

MASTER'S THESIS

Master`s Programme in Multicultural and International Education

May 2019

Children with Deafblindness

and

Inclusive Education

Leaving no-/someone behind

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Abstract

This qualitative study investigates the situation for children with deafblindness in Malawi and Zambia. The study shows that the education systems in the two countries are heavily influenced by the global architecture of education. Additionally, while inclusive education has the potential to be a counter-hegemonic discourse, the actual implementation in Malawi and Zambia is underpinned by the Western educational discourse. The result is that the relevance and the impact of the inclusive education discourse is heavily reduced. The direct impact for children with comprehensive and complex disabilities, such as deafblindness, is that they experience being excluded and from education, and alienated by the very discourse that claim to promote their inclusion.

This study has been carried out in five districts in Malawi and Zambia. A total of seventy-four parents, teachers, and representatives from national and international NGOs have been interviewed. Seven schools have been targeted by this research. Findings show that children with deafblindness are marginalized and excluded in a number of ways. Factors that exclude all children, exclude children with deafblindness more. Efforts to include children can have the opposite effect for children with deafblindness. For children with deafblindness in Malawi and Zambia to see the right to education realized, the language of instruction policy must be revisited, resource rooms must be constructed at all schools across Malawi and Zambia, and teachers must be equipped with the knowledge they need to be able to provide quality education for children with deafblindness.

There is a rising call to de-colonize education in the Global South. Inclusive education as a normative theory has the potential to become a counter-hegemonic discourse that can transform education systems. This can only happen if the inclusive education discourse is also de-colonized, and the voices of children, parents and teachers in the Global South are heard.

Acknowledgements

The accomplishment of this study has only been possible through all the contributions by a number of individuals and organizations in Malawi, Zambia, and Norway, for which I am very grateful. Many people have contributed to the completion of this study, and I would like to mention some in particular.

First, I want to thank parents in Malawi and Zambia who have provided me with a lot of personal and very valuable information about their life situations and their challenges. The cyclone Idai struck Malawi and flooded some of the research areas only days after I had left them, and some of the parents who have contributed to this research have been affected severely. Luckily, the families are assisted to overcome the challenges.

I would also like to thank Sr. Emma Kulombe from Malawi and Mikala Mukongolwa in Zambia for assisting me with establishing contacts, for travelling with me to the different research areas, for valuable and interesting conversations, and for keeping me safe at all times, also through the cyclone Idai.

Professor Anders Breidlid at Oslo Metropolitan University has been my supervisor, and I owe him a great 'thank you' for all his contributions and valuable advice in our discussions and through e-mails: I would also like to thank him for carefully reading through my drafts and providing useful, critical and constructive comments. A great thank you also to my writing group at OsloMet, supervised by Ph.D. candidate and lecturer Merethe Skaraas. Thank you all for your discussions, comments and input. I have been fortunate to have you as colleagues and friends.

I would also like to extend my gratitude to some of my international colleagues and contacts who have contributed with valuable comments to the research proposal, especially Ingrid Lewis, director of Enabling Education Network; Ann Thestrup, development project coordinator from the Danish Deafblind Association; and Marit Haug from NIBR, a Norwegian research institute under Oslo Metropolitan University.

The Signo Foundation has supported me greatly with allowing me to use working hours to focus on the research, by contributing to cover some of the travel expenses, and by giving me

access to literature and other resources to complete the study. My boss, Knut Rune Saltnes, deserves a special thanks for all his support and understanding, and for doing some of my work to help me focus on the research. I am very grateful.

Thank you also to Sølvi Aspen Solvang for the two illustrations she has made for me. You are my favorite artist.

Last but not least, I would like to thank my wife and my family for their support and patience with me. Thank you to my daughter Emma, for proofreading. Without my family, it would not have been possible to complete the Master program and the research process.

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Abbreviations/Acronyms

CRPD	Convention on the Rights of Persons with Disabilities
CSIE	Centre for Studies on Inclusive Education
DPO(s)	Disabled Peoples Organization(s)
EENET	Enabling Education Network
GC4	General Comment No.4 2016, issued by the United Nations Committee on the Rights of Persons with Disabilities
IE	Inclusive Education
NGO(s)	Non-Governmental Organization(s)
MoEST	Ministry of Education, Science and Technology (Malawi)
MoGE	Ministry of General Education (Zambia)
PWD(s)	Persons with Disability(ies)
SDGs	Sustainable Development Goals
UNESCO	United Nations Educational, Scientific and Cultural Organization
WFD	World Federation of the Deaf
WFDB	World Federation of the Deafblind
WHO	World Health Organization

Terminology

‘Mainstream school(s)’ refer(s) to local government primary and secondary schools that are open for all children

‘Modality(-ies)’ is/are used related to communication. Modalities related to communication refers to the type or form of communication a person uses. Some few examples of different modalities are: spoken language, bodily tactile communication, tactile sign language, and sign language.

‘Deafblindness’ and ‘deafblind’ is written in one word in this thesis. The reason for this is to acknowledge that deafblindness is *one* distinct disability, and not a combination of two disabilities. In addition, the Convention on the Rights of Persons with Disabilities uses this term, hence it can be argued that ‘deafblindness’ and ‘deafblind’ is the legal term. This thesis avoids describing someone as a ‘deafblind person’, but uses ‘person with deafblindness’ to acknowledge that a person is first of all a person, a human being, and that human beings should not be defined by the impairment they might have.

‘Competent partner’ and ‘interpreter-guide’ is used to describe a person who interacts, communicates, guides, and assists a person with deafblindness. A ‘competent partner’ or ‘interpreter-guide’ can be anyone who knows the person with deafblindness: parents, siblings, friends, a teacher, a social worker, etc. The reason for using these terms is to underline the importance of persons with deafblindness having access to people in their surroundings who know them well, and who is knowledgeable about deafblindness and about different types of communication modalities that can be used to communicate with a person with deafblindness.

‘Cultural language’ refers to any spoken or signed language used by a group of people. Examples of cultural languages are Chichewa, Zambian Sign Language, Malawian Sign Language, Yao, Tonga, English, etc.

1. Introduction

The purpose of this qualitative study is to explore and analyze how education can be provided for children with deafblindness to “maximize personal, academic and social development both within and outside formal school settings” in line with the Convention on the Rights for Persons with Disabilities (CRPD) and the General comment No. 4 (GC4) issued by the United Nations Committee on the Rights of Persons with Disabilities on the right to inclusive education (United Nations Committee on the Rights of Persons with Disabilities (UNCRPD), 2016, p.10) using Zambia and Malawi as cases. The issue will be discussed from a legal, an ethnographic, and a philosophical perspective.

1.1. Relevance of the research

There is a huge gap in knowledge about children with deafblindness, and how inclusive education can be provided for children with deafblindness in Zambia and Malawi. This research can be used to inform international and national stakeholders, and the governments in the two countries, in developing educational projects, programs and policies.

There is limited research available describing the situation and results from inclusion in mainstream schools for children with deafblindness other than some case studies focusing on small groups of children (Correa-Torres, 2008). Research on inclusive education suffers from lack of universal understanding of what inclusive education is, and possible positive effects in terms of learning outcomes are not well documented. Some research shows that inclusive education gives persons with disabilities better chances in the labor market, greater academic success, more tolerant, peaceful, fair, equal and healthy societies, and greater development in social skills and independence (de Beco, 2014, p 264; Gomez-Zepeda, Petrenas, Sabando, & Puigdemívol, 2017, p.127; UNCRPD, 2016, p.1; World Bank and World Health Organization, 2011, p.205; Kleinert, Towles-Reeves, Quenemoen, Thurlow, Fluegge, Weseman & Kerbel, 2015, p.323). One challenge with much of the research on inclusive education and disabilities in general is that the results are often not disaggregated by impairment types. This impedes monitoring of the situation of persons with disabilities, and makes it difficult to use research to guide implementation of education programs that can meet all the individual needs of each child (UNCRPD, 2016, p.2, 12, & 18; United Nations Department of Economic and Social Affairs, 2018, p.41, 97, 126, & 326). Each person with impairment(s) has unique needs, and without

disaggregated data there is a risk that some learners can suffer from exclusion as a result of programs implemented to increase inclusion. This is also confirmed by the General comment No.4 (GC4), where the lack of disaggregated data is described as a barrier to inclusion, and in the Global Education Monitoring Report 2017/8 (UNCRPD, 2016, paragraph 4, 43 & 68; United Nations Educational, Scientific and Cultural Organization (UNESCO), 2017, p.194). Availability of disaggregated data and knowledge leads to visibility, acknowledgement, understanding and recognition. According to a report published by the World Federation of the Deafblind in 2018 countries that have recognized deafblindness “as a distinct disability and/or have a definition of deafblindness are more likely to provide specific support services”, something that is particularly evident in low and middle-income countries (Jensen & Serpa, 2018, p.8). Both Malawi and Zambia have recognized deafblindness as a distinct disability, but there is still no statistics or information available about deafblindness in national census or surveys.

1.2. Research question

How can quality education be provided for children with deafblindness in Zambia and Malawi to “maximize personal, academic and social development both within and outside formal school settings” in line with the Convention on the Rights for Persons with Disabilities (CRPD) and the GC4 (UNCRPD, 2016, p.10)?

To operationalize the research question, these two main questions are used:

1. To what extent are the education systems in Malawi and Zambia epistemologically and linguistically inclusive for children with deafblindness and for other children, disabled or not?
2. How do the authorities, teachers, parents, Disabled Peoples Organizations (DPOs) and Non-Governmental Organizations (NGOs) in Zambia and Malawi understand the concept of 'inclusive education' in relation to children with deafblindness?

1.3. Research Limitations

This research is carried out in two countries, over large geographical areas. Within the timeframe of the research, it has not been possible to stay for an extended period of time in any of the researched areas, and limited number of informants have been interviewed at each site. This means that this research has not been able to go in depth to investigate detailed information

on each location, but focus more on general and overarching issues related to education in general and inclusive education in particular related to children with deafblindness. Both rural and urban areas have been included in the research, limited to areas that are accessible by car, or in walking distance from roads¹. This means that the research cannot claim to be representative for deep rural areas.

Due to communication barriers not possible to overcome in this research, children with deafblindness have not been interviewed directly. None of the children included in the research through their parents are able to communicate well, or at all. This means that the voices of children with deafblindness are not captured directly, and the research cannot claim to present children with deafblindness' *own* perspectives. Children with deafblindness are extremely heterogeneous, and it is not possible within the frames of this research to describe all groups of children with deafblindness with in detail.

1.4. My position as a researcher

The way I view the world as a researcher is influenced by my cultural background, my educational background, life experiences, cultural context, people I have met, etc. What I am able to observe and understand depends to a large extent on my individual viewpoint.

'Epistemology' means theory of knowledge and refers to the nature (ontology), sources and scope of knowledge; or simply how what people believe and have learned determines how they view and understand the world. Peoples epistemological background is influenced by their cultural background, what types of knowledge they have acquired; theoretical, practical, theological, etc. (Breidlid, 2013, p.2). As a researcher I am aware that my values, my everyday conceptual schemes, my perspectives, the research paradigms I identify with, and the research community I belong to can influence what I am interested in researching, how the research is conducted, the techniques I use, and how the data is coded, analyzed, weighted and given meaning. Theoretical reading done earlier and throughout the research process can also lead to biased interpretations and is difficult to counteract. Theoretical reading can in some cases block me from seeing new, unrecognized aspects (Brinkman & Kvale, 2008, p.272). As a researcher, I am aware that interactions of everyday life, and the meetings I have had with people throughout the research process, has been affected by "typificatory schemes" I am influenced

¹ Less than 30 kilometers from the nearest road

by (Berger & Luckman, 1991, p.45). My interactions have been affected by how I, often unconsciously, typify people I meet as a ‘woman’, ‘man’, ‘Malawian’, ‘Zambian’, ‘young person’, ‘wears glasses’, ‘jovial type’, etc. Intersectionality between the different typifications can further affect my interpretations and my interaction with people I meet. Qualitative research is critiqued for presenting a biased subjectivity where the researcher only notices data supporting her/his own opinions and hypotheses and overlooks data that counter the hypotheses. As a qualitative researcher, I have done my best to be sensitive to the nuanced information informants and interviewees have given, and actively searched for information that disconfirmed my presuppositions. I have tried to ensure that interpretations made are credible and trustworthy, and have tried to minimize the influence of my own presuppositions (Brinkmann & Kvale, 2008, p.241, 272-273 & 285; Cohen, Manion & Morrison, 2018, p.17; Bryman, 2016, p.385-386)

Ties to funders of research can be a source of bias. In my case, I have worked with projects targeting persons with deafblindness in Malawi since 2008, and in Zambia since 2013. This places me in a situation where I have ties to projects and personal interests that may be a source of bias. Another risk has been that informants could perceive me as a gateway to funding opportunities for projects. As a mitigation strategy I have selected research areas outside of the target areas for the projects I am involved in, interviewed people from organizations the projects are currently not collaborating with, and have mainly interviewed people with no ties to the projects I am involved in. For more information see ‘2.3. Research sites’ and ‘4.3. Sampling’.

My professional background has also placed me in a position where trust and relationship with some of the people interviewed was already established. I have been ‘hanging out’ for a number of years, and I have well established relationships with people who has contributed to the research through being interviewed and through providing referrals to other interviewees – especially to parents with children with deafblindness – and who have played a role as gate-openers (Gusterson, 2008, p.93). However, this close relationship can have created a situation where I might be too familiar with the situation, hindering me from observing things an outsider would easily observe. The close relationship can also be a source of a reactive effect. The ‘reactive effect’ or the ‘social desirability bias’ means the response of informants in a research-process to the fact that they are being researched. Some informants may have given information according to their perceptions of what they thought that I wanted to hear (Cohen et al., 2018, Chapter 2 & p.555; Bryman, 2016, p.222 & 277). To overcome this, I have actively discussed

my intentions for the research with the informants, and have ensured all informants an opportunity to participate on an informed and voluntarily basis without any consequences for not participating. All have been given a possibility to withdraw at any time up until the thesis is submitted. Anonymity protects my informants, but I am at the same time aware that this also can deny the informants their voice as I as a researcher can interpret their statements without being gainsaid² (Cohen et al. 2018, p.122-126; Brinkman & Kvale, 2008, p.93-95).

I have worked for the Signo Foundation since 1995, in different positions, with different responsibilities. Signo is an independent freehold diaconal foundation within the Church of Norway. Signo offers services to around 700 people with deafness and 190 people with deafblindness in combination with additional disabilities. The kinds of services offered vary greatly and are as different as the people that take advantage of them. The core value is to understand and to be understood³. In this research project no person from Signo has been interviewed. In my current position in Signo, I work as a development advisor in the international department at the main office, with responsibilities for projects in Malawi and Zambia.

I have been engaged in a small-scale research project focusing on inclusive education and deafblindness in Malawi and Zambia, a research process that led me to go into this more comprehensive research on the same topic, as a part of a Master program in multicultural and international education at OsloMet – Oslo Metropolitan University in Norway. The reason for selecting this Master program was the focus on human rights, the critical perspective on international education, and the course in philosophy and methodology offered. In the field of deafblindness I have co-written a booklet and book about deafblindness for parents and teachers, which have been received well internationally. I have also worked together with some of the leading professionals in the field of deafblindness in the world, including Inger Rødbroe and (especially) Jacques Souriau, a highly acknowledged psychiatrist who has been in charge of national programs for persons with deafblindness in France, and who is currently a lecturer at a Master program in communication and deafblindness at the University of Groningen in the Netherlands. I have learnt a lot from working with him, and other professionals. From my experience with persons with deafblindness I have come to learn that the way the world is

² See also subsection '4.4.5. Authenticity' to see one strategy used in this research to allow the informants to gainsay the research findings.

³ <http://www.signo.no/in-english/> Accessed 2019.04.27

perceived for a person with deafblindness is profoundly unique, compared to how people who acquire conceptual understandings of the world through cultural languages perceive the world. This has helped me to understand the world from multiple perspectives in a way that is richer due to my experience with deafblindness.

2. Background

In the Convention on the Rights of Persons with Disabilities (CRPD) disability is defined as an evolving concept resulting from “interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations, 2006, p.2). The World Health Organization (WHO) (2016) estimates that as much as 15% of the world’s population lives with an impairment. The international community has given increased attention to the situation for persons with disabilities over the last fifteen to twenty years. As an example, the 2002 ‘Education for All Global Monitoring Report’ gave limited information about persons with disabilities, while the Global Education Monitoring Report 2017/8⁴, includes information about persons with disabilities throughout the report, and has a section discussing “accountability mechanisms ensuring the right to education of persons with disabilities” (United Nations Educational, Scientific and Cultural Organization 2017, p.193). The upcoming United Nations Educational, Scientific and Cultural Organization (UNESCO) Global Education Monitoring Report planned for 2020 will be on inclusion in education, where persons with disabilities will be one of the groups that will be given special attention as it is estimated that “one-third of all out-of-school children at the primary level have a disability” (UNESCO World Education Blog, 2018⁵). Children with sensory or cognitive impairments will more often lack access to education compared with children with physical impairments (World Bank and World Health Organization, 2011, p.207). The situation for children with deafblindness is not described in the WB/WHO-report (2011), or the UNESCO 2017/8-report, and it is difficult to find information about how the CRPD has affected the situation for this group in existing literature. A World Federation of the Deafblind report describes that there is a lack of comparable quality data on the situation for persons with deafblindness (Jensen & Serpa, 2018, p.3). This research project aims to contribute with academically sound and trustworthy knowledge about the situation for children with deafblindness in Malawi and Zambia.

Disabled Peoples Organizations (DPOs) and Non-Governmental Organizations (NGOs) who promote inclusive education claim to promote *all* children, with or without disabilities, but are usually not able to present information disaggregated by impairment type or describe how persons with low-incidence and complex disabilities can be, or are, included. Teaching material

⁴ Titled ‘Accountability in education: Meeting our commitments’

⁵ <https://gemreportunesco.wordpress.com/2017/06/12/the-2020-gem-report-will-be-on-inclusion-and-education/>
Accessed 2018.05.19

focusing on inclusive education often uses general terms to describe how children with deafblindness can be included, with statements like: “Yes, providing inclusive education is perceived as something that adapts to children, is broader than schooling and is not a rigid system to which children have to adapt.” (Stubbs, 2008, p.110). Statements like this have limited practical use for a teacher who tries to find information about how children with deafblindness can be included. Some claim that it is necessary to give inclusive education in mainstream schools priority over education in special schools to realize the right to inclusive education within the available resources, and that special schools should be shut down (de Beco, 2014, p.281; Stubbs, 2008; Mariga, McConkey & Myezwa, 2014). According to Lewis (2018) several actors within the current inclusive education discourse has a more pragmatic view, and are not demanding special schools to be closed, but rather that the specialist services found in special schools should be used creatively to promote inclusion and end segregation on a massive continuum of provision of educational services in many different types of settings “that do not promote segregation in the same way that many special schools historically have done” (Lewis, 2018⁶).

The CRPD has established inclusive education as a right for persons with disabilities. All states and organizations who promote inclusive education must ensure that children with all kinds of impairments, including deafblindness, can see this right realized. On the way to the realization of the rights, both long-term and short-term solutions must be discussed securing that children with deafblindness access education “delivered in the most appropriate languages and modes and means of communication for the individual” maximizing “personal, academic and social development” (UNCRPD, 2016, p.10). According to a report published by the World Federation of the Deafblind “there is a significant risk that efforts to implement the CRPD and inclusive SDGs⁷ will exclude persons with deafblindness, among other marginalised groups” (Jensen & Serpa, 2018, p.3).

2.1. The education system in Zambia

UNESCO (2017) describes Zambia as a lower-middle-income country, with a total population of just above seventeen million people, with widespread poverty. Around sixty-four percent have a daily income of less than two USD. Zambia offers seven years of compulsory primary

⁶ Ingrid Lewis, director of EENET in a personal e-mail dated 7th of June 2018.

⁷ Sustainable Development Goals, acronym in original.

school and two years of secondary school, both without tuition/school fees (UNESCO, 2017, pp.304, 310). According to the World Bank (2018), based on information from 2012, over eighty-nine percent of learners were unable to read by the end of grade two. Although the youth literacy rate is eighty-nine percent, forty-four percent of twelve-year-old (grade six) children were in 2010 found to be functionally illiterate (World Bank, 2018, p.71; UNESCO, 2017, p.368). Twenty-eight percent of learners are over-aged for their grade. Primary education completion rates are seventy-five percent among the general population, and transition rates from primary to secondary are sixty-four percent (UNESCO, 2017, p.320-321, p.328). Due to teacher absence, children will on average only receive about sixty percent of the teaching they are supposed to (World Bank, 2018, p.81). According to UNESCO (2017) there is a high perception of corruption in the education system. Seventy-seven percent of the population thinks that the education system is corrupt or extremely corrupt (UNESCO, 2017, p.426).

Zambia has a transitional language of instruction policy. Zambia has around seventy vernacular languages, and seven regional languages. Schools can select one or more of the vernacular languages in primary grades one to four. In grade five, schools must select one of the seven regional languages until the end of primary and secondary education (UNESCO, 2017, p.190; UNICEF, 2016, p.2-3; Linehan, 2004, p.2 & 8).

According to the 2015 National Disability Survey, Zambia has a disability prevalence of ten-point-nine percent among adults above eighteen, and of four-point-four percent among children aged two to seventeen. Disability prevalence is reported to be lower in rural than urban areas, and lower among males than females (Central Statistical Office, 2018, p.6). The survey contains no information about deafblindness, or information about people with combined hearing and visual impairments. Challenges with vision and hearing is reported separately rendering the dual sensory impairment invisible in the statistics. About fifty percent of children with different types of disabilities in school-going age have no access to educational services, and around a hundred-and-thirty-three-thousand school aged children with disabilities were not attending school in 2013 (Central Statistical Office, 2018, p.7). About twenty percent of all people with disabilities have never attended school. The highest level of education persons with disabilities normally attain is primary and secondary level. Very few persons with disabilities reach university levels (Central Statistical Office, 2018, p.7; Ndhlovu, Mtonga, Serenje & Muzata, 2016, p.126). According to UNESCO (2017) only around fifty percent of schools in Zambia have basic sanitation facilities or toilets (UNSECO, 2017, p.357).

2.2. The education system in Malawi

Malawi is a low-income country, with a total population of above eighteen million, around seventy-one percent of the population has a daily income of less than two USD. Malawi offers six years of free, compulsory primary school with school starting age being six (UNESCO, 2017, pp.302, 310-311). In the school year ending in 2015, almost thirty-six percent were over-aged for their grade in primary school, increasing to forty-four percent in lower secondary (pp.318, 326). According to UNESCO only around twenty-nine percent experience a home learning environment that stimulates their readiness to go to school. The completion rate for primary education among the poorest part of the population is twenty-nine percent among males, and forty percent among females. In lower secondary the percentage is reduced to seven (males), and five (females), and to two percent for both genders in upper secondary. More than eighty percent of children aged six to ten years have numeracy and literacy skills below the expected development level for their age. Youth literacy rates (in age bracket fifteen to twenty-four) are estimated to be seventy-three percent. Female literacy rates are significantly lower than male with only fifty-one percent (UNESCO, 2017, p.143, 332, 362, 368). Seventy-one percent of the population thinks that the education system is corrupt or extremely corrupt (UNESCO, 2017, p.425). The Civil Society Coalition for Quality Basic Education documented that materials for teaching and learning was not bought for four years despite funds being allocated in education budgets for this purpose. Only twenty-six percent of the schools have basic sanitation or toilet facilities (UNESCO. 2017, p.23, 356). Malawi is used to having to comply with donor conditionalities to receive funding. As an example, in 2015 the Global Partnership for Education required that Malawi in order to receive grants increased the ratio of female to male teachers in grades six to eight by ten percent in eight of the most disadvantaged districts (UNESCO, 2017, p.277).

Estimates from a SINTEF study show that disability prevalence is estimated to be three-point-two percent for children, and eight-point-six percent for adults (Eide & Munthali, 2018). Low school attendance and completion are considered the principal barriers for participation and inclusion in society for persons with disabilities. According to Eide and Munthali (2018) twenty-five percent of persons with disabilities in Malawi have not attended school. Among persons with disabilities above the age of fifteen who have attended school, the completion rate

is thirty-seven for primary education and less than twelve percent for secondary education (Eide & Munthali, 2018).

Chichewa is recognized as the national *lingua franca* in Malawi among around sixteen languages, and a large number of dialects (Kamwendo, 2016, p.222)⁸. Malawi has recently changed the language of instruction policy. Up until 2014, Chichewa was used as the language of instruction in grade one to four. From grade five and throughout the education, English was the language of instruction. From 2014, English is the language of instruction from grade one, with a potential devastating effect on learning outcomes (Kamwendo, 2016, p.222). As will be showed later in this research, the implementation of the policy has been slow, and all teachers and informants in this research were not aware of the new language of education policy, describing the old policy in all interviews where language was discussed.

2.3. Research sites

In Malawi the research was carried out in one district in the Northern Region, and two districts in the Central Region. In Zambia the research was carried out in one district in the Southern Region, and one district in Lusaka Region. The reason for selecting these research sites was that these areas are currently targeted by organizations implementing inclusive education projects. The choice of schools was also made because some of the schools have been targeted by international projects promoting inclusive education⁹, and it is interesting to know how the schools and its teachers understand and implement inclusive education. Targeting schools where teachers are not informed about inclusive education would probably have given less valuable information about how children with deafblindness fit within the inclusive education discourse. In both countries international organizations have collaborated with educational authorities to develop source books and learning materials planned to be used nationally. By including schools targeted by these projects, information from this research can be relevant for the whole education system in the two countries.

Profile of the targeted schools:

- School 1 ZAM: Mainstream primary and secondary school with more than one thousand children enrolled, Southern part of Zambia.

⁸ Some informants in this research said that Malawi has around seventy languages and dialects.

⁹ To protect the anonymity of the informants, the international organizations are not described.

- School 2 ZAM: Mainstream primary and secondary school with more than one thousand children enrolled, Southern part of Zambia
- School 3 ZAM: Special school with a limited number of learners enrolled at the school. Comprehensive home-based education program, Southern part of Zambia
- School 4 ZAM: Mainstream primary school with multiple resource rooms, more than two hundred learners with disabilities, and around six hundred learners without disabilities, Central part of Zambia.
- School 1 MWI: Mainstream primary school with more than two thousand five hundred learners, Northern part of Malawi
- School 2 MWI: Mainstream primary school with more than five thousand five hundred learners, Central part of Malawi
- School 3 MWI: Mainstream primary school with more than one thousand learners, boarding facilities for learners with disabilities, Central part of Malawi

3. Conceptual Framework

To understand how children with deafblindness are located in the inclusive education discourse as set out by the Convention on the Rights of Persons with Disabilities (CRPD), it is necessary to describe and define the concepts used to frame the research. The first subsection of this chapter describes different international definitions of deafblindness, with two main distinctions between a medical and a functional understanding of the condition. The subsection further describes some of the implications of the condition for participation in educational services. The second subsection locates the research within the framework of the CRPD, and focuses especially on the elements of Article 24 that specifically mention the rights to education for children with deafblindness. The background and drafting process of the CRPD is captured to give insights into how the relevant paragraphs of Article 24 are worded. It is necessary to describe this with a high detail level, because the text in the CRPD is in itself not always easily accessible and understandable for all, and there are different opinions on how the different paragraphs are to be understood, as will be shown.

3.1. Deafblindness

Deafblindness is a combined sensory impairment of degrees of visual and hearing impairment/loss. The condition is defined in two main ways. The *medical way* corresponds to legal definitions of blindness and deafness as used in e.g. USA focusing on the medical level of the reduction/loss of each of the senses to define if a person has the combined impairment. The *functional way* of defining deafblindness focuses on the functional effect of the impairment; the ability to communicate, to access information, and to orient and be mobile in one's surroundings, and not necessarily the medical degree of the reduction/loss of each of the senses. Both the functional and the medical way of defining deafblindness includes persons with residual vision and/or hearing (Ask Larsen & Damen, 2014, p.2569; Dammeyer, 2014, p.554).

This research uses the Nordic definition of deafblindness, which describes the condition in a *functional way*, viewing the condition as a combined hearing and vision impairment where it is hard for a person to compensate the loss/reduction of one sense with the other. The reason for using this definition is that there are no official definitions of deafblindness in the two countries included in this research. The Nordic definition has however been used in development projects and programs in the two countries, and this definition has influenced how persons with

deafblindness have been assessed and screened since 2011 in Malawi and 2016 in Zambia. This is reflected in an inclusive education sourcebook published by the Malawi Ministry of Education Science and Technology (MoEST) in 2016 where “deaf blindness” is described close to the Nordic definition (MoEST, 2016, p.29). Interestingly, a list of characteristics of children with deafblindness included in the sourcebook focuses on several “inabilities”, “problems” and difficulties when describing learners with deafblindness. This is in stark contrast to the whole inclusive education discourse, where the school system, and not the children, is supposed to be viewed as the problem (Mariga et al., 2014, p.28; Stubbs, 2008, p.8 & 16).

The onset of deafblindness; whether the condition is congenital or acquired, has an important impact on the magnitude of the consequences of the impairment. The condition affects communication, social life, orientation and mobility, and access to information, usually to a larger extent for persons with congenital deafblindness than for persons with acquired deafblindness. Stimuli from other senses are important to compensate for the loss/reduction of auditive and visual stimuli. Accessing information via compensatory senses or by using impaired senses gives fragmented information and is energy-draining and time-consuming. Specialized services are usually required for granting access to activities in the society such as education. Interdisciplinary specialized competence is vital for provision of services (Janssen & Rødbroe, 2006, p.9-10; Janssen & Rødbroe, 2007; Souriau, 2009b, pp.93-94; Lie, Verngaard & Kulombe, 2016, p.4-6; Døvblindhet.no, 2018).

The World Federation of the Deafblind (WFBD) published a report in 2018 which describes that:

Each person with deafblindness connects, communicates and experiences the world differently. Each individual may face restrictions of participation that are affected by the level of support and barriers in their environment, the severity of the vision and hearing impairment and the age of onset, among other elements. (Jensen & Serpa, 2018, p.4, **bold** in original).

For this reason, it is vital that persons with deafblindness have access to services that are specifically designed to meet each individual person’s needs as a person with deafblindness, and not a combination of services that are designed for persons with deafness or blindness. According to the WFBD 2018-report, one of the most important support services people with deafblindness need is an interpreter-guide who can be a key to have access to different kinds of

services and fundamental human rights like healthcare, education, employment, recreation and culture (Jensen & Serpa, 2018, p.6).

3.1.1. Deafblindness and additional impairments

Deafblindness is often combined with additional impairments, especially among children with congenital deafblindness. According to the ‘2017 National Child Count of Children and Youth who are Deaf-Blind’ carried out by the National Center on Deaf-Blindness (NCDB) in USA eighty-seven percent of children and youth with deafblindness have one or more additional impairments. Around sixty-five to sixty-eight percent have cognitive impairments, sixty percent have physical impairments, fifty-one to fifty-three percent have complex health care needs, and over forty percent have four or more additional impairments (National Center on Deaf-Blindness, 2018, p.38-39). The definition of deafblindness used in USA differs from the Nordic definition as described earlier. This makes it challenging to transfer the information in the statistics cited here to other areas where other definitions are used. The WFDB 2018-report, using the Nordic definition, includes persons of all ages in twenty-two countries across the world and describes that between twenty percent and seventy-five percent have one or more additional impairments (Jensen & Serpa, 2018, p.48). One reason for the differences in numbers can be the different definitions used. Another reason is that the statistics from USA only include children below the age of twenty-two, while WFDB includes all age brackets. What we can derive from the information from these two sources is that persons with deafblindness is an heterogeneous group, with varying magnitudes of consequences of the condition and combination with other possible conditions. According to NCDB (2018) the “heterogeneous nature of the population cannot be overstated” (National Center for Deaf-Blindness, 2018, p.31). In the 2017 National Deaf-Blind Child Count more than seventy hereditary, prenatal and postnatal etiologies or causes of deafblindness are identified, each bringing unique challenges and issues. An overview of known etiologies that can cause deafblindness is shown in appendix 1. According to Sense International (2017) meningitis and cerebral malaria are some of the main causes for deafblindness in developing countries like Malawi and Zambia.

3.1.2. Characteristic features of deafblindness

Even though persons with deafblindness constitute an extremely heterogeneous group, and we have to assess how deafblindness appears in each individual, there are some main characteristic features of deafblindness related to the impact of the sensory impairment. Janssen and Rødbroe

(2006) describes four main groups of persons with deafblindness (Janssen and Rødbroe 2006 p.28-39):

1. Persons who have a total hearing loss and a total loss of vision.

For this group, the characteristic features of deafblindness are present in all situations in daily life. Persons in this group are totally dependent on having one-to-one interaction and assistance in large parts of their daily activities, and they will only be able to communicate through bodily senses. Children with congenital, or pre-lingual hearing and vision loss, rely on individually developed tactile communication methods. The transition to cultural language can be challenging for this group, and requires teachers or other competent partners with a high level of technical skills, theoretical knowledge and dedication (Souriau, 2009a, p.13; Souriau, 2009b, p.79-100).

Children with acquired total hearing and/or vision loss can be described in three groups. The first group consists of children who are born with hearing impairments or hearing loss, then develop blindness. This group will ideally be able to use sign language and belong to a deaf culture. However, the World Federation of the Deaf (2016) describes that since most children who are born with a hearing loss have hearing parents who do not know sign language, many children will not learn sign language in their homes. When the vision loss occurs, tactile sign language can be used to communicate (World Federation of the Deaf, 2016, p.2; Senses Australia, 2019). The second group consists of children who are born with a visual impairment or vision loss, then develop a hearing loss. The third group consists of children who are born with normal hearing and vision, then develop deafblindness. Both the second and the third group will usually be able to communicate with a spoken language and will need to learn tactile sign language (Senses Australia, 2019).

2. Persons who have a total loss of vision and have residual functional hearing

For this group, the consequences of the dual impairment are most significant when it comes to developing interaction and communication. Most will communicate bodily and tactually with support from the residual hearing. The residual hearing can motivate to explore, interact and communicate, and make the world more coherent and meaningful. When establishing and developing communication using cultural languages (signed or spoken), the bodily and tactile senses are usually important when situations become more complex, or when experiencing and

learning new things, as it is often more challenging to understand something new using the residual senses alone (Janssen & Rødbroe, 2006, p.31-34).

3. Persons who have a total loss of hearing and have residual functional vision.

For this group, the characteristic features of deafblindness vary depending on the degree of the visual impairment as well as possible additional impairments and motor functions. Communication is always affected seriously, and will only develop when supported by touch and bodily movement. Visual communication in a classroom, or in groups, depend on specific adaptation of the social and physical environment, including light conditions, position and distance to communication partner(s), tempo of communication and more (Janssen & Rødbroe, 2006, p.34-36).

4. Persons who have residual functional hearing and residual functional vision.

Counterintuitively, interaction and communication are often affected most seriously for this group of persons with deafblindness. This is due to the fact that for this group, deafblindness is often overlooked by care persons and teachers/other professionals, who often have limited understanding of the serious consequences of the combined sensory impairment. Tactile strategies will often be needed in exploring the world, in complex situations and when introduced to new elements in communication (Janssen & Rødbroe, 2006, p.37).

3.1.3. Consequences for service provision

People involved in service provision for persons with deafblindness, such as educational services, must know each individual well, and must be knowledgeable about deafblindness, as well as the impact of any additional impairments (Lie et al., 2016; Souriau, 2009b, pp.93-94). According to Souriau (2009b) children with deafblindness should be surrounded by family members and a limited number of highly skilled professionals, working as a team. It is more difficult to ensure that a larger group fully knows and masters the symbolic and linguistic system of each individual, and knows the life story of the individual (Souriau, 2009b, p.94). Children with deafblindness need a bodily approach to develop communication, requiring partners with specific competence on different communication modalities used with persons with deafblindness, and competence on how communication is developed (Lie et al., 2016, p.10; Janssen & Rødbroe, 2007). Due to the high amount of energy needed to process sensory inputs received from a more limited register of senses, persons with deafblindness need more time to perceive and process communication with people in the surroundings. The extended

need for time may lead persons with deafblindness to take pauses or breaks in the communication, something that can be mistaken for not being willing or interested in taking part in interaction and communication, and may lead the interaction partner to interrupt and interfere the cognitive processing of the sensory inputs. This extended time to process sensory stimuli, and the extended need for pauses and breaks, have a huge effect on how classroom activities must be adapted. In mainstream classrooms this can be challenging to accommodate (Janssen & Rødbroe, 2006, p.12; Janssen & Rødbroe, 2007, p.41-42; Lie et al., 2016, p.5). Sudden, complex and overwhelming sensory inputs may be confusing and stressing for a child and can make the child withdraw (Janssen & Rødbroe, 2007, p.31; Janssen & Rødbroe, 2006, p.54). In classrooms with many children, this can represent a barrier for learning, participation and inclusion. This means that a mainstream classroom cannot be considered to be truly inclusive for children with deafblindness unless necessary individual adjustments are made to accommodate the individual child.

For communication to be efficient it is advantageous to use cultural languages through speech or sign language. According to Janssen and Rødbroe (2006) it is difficult to know a child's preferred modality (i.e. speech or signs) before it is introduced, and a child can prefer one modality for expression and another for perception, or a mix of modalities. Teachers are at risk of choosing a modality a child does not prefer and has more difficulties with (Janssen & Rødbroe, 2006, p.54; Lie et al. 2016, p.5 & p. 10-12).

3.1.4. Setting the frames: Three extreme cases – and one fictional case from Zambia

As shown, persons with deafblindness are extremely heterogeneous. To illustrate just how broad the approach to persons with deafblindness must be, three extreme cases will be used to exemplify this. The first case is found in The New York Times, in a short article published June 14, 1982:

Shut off from the seeing and hearing world by blindness and deafness, Adeline Becht has proved herself in the classroom and is ready to take on the clinic.

The 48-year-old Portland woman graduated today from the University of Oregon with two doctoral degrees in clinical and counseling psychology.

She said she planned to expand her private counseling practice in Portland.

Miss Schmidt credited her academic achievement in large part to Beth Schmidt, her interpreter, who sometimes spent 18 hours a day attending lectures and transcribing them into Braille.

In an interview in The Oregon Journal, Miss Becht said she lost her sight and hearing because of childhood drug addiction stemming from treatment for osteomyelitis and alcoholism.

She said she can diagnose and treat psychological problems as effectively as her peers. "My faith is very, very strong," she said. (New York Times, 1982)

A short biography of Adeline Brecht is included in appendix 2. The example serves to show that some children with deafblindness can reach the highest level of formal if adequate and necessary support is given.

The next two cases are presented together. David Brown (2017) held a presentation about deafblindness, self-stimulation, and availability for learning at the 9th Deafblind International European Conference on Deafblindness in Aalborg, Denmark, September 2017. In his presentation he described that "most children with congenital deafblindness today have significant medical issues which result in other sensory systems, as well as vision and hearing, also not working properly, including perception of pain, smell, taste, touch, and balance" (Brown, 2017). If a child has a challenge in one sense, this may lead to functional problems of other intact and seemingly unrelated senses. According to Brown (2017) the vestibular and the proprioceptive senses are of particular importance. Some children with congenital deafblindness may experience a sense of being out of balance, something that could seriously affect availability for learning. During the presentation, Brown compared the experience of being out of balance to walking, tripping, and feel that you are falling. When falling, the full capacity of the brain is directed to regaining balance. The brain is only open for other business when the postural integrity is restored, when balance is regained. According to Brown (2017), some children with congenital deafblindness may experience this sense of falling most of the time when they are moving. Only when fixing themselves in, at times, extreme positions, they may feel that they have postural integrity, and their brain is available for learning. Brown showed a number of photos with examples of positions, and two of these photos are illustrated here:



Figure 1. Case 2 - Applying pressure to the head. Illustration by Sølvi Aspen Solvang based on a photo from David Brown's presentation



Figure 2. Case 3 - Fixing the body between a chair and a table. Illustration by Sølvi Aspen Solvang based on a photo from David Brown's presentation

According to Brown (2017), all behaviors of a child with congenital deafblindness are functional. Even if they for some may appear 'bad', as self-stimulation, and as something to be stopped in a classroom situation, they could also "be seen as actually quite smart adaptive responses," and understanding, "accepting, or re-channeling or even encouraging these behaviors can be much more helpful than merely trying to stop them" (Brown, 2017). These two examples serve to show that for some children with congenital deafblindness to successfully be included in a learning environment that maximizes personal, academic and social development, the environments must be flexible, and must aim to understand and support all functional behavior of a child.

The situation for many children with deafblindness within the research context can be exemplified by presenting 'Agatha'. Agatha is based on information from three cases studies about three children with deafblindness I have been given access to by three families. To protect the anonymity of the children and their families I have mixed their stories, and changed some

of the information with information about deafblindness presented earlier in this chapter. The case studies are written by lecturers at Zambia Institute of Special Education and a previous head teacher from School 4 Zambia, as a part of a pre-master program supervised by a lecturer at the Master Program ‘Communication and Deafblindness’ offered at the University of Groningen in the Netherlands.

Agatha is a fictional girl. She is eight years old, and has congenital deafblindness with total loss of both vision and hearing. Due to her family situation, where lack of information about her condition, lack of early intervention, and limited time and resources for the mother and the siblings to be together with Agatha, she is pre-lingual and has very limited communication skills, no orientation and mobility skills, and is totally reliant on her family. Agatha’s parents are divorced, mainly because her father refused responsibility for a girl with this condition. Agatha’s mother consulted a witch doctor, and was advised to move to another part of the country: The witch doctor gave this advice because he believed that the reason for Agatha’s condition was a spell cast upon the family. The mother loves Agatha, wanted to do what she thought was the best, and followed the advice. The family moved from the northern part of the country to an area closer to the capital. Agatha now lives with her mother and her four siblings in a rural area, six kilometers from the nearest road, and twelve kilometers from the closest school. The mother is unemployed, and the family relies on food and income from vegetables they grow and from their seven chickens, two goats and one cow.

Agatha’s story was presented to informants in several of the interviews, and was used as an example when discussing what inclusive education looks like for children with deafblindness.

3.2. The United Nations Convention on the Rights of Persons with Disabilities

This section locates the research within the framework of the Convention on the Rights of Persons with Disabilities (CRPD), and focuses especially on the elements of Article 24 that specifically mention the rights to education for children with deafblindness. Some critical discussions in the drafting of Article 24, section 3, paragraph c is described in details from different perspectives to shed light on how this paragraph is worded, and how this was understood by those who took part in the drafting process of the convention.

3.2.1. Article 24

The CRPD is by January 2019 ratified by 177 countries¹⁰, and has contributed to changing the view on disability from a medical approach to a social model with persons with disabilities as rights holders and not recipients of welfare (Sabatello & Schulze, 2014, p.2; UNCRPD, 2016, p.1). In the CRPD, focus lies on the environmental and social barriers that exclude persons with disabilities from enjoying human rights and participating in society and has made persons with disabilities more visible within the human rights discourse, showing the necessity of a multilateral treaty. Disability activism also gained momentum in the international process of developing the CRPD, and disabled peoples' organizations (DPOs) were important stakeholders in the discussions (Sabatello & Schulze, 2014 p.2 & 6). The CRPD is “the first international legally binding instrument to specifically promote inclusive education as a right” (Stubbs, 2008, p.21).

This research focuses specifically on Article 24, which states:

“States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning” (United Nations, 2006 p.16).

3.2.2. Article 24, section 3, paragraph c

Article 24, paragraph 3 has the only reference to ‘deafblindness’ in the Convention and describes states’ responsibilities to ensure “life and social development skills to facilitate their full and equal participation in education and as members of the community”, including “communication, orientation and mobility skills” (24.3.a.); “learning of sign language and the promotion of the linguistic identity of the deaf community” (24.3.b.); and “ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development” (24.3.c) (UN, 2006, p.17). For persons with deafblindness it was important that deafblindness was recognized as a unique disability in the CRPD (Grandia, 2014, p.147).

Article 24, paragraph 3 was constructed as compromise among disability groups. The World Federation of the Deaf (WFD) (2016) states that the drafting history of the CRPD “clearly

¹⁰ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>, accessed 2019.01.11

shows” that Article 24 is meant to secure the right to inclusion in mainstream schools for children with deafness, deafblindness and blindness, but at the same time not prohibit alternatives (World Federation of the Deaf, 2016, p.7; World Federation of the Deaf, 2018, p.2-3; MacQuarrie & Laurin-Bowie 2014, p.42). According to WFD (2016; 2018), this means that no mainstream school can exclude any child who has deafness, blindness or deafblindness, and that education delivered in mainstream schools should not be the only available modality. ‘Deaf schools’ are described in WFD’s position paper on inclusive education, where hearing children can be reverse mainstreamed into the schools for the deaf (WFD, 2018). This gives state parties a leeway in implementing the right to education. This perspective is also confirmed by several of the key actors in the drafting process of Article 24.3.c of the CRPD (de Beco, 2014, p.286; de Beco, 2016, p.52; Shaw 2014, p.69). Kauppinen and Jokinen (2014) describe some of the challenges they experienced as representatives for the WFD in the drafting process of the CRPD where they advocated for persons with hearing loss to have “the right to choose education in their own groups during primary education” (Kauppinen & Jokinen, 2014, p.138). According to Kauppinen and Jokinen (2014) the “toughest opposing parties were found among DPOs¹¹, mostly among wheelchair users and organizations for persons with intellectual disabilities”, while “good and loyal allies” were found among the organizations of persons with blindness and deafblindness who “supported the efforts of the WFD” (Kauppinen & Jokinen, 2014, p.136). Shaw (2014) describes the process from a civil society activist point of view representing the Centre for Studies on Inclusive Education (CSIE) in the drafting process. One of CSIE’s aims in the process was to ensure that the CRPD would prohibit separate special education based on impairments. Shaw (2014) describes:

CSIE’s biggest critics were the World Blind Union, the World Federation of the Deaf, and the World Federation of the Deafblind. They insisted that the so-called “twintrack” approach to education for persons with disabilities of both inclusive education and separate “special” education had already been settled. (Shaw, 2014, p.62).

Shaw (2014) describes that the discussion was not settled, and that the text “a free and informed choice between general and ‘special’ systems” was subsequently removed from the draft convention (Shaw, 2014, p.62). As a compromise to satisfy “the needs and wants of those desiring separate educational facilities”, Article 24, para. 3, section c was included to provide an opening for alternatives to mainstream schools (Shaw, 2014, p.63).

¹¹ DPOs is an acronym for Disabled People’s Organizations. Acronym used in original.

The General comment No.4 (GC4), issued by the United Nations Committee on the Rights of Persons with Disabilities, clarifies what Article 24, para. 3, section c of the CRPD means. In the GC4, paragraph 35, section c, it is stated that:

Students who are blind, deaf or deafblind must be provided with education delivered in the most appropriate languages and modes and means of communication for the individual, and *in environments*, which maximize personal, academic and social development *both within and outside formal school settings* (UNCRPD, 2016, p.10, *italics added*).

This confirms that provision of education for children with deafblindness can happen in multiple environments, and that these multiple environments should be found both within and outside formal settings.

3.2.3. Legal definitions

Legal definitions of exclusion, segregation, integration and inclusion are found in the GC4, paragraph 11, where ‘inclusion’ is defined as:

“a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences” (UNCRPD, 2016, p.3).

‘Segregation’ is described as occurring “when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities” (UNCRPD, 2016, p.3). This seems to contradict the statements found in paragraph 35 of the GC4, and the understanding of Article 24 as a compromise to secure alternatives to mainstream schools for children with deafness, blindness or deafblindness as described above. This research project has directed its attention to the tension between the divergent understandings of the CRPD and the GC4, to clarify how this should be understood for children with deafblindness. What does inclusive education actually look like for children with deafblindness?

4. Methodology and methods

This chapter presents the research approaches used in the research, and the principles that underpin these approaches. The chapter continues to present the methods used and choices made throughout the research process, and describes how these methods are used to produce and analyze the research data.

4.1. Ontological and epistemological basis for the research

This research is based within the transformative research paradigm, but borrows concepts and understandings from both the interpretive paradigm, and the indigenous research paradigm described by Chilisa (2012). According to Chilisa (2012) research paradigms describe worldviews “informed by philosophical assumptions about the nature of a social reality (ontology), ways of knowing (epistemology), and ethics and value system (axiology)” (Chilisa, 2012, p.20). A research paradigm includes considerations about methodology; appropriate approaches to carry out the research in a systematic way, and the principles that underpin theoretical assumptions (Cohen et al., 2018, p.186; Chilisa, 2012, p.20-32). In this research, research paradigms are considered as stereotypical representations, and none of the paradigms can fully describe this research. The reason for doing this research is that I have been interested in understanding how people describe children with deafblindness related to inclusive education. It has been challenging to reconcile the knowledge I have about deafblindness with the way in which inclusive education has been presented to me. I have found familiarities in my desire to arrive at conclusions about this issue in the way Chilisa (2012) describes the transformative paradigm as breaking down myths and contributing to empowerment of people. This research aims to contribute to a change in the understanding of inclusive education for children with deafblindness in Malawi and Zambia. However, it has also been important to me to understand the origins of the inclusive education discourse to see if the discourse is understood as relevant to people in their own context, or if it can be explained in light of the global architecture of education. This could possibly locate the research closer to the indigenous research paradigm. The research is underpinned philosophically by being informed about indigenous knowledge and post-colonial discourses found in both the transformative and the indigenous research paradigm (Chilisa, 2012, p.40; Tuhiwai Smith, 2012).

The research is based in an ontological understanding that can be described as a mix of the interpretive, the transformative and the indigenous research paradigms. As the interpretive and

the transformative paradigms describe, the research acknowledges that multiple realities exist, and that these are socially constructed and shaped by values based in human rights, politics, democracy and social justice, disability issues, culture, economy, and gender. However, the research is also based in an understanding that these values and realities are socially influenced by interactions between human beings, the environment in which they live, and their belief systems. This places the research ontologically in the intersection between the interpretive, the transformative and the indigenous research paradigms (Chilisa, 2012, p.40; Phil, 2015, p.44). Epistemologically the research is based in an understanding that knowledge is socially constructed, constantly changing, subjective, and bound to culture, context, history, and power relations (Chilisa, 2012, p.35, 40).

In this research a number of data collection/production methods have been considered to give insight to a research question. As this research is based in an ontologically and epistemologically constructive and interpretive understanding of knowledge production, the terms data ‘production’ is preferred in this research, to indicate that the world and the social reality is viewed as a construct of interactions and in constant change. The term ‘collection’ related to data might have suggest that the world and social realities were viewed as more constant, and as if knowledge and information is ‘something’ uncontaminated and pure, waiting to be found in the minds and actions of the subjects, and where data collection is separate from the analysis. The two different ways of viewing the world and the way data comes about points to a main divide between qualitative and quantitative research approaches (Brinkmann & Kvale, 2015, p.57-58; Lund, 2005). However, using the term ‘production’ also has its challenges, as it can be understood as if the knowledge is produced as a result of the interaction between the researcher and the interviewee, and that this knowledge did not exist *before* the interview. All people, interviewed or not, *have* knowledge based on their background, culture, and more, as described above. This knowledge exists independently of me as a researcher, and independently of the methods used to include this knowledge into this research. Therefore, using the terms ‘production’ refers to the way the existing knowledge is transformed and reinterpreted during the interview situation, possibly changing it into something that can be slightly different from what another research process would end up with, even if the same questions were asked (Brinkman & Kvale, 2008, p.342).

4.2. Methods

This sub-chapter describes the methods used to produce data to inform the research. Research data has been produced through semi-structured qualitative research interviews with individual persons and in groups. In addition, unstructured classroom observations in inclusive mainstream schools, in resource units at inclusive mainstream schools and in special schools have been carried out.

4.2.1. Semi-structured research interviews

Semi-structured qualitative research interviews have been the main data production method used in the research process. A total of thirty-seven individual interviews; seventeen in Malawi and twenty in Zambia, and twelve group interviews; seven in Malawi and five in Zambia, have been carried out with a total of seventy-four informants. Interviewees include parents, teachers, community members, district and national government officials, and representatives of local and international disabled people's organizations (DPOs) and other non-governmental organizations (NGOs) working to promote inclusive education and human rights issues in Zambia and Malawi. The fieldwork was done from the end of August to the beginning of November 2018. In August to September I visited Malawi for three weeks. In October I visited Zambia for four weeks, before returning to Malawi again in the first week of November.

Qualitative semi-structured research interviews are pre-prepared conversations between a researcher and an interviewee in an often unequal power relationship. Some questions were pre-prepared in an interview guide (Appendix 3), but the questions were not used in the same order in all interviews, and not all questions were used in all of the interviews. A list of possible pre-prepared follow-up questions was developed to each question, but additional probing questions depending on the feedback from the interviewee were included to explore topics that arose during the interview, to follow the interest of the interviewee, or to try to understand the meaning of the interviewee's statements. Interpretive questions were used in the interviews to both try to analyze the meaning expressed by the interviewee, and to give the interviewee an opportunity to confirm or disconfirm my understanding of the meaning expressed. Remembering questions were also used in most interviews where earlier statements of the interviewees were used to give the interviewee a possibility to elaborate more on issues or contradictions, as well as relating different issues discussed to each other (Bryman 2016, p.475; Cohen et al. 2018, p.506; Brinkmann & Kvale, 2015, p.158-162, & 195).

In preparations for and during the interviews, I have been aware of the fact that interview situations placed me in a position where I asked questions and discussed issues that may not normally happen in a conversation between two people who I in most cases did not have a personal relationship with. This research is based on an understanding that knowledge produced in the semi-structured qualitative research interviews was produced socially in the interaction between the interviewees and me as a researcher. A semi-structured qualitative research interview is flexible without a set of fixed rules. The quality of the data produced depends on my skills as an interviewer, the trust and relationship that we were able to establish before or in the interview situation, my personal judgments regarding selection of questions from the interview guide, and my ability to listen actively and capture what was said and how it was said. My knowledge about the subject matter of the research also affects my ability to link the statements of the interviewees to a theoretical framework, and ask questions that can produce trustworthy and relevant knowledge without influencing the opinions of the interviewee with my own theoretical perspectives (Brinkmann & Kvale, 2015, p.70; Bryman 2016, p.384-386). This was sometimes also a bit frustrating in some of the interview situations. I realized that some of my questions related to the CRPD required a more specific knowledge about the subject matter than what I expected before the interviews. I felt that if only the interviewees had access to the same information as me, their responses might have been different. I tested this in one of the interviews, and gave more background information about the question, after the interviewee's first response. The interviewee stated that the information was new to the interviewee, and that the information gave new perspectives from which to discuss the subject matter. In the research log I noted the following:

One question I ask myself as a researcher is what is the most trustworthy way of doing research - should I provide more information to my interviewees, or should I behave more neutral? If I do not provide the information, I do not enable the interviewees to see new lesser-known perspectives. By giving the information, I may exert a heavy influence on their responses. My conclusion for now is that I should continue to be 'neutral' in the interviews.¹²

An important observation that emerges from this experience is that despite my intention to approach the research ontologically and epistemologically as described above, it can be difficult to overcome one's own background. In retrospect the decision to continue to be 'neutral'¹³ was

¹² Research log entry 2019.09.06

¹³ I use inverted commas (' ') on the term 'neutral' to indicate that I acknowledge that it is not possible to be completely neutral in qualitative research.

crucial for the continued research process. Had I given more information during this explorative phase of the research, the information produced in the later interviews would have had limited value. In the second phase of the research fieldwork, in February and March 2019, the findings were disseminated in both countries. At the dissemination workshops findings from both interviewees and literature were to be presented as equally correct and equally important. This gave a possibility for an equal discussion about the topic that was influenced to a lesser degree by my presuppositions and pre-knowledge. Qualitative research interviews have been critiqued for being dependent on the researcher, subjective, biased and influenced by the dynamic in the interview situation (Brinkmann & Kvale, 2015, p.196-199). By continuing to be ‘neutral’ in the interview situations I ensured that some of the challenges with qualitative research being dependent on the researcher was to some extent overcome. Had I presented more information in the interview situation, I might have been given the information I wanted, but the information would have been of less value to the research, because of the problematic way I would have influenced the dynamic in the interview situation. I tried to continue to be ‘neutral’ throughout all interviews, and also during the dissemination workshop. At the end of one of the dissemination workshops, one participant said that he still did not know my opinion, what my position was. I replied that I was glad that he still did not know, and that I would present my position after all had given their anonymous written feedback¹⁴. This indicates that I might have been successful in my effort to appear ‘neutral’ throughout the research.

Focus group interviews and discussions were carried out with parents, and only two individual interviews were done with parents. The reason for this was partly to mitigate a potentially perceived asymmetric power relationship between parents and me as a researcher, and partly because of practical issues. Within the timeframe of the fieldwork, it would not have been possible to include the same number of parents if the interviews were carried out individually in their homes. Inviting parents to come to group interviews and discussions in schools, and district rehabilitation centers, meant that more parents could be included (Cohen et al., 2018, p.527 & 531). Using focus groups can empower people to speak out, and can produce data that can give rich perspectives growing from synergies where several people contribute to common understandings. To try to achieve this, I encouraged participants to discuss freely, with fewer interruptions from me. This worked well in the focus groups with four and more participants. Focus groups with fewer than four participants took a form closer to a qualitative research

¹⁴ MWI WS 2

interview, where I asked questions and the participants replied more as individuals. There are potential challenges with focus groups, as some participants may feel discouraged from stating their opinions (Cohen et al., 2018, p.527). To encourage participation, I opened all focus groups with letting people know that all opinions and perspectives were welcome, and invited all to present themselves and share their stories to the other participants. Although some were more active than others, I got an impression that all felt comfortable with sharing their opinions in the discussions. Another challenge is that contributions made in a focus group are not anonymous. This may also discourage participation, and have other possible negative consequences (Cohen et al., 2018, p.337). To mitigate this, parents who were invited to the focus groups did in most cases already know each other, something that hopefully made them feel safer in the discussions.

4.2.2. Semi-structured observations

During the fieldwork I have visited seven schools in Malawi and Zambia. I intended to conduct semi-structured overt interpretive classroom observations to get information about the situation for children with deafblindness, and to see if any children were included in the classroom and the learning process. This proved to be challenging. Due to time constraints for the whole fieldwork, it was not possible for me to stay at each school for more than one or two days. This meant that it was not possible to overcome the reactive effect, and the influence of my presence in the classroom. It was clear in all of the schools and classrooms I visited that my presence changed the way the teacher and the students behaved. One example is that desks were placed differently than where they might normally be placed (see photo 5, subsection 5.2.1.). In addition, most students in the classroom seemed more interested in me than the teacher, so even if the teacher tried to continue teaching, many students did not really pay attention (Bryman, 2016, p.277). In the classrooms I visited there were no children with deafblindness, and only a limited number of children with disabilities in general. I visited a total of thirteen classrooms, including two resource rooms and four outdoor classes. Most classrooms, except for two of the classrooms and one of the resource rooms, were used at the time of my visit.

Despite challenges I encountered related to the observations in classrooms, I was able to capture some interesting information from observations. This include number of learners in the classrooms with and without (visible) impairments, availability of teaching and learning material, availability of desks and chairs, physical adaptations to classrooms, language barriers,

and issues related to language of instruction. Findings from observations are included in chapter five.

4.2.3. Lost in interpretation?

This research project has encountered some challenges related to interpretation between languages, including sign language. In Zambia there are more seventy-two different languages, including seven regional languages. In Malawi there are more than seventy different languages according to some of the interviewees. In both countries English is an official language, and most of the interviewees were fluent in English, or could understand English to some extent. A process of decoding and recoding between languages was necessary to carry out the research. Translation, in narrow terms, can be described as a form of re-expression of a statement where the original statement in one language is transformed into a copy in another (Conway, 2017, p.713). When doing research in areas with cultures and languages other than the researcher's own, the process of decoding and coding is however much more complicated than simply translating statements into copies in another language. It is also a question of carrying across the *meaning* in the statement from one language to another, which means that a process of interpretation is needed. A process of interpreting is always necessary, even when the interviews are carried out in a language both the interviewer and the interviewee are comfortable with. Sometimes concepts and ideas from one language are not easy to interpret to another (Conway, 2017, p.710-714; Desai & Potter, 2009, p.176).

Decoding and recoding to and from sign language to oral languages will always include an interpreting process. Sign language and oral languages differ in several ways in the words/signs that are used and in syntax. In addition, in sign language different aspects of information can be expressed at the same time, differentiating sign languages from spoken language (Leeson & Saeed, 2012, pp.246-260). Sign language interpreters were used in one of the interviews. The sign language interpreters were the ones the interviewees used in their daily life and work. This meant that the interviewees and the interpreters understood each other well, and that the interviewee and the interpreter had a relationship based on trust.

In both countries many of the informants were fluent in English, and most interviews were carried out without an interpreter. In both countries all interviews with teachers, representatives from DPOs and NGOs, and district and national government officials were carried out in English. I was however aware in all of the interviews that both the interviewees and I were not

using our respective mother tongues. I tried to avoid using technical terms, and tried to explain and simplify when their use could not be avoided. I also asked interpreting questions to ensure that I had understood correctly when I was in doubt, or I needed confirmation. Interpreters were used in interviews with parents, and parent representatives in school management committees, in both countries. However, in most interviews, parents were able to understand English, and would often start answer the questions before it was interpreted. This meant that the interviewees were able to check that my questions, and their responses, were interpreted correctly. During discussions with learners, an interpreter was usually necessary, as the children themselves had limited English skills, despite the fact that English had been the language of instruction for some years¹⁵.

The use of interpreter can be a disturbing factor in the conversation, as the interpretation will require breaks in the conversation. This can influence the knowledge that is produced in the interview situation, especially in focus group interviews/discussions. To overcome this, I asked the interpreter to interpret as literal as possible in one-to-one interviews, and allocated enough time to each of the interviews to give the interviewee a possibility to reflect on the questions before giving an answer to me. In focus group interviews/discussions, I asked the interpreter to mainly interpret colloquial during the sessions to minimize the disturbance. Due to the fact that several of the interviewees in most of the group interviews were knowledgeable in English, I had a clear impression that this worked quite well. When interpreting colloquial to me, the parents would comment to the interpreter if (s)he had forgotten some information, or presented the information in a way the interviewees did not agree with.

4.3. Sampling

This section describes the decisions made in the sampling process. The first subsection describes how families with children with deafblindness were identified and included into the research. The second subsection describes how teachers, government- and NGO-informants were identified and included.

¹⁵ See also subsection '5.3.2. Linguistic inclusivity' for a more detailed description of the discussions with learners.

4.3.1. Families with children with deafblindness

The sampling process in this research project has given some challenges. On one side, this research has its focus on a low incidence group about which there is limited knowledge of its existence in the society in general. Another challenge was that it is time consuming to assess whether or not a person actually has deafblindness when using the Nordic definition of deafblindness. This is because this definition includes persons who might have a medical level of residual hearing and vision above the medical definitions of deafness and blindness, but due to the combination of the impairments the individual is not able to compensate the loss of one sense with the other. Therefore, I needed to limit the sample group to individuals who were already assessed and diagnosed with deafblindness according to the Nordic definition of deafblindness, and their families¹⁶. This means that the sample group cannot be considered to be representative for the whole population. It can be expected that more resourceful urban families will have a higher likelihood to have heard about deafblindness and have access to services, compared to less resourceful rural families. An additional challenge is that all families were identified through projects I have a professional involvement with, and even if I have done what I could to detach myself from my professional position when doing this research, the parents might still see me as a professional rather than an independent researcher. To try to overcome this I gave the parents comprehensive information about the research both when doing the interviews, and when meeting several of the parents to discuss the findings.

Within the available time allocated for fieldwork, it was not possible to meet with all of the families with children with deafblindness, as the already identified group lives all over the two countries included in the research. To solve this logistical challenge parents were invited to come together to different locations for the group interviews. Only three fathers volunteered to take part in the research. This means that the information from parents comes more from a female perspective rather than a male perspective. This can influence the information captured, and the conclusions arrived at. One example of how this can influence the conclusions arrived at is related to how mothers and fathers describe their own situation. Lamb (2010) discusses the role of fathers in child development, and describes that fathers are more likely to view a life

¹⁶ When this research project started, the only known assessment tool used in Zambia and Malawi was based on the Nordic definition of deafblindness. It was developed by Inger Roedbroe and Kenneth Verngaard (me) in 2011 to be used in Malawi. In 2016 the tool was updated by Sr. Emma Kulombe, the head of Chisombezi Deafblind Center and Kenneth Verngaard (me) to be in line with the updated Nordic definition (2016) referred to earlier in this thesis. From 2016 the tool has been used in both Malawi and Zambia in two projects coordinated by me on behalf of the Signo Foundation.

situation as positive or negative depending on how they perceive the attitudes expressed by their neighbors and acquaintances, compared to mothers (Lamb, 2010, p. 492). As the findings will show, families in especially Zambia experience that neighbors and relatives often have negative attitudes towards children with deafblindness and their parents. This could mean that if I had been able to interview more fathers, it could have given a somewhat different perspective on how parents understand their life situation.

A total of twenty-two parents were interviewed, nineteen mothers and three fathers¹⁷. To overcome some of the challenges with including a smaller sample group, I have tried to capture richer descriptions of the situation of each family and person. The parents have given stories from their daily life, the family situation, how they have perceived their own situation, and how they think that their neighbors and other community members perceive their situation. I have also been given permission by three families in Zambia to access case study reports written about three children with deafblindness. This has made it possible to understand the statements of the parents in a broader context, making the research findings more trustworthy and relevant (Cohen et al., 2018, p.203-226; Bryman, 2016, p.386).

To protect the anonymity of the families and the children with deafblindness included in this research, their individual diagnoses, conditions and possible additional impairments are not described clearly. To further protect the anonymity of the children, the numbers given below are not always correct. See footnote for more information¹⁸. The actual number in one or more of the groups described below were so low that it might have been possible to identify the child and the family based on the information. The information is included to give an overview of the children with deafblindness, to understand the profile of the children and families included in the research.

Group one:

Seven children have deafblindness with a total loss of both hearing and vision. Three have congenital deafblindness and four have acquired deafblindness. None are able to communicate with any cultural language. All are able to communicate with idiosyncratic bodily tactile gestures/signs. Most have additional physical impairments, and all are totally reliant on people

¹⁷ Malawi: One male, seven females, Zambia: two males, twelve females

¹⁸ Twenty children are included in this research through their parents. The total number described in the four groups here is twenty-five.

in their surroundings in all aspects of daily life. Most have some form of undiagnosed cognitive impairments.

Three have acquired deafblindness as a result of Cerebral Malaria. Due to brain damage as a result of cerebral malaria, they do not fit well into the groups as described in subsection 3.1.2. In the groups as described in literature, children with acquired deafblindness have learnt a cultural language (oral language or sign language), and will usually be able to transform these languages into a tactile communication form, often with tactile sign language. Most will usually also have residual vision and/or hearing. As a result of brain damages, some children included in this research have lost their acquired spoken language. Some of them have also acquired physical impairments. This means that this group is more similar to children with congenital deafblindness than to how children with acquired deafblindness is described in literature.

Group two:

Four children have deafblindness with a total loss of vision, and with some residual hearing. Two have congenital deafblindness. All were able to respond to auditive stimuli, but did not always communicate orally themselves. Some of the children in this group were able to use Braille.

Group three:

Three children have acquired and/or congenital deafblindness with a total loss of hearing, and some residual vision. Some children in this group were able to communicate with tactile sign language.

Group four:

Eleven children have congenital deafblindness with some residual hearing and vision. Most children in this group were able to communicate orally with a basic vocabulary. Most of the children have additional physical and cognitive impairments, and have challenges with motor skills and communication.

4.3.2. Other informants

When approaching interviewees within the government, DPOs and NGOs, I relied on already established contacts I have through my professional network. In addition, I have used the ‘snowball technique’ where respondents have referred me to other respondents (Gusterson,

2008, p.98). This worked quite well, and there were many people who were willing to be interviewed. In Malawi I actually had to reject some informants due to time constraints. One challenge with the 'snowball technique' is that it might have placed me at risk of ending up with a group of respondents that could have been relatively homogenous with similar opinions and interests. To mitigate this, I asked the interviewees to refer me to the persons they thought that could give me relevant information as well as persons they disagreed with; persons they would end up in tough discussions with if they meet in workshops or meetings. The advantage with the technique is that trust already established when you are referred by someone they already know, and that you can come in contact with persons who you otherwise would not have been able to reach (Brinkman & Kvale, 2008, p.138 & 207). When I already had interviewed or had appointments with all of the people one of the last informants suggested me to meet, including the ones the informant disagreed with the most, I realized that I had interviewed many of the most relevant people.

The way the research was carried out logistically, influenced the number informants from each category interviewed in each of the countries. The research fieldwork started in Malawi in August/September 2018 where government officials and representatives from different types of NGOs were interviewed. After having carried out fifteen interviews with a total of eighteen interviewees, I started to feel that I had reached theoretical saturation among this group of informants. I was to some extent able to predict what the interviewees would answer, and noticed that additional interviewees did not contribute with new information, but confirmed the already produced information (Cohen et al. 2018, p.224; Gusterson, 2008, p.107). As the fieldwork continued in Zambia in October 2018 it became clear that new government- and NGO-informants confirmed the information already produced in Malawi, rather than providing new perspectives. For this reason, I decided to interview fewer informants from the NGO/government category in Zambia compared to Malawi. In Zambia I focused more on interviewing parents and teachers. When I again got the impression that I had reached a saturation point, I could return to Malawi in November 2018, and interview teachers and parents there. This meant that I interviewed more government officials and representatives from NGOs in Malawi compared to Zambia, and more parents and teachers in Zambia compared to Malawi.

In total seventy-four people were interviewed in this research. For full overview see the list of informants in appendix 4.

4.4. Trustworthiness and relevance

In this research, the concepts of ‘trustworthiness’ and ‘relevance’ are used to evaluate the research findings. Trustworthiness and relevance are alternatives to validity and reliability to evaluate qualitative research. I argue that validity and reliability are concepts that fit best to evaluate quantitative research like this research project, because of validity and reliability’s emphasis on using the same methods and indicators in multiple research projects. Evaluating validity and reliability, they can be viewed as concepts closer to the realist worldview where reality is viewed as ‘hard’, single, and available for researchers to understand, making the concepts more relevant in quantitative research than in qualitative research. The operationalized definitions used in this research project will not easily be transferred to other research projects because the researcher, people contributing, the lived experience and knowledge the informants and the researcher had at the time the research was carried out, and context will be different. When using semi-structured interview guides, several of the questions asked during the individual interviews differ from one interview to another depending on the responses and statements from the interviewees. Even if another researcher should take use of the interview guide, she would most likely not find the same follow-up questions relevant, because the responses might be different. A new researcher would also most likely interpret the information different from me. If a researcher should decide to interview the same people interviewed in this research, their answers would most likely be slightly different in the next interview, because they might have developed new understandings during and after the interviews done in this research (Brinkmann & Kvale, 2015, p.3 & 15; Bryman, 2016, p.33 & 374-375, 384; Cohen et al. 2018, p.6).

Trustworthiness and relevance rest on the transferability, credibility, confirmability, dependability, and authenticity of the knowledge produced.

4.4.1. Transferability

The concept of transferability is similar to external validity; how research findings can be transferred to other contexts (Bryman, 2016, p.384). I have described the research context, theoretical perspectives, and research methods in a way that give the reader a possibility to assess whether or not the research findings can be transferred to other contexts. When viewing reality as multiple and socially constructed, I have done my best to ensure that the research has been carried out in line with best practices of research. I have done my best to transfer the

knowledge acquired during the course on research methodology in the master degree into the whole research process.

To better ensure that the research findings are transferrable to other contexts, the research has included more respondents than what would be common in ethnographic research, I have focused on two countries, and I have targeted a larger geographical area in each of the countries.

I have also shared the research with my interviewees, and with contacts I have within DPOs, NGOs, and with researchers I know (Bryman, 2016, p.384). This process started with the research proposal, where the proposal was shared with relevant contacts and possible research participants. I got relevant and useful feedback and advice for the further process from some highly skilled and experienced people¹⁹. To give readers a possibility to assess if I have been able to carry out the research in line with best practices of research, I have also carefully described the methods used here in this chapter, and how these are in line with literature on research methods.

However, it is also important to acknowledge that when doing research about inclusive education and deafblindness, transferability of conclusions arrived at can be challenging. As this thesis shows, people with deafblindness are extremely heterogeneous, and there is no universal understanding of what inclusive education is.

4.4.2. Credibility

Credibility relates to whether the findings are believable. To establish the credibility of the findings I have tried my best to ensure that the research is carried out in line with best practices. It has also been important to discuss the findings with the informants, and other interested people from the same areas where the research was carried out. In this way I could get confirmation – respondent validation – that what I have understood and emphasized in the findings is in line with how members of the researched community understand their own situation (Bryman, 2016, p.384; Cohen et al., 2018, p.253).

¹⁹ Including Ingrid Lewis, director of Enabling Education Network; Ann Thestrup, development project coordinator from the Danish Deafblind Association and married to Lex Grandia until he passed away. Grandia represented people with deafblindness in the drafting process of the CRPD; and Marit Haug from NIBR, a Norwegian research institute under Oslo Metropolitan University.



Photo 1. “Mutu umodzi susenza denga”. Makokola, Mangochi, Malawi. “One head cannot carry a roof”. Malawian proverb.²⁰

To this end I have re-visited four out of five research sites in the two countries in February and March 2019. In six dissemination workshops – two in Zambia in February; four in Malawi in March – the whole research process was presented. Two workshops were held with parents only due to the need for an interpreter (one in each country). As in the first phase of the fieldwork, parents were the

ones who gave voice to children with deafblindness. Persons with deafness, blindness and representatives for organizations of persons with deafblindness participated in the workshops. Four workshops were held in English (one in Zambia and three in Malawi) with all groups of informants, including parents who understood English. In the workshops for parents, the frames for the research, the research questions, my position as a researcher, and the findings were presented. In the four workshops held in English the background for the research, the research questions, my position as a researcher, the conceptual framework, the methodology and methods used, the research findings, and the theoretical framework I have used to analyze the findings were presented. The presentation is included in appendix 5. This way the participants have had an opportunity to comment on the whole research process, to confirm or disconfirm the findings, and to provide new perspectives to the research process. In their feedback, almost all interviewees confirmed that they felt that the research reflected their opinions and presented the situation as it is on the ground in the two countries. One said that the research only reflected the situation partly, stating “Yes/no its [sic] still a 50-50 situation”²¹, without clarifying what was not correct. Another workshop participant said that “what you have presented fit with the actual situations on the ground especially on physical adaptation and the methodologies”²². Yet another workshop participant stated that the findings “is a true reflection of the reality about inclusive education in Malawi”²³. The participants also stated that the research could be useful

²⁰ Photo taken at Makokola Conference Center, Mangochi, Malawi.

²¹ Participant ZAM WS 1

²² Participant MWI WS 2

²³ Participant MWI WS 1

“as a model for redefining inclusive education”²⁴, and “It will be useful at policy level, individual level, community level and school level leading to change of attitudes and perceptions towards children with deafblindness”²⁵.

In Malawi I referred to the Malawian proverb “*mutu umodzi susenza denga*” meaning “one head cannot carry a roof”. This proverb is commonly understood to mean that people have to meet and discuss and share information, in order for all to have a common understanding and agree. In this way I tried to make the workshops relevant to the participants. We were discussing their own situation in a way they hopefully could relate to their own experience and background, and I explained that I, as an outsider, needed to discuss the information I have been given in order for me to better understand what people actually had said to me.

There are also possible challenges linked to respondent validation that I needed to be aware of before facilitating the dissemination workshops. Informants might feel uncomfortable if their statements are presented and discussed. This can lead to defensive reactions and possibly also censorship and withdrawal from the research (Bryman, 2016, p.385). To mitigate this, I was careful when presenting all statements, especially when citing one of the informants present in the room. I also mentioned explicitly that the research was conducted in two countries, and that all statements could come from any informant in both countries. Another possible challenge is that the informants could develop empathic relationships with me as a researcher, and for that reason be more reluctant to critique findings they did not agree with (Bryman, 2016, p.385). To mitigate this, it was repeated several times during the dissemination workshops that the research was carried out by an outsider, underlining the importance of correcting any misconception I might have had, and critique what they felt did not represent them. In addition, participants were given an opportunity to give a written anonymous feedback to what was presented and discussed. It was however not possible within the timeframes of the research to give this opportunity to the parents who were unable to write themselves. All feedback captured during the dissemination workshops, including the anonymous feedback is included in appendix 6.

²⁴ Participant ZAM WS 1

²⁵ Participant MWI WS 1

4.4.3. Conformability

To ensure confirmability of the research, I have critically assessed if my own values and theoretical perspectives have influenced the research process and the conclusions arrived at to an extent that can make the research findings less trustworthy. This is reflected throughout this thesis. To give readers an opportunity to critically assess if my theoretical perspectives, presuppositions and values have influenced the research to an extent that makes the findings less trustworthy, I have included a section where I have described my position as a researcher (see 1.4. My position as a researcher). It is also important to recognize that no researcher can be completely objective (Bryman, 2016, p.384; Cohen et al., 2018, p.247).

4.4.4. Dependability

Dependability of conclusions arrived at can be viewed as a parallel to reliability in quantitative research. To ensure dependability I have carefully written a comprehensive research log, which documents and describes in detail the whole process of the research project. An anonymized version of the research log and all transcribed interviews will be made available for those who are interested in assessing whether my theoretical approaches are justifiable, and if the methods that are used are relevant and carried out according to best practices of research. This enables a sort of ‘audit’ of the research process and the conclusions arrived at which are more comprehensive than the criteria for evaluating reliability (Bryman, 2016, p.385-386).

4.4.5. Authenticity

To ensure authenticity of the research, I have throughout the research process, and especially when synthesizing the findings and during the analysis, critically assessed to what extent different opinions and perspectives presented to me by the interviewees are captured and understood. I have also assessed if the research has a potential to help the research participants to value different perspectives and to better understand their own context. This was done in discussions in the dissemination workshop, and in one of the questions the participants were asked to give anonymous responses to (Bryman, 2016, p.386; Brinkmann & Kvale, 2015, p.279).

It has been more challenging to assess if the research has served to sensitize and empower participants to act to change their situation, because the research process has been time limited, and it may only be visible if the participants act *after* the research has been disseminated, and

the final thesis is submitted to the university. However, in one of the workshops, one participant commented that some of the concepts described were advanced and difficult to understand, and the participant asked if an easy-to-read version of the thesis will be published. I have promised to write and share an easy-to-read version of the thesis and share this with all interviewees in addition to sharing this thesis. By doing this, it might be more likely that some people will have access to information that can inspire them to act (Bryman, 2016, p.386).

4.5. Analysis

The analysis of the data is rooted in grounded theory, meaning that theory is inductively developed based on empirical data (Brinkmann & Kvale, 2008, p.133; Bryman, 2016, p.572; Cohen et al. 2018, p.75). In addition to data produced through the research process, existing theoretical perspectives and literature is used to interpret the data. A key process of grounded theory is coding of data. Coding of data means to attach keyword(s) to segments of text to allow identification of the statement(s) (Brinkmann & Kvale, 2008, p.227).

In this research coding has been concept driven and data driven, including components both from the Charmaz approach and the Strauss and Corbin approach as described by Bryman (2016) (p.574). The process of analysis has been an integral part of the whole research process. By coding the data, it has been possible to get an overview of the quite comprehensive data set that has been produced through the research. Including the analysis as an integral part of the research process has also made it possible to counteract the dependency of the codes to my epistemological point of view. By developing codes throughout the research process, the codes are hopefully closer to the epistemology of the informants (Brinkmann & Kvale, 2008, p.228; Bryman, 2016, p.398-399).

Data driven coding used in this research include open, axial and selective coding. Open codes break down, examine, compare, conceptualize and categorize data that can be “grouped and turned into categories” (Bryman, 2016, p.572). In open coding I identified themes found in the data and labeled them to be categorized. Axial coding was used to search for patterns and connections across the open codes. One example of this is how the code “Attitudes” came to integrate “Culture – witchcraft”, “Needs specialization”, “Protection” and more. Selective coding was used to identify a core code and the relationship between the core code and other codes. This was then in turn compared with findings in literature and existing theory. One

example of this is how the core code “Perceptions of inclusive education” emerged to integrate open and axial codes like “Attitudes”, “Access - attendance”, “Removing barriers”, “Resources”, and “Skills of teachers”. This was in turn compared with existing literature on the inclusive education discourse (Bryman, 2016, p.572). NVIVO 12 was used to code the transcribed interviews.

After some initial interviews were conducted, I tested how to transcribe the interviews and how much of the interviews to transcribe. To begin with I transcribed the whole interview in a verbatim style. However, this soon proved to be far too time consuming, and not possible within the frames of this research. In agreement with my supervisor, Prof. Anders Breidlid, I decided to only transcribe samples of the interviews. Themes that were similar across the interviews were transcribed when establishing numbers of informants who had similar perspectives. Themes that were of particular interest to give light to the research questions were transcribed from the different interviews. There is a risk that some information could be lost when transcribing samples from the interviews. This was also one of the reasons why it was important to discuss the findings with the informants. One parent asked why I had not used all the information they had given in the interview, indicating that some information might have been lost.

4.6. Ethical considerations

My role as a researcher has been overt in this research. All informants have been informed about the research, and have given voluntarily consent to participate. To further clarify my role as a researcher, and the full extent of the research, informants and other interested people were invited to dissemination workshops as described earlier. This meant that all informants have been fully informed about the research to the best of my ability, and that informants have been given an opportunity to withdraw. However, even if all informants have given their informed consent; the research has been overt; anonymity and confidentiality of all informants is protected; all informants have been given the right to refuse/withdraw; respondent validation has been used to ensure credibility and more; there has still been some ethical challenges (Phil, 2015, p.48; Bryman, 2016, p.125-133; Brinkmann & Kvale, 2015, p.93-97). ‘Do not harm’ has been an important guiding principle throughout the research process. This is especially important as the group who receives the primary attention of this research, children with deafblindness, has been represented through their parents. It became clear that all children with

their families who are included in this research were themselves unable to communicate using any cultural language. All children were pre-lingual and had limited communication skills. It is an ethical problem when research is done about a vulnerable group who themselves are unable to be informed about the research, or meaningfully contribute to generation of information or validate the interpretations made (Bryman, 2016, p.137). For this reason, I have been careful when describing the children with deafblindness, and have avoided including identifiable information. This is also one of the reasons why the research is done over a large geographical area, as the children described could live in any of the two countries, in any of the five areas visited during the fieldwork, and cannot easily be identified.

I have also tried to be clear about my role as a researcher. Being a white male from a European country, with a professional background as a development adviser, put me in a position where I easily will be associated with potential benefits, power, and influence over their life situation. This might lead people to feel that they have to participate in the research, or may lead people to volunteer for the research based on personal interest. To mitigate this to some extent I described my position as a researcher and professional at the beginning of all interviews, and comprehensively during the dissemination workshops. My personal motivation for doing the research was also fully described. I also tried to carry out all interviews at the offices, schools and localities where the informants were on their “home ground”, or on a neutral location. This reduced expectations of getting transport allowances or other benefits. Most interviews were also carried out well before, or well after, lunch hour. Transport support and lunch was only offered during the dissemination workshops.

5. Findings

This chapter presents the empirical data produced during the fieldwork. The data is organized in three major thematic areas: “Perceptions about Inclusive Education”, “Resources and adaptations necessary to include children with deafblindness”, and “Cultural and linguistic inclusivity”.

During the fieldwork in Malawi and Zambia, and in the process of synthesizing the findings, it became clear that there was little difference in the perceptions about inclusive education between the two countries. Teachers in both countries would often come with similar information and statements; parents gave accounts of similar experiences, challenges and wishes; government officials in both countries would also often present quite similar views, and so on. In the process of synthesizing the findings, the similarities were so significant that the findings are not presented country-wise, but in thematic areas. The text, per thematic area, presents statements from informants from both countries. For each statement the nationality and position of the person quoted is indicated, to give readers an opportunity to assess whether the findings presented are similar across the two countries. The occasions where the findings did differ between the countries are specifically described.

Section 5.1. describes how the informants understand the concept of ‘inclusive education’ based on their own experiences and perspectives. Section 5.2. describes resources and adaptations that are available in schools in the targeted areas today, and to what extent these resources and adaptations contribute to or present a barrier to inclusion of children with disabilities, with a particular focus on children with deafblindness. Section 5.3. points to how the understanding of deafblindness, and people with disabilities in general, in some cases can be linked to cultural aspects. Section 5.3. also describes some of the consequences of the language of instruction used in schools in Malawi and Zambia.

As described in the methodology chapter, it was not possible within the frames of this research to interview children with deafblindness directly, as all of the families who participated in the research had children who were pre-lingual, or had limited communication skills. The information given by their parents gives children with deafblindness an indirect voice in this research.

5.1. Perceptions about Inclusive Education

The interviewees expressed differences in how they understood inclusive education. The most important perspective on what education should look like for children with deafblindness is that of parents because the parents indirectly carry the message from their children with deafblindness. Parents' perspectives are described in subsection 5.1.1. In general, there were three main ways of understanding inclusive education. The most common understanding described was that inclusive education was something that only happened within mainstream classrooms (described in 5.1.2.). The second most common understanding included resource rooms and units in addition to the mainstream classroom (described in 5.1.3). The least common understanding described inclusive education as the whole education system including multiple environments (described in 5.1.4.).

5.1.1. Parents perspectives on inclusive education and school environments

In a focus group interview with seven parents of children with deafblindness in Zambia, parents said that they understood inclusive education as meaning that all children “should learn in a class where they are together, and then the teacher to make sure that she teaches the same things to these two and this one with a disability understand what the teacher is talking about”²⁶. Parents said that they had never heard of any school where this actually happens. When asked if they thought that their own children would benefit from learning together in mainstream classrooms, they shook their heads, laughed and said “It can never happen. It is not something that can happen”²⁷. Parents were clear about what types of environments they felt were best for their children. One parent explained:

[We] cannot take these children to a school where they will be able to learn in a good environment. It is very difficult. The teachers there are not trained on how to teach these children, how to handle these children. These children they scream, they do a lot of things. Now, that teacher who has not been trained will not care about this child. This teacher will be just frustrated, will just say “you mother go and take this child. Go and find a school where they will accept this child”. So, that school... I have never heard of any school in Zambia... I have children who go where there are abled children. I have never found any child who is disabled [in those schools].²⁸

The parents underlined that teachers need knowledge about communication, about deafblindness, and they need to be passionate. Their perspectives regarding the teachers were influenced by their experiences. One parent said:

²⁶ ZAM PFG 1

²⁷ ZAM PFG 1

²⁸ ZAM PFG 1

The coming of the teachers [with knowledge about deafblindness] has really helped me to my side. Because it was difficult for me to leave [my child] alone home. [Name] had temper. Very high temper. (S)he could go into her [sibling's] room and tear books. (S)he was just frustrated. (S)he would shout, scream, sometimes just throw [things]. [The school and the teachers] has really helped me and the siblings. They can communicate now. They are friends. When (s)he comes home (s)he greets them, (s)he hugs them. They communicate very well.

One parent continued to describe how the contact with teachers and the school had changed her attitude towards the child, and said:

I used to see [her/him] in such a way that (s)he was a punishment to me, maybe. [...] I used to feel so bad. Sometimes I would look at [her/him]... Sometimes I would ask [her/him], [Name] why don't you speak? Out of frustration. So, when the teachers started coming, they really taught me how to handle [her/him]. And from that time up to today there is very good communication, very good relationship with [Name]. [...]. So, these teachers have really helped me.²⁹

Most parents having children with deafblindness interviewed, except two, said that they preferred that their child should be in a special school, or in a resource room. Parents in Zambia were more skeptical towards mainstream schools with resource units, compared to Malawian parents. In a group interview with five parents in Malawi, the parents said that they “don't mind if it is a special school or if it is a unit, as long as they are assisted in their own room”.³⁰

Two parents preferred their child to be in a mainstream school, and had children with deafblindness who currently are enrolled in a mainstream school in Malawi. Their children were aged twenty-one and thirteen, and had been in grade one for three years. They are not promoted to higher grades because they “cannot sit for exams, so they will not allow [them] to continue”.³¹ The two informed that their children attended the same class but that “the teachers have no interest in the children. [...] And the child doesn't know the teacher”. The two parents said that the only friends they have in class are each other.

The children know each other. They interact with each other. They sit next to each other. [...] If one is not around for a certain period the other is not happy because (s)he knows (s)he is alone in the school. Even though they are allowed to be in class, there is that segregation in class. There is space that is given to the two children, and whenever one is alone is when (s)he feels lonely because (s)he is left alone, there is nobody.

²⁹ ZAM PFG 1

³⁰ MWI PFG 2

³¹ MWI PFG 1

The two parents described that the teachers did not “assist them in the way they need to be assisted”, and “don’t assign the children to interact with these ones in the classes” but just leave the children “seated in the classroom”³². The two described that “what is happening is just placing the child in class while not learning”³³.

Accessibility was also described as challenging.

The other challenge we experience as parents, [...] is that in the first year the children were enrolled, the slab was good. We were able to move the children to class, but this year and last year there was no slab. [...] this has also prevented other children to drive the children using the wheelchair because they might drive the children and the wheelchair can fall down which is not good for the head.³⁴

Despite all of this, the two parents still wanted their children to go to the local mainstream school. The school is located close to where they live, and being at the school means that their children will at least be exposed to stimuli to “improve on the hearing” and to “know other children, and play with the other children”³⁵.

Most parents informed that they have tried to bring their children to local mainstream schools, but have been rejected. According to the parents, the schools stated that they are full, and do not have space for the child³⁶, or said that they did not have the knowledge to teach the child³⁷. One parent also said that for children to be enrolled, a medical doctor has to sign an assessment of the child. The doctor to whom one parent brought her/his child, refused to sign the assessment form, stating that the child was “un-educable”³⁸.

5.1.2. Inclusive Environments – all in the same classroom

The most common understanding of inclusive education presented across the two countries, and across most categories of interviewees, was that inclusive education mean that all children should be in the same classroom, at all times, learning the same curriculum and topics, taught

³² MWI PFG 1

³³ MWI PFG 1

³⁴ MWI PFG 1

³⁵ MWI PFG 1

³⁶ ZAM PFG 2

³⁷ MWI PFG 1, MWI PFG 2, ZAM PFG 1

³⁸ ZAM PFG 2

by the same teacher.³⁹ The only significant difference was that while most of the teachers (six out of ten) and both head teachers from Zambia expressed this understanding, none of the teachers and only one out of three head teachers in Malawi expressed this understanding. In addition, no NGO-interviewees from Zambia had this understanding, while five out of twelve NGO-interviewees in Malawi expressed this.

Two NGO-informants from Malawi, described inclusive education in this way: “Essentially it means that all learners should learn together, in the same school; mainstream, in the same mainstream classroom, with the same teacher, almost the same resources, sharing the same space”⁴⁰. A teacher from School 1 in Zambia said:

Inclusive education is where every child [...] is brought in school. They are learning together regardless of the status of the child, regardless of the abilities and inabilities of a child. They are all brought together to learn. [...] Into the same class. Those that are visually impaired, deaf, the blind, those who have physical disabilities are all brought together.⁴¹

‘Inclusive’ was understood as the ability of the teachers to adjust and adapt their teaching methods and strategies to enable all learners to get the same information from the same curriculum. An informant from a human rights organization in Malawi stated that bringing all into the same classroom “boils down to the type of expertise the teachers are provided”⁴². In addition, inclusion was understood as providing physical adaptations to the classroom or sitting positions. The physical adaptations of the schools visited, including photos of the adaptations, are described fully in sub-chapter “5.2.1. Resources and adaptations observed at the visited schools”.

5.1.3. Inclusive Environments – Inclusive education opens for units and special classrooms

The second most common way of understanding inclusive education included educational environments outside of the mainstream classroom⁴³. In addition to adaptations to mainstream

³⁹ Understanding expressed by: ZAM PFG 1, ZAM TEA 1, ZAM TEA 2, ZAM TEA 3, ZAM TEA 4, ZAM TEA 5, ZAM TEA 7, ZAM HTEA 1, ZAM HTEA 2, ZAM GOVT 4, ZAM GOVT 5, ZAM GOVT 7, MWI HTEA 2, MWI NGO 3, MWI NGO 6, MWI NGO 7, MWI NGO 9, MWI NGO 12, MWI GOVT 3, MWI GOVT 4, MWI INF 2, MWI INF 3,

⁴⁰ MWI NGO 6, MWI NGO 7

⁴¹ ZAM TEA 1

⁴² MWI NGO 3

⁴³ Understanding expressed by: MWI HTEA 1, MWI NGO 4, MWI NGO 5, MWI GOVT 1, ZAM TEA 6, ZAM GOVT 2, ZAM GOVT 8, ZAM GOVT 2, ZAM NGO 1, ZAM NGO 3, ZAM NGO 4, MWI HTEA 3, MWI TEA 1, MWI TEA 2, MWI TEA 3, MWI NGO 10, MWI NGO 11, MWI GOVT 2

classrooms, the informants described resource rooms where learners in need of specialized services could be accommodated. One NGO informant from Zambia said:

And within that inclusive education setup we will for example have a special room, like a resource room, where they could have specific attention or maybe, for specific needs to be addressed in that room. Where they could get all the appropriate support services that they would require as per condition.⁴⁴

When interviewees described units and resource rooms, they were asked how they interpret the UN definition of segregation as described in sub-chapter 3.3. in light of their understanding of inclusive education. The informants would often respond with questions like an NGO-informant from Zambia did:

But for example, a child that is autistic, they need some quiet time to calm down. How do you provide that environment when children are around? There is noise and there is some time that they need quiet. So how do you provide that if you have the environment within the same room?⁴⁵

The NGO informant from Zambia answered her own question and said:

It's not that they should be completely put in that room. It's when it's necessary and appropriate for their learning and their condition. Then you move them and provide the needed support and once they get that they can go back to the mainstream class.⁴⁶



Photo 2. School 3 MWI. Example of resource room visited.⁴⁷

Learners with vision loss from grade one (two learners), grade two (two learners) and grade three (three learners) were together in the same room, located centrally within the school compound at School 3 MWI. Two teachers followed up the learners. School 1 MWI had a newly

⁴⁴ ZAM NGO 1

⁴⁵ ZAM NGO 1

⁴⁶ ZAM NGO 1

⁴⁷ In all photos included in this thesis all faces are edited out using Apple Photo editing tool.

constructed resource room, which was not equipped by the time of the visit. School 2 MWI had no resource room. School 1 ZAM had a small resource room which was also used to store books and equipment, making the room overcrowded and difficult to move around, especially for a child using a wheelchair. School 2 ZAM did not have a resource room. School 3 ZAM had several resource rooms, but I did not have time to visit them.

Some informants pointed to the economic situation in Malawi and Zambia as a reason for the need for resource rooms, viewing resource rooms as not necessarily the best solution for a child with disabilities, but the only option. One NGO informant from Malawi said:

I think it is important to revisit the term inclusion with respect to the social-economic reality in Malawi. [...] inclusion from the generic understanding of it is unattainable in as far as we talk of inclusion of learners with deafblindness. If anything, we should [...] talk about establishment of resource centers in the mainstream schools to cater for the needs of learners with deafblindness.⁴⁸

Some teachers suggested that the topics taught in class were not necessarily relevant for all. For children with deafblindness, the head teacher from School 1 ZAM said that resource rooms were strongly needed to give “true life skills to be independent and be productive citizens”⁴⁹. Several of the teachers agreed to this pointing to the large class sizes, and the limited time they were able to allocate to each child. In an interview with two teachers in Malawi, one teacher said:

Government should build resource centers. [...] Government must have a resource person so that in the resource center they can go there and teach them so at least at the end of the day they can get something.⁵⁰

Several of the informants nuanced their perspectives during the interview. As shown above the most common understanding of inclusive education was that all should be placed in the same mainstream classroom. The internationally known SDG slogan “Leaving no one behind!” was stated by most of the interviewees. When discussing disaggregated information about impairment types among the children enrolled in the schools, it was apparent in all mainstream schools visited that only learners with mild to moderate disabilities were actually present in the schools.

⁴⁸ MWINGO 3

⁴⁹ ZAM HTEA 1

⁵⁰ MWI TEA 2

The two NGO informants from Malawi who initially said that inclusive education meant that everyone should be in the same classroom stated that:

In the case of Malawi, we are implementing what we call the twin track approach. Severe and profound cases which need specialist attention, there must be a specialist teacher. They are served in a resource room.⁵¹

The two suggested a pull-out system where the learners would shift between resource rooms and mainstream classrooms. The idea was that the learners would over time “have transitioned to the mainstream”. Related to the UN definition of segregation they said that:

The pull-out system is not segregation. You are preparing that child for inclusion. You want to teach that child to communicate and mobility skills for him or her to function properly in an inclusive environment. The resource room is there not as a segregative measure but as a preparatory stage for that child. It's no segregation. It's very important. It's some kind of support.⁵²

5.1.4. Inclusive Environments – Inclusive education means the whole education system

A small number of interviewees presented a third perspective of how they understood inclusive education⁵³. One NGO informant from Zambia stated that “inclusive education is *THE* education”, and described that inclusive education is “the main framework where inside you can find units and you can find special schools. That is the context in which the Zambian government is discussing inclusive education”⁵⁴. The Zambian NGO informant said that inclusive education is not “just about making everybody sit in a classroom”⁵⁵, and continued:

When you educate everybody, know that ‘everybody’ is about individuals. The individual rights are as important as the group rights in the class. [...] we shouldn’t look at education as classroom-based, we should look at home-based education, community-based education, and other forms of education.⁵⁶

A similar understanding was expressed by a Malawian government informant. The informant referred to the twin-track approach described in the National Strategy for Inclusive Education 2017-2021, and said that inclusive education is a “process and a reform to accommodate all learners in mainstream schools”⁵⁷. The Malawian government informant continued and said that “in this process and reform special schools will continue to provide services to some

⁵¹ MWI NGO 6, MWI NGO 7

⁵² MWI NGO 6, MWI NGO 7

⁵³ Understanding expressed by: ZAM GOVT 6, ZAM GOVT 9, ZAM GOVT 10, ZAM NGO 2, MWI NGO 1, MWI NGO 2

⁵⁴ ZAM NGO 2

⁵⁵ ZAM NGO 2

⁵⁶ ZAM NGO 2

⁵⁷ MWI GOVT 1

learners with special educational needs, while at the same time link up with mainstream schools”⁵⁸. The informant described that by linking up with mainstream schools, “the resources and expertise to cater for learners with deafblindness or comprehensive and complex disabilities that is now found in special schools, can be exchanged”, and suggested that “special schools should open up for non-disabled learners”, transforming the schools into mainstream twinning schools⁵⁹. According to the government informant special schools increase participation and learning for children that currently do not benefit from the mainstream schools, and closing special schools is a “wrong utopia that can be discriminatory”, before concluding that “special schools will continue to play that critical role, we just have to really give them that extra role for inclusive education”⁶⁰.

One NGO informant from Zambia said that “inclusion is a journey. It is not a destination”⁶¹. According to the Zambian NGO informant, as well as a majority of the informants from both countries, mainstream schools were for the time being only able to include children with mild to moderate impairments. Children with deafblindness can only to a limited degree benefit within the mainstream system, due to large systemic challenges in the education system, like “government resources are limited”, the classrooms are overcrowded, high learner to teacher ratio, “even on the skills and knowledge side”, and more⁶². Special schools were described as a part of the journey to eventually achieve full inclusiveness in the mainstream system. An NGO informant from Zambia said inclusive education was not about shutting down “special schools or specialist units”, but that it is “about demonstrating, and progressively learning from that demonstration, [...] and becoming better at including. That is the process that can close units, that is the only process that can close a special school”⁶³.

5.2. Resources and adaptations necessary to include children with deafblindness

This section looks into the availability of human and financial resources, and the implications this has for children with deafblindness. Subsection 5.2.1. describes physical adaptations observed at visited schools. Subsection 5.2.2. describes informants’ perspectives on the general resource situation in Malawi and Zambia related to inclusive education and children with

⁵⁸ MWI GOVT 1

⁵⁹ MWI GOVT 1

⁶⁰ MWI GOVT 1

⁶¹ ZAM NGO 2

⁶² ZAM NGO 2

⁶³ ZAM NGO 2

deafblindness. Subsection 5.2.3. describes informants' perspectives on the skills and knowledge inclusive teachers need. Subsection 5.2.4. describes how informants assess the extent to which international programs and projects are able to address possible resource gaps experienced by children with deafblindness and their families, as well as all other children, disabled or not.

5.2.1. Physical adaptations observed at the visited schools

The following photos give a representative presentation of physical adaptations observed in the schools visited. The photos are structured into adaptations to improve the situation for children with visual impairments; adaptations influencing the sound environment in the classrooms; and adaptations to ensure accessibility to classrooms and sanitary facilities⁶⁴.

The most common adaptations to accommodate learners with visual impairments related to improving the light conditions in classrooms and ensuring that the blackboards were readable for all learners.

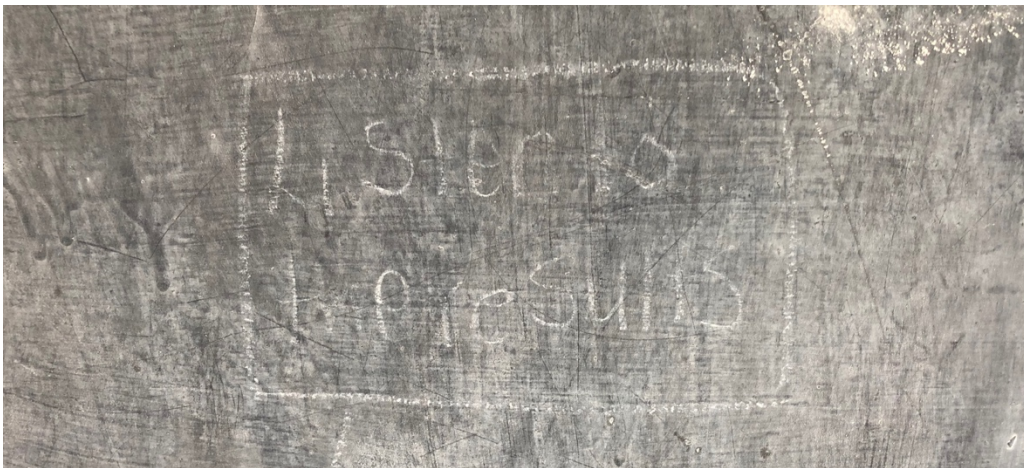


Photo 3, School 2 Zambia: Low readability.

Lack of cleaning equipment, and lack of paint to maintain the blackboard was a common challenge in most of the classrooms visited. Blackboards like the one in photo 3 was the most commonly observed type.

⁶⁴ Deafblindness is defined as *one* distinct combined sensory impairment, and not a result of a combination of two separate impairments. However, to better structure the information, the descriptions of the physical adaptations to accommodate learners with visual impairment and hearing impairments are described separately.

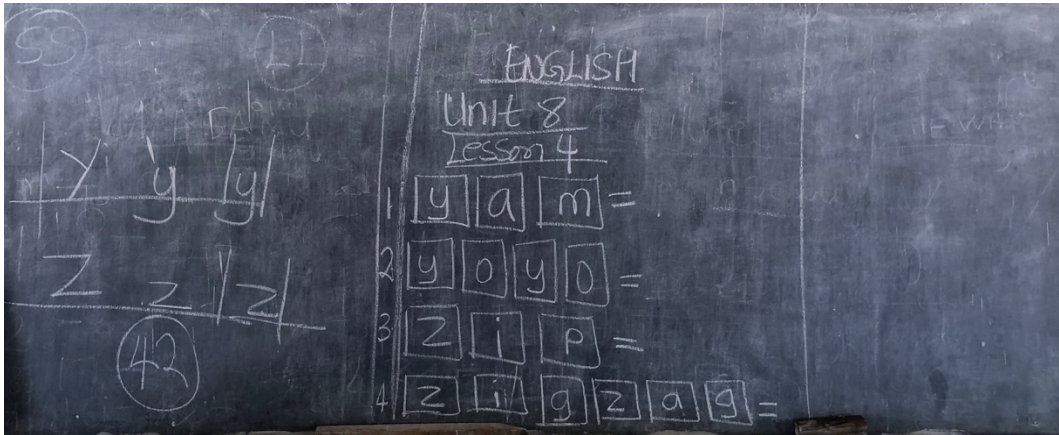


Photo 4, School 2 Malawi: High readability.

This photo shows the darkest blackboard in all of the classrooms visited. Only a few classrooms had blackboards with a readability like this. Photo 5 from the same classroom shows the blackboard from another angle, with light from windows reflecting on the blackboard. The picture illustrates how even the darkest blackboard can be challenging to read from certain angles.



Photo 5, School 2 Malawi: Illustration of placement of a child with visual and/or hearing impairment⁶⁵.

Notice that there is one table missing from the rows of tables on the right side of the picture. I did not notice this when I visited the classroom, but when looking at the photo I am wondering if the table was moved to the front because of my visit, and that it may not be there on a regular basis. As I did not notice this during the visit, I did not ask. When photo 5 was presented in one

⁶⁵ One person has been edited out of the photo.

of the dissemination workshops in Malawi, several of the participants reacted to the photo. “This is isolation. This is exclusion within inclusion!”, one participant said, referring to the positioning of one table in solitude in front of the rest of the tables.⁶⁶



Photo 6, School 1 Malawi. Transparent roof panels.

Notice that the transparent roof panels were placed in the middle of the room. In some of the classrooms these panels were placed closer to the blackboard to improve light conditions round the blackboard. In one dissemination workshop in Malawi, a teacher said that the transparent roof panels not only allowed penetration of light, but also penetration of heat. The teacher said that this makes the classroom warmer than before, making learners tired⁶⁷.

When it came to adaptations to ensure that children with hearing impairments would be able to hear what the teachers says, it was common to allow the learners to sit close to the teacher, like shown in photo 5. No other physical adaptations were observed. When rain falls on metal roof panels, the sound can be quite loud. One of the interviews in Zambia, done in the resource room at School 1 ZAM, had to be paused due to the noise from the rain because it was not possible to communicate without shouting⁶⁸. Metal roof panels was used in all classrooms in all schools visited, and challenges with noise during rainfall can be expected in all of the classrooms.

⁶⁶ MWI WS 1

⁶⁷ MWI WS 2

⁶⁸ Interview#26, time: 28:00



Photo 7, School 2 Malawi. Outdoor classrooms. 5 classes are visible in the photo.

The School 2 Malawi had a total of 18 outdoor classes. Only three of the outdoor classes observed at this school were located in an accessible place for children using wheelchairs. Large stones were used as replacements for chairs. The way the stones were placed meant that wheelchair users would have to sit outside of the stone circle. During the rainy season all outdoor classes had to be moved indoors, into the already crowded classrooms. This means that the classrooms will be largely overcrowded, and up to 300 children in one classroom was a common situation. 150 children sitting close together were observed in classrooms during the visit to School 2 Malawi in the dry season.

Physical adaptations to improve accessibility included ramps to the classrooms, and construction of accessible toilets.



Photo 8, School 2 Zambia. Example of a well-designed ramp going all the way to the door.



Photo 9, School 2 Malawi. Example of ramp.

Notice the threshold at the door. Even though the ramp here is quite flat and goes all the way down to the ground, the threshold at the doorway will still hinder wheelchair users from accessing the room unassisted. The teachers who showed me around the school said that the company responsible for constructing the ramps had limited knowledge about how the ramps should have been constructed.



Photo 10, School 2 Malawi. Example of ramp.

Limitations in understanding what a ramp should look like are very apparent in this photo. This classroom is in no way accessible for a wheelchair user. When I asked why the ramp had not been modified, no one could give a good answer other than lack of resources available.



Photo 11; School 2 Zambia.

This picture shows a classroom where the floor was crumbling generating potholes that hinder unassisted use of wheelchairs. Tables are placed in groups to promote group work and peer assistance.



Photo 12, School 2 Malawi. Toilet facilities.

These facilities are not friendly to any user, with no privacy and no accessibility for persons in wheelchairs.



Photo 13, School 3 Malawi. Toilet facilities.

In this school a new toilet was under construction. This toilet is the best example of an accessible toilet observed in all of the schools visited.⁶⁹ Because of the way the toilet is constructed, with a small hole, and made out of concrete, this toilet will need to be cleaned well to be hygienic.

An assessment of the extent to which the physical adaptations found in the schools visited are adequate to include learners with deafblindness will be included in chapter 7. Analysis.

5.2.2. The Zambian and Malawian governments' access to resources

High learner to classroom and high learner to teacher ratio in both countries, lack of textbooks and other learning material, limited access to assistive devices like hearing aids, glasses, wheelchairs, and limited number of resource rooms were highlighted by most of the informants as barriers for inclusion of children with deafblindness as well as all other children, disabled or not. A government official in Malawi stated:

Ideally there should be a resource center at every mainstream school. It is not possible at the moment. For now, we aim to have at least one resource center in each educational zone⁷⁰. There are 447 educational zones in Malawi. Only about 150 of them have resource centers.

⁶⁹ The toilet facilities in School 1 ZAM and School 3 ZAM was not visited.

⁷⁰ An educational zone in Malawi will usually consist of around 200 schools.

One NGO informant from Malawi stated that the government of Malawi is “trying quite a lot”, and continued:

if we are talking about learners with disabilities, it is a different story all together. Funding and resources might not be adequate but the government is doing something with regard to provision of funding and resources to the general education system. And mark the word ‘general education system’.⁷¹

The lack of resources available in both Malawi and Zambia does not only concern the school environment. Many of the parents with children with deafblindness interviewed have children with comprehensive mobility challenges. Some of their children need wheelchairs to move around. One mother from Malawi said that she did not have access to a wheelchair to assist her child, and that carrying the children on the back to school is tiresome. She was only able to do this once a week.⁷² Another parent from Malawi said:

Wheelchairs should be advocated for. Many children need wheelchairs. Because of wheelchairs they cannot go to school, because of mobility problems. So, the government should make sure that children who need wheelchairs should be provided according to their age, their sizes so that they will be able to take the children to school without problems.⁷³

However, even with a well-functioning wheelchair, bringing the children to school can be quite challenging. In a group interview with seven parents in Zambia they informed that many lived a long distance from the local mainstream school. One parent said that she used one and a half hour each way to the school, with her child sitting in the wheelchair. In the dry season, it was tiresome to bring the child to school, in the rainy season it was impossible⁷⁴. Similar stories were told when visiting both rural and semi-urban schools in Malawi. As there is no school transport offered, parents have to pay for taxi to bring the children to school. One parent from Zambia said that the result was often that the child would not have access to school because “when you don’t have money, the child will stay at home and (s)he will not attend classes”⁷⁵. An NGO informant from Zambia described an area where there could be as much as a hundred and fifty to two hundred kilometers to the closest school. It is “mission impossible to get a child into the school”⁷⁶.

⁷¹ MWI NGO 3

⁷² MWI PFG 2

⁷³ MWI PFG 1

⁷⁴ ZAM PFG 1

⁷⁵ ZAM PFG1

⁷⁶ ZAM NGO 2

Closing special schools and allocating all resources to the mainstream schools was not considered a viable option to strengthen mainstream schools. In Malawi, one NGO informant pointed to the fact that most of the special schools in the country are “owned by the churches and other institutions” and that the only thing the government does is to provide “salaries for teachers and have some supervision of some learning and teaching materials”.⁷⁷ Informants in Zambia said almost the same and stated that there are limited resources allocated to special schools today, so it would make little difference on the resource side if the funds were re-allocated. In both countries several informants stated that another challenge would be that the number of specialist teachers were few, and spreading them among a large number of mainstream schools could lead to a risk of the teachers being used to focus on non-disabled children more than children with disabilities. One NGO informant from Malawi said that Malawi is a developing country where “the resources are just not there. [Name of district] have more than 300 schools. The number of specialist teachers who are there is less than 10”.⁷⁸ Which would mean, if evenly distributed, to have a specialist teacher come in one day, once every one-and-a-half month to follow up all learners with special needs in each school.

Two teachers from Malawi said that some resources are there, but they are not spent in the best way. The two stated together, finishing each other’s sentences, that:

The main challenge is that the top officials they will spend a lot of money in hotels, going outside the country, discussing about the inclusive education in Malawi. Yes, they will spend a lot of money. It’s a waste of money. And then they will come to us and say do this, do that. And these learners they are suffering. They don’t have enough teaching and learning resources, and yet they have spent the money on conferences doing that. Most of the learners don’t even have the wheelchairs. Let us talk to these officials not to waste money.⁷⁹

An NGO informant from Malawi said:

We need to look at the socio-economic realities of Malawi and see how we can model inclusive education. I still believe that Article 24 should provide the basis, but we need to modify the provision of the same, and the implementation of the same in countries like Malawi which are under-resourced, but having un-adequate resources shouldn’t be an excuse for failures to provide education for persons with disabilities.⁸⁰

⁷⁷ MWI NGO 3

⁷⁸ MWI NGO 7

⁷⁹ MWI TEA 1, MWI TEA 2

⁸⁰ MWI NGO 3

5.2.3. Teacher's knowledge, skills and experience

The knowledge, skills, and experience of teachers to take use of inclusive teaching methods was a recurring theme in all interviews in both Malawi and Zambia. Expectations to mainstream teachers differed, but a common expectation was that mainstream teachers with a training to be an inclusive teacher from the teacher training colleges “will not have a problem on how to practice”, and will be able to “help each child at individual level”⁸¹, regardless of their impairment, socio-economic and cultural background, etc. When asked about specific strategies for inclusion of children with specific impairments interviewees sometimes seemed more uncertain. One NGO informant from Zambia involved in training of teachers stated that:

No, inclusive education actually does not go into... what inclusive education say... you know, the, the manuals are doing is to provide.... Strategies, styles, methodologies and approaches for engaging a learner with a disability, and... meaning that if you have... in other words, it is not a prescription of a protocol on a specific disability. That is something that those who have been trained in inclusive education will develop. [...] It does not matter, OK, who you are dealing with. You can be dealing with a person who is deafblind, you are dealing with a person who is blind only or deaf only, a person who has an intellectual disability.⁸²

When follow-up questions were asked, with examples of skills all teachers should have to accommodate children with different disabilities (like reading and writing Braille, or knowing sign language), it seemed like ‘include all’ did not necessarily actually mean all, but only children who were “mild, slow learners, gifted and whatsoever. Maybe eye problem. A little bit blind, not totally, but a little bit”.⁸³ When asked about children with more comprehensive disabilities like deafblindness, the interviewees suggested other environments, other competencies, and other teaching strategies. One teacher from Malawi said:

We take these learners to the resource center. Anyway, in short, we have a teacher specialist for that. [...] When we find those ones, then we take them to the resource center. Then at the resource center it's where we find a teacher who is specialized for them, with training for that disability so they know how to handle them.⁸⁴

5.2.4. Resources provided by international development projects and programs

This section shows how local stakeholders within education perceive the outcomes of the many development projects in Malawi and Zambia. Teachers, NGO- and government informants said that development projects have resulted in an increasing number of children with disabilities enrolled in schools. Many teachers accounted for a change in attitudes towards children with

⁸¹ ZAM NGO 1

⁸² ZAM NGO 2

⁸³ MWI TEA 1, MWI TEA 2

⁸⁴ MWI TEA 1

disabilities in a positive direction, and that the children in mainstream schools seem to be positive and welcoming towards their peers with disabilities within the school environment. However, except for two children enrolled in School 4 ZAM, there was no evidence of children with deafblindness or children with complex and comprehensive disabilities being enrolled in any of the schools visited, and parents informed that even though fellow learners were welcoming and positive within the school environment, their children were bullied outside the schools⁸⁵.

There was no evidence to suggest that international projects focusing on inclusive education have so far increased participation and learning outcomes for children with deafblindness in the areas where the research was carried out. Informants presented some major challenges related to the projects. Some head teachers said that the school and the teachers were offered training in inclusive education, but what they actually needed more was support to modify the physical environment, and more learning and teaching material⁸⁶. One head teacher⁸⁷ showed me the toilet facilities at the school, and said that all toilets at the school were not accessible for children using wheelchairs.

Most teachers said that the training they had been given was not sufficient. Malawian teachers interviewed had only been given two or three days of training. In two of the schools visited (School 1 ZAM and School 2 ZAM), the teachers and head teacher informed that they have been given more comprehensive training through a development project, but they still said more training was needed, especially on methods to include learners with severe impairments. Two teachers from Malawi⁸⁸ shared their notes from the only training they attended. Their notes, although quite comprehensive, showed that the training they had attended only gave basic information about the concept of inclusive education, some of the benefits, and key principles. The introduction to methodologies to include learners in the classroom seems quite superficial. The methods captured in the notes include “clear voice, instructions must be clear, sign of language [sic], use of gestures, seating plan, use of group leaders, individual help must be the same, distributing questions equally”⁸⁹. Two NGO informants from Malawi who facilitate

⁸⁵ See section 5.3.1 for more information

⁸⁶ ZAM HTEA 1, MWI HTEA 2

⁸⁷ MWI HTEA 2, School 2 Malawi

⁸⁸ MWI TEA 1, MWI TEA 2

⁸⁹ MWI TEA 1, MWI TEA 2, photos were taken of all notes from the training

trainings for teachers said that they were not able to do the training that was planned, and expected of them to do, because of lack of time and resources.

We want the training to be comprehensive. Taking the teachers gradually. For some of them this is a relatively new concept. We want to give them in depth material. But then, because the donor has set a limit on the budget where you are going to train a specific number. So, per school you are going to train fully 5 per school. For the rest we train them bits and bits. This has affected our approach. When you train in bits, they do not fully acquire the knowledge. Some of them we have only trained them in 2 units but there are 6.⁹⁰

An NGO informant from Zambia presented a similar view and stated:

One week they will train a group of teachers in how to assess a learner with a disability. Next week, a month later, they will train others on introduction to inclusion. Later on, another module. In other words; you have these head teachers and principals of institutions, and you have these other people who have been to workshops... different workshops at different times. It is like somebody whose eyes is closed and you ask “how does an elephant look like?”. Everybody talks about the part they have touched. OK, so nobody has the full picture.⁹¹

One NGO informant from Malawi said that it would have been better to train a more limited number of teachers comprehensively, rather than training a larger group superficially. One said that handling “the profound cases” is difficult for a teacher, “even if the training is comprehensive”⁹². The informant also said that the training they gave did not give much information to enable teachers to include ‘the profound cases’. The NGO informant said that “there are some things that are not there in the manual. Like for children who have profound disabilities like blindness, or hard of hearing”⁹³.

A Zambian government official pointed to what can be described as training fatigue as a challenge with international development programs. In a dissemination workshop in Zambia the government official said that “teachers have experienced that programs come and go. They don’t bother to learn the new stuff, because they know that sometime soon another program will come in”⁹⁴. A head teacher from Zambia pointed to allowances as a motivating factor to come for trainings, and not necessarily the content of the training. The head teacher said that “most of this, the teachers, the things that we are discussing. They actually know those things, but maybe the motivation factor also comes in. I wish we could not use money so much”⁹⁵.

⁹⁰ MWI NGO 6

⁹¹ ZAM NGO 2

⁹² MWI NGO 7

⁹³ MWI NGO 7

⁹⁴ ZAM WS 1

⁹⁵ ZAM HTEA 1

Sustainability of international development programs was presented as an additional challenge that influences the long-term impact of the program for children with deafblindness, and any type of disability. A head teacher from Zambia said:

When the program comes in, they come in with a lot of money. And usually the drive is money, and people they get to the program because of the money. And sometimes as the money begins to trickle off it means that also the interest. You only remain with the few who remain with passion. [...] If the money was used for the equipment, for example I have a machine here that can be used to test eyes, to test ears. If we only have money for logistical support, once that support leaves it means that everything.... We do need the money because that turns the world round, it drives everything, but where are we placing the money should be the question.⁹⁶

A Malawian district government official described a development program that was, at the time of the interview, soon to be phased out. The district government official started with saying that the “teachers are now equipped with knowledge”, and that the government would now “intensify monitoring” and direct grants to the schools ensuring that the “program will continue with the government”⁹⁷. When asked about availability of resources needed to intensify the monitoring, the district government official explained that the district office now had access to vehicles that was used for monitoring. However, when the “project is over, the vehicles are taken away, and it will not be possible to continue to monitor”. The district office used to have motorcycles provided by the government, but “all of them are broken down”. All this meant that the district office now “will be lowering the monitoring”. This could be critical for the long-term effect of the project as the district government official already had observed that “disappointingly some teachers have left the concept completely”⁹⁸.

A Zambian NGO informant expressed that support from international donors could in some cases be counterproductive, and could allow the government to not take its responsibility as a duty bearer. The responsibility to provide for some groups could then be considered as belonging to a development project, and not to the government itself. The NGO informant stated:

But a country cannot survive on a project. A country needs to be a duty bearer. A government receiving tax-payers money needs to be a duty bearer. The persons who are deafblind, deaf, those with physical disabilities, those who are blind, intellectual or other

⁹⁶ ZAM HTEA 1

⁹⁷ MWI GOVT 3. All quotes in the para. by same informant. Only first and last quote is footnoted to save space.

⁹⁸ MWI GOVT 3. All quotes in the para. by same informant. Only first and last quote is footnoted to save space.

psycho-social and mental health challenges are the rights holders and they need to make the government accountable for holistic interventions.⁹⁹

5.3. Cultural and linguistic inclusivity

This section will first present culturally rooted belief systems that according to the interviewees lead to negative attitudes towards children with deafblindness (subsection 5.3.1). Subsection 5.3.2. presents the extent to which the school systems are inclusive towards languages and knowledge children with deafblindness and children in general, disabled or not, bring to school. Subsection 5.3.2 also describes interviewees' perspectives on relevance, and origins of the inclusive education discourse, and the education systems in the two countries in general.

5.3.1. Witchcraft, deafblindness and disability

This subsection describes how culturally rooted beliefs impact children with deafblindness and their families. The findings in this area differ somewhat between the two countries. The magnitude of the challenges experienced is higher in Zambia compared to Malawi. According to several of the informants from all groups of interviewees in both countries, witchcraft is commonly used to explain why a person has an impairment, more often in Zambia than in Malawi. In a group interview with seven parents from Zambia, parents shared stories about how they themselves had tried to explain the condition of their children with witchcraft. One mother from Zambia said that she once thought that someone had bewitched her child, and that she even “knew who bewitched that child”.¹⁰⁰ Others said that their families accused them of being the cause for the condition. One mother said that her immediate family members accused her of having “sacrificed the child in order for her to be rich”, and continued to say that “I have nothing, I don’t even have a house where if I die today I can leave the child in it”.¹⁰¹ The parents explained that their understanding had been changed after receiving information about deafblindness, and seeing children with similar disabilities so they “now understand where this has come from”.¹⁰²

⁹⁹ ZAM NGO 2

¹⁰⁰ ZAM PFG 1

¹⁰¹ ZAM PFG 1

¹⁰² ZAM PFG 1

Witchcraft was also described as one of the reasons for why children with deafblindness were excluded in the communities in which they live, and from access to mainstream schools. In a group interview with seven parents in Zambia, one mother said:

I will put it that way... in our culture there are some who think that these children are cursed. Some they think that they bring bad luck. Others say, maybe if a person is pregnant, they will say “no if this child keeps on coming to this house, you will give birth to the same child. Your unborn baby will also be born the way this person is. So, our children are not accepted by the community.”¹⁰³

The parents said that other people believed the severity of the impairments of their children indicated that the witchcraft or curse placed upon them must have been particularly powerful. This was also confirmed by a *Zambian university lecturer*¹⁰⁴. Due to this, they felt that people reacted more to their own children compared to children with other types of impairments. One mother explained that “people would be looking at [her/him] as if: ‘Where does [s]he come from?’ As if [s]he was not a human being”.¹⁰⁵

Most parents in both Malawi and Zambia said that their children were bullied in or outside of the schools. In a group interview with seven parents in Zambia, parents said that parents of non-disabled children with deep culturally “rooted beliefs” and negative attitudes towards children with deafblindness, imparted the same attitudes in their own children¹⁰⁶. One mother said:

But when we put them together with those children. Those children are bullies. They come from different homes. They behave so strangely, so it is security wise. We want to protect them. They cannot protect themselves. They cannot. An able child will come and say “I’ll beat you!”. [Name] will not respond. [another name] will not respond. The child will just be there seated and will be treated in a very bad way.¹⁰⁷

As their children did not hear or see, they would not register or understand a threat, and as a consequence they would not respond to it, and would not be able to protect themselves. In a group interview with five parents in Malawi, parents described challenges with peer interaction. One mother said that when she brought food to the school and gave it to the teacher to assist her child, “the teacher don’t give [the food]. And sometimes the [other] children [in the class] themselves rob the food and eat instead of giving to the child”.¹⁰⁸ The seven parents from

¹⁰³ ZAM PFG 1

¹⁰⁴ ZAM GOVT 4

¹⁰⁵ ZAM PFG 1

¹⁰⁶ ZAM PFG 1

¹⁰⁷ ZAM PFG 1

¹⁰⁸ MWI PFG 2

Zambia said that if children in mainstream schools were exposed to children with deafblindness, it could contribute to changing the attitudes of the children in mainstream schools, but argued that their children needed quality education in safe environments, and that other's attitudes have to be changed *before* their children are exposed to the mainstream environment¹⁰⁹. The seven Zambian parents suggested that children in mainstream schools could instead get information about deafblindness and disabilities in general, and that special and mainstream schools should have exchange programs. The parents described that attitudes towards children with deafblindness is a barrier of such a magnitude that even if quality services are available in mainstream schools, the parents interviewed would still prefer the child to go to a special school¹¹⁰.

All parents interviewed expressed mixed emotions when describing their life situation. On the one hand, the parents expressed how much they cared for their children, and were proud of their children. In a group interview with seven parents in Zambia, one mother said that “us mothers who have these children we value our babies. We know that they can do something. The time we spend with these children, we learn a lot from them”.¹¹¹ However, the parents also expressed that their children could feel like a burden, and that they experienced that their families excluded them, and did not want anything to do with their children. Many of the mothers told that they were divorced, and that their ex-husbands had left them because of the child with deafblindness. One mother described that her close relatives had stopped visiting her and her child with deafblindness. The mother said:

I don't get visits from my family. When they come my child want to know who this is. [S]he touches them to know, and they feel uncomfortable. They have stopped coming, and will only call me on the phone.¹¹²

The way the parents described their children would also sometimes indicate their attitudes towards their own child. In a group interview with seven parents in Zambia, one mother said that she had seven children, and one child with deafblindness. The child with deafblindness was not included as a child among eight siblings, but as an extra child in addition to the seven other children. Another mother described how she felt alone before meeting other parents with

¹⁰⁹ ZAM PFG 1

¹¹⁰ ZAM PFG 1

¹¹¹ ZAM PFG 1

¹¹² ZAM WS 2

children with deafblindness thinking that she was “the only one with such a child”, and that she was looking at the child as a “very big challenge in my life”¹¹³.

Teachers and representatives from DPOs, NGOs and government officials presented many similar perspectives on attitudes towards inclusion of children with deafblindness and with disabilities in general. A Zambian government official said:

There are a lot of negative attitudes [...]. Not only towards the children with disabilities, but also to their teachers. The teachers are given call names. They are called “teachers for fools” and such things.¹¹⁴

DPO/NGO/govt’ informants described the attitudes of teachers in similar ways across the two countries. A government official from Malawi described two types of teachers. One group was, according to the informant, prepared to teach children with disabilities, because they had special needs education from a teacher training college. The other group were “regular teachers with little preparations”.¹¹⁵ An NGO informant from Zambia had a similar perspective, and stated:

I think for teachers it depends on whether the teacher has been exposed to inclusive education. Because the first reaction of most teachers will be that children with disabilities need to be in special school and they have no room. They will actually say “No, no, no, we are not... we don’t handle such children here. Go to that special school. Here in the school we don’t have such kind of children.” That is the experience of most teachers and schools.

The underlying factor that was presented as a barrier was the attitudes of teachers. A Malawian government informant said that “regular teachers” with little preparations and training “feel inept, they feel that they don’t have the skills, so their attitude is - I can’t. So, they are defeated.” The Malawian government informant said that the teachers might have tried and failed. “They may want to do it, but they feel, not I can’t, it is a specialized area”.¹¹⁶

However, teachers did not prescribe this to attitudinal factors. One teacher from Malawi described the situation like this:

It is very difficult for one teacher to handle all the learners and six different disabilities. This one we need... this one we need, and time as we are delivering the content. It is very hard. It is difficult. It is very tiresome work. It is challenging to us. In senior section we have thirty-five minutes in each period. You can add ten minutes extra time. Then this period again is suffering, and this period again, and this period, and this period up

¹¹³ ZAM PFG 1

¹¹⁴ ZAM GOVT 1

¹¹⁵ MWI GOVT 2

¹¹⁶ MWI GOVT 1

to dawn. [...] So, how can we handle all these learners? It is a challenge in our country.¹¹⁷

The teachers described that the feeling of not having adequate capacity to handle all learners in the classroom in a good way depended on the availability of time and knowledge, and not on the attitudes they had. A head teacher from Zambia said that teachers' attitude towards inclusion is "very positive looking at the point we started". However, the head teacher described that including a child with deafblindness would be "a little bit of a challenge for them. That would be the first experience of that kind because we don't have that such cases actually in [area]"¹¹⁸.

As shown in section 6.4.¹¹⁹ some compare the current inclusive education discourse to indigenous education as it was in pre-colonial Africa. This view was not shared by an NGO informant from Malawi. According to the NGO informant, the way inclusive education has been presented and implemented in Malawi, "inclusive education is not pointing back to indigenous education, I think it is just another Western education system"¹²⁰. Some interviewees suggested that indigenous education in its original form should be explored more, criticizing the current education systems in Malawi and Zambia. One NGO informant from Malawi said that children in schools in Malawi are only trained to pass exams, and continued: "They are not learning, but are memorizing. The education is preparing them for white-collar jobs, but not for life"¹²¹. Another NGO informant from Malawi said that:

We should depart from the formalized education system. We can go informal, we can go a little bit indigenous because not all aspects of indigenous technical knowledge are bad. Looking at pre-colonial Africa one is to see that societies were a bit more inclusive than today. Then we are talking about Westernization and modernization taking its toll on African societies. This should give us another thought to say: Can we rethink education and think about inclusive education?¹²²

The NGO informant continued and said that there is a need to look at the varying realities in countries where inclusive education is implemented, stating:

We can't export inclusive education from the republic of Ireland, or from Norway or from the UK to Uganda or to Malawi or to Zambia. We need to consider some modifications. Therefore, I think, thinking about what can work and what cannot work

¹¹⁷ MWI TEA 1; MWI TEA 2

¹¹⁸ ZAM HTEA 1

¹¹⁹ 3.3. Inclusive Education

¹²⁰ MWI NGO 1

¹²¹ MWI NGO 2

¹²² MWI NGO 3

in our setup is the key. Without necessarily completely deviating from the principles of the CRPD.

5.3.2. Linguistic inclusivity

As described in sections 2.1. and 2.2.¹²³ both Zambia and Malawi have a large number of vernacular languages. Observation in classrooms visited gave an impression of some of the challenges teachers and learners face. In School 2 MWI and School 3 MWI I tried to interact with the learners using English. After a visit to School 3 MWI the following observation was captured in the research log:

When I visited the classes I tried to ask them questions in English. In the lower grades the children did not understand what I was saying and the teacher had to translate what I said, as well as the responses from the children. In the higher grades the Head Teacher again had to translate to Chichewa, even though the children have had English as their LoI for up to 3 years, and have learnt English as a subject since grade 1. This led me to think that it might be challenging for the children to understand what the teachers says in English. However, my accent was different from what they hear in the daily school life, and might be more difficult to understand.

(Research log entry 2018.10.31)

Language of instruction was an unfamiliar topic for most interviewees. A Zambian NGO informant described that when it comes to language and inclusive education, the only thing that is discussed is sign language, “That’s the only thing I’ve come across people discussing”¹²⁴. When asked about their opinions on the effect of language of instruction (LoI), it was presented as a barrier to inclusion of children with deafblindness, as well as for most other children in schools, disabled or not. A teacher from Malawi described that she was forced to use “some local language, a little bit, so that they can relate”¹²⁵. Without using the local language, she said: “I can teach for ten minutes, but no any learner can know what you are doing, what you are teaching”¹²⁶. Another Malawian teacher said that the children had to adapt to the system, and learn the language of instruction:

But your question. I can get your question. You are saying: How do we handle a learner from Chiyao, Tumboka to Chichewa and then to English. But I told them in my class that, when you enter this class no more Chiyao. Don’t speak Chiyao here. You are going to speak Chiyao when you go home. It is a problem to us.¹²⁷

¹²³ 2.1. The education system in Zambia, 2.2. The education system in Malawi

¹²⁴ ZAM NGO 1

¹²⁵ MWI TEA 2

¹²⁶ MWI TEA 2

¹²⁷ MWI TEA 1

An additional challenge is that teachers are not always fluent in the language of instruction, or the vernacular language. An NGO informant from Zambia said:

[...] a teacher who is maybe from a different province is not knowledgeable about the language of instruction in the Southern Province. And this teacher is expected to teach children in a foreign language, Tonga. So, this has been cited as one of the barriers to effective learning [...] where they are trying to implement inclusive education.¹²⁸

Two NGO informants from Malawi¹²⁹ discussed some of the challenges with selecting a language of instruction in urban areas. When people migrate to urban areas like Lilongwe¹³⁰, the catchment areas of most schools are multilingual, “so what is the vernacular?”, one of the two said¹³¹. The two NGO informants said that Malawi tried to introduce vernacular language as language of instruction, but that several challenges were encountered. They described that using vernacular languages as language of instruction led to teachers often being placed at schools close to their origin, because they were fluent in the vernacular language. According to the two NGO informants, this was not popular among teachers. According to them teachers felt that the government wanted to oppress them, and deprive them of opportunities. With a teacher certificate, many teachers did not want to go back to the rural areas they came from, but wanted to move to larger towns and cities.

A Zambian NGO informant described some of her own experiences as a child struggling to understand the language of instruction in her school. Her parents did not know the language of instruction, and were unable to assist her with the homework. In this situation she said that her friends were what helped her to succeed. In a group of friends, all of them could help each other with the linguistic challenges¹³².

5.4. Chapter Summary

The findings chapter has showed how people in Malawi and Zambia understand inclusive education related to the physical environment in the schools, with accessible mainstream classrooms and resource rooms as two important components. The chapter has also described what different stakeholders within education think are necessary resources to achieve inclusive education. The chapter has showed that resources described as necessary are not available, not

¹²⁸ ZAM NGO 1

¹²⁹ MWI NGO 1, MWI NGO 2

¹³⁰ Capital city of Malawi

¹³¹ MWI NGO 1

¹³² ZAM NGO 1

only related to adaptations of infrastructure at schools, but also considering the learner to teacher ratio, availability of learning and teaching material, assistive devices such as hearing aids, glasses, wheelchairs and more, as well as improvements of the roads to the schools and support to transport for families living a long distance from the schools. The findings chapter has showed that the teachers need comprehensive training and education to be able to include learners with deafblindness, and that the training that so far has been provided is only sufficient to begin to include children with mild to moderate disabilities. The findings chapter has showed that many children in both Malawi and Zambia face challenges with the languages of instruction they are exposed to in the schools, and that cultural perceptions about disabilities represent a barrier to inclusion for children with deafblindness.

6. Theoretical framework

This chapter describes the theories that are used to analyze and critically reflect on the research findings. Subsection ‘6.1. Quality Education’ describes ‘education’ and ‘learning’ as concepts, before describing a global education discourse, languages of instruction, and culture and identity. To understand how children with deafblindness are located within the inclusive education discourse, it is necessary to position the inclusive education discourse within the global education discourses and describe the epistemology that underpins the global architecture of education. Describing the global architecture of education is important because this research argues that the education systems in Zambia and Malawi are heavily influenced by this Western discourse. Subsection ‘6.2. Meaning making’ deepens the perspectives on the concept of ‘learning’, and describe theories for how learning and cognitive development takes place. These theories are then discussed in relation to deafblindness. Subsection ‘6.3. Stigma theory’ discusses components and manifestations of stigma, and draws on a study from Nigeria to highlight how stigma can affect educational choices made by parents. Subsection ‘6.4. Inclusive education’ presents some theories about how inclusive education is understood, and discusses some of the terms used within the discourse. The section continues with a discussion about inclusive education as a Western educational discourse. The final subsection describes how inclusive education is theorized in this research, drawing on what is presented throughout the whole theoretical framework chapter, and the concepts presented in chapter ‘3. Conceptual framework’. This operationalization of inclusive education provides a framework through which the research findings will be analyzed.

6.1. Quality Education¹³³

This section presents education from a broad perspective. Inclusive education for children with deafblindness is not developed in a vacuum, but is influenced by larger educational discourses. This section describes the how ‘quality education’, as a part of a development discourse, is framed within the global architecture of education. The first subsection clarifies ‘education’ and ‘learning’ as concepts. The second subsection describes epistemology and the global architecture of education to understand the discourse in which inclusive education is framed. The third subsection describes how culture, identity and education is linked. The fourth subsection describes the importance of language in education and identity construction.

¹³³ ‘Quality Education’ is title of the fourth Strategic Development Goal (United Nations, 2019).

6.1.1. Education and learning

Before describing ‘inclusive education’, the terms ‘education’ and ‘learning’ need to be clarified. ‘Learning’ and ‘education’ is the process or action where knowledge is developed, transmitted and acquired, memorized and reproduced, understood and internalized. Learning and education make persons perceive something in new ways, changing them as persons (Carnell & Lodge, 2005, p.208). Education has a number of purposes. According to Freire (2005) the purpose of education is to develop a critical consciousness, or ‘conscientização’ to enable people to understand and recognize social, political and economic injustice, and contribute to a change their own situation and the society in which they live (Freire, 2005, p.109, 35-36 & 67). Woods (2005) describe the purpose of education as a process of passing on cultural values and beliefs; to promote personal, economic and social equality; and to promote personal freedom, tolerance, peaceful societies and social justice (Woods, 2005, p.84-85).

Education can be formal, informal and non-formal. Formal education is delivered in chronologically structured schools, universities and colleges, taking use of national standardized programs (Raynor, 2008, p.121; Carm, 2018). Non-formal education can be described as any systematic and organized learning activity that is done outside the frames of the formal school system “to provide selected types of learning to particular subgroups in the population, adults as well as children” (Carm, 2018). Informal education can be described as lifelong learning activities and knowledge transmitted and acquired outside of non-formal or formal structures where people acquire and accumulate “skills, knowledge attitudes, and insights from daily experiences and exposure to the environment, and is generally unorganized and unsystematic” (Carm, 2018; Raynor, 2008, p.122).

6.1.2. Epistemology and the global architecture of education

Breidlid (2013) describes ‘epistemology’ as ‘theory of knowledge’, meaning “the nature, scope and sources of knowledge”, or how “people view and make sense of the world according to what they have learned and what they believe” (Breidlid, 2013, p.2). Development of knowledge happens through repeated interaction between already acquired knowledge and new occurrences, which will confirm, disconfirm and recreate people’s knowledge. What people

know, how they view the world is closely linked to the context and culture they are situated within.¹³⁴

Breidlid (2013) describes that Western epistemology has a dominating position over education systems in the South. This has a major impact on how people's identity is constructed, often leading to people in the South being marginalized and subalternized (Breidlid, 2013, p.1; Odora Hoppers, 2002, p.17; Shiza & Makuvaza, 2017, p.3-4). According to Tucker (1999) a development discourse located within an imperial process transforms people to 'objects' where "developed" countries manage, control and even create the Third World economically, politically, sociologically and culturally" (Tucker, 1999, p.1). This means that some people's lifestyles, values, imagination, and hopes are shaped by other people who do not share their lifestyles, values, imagination, or hopes. This process is obscured in a discourse where 'development' is portrayed as a "necessary and desirable process, as human destiny itself" (Tucker, 1999, p.1). According to Breidlid (2013) Western science and knowledge have enjoyed a hegemonic global position since the period between 1400-1600 AD. Since then, there has been a perception of European superiority, contributing to military, economic, political, and epistemological domination over countries in the global South (Breidlid, 2013, p.7). European secular and universalistic thinking with an ideal of a reasoned and independent individual "as the source of all knowledge and experience" was shaped by philosophers like Descartes and Locke (Breidlid, 2013, p.8; Tuhiwai Smith, 2012, p.62). However, according to Tucker (1999) this 'universality' was not universal, but a Christian and European secularity created by the struggle between the Church and science in Europe. In addition, 'development' is not a natural process or a transcultural concept with universal validity, but Western myth without equivalents in many languages, and can as such not easily be replicated in countries in the South (Tucker, 1999, p.2). Hegemony of Western knowledge originates from a specific way in which European intellectuals, academics, scientists, teachers, and writers have described the 'Orient'. The concept of, and knowledge about the 'Orient' and the 'Oriental' has been generated and created out of an unequal power relationship (Said, 2003, p.40). Tucker (1999) describes that this has created a descriptions and understandings of countries and societies in the South based on "historical imagination" where cultures are reduced to frozen stereotypes, and where development discourses have been used to legitimize human exploitation, colonialism, slavery, and genocide (Tucker 1999, p.8).

¹³⁴ See also '1.4. My position as a researcher' and '4.1. Ontological and epistemological basis for the research' for information about the ontological and epistemological assumptions this research is located within.

Western epistemology's hegemonic position is linked to what can be described as the 'global architecture of education'. Jones (2007) describes the global architecture of education as a "complex web of ideas, networks of influence, policy frameworks and practices, financial arrangements and organizational structures—a system of global power relations that exerts a heavy, even determining, influence on how education is constructed around the world" (Jones 2007, p.325).

Jones (2007) describes that much of today's professional and academic life can be understood in terms of the global reach of transnational academic and epistemic communities and networks. Academic and epistemic communities and networks interact with states, transnational organizations, civil society, and the private sector to influence policy development and implementation through research, and methods of creating and confirming knowledge (Jones 2007, p.330). Knowledge production about the South is carried out in an unequal power relationship where resourceful Western scholars too often are the ones carrying out studies about the South, while Southern scholars are deprived of resources to neither study the South, nor the West/North. This has resulted in a situation where scholars, students and people in the South "can no longer recognize themselves in the discourses that claim to portray them" (Tucker, 1999, p.13). This creates an epistemological gap that according to Breidlid (2013) is found in teaching methods and contents in classrooms in today's South. The contents and methods used are only "minor adaptations of what is being taught in the West/North", something that makes it difficult for students in the South to understand because "their own cultures and worldviews are seldom, if ever", considered "beyond their folkloristic aspects" (Breidlid, 2013, p.2-3).

6.1.3. Culture and educational quality

'Culture' is a wide concept not easily captured in a single definition. According to Engen (2011) culture can be described as a collective consciousness, meaning the perspectives, evaluations, and knowledge shared by a specific group of people. This implies that people's collective consciousness must be explained closely related to their social context, and that this consists of a set of techniques used by people to "systematize, explain and legitimize the world which surrounds them" (Engen, 2011, p.256-257). According to Breidlid (2015) citing Hofstede (1991) culture can be described as a collective mind soft-ware (Breidlid, 2015, p.14). Culture is always changing influenced by the members of a specific cultural community, and other

people and events outside of the community. People usually belong to several cultures, both on micro and macro level, something that influences individual perspectives on the cultural communities and world, contributing to a constant change in all cultural communities. ‘Culture’ is often used in combination with other terms to create concepts such as ‘learning culture’, ‘school culture’, and ‘national culture’. Contextualized this way ‘culture’ is used to describe shared understandings, values, and norms, or in in layman’s terms: “the way we do things around here” (Coleman, 2005, p.63).

Breidlid (2015) argues that many children in classrooms in the South experience a conflict between forms and content in teaching, and their home experiences. According to Breidlid (2015) this cultural and epistemological conflict between the homes and the classroom environment is an “overarching reason for the general unreceptiveness among students” (Breidlid, 2015, p.12). Breidlid (2009) describes that curricula found in many sub-Saharan African countries are copies and adaptations of Western curricula, failing to include indigenous knowledges dominant in the student’s home cultures. Vavrus (2009) confirms this by describing how teacher students struggled with transforming theoretical knowledge to practice, because they did not have “a cultural framework in which to place the discourse and methods used in our class” (Vavrus, 2009, p.306).

6.1.4. Language, identity and educational quality

The word in language is half someone else’s. It becomes ‘one’s own’ only when the speaker populates it with his own intention, his own accent, when he appropriates the word, adapting it to his own semantic and expressive intention. Prior to this moment of appropriation, the word does not exist in a neutral and impersonal language (it is not, after all, out of a dictionary that the speaker gets his words!), but rather it exists in other people’s mouths, in other people’s concrete contexts, serving other people’s intentions: it is from there that one must take the word, and make it one’s own. And not all words for just anyone submit equally easily to this appropriation, to this seizure and transformation into private property: many words stubbornly resist, others remain alien, sound foreign in the mouth of the one who appropriated them and who now speaks them; they cannot be assimilated into his context and fall out of it; it is as if they put themselves in quotation marks against the will of the speaker. Language is not a neutral medium that passes freely and easily into the private property of the speaker’s intentions; it is populated – overpopulated – with the intentions of others. Expropriating it, forcing it to submit to one’s own intentions and accents, is a difficult and complicated process. (Bakhtin 1981, pp. 293-294)

The seasoned reader will undoubtedly notice that this quote from Bakhtin (1981) is an often-used quote, and that this thesis uses a much longer quote than what is common. The quote is

often used to describe the dialogical development of the mind, knowledge and language (Linell, 2009, p.76), or challenges with translations between languages (Daniels, 2009, p.25). In this extended form, the quote shows that Bakhtin (1981) places emphasis on the contextual situatedness of language development, and the challenges that can arise when trying to use, or forcing the use, of a word or a language that is not your own. The importance of context in language development has been emphasized by several scholars: for example, Linell (2009) states that we become persons through interaction with other people, a process in which communication and language are particularly important aspects. People borrow words in interaction with others within a sociocultural framework. For this reason, context becomes essential to language: people depend on prior experiences and knowledge to be able to appropriate and conceptualize the meaning transmitted through language (Linell, 2009, pp.77-79). In a similar line of reasoning, Breidlid argues that (2009) students face difficulties with grasping new concepts when they are different from their own cultural environment to an extent that makes it challenging to find good words for a concept in the student's familiar language (Breidlid 2009, p.146). Piper, Zuilkowski and Ong'ele (2016) state that a mismatch between students' mother tongue and the language of instruction in many sub-Saharan African countries can be one explanation for students' challenges with learning (Piper, Zuilkowski & Ong'ele, 2016, p.776). It thus becomes evident that language of instruction must be considered in efforts to bridge the epistemological gap between knowledge systems (Breidlid 2009, p.146).

According to Ssebbunga-Masembe, Mugimu, Mugagga, and Backman (2015), language in education policies must acknowledge linguistic diversity, as it impacts the student's ability to learn. The language used in the learning process is a crucial factor "because the transfer of knowledge and skills is mediated through the spoken or written word" (Ssebbunga-Masembe, Mugimu, Mugagga & Backman, 2015, p.172). Several studies document that it is advantageous for the learning outcome to be taught in a familiar language, and that learning academic and conceptual skills in a familiar language also promotes learning of other languages (Breidlid, 2013, p.60-61; Brock-Utne, 2015 p.2; Ssebbunga-Masembe et al. 2015, p.176; Piper et al., 2016, p.790; Biseth, 2008, p.5).

Ssebbunga-Masembe et al. (2015) describe that foreign languages as language of instruction in schools is a threat to identity formation of the individual, and a threat to African identity. This can compromise African thinking and values because the foreign languages that are used in education come from very different cultural, economic, and social contexts. According to

Ssebbunga-Masembe et al. (2015) it is only possible to properly communicate African cultural history through languages that are linked to the different African cultural contexts (Ssebbunga-Masembe et al. 2015, p.176). Ngũgĩ wa Thiong'o (1986) describes that language as a carrier of culture, history, values and identity is inseparable from the community in which it is used. Forced use of the language of the colonizers led to a colonization of the mind, and affected how people see themselves in relation to the world. Being taught in a foreign language can result in alienation of children from their history, culture and identity (Ngũgĩ, 1986, p.15-16; Tuhiwai Smith, 2012, p.38; Breidlid, 2013, p.11; Biseth, 2008, p.7).

6.2. Meaning making

This section describes theories for how learning and cognitive development takes place, and how these theories are applied to persons with deafblindness. The first subsection describes how 'dialogism' describes cognitive development and how people understand themselves and others, and present monologism as a counter-theory to dialogism. The second subsection describes Vygotsky's (1978) theory of the zone of proximal development as a pedagogical frame for how learning takes place. The third subsection describes how people with deafblindness depend on a limited register of sensory inputs to make meaning, highlighting the importance of the interaction partners. This is explained by drawing on both dialogism and the theory of the zone of proximal development.

6.2.1. Dialogism vs monologism

Linell (2009) describes 'dialogism' as an epistemological theoretical framework for how people acquire knowledge and ascribe meaning to the world they are a part of. According to Linell (2009) 'dialogicality' is an ontological assumption within dialogism, meaning that all human beings are interdependent with other human beings, and the nature of the mind is developed through contextually situated interactions in self-other relationships (Linell, 2009, p.30). Within this theoretical framework human beings are viewed as social beings totally interdependent with others. This points to a unity between self and other, a dependency on 'other' to become 'one-self'. The 'other' is not necessarily a physical person, but an inner representation of 'others' (*alter*) in the mind of one-self (*ego*). Human cognition can then be described as a conversation between alter and ego. The 'other' is diversified into direct interaction partners, generalized others, and peripheral others, leading to a corresponding complexity in the dialogical self (Linell, 2009, p.69). Dyadic oppositions form the basis for how people make sense of the world. To understand what is argued for, one must understand what is being argued

against. Good is understood as the dyadic opposite of bad, moral the opposite of immoral. Dichotomies emerge when dyadic oppositions make up mutually exhaustive and exclusive categories. What fits in one category cannot fit in the opposite (Marková, 2016, pp.1-8¹³⁵; Linell, 2009, p.35). Dialogism suggests that instead of viewing ‘self’ and ‘other’ - or other dyadic oppositions - as dichotomies, they should all be understood as a part of a unity, and co-constructive of selves (Eilertsen, 2016, p.17 in article three; Linell, 2009, p.42).

Linell (2009) describes dialogism as a counter-theory to monologism. Within monologism, communication is conceived as a transfer of messages from a sender to a receiver. Language is then understood as a system of more fixed meanings and static signs, where context is perceived as external to languages, communication and thinking (Linell, 2009, p. 36; Marková, 2016, pp.1-8¹³⁶). The role of individuals and ‘others’ in monologism differs from dialogism. In monologism human beings are viewed as rational autonomous individuals, instead of parts of a socio-cultural group. Dialogism assumes that other people have other perspectives, opinions, and types of knowledge, or in other words – that people have a ‘theory of mind’, meaning that others have a mind of their own. Acknowledging that people have other perspectives, opinions and knowledge – a theory of mind – can help to understand other people’s meanings and intentions. Sense-making in everyday life will then depend on engagements and relations with other people over time (Linell, 2009, pp.42-43). Monologism on the other hand, with an individualistic perspective, views other minds as something that is problematic to understand because the self is the origins of knowledge. Others then become other individuals with their own perspectives and agencies. Monologism is, according to Linell (2009), “a part of a major tradition in Western philosophy and science, which has tried to reduce the world to rational individual subjects” (Linell, 2009, p.45).

Using dialogism in this thesis is relevant for several reasons. Firstly, as section ‘6.4. Inclusive education’ shows, one important basis in the inclusive education discourse is to adapt the education to each learner. This necessitates a mutual dialogue between the individual learner and the system surrounding the learner, to understand the individual’s strengths, needs, and preferences. From this perspective it can be argued that ‘inclusive education’ in its theoretical and ideological form is underpinned by dialogism. Dialogism is applied to analyze the extent to which governments and international organizations in Malawi and Zambia have implemented

¹³⁵ Online edition. Individual pages are not numbered, chapters indicated by first and last page.

¹³⁶ Online edition. Individual pages are not numbered, chapters indicated by first and last page.

inclusive education in a mutual dialogue with the teachers, learners, and parents. Dialogism is also a common theory used to analyze interactions and communication related to persons with deafblindness, something that will be showed in subsection 6.2.3. Finally, the difference between dialogism and monologism is applied to explain some of the challenges that are encountered when people with different ontological and epistemological assumptions and backgrounds meet in an unequal power relationship. In this thesis: the meeting between Western education systems and its promoting agents, and children in schools in Malawi and Zambia, with or without disabilities.

6.2.2. Zone of proximal development

Vygotsky (1978) describes the zone of proximal development as the distance between a person's actual development level, and the prospective development level. Functions that are in the zone of proximal development one day; "the "buds" or "flowers" of development", will be the actual development level a future day (Vygotsky, 1978, p.86). With this model Vygotsky (1978) describes how individuals develop competencies and ideas assisted in individually situated interactions (Vygotsky, 1978, pp.86-87). Turned into practice, cognitive development can be viewed as almost imperceptible increments over time in a process where knowledge, language, and all types of activities are initially scaffolded by a more competent partner through social participation and imitation, until it becomes part of a person's "competence repertoire" (Böttcher & Dammeyer, 2016, p.16; Linell, 2009, p.85; Daniels, 2009, pp.26-27)

Thybo (2013) describes that if a newly introduced word, knowledge or activity is close to prior experiences and knowledge, this consolidates already acquired knowledge, and enables acquisition of new knowledge. People are at risk of failing to acquire new knowledge if newly introduced words, knowledge or activity is far from the already consolidated knowledge. According to Thybo (2013) this can lead to loss of motivation and some may experience a "destructive feeling of defeat" (Thybo, 2013, p. 300-301, translated from Danish).

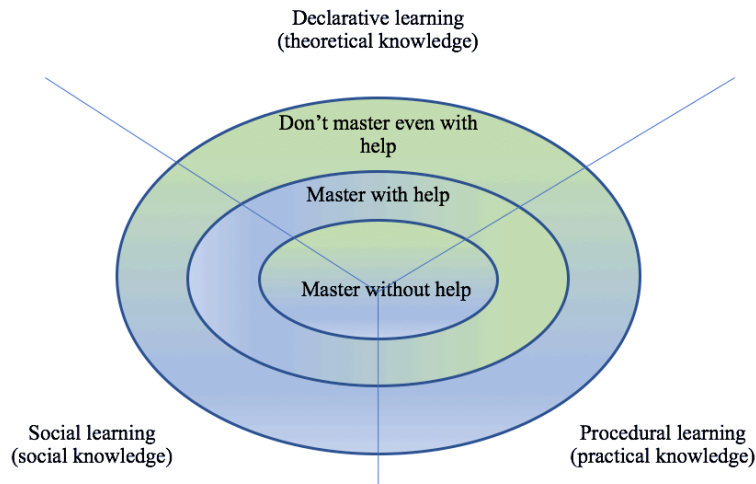


Figure 1. Zone of proximal development. Thybo, 2013, p.300. (Own translation from Danish)

New knowledge should therefore build on prior knowledge and be presented in a coherent form where social, procedural and declarative learning is combined. This will enable children to develop robust consolidated knowledge (Thybo, 2013, p.305-306; Richey & Nokes-Malach, 2015). Applying the theory of the zone of proximal development to what is described above regarding epistemology, language and culture, the model can be used to describe how teaching in many classrooms in the South may be at risk of being in the third zone shown in figure 1, which mean that learners will not master to acquire knowledge, even with help, because the knowledge and languages used are far removed from the already consolidated knowledge.

6.2.3. Meaning making from a limited register of sensory inputs

According to Ask Larsen (2003) inputs to the brain come from three mains sources. The first is the body's sensory system taking up information from external stimuli (exteroceptive stimuli). The second source is kinesthetic stimuli that are produced from the balance and motor systems within the body (proprioceptive stimuli). The third source is stimuli from inner sensations like hunger, pain, and arousal (interoceptive stimuli). In addition, Ask Larsen (2003) includes cognition and consciousness as an important source to the brain giving input to the brain itself. Distal visual and auditory stimuli, i.e. stimuli coming from a distance, are normally the most prominent sources of external stimuli to the brain. Persons with congenital deafblindness have limited to no sensory stimuli from these distal senses, meaning that the brain receives exteroceptive stimuli from a limited register of bodily senses. This means that persons with congenital deafblindness depend on inputs to the brain from tactile sensory stimuli, proprioceptive stimuli, and interoceptive stimuli to perceive and cognize information, and that a large part of mental representations are created from bodily experiences (Ask Larsen, 2003,

p.49; Souriau, Vege, Estenberger & Nyling, 2008, p.16). Ask Larsen (2003) suggests four perceptual modes for how impressions from the surroundings can leave mental and physical traces for persons with congenital deafblindness. The first is the perceived inner state (interoceptive; hunger, pain, emotions, etc.), the second is perceived movement of the body (proprioception), the third is tactile sensations (exteroceptive), and the fourth is perceived location (extero- and proprioception combined) (Ask Larsen, 2003, p.49; Nafstad & Rødbroe, 2013, pp.42-43). This means that persons with deafblindness will understand the nature of the world they live in a different way than people who get impressions from the world through a larger register of senses; the ontological assumptions are different. This also means that the way persons with deafblindness acquire and develop knowledge about the world is different; the epistemology is different. As persons with deafblindness belong to an extremely heterogeneous group, the ontological assumptions and the epistemology will also be different from one person with deafblindness to another. Souriau (2009a) refers to the interaction between a person with congenital deafblindness and a hearing and seeing partner as an interaction between two different cultures, threatening the power symmetry in the relationship. Persons with deafblindness depend on the ability of the interaction partner to imagine and understand the ontological and epistemological assumptions of the person with deafblindness. This is a time consuming and resource demanding process, and requires that the interaction partner must be touched and engraved by the same impressions that the person with deafblindness experiences (Souriau 2009a, p.16).

Nafstad and Rødbroe (2013) draw on dialogism to describe the dynamic relational processes that can bridge the ontological and epistemological gap, and give a person with deafblindness her own voice in a dialogue. Sharing experiences, doing the same activities, and exploring the same elements in the surroundings can be a way for an interaction partner to attempt to be touched and engraved by the same impressions as the person with deafblindness. This can lead to a situation where a person with deafblindness may experience that her perspectives are interesting for the other. The 'other' should here be understood as the *alter*, the inner representation of the other. This can give a person with deafblindness an opportunity to take a role as co-author in producing shared meaning in a dialogue. The co-created meaning is dependent on responses and contributions from the other (alter). This is contrasted by monologism, where a communicated message is understood as having a fixed meaning, stated by one communication partner, and decoded by the other (Nafstad & Rødbroe, 2013, pp.33-34; Souriau et al., 2009, pp.17-18).

The theory of the zone of proximal development is also important when it comes to children with deafblindness. Nafstad and Rødbroe (2013) describe that it can be difficult to identify the zone of proximal development for a child with deafblindness, because it can be difficult to understand the signs and indications of when the child has acquired a new skill and is ready to move on. This leads to a risk that the child does not develop according to her potential, and becomes bored (Nafstad and Rødbroe, 2013 p.26). On the other hand, teaching that is not within the zone of proximal development can be experienced as “too overwhelming, too sudden, too complex,” something that may confuse and stress the child and make her withdraw from a learning situation (Janssen & Rødbroe, 2006, p.54; Janssen & Rødbroe, 2007, p.31).

6.3. Stigma theory

Stigma theory can be used to further understand barriers to inclusive education and educational opportunities for persons with deafblindness. This subchapter describes components and manifestations of stigma, and draws on a study from Nigeria to show how stigma can influence educational choices.

Link and Phelan (2001) argue that stigmatizing processes likely have strong effects on how life chances like “earnings, housing, criminal involvement, health, and life itself” are distributed (Link & Phelan, 2001, pp.363 & 382), and are tied to processes of exclusion and devaluation that can limit an individual’s opportunities. Goffman (1963) initially defined stigma as “an attribute that is deeply discrediting”, which contributes to the bearer of said stigma being reduced “from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p.3). Many definitions of stigma focus on the recognition of difference, and a following devaluation, as two essential components of the concept (Bos, Pryor, Reeder & Stutterheim, 2013, p.1). Goffman (1963) emphasizes that stigma should be seen as contextual and based in the relationship between a particular attribute and the specific stereotypes associated with it in a given context. An attribute that leads to stigmatization in one context might be perceived as usual in another (Goffman, 1963, pp.3-4). Stigma is seen as grounded in social interactions, and therefore not based in the person, but the social context the persons find themselves in, and is as such a social phenomenon (Bos et al., p.1).

6.3.1. Components of stigma

Stigma is a complex concept and includes a variety of processes and components. Link and Phelan (2001) argue that stigmatization occurs at points where four interrelated components converge, the first of these being a distinguishing and labelling of differences (Link & Phelan, 2001, p.367). This process determines which factors, points of identity, and differences are perceived to matter socially. The process of labelling relies on simplification in order to create broader groups, i.e. assigning heterogeneous groups of people into one overarching category (Link & Phelan, 2001, p.367). Grouping can sometimes lead to oversimplification. Examples of oversimplified categories could be “women” or “disabled”, neither of which are groups who should be understood as homogeneous. This process is also highly context dependent, and which attributes are determined to be salient will differ greatly in different contexts (Link & Phelan, 2001, p.367). The second component outlined by Link and Phelan (2001) is that dominant cultural beliefs link “labelled persons to undesirable characteristics” and negative stereotypes (Link & Phelan, 2001, pp.367-369). This linking of specific attributes and corresponding stereotypes is an often “automatic” process to facilitate “cognitive efficiency”, and thus happens without conscious thought, especially in “split-second decisions” (Link & Phelan, 2001, p.369). The third component is that labelled persons are placed in distinct groups to create clear separations between perceived “us” and “them” categories (Link & Phelan, 2001, pp.367 & 370). The linking of negative attributes to specific groups makes such a clear us/them separation desirable, and “becomes the rationale for believing that negatively labelled persons are fundamentally different from people who don’t share the label” (Link & Phelan, 2001, p.370). Finally, the labelled persons experience discrimination and loss of status as a component of stigma (Link & Phelan, 2001, p.370). The components outlined form the basis on which the rationale for “devaluing, rejecting, and excluding” the labelled individuals is formed (Link & Phelan, 2001, p.370). In this way, stigma becomes a complex process of interrelated components that support and amplify each other, contributing to discreditation and devaluation.

6.3.2. Manifestations of stigma

Stigma can manifest in a variety of ways, and Pryor and Reeder’s (2011) conceptual model outlining four interrelated manifestations of stigma provides a useful framework for understanding some of the ways in which stigmatization concretely affects persons with deafblindness with regards to educational opportunities (Pryor & Reeder, 2011, p.791; Bos et al. 2013, p.2).

Bos et al. (2013) describe that the first manifestation of stigma outlined by Pryor and Reeder (2011) is public stigma, representing “people’s social and psychological reactions to someone they perceive to have a stigmatized condition” (Bos et al., 2013, p.2). This can trigger negative behavioural reactions both from the stigmatizing and the stigmatized. These reactions can be implicit – immediate and reflexive, or explicit – derived from a rule-based system and involving conscious action (Bos et al., 2013, pp.2-3). Negative reactions like anger seem to be more common if the stigmatized is somehow perceived to bear personal responsibility for their condition (Bos et al., 2013). This connects to Falk’s (2001) ideas of existential and achieved stigma, where the former refers to determined conditions like race, and the latter refers to situations in which being prescribed to belong to a stigmatized group can somehow be connected to the stigmatized’s own actions (Falk, 2001). Bos et al. (2013) suggest that high levels of perceived responsibility for achieved stigma can lead to stronger negative reactions (Bos et al., 2013, pp.3-4).

The second manifestation of stigma is self-stigma, or the “social and psychological impact of possessing a stigma” (Bos et.al. 2013, p.2). Self-stigma is in many ways based in public stigma, which can impact the self in different ways: enacted stigma, or the negative treatment of a stigmatized person; felt stigma, where the stigmatized person expects or experiences stigmatization; and internalized stigma, which describes psychological distress and reduced self-worth as a result of public stigma (Bos et al., 2013, p.3). Thirdly, stigma can also manifest in negative reactions to people connected to stigmatized individuals or groups, or “*stigma by association*” (Bos et al., 2013, p.2, *Italics* in original). Research shows that friends, family, caregivers and other persons connected to the stigmatized themselves experience devaluation as a result of this connection. Stigma by association is connected to “lover self-esteem and psychological distress” (Bos et al. 2013, p.4). Finally, stigma can manifest as structural stigma, which refers to how societal institutions and ideologies contribute to the perpetuation and exacerbation of stigmatization (Bos et al., 2013, p.4; Corrigan & Lam, 2007). Recent literature has found that stigma “is perpetuated by hegemony and the exercise of social, economic and political power”, and can further inequalities (Bos et al., 2013, p.4).

A recent study from Nigeria shows that stigma can impact the educational choices that parents make on behalf of their children with special education needs. The study shows that the impact of stigma makes parents more often prefer private special schools rather than mainstream schools, or that they keep their children at home to protect them (Uba & Nwoga, 2016,

p.975&986). Most of the mothers in the study reported to have experienced discrimination and devaluation from their community, sometimes even from schools (Uba & Nwoga, 2016, p.984). Uba and Nwoga (2016) argue that stigmatization of persons with disabilities might be rooted in superstition or what they term a “superstitious construction of reality” – with one participant expressing that the community believed her son with special education needs was cursed or possessed as a result of wrongdoing by their ancestors. This indicates that spiritual understandings of reality might still be a dominant way of seeing the world in several African countries (Uba & Nwoga, 2016, p.984), and that stigma in this context might be better understood in connection with such worldviews.

6.4. Inclusive education

This subchapter opens with a subsection describing how inclusive education is understood by different scholars and practitioners. The second subsection provides a critical perspective on some of the discursive terms and concepts used in literature and research about inclusive education. The third subsection links the inclusive education discourse to the global architecture of education, and describes a rising call to decolonize inclusive education. The fourth subsection describes the theoretical approach to inclusive education, and outlines three dimensions of inclusive education to understand and analyze the research findings.

6.4.1. Theories of inclusive education

The General comment No.4 (GC4) issued by the United Nations Committee on the Rights of Persons with Disabilities, provides a legal definition of inclusive education as described in subsection 3.2.3. However, it is challenging to operationalize the definition into a universal understanding of what inclusive education should look like. Some understand inclusive education as related to how a school or a community welcomes a child with special education needs and values their contributions and the diversity this brings. Inclusive education is also understood as the process of reducing barriers to participation, and granting membership in a community where all needs are seen and met (Hick, Kershner & Farrel, 2009, p.2; UNESCO, 2017, p.192-193). Some understand inclusive education as participation of children with disabilities in schools “in their home community in ordinary/regular classes with peers of their own age” (Mariga et al., 2014, p.27; Hick et al., 2009, p.2), while others state that inclusive education is not a “one-size-fits-all approach” with all students in the same “classroom all the time, regardless of support needs”, but something that can be found in non-formal settings like

home-based and community-based settings (MacQuarrie & Laurin-Bowie 2014, p.42; Enabling Education Network, 2018).

Inclusive education is also described by drawing lines to indigenous education in Africa, highlighting some similarities. Stubbs (2008) describes indigenous education as:

“based on strong family ties and the value of the individual (...); used flexible formats and locations, responding to individual learning needs; used any convenient physical or social space and all community members as resources; had relevant and functional content and methods, such as: cooperative and collaborative learning, child-to-child, peer tutoring, learning-by-doing and apprenticeship in real life” (Stubbs, 2008, p.27).

According to Qvortrup and Qvortrup (2018) one understanding of inclusive education has become prominent. They refer to the ‘Manchester definition’ which states “Inclusion is the continuous process of increasing the presence, participation and achievements of *all children and young people* in local community schools (Qvortrup & Qvortrup, 2018, p.803, *Italics in original*). The emphasis is on *all children*, where inclusion is not limited to be something only related to groups labeled as having ‘special needs’ or ‘disabilities’. Some key ideas are similar across the theories of inclusive education. Inclusive education is about increasing participation and preventing exclusion from enjoyment of educational services, and about participation in communities and culture (Antia, Stinson & Gaustad, 2002, p.214; Florian & Black-Hawkins, 2011, p.814). Inclusive education remains a complex, contested, and controversial issue where the practices at classroom level are not clearly described (Qvortrup & Qvortrup, 2018, p.804; Hick et al., 2009, p.2; Florian & Black-Hawkins, 2011, p.814).

To solve the challenges with describing what inclusive education is, the concept is often described as an opposite to what it is not. Mariga et al. (2014) states that: “Inclusion and inclusive education is not another name for special education needs”, but it is a “common vision that covers all children of the appropriate age range and the conviction that it is the responsibility of the *regular* system to educate all children” (Mariga et al., 2014, p.25, *Italics added*). The dyadic opposite to the *regular* is the *irregular*, in this case special needs education, which view “the child as the problem, not the system or the teacher. It defines the whole child solely on the basis of his/her impairment and segregates them on this basis” (Mariga et al., 2014, p.28; Stubbs, 2014, p.43; Ministry of Education Science and Technology – Malawi, 2016, pp.4¹³⁷). What becomes clear is that the two entities are presented in a dichotomous framework

¹³⁷ The direct quote is from Mariga et al. 2014, p.28, but all three sources use almost the exact same sentence.

where inclusive education is seen as the regular, viewing the system and the teachers as the problem, while special schools are irregular, and view the child as the problem (Stubbs, 2008, pp.43-44). de Beco (2014) confirms the dichotomy when stating that inclusive education is “obviously not equal to education in special schools, which would lead to a segregated education system” (de Beco, 2014, p.275). Units and special classrooms are also often categorized as an opposite to inclusive education, that even if it is attached to a mainstream inclusive school it is still “based on the same philosophy as special schools. This practice promotes exclusion and is therefore a strategy to avoid” (Mariga et al., 2014, p.28; Stubbs, 2014, p.44; Ministry of Education Science and Technology – Malawi, 2016, p.4).

Some of the challenges with describing inclusive education as a dichotomy to special education and education in units and special classrooms become apparent when scholars and practitioners describe children with comprehensive and complex disabilities. To illustrate this point, two quotes from Mariga et al. (2014) are interesting. Mariga et al. (2014) initially state that:

People will often argue that children with severe disabilities cannot be taught in ordinary classrooms. This is a very good example of how education systems need to change. Education in its true sense does not mean only reading and writing. For learners with severe disabilities, it means being equipped with functional skills that enables them to be part of the family and community. For the severely disabled, inclusion and recognition by society is of great importance to their future life as citizens of their local community. (Mariga et al., 2014, p.30)

This quote serves to illustrate that when describing children with ‘severe disabilities’, the writers attempt to broaden the perspectives on education stating that it is more than ‘reading and writing’, it is also about functional skills. With the already presented dichotomy, this functional skills training should then be expected to happen within mainstream classrooms. In a second quote Mariga et al. (2014) provides an answer to this:

In fact, throughout history and across cultures, there are many forms of education based on particular philosophies, spiritual and religious beliefs or systems. One tradition uses non-formal approaches and is often relevant, practical, and flexible, oriented to local cultures and people, and utilising local resources and personnel. Priority is given to preparation for real life; that is activities of daily living, employment and citizenship. [...]. Mariga et all [sic] (1986) used these approaches in rural Africa and experience suggests that they lead to the acceptance of the persons with severe disabilities and their general inclusion (Mariga et al., 2014, p.30).

According to this, the answer is non-formal education, which per definition happens outside of the formal school structures. This means that according to Mariga et al. (2014) there are really

only two possibilities: children with complex and comprehensive impairments like deafblindness have an option between attendance in a mainstream classroom and non-formal education. It is contractionary that Mariga et al. (2014) present non-formal education as the answer to “changing the educational system” (Mariga et al., 2014, p.30). Mariga et al. (2014) offers no explanation as to who should take responsibility, or implement the non-formal education suggested. With this, Mariga et al. (2014) pushes children with deafblindness out of the education system.

The seasoned reader will critique this subsection for discussing the theories of Mariga et al. (2014) and Stubbs (2008), and critiquing their more narrow theories of how inclusive education is understood, and not discussing other theories that open for alternative educational settings, sensory rooms, etc. (MacQuarrie & Laurin-Bowie 2014, p.42; Enabling Education Network, 2018). The reason for the choice of this focus is that Stubbs (2008) and Mariga et al. (2014), have had a strong influence on how inclusive education is described in a sourcebook about inclusive education developed by the Ministry of Education Science and Technology – Malawi (2016). In fact, if the three sources are compared it is clear that Stubbs (2008) has been a source for the writings of Mariga et al. (2014). Many of the statements in Mariga et al. (2014) are almost the same, or exactly the same as in Stubbs (2008). The Ministry of Education Science and Technology (2016) references both sources, and uses a text that is more or less a copy of Mariga et al. (2016) when describing inclusive education. The perspectives of Stubbs (2008) and Mariga et al. (2014) have had a strong influence on how inclusive education is understood in Malawi, and are for this reason discussed here. A similar sourcebook for Zambia was not finalized by the end of the fieldwork, and the NGO responsible for developing it has not been willing to share the draft. It is therefore not clear what this sourcebook uses as its theoretical basis. However, as showed in the findings chapter, there were no significant differences in findings between Zambia and Malawi when it comes to how inclusive education is understood.

Inclusive education can be described as a normative theoretical ideology. According to Lindsay (2007) policies are formulated based on research evidence and ideology, where ideology is the strongest of the two (Lindsay, 2007, p.2). The Director of the European Agency for Development in Special Needs Education, Cor Meijer, argued during a speech at the 2010 Madrid conference ‘Inclusive Education: A way to promote social cohesion’, that inclusive education is a normative issue. Meijer’s speech is cited in a synthesis report from the European Agency for Development in Special Needs Education (2012) in this way:

[...] although there is an expectation of clear evidence of the effectiveness of inclusive education for all learners, this is not widely available. Due to the lack of clarity around the terminology, the complexity of the issues involved and also the difficulties in applying 'scientific' methodology, research into this area is often not conclusive. However, Meijer continues: *'the relevance and necessity of social cohesion as well as inclusive education are purely normative issues. And we should keep them there!'* (European Agency for Development in Special Needs Education, 2012, p.8, *Italics in original*).

In this way, Meijer argues that ideology and values, and not research, should guide the inclusive education discourse. According to the European Agency for Development in Special Needs Education (2012) inclusive education is now rooted in the Convention on the Rights of Persons with Disabilities, and it is not necessary to revisit definitions or provide justifications for the discourse. Instead, States, educational authorities and teachers "should commit to key values" (European Agency for Development in Special Needs Education, 2012, p.32). Lindsay (2007) describes that from a human rights perspective on inclusive education, "research evidence is considered at best not central [...] or even irrelevant" (Lindsay, 2007, p.2).

As a normative theory, it can be argued that inclusive education is underpinned by dialogism, as described in 6.2.1. Inclusive education as a theory, and the definition of 'inclusion' described in para. 11 in the GC4, necessitates a mutual dialogue between all actors within the education system. The GC4 describes that 'inclusion' is defined as "a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education" (UNCRPD, 2016, p.3). In para. 35 of the GC4, emphasis is placed on providing education in "languages and means and modes of communication" that is appropriate for the individual child (UNCRPD, 2016, p.10). It is not possible to achieve a systemic reform to make the education relevant to each child, without a dialogical approach where all actors are given a voice, and have an influence over the outcome. Without a dialogical approach, children with disabilities and their parents will not be able to describe how they want the education modified and changed to be adapted to *them*, to their individual strengths, communication forms, languages, contexts, challenges and needs. Without a dialogical approach head teachers and teachers will not have an influence over how they are to adapt the teaching in a way that is relevant to the children they have in their schools and their classrooms. However, academically sound research must inform the implementation of this normative theory, not the norms themselves as Meijer argues above.

6.4.2. Discursive concepts

The English language consists of up to a million words. This does not prevent the same words from frequently being used to describe very different approaches (Gillborn & Youdell, 2009, p.173). Subsection 3.2.3. describes the legal definition of ‘inclusion’ as found in the GC4. ‘Inclusion’ is here defined as a process and a profound structural change where the existing system adapts to all members of the system, and not the other way around. ‘Integration’ is described as a process where membership is granted, but where the member must adapt to the system. In indigenous knowledge discourses, in discussions about how indigenous knowledges¹³⁸ can be a part of the (Western) education system, the term ‘integration’ is commonly used to describe a dialogue between knowledge systems, where the existing system (Western) must adapt to the integrated system (indigenous knowledges), whereas ‘inclusion’ is considered as the new system having to adapt to the existing system (Seehawer, 2018, p.94; Odora Hoppers, 2002, p.20). This means that within different educational discourses the same terms are used in close to opposite ways, contributing to the challenges with operationalization of the term ‘inclusion’.

Some key terms used in inclusive education discourse is ‘disability’, ‘disabilities’ and ‘disabled’. The terms are used to describe the interaction between people with impairments and environmental and attitudinal barriers hindering participation in society¹³⁹, and the terms are used in much of the research about inclusive education (as shown in this section and section ‘1.1. Relevance of research’). Section ‘3.1. Deafblindness’ shows the heterogeneity among persons with deafblindness, and the need for individual approaches to each child. The section does not discuss intersectionality other than pointing to the heterogeneity among people with deafblindness, and the effect of additional impairments. In addition to having ‘deafblindness’, a child with deafblindness is also a *girl*, a *boy*, is *transgender*, comes from a *rich* family, a *poor* family, from a *rural* area, from an *urban* area, has a *sexual orientation*, belongs to a *religious belief system*, belongs to an *indigenous group*, etc. With this it becomes clear that even the term ‘deafblindness’ may be a too broad and overgeneralized term. The GC4 para 4 describes that “lack of disaggregated data and research” is in itself a barrier to inclusion impeding the “development of effective policies and interventions to promote inclusive and quality education” (UNCRPD, 2016, p.1-2). In para. 43 the UN Committee states that “all data

¹³⁸ The term ‘knowledges’ is used intentionally in plural to acknowledge the diversity among indigenous epistemologies. See Seehawer, 2018, p.92; Breidlid, 2013, p.1.

¹³⁹ See definition of ‘disability’ in the preamble of the CRPD

collected and all international assistance spent on education should be disaggregated by impairment” (UNCRPD, 2016, p.12). According to May (2009) advocacy efforts rooted in group-based identities assume a homogeneous conception of the group (May, 2009, p.40). Banks (2009) describes the importance of identity groups to facilitate the realization of human rights. Individuals attain goals more successfully when working in groups. However, identity groups can also hinder realization of individual rights if group unity is not balanced by diversity. Unity without diversity can lead to oppression and hegemony, and diversity without unity can lead to fracturing (Banks, 2009, p.307&310).

The terms ‘disability’, ‘disabled’, ‘deafblindness’ etc. are needed to both describe groups, to fight for the rights of groups, and to describe programs and interventions to change the situation for the groups. The problem arises when the terms are too broad, and not clearly defined. When we know that persons with deafblindness make up an extremely heterogeneous group, making it impossible to describe one way to approach this small group, the terms ‘disability(-ies)’ and ‘disabled’ are far too broad to be used as terms to describe how a group of children can be included in the education system. Research on ‘disability(-ies)’ and ‘disabled’ is also likely to be of limited practical use, if it is not disaggregated by impairment type, gender, age, etc. This can be illustrated with a thought-experiment. Look at one sentence found in the GC4, para. 2, where it is stated: “*only inclusive education* can provide both quality education and social development for persons with disabilities, and a guarantee of universality and non-discrimination in the right to education” (UNCRPD, 2016, p.1, *Italics added*). Knowing that it remains unclear what ‘inclusive education’ actually means, and that ‘disabilities’ is an overgeneralized term - would this sentence be acceptable if ‘persons with disabilities’ was replaced with ‘girls and women’?

6.4.3. Decolonizing inclusive education

According to Muthukrishna and Engelbrecht (2018) there is a rising global call for decolonization of education in countries in the Global South. Decolonizing education is about recognizing that knowledge production is closely linked to power and that individuals know, act, and think from a particular position. Within debates about decolonization, some have critiqued inclusive education for being part of a colonial discourse formed by Western hegemonic epistemology, first developed in high-income countries in the Global North, and imposed on countries of the Global South (Muthukrishna & Engelbrecht, 2018, p.1-2). Muthukrishna and Engelbrecht (2018) claim that the Convention on the Rights of Persons with

Disabilities (CRPD), as well as research about inclusive education, is based on what is considered as best practices found in high-income countries, leading to a conceptualization of inclusive education that exclude economic realities, indigenous knowledges, culturally relevant knowledge, local expertise, contextual priorities, and social histories (Muthukrishna & Engelbrecht, 2018, p.2-3; Singal & Muthukrishna, 2016, p.202). According to Goodley and Swartz (2016) it can be problematic to export analyses that are not always critically evaluated, stating:

What tends to be obscured in these ‘global’ documents, however, is that global north disability studies and their products, as promoted by bodies such as the WHO and the World Bank, tend to be emblematic of the cultural contexts from which the theories emerged. These theories come from the global north. (Goodley & Swartz, 2016, p.72)

Gilroy and Donnelly (2016) argue that research on disability among indigenous people can be disabling by imposing views of ‘disability’ developed in the Global North, and call for culturally suitable and ethically sound research methods to decolonize research concerning indigenous people with disability (Gilroy & Donnelly, 2016, p.558; Staples & Mehrotra, 2016, p.35).

6.4.4. Theoretical approach to inclusive education used in this research

This research is placed within the inclusive education discourse primarily using the CRPD as the starting point for the research. This means that the definition of ‘inclusion’ as found in the General comment No. 4 (GC4) is the one used in this research (see subsection 3.2.3. Legal definitions). Being aware that the definition could be considered as a part of a discourse originating from the Global North, it is necessary to operationalize the concept to include perspectives from the Global South. To operationalize the concept, this research draws on dimensions of inclusion suggested by Qvortrup and Quortrup (2018), the World Federation of The Deaf (2018) position paper on inclusive education, Enabling Education Network (EENET) definition of inclusive education (2019), the GC4 as a legal source, and decolonizing methodologies as presented by Tuhiwai Smith (2012), and Gilroy, Donnelly, Colmar and Parmenter (2013).

Qvortrup and Quortrup (2018) suggest three dimensions of inclusion being; (1) Levels of inclusion; meaning that inclusion is more than about physical placement, but also about a sense of belonging and social participation. (2) Arenas of inclusion; meaning that inclusion go beyond the classroom learning community, and extends to other social arenas within the classroom and

at the school. (3) Degrees of inclusion; meaning that a person can be more or less included and/or excluded in different situations (Qvortrup & Quortrup, 2018, p.810-814). This operationalization answers to what the World Federation of the Deaf (WFD) (2018) state is an important aspect of inclusion, the experience of being included. It does not however answer to all aspects of the environments in which learning takes place, as described by WFD, (2019) the GC4, and EENET (2019). While Qvortrup and Qvortrup (2018) include after-school activities and arenas, the school learning arenas are described as being within mainstream schools. WFD (2018) expands inclusion to something that can happen in “deaf schools” where hearing learners can be (reverse) mainstreamed (World Federation of the Deaf, 2018). EENET (2019) expands inclusion to something that can happen within and outside formal school settings, and includes a focus on lifelong learning. The positions of both the WFD (2018) and EENET (2019) is supported by the GC4 as shown in subsection 3.2.1. Qvortrup and Qvortrup (2018) do not discuss language of instruction, and mention only languages of children from minority backgrounds. EENET (2019) describes that education must be restructured to respond to diverse languages, and ethnic and religious background of each learner, while WFD (2018) only mentions the need for sign languages. None of them discuss the epistemological background a child brings to school, and the meeting between a child’s primary discourse (knowledge from their homes) and the secondary discourse (knowledge in the schools). Only WFD (2018) discusses cultural identity. However, WFD (2018) discusses this from a perspective of a deaf cultural identity, and not from a wider cultural perspective.

As this research focuses on Zambia and Malawi, it is also important to include the perspectives in policies and strategies found in the two countries. The Zambian Disability Act of 2012 describes an inclusive education system at all levels ensuring that persons with disabilities have access to inclusive quality education on equal basis with peers. The Disability Act of 2012 also states that “the Government shall establish special schools for persons with disabilities to enable persons, who by reason of their disability cannot be enrolled in inclusive educational facilities” (§23.2). The Malawian National Strategy on Inclusive Education 2017-2021, describes a twin track approach to service delivery as a core value where “some learners with SEN¹⁴⁰ will continue receiving their education in special settings as the system moves towards full inclusion” (Malawi Government, Ministry of Education Science and Technology, 2017, p.11).

¹⁴⁰ SEN is an acronym for Special Educational Needs. Acronym in original.

Based on this, this research takes use of an operationalization of inclusive education differentiated into three intersectional dimensions: The physical dimension; the cognitive dimension; and the emotional dimension.

The physical dimension includes all environments in which inclusion takes place, and relates to the extent to which a child has access to physical learning environments that best corresponds to a child's strengths, preferences, and needs, on equal basis with all others to maximize personal, social and academic development. The physical learning environments should be flexible and can be found within and outside formal school settings. The physical learning environments can change throughout the day, and may vary over time. **The cognitive dimension** relates to the extent to which education is delivered in languages and means and modes of communication that best correspond to the individual child's communication modality and language(s). The cognitive dimension also relates to the extent to which education is delivered in a way that promotes active participation, and best correspond to the individual child's (multiple) identity(-ies), epistemological, cultural and contextual background, and is delivered in line with the principles found in Vygotsky's (1978) theory of the zone of proximal development, to maximize personal, social and academic development. **The emotional dimension** relates to the extent to which a child feel that she is welcomed by, and participates actively in the community and social group to which she wants to belong, and the extent to which a child feels and experiences that her identity, her communication form, her gender, her sexual orientation, her socio-economic background, her cultural and religious background, and so on, are valued, accepted and supported by other members of the environment where she is included, and the larger community.

6.5. Chapter summary

This chapter has presented the theoretical framework for this research. The chapter has described education from a broad perspective, showing the importance of acknowledging the origins of the global educational discourses, including the inclusive education discourse. Inclusion must be understood as a broad concept that must take into consideration languages of instruction, epistemologies, intersectionality, and theories of how learning and cognitive development takes place to be relevant for all learners. This chapter has also pointed to the importance of understanding the theories on both a general level, but also related to specific individual strengths, preferences and needs of heterogeneous members of larger generalized

groups. The concepts and theories presented in this chapter has led to the development of a theoretical operationalization of inclusive education that this research takes use of to analyze the research findings.

7. Analysis

This chapter presents an analysis of the research findings within the theoretical framework as presented in chapter 6. The three dimensions described in subsection 6.4.4., the physical, the cognitive and the emotional dimension, are applied to analyze the practical implementation of inclusive education in Malawi and Zambia. However, the global architecture of education, in which the inclusive education discourse is located, influences all three dimensions, and is discussed first in this chapter. The analysis is divided in three sections. Section 7.1. analyses the education systems in Malawi and Zambia in light of this Western discourse. Section 7.2. continues to analyze the implementation of the inclusive education discourse in Malawi and Zambia. In order to understand how the implementation of the inclusive education discourse has affected children with deafblindness, it is necessary to analyze how the inclusive education discourse is located within the global architecture of education. Section 7.3. introduces dialogism as a counter-hegemonic theory and monologism as a Western individualistic theory. The two theories are applied in the discussions in subsections 7.3.2. and 7.3.3 where the physical and cognitive dimensions of inclusive education are used as a framework to analyze the extent to which inclusive education in Malawi and Zambia is implemented in a way that maximizes personal, social and academic development for children with deafblindness. Subsection 7.3.4. draws on stigma theory and discuss inclusion within the emotional dimension.

7.1. Zambia, Malawi and the global architecture of education

This section analyzes the education systems in Malawi and Zambia in light of theories about education as presented in the theory chapter. Subsection 7.1.1. discusses the extent to which the education systems in Malawi and Zambia are influenced by the Western educational discourse. Subsection 7.1.2. discusses languages of instruction used in Malawi and Zambia, and the effect this have for all children.

7.1.1. The education systems in Malawi and Zambia and the global architecture of education

The education systems in Malawi and Zambia are both heavily influenced by the Western education discourse. This leads to challenges in the classrooms in Malawi and Zambia, making it frustrating for teachers to teach, and reducing the relevance of the education for children, contributing to low learning outcomes.

As showed in the theory chapter, Western epistemology has a hegemonic position over education systems in the Global South where countries in Global South are dominated epistemologically, politically and economically by countries from the Global North (Breidlid, 2013; Odora Hoppers, 2002; Shiza & Makuvaza, 2017; Tucker, 1999; Said, 2003). This domination is linked to the global architecture of education, described by Jones (2007) as a global system of power determining how education systems are constructed. Research and knowledge production are too often carried out in an unequal power relationship dominated by resourceful academic and epistemic communities, and Western scholars. This leads to an ideal of rational and independent individuals as the source of experience and knowledge, and a situation where students, teachers and people in the South are alienated by the discourses that portray them (Breidlid, 2013; Tuhiwai Smith, 2012; Tucker, 1999; Jones, 2007).

Before discussing the findings, it can be useful with a short reminder about the situation in the education systems in Malawi and Zambia as presented in section 2.1. and 2.2. Learners in both countries struggle to get a minimum learning outcome, where girls and disadvantaged (by poverty, disability, geography, etc.) learners struggle the most. Some examples: in Malawi more than eighty percent of children aged six to ten have numeracy and literacy skills below the expected development level for their age; in Zambia about fifty percent of children with disabilities in school going age were not attending school in 2013. See subsection 2.2. and 2.3. for more information. There could of course be several explanations for this situation, but the findings suggest that there is a clear link between the situation in the two countries and the influence of the global architecture of education.

Findings show that the influence of the global architecture of education is visible in a number of ways in Malawi and Zambia, both explicit and implicit. Some informants stated this explicitly when describing how pre-colonial societies were more inclusive before “Westernization and modernization [took] its toll on African societies¹⁴¹”, or when stating that education prepares children to pass exams, memorize, and for “white-collar jobs, but not for life¹⁴²”. The findings show that transferred Western concepts are implicit in educational discourses in Malawi and Zambia. This research is carried out in two culturally and linguistically heterogeneous countries, and in geographical locations far from each other within each country. Based on this it could be expected that people’s culture and perspectives on

¹⁴¹ MWINGO 3

¹⁴² MWINGO 2

education might vary across the two countries and across the different geographical locations (Engen, 2011; Coleman, 2005). There is no evidence in the research findings that suggest that there is any difference based on cultural or linguistic diversity across or within the two countries regarding people's perspectives on inclusive education. The findings show the opposite. When interviewees described inclusive education, they described it in very similar ways, as shown in the findings chapter. Similar phrases were used, similar techniques were presented, similar justifications and slogans were recited. The slogan 'Leaving no one behind' that was used by close to all informants is a slogan that is developed by the global community during the development of the Sustainable Development Goals, not by teachers in Malawi or Zambia (United Nations Committee for Development Policy, 2018). This shows that training programs about inclusive education are developed by international organizations based on an idea that if it works on one country, it will work in another. This interpretation is in line with how the development discourse is described by several critical scholars and researchers. Development agents within a development industry with separate and conflicting interests present research that promotes best practices developed in other countries, often perfectly aligned with the solutions they sell themselves (Tvedt, 2009; Ferguson, 1994; Kamat, 2012; Klees, 2012; Samoff, 2012). The result of all this is that Western concepts are implicit, taken for granted, and not problematized in the educational discourses in Malawi and Zambia, reducing the relevance of the education to the local contexts where it is implemented, and reducing learning outcomes.

7.1.2. Language of instruction

Languages of instruction in Malawi and Zambia have negative impact on learning outcomes for all children, and disadvantage children with deafblindness more than their peers. As showed in subsection 6.1.4. context is essential to language. People borrow words in interaction with others and depend on prior experiences and knowledge to be able to appropriate and conceptualize the meaning transmitted through language (Bakhtin, 1981; Linell, 2009). Understanding new concepts in an unfamiliar language is challenging, and reduces learning outcomes (Breidlid, 2009; Piper et al., 2016), while it is advantageous for the learning outcome to be taught in a familiar language, including learning of other languages (Breidlid, 2013; Brock-Utne, 2015; Ssebbunga-Masembe et al. 2015; Piper et al., 2016; Biseth, 2008).

Findings in this research confirm findings from other studies and show that children in general in the researched areas in Zambia and Malawi have challenges with understanding the

languages of instruction¹⁴³. Some teachers switch between languages, and use local languages to enable children to understand¹⁴⁴, while other teachers insist on using only the official language of instruction in the classroom¹⁴⁵. As shown in the findings, children in Malawi can experience that their teachers say: “when you enter this class no more Chiyao. Don’t speak Chiyao here. You are going to speak Chiyao when you go home”¹⁴⁶. With this it is possible to draw a direct link to Ngũgĩ’s (1986) experiences with being denied to use Gĩkũyũ at school, and the way he describes the colonization of the mind that can result in alienation of children from their history, culture and identity (Ngũgĩ, 1986; Tuhiwai Smith, 2012; Breidlid, 2013). The findings in this research show that being taught and teaching in a language that is not familiar has negative effects for the learning outcome for children, and that this is frustrating for the teachers¹⁴⁷.

As this research confirms findings from other studies regarding language of instruction, it is not necessary to provide a comprehensive general analysis on this issue. However, the negative effects of languages of instruction will be discussed in more details related to inclusive education and children with deafblindness in subsection 7.2.2., providing new insight to the language of instruction discourse.

7.2. Inclusive education and the global architecture of education

To understand how children with deafblindness are located within the inclusive education discourse, it is necessary to analyze how the inclusive education discourse is positioned within the global educational discourses. Subsection 7.2.1. analyses the extent to which the implementation of the inclusive education discourse can be explained in light of the global architecture of education, as transferred by international development organizations. Subsection 7.2.2. analyses the extent to which the language of instruction discourse is a part of the inclusive education discourse as visible in Malawi and Zambia, and the effect this has for children with deafblindness.

¹⁴³ Observations described in subsection 5.3.2, MWI TEA 2, ZAM NGO 1

¹⁴⁴ MWI TEA 2

¹⁴⁵ MWI TEA 1

¹⁴⁶ MWI TEA 1

¹⁴⁷ ZAM NGO 1, MWI NGO 1, MWI NGO 2, MWI TEA 1, MWI TEA 2

7.2.1. Inclusive education and the global architecture of education

Inclusive education, as visible in the way it is implemented in Malawi and Zambia, is heavily influenced by the Western educational discourse, leading to reduced relevance and reduced possibilities of achieving inclusion of all children, and particularly children with deafblindness.

The dislocation of the knowledge and languages children bring to school, and the hegemonic position of Western epistemology as discussed section 7.1. have a major impact on learning outcomes and identity construction for children in schools in the Global South (Breidlid, 2013; Breidlid, 2015; Seehawer, 2018; Odora Hoppers, 2002; Shiza & Makuvaza, 2017; Breidlid, 2013; Brock-Utne, 2015; Ssebbunga-Masembe et al. 2015; Piper et al., 2016; Biseth, 2008). The inclusive education discourse is also critiqued for being a part of the Western hegemonic epistemology, based on research and theories from the Global North (Muthukrishna & Engelbrecht, 2018; Singal & Muthukrishna, 2016; Gilroy & Donnelly, 2016; Goodley & Swartz, 2016).

Findings show that the influence of the global architecture of education is visible within the inclusive education discourse in a number of ways in Malawi and Zambia, both explicit and implicit. Two Malawian teachers stated this explicitly when they critiqued educational authorities for wasting money. The two teachers stated that “top officials [...] going outside of the country, discussing about the inclusive education in Malawi. [...] And then they will come to us and say do this, do that”¹⁴⁸. A participant in one of the dissemination workshops said that “for us inclusive education is somebody coming from the UK, Germany, Norway telling us what to do”¹⁴⁹. Some informants pointed to the socio-economic realities and claimed that inclusive education might work in rich countries, but not in poor countries like Malawi and Zambia. This shows that inclusive education is perceived as a foreign concept. The findings also show how the implementation of inclusive education is carried out with donor conditionalities in line with what is discussed in subsection 7.1.1. where international actors transfer concepts from one country to another. Two NGO informants from Malawi, who train teachers, stated that they wanted to train teachers gradually and in depth, because inclusive education is a relatively new concept. However, due to donor conditionalities they were only able to train a few teachers fully, and “the rest we train them bits and bits. This has affected our

¹⁴⁸ MWI TEA 1, MWI TEA 2

¹⁴⁹ MWI WS 4

approach”¹⁵⁰. Another example of the influence the global architecture has on the education systems is the training fatigue a Zambian government official described when stating that “teachers have experienced that programs come and go. They don’t bother to learn the new stuff, because they know that sometime soon another program will come in”¹⁵¹. Over a number of years different actors within the global architecture of education have come to Malawi and Zambia with a variety of programs with different focus. Inclusive education is then viewed as “just another Western education system”¹⁵². One statement from a workshop participant in Malawi can be used to sum up this paragraph:

We have so many international projects - the problem is that international projects come with strings attached and objectives of what they want to do. They are not coordinated. They do what they have in their plans with little contact between the projects. Many are doing similar things but not coordinated. Some districts are more favored and receive many donors and projects. Distribution of the projects is not fair. It is not backed by research. Results don't reflect what is on the ground. You do it as the donor says.¹⁵³

Findings from observations also show how the implementation of inclusive education is located firmly within the global architecture of education. As shown in photos in subsection 5.2.1, classrooms in Malawi and Zambia are structured according to a standard Western model with a blackboard in front, and individual tables directed towards the teacher. One classroom as showed in Photo 11 was organized with tables in groups to promote group work and peer assistance. This might be a good idea, and might be positive for many children. The problem is that the tables and benches are linked together and cannot be separated. In addition, the room is too small to allow space between the groups of tables, making it impossible for a child in a wheelchair to join most of the groups in the photo, unless the child is placed *behind* the other children sitting on the benches. A hegemonic Western approach with a focus on transfer of best practices will give directions to place tables in classrooms in groups, because experience shows that this promotes inclusion. A counter-hegemonic approach would include children, teachers, and parents, and investigate: how do you think children should be placed in *your* classroom to promote interaction between all children in *your* class? Another finding also showing the transfer of Western concepts is the translucent roof panels installed in many classrooms. When transferring the Western classroom buildings to areas where electricity is not available or

¹⁵⁰ MWI NGO 6, MWI NGO 7, ZAM NGO 2

¹⁵¹ ZAM WS 1

¹⁵² MWI NGO 1

¹⁵³ MWI WS 4

expensive, light conditions in the classrooms can be challenging. Translucent roof panels are an easy quick fix. If teachers were consulted, they would inform that translucent roof panels make the classrooms warmer, and that children become tired. A solution that might improve the situation for children with visual impairments, leads to a worsened situation for all children. Knowing that energy loss is already a challenge for children with deafblindness (Janssen & Rødbroe, 2006; Janssen & Rødbroe, 2007; Lie et al., 2016) it becomes clear the situation further reduces chances of their successful inclusion.

This shows that adaptations that are done to promote inclusive education without considering local conditions and consulting teachers and parents in the schools, can actually lead to a worsened situation for many, and even worse for children with deafblindness. This also confirms that the implementation of the inclusive education discourse is underpinned by Western thinking and the global architecture of education.

7.2.2. Language of instruction and inclusive education

This research argues that language of instruction is not considered within the inclusive education discourse as is visible in Malawi and Zambia. This is surprising, as the whole idea behind inclusive education is to adapt the teaching to the learner. As shown in subsection 6.4.1, and subsection 7.1.2. language is hugely important in a learning process. The fact that such an important aspect of the educational experience of a child is overlooked in the implementation of inclusive education in Malawi and Zambia both suggests (again) that inclusive education has its origins outside of the two countries, and reduces the chances of achieving one of its primary objectives: giving children access to a learning environment that is adapted to the child, and that leads to a relevant learning outcome.

Findings show that language of instruction receives little attention in the implementation of inclusive education in Zambia and Malawi. In the interviews it became clear that most interviewees had not really given language of instruction much thought. A Zambian NGO informant described that when it comes to language and inclusive education, the only thing that is discussed is sign language¹⁵⁴. None of the informants described any languages related to inclusive education, other than sign language, before asked. The findings related to language of instruction in this research give new insight in three areas. The first is that language of

¹⁵⁴ ZAM NGO 1

instruction is not a part of the inclusive education discourse as it is implemented in Malawi and Zambia.

The second way the findings about language of instruction give new insight is that they also suggest that the implementation of inclusive education has a strong focus on children with disabilities, and not necessarily on *all* children, or on all the dimensions that make up each child, as claimed within the discourse. Findings confirm this in the way interviewees described inclusive education, exemplified by a teacher from School 1 in Zambia: “Inclusive education is where every child [...] those that are visually impaired, deaf, the blind, those who have physical disabilities are all brought together”¹⁵⁵. Even if the teacher starts by stating ‘every child’, all the concrete examples focus on different types of disabilities. With a broader focus on *all* children, language of instruction would have emerged as a barrier that needs to be addressed in the implementation of inclusive education. The focus on disability is also implicit in the way the implementation of inclusive education only addresses one dimension of a child – the disability – and ignores that a child in addition to having an impairment also has a gender, speaks a language, has knowledge they bring from their homes, etc. In other words, findings suggest that the implementation of inclusive education in Malawi and Zambia overlooks intersectionality, and has a narrower focus on ‘disability’. Findings also show that when teachers and informants in Malawi and Zambia state ‘all’ and ‘disabled’, they actually refer to children with mild to moderate disabilities. Children who are have ‘severe disabilities’, deafness, blindness and deafblindness are usually referred to special schools, or denied access¹⁵⁶. This means that the focus in the implementation of inclusive education is first narrowed down to ‘disabled’, then again to children with mild to moderate disabilities only.

A third new insight is that because the language of instruction is not paid attention to, children with deafblindness are placed in an even more disadvantaged position than their hearing peers. Some children with deafblindness have residual hearing and vision, and can sometimes be able to communicate orally in their vernacular language. With a hearing aid or other adaptations (clear voice, close distance, etc.), and with help from lip-reading, some children are able to communicate quite well (Janssen & Rødbroe, 2006). However, as deafblindness is often overlooked by care persons and teachers/other professionals among children with residual

¹⁵⁵ ZAM TEA 1

¹⁵⁶ Expressed by: ZAM PFG 1, ZAM PFG 2, MWI PFG 1, MWI PFG 2, MWI HTEA 1, MWI TEA 1, MWI TEA 2, ZAM TEA 4, ZAM TEA 6, ZAM TEA 7

hearing and vision, communication can sometimes be affected more seriously in this group compared to other groups of children with deafblindness (Janssen & Rødbroe, 2006). When the child is introduced to a new language, it can take much longer for the child to be able to understand, and tactile strategies are often needed (Janssen & Rødbroe, 2006; Janssen & Rødbroe, 2007; Lie et al. 2016). If taught in a familiar and already acquired language, it is possible to understand what people communicate by combining the residual hearing with visual information from lip reading/sign language. When the languages used in communication are new, the child will struggle a lot more than her peers with acquiring the new language, due to the lack of familiar words and un-known lip movement. It requires a lot of resources, and is time consuming to process sensory inputs from a limited register of senses (Janssen & Rødbroe, 2006; Janssen & Rødbroe, 2007; Lie et al. 2016). Findings show that teachers do not have this extra time to give to each individual child in overcrowded mainstream classroom with a high learner to teacher ratio. The problem is further reinforced by the fact that parents often do not know the language of instruction, and cannot help acquire the new language. With this, it becomes clear that the negative effect of being taught in a foreign language is multiplied for children with deafblindness.

If we apply Vygotsky's (1978) theory of the zone of proximal development (as described in subsection 6.2.2.) to the discussion on language of instruction, combined with knowledge about children with deafblindness, it is possible to further describe the complexity of the situation. Nafstad and Rødbroe (2013) describe that it is challenging to identify the zone of proximal development when teaching a child with deafblindness. Janssen and Rødbroe (2006; 2007) describe that teaching that is not within the zone of proximal development can confuse and stress a child leading to withdrawal from a learning situation. All this means that being taught in a foreign language presents a challenge for many children in schools in Malawi and Zambia, but it is a far more profound challenge for a child with deafblindness.

7.2.3. Dislocation of children with deafblindness within the inclusive education discourse

Children with deafblindness are dislocated within the inclusive education discourse. In the same way as language and context are invisible in the way inclusive education is implemented in Malawi and Zambia, so is also information about children with deafblindness. This leads to reduced chances for children with deafblindness to have access to education that is relevant to them.

As shown earlier in the analysis, in the implementation of inclusive education the target groups have been narrowed down to children with mild to moderate disabilities. This can be seen in relation to why NGO-informants in both countries state that it is not necessary to have specific information and knowledge about different impairment types to be an inclusive teacher. As an NGO-informant from Zambia said about inclusive education: “it is not a prescription of a protocol on a specific disability. That is something that those who have been trained in inclusive education will develop”¹⁵⁷. This assumption underlines that the target group is actually narrowed down. It also raises a question about how teachers are supposed to develop methods to include all. Where will they get the information or training? Informants in Malawi referred to a sourcebook developed by the Ministry of Education, Science and Technology in Malawi, with support from Save the Children Malawi and the Royal Norwegian Embassy. According to the informants “there are some things that are not there in the manual”¹⁵⁸. Like children who have profound disabilities like blindness, or hard of hearing”¹⁵⁹. An analysis of the sourcebook can shed more light to how children with deafblindness are dislocated within the inclusive education discourse. The “sourcebook for pre-service teacher educators and practicing teachers” developed by the Malawian government presents “inclusive strategies, tools and approaches that teachers and other stakeholders may use to ensure *all* children learn and develop in a safe and inclusive education system” (Ministry of Education Science and Technology, 2016, title page, and VIII-IV. *Italics added*). The sourcebook describes “deaf blindness” as “a condition in which a person losses [sic] both their hearing and vision”, and states that “IE¹⁶⁰ approaches can help to address hearing and visual needs of such learners” (Ministry of Education Science and Technology, 2016, p.29). The sourcebook presents some suggestions for “ways of supporting learners with disabilities” (Ministry of Education Science and Technology, 2016, p.31). For learners with ‘deaf blindness’ teachers are advised to “take time to listen to what the learner is trying to communicate”, “use tactile methods or augmentative alternative accommodation [sic¹⁶¹]”, “use pictures to express wishes” and “modify questions that require labelling parts of an object for example name the parts of a flower” [the last suggestion is included two times, once with ‘Deaf and partial vision’ in brackets, once with ‘deafblind’ in brackets] (Ministry of Education Science and Technology, 2016, p.33).

¹⁵⁷ ZAM NGO 2

¹⁵⁸ ‘Manual’ refers to the sourcebook

¹⁵⁹ MWI NGO 7

¹⁶⁰ IE is an acronym for ‘Inclusive Education’. The acronym is used in the source.

¹⁶¹ The correct term is ‘augmentative and alternative *communication*’.

Some of the advice offered in the sourcebook might be useful in including children with mild to moderate acquired deafblindness, with both residual hearing and vision, and with no additional disabilities. The problem is the lack of relevance this book has for teachers. The sourcebook in no way reflects on the diversity of communication forms used by persons with deafblindness, as showed in section 3.1. where bodily tactile communication methods are key strategies. Teachers interviewed have explicitly stated that they do not have the knowledge they need to teach children with deafblindness. It is doubtful that a teacher would find any of the suggestions in the sourcebook useful to provide educational services to a pre-lingual learner with congenital deafblindness, additional impairments, challenges with balance, and limited mobility skills. The findings show that both teachers with more comprehensive training in inclusive education, and teachers with one-time trainings, state that they need more training in both inclusive education and training about different types of disabilities to be able to include learners with more comprehensive and complex disabilities like deafblindness. The assumption within the inclusive education discourse, as presented by informants, is that the teachers themselves are to develop these methods after being trained in inclusive education. Teachers in resourceful countries, with comprehensive libraries at their schools, with easy access to internet-resources and additional training, might be more successful in developing these methods themselves. Teachers in the targeted schools in Malawi and Zambia do not have these resources. This again suggests that the implementation of inclusive education is developed by Western external actors in order to meet Western driven educational policies rooted in the global architecture of education. This shows that there is a huge gap in the inclusive education discourse as it is seen in Malawi and Zambia. Children with deafblindness are placed in a dislocated position, in the center of this gap.

7.3. Dialogism in essence – monologism in presence

This section discusses dialogism and monologism as a counter-theory, and argues that while dialogism can be viewed as underpinning inclusive education in its ideological form, the actual implementation of inclusive education is underpinned by monologism. The tension between inclusive education ideology and its implemented form can partly explain the dislocation of children with deafblindness. This section also draws lines to the global architecture of education and argues that monologism is a Western individualistic theory, while dialogism is a counter-hegemonic theory. The two theories are applied in the discussions in subsections 7.3.2. and

7.3.3. where the physical and emotional dimensions of inclusive education are used as a framework to analyze the extent to which inclusive education in Malawi and Zambia is implemented in a way that maximizes personal, social and academic development for children with deafblindness. This section ends with an analysis of the emotional dimension where stigma theory is used to shed light on the findings, and argues that stigma influences the educational choices made by parents for their children.

7.3.1. Ideology transformed to practice

Inclusive education could be considered a theory that, in its ideological form, is underpinned by dialogism. However, it is visible in Malawi and Zambia that monologism underpins the actual implementation of interventions directed at giving teachers the knowledge they need to become inclusive teachers. The mismatch between inclusive education in its ideological form and the actual implementation of the discourse reduces the relevance and results in teachers having difficulties to teach and learners having difficulties to learn. This also leads to exclusion of children with deafblindness from the mainstream formal education system.

Dialogism, as described in subsection 6.2.1., is a non-dualistic framework, where contextually situated interactions between two interdependent parts of a unity is the basis to develop personal and shared understandings. Dialogism describes a unity between self and other, and a dependency on ‘other’ to become ‘self’. The ‘other’ is not necessarily a physical person, but an inner representation of ‘others’ (*alter*) in the mind of one-self (*ego*) (Linell, 2009; Eilertsen, 2016). Monologism, as presented in subsection 6.2.1 is a counter-theory to dialogism. Monologism is underpinned by Western individualistic thinking, where language is a tool to transfer messages, and where context is external to languages, communication and thinking. ‘Others’ are other individuals, and not others as a part of a context (Linell, 2009; Marková, 2016).

Applying dialogism and monologism to the discussions earlier in this chapter can give new insight to the findings. Findings referred to earlier in this chapter show that the global architecture of education is underpinned by monologism. This is visible in a number of ways: transfer of Western concepts, methods, languages, etc. The findings also suggest that this leads to reduced relevance of the education and lower learning outcomes, especially for children with deafblindness. Dialogism can shed light on why Western education is less relevant for children in schools in Malawi and Zambia. In the process of meaning-making, dialogism describes a

dialogue between one-self (ego) and the inner representation of the other (alter). It is difficult to make meaning out of new information, when the basis for the information is external and foreign. There is a risk that the inner representation of the new knowledge is different from how the knowledge is understood in the foreign system. The outcome is that children will not understand the information in the way it is understood in the foreign system. In addition, the already acquired knowledge is also at risk of becoming more unstable. This understanding is also in line with Vygotsky's (1978) theory of the zone of proximal development, and the way Thybo (2013) and Richey and Nokes-Malach (2015) describe that new knowledge should build on prior knowledge and be presented in a coherent form. When teachers fail to do so, this can lead to a child's feeling of defeat (Vygotsky, 1978; Thybo, 2013; Richey & Nokes-Malach, 2015).

7.3.2. Inclusion within the physical dimension

As shown in the theory chapter 6.4. 'Inclusive education' there is no universal understanding of the concept of inclusive education. The findings confirmed this where interviewees in both Malawi and in Zambia showed a varied understanding of the concept. As shown in the findings, all informants relate their understanding of inclusive education to certain physical structures and environments. The lack of clarity about what inclusive education is, and the understanding of inclusive education as being linked to certain physical structures, put children with deafblindness at risk of being placed in environments that do not correspond to their learning needs, or at risk of not having access to education in any form.

As described in the theory chapter subsection 6.4.4., the physical dimension includes all environments in which inclusion takes place, and relates to the extent to which a child has access to physical learning environments that best correspond to a child's strengths, preferences, and needs, on equal basis with all others to maximize personal, social and academic development. How inclusive education is understood within the physical dimension, and how this leads to a risk of exclusion of children with deafblindness, can be analyzed by applying the theories of dialogism and monologism as presented in subsection 6.2.1, and 7.3.1.

Findings show that a mutual dialogue suggested by dialogism is not very likely to have taken place in the implementation of inclusive education in Malawi and Zambia. Parents in both countries stated clearly that the best for their children would be to have access to a special school, or a unit at a mainstream school. Only two of the twenty children included in this

research had access to a learning environment parents felt was appropriate to their strengths, preferences and needs. The physical adaptations parents described their children needing are not taken into consideration by schools and educational authorities in the parent's encounters with the education system. Provision of properly sized and well-functioning wheelchairs to enable participation has not been met, or even considered, by schools or educational authorities. Parents advocated for ramps to be constructed, but the quality of the ramps is poor¹⁶², if they are at all provided. Head teachers and government informants said improvements to the physical structures were the most important aspect to be addressed¹⁶³. However, stakeholders implementing inclusive education focus on provision of training, and not physical adaptations to the extent head teachers and teachers want. Head teachers and government informants from both Zambia and Malawi stated that the provided training was not necessarily relevant and cost effective, and that payment related to attendance could be a motivating factor for teachers to attend. Instead of using money to train teachers what they already know¹⁶⁴, or don't bother to learn¹⁶⁵, the head teachers and government informants meant that improvements to the physical environment, and provision of learning and teaching material, would have a better effect than training teachers¹⁶⁶. The lack of dialogue between parents and teachers, and between teachers and stakeholders implementing inclusive education, shows that implementation of inclusive education is underpinned by monologism.

Findings show that the narrow understanding of inclusive education promoted by Mariga et al. (2014) and Stubbs (2008) and the Ministry of Education, Science and Technology – Malawi, as all being in the same classroom at all times, is the most common understanding of inclusive education. This understanding is not relevant to children with deafblindness. The drafting process of the Convention on the Rights of Persons with Disabilities (CRPD), as described in subsection 3.2.2., clearly shows that Article 24. para. 3, section c was constructed as a compromise meant to secure the right to inclusion in mainstream schools for children with deafness, deafblindness and blindness, but should not prohibit alternatives (World Federation of the Deaf, 2016; World Federation of the Deaf, 2018; MacQuarrie & Laurin-Bowie, 2014; de Beco, 2014; de Beco, 2016, p.52; Shaw 2014, p.69; Kauppinen & Jokinen, 2014; Grandia, 2014). The General comment No.4 (GC4), issued by the United Nations Committee on the

¹⁶² As exemplified in Photo 9 and Photo 10

¹⁶³ ZAM HTEA 1, MWI HTEA 2, MWI GOVT 1

¹⁶⁴ ZAM HTEA 1

¹⁶⁵ ZAM WS 1

¹⁶⁶ ZAM WS 1, ZAM HTEA 1, MWI HTEA 2

Right of Persons with Disabilities, uses the terms “environments” – in *plural* – ‘*within and outside formal school settings*’, clearly indicating that mainstream classrooms cannot be understood as the only modality for children with deafblindness (UNCRPD, 2016, p.10, *Italics added*).

7.3.3. Inclusion within the cognitive dimension

As described in subsection 6.4.4. the cognitive dimension relates to the extent to which education is delivered in languages and means and modes of communication that best correspond to the individual child’s communication modality and language(s). The cognitive dimension also relates to the extent to which education is delivered in a way that promotes active participation, and best corresponds to the individual child’s (multiple) identity(-ies), epistemological, cultural and contextual background, and is delivered in line with the principles found in Vygotsky’s (1978) theory of zone of proximal development, to maximize personal, social and academic development. Previous subsections in the analysis have shown that the implementation of inclusive education in Malawi and Zambia is underpinned by a Western educational discourse, and that languages of instruction give children in general, and children with deafblindness in particular huge challenges in their educational experiences. This subsection focuses on how training of teachers is designed, and argues that the way this is done reduces the chances of achieving good learning outcomes for all children in schools, and especially for children with comprehensive and complex disabilities, such as deafblindness.

How the training is designed and implemented is analyzed by applying the theories of dialogism and monologism as presented in subsection 6.2.1, and 7.3.1. In monologism rationality depends on knowledge, and if others behave ‘irrational’ this can be prescribed to *lack* of knowledge, and not that they have *other* knowledge. Provision of training can be used as a way to develop the rationality of others. In this perspective, you do not need to discuss with the other before the training, because they will develop understandings and rationality, leading to a desired change in behavior *after* the training, when they have the knowledge.

Findings show that teachers are little likely to have taken part in a dialogical approach to find a unified method to implement trainings. Most interviewees described that training of teachers was a key to achieve inclusive schools. Once the training was given, teachers were expected to be able, and develop methods to include all learners. If a dialogical approach was used in the implementation, the training would have been designed differently. The findings show that by

entering into a mutual dialogue, it would have become apparent that teachers feel that general training in inclusive education is insufficient¹⁶⁷. It does not address fully what the teachers think is needed to become an inclusive teacher. With a monological approach, teachers can be trained, and if the teachers after the training are unable to include all, the responsibility of the failure can be placed on them. Teachers can then be viewed as the problem, unwilling to implement what they are trained to. This can also partly explain why head teachers and government informants describe teachers as more interested in financial gains from the training¹⁶⁸, or that “they don’t bother to learn”¹⁶⁹. From a dialogical perspective, the mismatch between expectations to teachers, and how others assess their performance, can be explained in terms of relevance. Training that is not designed and implemented in a dialogue with the teachers, have reduced relevance, and reduced chances to change the situation it is intended to change. The teachers themselves expect knowledge on specific methods, but receives standardized training that does not fully respond to the challenges they have in their own classrooms.

7.3.4. The emotional dimension and stigma

Children with deafblindness in Malawi and Zambia, and their parents, experience exclusion due to stigmatization. Parent’s experiences of themselves and their children being stigmatized, bullied and excluded can partly explain some of their opinions and perspectives towards inclusive education, as well as their educational preferences. This subsection will take use of stigma theory and discuss the extent to which children with deafblindness experience inclusion within the emotional dimension. As it has not been possible within this study to interview children with deafblindness directly, parents give their children an indirect voice. As described in subsection 6.4.4., the emotional dimension relates to the extent to which a child feels that she is welcomed by, and participates actively in, the community and social group to which she wants to belong, and the extent to which a child feels and experience that her identity, her communication form, etc., are valued, accepted and supported by other members of the environment where she is included, and the larger community.

Findings show that people in the surroundings sometimes feel uncomfortable with the tactile communication form used by many children with deafblindness, and that this leads to isolation

¹⁶⁷ Expressed by teachers and head teachers at School 1 ZAM and School 2 Zam, MWI TEA 1, MWI TEA 2, MWI NGO 6, MWI NGO 7, ZAM NGO 1

¹⁶⁸ ZAM HTEA 1

¹⁶⁹ ZAM WS 1

of the children and their families. This can be explained by what Pryor and Reeder (2011) describe as public stigma, where people in the surroundings can react negatively to someone they perceive to have a stigmatized condition (Pryor & Reeder, 2011, p.791). The reactions towards the stigmatized can be stronger if the stigmatized, or the stigmatized by association, are somehow responsible for the condition. Findings show that it is common, especially in Zambia, to view disability as an outcome of witchcraft. Parents give accounts of being accused of having bewitched their children for financial or other gains. In addition, the severity of the condition was explained as the result of a particularly powerful curse. This can place children with deafblindness and their parents in a situation where they are at greater risk of being bullied and excluded, compared to families with children with milder disabilities.

The findings show that children with deafblindness, and children with other types of disabilities, are often bullied and excluded outside of the schools due to what the parents explained was deep culturally rooted beliefs¹⁷⁰. Parents said that some feared that the condition might be contagious and refused their own children to interact with children with deafblindness. This can be explained by what Bos et al. (2013) describe as stigma by association. People might fear that they, or their children, might be stigmatized themselves as a result of being associated with a child with conditions explained as outcomes of powerful curses. Not only are children with deafblindness stigmatized; so are their teachers. Findings show that special needs teachers are called “teachers for fools¹⁷¹”. This explicitly shows the stigma by association. The results are multiple, but two must be described here. The first is that children with deafblindness, and their families, suffer from exclusion to a stronger degree than other groups of children with disabilities and their families. The second shows how stigma can intersect with other factors to reinforce exclusion and reduced learning outcomes. Being stigmatized can have a negative impact on learning outcomes due to the fact that children with deafblindness, as a result of stigma, can have less access to peer-assistance outside of school. One example is language. As shown above, if parents do not know the language of instruction, findings show that children can benefit from peer assistance when struggling to understand the language of instruction. Due to being stigmatized and excluded, children with deafblindness do not have the same access to peer assistance. This shows that children with deafblindness are disadvantaged in multiple ways when different exclusionary factors intersect.

¹⁷⁰ ZAM PFG 1

¹⁷¹ ZAM GOVT 1

It can also be argued that children with deafblindness suffer from structural stigma as described by Bos et al. (2013) where societal institutions and ideologies contribute to the perpetuation and exacerbation of stigmatization (Bos et al., 2013; Corrigan & Lam, 2007). As shown in subsection 7.3.2., some of the literature used within the inclusive education discourse reduces educational choices for children with deafblindness to a choice between attending mainstream classrooms, or non-formal education. The sourcebook described in the same subsection include suggestions for teaching strategies that are not relevant for many children with deafblindness. This can be viewed as a form of structural stigma that can lead to exclusion of children with deafblindness from formal education. On the other hand, findings show that parents do not have these negative experiences from their encounters with special needs schools. Parents inform that they feel that they are supported, and that they are enabled to interact and communicate. This does not mean that special needs schools *are* actually better solutions for children with deafblindness, but it means that parents have good reasons to *feel* that special needs schools are preferred choices.

Parents' feeling of not being valued, of being excluded and stigmatized together with their children, and of their children being bullied, indicates that children with deafblindness in Malawi and Zambia cannot be considered as included within the emotional dimension. Their communication forms are, due to public stigma, many times not valued. Their condition is sometimes explained by belief systems that contribute to exclusion due to stigma by association. Their teachers are not valued, both stigmatizing the teachers by association, and devaluing children with deafblindness. Literature about inclusive education can be viewed as contributing to structural stigma. All this can explain, in line with what Uba and Nwoga (2016) describe from their study in Nigeria, that stigma influences parents' educational choices making them more positive towards special needs education, more focused on protecting their children, and less positive to inclusive education.

8. Conclusions

As my thesis shows, the education systems in Malawi and Zambia are heavily influenced by Western epistemology and the global architecture of education. Additionally, while inclusive education as a normative theory has the potential to be a counter-hegemonic discourse underpinned by dialogism, the actual implementation in Malawi and Zambia is underpinned by the monologicistic Western educational discourse. The result of this is that the relevance and the impact of the inclusive education discourse is heavily reduced. The direct impact for children with comprehensive and complex disabilities, such as deafblindness, is that they often experience being excluded from education, and alienated by the very discourse that claims to promote their inclusion.

The proceeding analysis shows that children with deafblindness are marginalized and excluded in a number of ways. Factors that exclude all children, exclude children with deafblindness more, like challenges with language of instruction. Adaptations done to the physical environment in schools intended to include children, like translucent roof panels and grouping of tables in the classroom, can have the opposite effect for children with deafblindness, and lead to a worsened situation. The belief that teachers will be able to include all if they are only trained in ‘inclusive education’ is a naïve assumption that reduces the relevance of the implementation of the inclusive education discourse. This assumption is in itself a contradiction to the whole idea that underpins inclusive education: for education to be relevant, it must be adapted to each individual child on their individual terms. How is it possible to imagine a one-size-fits-all-training that will enable teachers to understand and meet all individual needs of all children – when people are extremely heterogeneous, when people have a language, a gender, an impairment or a combination of more impairments, a culture, an epistemological background, etc., etc.? How is it possible to imagine that teachers in Malawi and Zambia will develop methods to include children with deafblindness when they do not have access to information, material, libraries, or even time to do so? And – why should teachers develop the methods? The methods are already developed, and teachers want to be trained in those methods. The result of this assumption is that in the implementation of the discourse, ‘inclusive education’ reduces itself to be about increasing attendance of a limited number of children with mild to moderate disabilities, with few efforts done to improve learning outcomes, and with little relevance to children with comprehensive and complex disabilities, like deafblindness.

This also contributes to a continued stigmatization of children with deafblindness and their families.

For children with deafblindness in Malawi and Zambia to see the right to education realized, the language of instruction policy must be revisited. When the Convention on the Rights of Persons with Disabilities describes “the most appropriate languages and modes and means of communication” this includes the vernacular languages, bodily tactile communication, tactile sign language, and all individual communication forms used by children with deafblindness (UNCRPD, 2016, p.10). All children should receive education in a familiar language, but this is particularly important for children with deafblindness.

For children with deafblindness in Malawi and Zambia to see the right to education realized, resource rooms must be constructed at all schools across Malawi and Zambia. The governments of Malawi and Zambia, together with the international donor community, must increase their efforts to provide educational environments that can accommodate and give access to all children. Those environments do not necessarily have to be formed based on Western concepts of a classroom, but should be designed based on local experiences and expertise.

For children with deafblindness in Malawi and Zambia to see the right to education realized the two governments, and the international donor community, must strengthen their efforts to equip teachers with the knowledge they need to be able to provide quality education for all children, including children with deafblindness. This means that the contents, the teaching methods, approaches, structures, and strategies must be epistemologically relevant to children in their local schools, and teachers must have access to training they themselves find relevant and useful to their situation in the classroom and school.

There is a rising call to de-colonize education in the Global South. Inclusive education as a normative theory has the potential to become a counter-hegemonic discourse that can transform education systems. Underpinned by dialogism and research, inclusive education can lead to education systems that sees, meets, understands and communicates with all children. This can only happen if the inclusive education discourse is de-colonized, and the voices of children, parents and teachers in Malawi and Zambia are heard.

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Appendix 1 – Overview of some etiologies that may cause deafblindness

Source: http://deafblindindicators.eu/wp-content/uploads/2016/06/1_10Aetiology-table.pdf

Accessed 2019.01.23



Table: Identified primary aetiologies that may cause deafblindness

Aetiology		Aetiology	
Hereditary/Chromosomal Syndromes and Disorders			
101 Aicardi syndrome		132 Moebius syndrome	
102 Alport syndrome		133 Monosomy 10p	
103 Alstrom syndrome		134 Morquio syndrome (MPS IV-B)	
104 Apert syndrome (Acrocephalosyndactyly, Type 1)		135 NF1 - Neurofibromatosis (von Recklinghausen disease)	
105 Bardet-Biedl syndrome (Laurence Moon-Biedl)		136 NF2 - Bilateral Acoustic Neurofibromatosis	
106 Batten disease		137 Norrie disease	
107 CHARGE Syndrome		138 Optico-Cochleo-Dentate Degeneration	
108 Chromosome 18, Ring 18		139 Pfeiffer syndrome	
109 Cockayne syndrome		140 Prader-Willi	
110 Cogan Syndrome		141 Pierre-Robin syndrome	
111 Cornelia de Lange		142 Refsum syndrome	
112 Cri du chat syndrome (Chromosome 5p- syndrome)		143 Scheie syndrome (MPS I-S)	
113 Crigler-Najjar syndrome		144 Smith-Lemli-Opitz (SLO) syndrome	
114 Crouzon syndrome (Craniofacial Dysotosis)		145 Stickler syndrome	
115 Dandy Walker syndrome		146 Sturge-Weber syndrome	
116 Down syndrome (Trisomy 21 syndrome)		147 Treacher Collins syndrome	
117 Goldenhar syndrome		148 Trisomy 13 (Trisomy 13-15, Patau syndrome)	
118 Hand-Schuller-Christian (Histiocytosis X)		149 Trisomy 18 (Edwards syndrome)	
119 Hallgren syndrome		150 Turner syndrome	
120 Herpes-Zoster (or Hunt)		151 Usher I syndrome	
121 Hunter Syndrome (MPS II)		152 Usher II syndrome	
122 Hurler syndrome (MPS I-H)		153 Usher III syndrome	
123 Kearns-Sayre syndrome		154 Vogt-Koyanagi-Harada syndrome	
124 Klippel-Feil sequence		155 Waardenburg syndrome	
125 Klippel-Trenaunay-Weber syndrome		156 Wildervanck syndrome	
126 Kniest Dysplasia		157 Wolf-Hirschhorn syndrome (Trisomy 4p)	
127 Leber congenital amaurosis		158 Rosenberg Chutorian Syndrome	
128 Leigh Disease		159 Wolfram Syndrome (DIDMOAD)	
129 Marfan syndrome		160 Zelweger Syndrome (Cerebrohepatorenal Syndrome)	
130 Marshall syndrome		199 Other	
131 Maroteaux-Lamy syndrome (MPS VI)			



Pre-Natal/Congenital Complications	Post-Natal/Non-Congenital Complications
201 Congenital Rubella	301 Asphyxia
202 Congenital Syphilis	302 Direct Trauma to the eye and/or ear
203 Congenital Toxoplasmosis	303 Encephalitis
204 Cytomegalovirus (CMV)	304 Infections
205 Foetal Alcohol syndrome	305 Meningitis
206 Hydrocephaly	306 Severe Head Injury
207 Maternal Drug Use	307 Stroke
208 Microcephaly	308 Tumours
209 Neonatal Herpes Simplex (HSV)	309 Chemically Induced
299 Other	399 Other
Related to Prematurity	Undiagnosed
401 Complications of Prematurity	501 No Determination of Aetiology

Appendix 2. Biography Adeline Charlotte Becht

Retrieved from https://prabook.com/web/adeline_charlotte.becht/1705224, 2019.04.11.

Adeline Charlotte Becht – consultant, Counseling psychology educator

Adeline Charlotte Becht, American counseling psychology educator, consultant. Member of advisory board Department of Health, Education and Welfare, 1973-1975; board directors Oregon Council Orgns. Serving the Deaf, 1974-1975.

Background

Becht, Adeline Charlotte was born on March 11, 1937 in Muskegon, Michigan, United States.

Education

Bachelor in Psychology, Cascade College, 1964. Master of Education in Counseling and Guidance, Lewis and Clark College, 1976. Master of Arts in Clinical Psychology, University Oregon, 1982.

Doctor of Philosophy in Counseling and Clinical Psychology, University Oregon, 1982.

Career

Founder, director corporation blind, deaf, deaf-blind adults, Living Rehabilitation Center Inc., Portland, Oregon, 1971-1981; intern in psychology, Riverside Hospital (now named Pacific Gateway Hospital), Portland, 1980-1981; private practice, Portland, 1980-1989; instructor communications, American sign language for the deaf, Notre Coeur College, Portland, 1984-1986; Adjunct Professor counseling psychology, Lewis and Clark College, Portland, 1987-1992; retired, 1992. Visiting lecturer, workshop facilitator special education Lewis and Clark College, Portland, 1971-1992. Consultant on deafness for psychiatric patients Pacific Gateway Hospital, Portland, 1974-1992.

Visiting instructor deaf specialist training Western Oregon State College, Monmouth, 1974-1980.

Membership

Member of advisory board Department of Health, Education and Welfare, 1973-1975. Board directors Oregon Council Orgns. Serving the Deaf, 1974-1975.

Interests

Other Interests

Avocations: music from braille, fine arts, knitting, pottery, reading.

Appendix 3

INTERVIEW GUIDE FOR GOVT/NGO/DPO/TEACHERS

1. What is inclusive education?
2. Are schools supported with adequate funds and resources to provide quality primary education for non-disabled children?
3. How is the attitude among teachers, other learners and parents towards inclusion of children with deafblindness?
4. The UN Committee on the Rights of Persons with disabilities states that: only inclusive education can provide both quality education and social development for persons with disabilities, and a guarantee of universality and non-discrimination in the right to education. – What are your thoughts when you hear this statement?
5. Do you think that inclusive education is a cost-efficient solution?
6. What is your opinion on special schools?
7. The United Nations Convention on the Rights of Persons with Disabilities states that children have the right to inclusive education. The United Nations Committee on the Rights of Persons with Disabilities states that a child should not be sent away from their home. How do you understand this related to your view on special schools?
8. The CRPD 24.3. states: States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. – What is your opinion about the meaning of this?
9. The UN Committee on the Rights of Persons with Disabilities have commented on 24.3.C stating that: Students who are blind, deaf or deafblind must be provided with education delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize personal, academic and social development both within and outside formal school settings. The Committee emphasises that for such inclusive environments to occur, States parties should provide the required support, including by way of resources, assisted technology, and provision of orientation and mobility skills. – What does this mean?
10. The Committee defines:

Segregation occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities. – Thoughts?

Inclusion involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of

the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences. Placing students with disabilities within mainstream classes without accompanying structural changes to, for example, organisation, curriculum and teaching and learning strategies, does not constitute inclusion. Furthermore, integration does not automatically guarantee the transition from segregation to inclusion. – Thoughts?

11. Do you think that the CRPD open for the right to special needs education in special schools?
12. How does donor conditionalities effect the implementation of programs and projects focusing on inclusive education and education in general?
13. Have you experienced donor driven conditionalities that has been in conflict with your internal agenda?
14. Do you think that parents should be allowed to choose freely between special schools and mainstream schools?
15. What do you think should be the role of special schools and mainstream schools?
16. Are you familiar with policies and guidelines related to inclusive education in Malawi/Zambia?

Appendix 4 – List of informants

ZAMBIA

	Parents of children with deafblindness - Zambia	Total number interviewed: 14, 12f, 2m
Code	Description	Archive/doc#
ZAM PAR 1	Male, father of a child with deafblindness	Interviews/Signed consent/scan #25 Interviews/Transcribed/Interview#22
ZAM PFG 1	Group interview with 7 parents Female (scan#26) Female (scan#27) Female (scan#28) Female (scan#29) Female (scan#30) Female (scan#31) Female (scan#32)	Interviews/Signed consent/scan #26 - #32 Interviews/Transcribed/Interview#23
ZAM PFG 2	Group interview with 6 parents Male (scan#41) Female (scan#42) Female (scan#43) Female (scan#44) Female (scan#45) Female (scan#46)	Interviews/Signed consent/scan #41-46 Interviews/Transcribed/Interview#48
	Head Teachers - Zambia	Total number interviewed: 2, 1f, 1m
Code	Description	Archive/doc#
ZAM HTEA 1	Male, Head Teacher, School 1 ZAM	Interviews/Signed consent/scan #33 Interviews/Transcribed/Interview#24
ZAM HTEA 2	Female, Deputy Head Teacher, School 2 ZAM	Interviews/Signed consent/scan #39 Interviews/Transcribed/Interview#29
	Teachers - Zambia	Total number interviewed: 10, 8f, 2m
Code	Description	Archive/doc#
ZAM TEA 1	Female, teacher, Inclusive Education Coordinator at School 1 ZAM	Interviews/Signed consent/scan #34 Interviews/Transcribed/Interview#25
ZAM TEA 2	Male, teacher, at School 1 ZAM	Interviews/Signed consent/scan #35 Interviews/Transcribed/Interview#26

ZAM TEA 3	Female, teacher at School 1 ZAM	Interviews/Signed consent/scan #36 Interviews/Transcribed/Interview #27
ZAM TEA 4	Female, teacher, Inclusive Education Coordinator at School 2 ZAM	Interviews/Transcribed/Interview #28 Interviews/Signed consent/scan #37
ZAM TEA 5	Female, teacher at School 2 ZAM	Interviews/Transcribed/Interview #28 Interviews/Signed consent/scan #38
ZAM TEA 6	Female, special needs teacher, School 3 ZAM	Interviews/Signed consent/scan #47 Interviews/Transcribed/Interview #31
ZAM TEA 7	Male, special needs teacher, School 3 ZAM	Interviews/Signed consent/scan #48 Interviews/Transcribed/Interview #31
ZAM TFG 1	Group interview with teachers at School 4 ZAM Female (scan#56) Female (scan#57) Female (scan#58)	Interviews/Signed consent/scan #56-58 Interviews/Transcribed/Interview #39
	Government representatives - Zambia	Total number interviewed: 10, 1f, 9m
Code	Description	Archive/doc#
ZAM GOVT 1	Male, Education Officer – Ministry of General Education -Teacher Education Specialised Services	Interviews/Signed consent/scan #19 Interviews/Transcribed/Interview #16
ZAM GOVT 2	Male, Principal, Zambian teacher training college	Interviews/Signed consent/scan #20 Interviews/Transcribed/Interview #17
ZAM GOVT 3	Female, Curriculum Specialist at the Curriculum Development Center under the Ministry of General Education.	Interviews/Signed consent/scan #21 Interviews/Transcribed/Interview #18
ZAM GOVT 4	Male, lecturer at the University of Zambia. One of his fields of specialization is IE.	Interviews/Signed consent/scan #22 Interviews/Transcribed/Interview #19
ZAM GOVT 5	Male, magistrate in the northern part of Zambia, and has a lot of experience with disability law	Interviews/Signed consent/scan #23 Interviews/Transcribed/Interview #20

ZAM GOVT 6	Male, District Education Standards Officer, District Education Board Office, southern part of Zambia	Interviews/Signed consent/scan #49 Interviews/Transcribed/Interview#32
ZAM GOVT 7	Male, District Resource Centre Coordinator at a District Resource Centre in the southern part of Zambia	Interviews/Signed consent/scan #50 Interviews/Transcribed/Interview#33
ZAM GOVT 8	Male, Curriculum Specialist at the Curriculum Development Center under the Ministry of General Education.	Interviews/Signed consent/scan #53 Interviews/Transcribed/Interview#36
ZAM GOVT 9	Male, Education Standards Officer for Ministry of General Education	Interviews/Signed consent/scan #54 Interviews/Transcribed/Interview#37
ZAM GOVT 10	Male, responsible for following up an inclusive education project on behalf of the Ministry of General Education	Interviews/Signed consent/scan #55 Interviews/Transcribed/Interview#38
	Dissemination workshop participants	Total number interviewed: 22, 17f, 5m
Code	Description	Archive/doc#
ZAM WS 1	<ul style="list-style-type: none"> • Male, Lecturer, Zambia Institute of Special Education (ZAMISE) • Female, Program Officer, Disability NGO, ZAM NGO 1 • Male, Education Standards Officer Ministry of General Education, ZAM GOVT 9 • Female, Deputy Head, Special Needs School • Female, Project Manager, School 4 ZAM • Male, Senior Advisor, Disability NGO, • Female, Parent; ZAM PFG 1, ZAM WS 2 • Female, Teacher, School 4 ZAM, ZAM TFG 1 • Female, Lecturer, ZAMISE; • Female, Teacher, School 4 ZAM, ZAM TFG 1 • Female, Headteacher, School 4 ZAM • Female, Sister, Catholic sister order; • Female, Teacher, School 4 ZAM, ZAM TFG 1 • Male, Lecturer, Disability NGO • Female, Head Teacher, Mainstream school, Lusaka; • Female, Teacher, School 4 ZAM • Female, Parent, teacher • Male, Curriculum Specialist at 	Presentations/ZAM WS 1

	Curriculum Development Center, Ministry of General Education. ZAM GOVT 8	
ZAM WS 2	Workshop with 4 parents Female (scan#26) Female (scan#28) Female (scan#30) Female (scan#31)	Presentations/ZAM WS 2
	Representatives from NGOs - Zambia	Total number interviewed: 4, 2f, 2m
Code	Description	Archive/doc#
ZAM NGO 1	Female, head of NGO working to implement inclusive education project	Interviews/Signed consent/scan #24 Interviews/Transcribed/Interview#21
ZAM NGO 2	Male, head NGO implementing inclusive education project	Interviews/Signed consent/scan #40 Interviews/Transcribed/Interview#30
ZAM NGO 3	Female, Program Officer for NGO working to implement projects targeting people with disabilities	Interviews/Signed consent/scan #51 Interviews/Transcribed/Interview#34
ZAM NGO 4	Male, program coordinator in a human rights NGO, rights of persons with disabilities, children's rights	Interviews/Signed consent/scan #52 Interviews/Transcribed/Interview#35

MALAWI

	Parents of children with deafblindness - Malawi	Total number interviewed: 8, 7f, 1m
Code	Description	Archive/doc#
MWI PFG 1	Group interview 2 parents Female (scan#67) Female (scan#68)	Interviews/Signed consent/scan #67-68 Interviews/Transcribed/Interview#45
MWI PFG 2	Group interview with 5 parents Female (scan#69) Female (scan#70) Female (scan#71) Female (scan#72) Female (scan#73)	Interviews/Signed consent/scan #69-73 Interviews/Transcribed/Interview#46
MWI PAR 1	Male, parent of child with deafblindness	Interviews/Signed consent/scan #74 Interviews/Transcribed/Interview#47

	Head Teachers - Malawi	Total number interviewed: 3, 1f, 2m
Code	Description	Archive/doc#
MWI HTEA 1	Female headteacher at School 1 MWI, Northern Region of Malawi	Interviews/Signed consent/scan #9 Interviews/Transcribed/Interview#8
MWI HTEA 2	Male, Head Teacher, School 2 MWI	Interviews/Signed consent/scan #61 Interviews/Transcribed/Interview#42
MWI HTEA 3	Male, Head Teacher, School 3 MWI	Interviews/Signed consent/scan #66 Interviews/Transcribed/Interview#45
	Teachers - Malawi	Total number interviewed: 3, 2f, 1m
Code	Description	Archive/doc#
MWI TEA 1	Female, teacher at School 2 MWI	Interviews/Signed consent/scan #62 Interviews/Transcribed/Interview#43
MWI TEA 2	Female, teacher at School 2 MWI	Interviews/Signed consent/scan #63 Interviews/Transcribed/Interview#43
MWI TEA 3	Male, specialist teacher, School 3 MWI	Interviews/Signed consent/scan #65 Interviews/Transcribed/Interview#45
	Representatives from NGOs - Malawi	Total number interviewed: 12, 1f, 11m
Code	Description	Archive/doc#
MWI NGO 1	Male, senior program officer in an international NGO working with projects targeting persons with different types of disabilities in Malawi	Interviews/Signed consent/scan #1 Interviews/Transcribed/Interview#1
MWI NGO 2	Male, program officer in an international NGO working with projects targeting persons with different types of disabilities in Malawi	Interviews/Signed consent/scan #2 Interviews/Transcribed/Interview#1
MWI NGO 3	Male, program coordinator in a human rights NGO, gender, disability, inclusion	Interviews/Signed consent/scan #5 Interviews/Transcribed/Interview#4
MWI NGO 4	Male, program officer at a DPO, responsible for implementation of inclusive education programs	Interviews/Signed consent/scan #6 Interviews/Transcribed/Interview#5

MWI NGO 5	Male, program officer, inclusive education specialist in an international NGO working with projects targeting persons with different types of disabilities in Malawi	Interviews/Signed consent/scan #8 Interviews/Transcribed/Interview #7
MWI NGO 6	Male, program officer at a NGO, responsible for implementation of inclusive education programs	Interviews/Signed consent/scan #10 Interviews/Transcribed/Interview #9
MWI NGO 7	Male, program officer at a NGO, responsible for implementation of inclusive education programs	Interviews/Signed consent/scan #11 Interviews/Transcribed/Interview #9
MWI NGO 8	Male, program coordinator in a human rights NGO, children's rights	Interviews/Signed consent/scan #12 Interviews/Transcribed/Interview #10
MWI NGO 9	Male, research and advocacy officer, NGO of persons with disabilities	Interviews/Signed consent/scan #15 Interviews/Transcribed/Interview #13
MWI NGO 10	Male, executive director, NGO of persons with disabilities	Interviews/Signed consent/scan #16 Interviews/Transcribed/Interview #14
MWI NGO 11	Male, board member, NGO of persons with disabilities	Interviews/Signed consent/scan #17 Interviews/Transcribed/Interview #14
MWI NGO 12	Female, executive director, NGO of persons with disabilities	Interviews/Signed consent/scan #18 Interviews/Transcribed/Interview #15
	Government representatives - Malawi	Total number interviewed: 4, 1f, 3m
Code	Description	Archive/doc#
MWI GOVT 1	Male, Disability Inclusion Specialist under the Ministry of Education, Science and Technology	Interviews/Signed consent/scan #3 Interviews/Transcribed/Interview #2
MWI GOVT 2	Male, Director, Ministry of Education, Science and Technology	Interviews/Signed consent/scan #4 Interviews/Transcribed/Interview #3
MWI GOVT 3	Male, desk officer responsible for special needs education at District Education Manager's Office	Interviews/Signed consent/scan #13 Interviews/Transcribed/Interview #11
MWI GOVT 4	Female, District Education Manager	Interviews/Signed consent/scan #14

		Interviews/Transcribed/Interview#12
MWI GOVT 5	Male, Desk Officer for Primary Education (DOPE), District Education Manager's Office	Interviews/Signed consent/scan #59 Interviews/Transcribed/Interview#40
	Other informants - Malawi	Total number interviewed: 3, 1f, 2m
Code	Description	Archive/doc#
MWI INF 1	Female, the Norwegian Embassy in Lilongwe, Malawi, education sector	Interviews/Signed consent/scan #7 Interviews/Transcribed/Interview#6
MWI INF 2	Male, Chairperson School Management Committee, School 2 MWI	Interviews/Signed consent/scan #60 Interviews/Transcribed/Interview#41
MWI INF 3	Male, Chairperson School Management Committee, School 3 MWI	Interviews/Signed consent/scan #64 Interviews/Transcribed/Interview#44
	Dissemination workshop participants	Total number: 38, 16f, 22m
Code	Description	Archive/doc#
MWI WS 1	<ul style="list-style-type: none"> • Male, officer at human rights NGO, informant MWI NGO 8 • Female, independent consultant, experience from evaluation of disability programs • Male, senior program officer, disability NGO, informant MWI NGO 1 • Female, Inclusive education officer, Ministry of Education, Science and Technology • Male, Inclusive education officer, Ministry of Education, Science and Technology • Male, Inclusive education officer, Ministry of Education, Science and Technology • Male, disability specialist, Ministry of Education, Science and Technology • Male, special needs & inclusive education officer, disability NGO, informant MWI GOVT 3 (has changed job after the interview) • Female, senior officer, Ministry of Health 	Presentations/MWI WS 1

MWI WS 2	<ul style="list-style-type: none"> • Male, Deputy Headteacher, School 3 MWI • Female, special teacher, from a school that was not visited during the research • Female, special teacher, from a school that was not visited during the research • Female, teacher, School 3 MWI • Male, special teacher, School 3 MWI, MWI TEA 3 • Female, Executive Director, special needs school, not visited during the research • Male, Headteacher, School 2 MWI, MWI HTEA 2 • Male, Desk Officer for Primary Education (DOPE), District Education Manager's Office, MWI GOVT 5 • Male, project officer, NGO health/education • Male, project officer, NGO health/education • Male, programs manager, NGO health/education • Male, driver, NGO health/education 	Presentations/MWI WS 2
MWI WS 3	<ul style="list-style-type: none"> • Female – (consent#69) • Female – (consent#70) • Female – (consent#71) • Female – (consent#73) • Male – (consent#74) 	Presentations/MWI WS 3
MWI WS 4	<ul style="list-style-type: none"> • Male, executive director, NGO of persons with disabilities (MWI NGO 10) • Female, teacher, special needs school (not one of the researched schools) • Male, lecturer, teacher training college • Female, field officer, NGO providing services for children with disabilities • Female, deputy principal, teacher training college • Male, sign language interpreter • Male, lecturer, teacher training college • Male, communication officer, NGO of persons with disabilities • Male, member, NGO of persons with disabilities • Male, research and advocacy officer, NGO of persons with disabilities • Female, Dean of Education, university • Female, project coordinator, NGO of persons with disabilities 	Presentations/MWI WS 4

Appendix 5: Presentation used at dissemination workshops

Children with
Deafblindness
and
Inclusive Education

Kenneth Verngaard
Oslo Metropolitan University

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Mutu umodzi susenza ndenga

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Objectives for the workshop

- Develop new knowledge about inclusive education and deafblindness
- Present frames for research:
 - My position as a researcher
 - Conceptual framework
 - Methododology
- Disseminate findings
- Analysis – theoretical framework

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Program

- Refreshments – 10:30-10:45
- Lunch – 12:30 – 13:30
- Refreshments – 16:00

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The researcher

- Kenneth Verngaard
- 45 years old
- Married, three girls (25, 22, 18)
- Worked for the Signo Foundation for 24 years
 - With clients with autism, deafblindness, other impairments – all in combination with hearing loss
 - Administration – staff management, in service training
 - International department since 2008 – Malawi, Uganda, Zambia
- Master student 2017-2019 OsloMet
 - Master in multicultural and international education

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The researcher



The researcher



The researcher



The researcher

- Disability – undergone several large operations
- Would not be alive or would have been extremely poor if I had not been born in Norway
- Will not look for a new career, will not get more money
- Interested to give back to society what society has given to me
- What bothers you?
 - How is the situation for children with deafblindness in Malawi and Zambia?

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The researcher

- Paper folding activity
- Epistemological background
- As a researcher I am aware that my values, my everyday conceptual schemes, my perspectives, the research paradigms I identify with, and the research community I belong to can influence what is researched, how the research is conducted, the techniques I use, and how the data is coded, analyzed, weighted and given meaning.

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The research - relevance

- Little research done
- Lack of a universal understanding of what inclusive education is
- Results are often not disaggregated by impairment types
- General Comments no.4 (2016): lack of disaggregated data is a barrier to inclusion

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Research question

- How can quality education be provided for children with deafblindness to “maximize personal, academic and social development both within and outside formal school settings” in line with the Convention on the Rights for Persons with Disabilities (CRPD) and the General comment No. 4 (2016) issued by the United Nation Committee on the Rights of Persons with Disabilities on the right to inclusive education (UN 2016, p.10)?

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Research question

1.

How do parents, the authorities, teachers, Disabled Peoples Organizations (DPOs) and Non-Governmental Organizations (NGOs) in Zambia and Malawi understand the concept of 'inclusive education' in relation to children with deafblindness?

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Research question

2.

What types of resources and adaptations are needed to ensure inclusive quality education for children with deafblindness, and to what extent are these resources available?

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Research question

3.

To what extent are the education systems in Malawi and Zambia epistemologically and linguistically inclusive for children with deafblindness and for other children, disabled or not?

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Part 2

- Conceptual framework:
 - Deafblindness
 - CRPD
 - Inclusive education

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Definition of disability- CRPD

Disability is an evolving concept and disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

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Nordic definition of deafblindness

Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability.

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Congenital deafblindness

Being born with deafblindness, OR develop deafblindness before development of language.

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Acquired deafblindness

Persons who develop deafblindness after they develop a language:

1. Born deaf or with hearing impairment, then develop blindness. Sign language/deaf culture.
2. Born blind or with visual impairment, then develop deafness. Spoken language/need to learn sign.
3. Born with normal hearing/vision, then develop deafblindness. Spoken language/need to learn sign.

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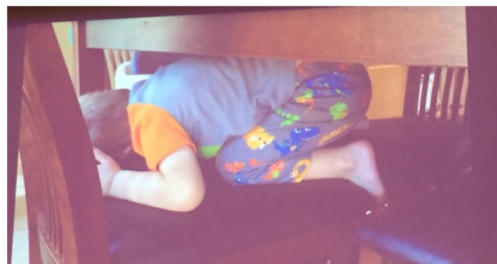
Communication

- Development of communication
- Communication means to share something
- Be in contact
- Communication is co-created and developed by both communicators
- Communication can happen with or without a formal language

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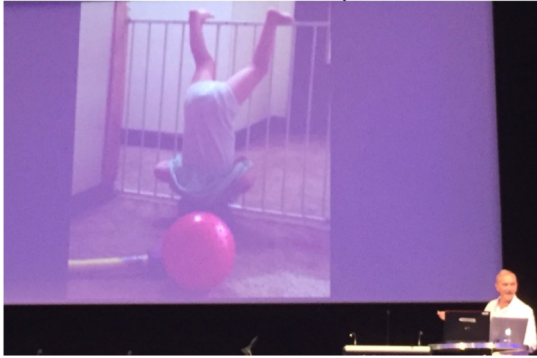
One extreme example



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Another extreme example



Yet another extreme example

A friend of mine – you might know him – a Zambian - is now doing his Ph.D.

He has deafblindness.

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Deafblindness- recap

- Discuss with your neighbor for one minute about deafblindness.
- Each pair of two to say one thing about deafblindness to the rest of the group

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United Nations Convention on the Rights of Persons with Disabilities

Article 24:

States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning (...)

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United Nations Convention on the Rights of Persons with Disabilities

Article 24:

States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure **an inclusive education system** at all levels and lifelong learning (...)

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United Nations Convention on the Rights of Persons with Disabilities

Article 24:

an inclusive education system

- Inclusive education is stated as a right
- **All** children, including children with deafblindness and complex disabilities must be included
- The question is **how** we work to ensure that the right is realized for children with deafblindness, not if we agree or disagree that it is a good idea

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Key question:

What is inclusive education?

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Key principles Article 24

24.2.a:

PWDs “are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability”

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Key principles Article 24

24.2.b:

PWDs “can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live”

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Key principles Article 24

24.2.e:

“effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion”

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Key principles Article 24

The CRPD 24.3. states:

States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community.

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Key principles Article 24

24.3.c

“ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.”

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CRPD - recap

- Discuss with your neighbor for one minute about the CRPD.
- Each pair of two to say one thing about the CRPD to the rest of the group

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Interview question

What is inclusive education?

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Definition of inclusive education

There is no universally agreed understanding of what inclusive education is, even though the GC 4 paragraph 11 offers a legal definition of inclusive education

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Legal definition of inclusive education

Inclusion involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences.

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Legal definition of inclusive education

Placing students with disabilities within mainstream classes without accompanying structural changes to, for example, organization, curriculum and teaching and learning strategies, does not constitute inclusion.

Furthermore, integration does not automatically guarantee the transition from segregation to inclusion

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Who are included now?

- Children with physical disabilities are more likely to access education compared to children with intellectual or sensory impairments (WB/WHO 2011, p.207).
- Significant risk that efforts to implement the CRPD and inclusive SDGs will exclude persons with deafblindness, among other marginalised groups. (WFDB 2018, p.3)

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Who are included now?

- deafblindness is not recognized in many countries, individuals have to select either deaf or blind on official forms and documents, which leads to invisibility in statistical or administrative data. (WFDB 2018, p.9)
- Children with deafblindness are 17 times less likely to be in school than non-disabled children, and twice less likely to be in school compared to children with other types of disabilities (WFDB 2018, p.47)

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Who are included in Malawi?

- Group discussion:
- Who are included in mainstream schools in Malawi?
- Are CWDs integrated or included?

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Part 3 - Methodology

- Ethnography - explores the social world or culture, shared beliefs and behaviors
- The research is based in an ontologically constructive and epistemologically interpretive understanding of knowledge production. This means that data has been produced rather than collected, and that qualitative research methods have been the preferred research methods.
- Knowledge is produced in the interactions between human beings, the environments in which they live and the culture – society - technology

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Method: Semi-structured qualitative research interviews

- Qualitative semi-structured research interviews are pre-prepared conversations between a researcher and an interviewee in an often unequal power relationship

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Method: Observations

- Visits to schools in Zambia and Malawi
- Classrooms
- School ground
- Toilet facilities
- Physical adaptations
- It was quite clear in all of the schools and classrooms I visited that my presence changed the way the teacher and the students behaved

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Method: Lost in interpretation?

- A process of interpretation is always necessary
- Using interpreter – risky business
- Literal or colloquial?
- Culture

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Method: Sampling

- Families identified through the project
- Contacts and network
- Snowball technique
- Gender
- Two countries

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Method: Trustworthiness and relevance

- Trustworthiness and relevance are alternatives to validity and reliability to evaluate qualitative research.
- Validity and reliability - fits best to evaluate quantitative research
- Evaluating validity and reliability can be viewed as concepts closer to the realist worldview where reality is viewed as 'hard', single, and available for researchers to uncover

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Method: Trustworthiness and relevance

- Transferability
- Conformability
- Authenticity
- Dependability

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Method: Ethical considerations

- Do no harm
- Sensitive information about disabilities and family situations
- Issues discussed may be sensitive
- Relationships – social desirability bias
- Information and written consent
- Can withdraw
- Anonymity

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Methodology and Methods - recap

- Discuss with your neighbor for one minute about the methodology and the methods described.
- Each pair of two to say one thing about the methodology and the methods to the rest of the group

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Part 4 - Findings

- Perceptions about Inclusive Education
- Resources (needed and available)
- Cultural and linguistic inclusivity
- Attitudes – language of instruction – indigenous knowledges
- Little difference between Zambia and Malawi – findings presented together

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Findings part 1: Perceptions about inclusive education

- Parents perspectives
- Environments
- Resources
- Skills and knowledge

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Parents perspective

- Most parents having children with deafblindness who were interviewed, except two, said that they preferred that their child should be in a special school, or in a resource room.
- Parents in Zambia were more skeptical towards mainstream schools with resource units, compared to Malawian parents.

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Parents perspective

- *Even though they are allowed to be in class, there is that segregation in class. There is space that is given to the two children, and whenever one is alone is when (s)he feels lonely because (s)he is left alone, there is nobody. So, these two, when they are together they look at each other, they know 'my friend is here' then consolation comes in. But when you are alone you don't have that consolation. Even the teachers they don't assign the children to interact with these ones in the classes. For example, just to open the book – no child is assigned. Even the teacher doesn't go there to help the children to open the books. The children are just being seated in the classroom.*

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Parents perspective

The parents underlined that teachers need knowledge about communication, about deafblindness, and they need to be passionate.

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Inclusive environments

- All in the same classroom
- Units and resource rooms
- The whole education system

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All in the same classroom

- A majority of all of the informants, across the two countries, and across all categories of interviewees
- All children being in the same environment meaning
 - in the same classroom,
 - at all times,
 - learning the same curriculum and topics,
 - taught by the same teacher

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All in the same classroom

Inclusive education is where every child, education for all, every child is brought in school. They are learning together regardless of the status of the child, regardless of the abilities and inabilities of a child. They are all brought together to learn. [...] Into the same class. Those that are visually impaired, deaf, the blind, those who have physical disabilities are all brought together

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All in the same classroom

- “boils down to the type of expertise the teachers are provided”
- Physical adaptations to the classroom or sitting positions to accommodate different challenges and needs.

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Inclusive education opens for units and special classrooms

- 2nd most common perspective
- *And within that inclusive education set up we will for example have a special room, like a resource room, where they could have specific attention or maybe, for specific needs to be addressed in that room. Where they could get all the appropriate support services that they would require as per condition.*

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Inclusive education opens for units and special classrooms

- United Nations Committee on the Rights of Persons with Disabilities – General comment no.4 2016:
- **Segregation** occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities.

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Inclusive education opens for units and special classrooms

- *It's not that they should be completely put in that room. It's when it's necessary and appropriate for their learning and their condition. Then you move them and provide the needed support and once they get that they can go back to the mainstream class. It's not that they should be removed from that class permanently, no, just for specific moments*
- Is the definition relevant?

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Inclusive education opens for units and special classrooms

- The resource rooms were understood more as an environment where individual barriers to inclusion could be addressed, rather than being a question of segregation, and many said that the definition did not feel relevant, as the idea was not to respond to the impairments, but the individual communication-, mobility- and learning barriers
- Thoughts?

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Inclusive education opens for units and special classrooms

- *I think it is important to revisit the term inclusion with respect to the social-economic reality in Malawi. In my own understanding inclusion from the generic understanding of it is unattainable in as far as we talk of inclusion of learners with deafblindness. If anything, we should be talking about modifying the system, talk about establishment of resource centers in the mainstream schools to cater for the needs of learners with deafblindness*
- Thoughts?

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Inclusive education means access to any type of education

- "inclusive education is *THE* education"
- Inclusive education is "the main framework where inside you can find units and you can find special schools. That is the context in which the Zambian govt is discussing inclusive education."
- Twin track approach
- Thoughts?

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Findings in literature about environments

24.3.c

"ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development."

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Article 24.3.C.

- Article 24 "does not prevent state parties from establishing special schools, but neither does it compel them to be equipped with such schools" (De Beco 2016, p.52)
- According to Stubbs 24.3.C. allows "the possibility of segregated education" for the mentioned group (Stubbs 2008, p.22).

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Article 24.3.C.

- 24.3.C allows for 'the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development'.
- **both within and outside formal school settings**

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Article 24.3.C.

- The environment can be variable, depending on the child's learning needs, and
- This may be in formal or informal settings.

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Article 24.3.C.

- This allows for one-on-one instruction in mainstream schools when it is needed
- Home-based education when required
- Non-mainstream classroom environments, such as sensory rooms, orientation and mobility training etc

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Article 24.3.C.

- It does not, however, allow for completely segregated systems whereby children with deafblindness are cut off from society and are in a completely separate educational system because of impairment. (Grey 2017)
- The difference is between responding to child's learning needs vs responding to impairment.

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Article 24.3.C.

- WFD: the drafting history of the CRPD "clearly shows that governments and other stakeholders understood the need for deaf children (and deaf-blind, and blind children) to be educated with others like themselves with dignity and as a matter of choice" (WFD 2016, p.7).
- WFD states that "Article 24 should not be misread as mandating mainstream schools as the only modality of education for all deaf children"
- Deaf schools are referred to in WFD position paper on inclusive education

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Opening for other groups as well?

24.2.e:

"effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion"

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Environments - recap

- Discuss with your neighbor for one minute about the environments where inclusive education takes place.
- Each pair of two to say one thing about these environments to the rest of the group

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Access to resources

- Physical adaptations
- Human resources
- General infrastructure
- International development

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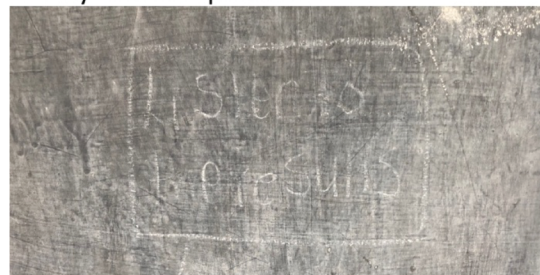
Access to resources

Access to economic and human resources and physical adaptations to the school environment has been highlighted by most interviewees as an overarching factor that can promote or represent a barrier to inclusion of children with deafblindness as well as all other children, disabled or not

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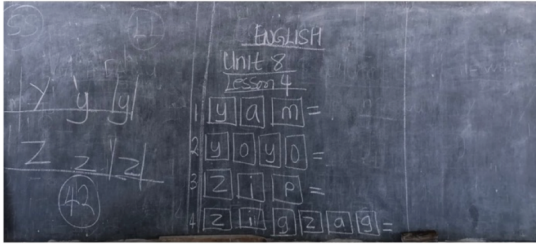
Physical adaptations



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Physical adaptations



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Physical adaptations



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Physical adaptations



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Physical adaptations



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Physical adaptations



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Physical adaptations



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Physical adaptations



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Physical adaptations



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Physical adaptations



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What are your thoughts about these physical adaptations?

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Access to resources

- High learner to classroom ratio
- High learner to teacher ratio
- Lack of textbooks and other learning material,
- Limited access to assistive devices like hearing aids, glasses, wheelchairs,
- Limited number of resource rooms

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Access to resources

- General infrastructure
- Transport

when you don't have money, the child will stay at home and (s)he will not attend classes

JSELO
MET

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Access to resources

- International development projects the solution?

When the program comes in, they come in with a lot of money. And usually the drive is money, and people they get to the program because of the money. And sometimes as the money begins to trickle off it means that also the interest. You only remain with the few who remain with passion.

JSELO
MET

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International development projects

We want the training to be comprehensive. Taking the teachers gradually. For some of them this is a relatively new concept. We want to give them in depth material. But then, because the donor has set a limit on the budget where you are going to train a specific number.

JSELO
MET

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International development projects

So, per school you are going to train fully 5 per school. For the rest we train them bits and bits. This has affected our approach. When you train in bits, they do not fully acquire the knowledge. Some of them we have only trained them in 2 units but there are 6

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International development projects

- One off superficial trainings vs continuous professional development
- Government willing/able (in terms of resources) to continue training?

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- International development projects – after the project ends
- *– our teachers are now equipped – what we are going to do is to intensify monitoring, and grants to the school. The program will continue with the govt.*
 - CPD – *continue to be reminded what they have learnt through the project, monthly trainings, at least every year,*

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- International development projects – after the project ends
- *We had vehicles that we used for monitoring, but when project is over, vehicles are taken away, will not be possible to continue to monitor. We used to have motorcycles provided by the govt – all have broken down*
 - Resources?
 - *We have got little, those will be spread, including to the program. But we will be lowering the monitoring.*

JSELO
MET

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International development projects – after the project ends

- *disappointingly some teachers have left the concept completely*
- *In-service training of teachers is of little use. Teachers have experienced that programs come and go. They don't bother to learn the new stuff, because they know that sometime soon another program will come in.*

JSELO
MET

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Resources - recap

- Discuss with your neighbor for one minute about the access to resources.
- Each pair of two to say one thing about access to resources to the rest of the group

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Teacher's knowledge, skills and experience

- All mainstream teachers expected to be able to take use of inclusive teaching methods
- Not equally clear what those methods consisted of
- Assumption: if a teacher is trained in inclusive methodologies, she would then be able to include all learners in the classroom
- *"will not have a problem on how to practice", and will be able to "help each child at individual level»*

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Teacher's knowledge, skills and experience

- Teachers are *"trained to be specialized in one area, blindness, deafness or deafblindness"*
- *"Not trained to be an inclusive teacher"*

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Teacher's knowledge, skills and experience

- Specific strategies for inclusion of children with specific impairments?
- *No, inclusive education actually does not go into... what inclusive education say... you know, the, the manuals are doing is to provide.... Strategies, styles, methodologies and approaches for engaging a learner with a disability, and... meaning that if you have... in other words, it is not a prescription of a protocol on a specific disability. That is something that those who have been trained in inclusive education will develop.*

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Teacher's knowledge, skills and experience

- The dream teacher:
- Fluent in sign language
- Knowledgeable in tactile communication forms
- Able to read and write Braille
- Fluent in the language of instruction used at the school
- Able to understand the individual needs of all the children in the classroom, and adapt the teaching accordingly

JSELO
MET

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Teacher's knowledge, skills and experience - recap

- Discuss with your neighbor for one minute about the teacher's knowledge, skills and experience.
- Each pair of two to say one thing about the teacher's knowledge, skills and experience to the rest of the group

350 MET

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Cultural and linguistic inclusivity

Culturally rooted belief systems
Indigenous knowledges

Language of instruction

350 MET

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Attitudes towards inclusion of children with deafblindness

- Witchcraft described as one of the reasons for why children with deafblindness were excluded in the communities in which they live, and from access to mainstream schools
- the severity of the impairments indicated that the witchcraft or curse placed upon them must have been particularly powerful

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Attitudes towards inclusion of children with deafblindness

- Children with disabilities and people with disabilities at all ages experience negative attitudes.
- Parents expressed mixed emotions
 - Value and love
 - Very big challenge in my life

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Attitudes towards inclusion of children with deafblindness

I will put it that way... in our culture there are some who think that these children are cursed. Some they think that they bring bad luck. Others say, maybe if a person is pregnant, they will say "no if this child keeps on coming to this house, you will give birth to the same child. Your unborn baby will also be born the way this person is. So, our children are not accepted by the community.

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Attitudes towards inclusion of children with deafblindness

- Bullied – deep culturally rooted beliefs
- Protection
- the attitudes have to be changed *before* their children should be exposed to the mainstream environment

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Attitudes towards inclusion of children with deafblindness

- Prescribe attitudes to others
- all interviewees expressed that they were positive towards including children with deafblindness into the education system
- cultural aspect: *"are taught to sympathize with disadvantaged persons"*

350 MET

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Attitude or workload?

- *"regular teachers" with little preparations and training "feel inept, they feel that they don't have the skills, so their attitude is - I can't. So, they are defeated."*
- *It is very difficult for one teacher to handle all the learners and six different disabilities. This one we need... this one we need, and time as we are delivering the content. It is very hard. It is difficult. It is very tiresome work. It is challenging to us*

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Attitudes towards inclusion of children with deafblindness

- Parents not willing – have to be convinced?
- Somehow yes, somehow no. We want to take the child to school. For me there was so much fear. How will she be treated? Maybe the teacher will slap the child. The community and the friends have not accepted the child. How will the situation be in the school?

JSLO/MET

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Attitudes- recap

- Discuss with your neighbor for one minute about the attitudes.
- Each pair of two to say one thing about the attitudes to the rest of the group

JSLO/MET

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Cultural and linguistic inclusivity

*Culturally rooted belief systems
Indigenous knowledges*

Language of instruction

JSLO/MET

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Language of instruction

- Observation in classrooms visited
 - Not able to communicate using English
 - Often not able to communicate in language of instruction

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Language of instruction

- *a teacher who is maybe from a different province is not knowledgeable about the language of instruction - and this teacher is expected to teach children in a foreign language, Tonga – Yao - Nyanja*
- *So, this has been cited as one of the barriers to effective learning for the children in an inclusive way where they are trying to implement inclusive education.*

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Language of instruction

- Mother Tongue /Vernacular languages not mentioned in the IE strategies – only sign language
- Challenging in urban areas – multilingual: what is the vernacular?

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Language of instruction

I can teach for 10 minutes, but no any learner can know what you are doing, what you are teaching. Unless I put some local language, a little bit, so that they can relate.

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Language of instruction

But your question. I can get your question. You are saying: How do we handle a learner from Chiyao, Tumboka to Chichewa and then to English. But I told them in my class that, when you enter this class no more Chiyao. Don't speak Chiyao here. You are going to speak Chiyao when you go home. It is a problem to us.

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Language of instruction

- Parents sometimes unable to assist their children after school due to language issues – peers can
- Parents inform that their children are excluded outside of the school – no peers to assist them with language challenges

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Indigenous Knowledges – findings from literature

- Inclusive education is not a new idea. Communities have practiced inclusion for centuries. It is important to acknowledge and build on this wherever possible, so that inclusion becomes sustainable, with community ownership and involvement. Indigenous education in Africa was, and is, inclusive, reflecting many of the principles in today's vision of quality, inclusive education for all (Stubbs 2008)

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Indigenous Knowledges – findings from literature

- based on strong family ties, the value of the individual, coexistence and survival
- used flexible formats and locations, responding to individual learning needs; used any convenient physical or social space and all community members as resources
- had relevant and functional content and methods, such as: cooperative and collaborative learning, child-to-child, peer tutoring, learning-by-doing and apprenticeship in real life.
 - Stubbs 2008

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Indigenous Knowledges

We should depart from the formalized education system. We can go informal, we can go a little bit indigenous because not all aspects of indigenous technical knowledge are bad. Looking at pre-colonial Africa one is to see that societies were a bit more inclusive than today. Then we are talking about Westernization and modernization taking its toll on African societies. This should give us another thought to say: Can we rethink education and think about inclusive education?

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Indigenous Knowledges

- *Inclusive education is not pointing back to indigenous education, I think it is just another Western education system.*
- *Children are being trained to pass exams. They are not learning, but are memorizing.*
- *The education is preparing them for white-collar jobs, but not for life.*

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Inclusion of all learners- recap

- Language of instruction – indigenous knowledges
- Discuss with your neighbor for one minute about the attitudes.
- Each pair of two to say one thing about the attitudes to the rest of the group

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Part 5 – Analysis – theoretical framework

- Epistemology and the global architecture of education
- Identity construction
- Dislocation of indigenous knowledges
- Zone of proximal development

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Purpose of Education

- To pass on cultural values, knowledge and beliefs;
 - Give people critical consciousness about themselves to become who they want to be;
 - Enable acquisition of desirable goods to resolve conflict, spread tolerance and concern for the common good as well as for own prosperity;
 - Promote economic and social equality
- Woods 2005, p.84-85

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Epistemology- knowledge

- Theory of knowledge
- The nature, scope and sources of knowledge
- The way people view and make sense of the world according to what they have learned and what they believe

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Western knowledge

- An autonomous individual, behaving based on rationality and reason to understand the world
- Humanity placed at the center of the universe
- Universality or Christian secularity?

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Western knowledge

- Hegemony of Western knowledge
- The lives, hopes, plans and imagination of some people are shaped by others who does not share their lifestyles, hopes or values.

Tucker 1999, p.1

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Colonization of the mind

- Ngũgĩ wa Thiong'o : "its most important area of domination was the mental universe of the colonized, the control, through culture, of how people perceived themselves" (Bredlid 2013 p. 10).
- Epistemic genocide
- Frantz Fanon – the wretched of the earth



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The Global Architecture of Education

- A "complex web of ideas, networks of influence, policy frameworks and practices, financial arrangements and organizational structures—a system of global power relations that exerts a heavy, even determining, influence on how education is constructed around the world" (Jones 2007, p.325).
- The leading international organizations promoting education, like the World Bank, UNESCO, UNICEF, and OECD are all heavily influenced by Western epistemology

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Identity construction

- Identity and identity construction cannot be separated from culture
 - Culture plays an important role in learning because of its impact on developing a person's mental and cognitive soft-ware.
 - Humans are born into a cultural context formed by generations of lived experiences and social processes, and are shaped by those
- Thybo 2013, p.273.

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Dislocation of indigenous knowledges

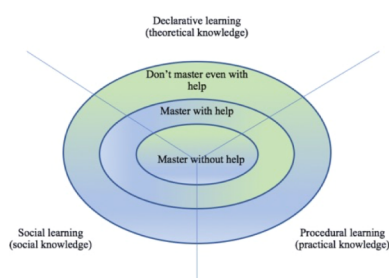
Huge cultural and epistemological gap between the languages, knowledges and worldviews learners bring from their homes, their peers, and local communities, and the knowledge and worldviews they are exposed to in schools, making it difficult for students to understand and challenging for teachers to teach

Bredlid 2013

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Zone of proximal development



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Zone of proximal development

- Thybo (2013) argues that if new introduced knowledge is close to what the learner already knows, the existing knowledge is consolidated, and new knowledge can be acquired.
- If the new introduced knowledge is too far from the existing consolidated knowledge, the learner will be in risk of failing to acquire the knowledge, loose motivation and experience a “destructive feeling of defeat” (Thybo 2013, p. 300-301, translated from Danish).

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Theoretical framework- recap

- Global architecture of education – identity construction – dislocation of indigenous knowledges – Zone of proximal development
- Discuss with your neighbor for one minute about the theoretical framework.
- Each pair of two to say one thing about the theoretical framework to the rest of the group

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Recap of the whole day

- My position as a researcher
- Conceptual framework
- Methododology
- Disseminate findings
- Analysis – theoretical framework

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Questions

1. To what extent do you feel that what I have presented fit with the actual situation on the ground?
2. To what extent and how do you think that this research can be useful?
3. To what extent do you think that the theoretical framework is relevant to analyze the findings?

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Thank you!

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Analysis – some final thoughts

1. Flexible formats are needed
2. Stand alone special schools should be avoided – enroll non-disabled learners - Locate schools together as twinning schools
3. A fundamental rethink of the education system is needed
4. In the same way that indigenous knowledges are dislocated within the global architecture of education – so are children with deafblindness within the inclusive education discourse as it is visible in Malawi and Zambia today
5. For learners to truly be included, schools must reflect their languages, culture and identity – disabled or not – this is especially important for children with deafblindness

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Appendix 6: Feedback from Dissemination workshops

Dissemination workshop 2019.02.20

Code: ZAM WS 1

Participants:

- Male, Lecturer, Zambia Institute of Special Education (ZAMISE)
- Female, Program Officer, Disability NGO, ZAM NGO 1
- Male, Education Standards Officer Ministry of General Education, ZAM GOVT 9
- Female, Deputy Head, Special Needs School;
- Female, Project Manager, School 4 ZAM;
- Male, Senior Advisor, Disability NGO,
- Female, Parent; ZAM PFG 1, ZAM PFG 3
- Female, Teacher, School 4 ZAM, ZAM TFG 1
- Female, Lecturer, ZAMISE
- Female, Teacher, School 4 ZAM, ZAM TFG 1
- Female, Headteacher, School 4 ZAM
- Female, Sister, Catholic order
- Female, Teacher, School 4 ZAM, ZAM TFG 1
- Male, Lecturer, Disability NGO
- Female, Head Teacher, Mainstream school, Lusaka
- Female, Teacher, School 4 ZAM
- Female, Parent, teacher
- Male, Curriculum Specialist at Curriculum Development Center, Ministry of General Education. ZAM GOVT 8

Feedback during the presentation:

Who are included?

In Zambia there is inclusion-confusion - including all in one class is what many think is inclusive education. That is wrong.

Policy - severe --> special schools
mild to moderate – mainstream

In inclusion I expect that the child will learn new skills. Inclusion is only for the mild to moderate. They are learning something. Here in Zambia I have never seen a severely disabled child included. Mild to moderate yes, severe no.

The program should meet the individual need. Assessment superficial - do not describe the individual child and their learning potential.

Included or integrated?

They are integrated, but we think we are including. In Zambia there is no inclusion. According to the definition, we don't do that.

I found a child. completely deaf, placed in a classroom. The child did not know sign language, teacher did not know signs. The boy was seated in class, the teacher was busy with other things and alone.

It is only integrated. The adaptations that are needed are not really there. Munali: The children have protested. Time and again they rise up and say NO we are not getting education.

Now we fail to even teach the ordinary child.

Comment about international development programs:

In-service training of teachers is of little use. Teachers have experienced that programs come and go. They don't bother to learn the new stuff, because they know that sometime soon another program will come in. It is better to train the student teachers. In that way they will have the knowledge imparted in them from the beginning.

Anonymous feedback to the questions:

All participants were asked to submit a written reply to the following questions after the research was presented in a 7-hour workshop. All answers were given anonymously.

Do you think that I have understood what people have said to me?

- I surely believe that you have understood all that was said to you
- Yes, you have understood them very well
- You have understood what people have said
- Yes
- Yes
- Yes, because you had interviews with them
- Yes
- Yes you did because you wrote what you were told
- Yes you did understand and in many ways you wrote the actual words people said
- Yes you have understood by writing whatever they told you or observed
- Yes – you have understood but more information on inclusive education is needed on your slide

Do you feel that what I have presented fit with the actual situation on the ground?

- Yes, you did. Your presentation clearly shows that you have carried out the research
- It is true what you have presented fit with the actual situation on the ground as moved by the richness
- Yes, it does all what you have said is what is on the ground. I know it as special education teacher.
- Yes, it is the actual situation on the ground
- Yes
- Yes/no it's still a 50-50 situation
- Somewhat
- Yes, because that is what is on the ground
- The presentation generally reflected what is on the ground because you interacted with the people and recorded what they said
- Yes, it does fit with the actual situation on the ground of which we were able to recognize ourselves and we move throughout the country we could [un-readable] more issues would come through.
- What you have presented its fit to the actual prevailing situation as there is support of needs, [name of researcher].

- To a larger extent, yes!

Do you think that this research can be useful for you?

- In many ways, especially as a model for redefining inclusive education and picking on “best practices” to set the foundation.
- Very much useful
- The research is very useful especially this time when the Zambians are thinking of implementation of Inclusive Education
- Very useful and can be used as evidence information of research findings in Inclusive Education
- Yes
- Very much useful especially for me as student
- Yes
- Very useful indeed
- Yes, it will be very much useful as it clears [sic] defines what we are struggling with here in Zambia and will give us the necessary results that am sure will be of help
- Very useful to everyone Parents, Teachers, Learners, NGOs and even the ministry itself
- Yes. The research can be very useful
- So much, and it can be used as a model to the parents teachers both for normal and differently abled

Do you think that the theoretical framework is appropriate to analyze the findings?

- It is appropriate Kenneth continue.
- Exactly – I have learnt a lot and I will also use some concepts during my research
- The theoretical framework is appropriate for analyzing the finding but adjust the information.
- Very much appropriate. I liked very much the concept of zone of approximal
- Yes, it is because it gives a true reflection of what you got on the ground.
- Yes
- Yes, it is appropriate because in your findings you were not biased
- N/A – Didn’t listen at it
- Yes but maybe use simple language for all to understand
- The theoretical framework is very appropriate
- It is appropriate Kenneth
- Yes!

General comments given in plenary:

- Present more negative findings compared to positive my [my response: maybe, but I have tried to reflect what people have said. However – I will go through the findings again, and see if I can include more positive findings]
- Balanced - you went on the ground and discussed with them - seems like you report what you have been told by the people you met
- Not biased - seemed to be for inclusion, then for special needs - seemed not to be biased towards any of the two
- You did a good job. In your family you have no-one with this disability, or with knowledge on witchcraft. You have been looking for what is on the ground.
- We are lagging behind on deafblindness,
- You presented yourself and what that bothers you

- You have not put any comment to condemn what people have said
- What he has put up there is a true reflection of what people said - he has not added or subtracted
- Physical adaptations are also important. I realize that now.
- You appear to have knowledge in this area - would also like to see comparison between rich and poor countries.

Dissemination workshop 2019.03.08

Code: MWI WS 1

Participants:

- Male, officer at human rights NGO, informant MWI NGO 8
- Female, independent consultant, experience from evaluation of disability programs
- Male, senior program officer, disability NGO, informant MWI NGO 1
- Female, Inclusive education officer, Ministry of Education, Science and Technology
- Male, Inclusive education officer, Ministry of Education, Science and Technology
- Male, Inclusive education officer, Ministry of Education, Science and Technology
- Male, disability specialist, Ministry of Education, Science and Technology
- Male, special needs & inclusive education officer, disability NGO, informant MWI GOVT 3 (has changed job after the interview)
- Female, senior officer, Ministry of Health

Feedback during the presentation:

Who are included in Malawi today?

- Mostly mild physical disabilities,
- there is a sensitivity that children with disabilities should be included, teachers, parents, peers
- there is a process going on, adaptations of methodologies, provision of assistive devices, not fully inclusive according to the definition, but something is being done
- More appropriate question - who are enrolled, who attend? - inclusion is not there, they participate, but not as the definition describes, we have a long way to go –
- We need a survey, they are there but how do they benefit?
- For children with deafblindness – we don't have the necessary things in place, number of assistants, teachers,
- Is inclusive education really something for a poor nation like ours?
- A child with no disabilities struggle to get access to education. We are very far away.

Comment on methods/methodology:

- On paper the methods seem very good, but did they work well practically?
- Might be challenging to keep anonymity? List of informants must secure that people are kept anonymous.
- Worried how the analysis will be done looking at the complexity of the topic
- Snowball technique very suitable - a lot of debate about the issue
- Ontology - culture - outsider – have you been able to really understand what people have said to you?

- Interviews – Malawian usually want to impress the researcher, will not always say what is actually on the ground.
- With such a broad scope I'm worried that the findings might be too general?
- Have you had challenges with interpretation? Fear that what might have been a great research runs into problems with things being lost in interpretation. You are a Norwegian man trying to understand two African countries. Malawi and Zambia are also culturally quite different, and with a lot of different cultures in each of the countries.
- I also fear how you will understand – There used to be a control regime in Malawi - fear of speaking openly, not the same in Zambia. Your responses might be influenced by that.
- Zambia a step ahead developing index – is the situation similar between the two countries in the education sector?
- Disaggregation – with such a broad scope the findings may not go to the depth of each of the categories
- It is good to see that data is not collected but produced.

Comment to the first slide on the findings:

- Similar findings indicate that it is a comparative study – clarify if it is meant to be comparative or not.

Comment to photo from classroom with one table in front:

- This is isolation. This is exclusion within inclusion!

Later slide in findings:

- Define target group for the research report better - focus the findings to fit with the intended target group.

Environments recap

- Environment must be considered seriously when it comes to children with deafblindness
- Special rooms needed
- In the context of Malawi, we cannot expect that children with deafblindness are included. The environment is not conducive
- 24.3.c explains better to us how we can solve this
- Twin track - include in mainstream, but at the same time provide alternatives
- Develop communication skills first, then the children might be included
- To have every teacher specially trained in DB is not feasible in Malawi
- In our situation - based on what the parents are saying we need special education

Physical adaptations – photo with table moved close to the blackboard

- What are your immediate thoughts when you see the photo?
- Isolation
- There is exclusion within inclusion

Thoughts about physical adaptations?

- We have to come up at universal design to ensure that all our schools are actually accessible

Resources recap

- Govt official: More advocacy has to come in. We have to know what is on the ground like you are doing now with your research. Then we can act to change the situation.

Anonymous feedback to the questions:

To what extent do you feel that what I have presented fit with the actual situation on the ground?

- I feel that the information gathered was very broad but that the narrowing down to findings has left much on the way. But, yes it captures it. The question is if the analysis has provided the recommendations that are the most important and can practically be used.
- I feel the presentation fit well with the actual situation on the ground; it is true that there are no adequate resources to meet the needs of children/learners with disabilities. No relevant knowledge and skills to teach and support the learners, the school environment is not conducive for learners especially those with deafblindness. Government and developing partners are not investing in the most effective way and usually placing priorities wrongly.
- You have captured 90% of what is on the ground.
- It is indeed fitting with the situation in terms of your findings in how people (stakeholders) are in the process of inclusive education. In the current situation getting all learners in the mainstream and the term education for ALL is not based on the quality of education.
- In terms of capturing what people have said, I think you have faithfully captured their perceptions without being influenced by any biases which you might have.
- What you have presented is a true reflection of the reality about inclusive education in Malawi.
- Most of the information was a clear indication of how people perceive IE, and such that the most important thing.
- It describes the shortfalls that are on the ground but it should have carried more substance if the children who are deafblind were also participants in your study.
- I think most of the information presented in this document are what is actually on the ground. However, the challenge remains the fact that not everything can be captured from another person's mouth. Considering that observation did not really work, I feel that some more information giving the real details of the actual situation and environment could have been missed.

To what extent and how do you think that this research can be useful?

- I feel it would be useful to narrow the findings down to the deafblind learner then to leave it a generic approach to education and its flaws.
- This research will provide a background of the basic situation in term of perception of deafblindness and probably what stakeholders need to start taking steps to addressing these critical aspects of development. It will sort of conscientize the players to commission an in-depth research into the matter.
- It can be useful by changing the perception of inclusive education for learners with deafblindness right away from the family, school, and after school.
- It will be useful at policy level, individual level, community level and school level leading to change of attitudes and perceptions towards children with deafblindness.
- The research is useful because it has looked into the perception of people (how people think) in relation to IE, the environment which is not really conducive, the resources

etc. I feel there is a lot to be done in the implementation of IE. This will lead to mindset change by all stakeholders in the implementation of IE.

- This research can particularly inform the implementation of the National IE Strategy in Malawi. The issues which you have highlighted as a part of findings align well with some of the primary areas of the IE strategy. Additionally, the findings can be useful to teachers.
- As an advocacy officer for inclusive education, I believe the information is a realistic presentation of the situation on the ground. The conditions are in dire need of review.
- It has to be presented at a higher level so that it can talk to the policy which are in existence to see if the research findings are talking to the policies.
- The research can be used in the sense that it has highlighted more of the real issues that are there on the ground in our school. The research is an eye opener to the issues happening in the schools; what strategies are there, who and how much do they know about inclusive education, so far what is working and what is not working and knowing these will set a good platform on what other steps to take to ensure that education is actually inclusive to everyone.

To what extent do you think that the theoretical framework is relevant to analyze the findings?

- Please use an analytical framework that brings us closer to answering the deafblind learner or go deeper into specific analysis of problem so the research can be more useful to the subject of research/the deafblind child.
- Indeed, knowledge emanates from what you can do without help and support from others strengthen the knowledge you already have. Therefore, it's important to support children with deafblindness from the tender age. This is not the work for parents only. Teachers, peers, and all stakeholders should or must develop positive attitudes towards learners with deafblindness. It is a fact that inclusion starts right away for the family. Therefore, education should respond to the needs of the family and the entire family.
- The theoretical framework has gathered all the information got from the respondents. It has been good and relevant to the models and delivering of education while the stakeholders can facilitate the implementation of IE.
- The theoretical framework is hard to digest, unless one have access to the full Research paper which may contain details which can facilitate understanding the theoretical framework.
- It's very useful as it gives us the opportunity and window to explore this different fields in special needs.
- The theoretical framework is too detailed, fit for a PhD study – I feel it is going to make the analysis of the data to be complex.
- The theoretical framework is very relevant to analyze the findings as it is bringing out the background of education and how the nature of the system it-self might be one of the reasons. There are problems to include everyone in the system. This give a good background to carry on to create a better future of the system.

General:

- Congratulations! You are very daring to tackle a question that hasn't been. You have enough material for your PhD. Keep digging!!

Dissemination workshop 2019.03.11

Code: MWI WS 2

Participants:

- Male, Deputy Headteacher, School 3 MWI
- Female, special teacher, from a school that was not visited during the research
- Female, special teacher, from a school that was not visited during the research
- Female, teacher, School 3 MWI
- Male, special teacher, School 3 MWI, MWI TEA 3
- Female, Executive Director, special needs school, not visited during the research
- Male, Headteacher, School 2 MWI, MWI HTEA 2
- Male, Desk Officer for Primary Education (DOPE), District Education Manager's Office, MWI GOVT 5
- Male, project officer, NGO health/education
- Male, project officer, NGO health/education
- Male, programs manager, NGO health/education
- Male, driver, NGO health/education

Feedback during the presentation:

Who are included in Malawi today?

- Children who are physically challenged, visually impaired
- Mild physical, not severe
- Nobody would like to be associated with children with disabilities
- Teachers say my role is teaching, not caring
- Only one specialist teacher pr 10-15 schools, without a specialist teacher, the learner will just be seated
- 120 learners – they will be fighting if I tend to the one with disabilities

Integrated vs included:

- they are not included but integrated, human resources, curriculum, classrooms, lack of resource rooms
- The church has established specific schools for different groups of impairments, from the govt side nothing is done
-

Comment on methods/methodology:

- The sampling seems to have been done in a relevant way - snowball, gender considerations, groups interviewed
- Gender perspective: Men in higher positions - women in lower positions - women giving information on grassroot level – should women be weighted more?
- You should be aware that when you go to a school to do observations - people behave differently, they prepare for visits to present the school in the best way, sweep floors etc. The situation at the schools you visited may be worse when no one comes to visit the school.
- Ethical considerations - good - in Malawi we respect one another and seek consent
- Why select snowball technique? [Reply: to come in contact with as many relevant interviewees as possible, and to find interviewees who had alternative and opposing perspectives]

- Have you been able to test the interview guide? [Reply: Yes, the interview guide was tested in a small-scale research project in 2017. Adapted after the research was concluded.]

Environments recap

- Findings are in line with what we experience.
- The difference between Malawi and Zambia might depend on who you interviewed. I know a number of teachers who think that IE means that all should be in the same classroom

Resources recap

- Human resource is an issue. Those who can provide are few
- Monitoring - few budget allocations as regards to monitoring, hindering tracking of progress.
- Maintenance of the resources - potholes, most schools receive school improvement grants, should be used to repair
- Govt should ensure that IE is taught at Teacher Training Colleges
- Before IE the govt should ensure accessibility, make measures
- Comment from headteacher school 2 MWI: We are going to change it.
- Monitoring - are the teachers empowered to monitor the situation at the school? should be included in IE training
- Priorities of the schools and teachers not always in line
- Roof - translucent - allow penetration of heat, makes the room warm, and learners tired
- Tight space between tables
- Toilets - should have accessible toilets, boys and girls should have separate toilets with doors
- Projects come in with resources, a lot of funding, material, when it comes to an end it is difficult to sustain, only those with passion remain
- Monitoring - maybe something could be done with funds that are planned for other projects - when monitoring other projects, they could also monitor IE

Teacher's knowledge, skills and experience - recap

- For teachers to become teachers for special need, there is an advert, and people can go for courses
- Teachers only get an introduction to special needs education at Teacher Training Colleges (TTCs), a quarter page
- There is a need for hands on experience to be able to understand how to teach learners with disabilities. No room for hands on training in TTCs
- Teachers need time and room to assess the learners they have in the classroom, and then relevant knowledge
- Teachers should know the learners and then plan, but the opposite is true. We first plan, and then we meet the learners.

Attitudes towards inclusion of children with deafblindness

- There are cultural differences - some tribes don't recognize people with disabilities
- Yes, we have Umuntu, but it is not really practiced too much
- Witchcraft is dying out in Malawi
- Cultural beliefs play a major role - don't use scientific explanations

Attitudes - recap

- Believing in witchcraft is less common nowadays

Inclusion of all learners - recap

- This is right. We have done so many changes to the education system because donors are instructing us to do so

Recap of the whole day

- Methodologies are fine - but these are just slides, is it possible to separate the findings, how best can Malawians learn from Zambia?
- Biases: you were afraid to show us your mind - I was expecting you to come up strongly to give us advise and recommendations
- IE must be clearly spelled out - debate what you think and what people have said
- We have not read all the literature, we are just told do this
- Zone of proximal development must be well explained in the thesis, then people can understand and it might make a difference
- I don't know exactly where you are, and what your opinion is about this. Will you tell us your position?
- The Education system is not driven by Malawians and Zambians. Where are you as a researcher? Are you a Western educationalist or are you in the shoes of us? [Reply: I am a Western educationalist, but I'm trying my best to understand your perspectives, using your shoes. That is also why I have facilitated these workshops. Then you can assess if I have been able to understand people I have interviewed]
- What we are learning is not from our culture. We have lost our culture because of the Western education system.
- We want the research to be presented again after the research is done – with recommendations and a way forward
- Include policy makers when you present your perspectives when the research is done.
- Have you met PTAs? [Reply: No, I have not been able to do so. This is a gap in the research]

Anonymous feedback to the questions:

To what extent do you feel that what I have presented fit with the actual situation on the ground?

- It is hundred percent because everything you have presented is what is happening on the ground.
- The presentation is giving true reflection on the ground.
- This fit with the actual situation in the ground because of the following:
 - In Mw we are not yet there on issues relating to inclusive education
 - Infrastructure
 - Human Resources
 - Learning and teaching material
 - Even assistive devices
- In real sence [sic]we observe real situation in the field whereby we need to polish up for the betterment of bright nation through inclusive education
- Very little has been said on the cultural i.e. witchcraft not on how children with deafblindness can be included in education system

- It fits the situation on the ground in the sense that it would help the education system to suit the Malawian culture, belief, etc.
- Yes what you have presented fit with the actual situations on the ground especially on physical adaptation and the methodologies
- The presentation fits the actual situation on the ground but need a lot of explanations on the scenarios
- 80%. The presentation was quite educative and reflective of what is on the ground. Except that it did not specify countries situations.
- 100% fit with the actual situation on the ground.
- The presented work fit the actual situation on the ground coz every angle has been looked upon mostly the wellbeing of the child with disability in terms of resources etc.

To what extent and how do you think that this research can be useful?

- The research will be useful if it will be proper followed and implemented by teachers and stakeholders.
- It can be useful to the whole country, hence it gives information of our stand on inclusive education and children with deafblindness as a country.
- 90% can be very useful in redefining or planning our education system.
- Useful in the sense that it can assist our education to be inclusive disregarding or [our?] cultural and ethnic beliefs
- This research is very useful since it help [sic] teachers to improve inclusive education
- The research can be help to accommodate all learners regardless of diverse needs so that they develop into independent individuals after they [sic] education cycle
- It will be useful if you pin point issues and narrate them in simple and straight forward points
- This research will make inclusive on better position near future since rome [sic] was not built in a day
- The research can be useful. Because it has opened eyes that we need to be understand all the concepts of disabilities hence supporting uniquely to a specific impairment hence [un-readable]
- The research is very useful and can be a tool to advocate the policy makers to change our education system in Malawi
- 100% and can be useful in changing educational system that will suit the Malawian child.

To what extent do you think that the theoretical framework is relevant to analyze the findings?

- The framework is 100% relevant to analyze the findings and its very good research waiting for wayforward [sic] so that we can make Malawian education system to be of high quality
- The analysis is giving the whole picture of how and what can Malawi do to improve education → country involvement
- The theoretical was good since it had to search for what legal framework are saying, policies and what people on the ground are saying about this
- It is relevant to analyse the findings because everything is from the grassroots level
- It is relevant because it has depict the type of education needed for all. Elaboration needed.

- It is relevant to theoretical finding because it can change my mindset for people with disabilities
- The theoretical framework is relevant to analyse the findings in a way that it will assist building good inclusive education in Malawi.
- This helps 80% as to understand the genesis of education in Malawi and whether it promote our cultural knowledge or not.
- The framework is very relevant to analyze the findings.
- The theoretical framework is relevant if the procedures are followed

Dissemination workshop 2019.03.12

Code: MWI WS 3

Participants:

- Female – (consent#69)
- Female – (consent#70)
- Female – (consent#71)
- Female – (consent#73)
- Male – (consent#74)

Feedback during the presentation:

None of the parents were able to communicate with English. Some of them were able to understand what I said to them, and what the interpreter said to me. This allowed the participants to confirm that the interpreter actually was able to interpret the questions in a good way. Two persons contributed to interpreting. One is an educationalist from a special school, and the other is a community-based rehabilitation worker from a parastatal organization aiding people with disabilities. The parents knew both of them well, and had an established relationship based on trust. The parents used four different vernacular languages, but all of them understood Chichewa well, and Chichewa and English were used in the discussions.

Because I had to use interpreters, it was not possible to go through the whole presentation. The reason was both time constraints, and due to the fact that some of the components in the presentation are advanced, and not easily accessible for all. The education level among the parents is low. For this reason, only the main frameworks of the research, my position as a researcher and the findings from the research was presented. I did not ask the parents to write anonymous feedback, because most of them are unable to read and write. The feedback from the parents was captured during the presentation.

Comment on Parents perspective:

- Father: Good if they can learn in mainstream for social interaction.
- Mother: not possible, have experience that the child is just placed in the classroom, and nothing is happening.
- Mother: the children with disabilities should have their own room. If they are in the mainstream, the teacher will only focus on the other learners and not on the ones with a disability
- (Long discussion between the parents)

- Mother: her child was advised to be in a primary school, but the teacher had struggles and was not working with the child, the teacher only used the name but did not interact in any way
- Father after long discussion: I misunderstood the question. The question was not clear. He meant that it could be ok if there was one teacher who had a specific responsibility for the learners with disabilities, in addition to the mainstream teacher.
- Mother: the teacher in a mainstream classroom have not time to assist a child with disabilities, they learn slowly
- Mother: the child cannot go to the toilet independently
- About teachers: They need to care for the children, assist them to go to the toilet, the teacher has to know the individual signs the child is using – thirsty, hungry, want to go to the toilet, has to know the health situation and be able to observe if the child is ok, or if the child is sick. Is the child active one day and quiet another?
- We as parents need to work together with the teacher and give information
- The teachers should be able to assess if the parents are taking care of their children in a good way, and take action if not

Comment to Inclusive environments:

- Me: How do you understand inclusive education?
- Mother: It is a school where all children come together in one class
- Father – two blocks – one for children with disabilities, one of non-disabled
- Mother: All children with disabilities can come to the same school, regardless of disability, but without non-disabled

Comment to All in the same classroom:

- Me: What are your thoughts?
- Parents:
- It's not possible.
- Me: Why?
- Parents:
- Father – children without disabilities it is easier to learn, with deafblindness it can take a long time, can take months to learn something another child learn in a day
- Mother: not possible – don't hear anything, or will hear but not understand, the child will respond with making noises as well, not allowed in class, need a teacher who is together with the child, without this teacher the child is just seated in class
- The child is not able to sit, will often fall asleep, warm in the classroom, the teacher does not notice

Comment to Inclusive education opens for units and special classrooms

- Mother: not possible. Non-disabled children will come to the resource rooms and laugh at them, the children with disabilities will feel bad
- Sometimes the child is well dressed but you have to carry them – people will say: Why isn't the child walking? You should walk yourself!

Comments to Inclusive education means access to any type of education

- Observation: When I'm using the term inclusive education, I'm unsure if they understand what the concept means
- Me: How would you describe inclusive education to your neighbor?
- Parents are divided:

- Majority: All children with disabilities (different disabilities) in one school
- Minority: Could be located at the same place, (twinning schools) but the teachers should be different
- Me: Your neighbor asks: What is inclusive education? - This is what you would answer?
- Parents: All children with disabilities should have their own schools, all types with disabilities at the same place

Comments to slide with photo of desk in front

- Me: How would your child feel here?
- Parents:
- This is also promoting segregation. No-one is there to be together with the child. That is isolation.

Comments to slide with photo of outdoor classroom under trees

- Mother: sometimes snakes fall down from the trees. My child would not be able to notice this, and would not be able to run away. All the other children would run away, and my child would be alone.

Comments to slide with photo of classroom with desks grouped

- This will not work for our children. During discussions the child is not able to take part. The other children will be saying – Why is this child in this group?

Comments to slide with photo of toilet facilities, not adapted

- Our children are not able to walk. Not possible to use a toilet like this

Comments to slide with photo of toilet facilities, newly constructed

- My child can be able to use this toilet with assistance

Comments to Access to resources – don't have money

- True

Comments to Attitudes towards inclusion of children with deafblindness

- Not because of witchcraft – the children are just born like that.
- Father: Some people fear to interact with children with disability, fear that they may give birth. Us parents are telling that they have to accept our children as they are.
- Not common.
- Born with – not bewitched – illness: my child has been bewitched?

Comments from ZAM WS 2 about tactile communication being uncomfortable for family members, was shared with the parents.

- Father: this might happen
- Mother: my family chats with her, relatives and neighbors come and are together with her

Read slide describing that children are cursed, bring bad luck, etc.

- no - this is not common here. We think the child bring luck. Others might think that they bring bad luck, but not common

Parents not willing to send their child to school?

- Fathers – it happens – might not have willingness if they have not come together with other parents to discuss about their children
- Read slide out loud:
- For mainstreams schools, parents have that fear. Will they be well received? Treated well? High fear for mainstream – not for special schools: know that their child will be taken care of.
- Some parents want to send their children to special schools to rid themselves of the burden

Comments to language of instruction, slide describing teaching for 10 minutes

- That is true.
- Me: What should be done?
- Parents: In the homes the parents should use more Chichewa. In a village there will always be someone who can speak Chichewa. Could be a village teacher. Will often understand Chichewa, but more difficulties with speaking

Recap of the whole day

- Mothers/Father: The findings should describe better what is from Malawi, and what is from Zambia.
- Similar things should be put together, differences should be described clearly.
- Father: The pictures – new development plans for schools should consider better the needs of children with disabilities, to give access to classes
- Father: Teachers for the deafblind should be specific for the deafblind, Should not mix with others. Passionate teachers.
- Not right that parents accept that their child should learn together with other children
- Me: Is there any information that you have given to me, but I have not used it.
- Parents:
- Pre-schools – must describe the need for pre-schools.

Dissemination workshop 2019.03.13

Code: MWI WS 4

Participants:

- Male, executive director, NGO of persons with disabilities (MWI NGO 10)
- Female, teacher, special needs school (not one of the researched schools)
- Male, lecturer, teacher training college
- Female, field officer, NGO providing services for children with disabilities
- Female, deputy principal, teacher training college
- Male, sign language interpreter
- Male, lecturer, teacher training college
- Male, communication officer, NGO of persons with disabilities
- Male, member, NGO of persons with disabilities
- Male, research and advocacy officer, NGO of persons with disabilities
- Female, Dean of Education, university
- Female, project coordinator, NGO of persons with disabilities

Feedback during the presentation:

Comments to CRPD - recap:

- Access to information - do not have books in braille available in schools
- Article 19 - independent living – the Malawian government is not doing much
- CRPD - the whole convention is relevant and signed, but little done in Malawi
- Sign conventions and policies to not be seen as backwards - but don't review or understand what they have signed

Comments Who are included in Malawi?:

- Physical disabilities, moderate
- Hearing impairments - slight to moderate
- Intellectual disabilities - mild
- Visually impaired - mild to moderate - low vision
- Many groups are found but only mild to a little bit of moderate
- They are integrated
- On paper it is inclusion but in practical terms only integrated
- Some private international schools are more inclusive, they have more resources.
- You should not include the private schools in this research because it will give a wrong perspective of the situation in Malawi. Maybe people will think that we are doing this already, but we are not!

Comments to Methodology and Methods - recap

- Like the sampling method - you are from the West, and it is good that you have met many different people - makes it more likely that you will get good information
- What about document analysis? How has that been done?
- What are the ages of the informants?
- Sample size?
- [The participants were showed the list of informants]

Comment Environments - recap:

- The findings are giving us a true reflection of what is on the ground in Malawi
- We have read the documents but not really analyzed them, accessibility of the documents,
- For us inclusive education is somebody coming from the UK, Germany, Norway telling us what to do

Comments to slide with photo of desk in front (Physical adaptations)

- That is segregation
- That was staged, they knew you were coming

Comments to What are your thoughts about these physical adaptations?

- This is embarrassing.

Comments to Resources - recap

- We have so many international project - the problem is that international projects come with strings attached and objectives of what they want to do. They are not coordinated. They do what they have in their plans with little contact between the

projects. Many are doing similar things but not coordinated. Some districts are more favored and receive many donors and projects. Distribution of the projects is not fair. It is not backed by research. Results don't reflect what is on the ground. You do it as the donor says.

- Sustainability - not - once they phase out, no continuation - what was used for the project goes out again. That limits the modeling of the best practices

Recap of the whole day

- Have you asked parents what they think is the purpose of education?
- Father – it is to take care of the parents when they get old
- Many think that it is no use to teach children with deafblindness - can't learn anything
- Socialization is important

Anonymous feedback to the questions:

To what extent do you feel that what I have presented fit with the actual situation on the ground?

- To a large extent the presentation fit to the actual situation on the ground.
- I feel that what you have presented fit with the actual situation on the ground because you manage to have interviews with teacher and parents from different countries
- The presentation really fit to the practical situation on the ground as it [unreadable] in the real issues which person/children with disabilities face is as far as inclusive education is concerned.
- It is very relevant considering that much of the issues were sourced from the actual ground and physically.
- What you presented is exactly what is happening on the ground and making/researching in in two different countries was the right way to go about it. The pictorial aspect was necessary to make your study rich.
- I feel what you have presented fit with the actual situation on the ground because I has captured the cultural aspect of Malawian systems of education, in how people look at db and other disabilities like visual impairment. It will really assist the db education if implemented.
- The presentation has tackled most of the situations on the ground, but what is mostly needed it to find time and interview more people for the research to be successful
- Your presentation fits very well with the actual situation of persons with deafblindness in Malawi. However I would have loved if you included information on
 - Statistics of children with deafblindness in Malawi
 - How many attend regular mainstream schools
 - Examine the local names which are appropriate/inappropriate used for CW Deafblind
- To be honest the situation here in Malawi fits to what you have presented and the findings as well. If I am to give percentage it would 85% because there is a lot to be done.
- The presentation has portrayed what is on the ground. However you will have included whether the parents send their children to school because they know the purpose of education.

- The presentation fits well with the actual situation on the ground because what has been presented is what the deafblind experience in the education and society as well.

To what extent and how do you think that this research can be useful?

- I for one feels that the research conducted is vital because it gives the true reflection of the situation on the ground such that it will be even more helpful in the implementation time because the researcher have seen by themselves what is need to people with disabilities and what is not need.
- This research can be useful in raising awareness to the community about the needs of the deafblind in inclusive education. Not much is being done.
- The research can be useful if the implementing agent had their input on what they think of inclusive education
- To a very large extent this research is very useful. Currently we do not much research conducted in deafblindness in Malawi [sic] - This research will provide a basis for advocating for the provision of inclusive education for CWD
- This research can help on how we can change and understand what inclusive education is in our own scenario as Malawi. This will help in the way we work on the ground – the way we practice inclusive education and disability as a whole.
- It will be useful in the implementation of db especially on how to come up with educational resources.
- This is a kind of study that would compliment to the work the government and civil society is doing as it will assist in coming up with lasting solution in inclusive education for a deafblind child in Malawi
- It is useful as it will influence policies to establish more accurate systems of education towards improving DB learners
- The findings of this research can highly be used in the real life situations. This is the case because the research has mentioned the things which are there in our societies regarding persons with disabilities. At the same time the research has helped to come up with suggested solutions which when applied can be of help.
- This research can be useful if people have been taught clearly what is inclusive education.
- The research can be useful to a large extent. The research’s findings are given to the stakeholders then they are implemented them accordingly especially where there is a need to improve so that inclusive education can be implemented successful.

To what extent do you think that the theoretical framework is relevant to analyze the findings?

- For the theoretical framework used I feel it is relevant to analyse the findings since there will be a relationship between it and what the interviewees have given.
- The theoretical framework is relevant to analyse the findings as it will try to relate the data collected and analysed and the practical issues on the ground.
- The theoretical framework is talking about how the education system has been compromised all this way and it is giving a clue on what has been affecting IE
- [Unreadable]
- You have relevant theoretical framework. I love that you have used the Zone of proximal development and also the Identity Construction. Very relevant and interesting.
- Theoretical framework is relevant to the extent that different levels will be included.

Appendix 7: Application for approval of the research to Norwegian Centre for Research Data



MELDESKJEMA

Meldeskjema (versjon 1.6) for forsknings- og studentprosjekt som medfører meldeplikt eller konsesjonsplikt (jf. personopplysningsloven og helseregisterloven med forskrifter).

1. Intro		
Samles det inn direkte personidentifiserende opplysninger?	Ja ● Nei ○	En person vil være direkte identifiserbar via navn, personnummer, eller andre personentydige kjennetegn.
Hvis ja, hvilke?	<input type="checkbox"/> Navn <input type="checkbox"/> 11-sifret fødselsnummer <input checked="" type="checkbox"/> Adresse <input type="checkbox"/> E-post <input type="checkbox"/> Telefonnummer <input type="checkbox"/> Annet	Les mer om hva personopplysninger er. NB! Selv om opplysningene skal anonymiseres i oppgave/rapport, må det krysses av dersom det skal innhentes/registreres personidentifiserende opplysninger i forbindelse med prosjektet. Les mer om hva behandling av personopplysninger innebærer.
Annet, spesifiser hvilke		
Skal direkte personidentifiserende opplysninger kobles til datamaterialet (koblingsnøkkel)?	Ja ○ Nei ●	Merk at meldeplikten utløses selv om du ikke får tilgang til koblingsnøkkel , slik fremgangsmåten ofte er når man benytter en databehandler .
Samles det inn bakgrunnsopplysninger som kan identifisere enkeltpersoner (indirekte personidentifiserende opplysninger)?	Ja ● Nei ○	En person vil være indirekte identifiserbar dersom det er mulig å identifisere vedkommende gjennom bakgrunnsopplysninger som for eksempel bostedskommune eller arbeidsplass/skole kombinert med opplysninger som alder, kjønn, yrke, diagnose, etc.
Hvis ja, hvilke	Bosted og diagnose	NB! For at stemme skal regnes som personidentifiserende, må denne bli registrert i kombinasjon med andre opplysninger, slik at personer kan gjenkjennes.
Skal det registreres personopplysninger (direkte/indirekte/via IP-/epost adresse, etc) ved hjelp av nettbaserte spørreskjema?	Ja ○ Nei ●	Les mer om nettbaserte spørreskjema .
Blir det registrert personopplysninger på digitale bilde- eller videoopptak?	Ja ● Nei ○	Bilde/videoopptak av ansikter vil regnes som personidentifiserende.
Søkes det vurdering fra REK om hvorvidt prosjektet er omfattet av helseforskningsloven?	Ja ○ Nei ●	NB! Dersom REK (Regional Komité for medisinsk og helsefaglig forskningsetikk) har vurdert prosjektet som helseforskning, er det ikke nødvendig å sende inn meldeskjema til personvernombudet (NB! Gjelder ikke prosjekter som skal benytte data fra pseudonyme helseregistre). Les mer. Dersom tilbakemelding fra REK ikke foreligger, anbefaler vi at du avventer videre utfylling til svar fra REK foreligger.
2. Prosjektittel		
Prosjektittel	Children with Deafblindness and Inclusive Education	Oppgi prosjektets tittel. NB! Dette kan ikke være «Masteroppgave» eller liknende, navnet må beskrive prosjektets innhold.
3. Behandlingsansvarlig institusjon		
Institusjon	Høgskolen i Oslo og Akershus	Velg den institusjonen du er tilknyttet. Alle nivå må oppgis. Ved studentprosjekt er det studentens tilknytning som er avgjørende. Dersom institusjonen ikke finnes på listen, har den ikke avtale med NSD som personvernombud. Vennligst ta kontakt med institusjonen. Les mer om behandlingsansvarlig institusjon .
Avdeling/Fakultet	Fakultet for lærerutdanning og internasjonale studier	
Institutt	Institutt for internasjonale studier og tolkeutdanning	
4. Daglig ansvarlig (forsker, veileder, stipendiat)		

Fornavn	Kristin Skinstad van der	Før opp navnet på den som har det daglige ansvaret for prosjektet. Veileder er vanligvis daglig ansvarlig ved studentprosjekt. Les mer om daglig ansvarlig . Daglig ansvarlig og student må i utgangspunktet være tilknyttet samme institusjon. Dersom studenten har eksterne veileder, kan biveileder eller fagansvarlig ved studiestedet stå som daglig ansvarlig. Arbeidssted må være tilknyttet behandlingsansvarlig institusjon, f.eks. underavdeling, institutt etc. NB! Det er viktig at du oppgir en e-postadresse som brukes aktivt. Vennligst gi oss beskjed dersom den endres.
Ettemavn	Kooij	
Stilling	Førsteamanuensis	
Telefon	+47	
Mobil	46935484	
E-post	Kristin.Van-Der-Kooij@hioa.no	
Alternativ e-post	Kristin.Van-Der-Kooij@hioa.no	
Arbeidssted	OsloMet - Storbyuniversitetet	
Adresse (arb.)	Postboks 4 St. Olavs plass	
Postnr./sted (arb.sted)	0130 Oslo	
5. Student (master, bachelor)		
Studentprosjekt	Ja • Nei ○	Dersom det er flere studenter som samarbeider om et prosjekt, skal det velges en kontaktperson som føres opp her. Øvrige studenter kan føres opp under pkt 10.
Fornavn	Kenneth	
Ettemavn	Verngård	
Telefon	99424330	
Mobil		
E-post	kenneth.verngard@gmail.com	
Alternativ e-post	kenneth.verngard@signo.no	
Privatadresse	Tassebekkveien 11	
Postnr./sted (privatadr.)	3160 Stokke	
Type oppgave	<input checked="" type="radio"/> Masteroppgave <input type="radio"/> Bacheloroppgave <input type="radio"/> Semesteroppgave <input type="radio"/> Annet	
6. Formålet med prosjektet		
Formål	The purpose of this qualitative study is to explore and analyse factors contributing to access, or lack of access to quality education for children with deafblindness in Zambia and Malawi. This research seeks to give light to how education can be provided for children with deafblindness to "maximize personal, academic and social development both within and outside formal school settings" in line with the Convention on the Rights for Persons with Disabilities (CRPD) and the General comment No. 4 (2016) issued by the Committee on the Rights of Persons with Disabilities on the right to inclusive education (UN 2016, p.10).	Redegjør kort for prosjektets formål, problemstilling, forskningsspørsmål e.l.
7. Hvilke personer skal det innhentes personopplysninger om (utvalg)?		
Kryss av for utvalg	<input type="checkbox"/> Barnehagebarn <input checked="" type="checkbox"/> Skoleelever <input type="checkbox"/> Pasienter <input type="checkbox"/> Brukere/klienter/kunder <input type="checkbox"/> Ansatte <input type="checkbox"/> Barnevernsbarn <input checked="" type="checkbox"/> Lærere <input type="checkbox"/> Helsepersonell <input type="checkbox"/> Asylsøkere <input checked="" type="checkbox"/> Andre	Les mer om forskjellige forskningstematikker og utvalg.

Beskriv utvalg/deltakere	Semi-structured interviews with individuals, and groups of, students, families, teachers, community members, local and national government officials, and representatives of local and international disabled people's organizations (DPOs) and other non-governmental organizations (NGOs) working to promote inclusive education in Zambia and Malawi, will be conducted to gather information about the problematique. In addition, classroom observations in inclusive mainstream schools, in specialized units at inclusive mainstream schools and in special schools will be conducted to see if "education is delivered in the most appropriate languages and modes and means of communication for the individual" in line with the CRPD and the GC4 (UN 2016, p.10).	Med utvalg menes dem som deltar i undersøkelsen eller dem det innhentes opplysninger om.
Rekruttering/trekking	The informants will be identified through the researcher's own network of contacts in the two countries, including government contacts, and schools. The DPOs and NGOs will also be identified through the researchers own existing network of contacts.	Beskriv hvordan utvalget trekkes eller rekrutteres og oppgi hvem som foretar den. Et utvalg kan rekrutteres gjennom f.eks. en bedrift, skole, idrettsmiljø eller eget nettverk, eller trekkes fra registre som f.eks. Folkeregisteret, SSB-registre, pasientregistre.
Førstegangskontakt	The researcher has been responsible for projects targeting children with deafblindness in the two countries for more than 10 years, and have established a comprehensive networks of contacts. Through the network of contacts and existing partner organizations, families and schools will be identified and contacted.	Beskriv hvordan førstegangskontakten opprettes og oppgi hvem som foretar den. Les mer om førstegangskontakt og forskjellige utvalg på våre temasider .
Alder på utvalget	<input checked="" type="checkbox"/> Barn (0-15 år) <input checked="" type="checkbox"/> Ungdom (16-17 år) <input checked="" type="checkbox"/> Voksne (over 18 år)	Les om forskning som involverer barn på våre nettsider.
Omtrentlig antall personer som inngår i utvalget	50	
Samles det inn sensitive personopplysninger?	Ja <input checked="" type="radio"/> Nei <input type="radio"/>	Les mer om sensitive opplysninger .
Hvis ja, hvilke?	<input type="checkbox"/> Rasemessig eller etnisk bakgrunn, eller politisk, filosofisk eller religiøs oppfatning <input type="checkbox"/> At en person har vært mistenkt, siktet, tiltalt eller dømt for en straffbar handling <input checked="" type="checkbox"/> Helseforhold <input type="checkbox"/> Seksuelle forhold <input type="checkbox"/> Medlemskap i fagforeninger	
Inkluderes det myndige personer med redusert eller manglende samtykkekompetanse?	Ja <input type="radio"/> Nei <input checked="" type="radio"/>	Les mer om pasienter, brukere og personer med redusert eller manglende samtykkekompetanse .
Samles det inn personopplysninger om personer som selv ikke deltar (tredjepersoner)?	Ja <input checked="" type="radio"/> Nei <input type="radio"/>	Med opplysninger om tredjeperson menes opplysninger som kan identifisere personer (direkte eller indirekte) som ikke inngår i utvalget. Eksempler på tredjeperson er kollega, elev, klient, familiemedlem, som identifiseres i datamaterialet. Les mer.
Hvem er tredjeperson og hvilke opplysninger registreres?	Children with deafblindness may be third parties. Parents will be interviewed about their children, and their schooling experience.	
Registreres det sensitive opplysninger om tredjeperson?	Ja <input checked="" type="radio"/> Nei <input type="radio"/>	
8. Metode for innsamling av personopplysninger		
Kryss av for hvilke datainnsamlingsmetoder og datakilder som vil benyttes	<input type="checkbox"/> Papirbasert spørreskjema <input type="checkbox"/> Elektronisk spørreskjema <input checked="" type="checkbox"/> Personlig intervju <input checked="" type="checkbox"/> Gruppeintervju <input checked="" type="checkbox"/> Observasjon <input type="checkbox"/> Deltakende observasjon <input type="checkbox"/> Blogg/sosiale medier/internett <input type="checkbox"/> Psykologiske/pedagogiske tester <input type="checkbox"/> Medisinske undersøkelser/tester <input type="checkbox"/> Journaldata (medisinske journaler)	<p>Personopplysninger kan innhentes direkte fra den registrerte f.eks. gjennom spørreskjema, intervju, lester, og/eller ulike journaler (f.eks. elevmapper, NAV, PPT, sykehus) og/eller registre (f.eks. Statistisk sentralbyrå, sentrale helseregistre).</p> <p>NB! Dersom personopplysninger innhentes fra forskjellige personer (utvalg) og med forskjellige metoder, må dette spesifiseres i kommentar-boksen. Husk også å legge ved relevante vedlegg til alle utvalgs-gruppene og metodene som skal benyttes.</p> <p>Les mer om registerstudier. Dersom du skal anvende registerdata, må variabeliste lastes opp under pkt. 15</p> <p>Les mer om forskningsmetoder.</p>
	<input type="checkbox"/> Registerdata	
	<input type="checkbox"/> Annen innsamlingsmetode	

Tilleggsopplysninger		
9. Informasjon og samtykke		
Oppgi hvordan utvalget/deltakerne informeres	<input checked="" type="checkbox"/> Skriftlig <input type="checkbox"/> Muntlig <input type="checkbox"/> Informeres ikke	<p>Dersom utvalget ikke skal informeres om behandlingen av personopplysninger må det begrunnes.</p> <p>Les mer. Vennligst send inn mal for skriftlig eller muntlig informasjon til deltakere sammen med meldeskjema.</p> <p>Last ned en veiledende mal her.</p> <p>Les om krav til informasjon og samtykke.</p> <p>NB! Vedlegg lastes opp til sist i meldeskjemaet, se punkt 15 Vedlegg.</p>
Samtykker utvalget til deltakelse?	<input checked="" type="radio"/> Ja <input type="radio"/> Nei <input type="radio"/> Flere utvalg, ikke samtykke fra alle	<p>For at et samtykke til deltakelse i forskning skal være gyldig, må det være frivillig, uttrykkelig og informert.</p> <p>Samtykke kan gis skriftlig, muntlig eller gjennom en aktiv handling. For eksempel vil et besvart spørreskjema være å regne som et aktivt samtykke.</p> <p>Dersom det ikke skal innhentes samtykke, må det begrunnes. Les mer.</p>
Innhentes det samtykke fra foreldre for barn under 15 år?	Ja <input checked="" type="radio"/> Nei <input type="radio"/>	Les mer om forskning som involverer barn og samtykke fra unge. Les mer.
Hvis nei, begrunn		
Innhentes det samtykke fra foreldre for ungdom mellom 16 og 17 år?	Ja <input checked="" type="radio"/> Nei <input type="radio"/>	Les mer om forskning som involverer barn og samtykke fra unge. Les mer.
Hvis nei, begrunn		
Blir tredjepersoner informert?	<input type="checkbox"/> Skriftlig <input type="checkbox"/> Muntlig <input checked="" type="checkbox"/> Informeres ikke	Merk at identifiserende opplysninger om tredjeperson er personopplysninger og skal behandles som dette på lik linje med andre personopplysninger. Dette innebærer blant annet at både informasjon og samtykke skal vurderes konkret i hvert tilfelle.
Informeres ikke, begrunn	All who are able to understand will be informed. In writing (Braille) if possible. However, in the case of children with deafblindness many will not have developed a cultural language, and can often not read or write, and are dependent on alternative communication methods, primarily through touch.	
10. Informasjonssikkerhet		
Spesifiser	Directly identifiable information will not be registered together with the rest of the data material. Names will be coded, and the coded list will be kept in a separate, password protected file.	NB! Som hovedregel bør ikke direkte personidentifiserende opplysninger registreres sammen med det øvrige datamaterialet. Vi anbefaler koblingsnøkkel .
Hvordan registreres og oppbevares personopplysningene?	<input type="checkbox"/> På server i virksomhetens nettverk <input type="checkbox"/> Fysisk isolert PC tilhørende virksomheten (dvs. ingen tilknytning til andre datamaskiner eller nettverk, interne eller eksterne) <input type="checkbox"/> Datamaskin i nettverkssystem tilknyttet Internett tilhørende virksomheten <input checked="" type="checkbox"/> Privat datamaskin <input checked="" type="checkbox"/> Videoopptak/fotografi <input checked="" type="checkbox"/> Lydopptak <input checked="" type="checkbox"/> Notater/papir <input checked="" type="checkbox"/> Mobile lagringsenheter (bærbar datamaskin, minnepenn, minnekort, cd, eksterne harddisk, mobiltelefon) <input type="checkbox"/> Annen registreringsmetode	<p>Merk av for hvilke hjelpemidler som benyttes for registrering og analyse av opplysninger.</p> <p>Sett flere kryss dersom opplysningene registreres på flere måter.</p> <p>Med «virksomhet» menes her behandlingsansvarlig institusjon.</p> <p>NB! Som hovedregel bør data som inneholder personopplysninger lagres på behandlingsansvarlig sin forskningsserver.</p> <p>Lagring på andre medier - som privat pc, mobiltelefon, minnepenne, server på annet arbeidssted - er mindre sikkert, og må derfor begrunnes. Slik lagring må avklares med behandlingsansvarlig institusjon, og personopplysningene bør krypteres.</p>
Annen registreringsmetode beskriv		
Hvordan er datamaterialet beskyttet mot at uvedkommende får innsyn?	The computer is password protected. Portable units will be kept in locked rooms.	Er f.eks. datamaskintilgangen beskyttet med brukernavn og passord, står datamaskinen i et låsbart rom, og hvordan sikres bærbare enheter, utskrift og opptak?
Samles opplysningene inn/behandles av en databehandler (ekstern aktør)?	Ja <input type="radio"/> Nei <input checked="" type="radio"/>	Dersom det benyttes eksterne til helt eller delvis å behandle personopplysninger, f.eks. Questback, transkriberingsassistent eller tolk, er dette å betrakte som en databehandler . Slike oppdrag må kontraktreguleres.
Hvis ja, hvilken		

Overføres personopplysninger ved hjelp av e-post/Internett?	Ja <input type="radio"/> Nei <input checked="" type="radio"/>	F.eks. ved overføring av data til samarbeidspartner, databehandler mm.
Hvis ja, beskriv?		Dersom personopplysninger skal sendes via internett, bør de krypteres tilstrekkelig. Vi anbefaler ikke lagring av personopplysninger på nettskytjenester. Bruk av nettskytjenester må avklares med behandlingsansvarlig institusjon. Dersom nettskytjeneste benyttes, skal det inngås skriftlig databehandleravtale med leverandøren av tjenesten. Les mer .
Skal andre personer enn daglig ansvarlig/student ha tilgang til datamaterialet med personopplysninger?	Ja <input type="radio"/> Nei <input checked="" type="radio"/>	
Hvis ja, hvem (oppgi navn og arbeidssted)?		
Utleveres/deles personopplysninger med andre institusjoner eller land?	<input checked="" type="radio"/> Nei <input type="radio"/> Andre institusjoner <input type="radio"/> Institusjoner i andre land	F.eks. ved nasjonale samarbeidsprosjekter der personopplysninger utveksles eller ved internasjonale samarbeidsprosjekter der personopplysninger utveksles.
11. Vurdering/godkjenning fra andre instanser		
Søkes det om dispensasjon fra taushetsplikten for å få tilgang til data?	Ja <input type="radio"/> Nei <input checked="" type="radio"/>	For å få tilgang til taushetsbelagte opplysninger fra f.eks. NAV, PPT, sykehus, må det søkes om dispensasjon fra taushetsplikten . Dispensasjon søkes vanligvis fra aktuelt departement.
Hvis ja, hvilke		
Søkes det godkjenning fra andre instanser?	Ja <input type="radio"/> Nei <input checked="" type="radio"/>	I noen forskningsprosjekter kan det være nødvendig å søke flere tillatelser. Søkes det f.eks. om tilgang til data fra en registerier? Søkes det om tillatelse til forskning i en virksomhet eller en skole? Les mer om andre godkjenninger .
Hvis ja, hvilken		
12. Periode for behandling av personopplysninger		
Prosjektstart	24.06.2018	Prosjektstart Vennligst oppgi tidspunktet for når kontakt med utvalget skal gjøres/datansamlingen starter.
Planlagt dato for prosjektslutt	16.05.2019	Prosjektslutt: Vennligst oppgi tidspunktet for når datamaterialet enten skal anonymiseres/slettes, eller arkiveres i påvente av oppfølgingsstudier eller annet.
Skal personopplysninger publiseres (direkte eller indirekte)?	<input type="checkbox"/> Ja, direkte (navn e.l.) <input type="checkbox"/> Ja, indirekte (identifiserende bakgrunnsopplysninger) <input checked="" type="checkbox"/> Nei, publiseres anonymt	Les mer om direkte og indirekte personidentifiserende opplysninger. NB! Dersom personopplysninger skal publiseres, må det vanligvis innhentes eksplisitt samtykke til dette fra den enkelte, og deltakere bør gis anledning til å lese gjennom og godkjenne sitater.
Hva skal skje med datamaterialet ved prosjektslutt?	<input checked="" type="checkbox"/> Datamaterialet anonymiseres <input type="checkbox"/> Datamaterialet oppbevares med personidentifikasjon	NB! Her menes datamaterialet, ikke publikasjon. Selv om data publiseres med personidentifikasjon skal som regel øvrig data anonymiseres. Med anonymisering menes at datamaterialet bearbeides slik at det ikke lenger er mulig å føre opplysningene tilbake til enkeltpersoner. Les mer om anonymisering av data .
13. Finansiering		
Hvordan finansieres prosjektet?	Private funding	Fylles ut ved eventuell ekstern finansiering (oppdragsforskning, annet).
14. Tilleggsopplysninger		
Tilleggsopplysninger		Dersom prosjektet er del av et prosjekt (eller skal ha data fra et prosjekt) som allerede har tilrådning fra personvernombudet og/eller konsesjon fra Datatilsynet, beskriv dette her og oppgi navn på prosjektleder, prosjektittel og/eller prosjektnummer.
15. Vedlegg		
Vedlegg	Antall vedlegg: 2. <input checked="" type="checkbox"/> interview_guide.docx <input checked="" type="checkbox"/> consent_form.docx	

Appendix 8: Approval of the research from Norwegian Centre for Research Data



Kristin Skinstad van der Kooij
Postboks 4, St. Olavs plass
0130 OSLO

Vår dato: 08.05.2018

Vår ref: 60110 / 3 / LAR

Deres dato:

Deres ref:

Tilrådning fra NSD Personvernombudet for forskning § 7-27

Personvernombudet for forskning viser til meldeskjema mottatt 27.03.2018 for prosjektet:

60110	<i>Children with Deafblindness and Inclusive Education</i>
Behandlingsansvarlig	<i>OsloMet - Storbyuniversitetet, ved institusjonens øverste leder</i>
Daglig ansvarlig	<i>Kristin Skinstad van der Kooij</i>
Student	<i>Kenneth Verngård</i>

Vurdering

Etter gjennomgang av opplysningene i meldeskjemaet og øvrig dokumentasjon finner vi at prosjektet er unntatt konsesjonsplikt og at personopplysningene som blir samlet inn i dette prosjektet er regulert av § 7-27 i personopplysningsforskriften. På den neste siden er vår vurdering av prosjektopplegget slik det er meldt til oss. Du kan nå gå i gang med å behandle personopplysninger.

Vilkår for vår anbefaling

Vår anbefaling forutsetter at du gjennomfører prosjektet i tråd med:

- opplysningene gitt i meldeskjemaet og øvrig dokumentasjon
- vår prosjektvurdering, se side 2
- eventuell korrespondanse med oss

Meld fra hvis du gjør vesentlige endringer i prosjektet

Dersom prosjektet endrer seg, kan det være nødvendig å sende inn endringsmelding. På våre nettsider finner du svar på hvilke [endringer](#) du må melde, samt endringskjema.

Opplysninger om prosjektet blir lagt ut på våre nettsider og i Meldingsarkivet

Vi har lagt ut opplysninger om prosjektet på nettsidene våre. Alle våre institusjoner har også tilgang til egne prosjekter i [Meldingsarkivet](#).

Vi tar kontakt om status for behandling av personopplysninger ved prosjektslutt

Ved prosjektslutt 16.05.2019 vil vi ta kontakt for å avklare status for behandlingen av personopplysninger.

Se våre nettsider eller ta kontakt dersom du har spørsmål. Vi ønsker lykke til med prosjektet!

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Vennlig hilsen

Marianne Høgetveit Myhren

Lasse André Raa

Kontaktperson: Lasse André Raa tlf: 55 58 20 59 / Lasse.Raa@nsd.no

Vedlegg: Prosjektvurdering

Kopi: Kenneth Verngård, kenneth.verngard@gmail.com



PURPOSE

The purpose of this qualitative study is to explore and analyse factors contributing to access, or lack of access to quality education for children with deafblindness in Zambia and Malawi.

METHODS AND SAMPLE

Interviews with individuals, and groups of, students, families, teachers, community members, local and national government officials, and representatives of local and international disabled people's organizations (DPOs) and other non-governmental organizations (NGOs) working to promote inclusive education in Zambia and Malawi

In addition, classroom observations in inclusive mainstream schools. Cf. email from the student on May 4, 2018, the Data Protection Official presupposes that no personal data are registered through observation, i.e. that no individual children may be recognised in the data material. Nevertheless, we presuppose that parents are informed in advance of planned observation in the classroom.

INFORMATION AND CONSENT

According to your notification form the sample will receive written information and will give their consent to participate. The information letter we have received is well formulated.

SENSITIVE INFORMATION

It is indicated that you intend to process sensitive personal data about health. This means that you must be even more careful with regards to use of the data, both when it comes to ethical issues, data collection and information security during the project.

INFORMATION REGARDING THIRD PERSONS

According to your notification form, you intend to register personal data about third persons. Cf. email from the student on May 4, 2018, we presuppose that this is not the case. Parents will only comment on their own children, which is not considered to be information regarding third persons as long as the children are minors. Other informants will talk about children/pupils in general, and will not comment on identifiable individual children.

DATA SECURITY

The Data Protection Official presupposes that you will process all data according to the OsloMet internal guidelines/routines for information security. We presuppose that the use of a personal computer/mobile storage device is in accordance with these guidelines.

PROJECT END

The estimated end date of the project is 16.05.2019. According to your notification form/information letter you

intend to anonymise the collected data by this date. Making the data anonymous entails processing it in such a way that no individuals can be identified. This is done by:

- deleting all direct personal data (such as names/lists of reference numbers)
- deleting/rewriting indirectly identifiable personal data (i.e. an identifying combination of background variables, such as residence/work place, age and gender)
- deleting digital audio/video