they shared. The same regards stakeholders and community workers, as their understanding could have affected which informants were recruited for this study. The assistant researcher's understanding of disability, acquired through work and education, did not necessarily correspond with mine. We attempted to see disability in a broad sense, but with a focus on physical disabilities and activity limitations.

Several stakeholders and community workers mentioned what they called "hidden children." They referred to individuals who could be hidden from the community due to the family's shame, experience of stigma, or fear of being accused of witchcraft. The stakeholders and community workers could not account for these children's existence. Therefore, in this study, only the informants who actually had a connection to community workers or stakeholders were reached. Informants without such connections (possibly "hidden children") could have brought other perspectives to this study, and this would have strengthened the study.

### **3.9 Reflexivity**

Daniel Chambliss and Russell Schutt (2010) described reflexivity as an important strategy for raising awareness about how our subjectivity as researchers may influence the research process. Attempting to gain an objective view on my own subjectivity within this study was thus of great importance (Kvale and Brinkmann 2009). My own interests, ideas, and values did initially compile this study. Being open and reflexive about this subjectivity and the prejudices, and their possible

influence on the conclusions of this study, helped to strengthen the trustworthiness of the research (Kvale and Brinkmann 2009). Some of these issues are therefore reflected in the theoretical framework above, and commented in the conclusion.

It is likely that my interpretations of the informants' responses did not match how they intended them to be perceived. I do not understand the vernaculars, and English is my second language. I have never experienced poverty, hunger, or been excluded from school due to finances or disability. Being a foreign master's student, a female, non-disabled, white Norwegian surely affected the research in more than one way. My mere presence during an interview probably affected the situation, and as an example, this might have interfered with the openness of the informant. As an attempt to decrease this gap, my interpretations of the interview and observations had to be carefully and constantly checked with the informant or assistant researcher.

Nevertheless, some of the gap might have been reduced due to the fact that I had previously worked in Livingstone. This was an advantage, especially in terms of having some basic experience related to the culture, greetings, and complexities that I could anticipate to meet. Wearing a *chitenge*, a traditional wrap-around-skirt worn by women, when entering homes of the informants was one small but important gesture in the *Zambian* culture that I made. My previous experience also indicated that when a (white) person from a different culture visits a compound or community, this often leads to expectations of some kind of benefit. Such expectations could further lead to participation based on misleading assumptions. As such, it was necessary to provide clear information about the study to all community workers, stakeholders, informants, and their families.

#### **4. PRESENTATION OF FINDINGS**

The presentation of the findings from this study will begin with a short introduction including the overview of the main findings. Next follows a table (Table 1). This table presents the findings in categories, and provides some examples of the physical and socio-cultural barriers that the informants have faced. The table further depicts the interrelation between physical and socio-cultural barriers; in other words, most of the findings are interrelated and cannot be disentangled. Consequently, there will be some overlap between the categories of the presented findings, and this continues in the discussion chapter. The findings should not be understood as being detached from each other or as isolated barriers challenging school participation. Following the table, the findings are presented in more detail. The informants' experiences related to education are presented, some within the general findings and others exemplified with descriptive quotations and excerpts or short cases. The findings from the interviews will be seen in relation to the concepts presented in the framework in chapter 2, and will be further discussed in the discussion chapter below.

##### **4.1 Overview of the main findings**

The informants in this study, young adults with physical disabilities, gave names to several challenging areas that they have met in relation to school. Some challenges represent manageable obstacles, while other challenges represent what seem to be experienced as insuperable barriers. All informants have a relation to school somehow, from having been harshly refused admission to completing higher education. Most of them have had the experience of attending classes, at least for a year or more, before dropping out. Some are in school today. The main barriers to schooling were explained as long distances to school, inadequate infrastructure and road constructions, lack of available transport, schools not being adequately staffed, equipped, or adapted, exclusionary behaviors from school personnel or families, informants' powerlessness, and violence or abuse. Economic hardship and poverty emerged as underlying and consequential factors to school participation, and thus are interrelated to both physical and socio-cultural challenges. Economic hardship applies to both the informants and their families but also to institutional challenges within schools.

Table 1

Categories of barriers to education	Instances of physical barriers	Instances of socio-cultural barriers
Infrastructure, distance and mobility to school	<ul style="list-style-type: none"> <li>• Badly constructed roads</li> <li>• No transport available</li> <li>• Inadequate or lacking assistive devices</li> </ul>	<ul style="list-style-type: none"> <li>• Potential violence or abuse along the way to school</li> <li>• Inability to pay for transport</li> <li>• Bullying on the way</li> </ul>
Limited adaptations or minimal materials in school	<ul style="list-style-type: none"> <li>• Lack of Braille or amplified letters</li> <li>• No alternatives to stairs</li> <li>• School buildings inaccessible</li> </ul>	<ul style="list-style-type: none"> <li>• No willingness from schools to make adaptations</li> <li>• Inability to pay for materials</li> <li>• No power to influence</li> <li>• Limited resources to buy necessary equipment (and provide enough staff)</li> </ul>
Negative attitudes and stigmatization	<ul style="list-style-type: none"> <li>• Nobody giving assistance in overcoming distance to school</li> </ul>	<ul style="list-style-type: none"> <li>• Low expectations from family</li> <li>• Little encouragement from teachers or administration</li> <li>• Bullying</li> </ul>
Violence and abuse	<ul style="list-style-type: none"> <li>• The way to school posing a potential arena for violence or abuse</li> </ul>	<ul style="list-style-type: none"> <li>• Violence or abuse along the way to school</li> <li>• Inability to pay for transport</li> <li>• Fear of violence or abuse</li> </ul>

#### 4.2 Infrastructure, distance and mobility

The findings from the interviews suggest that combinations of distance between home and school and mobility challenges are decisive factors in school participation.

Infrastructural components, such as road constructions and ditches, are disabling barriers. Several informants with walking impairments, who *have* assistive devices, described roads with sand or holes as obstacles when trying to move around with wheelchairs or crutches. Since some schools are located in the city center, for some, traveling there with a wheelchair is impossible without transport. Informants must then travel up to several kilometers one-way in order to reach town. This was the case for several informants with mobility limitations, who were still able to walk without assistive devices, or with limited visual function: "...the school was too far, so I could never manage to walk to and from there myself." Such statements were typical of informants in areas where inadequate road constructions dominate, yet within the city center as well, informants experienced similar barriers. These experienced barriers are in line with what David L. Hosking (2008) described as socially generated barriers, restricting participation in everyday life. Several informants were hindered from participating in school, and these barriers also restrained some from socializing with friends who do not live within a reachable distance. However, several informants described that moving around is possible within limited areas where the sand is harder, there are few hills, or where there is asphalt or concrete.



Other findings suggest that distance and road constructions are tackled when there are persons available to provide assistance, or if transport is available. Some informants explained that they had attended to school when they were young, and family members or peers would assist them; however, as they grew older and bigger in size, they could no longer be carried there or be pushed in a wheelchair. In addition, available transport seems to be another decisive factor for overcoming similar barriers, yet this is limited to the informants' (and the families') available economic resources.

One example related to how distance may be a challenge to school participation was given by an informant who had qualified for upper basic school. He explained that the distance to school was one contributing factor for why he could not proceed to grade 8. When he was younger, and smaller in size, family members would take him to school. Peers would sometimes also help him on the way home. He explained that today, he has no one to transport him to school and that the building is too far for him to reach on his own, and he is too large to carry. The wheelchair that he has been provided is not sufficient in itself to cope with his mobility challenges, and he suggested that to adapt the wheelchair into a handcycle might be enough to enable him to be more independent in moving himself. However, his family does not have the resources to provide for either transport to school or the adaptation of his wheelchair.

Another informant had never attended school. His case is related to mobility and distance as well, although with a slightly different angle than the previous case. He explained that he faces one major challenge every: his ability to move more than a couple of meters with his wheelchair. He declared this same barrier as the main reason why he never went to school. The informant explained that one of his dreams had always been for a school to be built next to his house, because "if it was that close, I could have joined." He said that he would take avail of any opportunity to go to school, even though he is an adult now, because he can still learn and make use of his hands.

### **4.3 Limited adaptations or minimal materials in schools**

Several informants who had attended school in Livingstone expressed, however indirectly, a need for the adaptation of school buildings. Schools that contain more than one floor restrain some informants from attending lessons, when there are no alternatives to using the stairs. For instance, there are consequences when almost every lesson is conducted upstairs.

One informant explained that she had challenges in school that affected her when she wanted to attend classes. What had enabled her to attend school in the first place was that there were schools located close to her home; thus she managed to reach the school premises. However, she enrolled in a school with two floors. Most of her classes were upstairs, and this prohibited her from participating in lessons. She explained that both the stairs and her activity limitation restricted her from reaching the classroom. To cope with the lack of classroom teaching, she copied notes from classmates. However, the lack of participation in lessons affected her grades negatively, and because of this, she had to choose an alternative to what she initially had aimed for in higher education. She further elaborated that the teachers and school administration did nothing to adapt the environment or otherwise accommodate her needs. She also stated that the responsibility for her participation in class was not solely on them but also on her: "I am the one who should advocate for myself, but there was little I could do." However, she emphasized that the teachers did care for her: "...they just could not put their minds into my issues or concerns." The latter is related to what the informant experienced as an overworked teacher in the classroom. The informant justified and even emphasized with the teacher; as such she expressed that she could not demand any special attention.

However, it was not only building construction that created barriers for the informants to access education. The findings also point to challenges with regard to a lack of adequate equipment or adaptations of existing school materials. Further, the findings show that these challenges lead to poor learning outcomes, and that several informants perceived learning as very complicated to manage. Yet most of the informants still described their time in school as very valuable, even when they did not learn to read or write. This reduced - or poor - learning outcome especially concerned all informants with visual impairments and reduced hand functions. Informants with limited visual function described following lessons on the blackboard

as strenuous and even impossible, and offered the same accounts for reading textbooks. There was no access to glasses, adapted texts with amplified letters, or training in reading Braille<sup>10</sup>. This applies to one informant who went to a so-called special teaching environment and another one within mainstream schooling. Moreover, having limited hand function suggests that writing is challenging, though not necessarily impossible with (or without) the availability of certain basic material. However, these informants expressed that they rarely were encouraged or even challenged to try to write, which, again, can be connected to a teacher's negative attitudes, which are further described in section 4.4. However, some informants expressed a feeling of being respected when "spared the trouble" of writing or participating in other school activities requiring the use of disabled or impaired (whatever one chooses to call it) body parts.

It is important to mention that a lack of equipment or adaptations in this context, such as glasses or simple assistive devices to enable writing, may be as connected to financial conditions as the availability of such devices. As such, available finances are interrelated to the barriers to schooling, as suggested in Table 1.

What was further expressed in relation to not "fitting into" the physical environment was a sense of powerlessness. This finding was clear through statements like, "I could never manage anything." This lack of power was expressed in relation to not being able to join a class or enter a school building. The same accounts were given for the lack of available learning equipment (e.g. school materials, Braille, or assistive devices). When probing for the informants' views on who is responsible for solving the above-mentioned barriers or challenges in school, most expressed that they did not know or provided statements like, "there's nothing I can do about it anyway." A couple of informants emphasized the government's lack of involvement in helping disabled students, yet a couple of others expressed that Non-Governmental Organizations would be better than the government at providing education for disabled students. However, when the research team probed for alternatives to solve the lack of adaptations or equipment, several informants suggested that perhaps they could attend skills training courses instead of mainstream school. Such courses train

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<sup>10</sup> There are other programs and schools that offer Braille in Zambia, but none of the informants in this study had attended or knew of them.

participants in various income generating activities, or offer small-scale skills training within different areas. However, several informants who have participated in such programs expressed disappointment at the lack of rewards afterwards, and still hold the belief that their future is better secured through schooling than other alternatives. The limited availability of such courses was also mentioned, together with barriers to access, similar to those in mainstream schooling.

Since they did not “fit in” at school, two of female informants presented a differing view from the rest of the informants. They stated that schooling is not necessarily what they need to secure a livelihood in the future. They explained that it is better to be at home, and that learning from home is more fruitful, as schools (currently) cannot cater to their needs. These informants’ statements portray one of the main points from the framework presented in section 2.2.1, that education is not unconditionally desirable for all, similar to Ingstad’s (2007) suggestion as to why disability must be seen according to the particular socio-cultural context. However, most informants represented a slightly different view, at least in terms of *believing* in education. Both the informants who are attending school and those who are not mentioned chores and responsibilities at home. Most expressed that these responsibilities are important to the family, and that they serve a valuable function at home. At the same time, they conveyed the importance of education in the form of schooling, as learning from home is “not enough.” Thus, the findings suggest the belief that schooling per se is what will make a person able to have a future - or to “lead an independent life” as most informants stated - something several informants expressed as being particularly important when one has some kind of disability. According to most of the informants, being responsible for home chores, or having a central role in the home, is gathered as less important than schooling (it was unclear whether they meant when one is of schooling age or in general) in relation to what will secure their future.

#### **4.4 Negative attitudes and stigma**

The findings from the interviews indicate that the majority of the informants have faced various negative attitudes and behavior from people in the community. Several face negative or discriminatory comments on a weekly basis, but their specific

experiences vary. This can occur on the way to school or during a school day. Another recurring finding is that several informants face comments directed toward their bodily attributes, pointing at characteristics outside what may be regarded as so-called normal. Several informants expressed bullying as *one of* the reasons for dropping out of school, for instance, “I don’t have the energy...to fight back,” and that negative comments from peers or others are “too much to handle.” One informant gave this as the only reason for dropping school. The findings also point toward prejudices; students with disabilities are seen as less able to perform in school. Thus, they have to cope with low expectations and little encouragement from teachers and in some cases family members, as mentioned in section 4.3. Similar findings indicate a form of oppression or devaluing of students with disabilities in Livingstone. These findings indicate that certain people see schooling for children and youth with disabilities as a waste of valuable resources, and that the money spent on their schooling can be invested in other concerns instead.

One example related to these findings is the story of an informant who described hearing comments from people in the community almost on a daily basis. Random people call her words like “lame” or otherwise comment on what she refers to as her “condition,” telling her, “disabled people do not belong in school.” On the way to or from school she is sometimes surprised by the negative content of what passersby say. She further explained how she tries to ignore these people and not take their words to heart; thus, she has to stay strong, because she does not want this to stop her from going to school. She told us that she shares these experiences with her parents, and explained that this helps her cope. She also emphasized that when she is *in* school, where people know her, she rarely experiences similar negative attitudes. The encouragement that she receives from friends and family is what she tries to focus on, and she expressed gratitude to the people who believe in her.

The findings from the majority of the informants who are in or have been to school indicate the same. Encouragement from the family is seen as indispensable with regard to informants’ present school participation, or was for the (limited) time that they were able to participate. Several informants emphasized that family encouragement in itself was one of the major reasons why she or he is or was in school (even just for the few years of enrollment). This parental encouragement also includes support in terms of fees, uniforms, and books, as much as for encouragement

and confidence in their scholarly abilities. As such, the findings indicate that encouragement or expectations from parents or caregivers influenced whether an informant goes to, or had gone to, to school.

On the other hand, several informants had faced little encouragement and met low expectations from their closest family members. These informants tended not to be in school or dropped out early. Hence, the parents' lack of involvement in trying to provide schooling is a recurring issue of concern that was expressed by some informants. Seemingly, this results in lower expectations and belief in one's own abilities. That being said, encouragement and support from family members is also interlinked to concerns such as the family's economic situation, the "severity" of the impairment, or the number of siblings to provide for. Furthermore, this appears to be linked to having siblings to help, for example, with transport to school; not having any siblings might determine school participation as well. However, some informants explained that they have faced lower prioritization than their non-disabled siblings when it comes to education.

Related to this is a finding repeated by most of the informants, and as described in section 1.1.4 and the framework of this thesis, complex issues such as poverty and development must be accounted for in addition (and in relation) to disability. The findings from this study indicate that economic hardship has influenced most of the informants' participation in school. Payment of school fees was frequently mentioned as a challenge, and for some, is an insurmountable barrier. As an example, one informant expressed powerlessness in overcoming this barrier as follows: "my parents would only focus on other financial obligations." Both the closest family members' and extended family's economic resources play a role here. Several informants emphasized a lack of third-party (non-familial) sponsors to help with the fees and other school related costs. Not having money for transport to and from school was also mentioned as a barrier in relation to negative attitudes and not being prioritized, accounting for the informants where distances and/or infrastructure prevented them from attending school.

An example related to these findings is of one informant who explained that all of her siblings are going or have been allowed to go to school, yet she remains at home because the family cannot afford to send her. She elaborated that her parents never

took her intense wish to go to school seriously, and that they are still not making the necessary effort to obtain resources for her to go. According to her, she can overcome her mobility limitation relatively easily, thus leaving the main responsibility for her not going to school with her parents' lack of effort and encouragement. This informant's case could be further linked to how parents experience a potential stigma from the surrounding community and, as such, shield their child, as suggested in the study by Kaplan et al. (2007). Or as Ingstad (2007) suggested in her study from Botswana, what for outsiders might look like neglect (or lacking encouragement as in this case), in reality, could be done to protect the child. This is discussed further in section 5.3.

Losing hope or feeling frustrated is common among the informants who have not been to school, or who dropped out early. These informants have often encountered low expectations and negative attitudes toward their disability. Several informants stated that there is nothing they can do once a teacher, headmaster or school administration in general denies them access. Here, powerlessness is often expressed in response to such rejections, in statements such as "it was impossible for me" or "there was nothing I could do." These rejections are based on disability, either because the school administration claims that it does not have the necessary means to cater to "such students" or because of what is experienced as pure discrimination. One informant straightforwardly stated, "I was not welcomed by the school because I have this disability." Certain school administrations have told the informants that they can request enrollment in school only after going to the hospital or clinic for treatment or rehabilitation, although treatment or rehabilitation may be of no relevance at all. Other school administrations have asked for medical papers concerning the disability before considering enrolling the informants, which, for some of them are not even obtainable; thus, the informants regarded this as an "excuse" for the school administration to justify denying them the opportunity for enrollment.

Some teachers or school administrations have told the informants to leave the mainstream school and enroll in a special school or department. Several informants experienced this as negative, in line with not being believed in. In connection to this, an informant with limited hand function expressed the following: "[the teacher] told me to go to [a special school] because that was where I could learn from." He is not the only informant who was told by school personnel that he should attend a special

school or special department instead of the mainstream school. This is in line with the low expectations regarding disabled students. On the other hand, it could also be related to the conceptual framework in section 2.1, where a study from northern Zambia (Miles 2009) found low confidence among teachers with respect to catering to students with special learning needs. However, the informants who were enrolled in special schools/departments have had positive experiences and expressed good learning outcomes outside the mainstream schools, albeit not without certain limitations. The following is the experience shared by one of the informants: "...when I was moved to [the special school], it was like...we were all the same, regardless of how disabled one was." This informant was enrolled, first, in a mainstream school and, later, in a special school. In the mainstream school, he learned well, he explained. The school administration nevertheless advised him to continue his education in a special school. His family followed the advice, also in part because the special school did not charge school fees, in contrast to the mainstream school. Once he was in the special school, he was no longer bullied, and he felt included socially. The first year there provided him with sufficient learning, but during the following years, the school's curriculum stopped providing him with new knowledge. This informant expressed concern about the lack of certificates issued that would allow further schooling. He explained that the special school did not follow the same curriculum as the mainstream school, and that the curriculum was made to accommodate students with diverse intellectual learning abilities. Therefore, this informant, similar to some others, was restrained in a situation where he lacked the opportunity to utilize his intellectual capabilities in school.

Negative attitudes and discrimination are not confined to encounters with teachers or school administrations. Several informants discussed similar experiences of seeking assistance from public administrations. In such cases, the informants' parents went to a department of a governmental district authority to ask for assistance after a school had rejected enrollment (as with the case described in the previous paragraph, and the introduction). This resulted in valuable support for one informant, whereas several others have been rejected for various reasons that seemed discriminatory or invalid to the affected informants.

Despite all the negative experiences, the findings also reveal success stories from mainstream schools. These mostly apply to informants with physical disabilities



where the need for assistance, additional equipment, or adaptations is relatively small, or where the school administration and/or teachers have shown positive attitudes toward students with disabilities.

A final finding was indirectly presented by most of the informants. They expressed a sense of powerlessness in relation to encounters with negative attitudes, stigmatization or discrimination. This sense of powerlessness is an overarching finding that will be elaborated on in chapter 5.

#### **4.5 Violence or abuse**

Several female informants briefly mentioned fear of or experiences of being exposed to violence or abuse. One more specifically described personal experiences of having been a victim of abuse (or rape, which is actually what this is about). The violence or abuse directed at these informants has happened either at school or while they were on the way to or from school. As a consequence of these traumatic experiences, and due to the fear of new incidents occurring, some informants have stopped going to school. In a couple of cases, the parents are the ones who withdrew them from school, fearing for their safety. One informant expressed a wish to return to school if a safer environment is provided. As such, some findings indicate that distance (the actual path that they must travel) between home and school may pose a threat to female students with disabilities. Thus, distance is not only a barrier in terms of mobility or infrastructure, as described in section 4.2 and in Table 1.

The fear of being abused or beaten was another finding in this study, and it came from female informants who have not experienced such violence or abuse. Nevertheless, they expressed anxiety or insecurity about moving to and from school. Other findings indicate that school personnel may pose a threat. One informant has been exposed to abuse at school, and she did not express any wish to return to school.

## **5. DISCUSSION OF FINDINGS**

This chapter is a discussion of the findings presented above and of certain categories related to the conceptual framework presented in chapter 2. Some of the discussed findings will in part be repeated within the different section below to make it clear that socio-cultural and physical barriers to education are interrelated. This is due to overlapping themes emerging from the findings, and that the socio-cultural and physical barriers to education cannot be disentangled.

### **5.1 Infrastructure, distance and mobility**

The findings of this study identify that the distance between home and school combined with mobility challenges create a major barrier to school participation. This is a socially generated barrier, and accordingly, it disables or hinders the informants from seizing the opportunity to participate in everyday life (Hosking 2008). Socially generated barriers are represented, for example, by the construction of schools in places that are not universally accessible, combined with infrastructure that is inadequate for most of the informants with mobility limitations. Such barriers are restricting school participation, as stated by several reports on the issue (Stubbs 2002; UNESCO 2010; WHO and The World Bank 2011; ZAFOD 2003). The socially generated barriers clearly present overwhelming challenges for the informants, and one may easily apply a Northern CDT- perspective and criticize the lack of political will or effort to empower persons with disabilities with adequate infrastructure (Pothier and Devlin 2006; Rioux and Valentine 2006). Thus, these physical barriers are connected to socio-cultural barriers through negative attitudes, stigma, and low prioritizations from politicians and decision makers. The informants are hindered from participating fully in school and other everyday life activities because of this. That being said, certain contextual issues must be taken into consideration before applying this perspective. Socially generated barriers exist for other reasons in Zambia than in the North. Zambia is a country with limited monetary resources (The World Bank 2013), and the GRZ (or other public institutions) is easily blamed for not distributing public spending on education for *all* (as aimed for in their national policies). However, there are other critical national needs that must be prioritized (Kandyomunda and Nyirenda 2010) and, as Grech (2009) suggested, the socially

generated barriers must be seen in relation to complex interconnected governmental concerns, such as diminishing poverty or securing development. In Livingstone, roads have been built in most areas, although the conditions of the roads vary from upholding a high standard to being more or less impassable even with a car. These roads are a “step in the right direction” toward dismantling the infrastructural barriers that disabled people face. That being said, this may serve as an example of how politician’s decisions about not giving priority to universal road constructions may pose as both physical and socio-cultural barriers in this study. Looked at another way, these lacking economic prioritizations that impeded the education of disabled Zambians contribute to what Jean-Francois Trani and Mitchell Loeb (2012) identified as an annual GDP loss due to the number of disabled people who are not accessing education and thus not finding employment.

Providing transport or assistive devices of various kinds could help an individual overcome these infrastructural barriers. However, lacking economic resources to cover transport costs or unadjusted (even inappropriate) assistive devices, such as wheelchairs, erect additional barriers. The GRZ does not claim any responsibility for providing school transport to children with disabilities, although the policy *Educating our Future* pronounces responsibilities upon securing the right to education for all. It states that this right is to be fulfilled, and that on no discriminatory grounds (disability, gender, poverty...) should anyone be prohibited from enrollment in school (MoE 1996). That being said, discrimination is obvious from the shared experiences of the informants who have either not been able or allowed to overcome the physical barriers they have faced. This is in line with findings from a publication by Martha Banda-Chalwe et al. (2012), who discovered that disabled people are discriminated against with respect to access to services, such as schools, precisely because of their limited ability to overcome the infrastructural barriers that they meet while trying to attend school.

Nonetheless, infrastructure, distance, and mobility are mostly identified as contributing factors in restraining school participation. The challenges that the informants have faced upon participating in school also depend on other factors. For instance, the number of siblings is not only connected to the tendency toward lower prioritization in school fee provision, as shown in section 4.4 concerning parents’ negative attitudes. The number of siblings may also determine school access. If one

has no siblings, then she or he might not have anybody to assist, for instance, with pushing one's wheelchair. On the other hand, if one has too many siblings, one might not be prioritized due to a lack of money. However, as they grew older, some informants were no longer assisted with their transportation to school due to the fact that they for instance had become heavier (or older, when it is likely that it is inappropriate to, for example, be carried on somebody's back). This seems like another reason why early schooling is more likely than continued schooling, which is also in line with the finding that many informants drop out early from school if they do attend. This is also in line with section 1.3, where the statistics show that enrollment in first grade is high, yet efforts must be made to *keep* children with disabilities in school.

## **5.2 Limited adaptations or minimal materials in schools**

The informant who explained that she could not attend her lessons because her classes were upstairs has clearly confronted a school with limited adaptations. The school administration had not done anything to accommodate her, and she placed responsibility on both her and the school administration for her missing participation in class. From a Northern CDT- perspective, discrimination against or the active stigmatization of the informant could be concluded on the basis of the lack of initiative from the school administration or teachers. However, the investigation of this informant's perspectives does not produce evidence of discrimination or stigma, and, interestingly, this particular informant identified overworked teachers as a reason for the school's lack of adaptations. She was not excluded from class because her teachers did not care or because of pure discrimination based on her activity limitation. As mentioned in the framework chapter, Miles (2009) reported in a study concerning northern Zambia that mainstream school teachers were tackling a number of challenges in relation to teaching, such as a lack of materials or unsatisfying teaching environments. In this informant's example, what began as a lack of adaptations within a school turned out to also be related to the issue of overworked teachers. Again, this could be linked to deficient economic resources to ensure sufficient staff in schools (WHO and The World Bank 2011), and is thus a factor interrelating physical and socio-cultural barriers to class participation, as portrayed in Table 1. This is also in line with what Ingstad's (2007) study in Botswana suggested,

namely, how immensely important it is to investigate socio-cultural perceptions when trying to understand the situation of a disabled informant in school, as a pure picture of discrimination or stigmatization is not how the informant experienced it. On the other hand, the informant did state that the school administration did nothing for her. Whether the school administration did nothing, or the teachers were overworked, the situation still affected the informant in such a way that she could not attend classes and her grades suffered.

Poor learning outcomes constitute another finding that is seemingly related to a shortage of adaptations or materials in school, or a lack of learning challenges from teachers. Similar situations have been supported by several of studies (Banda-Chalwe, Nitz, and de Jonge 2012; Ingstad 2007; Lewis 2003; Miles 2011; WHO and The World Bank 2011). This finding was particularly conveyed by informants with limited visual function or reduced hand function, as these are clearly experienced as barriers to following lessons that are designed to target “able-bodied” students. Interestingly, the informants who had been enrolled in schools still expressed the value of school, even when they also expressed having faced huge challenges and not having learned to read or write. From a CDT- perspective, these barriers to education are socially generated, meaning that the lack of adaptations as a factor in itself substantiates disability. More so, the impairment alone, whether it is reduced sight or limited hand function, cannot explain the poor learning outcome. It must be seen in relation to the challenges that the informants faced, or what Hosking (2008) referred to as barriers generated within the social environment. When approaching the findings from the interviews in this way, disability is not something inherent; but rather, it is a barrier created by society that hinders genuine school participation and actual learning. As such, the socio-cultural and physical barriers to education are further interlinked.

Taking this further, one may consider the background of the identified barriers. Why is it that the informants have not received any adapted lessons, school materials, or adequately constructed buildings? A few informants explained that they have not met a lot of encouragement or been given challenges to learn (in a positive sense) by their teachers. Even if they expressed a sense of being respected when “spared the trouble” of using “impaired” body parts in lessons, it is likely that this “sparing them the trouble” restrained their learning. What may seem related to this is what Miles (2009)

found in the study conducted in northern Zambia. The teachers in that study often felt like they were stepping into a field “belonging” to special teachers when teaching students with disabilities. The teachers actively avoided this due to what they saw as a lack of competence in a field belonging to special education only. If this is the case in the present study, then it is possible that the informants have not been given enough challenges or encouragement from teachers due to the teachers’ lack of confidence. It may be difficult for a teacher to know how far she or he can push or encourage a disabled student if she or he has no knowledge of or experience with working with students with impairments. As such, not only are adaptations of the physical environment necessary, so too are adaptations of teachers’ training. This is in line with what Tsitsi Chataika et al. (2012) suggested in their article, namely, that the teacher training does not prepare teachers for how to include disabled students in mainstream schools. Thus, adopting the teacher’s perspective - without justifying any of the negative attitudes or stigmatization experienced by the informants in this study - can be of value, as the informants’ exclusion from school is not necessarily about pure discrimination.

It is also important to mention that community schools around Livingstone are increasingly improving school access and enrollment, but these schools are also likely to be limited in adaptations. Community schools are built because of positive community initiatives as mentioned in section 1.1.2 above, but are seldom built with the purpose of including students with disabilities. The community schools are built with limited resources at hand, and are not obliged to be following any building design that will cater for e.g. wheelchair ramps or accessible toilets. As such, the positive community initiatives are in the end also excluding disabled students from participation in school. For most informants in this study, community schools were the closest or only available option for education.

As mentioned earlier, shortages of books with amplified letters, Braille, glasses, or assistive writing devices are also barriers to learning and schooling. The availability of these things is one concern; having the financial means to obtain them is another. From a Northern CDT- perspective, it is tempting to blame the GRZ for uneven and insufficient public spending on education in general, or school constructions solely based on what Dianne Pothier and Richard F. Devlin (2006) referred to as “able-bodied” norms. The former must surely be addressed; however is it a complex

explanation involving matters related to Zambia's poverty and development. Elaborating on these matters is of great importance, and the issues are in need of further investigation that would require delving deeper into the structural issues; however, this study focuses on personal experiences. The lack of adaptations for those outside the so-called able-bodied norms, or a lack of pro-disability materials in schools, are also connected to socio-cultural barriers. The lack of adaptations to meet the informants' needs perhaps not only reflects negative attitudes or stigmatization from teachers, but even from a top-down policy perspective. CDT requests that this "assumed inevitability" of schools being based on "able-bodied" norms, is confronted (Pothier and Devlin 2006, 7), and as such, a firm statement on the lack of pro-disability materials is evident in the exclusion of disabled students. That being said, according to the findings from a study on educational inclusion in northern Zambia by Kaplan et al. (2007, 33), a lack of materials in schools may initially be given as a reason for not participating in school. However, with closer investigations, that study discovered that this was the case only on the surface; the attitudes and behaviors of "members of a school community" were often more decisive with regard to inclusion or exclusion in school than the lack of materials. These negative attitudes therefore establish a link between physical (lack of school adaptation) and socio-cultural (attitudes and stigma) barriers to education, as suggested in Table 1. Hence, the following section on attitudinal barriers is significant to this discussion.

### **5.3 Negative attitudes and stigma**

The findings in this study suggest that most of the informants have faced negative comments or attitudes from people in their environments. The frequency of these encounters has varied, however, and there are some connections between the "severity" of the impairment and the frequency of the negative comments. However, informants with "minor" impairments were also subjected to similar attitudes. A study by Susan R. Whyte and Herbert Muyinda (2007) from Uganda reported similar findings, namely, that disabled persons are bullied even when they "only" have minor walking limitations. Similar findings were also reported in a qualitative study conducted in Malawi concerning violence and abuse against women with disabilities, and highlighting findings that disabled girls experienced teasing from peers or ignorance from teachers (Kvam and Braathen 2006). Hence, these negative

encounters do not necessarily represent anything socio-culturally specific for Livingstone. Bullying and stigmatization represent a worldwide phenomenon for people with disabilities, who may be regarded as being outside the “able-bodied” norms (WHO and The World Bank 2011). What causes concern and is noticeable from the findings from Livingstone, however, is how some informants have been excluded from, or have chosen to drop out from, school *because of* these negative attitudes (though often, this represents one among several reasons for exclusion from school or dropping out). As such, negative attitudes create a socio-cultural barrier to participation in school, as shown in Table 1.

Other findings indicate that the informants meet negative attitudes from people who claim that schooling for disabled people is a waste of money - money that could be better allocated elsewhere. This indicates an attitude in which disabled people are seen as less able to learn or less worthy of participation in school. Such views are likely to influence informant negatively, leaving her or him with low self-esteem or a feeling of being less worthy than others. Similarly, Banda-Chalwe et al. (2012) found that a lack of positive encouragement from people around may indicate a socio-cultural view where disability is somehow equated with incapacity.

This feeling of being less worthy is reflected in findings where the informants have been less prioritized than their siblings with respect to schooling. Similar experiences were obtained in the study from Malawi where some interviewees explained that they did not receive encouragement, either from family and parents or teachers (Kvam and Braathen 2006). Consequently, the informants’ participation in school is dependent on their parents’ or family’s supportive encouragement and positive expectations - a belief that their disabled children can perform in school and that it is worth spending resources on their education. However, in some cases, families might not have any other choice but to allocate their resources to only some of their children; it is far from always a case of parents’ negative attitudes or seeing their child as incapable. Whyte and Muyinda (2007), in their study in Uganda, provided an alternative view as to why some siblings could be prioritized over a disabled child. The case in Uganda was that the educated sibling could take care of the disabled sibling in the future. Not knowing if this is the case in any of the informants’ lives or their parents’ plans, as it was not brought up during the interviews, it is still likely that some of the informants will be dependent on their siblings, families, spouses, children, or extended families



in the future. Particularly when taking into account the socio-cultural aspect of shared responsibilities, mentioned in the framework of this thesis (Ingstad and Whyte 2007; Singal 2010). At least this could be the case if no job is available, or other income generating activities exist, as often is the case for disabled people in Livingstone (Trani and Loeb 2012).

Parents' lack of encouragement or negative attitudes leading them to not send their disabled child to school can also be seen in relation to Ingstad's (2007) observation that outsiders may misunderstand parents' caring as neglect. In this present study, if a parent refuses to send a child with a visual impairment to a mainstream school, where she or he is to be taught in classes of maybe 60 students, and with a teacher who has limited training in how to cater to the child's needs, is that necessarily a case of a negative or stigmatizing attitude? Perhaps it is a parent's best intention to protect the child from bullying. An alternative view to parents' lack of encouragement with regard to schooling could be what Miles (2011) found in a recent explorative study conducted in Zambia and Tanzania. The findings from that study indicated that some parents' embarrassment concerning their child's disability was a barrier to school participation. In this present study, the parents were not interviewed, and this is a weakness. The informants' views are valid as they represent their own experiences and perceptions; however, if the parents' experiences and arguments had been included, this could have widened the scope of this study.

The attitudinal barriers that the informants have experienced are discriminatory and devaluing because they restrict their participation in school. CDT calls for this discrimination and devaluing of disabled people to be confronted, even eradicated, as persons with disabilities are just as worthy of being valued and heard as any other individual (Pothier and Devlin 2006). Whoever contributes to creating such barriers is who (or what) should be confronted, whether it is a neighbor in the community, peers, or a teacher. Maybe is it a lack of knowledge about disabilities in general that creates insecurity and thus leads to negative attitudes or discrimination? For instance, Miles (2009) provided an example from her study in northern Zambia: certain teachers assumed that disabled children in general were disruptive, and thus disapproved of including them in their lessons. This could reflect a kind of discomfort in meeting people who are "different" from oneself. This, however, may not in any way justify negative or discriminatory attitudes. What remains to be elaborated here then, is how

this confrontation and eradication could be achieved. Starting by listening to the lived experiences from the bottom-up (as in this study) is one way to acknowledge and investigate who and what create such attitudinal barriers for the informants. However, negative attitudes or stigma are not only found on the ground. The above-mentioned study by Banda-Chalwe et al. (2012) also highlighted discriminatory inclinations on the part of the GRZ when persons with disabilities are excluded from participating in education and, as such, negative attitudes are likely to spread from the top-down. However, the informants themselves did not explicitly point to barriers built by the GRZ. Nevertheless is it relevant to this study, as these negative attitudes and stigma likely influence, for instance, prioritizations in policies and the implementation of education for *all*. Since special education remains the solution, as opposed to inclusive education, in Zambia, teachers in mainstream schools are likely to be influenced by such views during their training. This could lead to disabled students facing rejection from the mainstream schools when they try to enroll.

Further, the top-down spreading of negative attitudes (or at least a lack of empowering families with disabled children) can be seen in relation to the lack of support that families get from public services. When a family in Livingstone has a child with a disability in Livingstone, the family's life is likely to be affected quite strongly, for example, in a financial sense. A disabled family member is likely to be in need of more assistance and accommodation than other family members. If a parent or another family member suddenly needs to spend a certain amount of time every day transporting a disabled family member to and from school, valuable time that might have previously been devoted to already scarce income generating activities will be lost. This is because the responsibility to take care of the disabled child mainly falls on the family. The same finding was reported in a qualitative study carried out in a rural district outside of Livingstone (Magnussen 2011). In addition, these families receive little (if any) support from the government to compensate for this income loss or the increased costs related to, for example, medical, school, or rehabilitation services. Therefore, members of the extended family often represent an important source of compensation, if somebody has income to share. However, the SNDP (GRZ 2011, 92) reports an increased number of bursaries targeted on vulnerable children (e.g. children with disabilities or orphans) to increase equitable access to education, where about 126.000 received bursaries in 2009, compared to 76.000 in 2005. Thus,

some families with disabled children of school age today might receive more support compared to the ones in this study. On the other hand, regarding support from community members, as probed for in the interviews, seem mostly to offer compensation in terms of social support, or by assisting the informants or their families with practicalities. One informant provided an example of the latter: if no family members are present, he calls his neighbors for help to transfer him, either when he needs to change his sitting position or when he needs to move to a shaded area outdoors.

Here, a contradiction to the social model of disability is apparent. The social model, utilized by the WHO, amongst others, is insufficient alone in the context of Livingstone. The social model represents a perspective that presupposes that people with disabilities are individually responsible and look after for themselves and their own lives (Singal 2010). In such a context (mainly Northern), where emancipation and disability rights prevail, disabled people are enabled to live independently to a much greater degree than in Livingstone. The informants in this study are dependent on their parents, families or extended families, and this is also culturally appropriate and expected. If they cannot provide schooling or pay fees, then other sources of monetary support become essential. However, such support is not unconditionally available, at least not for the informants in this study. As an example, there is only limited monetary support that one can derive from public institutions (if any). In fact, findings from the interviews indicate that governmental district authorities mostly have rejected and cannot provide any necessary assistance to the informants (or their families) for enrollment in school. Thus, a social model explaining disability, where individual responsibility is key to overcoming barriers would be inadequate for the informants Livingstone. With the risk of sounding a bit extreme, the parents and (extended) families are crucial to the survival of the informants. Money that could have been spent on school fees may, at times, have to be re-directed to obtain food and shelter, as certain informants have experienced. As such, concerns from the social model such as emancipation, the right to attend school, and individual responsibility for disability school are out of line in the context of Livingstone. In such cases, survival and securing the basic needs of the family come before schooling.

### *5.3.1 Powerlessness*

A common feature in the findings related to negative attitudes, or stigma, is powerlessness. Powerlessness to not overcome barriers to school, either physical or socio-cultural or both, were repeatedly expressed in the interviews. In cases where the parents lack concern or the initiative to take an informant to school, some informants expressed a sense of powerlessness. In cases where siblings are prioritized with regard to schooling and the informant is not, powerlessness was recognized. Further, when the informants described being bullied, they often expressed a sense of powerlessness. The latter is also interconnected with negative attitudes and stigma. The two first are connected to other concerns as well, such as the family's economic hardship or parents' negative encounters with the school administration when requesting enrollment for their disabled child. Thus, what this factor of powerlessness represents, is one main connection between socio-cultural and physical barriers to education. This finding of powerlessness is echoed in CDT as well as by disability scholars, who claim that disabled people are subjected to powerlessness rather than "power to" (Hosking 2008; Pothier and Devlin 2006).

Powerlessness was expressed in relation to almost every challenge or barrier described by the informants. It may, for example, be related to not overcoming economic barriers to school. It was sometimes expressed in the form of a "sigh" directed to the physical impairment itself. Powerlessness was also expressed in relation to not getting assistance from public institutions, such as governmental district authorities. As mentioned above, the common feature here is nevertheless characterized by a "power over" rather than "power to" a person with a physical disability. Thus, powerlessness is a finding related to most cases where the informant lacks the capability to influence her or his enrollment in school. This reflects what Pothier and Devlin (2006) pointed to in describing CDT, where powerlessness is not only related to individual functional limitations but to social values and political prioritizations.

Several informants, who expressed powerlessness with regard to their unknown future, explained that they worry about how to sustain their lives when their parents pass away sometime in the future. This statement is surely relevant to this study, as education is not necessarily what will allow them to generate an income in the future. Whether or not this is related to disability remains uninvestigated in this study, as this

worrying is likely to be a concern for non-disabled persons in Livingstone as well. That being said, one informant who had completed higher education expressed powerlessness with regard to not getting a job. Neither public nor private employers would hire her once they saw that she had a walking limitation, and she had been trying for several years to get a job. As a result, the money spent on her education so far has not paid off in terms of work experience or salary. Thus, powerlessness toward unmanageable barriers *to* education is one important issue to look into, and powerlessness with regard to getting a job *after* education is another.

Based on this, the focus cannot merely be on the right to education; it must also be on the outcome that one's education leads to. This particularly concerns disabled people because, for them, education leads to work and income to a lesser degree than for non-disabled people (Trani and Loeb 2012). According to the findings from the interviews, then, Zambia's educational rights are currently not applicable, or attainable, since the long-term aim is that education should lead to "...economic well-being and to enhance the quality of life..." (MoE 1996, 4). As Ingstad's (2007) study suggested, the applicability and attainability of certain goals are not always in line with what reality looks like; it depends more on whose ideology dominates. It remains to be seen if education in Livingstone can provide disabled people with the capabilities to sustain their economic well-being. Based on the informants' experiences, the policy goals of education leading to economic well-being are not attainable at the moment, and this related to another point from the framework in 2.2.1. For the informants and their families, who cannot afford school fees, other concerns are likely to be pressing. For a family in peri-urban Livingstone, this could be limited economic resources, as is the case for several of the informants in this study, and spending their scarce resources on education may lead into further economic hardship. Even though a long-term plan may be that education could lead to income sometime in the future, this is not necessarily the case either, as pointed out above. As such, for some informants and their families, their concerns are likely focused on survival today and the securing of basic needs, rather than education rights and future income. This relates to Singal's (2010) argument for why participatory research is more important in a global South context than emancipatory research, as lives in the global South tends to be more focused survival than emancipation. This will continue to be the case in Zambia, at least until DPOs and disability movements

are thoroughly in place. Moreover, participatory research allows the informants' voices to be heard and aims at learning about the real experiences, as was the focus of this study. Further, the focus of "survival" depicts a situation where the informants and their families face complex issues besides not being enrolled in school or getting a job. In this context, as Ingstad (2007) and Grech (2009) both highlighted, educational rights may seem more Utopian than applicable, and as such also to peri-urban Livingstone.

Then, is this a sign that the education is insufficient? The same informant as above, who still has not got a job, although she completed a certificate in higher education, also completed a vocational skills training course. However, after this vocation training, she also experienced exclusion from employers. Moreover, it is likely that actors in the labor market exclude disabled people. This informant wisely chose both higher education and vocational training according to her abilities, meaning that her walking limitation is not likely to affect potential work performance in a negative way. As such, employers would not have any reason to exclude her due to her disability. However, the general labor market in Livingstone should also be considered. This informant is by no means alone in being unemployed thus, it is likely that employers can pick and choose whomever they want. This does not necessarily indicate any conscious discrimination on the part of employers. Notwithstanding that, the informant's comprehension and experience are that she has been unable to get a job because of her disability. Furthermore, according to the study on poverty and disability in Zambia by Trani and Loeb (2012, 24), people with disabilities are over-represented as compared to the "able-bodied" proportion of the unemployed.

When such experiences are described, it is appropriate to investigate whether education is an unconditional need for people (with disabilities). Ingstad's (2007) observation from Botswana that education is not necessarily the most pressing need is relevant here. At least, education *alone* is not the most pressing need; further efforts on the part of the labor market and employment rights (quotas for persons with disabilities?) is one suggestion. The point is, however, that other societal structures must also be addressed in *addition* to education.

Further, the public administration and school administration create other barriers (in addition to exclusionary teachers). The informants expressed a kind of powerlessness

toward these administrations when they are not heard or helped. This indicates that the public or school administrations show a kind of disrespect, or even discrimination, toward the informants; especially by not even *attempting* to enroll a student with a physical disability in school. First, disrespect is a clear contradiction of the educational policies that these public institutions are supposed to work in line with. Second, the administrations serve as barriers to education by not fulfilling their role to as serve their citizens. Does this mean that disabled people are established as a kind of “second-class” citizens who are not so important to prioritize which, as CDT argues is an overall pattern within public services throughout the world (Rioux and Valentine 2006)? Mwamba D. Kalabula (2000) from UNZA also suggested this. He claimed that both the government and educators in Zambia (together with other African countries) consider resources spent on disabled people’s education as a “waste” because disabled people are not likely to contribute any resources back in the country’s economy. As such, under the surface, an individual’s productivity is what determines citizenship rights (e.g. education), her or his value, and personhood. These liberalist assumptions are identified as a major discriminating factor within CDT (Pothier and Devlin 2006). Hence, if an individual is not able (or actually not *allowed*, like the informants in this study) to contribute back to society or the national economy, she or he is not worthy of prioritization in budgets. MoE (1996, 2), basing the national education policy on the country’s values of a liberal democracy, still has a long way to go in including people with disabilities in school while securing the same educational outcomes for *all* (as they aim for). The point here is not to criticize Zambia’s values in making the policies for its citizens, but rather the consequences of educational access as experienced by the informants. If only the ones who provide Zambia with the most productivity and income are always valued (prioritized), vulnerable groups, such as disabled people are likely to continue to lag behind in education. It would be interesting to address the bigger picture in distribution politics, and whether a liberal (utilitarian) prioritization of the country’s resources will secure disabled people’s education. This topic merits of further investigation; nevertheless, is it important to mention such scrutiny.

One last barrier, brought up by informants in relation to powerlessness, is that of economic hardship. This is not directly linked to disability per se, but is it a challenge that the informants repeatedly expressed during interviews. Thus, economic hardship

will briefly be discussed here. Economic hardship has a firm connection to poverty, as described in section 1.1.4. As mentioned above, poverty and disability are further related and dependent, as evinced in a number of studies (Banda-Chalwe, Nitz, and de Jonge 2012; Filmer 2008; Goodley 2010; Grech 2009). In several informants' cases, there is direct relationship between the family's economic resources and whether the informant goes to school. The informants expressed powerlessness with regard to not being able to obtain the money they need, that the family is unable to provide the necessary money for the informant to attend school, or not being prioritized in the family. School fees, the purchase of uniforms, books, and shoes, and transport are all monetary costs that seem extremely difficult (or impossible) to obtain on many occasions. A lack of financial resources is decisive with respect to school participation, and it underlines the importance of investigating disability and schooling in line with development and poverty. However, Trani and Loeb (2012) challenged this interdependency between poverty and disability in Zambia when measuring poverty strictly by an index of owning assets. When poverty is measured in a broader socioeconomic sense by capabilities (e.g. access to education, health services, or employment), there is a more obvious interdependency between poverty and disability. Disabled people are less likely to be educated, to receive quality health services, and to be employed in Zambia, and thus also to generate income in the future (Trani and Loeb 2012). An informant's enrollment in school requires economic resources from the family (shared responsibility). If she or he also needs daily transport money, the costs increase, and several families cannot provide for this. That being said, the findings from this study cannot clarify whether the families' economic status affects their disabled children's access to schooling, if it is the disability that has put the family on the edge of economic hardship, or if this economic status affects school participation for their children in general. What can be said, however, is that the school fees and other school related costs link the physical and socio-cultural barriers to education for disabled children, as suggested in Table 1.

As a final remark about powerlessness, negative attitudes and stigma, the findings that are presented and discussed here are what the informants have expressed as the challenges or barriers to education. The focus is thus on the problems, and this does not leave sufficient room for the factors of success. Hence, it is important to underline that most of the informants are well cared for by their families. Active stigmatization



and negative attitudes from families (close or extended) was not a frequently reiterated finding in this study. This is in line with disability studies from Zambia and/or neighboring southern African countries, that have concluded that families in general do care and cater as well as they can to their physically disabled children (with few exceptions) (Ingstad 2007; Whyte and Muyinda 2007; Kvam and Braathen 2006; Eide and Loeb 2006; Magnussen 2011).

#### **5.4 Violence or abuse**

Related to the above-mentioned negative attitudes are violence and/or abuse. In this study, stories of abuse and violence are clearly related to gender. Not only does this confirm certain individuals' negative attitudes toward young disabled females; it also reflects harmful and severely oppressive behaviors. The findings suggest that the female informants face a "double burden" by being both female *and* having a disability. By being female, they are already disadvantaged and vulnerable to abuse. In addition, if having a physical disability, they become more vulnerable, as they have less of a chance to defend themselves. Clearly, such experiences may cause trauma and long-term effects (Kvam and Braathen 2006), and in cases where incidents of abuse have occurred in relation to school, it has led some informants to stop attending school. Thus, violence and abuse (of the fear of so) also represents a barrier to schooling.

It is important to mention that such sensitive issues were not directly brought up during the interviews. However, the female informants brought issues of violence and abuse up themselves, either when explaining their reason for dropping out of school, or in relation to the challenges that they faced in daily life or regarding school. There is also a possibility that the other informants did not feel confident bringing up such personal and sensitive challenges and encounters in the interview setting, and it is also well known that such experiences may be extremely difficult to share. The same was observed and suggested in the above-mentioned study from Malawi. In that study, disabled women explained that they had heard about the sexual abuse of children with disabilities, but had not personally experienced it (Kvam and Braathen 2006). As such - and this will only remain as a speculation - the lack of more personal experiences of abuse does not guarantee that such did not happen to other informants (and this also

applies to male informants). The issue of abuse and disability is not directly covered in the framework of this thesis either. That being said, the matter of abuse and disability is clearly connected to severe forms of oppression, powerlessness, and discrimination. The matter is also an important finding concerning the barriers that young adults with disabilities describe in relation to their education.

An interrelation between physical and socio-cultural barriers may also be elaborated on here. One barrier is how the distance to school restricts several informants. For some female informants in this study, distance also represents danger. They become vulnerable targets for violence or abuse on the way to school (especially when moving alone). The school environment may also build as an institutional barrier, related to an informant who was abused at the school premises. Others expressed a *fear* of something happening to them, although they expressed that they themselves had never been victims of violence or abuse.

This vulnerability, or the double burden, clearly is a barrier to school, but this also relates to other areas of concerns. Ingstad (2007, 245) addressed a similar issue in her study from Botswana, where girls with disabilities may be more vulnerable to abuse than those without disabilities. She further suggested that girls with disabilities might be more at risk of contracting HIV/AIDS than non-disabled girls as “they cannot negotiate for the use of condoms, and at the same time men probably see them as likely to be virgins and thus safe partners.” The girls in Ingstad’s (2007) study all had an intellectual disability, and that in itself puts them in a different position than the informants in this study. The informants in this present study, who discussed being victims of abuse, may thus not only face consequences that cause them to drop out of school; they are also at risk of acquiring sexually transmitted infections, such as HIV/AIDS, as a result of being robbed the right to control and make decisions concerning their own bodies. However, the issue of gendered abuse and disability in Zambia is profoundly under-researched, and it is therefore a field in need of further investigation, both in relation to school and with regard to every other consequential barrier to which this may lead.

## 6. CONCLUSION

Referring to the framework in chapter 2 of this thesis, it was argued that there is an interrelated composition of bodily, societal, physical, attitudinal, structural, developmental, and other local contextual concerns that determine school participation for people with disabilities. Further, it was argued that disability must be defined and investigated in a broad but contextual sense, because it is experienced differently from individual to individual, and thus grassroots perspectives are valuable. The impact on a person's life will depend on the barriers that he or she faces in society, the personal (and family's) responses to those barriers, and the capabilities to overcome them. Using the local context of Livingstone, this study has shown that an interrelated composition of socio-cultural and physical barriers restricts or limits education for young adults with physical disabilities. As depicted in Table 1 in chapter 4, infrastructure, distance to school, and mobility are barriers to school, together with limited adaptations and minimal pro-disability materials in the school. Negative attitudes and stigmatization, together with violence and abuse, are also active barriers to school participation for young adults with physical disabilities. These physical and socio-cultural barriers are interrelated by issues such as poverty and powerlessness, and illustrate how societal generated structures deprive disabled people of control, empowerment, and prioritizations (e.g. from the GRZ). Powerlessness is connected to not being able to overcome the barriers faced with regard to school participation, such as badly constructed roads (physical barrier) or little encouragement from parents (socio-cultural barrier). This depicts a situation where young adults with disabilities are deprived the power to influence their own situation. Economic hardship (poverty) is another barrier to school, and it is often related to powerlessness. The management of sending children to school mainly remains the responsibility of the family or extended family. This requires an allocation of resources that, for many families, are already scarce. The willingness to pay for schooling for disabled children is one barrier (socio-cultural), and the opportunity to pay, for instance, for transport to school (physical) is another barrier in places where inadequate infrastructures prevail.

The perspectives and experiences identified within this study have confirmed that statements from the standing national education policy (MoE 1996) diverge from

people's lived experiences. Some of the tasks that the policy has taken on to improve are in line with the physical barriers found in this study, such as inadequate infrastructure, school buildings, and school materials. The socio-cultural barriers as expressed in this study, however, are not as explicitly targeted in the policy, except for general comments on aiming for a discrimination-free school. In general, seeing that the policy is 17 years old, implementation is really lagging behind. In addition, the GRZ is not sustaining its policy commitments to resource allocation on education. Hence, this study shows that disabled persons are still confronting insurmountable barriers to education; however, what is concurrent between the informants' perspectives and the education policy is the view that education is the way to a future of economic well-being. The SNDP (GRZ 2011) target increased enrollment in school for students with disabilities, but has a general focus on accessibility over quality and learning. What is also lacking there, compared to the findings of this study, is a focus on how to achieve increased learning outcomes and the students' completion of their education (not merely accessing it), and to overcome the socio-cultural barriers as identified in this study. It is crucial to aim higher than just enrolling disabled students in school, but also to make efforts and devise methods to keep them there. Thus, a change toward an inclusive education approach in policies and development plans could be valuable. Securing education as a right for all will also require the Republic of Zambia to step up and include it in the coming constitution. Last, but not least, the socio-cultural and physical barriers identified in this study cannot be disentangled in policies. They are interrelated and contribute to exclusion from school.

## **6.1 Implications**

With respect to the barriers identified in this study, there are several aspects to consider in terms of improving the school situation for disabled students. Removing one barrier at a time is not necessarily a suitable approach, as the barriers are interrelated. A more comprehensive approach is likely to open the door for improvements; however, there is a need to identify additional barriers that this study did not reveal. Physical disabilities constitute one "classification" of disabilities, but this study should by no means be seen as reflecting all views of the persons with physical disabilities in Livingstone. One person with a disability is likely to have

different experiences and perceptions from another; as such, trying to “classify” one disability as being similar to another is like entering foul waters.

In terms of future research, examinations of the educational experiences of students with intellectual disabilities would likely add new and valuable perspectives and identify other barriers; therefore, such research is recommended. In addition, parents are likely to have valuable experiences regarding educational barriers for their children, and conducting such research could shed light on the grassroots perspectives from another angle. Further research into local perceptions of disabilities could also contribute to a more comprehensive understanding of the barriers, as there is a need for more locally initialized and produced research on the educational barriers of students with disabilities. At the same time, it is important to be critical of this very study when it comes to its limitation of being initialized, performed, and interpreted by a non-disabled master’s student from the North, despite the efforts for reflexivity mentioned in section 3.9. Locally contextualized and interpreted research will decrease the risks of heightening disability issues as a problem, when they, in reality, are not, as suggested in the framework of this study, where Northern researchers may ascribe problems or needs to a disabled person that are actually not the case.

Based on the findings and analysis in this study, the following implications are suggested: education needs to be increasingly available to persons with disabilities, and efforts should be made to ensure safety for girls on their way to and from school and on school premises. Further, transport services need to be established or strengthened, and infrastructure must allow persons with reduced mobility to move independently with, for example, crutches or wheelchairs. Also, it is suggested that school buildings, materials, and equipment are to be adapted to suit individual needs. Moreover, school fees should be abolished in practice - not just on paper - including insurmountable costs for uniforms, books, and related materials. Finally, empowerment, respect, and rights should replace the stigma, negative attitudes, and powerlessness through, for example, sensitization or awareness campaigns for schools, active inclusion in all forums to secure the mainstreaming of disability issues, and genuine prioritization in public spending on education. Schooling is arguably one of the best existing interventions and arenas for inclusion and integration for disabled children, and inclusion may thus also decrease stigmatization and negative attitudes in the long run.

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# Attachment 1 - Tilbakemelding på melding om behandling av personopplysninger

Norsk samfunnsvitenskapelig datatjeneste AS  
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



Harald Hårfagnes gate 29  
N-5007 Bergen  
Norway  
Tel: +47-55 58 21 17  
Fax: +47-55 58 96 50  
nsd@nsd.uib.no  
www.nsd.uib.no  
Org.nr. 985 321 884

Erika Kathleen Gubrium  
Institutt for sosialfag  
Høgskolen i Oslo og Akershus  
Postboks 4 St. Olavs plass  
0130 OSLO

Vår dato: 31.05.2012

Vår ref:30652 / 3 / MSI

Deres dato:

Deres ref:

## TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 11.05.2012. Meldingen gjelder prosjektet:

30652

*Disabled Access. A Study on Community-Based Rehabilitation and Disabled Youth's  
Access to Educational Services*

Behandlingsansvarlig  
Daglig ansvarlig  
Student

Høgskolen i Oslo og Akershus, ved institusjonens overste leder  
Erika Kathleen Gubrium  
Siv-Hege Madso

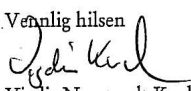
Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, [http://www.nsd.uib.no/personvern/forsk\\_stud/skjema.html](http://www.nsd.uib.no/personvern/forsk_stud/skjema.html). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://www.nsd.uib.no/personvern/prosjektoversikt.jsp>.

Personvernombudet vil ved prosjektets avslutning, 20.03.2013, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen  
  
Vigdis Namtvedt Kvalheim

  
Marte Sivertsen

Kontaktperson: Marte Sivertsen tlf: 55 58 33 48  
Vedlegg: Prosjektvurdering

Avdelingskontorer / District Offices

OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no  
TRONDHEIM: NSD, Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47-73 59 19 07. kyrrsvara@svl.ntnu.no  
TROMSØ: NSD, SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47-77 64 43 36. nsdmaa@svuuit.no

## Attachment 2 - Re: Exemption from full ethical clearance



### THE UNIVERSITY OF ZAMBIA

#### DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

##### HSS/ED/LAW/INESOR RESEARCH ETHICS COMMITTEE

Telephone: 290258/291777  
Fax: +260-1-290258/253952  
E-mail: [Director@drgs.unza.zm](mailto:Director@drgs.unza.zm)  
IRB: 00006464  
IORG: 0005376

P.O Box 32379  
Lusaka,  
Zambia.

29th August, 2012.

Ms. Siv-Hege Madso,  
Mambo Way 50,  
Livingstone,  
Zambia.

Dear Ms. Madso,

#### **Re: Exemption from full ethical clearance**

With reference to your MA research project entitled:

#### **Disabled Access: A Study of Community-Based Rehabilitation and People with Disabilities' Primary Education in Southern Zambia.**

It has been noted that you have already received ethical clearance from your university in Norway through *The Norwegian Social Science Data Services* and *The Data Protection Official for Research*. As there are no ethical issues that would prevent you from carrying out your project here in Zambia, you now have an exemption from full ethical clearance to proceed with your research.

Please note that notwithstanding ethical clearance given by the HSS Research Ethics Committee, you must also obtain express written authority from the Permanent Secretary, Ministry of Health, before conducting your research. The address is: Permanent Secretary, Ministry of Health, Ndeke House, P.O. Box 30205, Lusaka. Tel: +260-1-253040/5; Fax +260-1-253344.

*Clive Dillon-Malone*

Professor Clive Dillon-Malone,  
Chairperson,  
HSS Research Ethics Committee.

cc. Director, Directorate of Research and Graduate Studies.  
Assistant Director, DRGS.  
The Secretary, DRGS.

## Attachment 3 – Re: Request for Authority to Conduct Research

All Correspondence should be addressed to the  
Permanent Secretary

Telephone: +260 211 253040/5  
Fax : +260 211 253344



REPUBLIC OF ZAMBIA  
**MINISTRY OF HEALTH**

In reply please quote:

MH/101/17/6

No.....

NDEKE HOUSE  
P. O. BOX 30205  
LUSAKA

8<sup>th</sup> November, 2012

Siv-Hege Madso  
Masterstudent at HIOA,  
Schwensens gate 4  
0170 Oslo  
Norway

Dear Ms Madso,

**Re: Request for Authority to Conduct Research**

The Ministry of Health is in receipt of your request for authority to conduct a study on **“Disabled access: A study on community-based rehabilitation and people with disabilities primary education in Southern Zambia.”** I wish to inform you that following submission of your research proposal to my Ministry, our review of the same and in view of the ethical clearance, my Ministry has granted you authority to carry out the study on condition that:

1. The relevant Provincial and District Directors of Health where the study is being conducted are fully appraised;
2. Progress updates are provided to MoH quarterly from the date of commencement of the study;
3. The final study report is cleared by the MoH before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the MoH, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, and all key respondents.

Yours sincerely,

Dr. P. Mwaba  
Permanent Secretary  
**MINISTRY OF HEALTH**

Cc: District Medical Officer



**THE UNIVERSITY OF ZAMBIA  
DIRECTORATE OF RESEARCH AND GRADUATE STUDIES**

Telephone: 260-211-280258/293937  
Telefax: 260-211-280258/293937  
E:mail: [drgs@unza.zm](mailto:drgs@unza.zm)  
IRB:00006464  
IORG:0005376

P O BOX 32379  
LUSAKA, ZAMBIA

**HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE**

**CONSENT FORM  
(Available in vernaculars)**

**TITLE OF RESEARCH:** *Disabled education? A study concerning young adults with physical disabilities and their experiences with school in Livingstone, Zambia.*

**REFERENCE TO PARTICIPANT INFORMATION SHEET:**

1. Make sure that you read the Information Sheet carefully, or that it has been explained to you to your satisfaction.
2. Take note of whether tape or 'audio' recording will be used.
3. Your participation in this research is entirely voluntary, i.e. you do not have to participate if you do not wish to.
4. Refusal to take part will involve no penalty or loss of services to which you are otherwise entitled.
5. If you decide to take part, you are still free to withdraw at any time without penalty or loss of services and without giving a reason for your withdrawal.
6. You may choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.
7. The information collected in this interview will be kept strictly confidential.
8. If you choose to participate in this research study, your signed consent is required below before I proceed with the interview with you.

**VOLUNTARY CONSENT**

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

I now consent voluntarily to be a participant in this project and understand that I have the right to end the interview at any time, and to choose not to answer particular questions that are asked in the study.

My signature below says that I am willing to participate in this research:

Participant's name (Printed):

.....

Participant's signature: ..... Consent Date:

.....  
Researcher Conducting Informed Consent: **Siv-Hege Madsø**

Signature of Researcher: ..... Date:

Signature of parent/guardian: ..... Date:

.....





**THE UNIVERSITY OF ZAMBIA**

**DIRECTORATE OF RESEARCH AND GRADUATE STUDIES**

*Telephone:* 290258

*P O Box 32379*

*Fax:* +260-1-290258/253937

*Lusaka, Zambia*

*E-mail* [drgs@unza.zm](mailto:drgs@unza.zm)

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**HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE**

**PARTICIPANT INFORMATION SHEET**

**TITLE OF RESEARCH:**

*Disabled education? A study concerning young adults with physical disabilities and their experiences with school in Livingstone, Zambia.*

**PURPOSE OF THE STUDY:**

You are hereby invited to participate in the study titled above, where the aim is to gather information concerning persons with disabilities' experiences on participating or not participating in education in Zambia. The aim is to perform a fieldwork study in partial fulfillment of a master level program. A Norwegian master student from the University College of Oslo and Akershus, together with a Zambian assistant researcher and interpreter, will perform the interviews.

**DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT:**

The study will include a method of personal interviewing. The aim is to gain an understanding of your personal perspectives and experiences concerning your school history. Approximately twenty (20) informants between the ages of 18-24 will be interviewed. The interview will be conducted in English, however together with a Zambian assistant researcher when/if translation is needed.

We hope that you will talk to us for about half an hour up to one hour and a half. We would like to come to your home to do the interviews, as we believe that the home environment may be an informal and relaxed environment for conducting interviews.

If you would like to participate, we will ask you questions like the following:

- Tell us *your* history about schooling when growing up.
- Did you participate in primary education? Did you drop out? Did you complete?
- What do you think are the backgrounds for why you did / did not go to school?

Your personal involvement is important to us in order to gain knowledge of primary education in southern Zambia for individuals who grow up with some kind of physical disability.

**CONFIDENTIALITY:**

For practical and reliability reasons, the interview will be recorded on tape (Dictaphone). We assure you that the information you share with us will be kept strictly confidential at all times. When your information is used in the thesis (report), no names or any personal data will be given. All data material with personal information will be kept confidential, the tape recordings included. This means that the data material is kept secured in a password locked computer and back-up system, where **only** the student has access. Further, the data material will eventually be made anonymous and the recorded tapes will be deleted when the study is completed, by 20<sup>th</sup> March 2013 the latest.

**VOLUNTARY PARTICIPATION AND WITHDRAWAL:**

Please make note that participation in this study is entirely **voluntary**.

At any time before, during and after the interview you are welcome to ask questions or clarify for more information. You may choose not to answer questions raised during the interview without giving any reason for this. You are also free to give notice about anything you do not want to discuss, this is entirely up to you.

It is your right to withdraw yourself from the study **at any time** without having to give reason for this, and this will have no consequences for you.

**RISKS AND BENEFITS:**

When the study is completed you are welcome to receive a copy of the thesis for free. This is your to keep and is available through CBR Zambia and Mr. Alick Nyirenda. You are also welcome to participate at the dissemination of preliminary study findings, given by the student in Livingstone, October 2012. Invitation to this will follow at a later stage.

A possible risk that you might face can be of emotional character, when presenting your own experiences of access to primary education at age of schooling. We account for this when performing the interviews, and most certainly will give room for such. Hence, we will emphasize that you **at any time** are free to avoid answering questions you do not feel like answering.

**CONTACTS FOR QUESTIONS (Names, addresses and phone numbers of the following):**

- 1. Principal Investigator:** Ms. Siv-Hege Madsø. **Address:** office of CBR-Zambia, plot no. 215, Mosi-O-Tunya Road, Livingstone. **Phone number:** 0969258074 / +47 958 84 042. **E-mail:** [s167826@stud.hioa.no](mailto:s167826@stud.hioa.no)
- 2. Chairperson, Humanities and Social Sciences, Research Ethics Committee, University of Zambia.**
- 3. Supervisor in Norway:** Mrs. Erika K. Gubrium. **Address:** Høgskolen i Oslo og Akershus, Pb. 4 St.Olavs plass, 0130 Oslo, Norway. **Phone number:** +47 413 66 534. **E-mail:** [erika-gubrium@hioa.no](mailto:erika-gubrium@hioa.no)

## Attachment 6 – Interview guide

### **Interview guide – adults 18-24 years of age**

[Introduction of assistant researcher and me.]

[Thank you for allowing us into your home]

[Go through the intentions of the interview and fieldwork: to learn more about the challenges and success factors that individuals with various physical disabilities face when attending primary education in Zambia. I am interested in hearing about *your* story concerning school. Were you allowed to attend school, did you complete, did you proceed to higher education, did you drop out, maybe you were never enabled to participate and so on... Further continue with questions about what *you* think is the background for your school story. Every answer is a good answer.]

[Question about consent]

[Recorder ON]

**Interview questions (main questions, supply questions if necessary):**

#### **Demographics:**

- **Year of birth?**
- **Where did you grow up?**
- **Are you studying? If so, what grade? If not, have you been studying, or when did you stop?**
- **Onset of physical disability / challenge. Kind of disability.**

#### **How is your current life situation?**

- Work, family, marriage, kids...
- Do you face any challenges?

#### **Can you tell me about your school history when growing up?**

- Primary education, special education, home teaching, secondary or higher education, dropped out, “repeated” class(es) once or more.
- Neighbors attending school?
- Any other community or governmental educational program?

[Break] (If necessary)

**If you went to school, how are your experiences about this?**

- Peers? Teachers?
- How would you describe your relationship to the school authorities?
- Community's responsibility?

**If you did not go to school, how are your experiences concerning this?**

- Relationship with teachers? Peers?
- How did you cope?
- What other “informal” learning situations have you been included in?
- Domestic work?

**What are *your own impressions* of the reasons for why / why not you went to school?**

- What would you explain as your challenges? Stigma?

**What do *you think* could have changed your situation of not going to school?**

- (Anything – miracles as well!) E.g. money, transport, living in town, and so on...

**How has your family supported you in your education?**

- Responsibilities for assisting you *going* to school?
- Responsibilities for you *not going* to school?

**During your education, did you ever see any children with activity limitations/disabilities?**

**What is *your view* on children with disabilities going to school?**

**What have you *others* say about children with disabilities and school?**

**What have you heard about the right to go to school in Zambia?**

[What you've said during this interview will be written down. Do you want a copy of this?]

YES            NO

[Do you want to have a copy of the thesis where the findings from all interviews are presented?]

YES            NO

[Thank you!]

[Dictaphone / recorder OFF]