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The discrepancy between policy and practice  
in primary education for children with  
disabilities in Kabarole district, Uganda

**The implementation gap explored  
through the lens of the capability approach**

## **Abstract**

World-wide 57 children of primary school going age remain out of school, and more than half of these children live in sub-Sahara Africa. According to the Ugandan legal framework, all children should be given free, accessible education however, there appears to be a discrepancy between the policy and practice. Especially children with disabilities (CwDs) are likely to be excluded from education. The discrepancy is evident by the percentage of 82.4% of CwDs that are out of school in the Kabarole district in Uganda, where this research was accomplished.

To explore possible explanatory factors behind this discrepancy, I researched the situation of CwDs who are enrolled in primary schools in the Kabarole district in Uganda using participant observations of special needs classes in two different schools that provide education for CwDs. Semi-structured interviews were conducted with eight teachers and the headmaster/mistress of the two schools, as well as the special needs education officer of the local government.

The discrepancy between education policy and reality is in this research presented as the implementation gap. The reasons for the implementation gap lays at different levels. The lack of demographic data and lack of funding, the unclear and inconsistent definition of CwDs, and the undefined duty bearers makes it difficult for targeted policies. These are political barriers that influence the enrolment in education.

The term ‘Special Needs Children’ and ‘CwDs’ are mixed, both in policy and in schools. With varying formulations, these terms describe the same large, complex group of children. Children with a wide range of physical and mental impairments are defined by these terms, as well children from low-income households, orphaned children, children with illnesses like HIV/AIDS and ‘slow learners’. The causes for the special needs are interrelated and poverty appeared to be an underlying economic implementation barrier. Physical barriers are found in the educational infrastructure: there are is a lack of resources (books, pencils, desks), lack of assistive devices (glasses, hearing devices, wheelchairs), few special needs education teachers and the regular classrooms are overcrowded (up to 120 children per teacher). A social barrier to education appears because people in the community and parents have a negative attitude towards CwDs. CwDs face many obstacles enrolling in education. It is the environment rather than the impairments itself that disable the children.

Keywords: Children with disabilities, Education, policy implementation, Kabarole, Uganda

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## **LIST OF ABBREVIATIONS**

- CRC – Convention on the Rights of the Child
- CRPD – Committee on the Rights of Persons with Disabilities
- CwDs – Children with Disabilities
- HM – Headmaster/ Headmistress
- ICF – International Classification of Functioning, Disability and Health
- ICIDH – International Classification of Impairments, Disabilities and Handicaps
- IE – Inclusive Education
- MoES – Ministry of Education and Sports
- NGO’s – Nongovernmental Organisations
- NSD – Norwegian Centre for Research Data
- OECD - Organisation for Economic Co-operation and Development
- OVC – Orphans and Vulnerable Children
- PLE – Primary Leaving Examination
- PTA – Parent Teacher Association
- PwDs – People with Disabilities
- SDGs – Sustainable Development Goals
- SEN – Special Educational Needs
- SNE – Special Needs Education
- SSA – Sub- Saharan Africa
- UBOS – Uganda Bureau of Statistics
- UDHR – Universal Declaration of the Human Rights
- UN – United Nations
- UNEB – Uganda National Examination Board
- UNESCO - United Nations Educational, Scientific and Cultural Organisation
- UNICEF - United Nations International Children's Fund
- UPE- Universal Primary Education
- UPIAS – Union of the Physically Impaired Against Segregation
- WHO – World Health Organization



## **1. INTRODUCTION**

In this thesis, different topics of my interest are brought together in a study: children with disabilities, education and policy. This study is a case study of a primary school that provides special needs education in the Kabarole district in the west of Uganda. This study explores the concept of ‘disability’ in the educational context and specifically looks at the difference between policy and practice. By participant observation, interviews and document analysis, a holistic picture of the situation of children with disabilities (CwDs) in education is created and the implementation gap of education policy is explored.

Globally, there is an ‘education for all movement’ to provide quality education for all children, youth and adults. At the United Nations (UN) Summit in September 2015, world leaders adopted the 17 Sustainable Development Goals (SDGs). The objective of these goals is a multinational collaboration for an agenda of sustainable development for 2030. Aims of the SDGs is to end poverty, fight inequality and tackle climate change, while leaving no one behind. My study concerns one of these goals to provide inclusive and quality education for all (UN, The Sustainable Development Agenda n.d.).

Since the international movement towards education for all, primary education enrolment in developing countries has improved and has reached an involvement rate of 91%. Worldwide 57 million children remain out of primary school and more than half of them live in sub-Saharan Africa (UN, Goal 4: Quality Education n.d.). Uganda is one of the countries in sub-Saharan Africa, where many children are out of school. A particularly vulnerable group is CwDs; in 2014, 19% of CwDs the ages 7 to 16 had never been to school (Riche and Anyimuzala 2014, 27).

### **Relevance of education**

Uganda is classified by the UN among the least developed countries globally. Least developed countries characterises low income countries, facing severe structural weaknesses to sustainable development and are highly vulnerable to economic and environmental shocks. Similarly, least developed countries have low levels of human assets (UN, Least Developed Countries n.d.). The Universal Declaration of the Human Rights (UDHR) specifically concerns education as a fundamental human right in article 26. Education is considered essential for sustainable development (UN, UDHR 1948). Sen claims that education has ‘direct relevance to the well-being and freedom of people’ and plays an ‘indirect role through influencing social

change’ and ‘economic production’(Snilstveit, et al. 2015, 1). There is a correlation between education and economic growth, especially in developing countries. Studies prove a positive relationship between education and other development indicators, like health status, maternal and infant mortality, lower population growth and lowered crime (ibid.). The relevance of education is reflected in the UNESCO initiative of ‘Education for All’ and the SDGs of the UN. More on this will be explained in chapter 3 on policy analysis.

## Uganda

Uganda is a landlocked country in Eastern Africa and is located between Kenya in the east, South Sudan in the north, The Democratic Republic of Congo in the west, and Tanzania and Rwanda in the south. The country is located on the equator and has an equatorial climate, with much rain and sunshine on a relatively high latitude. Uganda’s culture is diverse and involves many religions, tribes, traditions, beliefs and languages. The population contains different ethnic groups and this plays an important role in the life of the Ugandan people. The national language is English and Swahili; both are widely spoken (UBOS 2014a, 1-4). Uganda’s population is growing exponentially and between the housing census of 2002 and 2014 the population grew from 24.2 to 34.6 million respectively (UBOS 2014a, 8). In 2016 the population was 40 million (Population Pyramid 2016).

The youth (0-17) represents the population by 52.8% of the Kabarole district. People between 18 and 30 are the second largest group with 23.6%, people aged 31-59 are 18.8% of the population. In a staggering disparity, the elderly population (60+) represents only 4.9% of Kabarole district (UBOS 2014b, 20). The demographic distribution is illustrated in figure 1.

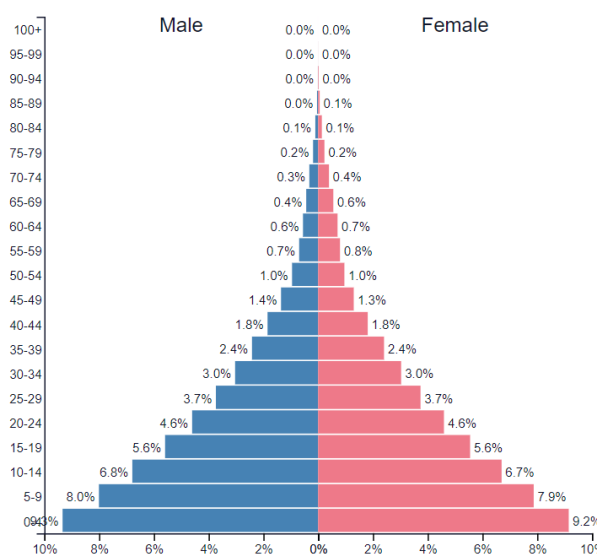


Figure 1: Population pyramid Uganda (Population Pyramid 2016)

According to the national housing census of 2014, Uganda's governmental structure is organised: 112 districts, 181 counties, 1,382 sub-counties and 7,241 parishes (UBOS 2014a, i).

In the constitution of the Republic of Uganda, article 30 and 34 mention the provision of education as a human right and a basic education as an entitlement for all children. The Universal Primary Education program and the Universal Secondary Education program were implemented in 1997 and 2007 respectively. Education is accentuated as an aspect of Human Capital Development in the National Development Plan II (2015/16-2019/20). As illustrated, there has been a global and domestic motivation to improve school attendance (UBOS 2014a, 4). Despite these efforts, not all children have access to education. For example: in Kabarole 11.8% of children between 6 and 15 are not attending school and only 82.4% of the children between 6 and 12 attends primary school. 17.5% of children between 10 and 17, as well as 24.6% of adults (18+) are illiterate (UBOS 2014b, 21-22).

In the National Housing Census of 2014, children that are considered to be CwDs in the Kabarole district represent only 4.4% of the persons between 2 and 18 years of age. An individual is considered disabled if one out of the four questions on disability in the questionnaire in the census, were answered in negation. These questions considered seeing, hearing, walking/climbing steps and remembering/concentrating (UBOS 2014b, 4-23-62). In the theoretical framework the term 'disability' will be discussed and in the findings, the meaning of disability in an educational context in Uganda is discussed.

### **Complications for education for CwDs in Uganda**

Abimanyi-Ochom and Mannan (2014, 2-6) state that there is a lack of data in monitoring and evaluating disability intervention policy. The Ugandan government executes a housing survey around every 10 to 12 years and a demographic health survey every four years. Due to rapid changes of living conditions for people with disabilities, there is a need for improved disability data collection, carried out more frequently. Different studies show that data on the prevalence of disability are limited on national as well as a local level. Generally, there is limited research on people with disabilities in Uganda. Additionally, the article states that there is no consistent definition of disability through legal documents and therefore no reliability in measurement of policy outcomes. Similarly, the methods that are used in data gathering differ from study to study. It is difficult to do targeted disability interventions, because of the lack of a consistent

definition and the lack of consistent data on the prevalence of disability. This will be further discussed in the chapter ‘policy analysis’.

Studies show a correlation between poverty and disability. 80% of people with disabilities live in long term poverty with limited access to public services like education. Households with people with disabilities have a higher likelihood to live in poverty, than households without people with disabilities (Abimanyi-Ochom and Mannan 2014, 3).

Firstly there is a structural insolvency of accessibility to persons with disabilities in education; the system lacks adaptations to people with physical and mental impairments, that could ensure CwDs in succeeding in education. Another barrier faced by people with disabilities is the negative attitudes and perceptions that are a great obstacle to disability inclusion. Especially people with severe cognitive or intellectual disabilities are marginalised and face discrimination. Finally, there is a lack of provision for assistive devices. These are just a few reasons for high school dropout rates and high illiteracy rates for people with disabilities. This results in limited opportunities for employment and access to the labour market for disabled people and this leads to poverty for people with disabilities. As a result, people with disabilities are a vulnerable group (Abimanyi-Ochom and Mannan 2014, 5).

Summarising, the Ugandan government has put large efforts in developing a ‘comprehensive body of legislation’ to enable people with disabilities to be included in society. However, there is a gap between the law, policies and practice. In the article of Abimanyi-Ochom and Mannan (2014, 5) the implementation gap is explained: *‘The implementation gap is about negative cultural attitudes towards disability, poor funding, inadequate training in inclusive education and limited access to accessible information and assistive mobility devices. The implementation gap makes monitoring progress difficult and discourages prioritising resource allocation to disability’* (Abimanyi-Ochom and Mannan 2014, 5).

### **Scope of study**

The difficulty to access education for CwDs is the main concern of this research. To efficiently enrol all children in education, the implementation of the education policy is studied and related factors to implementation are investigated. The complexity of the implementation of education policy is presented in this research and recommendations for more effective implementation are suggested.

To understand the educational context in Uganda, this study focuses on two primary schools that provide special needs education in the Kabarole district in Western Uganda. To create a holistic picture, different perspectives are sought. I participated in the special needs class for nine weeks, which gave me a day-to-day perspective of the school. I also conducted semi-structured interviews with Special Needs Education teachers (SNE teachers) and teachers assigned for the general school population. Furthermore, the organisational side has been researched comprehensively, through interviews with the headmistress (HM) and the special needs education officer (SNE officer) from the local government. The legal framework is studied, including laws, acts and policy documents.

### **Objective of the study**

The objectives of the study are to define CwDs in an educational context through the lens of the capability approach. The effect of the (in) availability of commodities is explored and the influence of different environmental facets are studied, to explain the complexity of the implementation of education policy in practice.

### **Research questions**

What could explain the discrepancy between education policy and the implementation of education policy for children with disabilities in the Kabarole District in Uganda?

#### *Sub questions*

1. How do policies aim to include children with disabilities in primary education in Kabarole district?
2. How is 'disability' conceptualised in the educational context through the lens of the capability approach in Kabarole district?
3. How does the (in) availability of commodities affect the participation of children with disabilities in primary education in Kabarole district?
4. How does the political, economic, physical and social/ cultural environment influence the participation of children with disabilities in primary education in Kabarole district?

### **Study limitations**

For the master thesis, a full year (from April 2017 to May 2018) was available to design the research, collect data, analyse it and write a thesis. The collection of the data was done in three months: from mid-September to the end of November of 2017. In this time, 25 days of

observation in the school were done, 12 interviews were conducted and legal documents were collected. Considering the fact that I was new to the Ugandan setting, and had to gain a picture of the educational system, I needed time to adopt to the culture and visualise the context.

### *Language*

Even though English is an official language of Uganda, not all people speak English, especially young children and less educated people. From the 3<sup>rd</sup> grade, children are taught in English, and the younger children are taught in the local language. In the special needs class, the spoken or informal language is Retooro, and the lessons were in English and in sign language. This made it sometimes difficult for me to understand what was going on in the classroom. Body language often explained the situation, and if I still did not understand the situation, the teachers were always willing to explain to me what happened. Through the interviews I got the chance to go deeper into what I had seen in the observation.

### *Insider/ outsider*

I am a white European student in an African setting, where my interpretation of situations can be affected due to cultural differences. Additionally there could be an interviewer effect, meaning that the participant tells what they think that the researcher wants to hear. Mullings (1999, 339) explains this phenomenon as an insider/outsider problem, which is discussed in cross-cultural studies. *'[...]social characteristics of an interviewer and a respondent, such as age, race and sex are significant during their brief encounter; different pairings have different meanings and evoke different cultural norms and stereotypes that influence the opinions and feelings expressed by respondents'* (Turner and Martin cited in Mullings 1999, 339). Mullings (1999, 340) states that being an insider gives the researcher the opportunity to use the knowledge about the group more intimate insights into their opinions. However, the outsider can create a more objective view of the target group.

### *Opinion*

During observations and interviews, I did not express my opinion about certain expressions or activities, as to not affect the validity and objectivity of the research. This was often difficult when they spoke of 'mental retardation', which sounds very stigmatising to me. Some situations proved difficult to conceal my opinion, for example the use of corporal punishment. Children get corporal punished for many reasons, mostly for misbehaviour or for 'sins' like stealing. I did not express my negative opinion about corporal punishments, although in my

culture this is an unacceptable way of punishment. This became a problem when I was alone with the children in the classroom. I had a hard time keeping children at their benches, when they found out that I did not use corporal punishment. Teachers recommended that I employ a stick, for the use of corporal punishment. I noticed that for me, normalisation of corporal punishment happened to me. The first two weeks I felt very sad and powerless when I saw children being beaten. However, I had to accept that this is the main method for teachers to control the number of children that are in class. It is a part of the culture, and it was the culture that I aimed to capture. There was not much to do for me than accept this method of punishment. I stated that I would not use corporal punishment, nonetheless I never expressed my opinion about it, to not influence the trust of the teachers in me.

### **Use of this research**

This research is an exploratory in-depth study. Local governments and other districts may recognise the barriers and opportunities of CwDs and education that is presented in this research. This study could help to develop further policy measures in the future. Moreover, policy makers and other stakeholders in the Kabarole district might be able to use this study for implementation of education for CwDs s.

### **Outline of the thesis**

This thesis is divided into nine chapters. The first chapter presents the scope of the study, the background and the context of the study. Furthermore, the objectives of the study and the research questions are described, as well as how this study can be used. The second chapter presents the methodology that is used for this study. The process of the study is explained, from gaining access, the methods that were used to collect data to the analysis and the validity and reliability of this research are presented. In the third chapter, the choice for the capability approach as a theoretical framework is presented. Furthermore, literature on special needs education and policy is presented. Chapter four shows the analysis of the global and regional legal framework and the definition in the Ugandan legal context and aims to answer the sub-question: ‘How do policies aim to include children with disabilities in primary education in Kabarole district in Uganda?’ In chapter 5 to 7 the findings of this study are presented and the capability approach is used to structure the findings. In chapter 5 the concept of ‘children with disabilities’ is explained in the Ugandan context by looking at ‘personal characteristics’. Answers for the sub-question ‘How is ‘disability’ conceptualised in the educational context through the lens of the capability approach in Kabarole district?’ are presented. Chapter 6

presents the commodities that influence the children's school attendance which are called 'commodities' in the capability approach. Findings aim to answer the question: 'How does the (in) availability of commodities affect the participation of children with disabilities in primary education in Kabarole district?' Chapter 7 shows how the environment plays a role which, according to the capability approach, consists of the political environment, economic environment, the physical environment and the social/cultural environment and the following question is answered: 'How does the political, economic, physical and social/ cultural environment influence the participation of children with disabilities in primary education in Kabarole district?' In the discussion in chapter 8 the findings will be brought together and analysed by using the capability approach, and a comparison is made between the legal framework (presented in chapter 4) and the reality (presented in chapter 5 to 7). In chapter 9 the conclusion of this research is presented, as well as policy recommendations for Uganda. In the last two chapters (discussion and conclusion) the main question is answered: 'What could explain the discrepancy between education policy and the implementation of education policy for children with disabilities in the Kabarole district?'



## 2. METHODS

This chapter will outline the decisions that were made throughout the research process (Bryman 2012, 46). To study the provision of education for CwDs in the Kabarole district in Uganda, a qualitative study was chosen, in which different methods of data collection enable the researcher to create a holistic picture of the situation.

Through the Oslo Metropolitan University I got in touch with professor Louise Ackers, the founder of the NGO 'Knowledge for Change' in Fort Portal. Knowledge for Change is a charity organisation that aims to improve health centres in Uganda and organises student placements. Through 'Knowledge for Change' I could get in touch with school A in Fort Portal: the only school in the municipality that provides education for Special Needs Children. I participated in the special needs class within the school for 10 weeks and I did observations and interviews with teachers and the headmistress (HM). Once I started to collect data, I found out that in the Kabarole district, two other schools provide primary education for CwDs: School B and School C. School B is included in this research, but school C is not, since this is a private primary school, and the costs are very high for attending this school. Opposite to the other schools, there is no involvement of the government in school C.

### Case study

Case study can be used when the researcher is studying a complex social phenomenon and does an 'in-depth' exploration of the topic (Yin 2009, 18). The topic of this research is 'children with disabilities' enrolment in primary education, which is related to multiple factors and a broader picture is to be captured to understand the reasons behind their enrolment. Other factors appear to play a role: the definition of 'children with disabilities', the (in) availability of commodities, the infrastructure of the education system and attitudes of people towards CwDs. This study shows how all these factors are interrelated.

One can discuss what is considered as a case. A case can be a person or several persons, an event or an entity. In this research, the case study is on a school that provides special needs education (Miller and Brewer 2003, 23). Yin (cited in Miller and Brewer 2003, 22) defines case study as '*an empirical inquiry that investigates a contemporary phenomenon within its real-life context when the boundaries between phenomenon and context are not clearly evident, and in which multiple sources of evidence are used*'. This applies to this research since the phenomenon 'children with disabilities' is explored and the meaning in the educational context

in Uganda. In this research the capability approach is used, which has its focus on the interrelation between the individual character of the person, the commodities and the environment. With using the capability approach, the boundaries between the phenomenon and the context are explored and different perspectives on the phenomena are included in the study, to expose different perspectives and create a holistic picture of the phenomena (Miller and Brewer 2003, 22). In this study different perspectives within the school were sought to show different contexts, to uncover different parts of 'real-life' and to create a natural picture (Miller and Brewer 2003, 23).

One can ask why only one school is used as a case study. The school is known in the municipality as the only school that provides education for special needs children. The school has a special needs classroom where children with hearing impairments and intellectual disabilities are taught. To explore the phenomena in the district, additionally two other schools that provide education for CwDs were visited. Here I conducted interviews with the HMs and at one school I interviewed a SNE teacher and taught children with learning disabilities a twice. However, due to the limited size of the study and time limitations, I could not do in depth research using regular observations because it would be too time consuming to do on more than one school. Therefore, I decided to do an in-depth case study on one school, and explore the other two schools through visits and interviews. For the same reason there were no regular schools included. It would be very interesting to look at regular schools and explore how they include CwDs. However, time limitations led to the choice to do a single comprehensive case study. The data from school C, a private school, is not included in the research, since the relevance of government acts and policy is absent.

### **Ethnographic approach**

This study has an ethnographic approach. Ethnography is based on field research where people are studied in their natural settings. The researcher directly immerses in the daily activities, to study social meanings and ordinary activities, so insider knowledge can be gained (Miller and Brewer 2003, 99). In ethnography, different methods are combined to capture people's views, beliefs and meanings (Miller and Brewer 2003, 100). The researcher aims to capture the social world as it is and studies it from the inside, to represent social reality in a textual form. Ethnography is particularly useful when quantitative data are not available and when social meanings of the people are unknown (Miller and Brewer 2003, 101-102). Usually ethnography contains repeated participant observation where the researcher is immersed in the setting that

is researched. Patterns in day-to-day life are observed. Ethnography has its foundation in anthropology and is now commonly used in social science to study culture or behaviour of people or groups. Patterns and social relations of a group or culture are studied.

When an ethnographic method is used, there are different roles the researcher can take. A complete observer or a complete participant, or a participant-as-observer or an observer-as-participant. I choose to be an observer-as-participant. People that are studied are aware of the fact that I am a researcher, called an 'overt approach' and the researcher collects observation data that are used for exploration in the follow up interviews (Jones and Smith 2017, 99). I chose to become an insider researcher and I could use my experience in the setting: the last four years I have been working in a school in Norway. It is however very important to be reflexive and cognisant of pre-conceived perceptions, to ensure validity of the findings. I was not in the classroom to teach the teachers new methods, instead I was there to learn about theirs. To ensure the validity, I adapted to their methods (Jones and Smith 2017, 100). I observed how they gave the children exercises and did the same kind of exercises with them. However, I was aware that I would never get a complete insider view, since I did not speak the local language, and my skin colour and nationality made me an outsider.

### **Participant observation**

With participant observation, the researcher aims to find out 'what is going on' in practice. It does not look only at what people say that is going on, but gives the researcher the opportunity to observe and experience what is going on, since the researcher immerses in the setting to explore the situation (Kemp 2001, 528). Participant observation can be used to generate understanding of other persons' world and the researcher develops knowledge about another person's way of thinking and acting. The researcher herself immersed in the setting and took part in daily activities of the persons that are studied. The daily routines and activities are reconstructed by using field notes, either while participating or directly after (Bryman 2012, 447-452). Tanner & Le Riche (cited in Kemp 2001, 528) state that the researcher must explore with an open mind set in participant observation and requires the researcher to be in the situation before judging it. When this method is used, unexpected factors can be found (Kemp 2001, 528).

For this research unstructured observation was done. By choosing unstructured observation, the researcher enters the field with some general ideas on the topic but not precisely what will

be observed. The researcher documents as much as possible about the setting and the participants and observes holistic, unstructured and unfocused. No checklist or coding schemes are used, but through a narrative style of observations, the researcher reports relevant information for answering the research questions (Given, Unstructured Observation 2008). No observation schedule was used for observation and the aim of the observation was to capture the behaviour and actions of the participants and develop a narrative account of the situation. The role of a 'partially participating observer' was chosen, meaning that observation is not the only data source. Additionally semi-structured interviews and documents were used as sources to capture a full picture of the situation of CwDs in education (Bryman 2012, 443). All the notable events that happened during the day and everything that possibly had something to do with enrolment in education for CwDs was taken note of (Bryman 2012, 273).

To understand the context of CwDs that are enrolled in education, the researcher did participant observations in the special needs class in school A. During participant observations, notes were taken on my smartphone after seeing or hearing something notable. I decided to use my phone and not a notebook, because that could influence the people that were observed. According to Bryman (2012, 448) using a notebook can make people self-conscious and taking short amounts of time out to write down notes on my phone was a more natural way of recording observations. At the end of the day, these notes were described in a field note diary on a laptop and the notes on the smartphone were deleted. Personal reflections were also taken note of, to keep track on how my own experiences of the daily life in the school. These notes were taken in italic to separate observations from the responses. This field note method was chosen according to Bryman (2012, 447-448).

### **Gaining Access**

The placement manager of Knowledge for Change organised a meeting with the HM of School A. In this meeting I explained the purposes of my visit. Authorisation was given by the HM to spend time in the Special Needs Class to do participant observation and to do interviews with the teachers. The HM of the school is the gatekeeper, and gatekeepers provide access to the research site. Through the connection of Knowledge for Change with a children's rehabilitation centre, I got in touch with School B. I was introduced to the HM and he gave authorisation to do interviews there.

### **Semi structured interviews**

Key informants were; teachers (both SNE teachers and teachers assigned to the general school population), the HM and the SNE officer from the local government. For further exploration two other interviews were done with the HM and a SNE teacher of School B.

When conducting semi-structured interviews, the researcher has a written interview guide, however, variation in the questions is possible for questions are formulated open and general, and the researcher has the opportunity to probe further into a topic (Bryman 2012, 716). Semi-structured research gives the researcher more control over the topics of the interviews compared to unstructured research. There are no fixed ranges of responses to the questions like in structured interviews. The researcher may move back and forth through the interview guide according to the informants' responses. The topics are based on the research questions and they may be open ended or specific (Given, Semi-Structured Interview 2012).

To capture a broad perspective of the teachers in the school, interviews were done with teachers from different grades and with differing years of work experience, to compare their opinions and experiences in working with CwDs. For this research 6 teachers from school A were interviewed: one was a SNE teacher, two teachers taught the first grade, one teacher taught the third grade and two teachers taught the sixth and seventh grade. The HM was also interviewed. The HM cooperates closely with the teachers and the local government. This interview aimed to link the legal framework to the actual situation in the school and to receive a perspective from the organisational side of the school. The interview guides consisted of the following topics: general information about the school, teachers' job and class, the conceptualisation of CwDs in education, the experience of the profession and the teachers education, the support for CwDs/ special needs, reasons for absenteeism or drop outs and the roles of the different stakeholders in providing education. In the interviews with the HM's, the focus is laid on policy and the different stakeholders of the government. The interview guides are to be found in appendix I.

### **Interview setting**

The interviews with the teachers were conducted within the school. The high workload of the teachers limited the time available for interviews and had to take place within the teachers' breaks. My approach was always the same: I introduced myself to the teacher and explained the reason for my participation in the school. I sought contact a few times and had small talk

conversations with them to get familiar with the teacher. After a few conversations I asked if they were interested in doing an interview with me. If so, they could pick a time and place that suited them for an interview. Most teachers picked the break time, between 1 and 2 o'clock, and chose their classroom for the interview location. Two teachers wanted to do the interview in the administration building, and one teacher wanted to sit outside, in front of the classroom. The location and time were most convenient and relatively quiet. It gave the interview an informal atmosphere which was very important because the aim of the interviews was to explore their opinions and experiences.

### **Confidentiality and consent**

To ensure the anonymity of the children and other participants, the schools are anonymous in this thesis. Additionally, names of children, teachers or HMs were anonymised. To ensure anonymity, no combinations of age, impairment and gender were revealed. CwDs are a vulnerable group, and it is of the highest importance that research will not negatively affect the children. By anonymising the schools, the children and other participants are less likely to be retractable. The schools are called 'school A' and 'school B'.

Before the placement in the school, I had a meeting with the HM in which I explained about the research and explained that I would like to do interviews with the teachers. The HM is the gatekeeper in the school and she gave me permission to do interviews with the teachers. A gatekeeper stands between the researcher and the potential respondent. The gatekeeper controls who accesses the research site and when the respondents are accessed (Lavrakas 2008). The HM gave her permission for the research: I was allowed to participate in the special needs class and regular classes and to do interviews with anyone that was willing to participate.

For recruiting participants, I had informal conversations with the teachers in which I explained them that I am a student of the Oslo Metropolitan University, that I am participating in the NGO Knowledge for Change and I told them about my research. I would then ask them if they were interested in doing an interview with me and explained that the interview is voluntary. Before the interview, I explained that the interview was for research purposes only and I stated that the participation was voluntary and that they could withdraw at any time without explaining their reasons and that the teachers' duty of confidentiality would not be violated. I explained that teachers should not reveal personally identifiable information about the children and I told them to leave out background information like names, age, gender, background,

specific incidents or diagnosis. Then I read the information letter/consent form with them, of which the content will be explained in the paragraph 'Ethical Considerations'. The information was given verbally and in the informed consent form so there would be no misunderstanding about the reason for the interview and the use of the information. Additionally, the participants received a copy of the informed consent letter with my contact information, as well as the contact details of the NGO Knowledge for Change and the Oslo Metropolitan University.

### **Documents**

To relate the practical experiences to the legal framework of education in Uganda, policies, laws and acts were studied for this research. The following documents were used: 1995 The Constitution of Uganda; 1996 National children's Act; 1996 Universal Primary Education; 2004 National Orphan and Vulnerable Children Policy; 2006 National Policy on Disability; 2006 Persons with Disabilities Act; 2011 Special Needs Education & Inclusive Education Policy. The acts were found in the official website of the Ugandan government: Uganda Legal Information Institute. The policies were found through searching on google.

### **Data analysis**

The interviews were transcribed and notes of participant observation documented in a field note diary. All information was printed out in hardcopies and four main themes were found: 'children with disabilities', 'education', 'barriers' and 'opportunities' Bryman (2012, 577).

An important part in analysing in social research is coding, which means as much as sorting and labelling the data that were collected. Here categories and theoretical ideas are sought within the information. The researcher elaborates and links codes and reflects what they mean in the context and in the broader story. During the analysis of ethnographic research, the researcher has the research questions in mind during the data collection. The researcher has to have some leading ideas on how she wants to answer to the initial puzzle (O'Reilly 2009, 34-38).

For optimal and efficient analysis a computer-assisted qualitative data analysis program was used, called NVivo. The codes in Nvivo are called 'Nodes'. Initially, four Nodes were created: 'Children with disabilities', 'Education for CwDs', 'Barriers' and 'Opportunities'. All the transcribed interviews were imported into the 'Source' folder, as well as the field notes and the legal documents. After this, the coding process in NVivo could start. All relevant information

was placed in the Node of the theme. It appeared to be insufficient specific to have four Nodes and within the Nodes so within the main Nodes, more focused nodes were created. These are called: 'hierarchically organised nodes' and the information was placed in these hierarchically organised nodes.

After all information about these themes is organised in the nodes, Nvivo enables the researcher to open a Node and receive an overview of all the different sources that gave information on that theme in one document. This is an advantage in comparison to non-computer-assisted analysis, and saves the researcher a lot of time. A word-document was created called 'findings' and all the information on the different themes was written here. After writing up the findings, the themes were re-structured and applied to the theoretical framework. Now connections could be made between the different findings.

### **Validity and reliability**

According to Schwandt (2007, 309 - 310) validity in social science means the validation of the statement that findings capture the social reality holistically. Bryman (2012, 389) adds that validity assesses if a researcher observes, identifies or measures what he or she says to do. Reliability shows how consistent the outcomes of the research are and shows the measures of concepts (Bryman 2012, 389-390). We distinguish between internal and external, both for validity and reliability.

**External reliability** is reached when the study is replicable and assesses of the repeatability of the study and if similar outcomes be found when the study would be repeated (Bryman 2012, 390). This is very difficult in the social world, because it is changeable it is impossible to freeze the social world. By stating detailed information of which steps were taken in the research, I believe I can prove that the research is replicable. If another researcher follows the same steps as I described them, he or she will find similar data. Every person has their own point of focus, but if open observation were made again with a focus on sub-topics, and the same questions were asked in the interviews other researchers would get outcomes that are identical to those presented in this thesis.

When we assess **internal reliability**, we aim to show certainty in the findings. When there are several observers, do they give the same information? A way to ensure this is the triangulation. Triangulation is described earlier and is present in this research: different methods are used and



different perspectives are sought (Bryman 2012, 390). Triangulation is important when studying a social phenomenon. Triangulation means that a multi method approach is sought for data collection and for analysis. When a variety of methods are used, the studied phenomena can be understood best. Similarly, the usage of different methods allows the researcher to cross check findings (Bryman 2012, 717). Since the 50's and 60's of the 19<sup>th</sup> century, the credibility of research was strengthened by triangulation to measure validity. The use of triangulation minimises the risk of bias which is very important in qualitative social research; social research is often criticised for its context dependency. Different research techniques measure different perspectives of a research problem and different dimensions of the units of study are identified, explored and understood. Findings are strengthened and interpretations enriched. (Given, Triangulation 2012). In this research the following methods are used: participant observation, semi- structured interviews and documentary analysis.

**External validity** is about generalisations of the findings for other social settings. The problem of generalisation arises especially in case studies, because they only represent small samples (Bryman 2012, 390). Miller and Brewer (2003, 23) mention the critique that case studies lack sufficient sample size to draw conclusions for other cases and are therefore not generalisable. Here we must distinguish between statistical and analytical generalisation. Quantitative studies that include surveys can draw statistical generalisations. Qualitative research, specifically case studies, rely on analytical generalisation: the generalisation to theory. Outcomes can be cross-checked by looking at other studies and theories that were done in other settings. A case study uses repetition in observation, so patterns can be discovered and can be related to general theory (Miller and Brewer 2003, 23). With the additional explorative interviews in other schools, this research looks further than only school A and increases the external validity.

For assuring the **internal validity** of the study, the researcher's findings should match the theoretical ideas that are developed through the study (Bryman 2012, 390). Through participation in a social group over time, a researcher has the chance to cross check the similarity between observation and concepts that were found in the literature. With the justification of internal validity, and a researcher explains the credibility of the research. In social research, an important question that arises is if the researcher understood the reality of the social world that was studied. Here again, triangulation is a technique used for cross checking the findings. In this research, many concepts were looked at from different angles: through the participant observant perspective a picture of the school day of CwDs was captured.

The findings in the observation were checked by informally asking the teachers and in the interviews and the findings were searched for in the literature. Because several methods were used, a balanced view was created and internal validity ensured.

### **Ethical considerations**

Ethical approval is given by Norwegian Centre for Research Data (NSD) in Bergen for the data collection on the 13<sup>th</sup> of September 2017 and is found in appendix II. In social research, ethical issues are discussed and the main issues are broken down to four main areas by Diener and Crandall (cited in Bryman 2012, 135). A researcher of social science must assess; 1) Whether there is harm to the participants; 2) Whether there is a lack of informed consent; 3) Whether there is an invasion of privacy; 4) Whether deception is involved.

It is important not to risk to harm the target group. 'Harm' is defined as: *'physical harm, harm to participant's development, loss of self-esteem, stress and including subjects to performer reprehensive acts'* (Bryman 2012, 135). This research concerns a group of children that is often considered marginalised and stigmatised. During the research I was aware of this fact. No physical harm came to the participants by the researcher, nor was the participants' development effected, or was there any reason for loss of self-esteem. The children and teachers were rather glad to have extra hands in the class. This was stated again in the interview with the HM. The anonymity of the school ensured that participants are irrevocable.

When conducting interviews, it is important that the participants are provided with the following information, both verbally and in the informed consent form: the responsible institution; the purpose of the project; the methods used for the research; the information will be treated confidentially and the informant may withdraw at any time without stating a reason; the interview will be tape-recorded; the informants will be anonymous and will not be recognisable or retraceable through the information they give in the final report; all data will be deleted after finalising the project, both tape-recording and transcribed interview; contact information of me, the placement manager and my supervisor were given to the participant to contact us when any questions would appear (Bryman 2012, 135). All informants were properly informed about the meaning of the consent form. All participants voluntarily signed the informed consent (Creswell 2014, 97). The data from the different informants is numbered e.g. 'Teacher 1' to ensure anonymity. Names were never mentioned in the transcriptions of the interviews. All recorded and transcribed data will be deleted after this thesis is delivered, at the

latest by November 2018. A researcher must choose between an overt or covert role. The overt role means that the participants of the research know about the fact that I am a researcher; a covert role means that the fact that I am a researcher is unknown. In this research an overt role was taken. The children, teachers and other informants were aware of the fact that I am a researcher (Bryman 2012, 433).

### **3. THEORETICAL FRAMEWORK**

The concept 'disability' needs clarification before any questions about it can be addressed. 'Disability' is a changeable concept and is the direct opposite of 'ability'. The border between able-bodied and disable-bodied persons is complex and uncertain. One could ask: where do we draw the boundary around disability? Do we include the chronically ill, people with 'learning difficulties' and functionally impaired? To distinguish between 'able' and 'disable' and the degree of disability, disabilities are often categorised. When categorising disablement a problem of 'valuing' arises, because people that belong to the same 'impairment category' vary enormously and have different experiences of it. Many people experience a few years of disability during their lifetime. Boundaries between disabled and abled-bodied people are not continuous and therefore blurred (Marks 1997, 85 - 86).

This chapter presents different models to look at disability. The medical model, the social model and the model of the WHO's model of International Classification of Functioning, Disability and Health (ICF). The Capability Approach is used as a framework for this study. To conceptualise disability and to look for policy recommendations.

#### **The Medical Model of Disability**

A way of looking at disability is through the medical model of disability. The medical model of disability, also called the individual or treatment model, focuses on the 'abnormality' of the body. The condition of the person results in disorder or deficiency. The medical expert (e.g. doctor, therapist) examines the individual and the disability of the person is to be treated. Treatment aims to overcome or minimise the disability of the person, so that people can cope with their impairment in daily life. Medical treatment makes the person as 'normal' as possible. This way of looking at disabled people received a lot of critique in the 1970's and 1980's of persons with disabilities, starting from disability movement 'Union of the Physically Impaired against Segregation (UPIAS) in the United Kingdom (Marks 1997, 86-87). Critique was that the medical model focused too much on medical and the bio-psychological definition of 'normality'. An example of this problem is presented in the book by Barnes, Mercer and Shakespeare (2000, 25) of a person with a visual impairment. The disability is that the person is not seeing well. Glasses can, in most cases, completely take away the disability. This enables the person to participate in society as any other person without a visual impairment. In the western world, wearing glasses is no longer seen as a disability, because it is normalised (Barnes, Mercer and Shakespeare 2000, 25-27). Psychologists' criticism towards the medical

approach of disability is that it does not include the performance of a person with an impairment. Medicine focuses on the body and does not acknowledge cognitive and emotional factors of the disability: Every individual deals differently with an impairment and experiences it differently. However, also psychologists' perspective on disability is to look for the failure or abnormality of the individual (Marks 1997, 87-89).

UPIAS' looked at society's failures as a cause of disability of the individual. UPIAS stated: *'In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society'* (UPIAS cited in Barnes, Mercer and Shakespeare 2000, 28). A new approach required focus on how a person with impairments functions in the society, rather than to focus on the individual 'faults'. It is the society that needs to adjust to people with an impairment, instead of impaired people need to adjust to society. The defects of the environment have been undermined, since the focus was at 'normalising' the disabled. Globally, the claims made about the normality of the individual are not generalizable. Disability movements call for 'rights' and not for 'charity'. One should focus on the question how 'the disabled' are identified and how society produced that category of disability (Marks 1997, 87-89).

### The Social Model of Disability

UPIAS' criticisms were developed into a model by Michael Oliver in 1983: the social model of disability. The social model focuses on the disabling barriers and on the experience of disability and includes a range of influencing factors. Oliver stated that the medical model is to be seen as an individual model, where medicalization plays a main role (Oliver 1996, 30). Tony Makin, in his book chapter (2002, 186) explains the medical and social model of disability, according to the following figures:

Figure 2 Medical model of disability

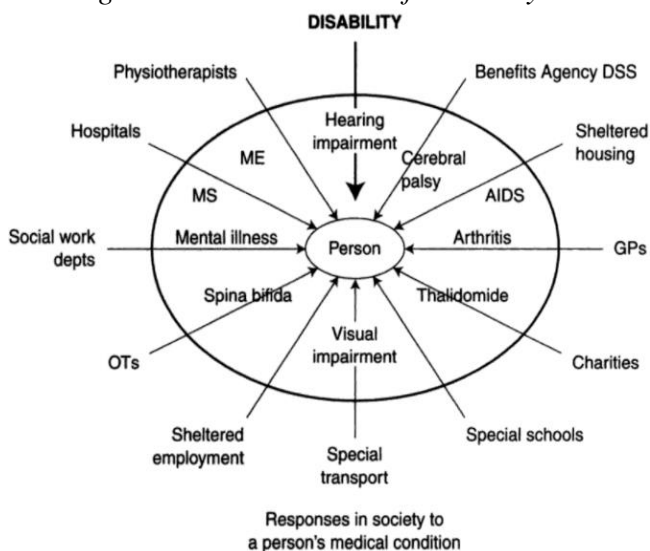
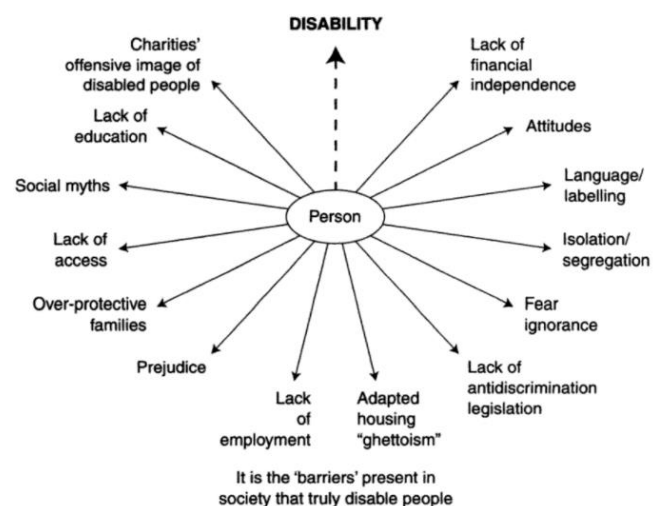


Figure 3 Social model of disability



In these models Makin presents examples of the medical model and the social model. The medical model shows the person in the middle with its medical condition, and outside the circle we see the responses of society to the medical condition of the person. We see the medical or social support that the individual may receive, in order to fix or minimise the problem. The medical model's definition of 'medical conditions' are not only impairments, also diseases and mental illnesses. This model shows the involvement of different sectors with the person with a disability: it mentions special transport, special schools, sheltered housing and employment. The social model of disability shows barriers in society that disable the individual. This figure shows a few examples of what is lacking in society: lack of education; social myths; lack of access; prejudice and attitude. With the social approach of disability, the social environment and the failure of the environment to adapt to the impairment became the main focus. We need to reconsider culture, institutions and relationships, and focus on the social change, rather than the individual faults. There is a need for the society to adapt to the different needs of people, which should result in a more inclusive society. With the social environment being more sensibly organised for everyone we learn to live with a broader range of differences. Adaptation of the environment results in the benefit of the whole community (Marks 1997, 88-89). Summarised, the social model looks at the social barriers that restrict people with impairments to participate fully in activities that disable them. This would mean that *all* restrictions for people with disabilities would exist because of the social barriers, which imposes that not the impairment, but the society's response to the impairment creates a disability (Thomas 2004, 577).

Critics agree that the social model is flawed in essence, because it denies the impact of the impairment on disability (Shakespeare, Watson, Bury and Williams, cited in Thomas 2004, 577-580). Disability is constituted because of the causal effects of the daily restrictions due to the impairment. They argue is that the physical aspect of the disability, also called 'the body' is not concerned and that sociology must 'bring the body back in' (Williams & Bendelow cited in Thomas 2004, 576). Bury mentions that the social model is over-socialised and that *'disability is also influenced by context and culture.'* (Bury cited in Thomas 2004, 575). Shakespeare and Watson (cited in Thomas 2004, 574) go as far as stating that everyone is disabled in varying degrees. This gives a different perspective on the distinction between the 'disabled' and the 'normal'.

## **International Classification of Functioning**

The most utilised international definition of ‘disability’ was developed by the World Health Organization (WHO). In 1980 the WHO published definitions of impairments, disabilities and handicap called ‘the International Classification of Impairments, Disabilities and Handicaps’ (ICIDH) (Marks 1997, 86). The definition by WHO of ‘impairment’, ‘disability’ and ‘handicap’ in 1980 are as follows:

*‘Impairment is seen as a loss or abnormality of psychological, physiological, or anatomical structure or function (WHO, ICIDH 1980, 47)’.*

*‘Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (WHO, ICIDH 1980, 143)’.*

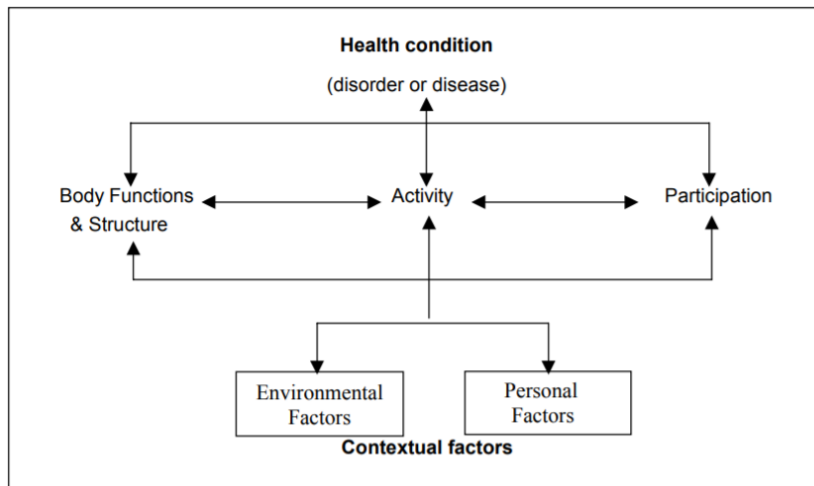
*‘A handicap is a disadvantage for a given individual resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual (WHO, ICIDH 1980, 183)’.*

With WHO definitions of 1980, the term ‘impairment’ is used for those parts or systems of the body that do not function as they usually do. Disability is what the individual cannot do as a result of the impairment. The definition of ‘Handicap’ refers to the consequences of the impairment or disability, that limits the individual to participate in society and fulfil the social roles and recognises that the social role depends strongly on cultural contexts and social groups (Barnes, Mercer and Shakespeare 2000, 23).

## **ICF Model**

The ICIDH model was recently revised and renamed the International Classification of Functioning, Disability and Health, where ‘Handicap’ in the ICIDH-1 is replaced by ‘Health’ in ICIDH-2, and ICIDH-2 is now officially called ICF. ICF is called the biopsychosocial model and includes the biological, individual and social view on functioning. In the ICF: *‘Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).’* (WHO, WHO/EIP/GPE/CAS/ICIDH-2 FI/ 01.1 2001, 164). In figure 4, the model of disability as a basis for ICF is shown.

Figure 4 ICF model of disability



(WHO, WHO/EIP/GPE/CAS/ICIDH-2 FI/ 01.1 2001, 16)

The ICF model uses a five point scale: ‘no impairment’ – ‘mild’ – ‘moderate’ – ‘severe’ – ‘complete’ to assess the level of disability of the individual. It includes the perspective of the body, the person and the person in society, so it includes factors from both the medical and the social model and how they interact. The individual’s functioning in society, the activities that the person can do and the participation in society are main factors of the ICF model (Trani, et al. 2011, 147).

### **Critique ICF model**

Although the ICF model looks at the well-being of the person and not only as the absence of disease, Trani et al. (2011, 147) state that policy makers need more information about factors that contribute to well-being of the person. There are many factors that are considered to contribute to well-being and the ICF model does not include the individual values, beliefs and preferences. There is a need for individual assessment of well-being and the possibilities that are provided by the environment that are convertible by the individual to contribute to wellbeing. The ICF model does not assess individual freedom of choice to achieve functioning in society (Trani, et al. 2011, 146-148).



## Capability approach

Some claim that the capability approach closes the gap that the previously described models left behind. The capability approach looks at disability at different levels and accounts for human diversity. Individual experiences of disability are not considered in the previous models, are included in the capability approach. Here, the capability approach is explained, and how it applies to disability, education and policy.

The capability approach by Amartya Sen was originally developed to analyse different concepts in welfare economics like well-being, quality of life and poverty. The capability approach focuses on the life that people are able to live, in terms of what they are able to *be* and to *do* and what they value being and doing.

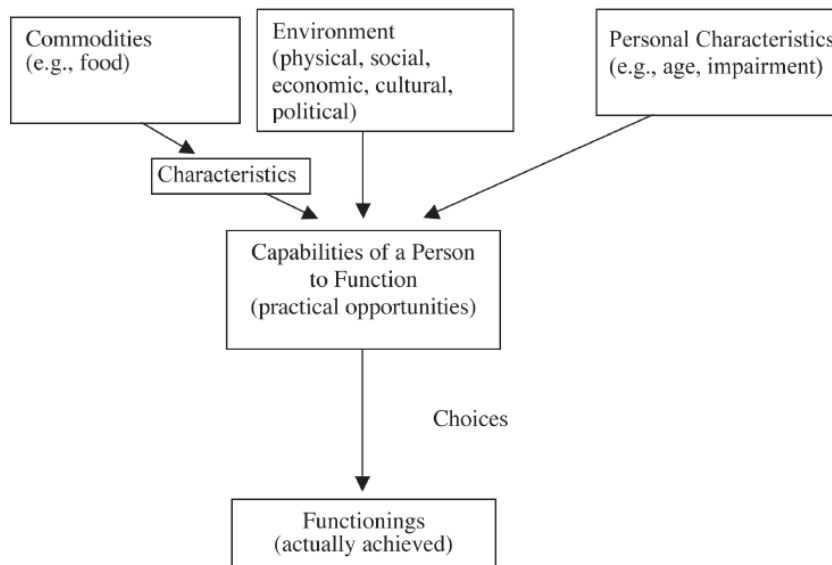
In the capability approach the main concepts are ‘capability’ and ‘functioning’. Here ‘capability’ means the practical opportunity and ‘functioning’ is the outcome: something that the person ‘does’ or ‘is’. An example is provided in Mitra (2006, 238) of different capability sets with the same functioning: Two people who are starving achieve the same functioning, however one is starving due to poverty and the other due to religious belief and has decided to starve. The first person does not have a choice to starve, but starves because limited opportunities, and the second person chooses to starve, because of religious beliefs. This example shows the person’s freedom of choice. How ‘well-being’ someone is, depends on the commodities available to the person and its freedom and capability to make the choices to achieve the well-being. In the capability approach, the choice of the individual of how commodities (like food or money) are transferred into functioning is of the main concern. The different sets of capabilities, gives people a different range of freedoms to make choices (Mitra 2006, 238-239). As presented in the example, two people with the same functioning have different levels of well-being, because of different capability sets.

Sen distinguishes between basic functioning (like nutrition, shelter and sanitation) and complex functioning (happiness and self-respect). Sen did not develop a list of functioning. The reason is that the ability to function depends on the environment and on the choice of the individual. The scope and length of the list would vary from person to person and is depending on the context in which the person lives. Moreover, Sen mentions that in developing countries, poverty influences basic capabilities: life expectancy, child mortality, nutrition, shelter and education (ibid).

## Capability approach and disability

Sen has not paid as much attention to ‘disability’ as to ‘health’ in the capability approach. Mitra (2006, 239) presents a scheme in which the capability approach applies to disability:

*Figure 5 Capability approach applied for disability*



In this figure we see the three factors that influence the person’s capabilities to function: the commodities, the environment and the personal characteristics. Then the choices of the person are the practical opportunities and results in ‘functioning’ of the person: the actual achievements. In the capability approach, disabilities are all factors that limit the person to achieve what he or she can be or do and looks at the individual capability to achieve outcomes.

The capability approach looks at ‘impairments’ under ‘personal characteristics’. The different environmental aspects can negatively influence the well-being of the person and therefore deprive him/her: Physical (stairs for a wheelchair user can be a physical barrier), economic (costs for medication can be an economic barrier), political (not having the right to vote is a political barrier) and social or cultural (people seeing a disability as a curse can be a cultural barrier). Finally, the lack of commodities can result in economic restrictions and can result in deprivation (Mitra 2006, 241).

Looking at the cultural and contextual subjectivity of disability, ‘disability’ can be identified for specific regions. Each context requires relevant functioning, and functions are ranked differently. A minimum level below which a person can be considered disabled, differs depending on the environment and the commodities of the person. What opportunities does

every person have in terms of education, leisure and social life depends on the standards of the person and the basket of goods (Mitra 2006, 242).

Mitra (2006, 241) differentiates between potential disability and actual disability. As explained above, deprivation of capabilities can lead to deprivation in functioning and is therefore seen as a potential disability. However, it is possible that the individual uses commodities to adapt to this potential disability and to achieve functioning. This means that the person is not actually disabled, only potentially. The person's ability to find compensating abilities and to adapt to alternative functioning is very important in the capability approach. If the person with a disability is able to be and to do using other ways to function, it does not necessarily lead to a restriction in functioning.

### **Capability approach and special needs and inclusive education**

In the 70's the concept of 'special educational needs' (SEN) came into existence and was at the time a very positive way of seeing the individual needs of students in education. A learner focused school environment was a key aspect of SEN. Later, SEN got negative associations: it was seen as poorly defined and as having a general shortfall. It appeared to identify difficulties and disabilities and did not focus on the possibility of academic and social participation. The new, rights-based approach was 'inclusive education'. It implicated social and school transformation and aimed for 'diversity' in education. For inclusive education, regular schools needed reconstruction in all forms to welcome diversity. In the last decade, negative reactions arose towards inclusive education: it was criticised to be a utopian orientation and an adverse reaction has been recognised (Norwich 2014, 16-17). The 'sameness' of students and the equal provision of education is in contrast with addressing the need of individual students, and creates the risk of labelling and dividing in the debate on the 'dilemma of difference'. Conceptualising differences and the special needs caused by individual limitations is a difficult problem occurring in the current education system (Terzi 2005, 443-444).

Though the dilemma of difference is addressed, resolving it in practise is not necessarily happening (Norwich 2014, 18). The capability approach's focus on diversity, equality and social justice is relevant for inclusive education because it could avoid negative labelling. Inequality can be addressed by the normative framework of the capability approach. Terzi (2005, 445) argues that the capability approach provides a new look at disability and special needs in the debate on differences in education.

She mentions that the individual characteristics in relation to impairment are ignored. The interplay between the child and the educational system and the interaction of those is needed to overcome the disabling barriers of the individual child (Terzi 2005, 445-449). Furthermore, impairment affects functioning in education. The individual child and the schooling environment are related and the functioning of the child depends on how the two elements interact. Looking through the lens of the capability approach we go beyond the debate of the 'dilemma of difference' and gives a new dimension to what is seen as disability in education in terms of justice (Terzi 2005, 454-457).

Dyslexia is used as an example for this theory: dyslexia itself is not an absolute disadvantage, as long as the school system adapts. Does the school system not adapt to the child's needs of adaptation? Then this restricts the child in participation and a 'disability' occurs because the functioning of the child is restricted. Another example is given about children with a hearing impairment: while listening and communicating are fundamental functions of the school system, a hearing impairment restricts the child from basic functioning and relevant capabilities. However, people with a hearing impairment that can 'lip-read' and communicate in sign language, and this can contribute to 'alternative functioning'. Alternative functioning in education could however only be useful if the environment of the child adapts and can sign (Terzi 2005, 454-455). The personal characteristics (the child with an impairment), the environment (school system) and commodities (adjustments e.g. sign language or lip-reading) are all taken into consideration in the capability approach as a framework for special needs education (Terzi 2005, 456-457).

### **Capability approach as a framework for policy**

For achieving the same level of well-being, people with disabilities might need different types and amounts of capability inputs than non-disabled people. Conversion factors exist of internal and external factors. The personal characteristics and individual choices are internal factors, and commodities and the environment are external factors. Sen (cited in Trani et al. 2011, 145) explains that many freedoms depend on the assistance and actions of others. Trani et al. (2011, 143) speak of 'external capabilities' which are the ones where a person depends on another person to share its conversion factors with them. Public policy can affect the commodities that the person can convert into capabilities. Especially when a disability is socially or culturally constructed, public policy is a crucial basis for functioning and the implementation process is crucial (Trani, et al. 2011, 142-144).

For policy making and assessing disability, the capability approach includes factors that the currently used ICF model leaves behind. As previously mentioned, the personal factors that are important for functioning are individual beliefs, values and preferences and are related to environmental factors. In the capability approach, these personal factors are central. The ICF model assesses what the person has achieved, where the capability approach assesses the opportunities available to the person. The ICF model looks at the standard of the environment, and not what the person can do with the environment facilities (Trani, et al. 2011, 148-150).

Trani et al. (2011, 152) state that policies should intervene where a problem is identified. The problem, however depends on the values of a community. Therefore, Trani (2011, 152) recommend adapting policy to the onset and the needs of the community, to include values and requirements of the community. The needs, values and requirements, need to be identified at the community level.

The capability approach shifts the focus towards possibilities and choices to establish equality. It assesses the well-being of people in a more holistic and comprehensive way. The capability approach can be a tool for policy makers, to identify important dimensions of well-being. When these needs for wellbeing are identified, policy makers can look what the restrictions are for the development of wellbeing. Similarly, the commodities available and the commodities that have to be improved can be assessed. Trani et al. (2011, 152) point out that the values of communities are to be assessed, as well as the commodities that are available and lacking, to enable the individual to convert the possibilities into wellbeing.

### **Capability approach as a theoretical framework**

This study looks at education for CwDs through the lens of the capability approach and uses the theories of Mitra (2006, 239) of disability through the capability approach. This theory allows researchers to analyse disability at the capability level and at the function level. The capability framework helps to explain how disability results from the three types of factors: the individual's personal characteristics the individual's commodities and the individual's environment. If the person is actually disabled or potentially disabled, depends on if the impairment, the commodities or the environment places any restrictions on the individual's functioning, according to believes, values and preferences (Mitra 2006, 246).

For this research the functioning is education. The study looks through the capability approach how the different factors affect this functioning. Hereby the study assesses which children are potentially or actually disabled, both on a capability level and at a functioning level.

The findings of the research will be presented based on Mitra's Model. In 'Personal Characteristics' the conceptualisation of disability is discussed, and the meaning of disability in the educational context is conceptualised. The commodities chapter discusses the role of poverty and the availability of commodities in the provision of education. In chapter 7 the influence of the political, economic, physical and social/cultural environment are discussed. In the chapter 'Implementation gap' the discrepancy between the legal documents and the actual situation on the ground is compared and how the findings explain why the legal framework is not effectively implemented.

#### **4. POLICY REVIEW**

In this chapter, the legal framework of education for CwDs is discussed. Firstly, I will present the global movement towards Education for All and the international declarations and conventions concerning education. Then I will narrow down to the Ugandan situation of education, and will present the legal framework for the provision of education for CwDs. The definition of CwDs in different laws and policies is discussed and criticised. This chapter will present the answers for the sub-question: ‘How do policies aim to include children with disabilities in primary education in Kabarole district?’

##### **Education for All**

In the second half of the twentieth-century, education for all became one of the key objectives of international organisations and governments. Inclusion in education is an international policy goal, and different global conferences and meetings have contributed to the universally accepted goals of the United Nations (UN).

‘Education for all’ is mentioned in several international conventions. The Universal Declaration of Human Rights (UDHR) states that everyone has the right to free compulsory elementary education (UN, UDHR 1948, Article 26). The Convention on the Rights of the Child (CRC) encourages governments to provide free and equal access to primary education and develop secondary education for all children (UN, CRC 1989, Article 28). In the Convention of the Rights of Persons with Disabilities of 2006, declared by The Committee on the Rights of Persons with Disabilities (CRPD) states that state parties recognise the right of Persons with Disabilities to education. It focusses on equal opportunities without discrimination and in full dignity, aiming to let every person develop to their full potential. Additionally, it mentions that talents and creativity, as well as physical and mental abilities must be given fullest opportunity for development. To realise this right, state parties shall ensure that CwDs are not excluded from the general education system due to a disability. CwDs alike all other children, have the right to access free and compulsory education; for the CwDs, individual needs are to be supported with extra assistance to ensure inclusive, quality education (CRPD 2006, Article 24).

In 1990, governments of 155 countries came together in the world education forum in Jomtien, Thailand. Here the Jomtien Agreement was signed, aiming to achieve ‘Education for All’. UNESCO and the World Bank Group, formulated six goals that were to be achieved by 2015.

These were later adopted in the Millennium Development Goals and are further explained below (World Bank 2014).

The Jomtien Declaration stated on inclusion that education has to contain child centred pedagogy in which the children's individual differences are *'accepted as a challenge and not a problem'*. (Savolainen and Alasuutari 2000, 11). In the Jomtien Declaration principles were expressed which were reinforced in the Salamanca Framework for Action in 1994, at the World Conference on Special Needs Education in Salamanca, Spain. Governments from 92 countries and 25 international organisations agreed upon a Statement for education for CwDs. One of the rules stated: *'Schools should accommodate all children regardless of their physical, intellectual, social, emotional linguistic or other conditions. This should include disabled and gifted children, street children and working children, children from remote or nomadic populations, children from linguistic, ethnic or cultural minorities and children from other disadvantaged or marginalised areas or groups. [...] in the context of this framework, the term 'special educational needs' refers to all those children and youth whose needs arise from disabilities or learning difficulties.'* (Salamanca framework for action, cited in Savolainen, Kokkala and Alasuutari 2000, 11). A framework for action was adopted stating that schools should include all children, regardless of their physical, intellectual, social, emotional, linguistic or other special conditions. The framework concerned guidelines for action on national, regional and international level (UNESCO 1994, 6-7).

Another framework for action was made at the World Education Forum in Dakar, Senegal in 2000. 164 governments, different NGOs, Civil Society Organisations and private organisations came together and joined the collective commitment of Dakar framework for action (Riche and Anyimuzala 2014, 17).

In the United Nations Millennium Summit in September 2000, the Millennium Development Goals were adopted by all member states, including Uganda. This was a binding partnership to achieve eight goals by 2015. Goal 2 aimed to ensure Universal Primary Education: Children everywhere should have the ability to complete full primary schooling (UNDP, MDG n.d.). By 2015, substantial progress was made, however Universal Primary Education was not achieved. In 2013, worldwide 59 million children of primary school age were out of school. The Sustainable Development Goals (SDGs) aimed to close this gap. Goal 4 encourages States to



ensure inclusive and qualitative education and promote lifelong learning opportunities for all (UN, SDG 2015).

Internationally, the United Nations pushes governments to enable all children to go to school. The instruments that the UN uses are the Human Rights Conventions, more specifically the Convention on the Right of the Child and the Convention on the Rights of Persons with Disabilities. For all conventions, there is a committee of international experts, which monitors the implementation of the conventions by the states parties. States parties that ratified the conventions are obliged to send regular state reports to the committees the activities under the Convention in the country and how the rights are implemented. The committees replies then with a list of issues towards the states parties with concerns and recommendations. This gives the states parties a chance to specify how rights are implemented. Finally, the committee sends its 'concluding observations' (OHCHR n.d.). In this research these concluding observations according to the policies and laws of Uganda, are presented below. It is important to state that there are no formal consequences of these concluding observations. It is an instrument that can be seen as a guideline for state parties.

### **Inclusive education**

Inclusion is in principle the opposite of exclusion, and concerns children 'having special needs' or disabilities in education. Inclusion is often misused or misunderstood, and should rather be seen as a principle that aims to remove barriers to learning. There are two commonly accepted interpretations of 'inclusion': 1) Inclusion as physically being in the same place and doing the same things as other students and 2) inclusion as social acceptance and belonging. An individual has the right to participate and right to respect, but inclusion implies that an individual has the right to relevant learning. If we place the right to individual relevant learning is above the right to participation, this might imply that educational arrangement is different depending on culture and context and depending on individual needs (Norwich cited in Savolainen and Alasuutari 2000, 12). Some argue that inclusion is an 'unending set of processes' because inclusive schools that include all children of the neighbourhood are rarely found. 'Inclusion' is a term that involves complex values and their applicability is uncertain. Booth (cited in Savolainen and Alasuutari 2000, 12) states about inclusion that it is '*a proces of increasing participation and reducing exclusion*'. The shift from 'special needs education' to 'inclusive eductaion' is characterised by the focus of the adaptation of the individual student to fit into the school system, towards the school system to adapt to all individual learning needs

of the child and the effort on planning how schools can effectively reach out to all children (Savolainen and Alasuutari 2000, 12-13).

The debate on inclusion in education has shown arguments for and against inclusion. Some studies show that many teachers do not see inclusive education working. Teacher's opinion of inclusive education strongly depends on the experiences in the classroom with learners with special educational needs. Some studies show that the negative attitude of teachers and adults are a major barrier to education. An OECD study in eight countries shows that difficulties in realising inclusive education is that parents of CwDs want their child to be taught in different classes. The same study shows that children that are emotionally or socially challenged, can be seen as a threat to others in schools, which leads to safety issues. Another barrier is the wish of the CwDs to study together with children with the same or similar disabilities, at least part of the school day. However, the OECD study included western and northern countries, and may not be representative world-wide (Savolainen and Alasuutari 2000, 13-14).

### **Universal Primary Education in Africa**

Originally, in east-African countries, special schools were established by missionaries in the 1950s, which were in the 1960s developed towards more western teaching methods. These schools relied strongly on western donors and charity organisations. Due to limited space for learners, some of these donors and organisations pushed towards special classes in regular schools in the 1980s (Kristensen, Omagor-Loican and Onen 2003, 194).

A large increase in school enrolment has happened in Sub-Saharan African (SSA) countries since Universal Primary Education (UPE) was implemented. Studies show a large increase of the school attendance and a decrease in gender, income and region inequalities. The effect of girls' school enrolment was larger than others, especially in poor households (Lamichhane and Tsujimoto 2017, 4). Few studies focus on the school enrolment of CwDs. Regardless of the government's efforts of providing quality education for marginalised groups, the CwDs are left behind. In the literature, it is unclear if the low school attendance of CwDs is due to financial restrictions or institutional or environmental barriers. Lamichhane and Tsujimoto (2017, 5-7) suggest that the low enrolment rate of CwDs is due to the initial plan of the government to give every family the opportunity to send four children to school for free, and this resulted in parents not prioritising the CwDs. Similarly, the parents' contribution of uniforms, meals and books is suggested to be a barrier. Finally, it is stated that parents of CwDs are more likely to face

difficulties with sending CwDs to school and due to extra expenses they might fall in the poverty trap and are thus less likely to see the benefit of education for CwDs.

## **Uganda**

At the beginning of the 1990s, the national government of Uganda established a special educational needs programme in Uganda, with financial and technical help from the Danish International Development Agency (Kristensen, Omagor-Loican and Onen 2003, 194). The Government White Paper on Education was the framework of the Education and Sports Sector to reform education. This document sought “(...) *to contribute to the building of an integrated, self-sustaining and independent national economy*” (ESSP 2008, 11). In the current educational system, children spend two years in pre-primary education, followed by seven years of primary education. Children can continue four years at ordinary level secondary education and two years at advanced level secondary education. All levels are examined through national examinations (UBOS 2014a, 4).

## **Constitution of Uganda**

In 1995, the Constitution of Uganda was a legal framework to protect and promote the rights of people with disabilities in the following ways: Article 21 forbids discrimination, specifically against people with disabilities. Article 30 states that ‘All persons have a right to education’ and Article 34 concerns the rights of children, and states that a child is entitled to basic education, which is the responsibility of the state and the parents of the child. Article 35 concerns the rights of persons with disabilities and mentions that the state and society shall take appropriate measures to ensure the human dignity of persons with disabilities. Through laws, the parliament shall protect persons with disabilities (The Constitution of the Republic of Uganda 1995).

## **Universal Primary Education in Uganda**

The Universal Primary Education Program (UPE), was implemented in 1997 by Mr. Yoweri Kaguta Museveni, President of the Republic of Uganda and aimed to provide free primary education for four children per family. According to Kristensen, Omagor-Loican and Onen (2003, 195) there was given priority to the girl child and the disabled child. Since 2002, all children are offered free primary education. Primary education was not made compulsory and strictly speaking, neither entirely free. Parents are expected to contribute for pens, exercise books, school uniforms and even bricks and labour for classroom construction (ODI 2006, 1).

UPE increased the number of children in primary education significantly. Until the mid-90's, almost one out of three children were out of school in Uganda (Watkins 2000, 298). Between 1996 and 1998 the number of children in education almost doubled and there was an increase of more than two million additional children in the primary education system. The last housing census of 2014 shows that approximately 87% of children of primary school going age (6-12 years) attended school. It shows that 1 out of 10 children in Uganda of school going age, had never been to school (UBOS 2014a, 24-25).

Literature on the effects of abolishing the school fees is not widely existing and outcomes of the policy implementation are mainly measured in enrolment rates. A study shows that the impact of lifting primary school fees is large: a 60% increase over the time period 1992 to 1999-2000 appeared (Deininger cited in Kan and Klasen 2018, 4). However, there was still a financial barrier, especially for orphaned children. The same study found that the distance to school is an additional barrier to enrolment (Lastly cited in Kan and Klasen 2018, 5)

The elimination of school fees happened before improvements were made in infrastructure in the school system. The commodities available per pupil decreased and the pupil-teacher ratio increased. Under-investment in education in the decades before UPE resulted in failure to achieve quality improvements. Consequences were several problems in education in Uganda. Firstly overcrowded classrooms were a problem and the teacher-training program was not adapted to the increased need of teachers. On average the pupil-teacher ratio was 110:1. A pupil-teacher ratio of 40:1 is required for quality education, so state international regulations. Similarly, the construction of schools is a problem. There were no extra classrooms build or classrooms were not rebuilt after UPE implementation. The student per desk ratio was 3:1 in 2003. Another problem is the shortage of textbooks and the student per textbook ratio was 1:4 in 2003. The government aimed for a textbook per child, but due to the high costs of the books (\$4) financing this was unrealistic for poor families. (Watkins 2000, 300). The government aimed to overcome the problems in education and approved an Education Sector Investment Plan one year after the UPE implementation. (Grogan 2008, 187-188).

### **Children's Act**

In 1997 the Uganda Children's Act was implemented. This document states that all children have the right to live with a parent or guardian. The parent/ guardian has the duty to provide

the child with: education and guidance; immunisation; adequate diet; clothing; shelter; and medical attention. The children's act, section 9 states that parents and the state shall take appropriate steps to see that CwDs are assessed as early as possible, the amendment of 2016 mentions that this is to be done with the help of medical staff. The 1997 act states that CwDs shall be offered appropriate treatment, the amendment of 2016 states that the government shall provide facilities that are needed to address the needs of the child. Facilities for rehabilitation and equal opportunities in education shall be afforded and the amendment of 2016 states that education shall be suitable to address their disabilities or special needs. The amendment of 2016 states that a CwDs or Special Needs Children are not to be discriminated against or on account of their disability or special needs. The punishment of 5 years imprisonment and the financial penalty is mentioned. The board shall give first priority in funding and implementation of programmes for children with special needs and shall not divert funds for such programmes. The amendment act does not specify what is meant by 'appropriate steps' or who is responsible to carry out the 'appropriate steps' (The Children Act 1997, The Children (Amendment) Act 2016).

### **Persons with Disability Act**

The act aims to promote dignity and opportunities for People with disabilities (PwDs), and to develop and promote their participation in society. Moreover, it encourages government bodies and people of the community to recognise, respect and accept PwDs. All forms of discrimination against PwDs are to be eliminated and the attitude towards PwDs is to be promoted. PwDs are to be seen as capable and contributing members of society, sharing the same rights and freedoms as others. In section 5, the rights to education are clarified and how governments are to promote the enrolment of CwDs, with providing special annexes and inclusive education. The teacher training curricula are to be more focused on the individual learning needs. Special Education Teachers are to be enrolled in all schools. A percentage of 10% or more is to be budgeted at all levels for educational expenditure for the educational needs of persons with disabilities. Section 6 prohibits discrimination from educational services, explaining all forms of discrimination. Section 20 describes the duty to provide access to buildings, including building accessibility with ramps or elevators for people with mobility problems, specifically entrances and bathrooms. Section 21 points out the access to information: responsible governments have the duty to promote the right of people with disabilities access to information. Public information is to be provided in braille/ sign language and with sub-titles in the case of TV and phone companies shall provide special telephone

devices for the hearing-impaired. Section 28 shows the right to access supportive service and mentions that the government shall provide supportive social services to persons with disabilities (Persons with Disabilities Act 2006).

### **The National Policy on Disability**

The National Policy on Disabilities of 2006 describes how the persons with disabilities act is to be implemented. The policy recognises that PwDs are negatively affected by the design of infrastructure and other facilities, which results in barriers to access and utilisation of facilities and services. Through policies user-friendly facilities and infrastructure designs for the benefit of PwDs shall be designed by the government with the following interventions: laws and by-laws shall be put in place to promote user friendly facilities and infrastructure for benefit of PwDs; Sign language, braille and tactile shall be promoted among parents, service providers and communities; Accessibility shall be promoted in media campaigns and assistive devices; Services for PwDs shall be promoted; Building alliances shall focus on information, communication and technology for PwDs. The policy states that communities discriminate against and marginalize PwDs, because of negative beliefs, norms and customs. Limited understanding by the community about the causes of disability and on the rights, potentials and abilities of PwDs are a cause of this problem. The interventions of the policy are: To promote and strengthen awareness creation programmes on disability at all levels; To design and develop appropriate interventions by stakeholders at all levels; To promote theatre in development; To lobbying for the mainstreaming of disability concerns in sectoral programmes; Publicity through the media such as radio, TV, Newspapers, brochures and posters. This document contains 26 pages and lacks specific description of duty bearers. Although the government is often mentioned to be responsible, it is not clear which department (National Policy on Disability 2006).

### **National Orphans and Other Vulnerable Children Policy**

The National Orphans and Other Vulnerable Children Policy of 2004 aims to develop and realise the rights of orphans and other vulnerable children. The target groups of the policy are: Orphans and orphan households; Children affected by armed conflict; Children abused or neglected; Children in conflict with the law; Children affected by HIV/AIDS or other diseases; Children in need of alternative family care; Children affected by disability; Children in 'hard-to-reach' area; Children living under the worst forms of labour and Children living on the streets. (OVC policy 2004, 11) The policy states that education is an important requirement for

the development of the child. It mentions that many of the targeted groups in this policy are out of school and the ones that are in school are not attending class regularly. Interventions will include: *'Promoting access to education and retention of orphans and other vulnerable children in school; and improving the functional adult literacy and numeracy of care-givers.'* (OVC policy 2004, 10). In this policy, disability is defined as *'A substantial functional limitation of daily life activities of an individual caused by physical, sensory or mental impairment and environmental barriers.'* (OVC policy 2004, 14)

### **Equal opportunities act**

In 2007 the government of Uganda implements the 'Equal opportunities act' aiming to eliminate *'[...] discrimination and inequalities against any individual or group of persons on the ground of sex, age, race, colour, ethnic origin, tribe, birth, creed or religion, health status, social or economic standing, political opinion or disability[...]'* (Equal Opportunities Act 2007). With discrimination is meant any act that directly or indirectly marginalise or unequally treats persons and limits them in their enjoyment of rights. The act explains the responsibilities and duties of the different bodies that are involved. The act does not define disability.

### **Definition of children with disabilities**

Convention on the Rights of Persons with Disabilities (CRPD) gives a definition of 'Persons with Disabilities' in Article 1: *'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'* (CRPD 2006, Article 1).

The initial Children act of 1997 does not give a definition of CwDs. In the amendments of 2016 the term 'Children with Special Needs' is added to the term 'Children with Disabilities'. *'Children with special needs' means children who have long term physical, mental, intellectual or sensory impairments which may hinder their full and effective participation in society on an equal basis with others.'* (Children Amendment Act 2016). In comparison to the CRPD definition, we see that the Children Act does not mention the interaction of impairments with various barriers.

The People with Disabilities Act of 2006 defines 'disability' and 'a person with a disability'.

- *'Disability' means a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environment barriers resulting in limited participation'.*
- *"Person with disability" means a person having physical, intellectual, sensory or mental impairment which substantially limits one or more of the major life activities of that person'.* (Persons with Disabilities Act 2006, 4).

Within these two definitions there is a discrepancy: a 'person with a disability' definition includes intellectual impairments, where the 'disability' definition does not. Compared to the CRPD definition, lack to mention 'on equal basis with others'.

The National Policy on Disability defines disability as: *'permanent and substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation'* (National Policy on Disability 2006, 1). Though the policy is published in the same year as the act, 'disability' is slightly different described than in the act: the definition says in the policy that it is a 'permanent and substantial functional limitation', in the act is says 'substantial functional limitation'. Compared to the CRPD definition, 'intellectual impairment' and 'on equal basis with others' is not mentioned.

The policy focusses on the following disabilities: *I; Difficulty in hearing; II; Difficulty in speaking and conveying messages; III; Difficulty in moving around and using body parts; IV; Difficulty in seeing; V; Strange behaviour; VI; Epilepsy; VII; Difficulty in learning; VIII; Leprosy; IX; Loss of feeling; X; Multiple disabilities (A combination of any of the above disabilities)* (National Policy on Disability 2006, 1-2). The choice of these 10 categories is noteworthy. They aimed to be in line with the four categories that the CRPD mentions, where category 1-4 apply to physical impairments, category 5-6 to mental impairments, category 7 to intellectual impairment and category 8-9 to sensory impairments. Especially 5: strange behaviour is negatively formulated.

In the OVC-policy, disability is defined as: *'Substantial functional limitation of daily life activities of an individual caused by physical, sensory or mental impairment and environmental barriers.'* (OVC policy 2004, 14). In comparison to the CRPD definition, the 'intellectual impairment' is not mentioned, and the equal basis with others is not mentioned.



In the four definitions of different acts and policies that were presented, the definitions vary between each other, and none of them is completely in line with the CRPD definition. In three acts the ‘intellectual impairment’ is not mentioned in the definition. Additionally, ‘on equal basis with others’ is missing in three out of the four definitions. The ‘equal opportunities act’ which aims for equality of people with disabilities, does not give a definition of disability. Another notable difference between the CRPD definition and the Ugandan acts, is that the CRPD mentions ‘*barriers may hinder their full and effective participation in society*’ whereas the Ugandan framework speaks of ‘*[...] Substantial functional limitation of daily life activities*’ (OVC), ‘*[...] permanent and substantial functional limitation of daily life activities*’ (National policy on Disability) and ‘*[...] Substantially limits one or more of the major life activities of that person*’ (PwDs Act).

Summarising; the Ugandan framework looks how the impairment limits participation, whereas the CRPD focuses on the hinder of the participation because of the barriers in the environment. The Ugandan definitions do not apply to the social model of disability. In the social model of disability the society’s adaptation to the impairment, rather than the impairment of the person is in focus.

### **Measuring Disability**

In the Kabarole district housing census of 2014, four questions concerned ‘functional disability’. People were considered disabled if he or she had to cross off one of the four functional difficulties. The functional difficulties that were assessed were ‘difficulties hearing, even if the person is using a hearing aid’, ‘difficulty seeing, even if the person is using glasses’, ‘difficulty walking or climbing steps’ and ‘difficulty in remembering or concentrating’ (UBOS 2014b, 4-62). In Kabarole district, taking this definition of ‘disability’ 4.4% of persons between 2 and 17 years have some kind of disability (UBOS 2014b, 23). This is in line with the Washington Group set of questions that were recommended by the OECD for developing countries, to map disability (Madans, Loeb and Altman 2011).

### **Special Needs Education and Inclusive Education**

The structure of special needs education at the national level is organised through the Ministry of Education and Sports (MoES) and technical, administrative and leadership is provided by the commissioner of special needs education.

The mission and vision of the MoES are presented on the website of the ministry. The mission of the MoES is: *'to provide for, support, guide, coordinate, regulate and promote quality education and sports to all persons in Uganda for national integration, individual and national development'* and the vision of the MoES is: *'Quality and appropriate Education and Sports services, for all'* (MoES, MoES n.d.). The MoES has a Special Needs and Inclusive Education Department, which has the general objective to *'deliver special needs & inclusive education services in a coordinated and adequately resourced manner.'* And four specific objectives:

1. *Increased enrolment, participation and completion of schooling by persons with special learning needs.*
2. *Strengthen and systematize existing initiatives/programs on SN&IE.*
3. *Enhance participation of stakeholders in the management and implementation of SN&IE programs in Uganda.*
4. *Promote sporting programs for learners with special learning needs.*

(MoES n.d.)

On district level the District Education Officer is responsible for CwDs and learners with special educational needs, and many districts have an SNE officer (Kristensen, Omagor-Loican and Onen 2003, 195).

According to the national government currently two types of education are provided for CwDs. (MoES n.d.). Traditionally, some schools provide Special Needs Education (SN) in the form of an annex integrated in a regular school. Here children with special learning needs are supported with special services like sign language interpreters or braille transcribers. Special teaching methods are used and access to special resource rooms provided (MoES n.d.). Currently, the Inclusive Education approach aims to integrate children with learning difficulties in regular classes. It meets the individual learning needs of each student and is learner centred and flexible. Special teaching methods are used with special learning resources. Factors that form barriers to children's participation in learning, are taken into consideration. IE extends the opportunity for all children to *'play, learn, experience the feeling of belonging and develop in accordance with their potentials and difficulties; thereby obtaining good quality of life within their respective environments.'* (MoES n.d.).

Between 2007 and 2011, a draft Policy Special Needs Education (SNE) and Inclusive Education (IE) was developed with USAID Uganda and MoES. This policy is in line with the

Salamanca Statement and Framework for Action on Special Needs Education (1994). It mentions that this policy is in consonance with the constitution of 1995, the ‘Persons with Disabilities Act’ of 2006 and the ratification of the convention of the Rights of Persons with Disabilities in 2008 (MoES n.d.). More than 900 teachers were educated in special skills e.g. dyslexia, sign language, braille reading and writing, deaf blindness and specialised guidance and counselling (Riche and Anyimuzala 2014, 17). Between 2011 and 2015, the program “Accessible and Inclusive Education for CwDs” was carried out mainly by the MoES and UNICEF Uganda. The aim of this program was to reduce inaccessibility of school facilities and develop the Inclusive Education approach in schools (Riche and Anyimuzala 2014, 6).

### **Kabarole 5 year development plan**

In the Kabarole District five year development plan 2011/12-2015/16 the vision is: ‘*A beautiful district with prosperous and harmonious people*’. The intents of the plan are: ‘*to improve the people’s standards of living through efficient and effective delivery of services.*’ And the mission of the plan is: ‘*To achieve sustainable socio-economic development through efficient provision of quality services to the people in conformity with national policies and local priorities*’. The education related objective is: ‘*To increase the levels of education and literacy in the District*’ (Kabarole District Local Government Five Year Development Plan 2011/2012-2015/2016 2010, 9-10).

In the Kabarole district, the pupil - teacher ratio is 51:1, the pupil - classroom ratio is 93:1 and the pupil - textbook ratio is 3:1 (Kabarole District Local Government Five Year Development Plan 2011/2012-2015/2016 2010, 19). The government aided schools receive UPE funding, classroom construction and latrine construction and receive support from: ‘NGOs and International Agencies e.g. UNICEF, Save the Children in Uganda which have been providing training to teachers, head teachers and School Management Committees and Parents – Teachers Association (PTAs)’ (Kabarole District Local Government Five Year Development Plan 2011/2012-2015/2016 2010, 59). All primary schools have been inspected. The conclusion of the inspection is that ‘*teaching is going on*’. Teachers in underperforming primary schools have been trained. Teachers from grade 1 to 3 have been trained in Thematic Curriculum, grade 4 to 6 teachers have been trained in implementing new curriculum and 7<sup>th</sup> grade teachers have been trained in Mathematics, Science, SST and English teaching (ibid).

The constraints in primary schools are presented: *'Understaffing in many schools; Over-enrolment in many schools, and hence congestion in classrooms; Lack of safe water; Lack of enough latrines to meet the enrolment needs; Rural schools become inaccessible during rainy seasons due to poor roads; Rampant absenteeism of both teachers and pupils; Insufficient scholastic materials in schools; Low levels of professionalism among teachers do not fulfil some of the fundamental professional obligations like preparing to teach, marking children's books, assessment of learners, making and using instructional materials.'* (ibid)

The Kabarole district 5 years development plan shows that special need education is provided in two schools, however it mentions school B and school C and not school A (Kabarole District Local Government Five Year Development Plan 2011/2012-2015/2016 2010, 37-38). School C is privately funded and has no financial involvement from the government, which is stated by the HM of School C in the interview. That school A is not mentioned in the plan could be a result of a lack of adequate mapping of special need schools. Education statistics of the Kabarole district development plan present in that there are 124 government aided primary schools (Kabarole District Local Government Five Year Development Plan 2011/2012-2015/2016 2010, 59). The statistics show that there are 1,532 children with special needs of various categories such as physical, visual hearing and multiple impairments and autism of which 270 are enrolled in education (Kabarole District Local Government Five Year Development Plan 2011/2012-2015/2016 2010, 19, 60).

### **Critiques**

The UN Committee on the rights of persons with disabilities (CRPD), UNICEF and NUDIPU wrote critical reports on the legal framework of the Ugandan government. They will be shortly presented here.

UNICEF's situational report of 2014, states that there is no consistent and clear definition of disability in the regulatory framework. The definition varies between laws, acts and policies. The report states that there is a discrepancy between the CRPD definition of persons with disabilities and the Ugandan People with Disabilities (PwDs) Act. The PwDs does not mention the 'intellectual impairments' and does not mention the interaction of the impairment with the environment. This causes barriers for people with disabilities to have effective participation in society. The PwDs Act does not mention that participation has to be equal with others. The PwDs Act focusses on individuals' limitation of functioning and although they are mentioned,

the main focus does not lie on the environmental barriers that the person faces. The PwDs Act mentions the ‘substantial functional limitation’, however, it does not specify what this means. Another critique of UNICEF is that the attitudes of the social environment are not recognised in the definitions as a barrier. Therefore, the Ugandan definition of the PwDs Act is criticised for not fully applying to the social model of disability, and yet has to adopt the rights based social model of disability in the legal framework. Additionally, the report expresses that it is unclear who are actually responsible for the realisation of the rights of CwDs. The Children Act states that ‘parents of CwDs and the state’ are responsible, however it does not clarify which government body is responsible and how they are to carry out their duties. The report criticises that this hinders the accountability of the duty bearers and also hinders the *‘drafting and implementation of measures that will support the realisation of the rights of CwDs in Uganda’* (Riche and Anyimuzala 2014, 70-71).

In 2016 the UN sent the State party of Uganda the report of Concluding Observations. The Committee expressed the following issues: The current provision of segregated education has to be transferred into an inclusive education system. With the current system, the schools are not able to meet the needs of learners with disabilities. In addition to that, there are no reliable statistical data on CwDs and there is a lack of trained teachers to adequately teach the CwDs (CRPD 2016, 10). The Committee expressed its concerns about the stigmatisation of Persons with Disabilities (PwDs) specifically about those people with psychosocial and/or intellectual disabilities, persons with albinism and deaf-blind persons. This limits their access to education among other public services (CRPD 2016, 3-4). The access to transportation is seen as a challenge for PwDs by the Committee, and related to this, the implementation of the policies in the transport sector. Furthermore, there are concerns about the accessibility to information in an adjusted format for PwDs, meaning braille or sign-language or easy readable for persons with intellectual or psychosocial disabilities. The committee is concerned about low-cost information and communications technologies for persons with disabilities (CRPD 2016, 4).

The UN- CRPD Concluding Observations, recommends the Ugandan state parties to: *‘Harmonise definitions of disability in various laws and policies and systematically review all legislation and bring it into line with the Convention’* (CRPD 2016, 2).

1Similarly, the NUDIPU criticises definitions. NUDIPU is an umbrella NGO that brings together various categories of persons with disabilities, including those with physical, mental

and sensory impairments (NUDIPU, About us 2018). It states in its shadow report that the definitions of disability vary in different laws. Definitions focus on the substantial functional limitation of the individual and *'puts emphasis on the person with the disability rather than the social and environmental barriers which may hinder their full and effective participation in everyday life.'* It states that people with disabilities are hindered by the lack of clarity from accessing government services and programmes. It recommends the parliament to revise the definition of disability and be constant in the appliance of the definition in the legal framework. The definition should be in accordance with Article 1 of the CRPD and a social model and rights based definition is to be adopted (NUDIPU 2014, 6).

## 5. PERSONAL CHARACTERISTICS

The following three chapters present the findings of the study and are divided in personal characteristics, commodities and environment, according to Mitra's application of the capability approach to disability. Mitra (2006, 236) states that the capability framework '*helps to explain how disability may result from three types of factors: the individual's personal characteristics (e.g., impairment, age, race, gender), the individual's resources, the individual's environment (physical, social, economic, political).*' She explains that the actual disability depends on whether the impairment restricts the individual in achieving its functioning. This chapter concerns the second sub-question: 'How is 'disability' conceptualised in the educational context through the lens of the capability approach in Kabarole district?' To answer this question the definition of CwDs in education is explored in the interviews with teachers and the HMs.

### Age

The students in the schools that are included in this research, are between the age of 4 and 19. In school A 981 students are in primary school and 26 children in nursery school and in the registration book, I found that there are officially 40 children in the special needs class, 25 male and 15 female In School B there are around 400 children of which approximately 110 of them are CwDs / children with special needs. This term will be further explored later. The official primary starting age in Uganda is 6, but in the first grade children are found between the age of 4 and 12. In this research it shows that in the first grade children are between 6 and 15 years old as two teachers state in their interviews. The age distribution enlarges when at the higher grades and is at its major at the 7<sup>th</sup> grade where learners are between 10 and 20 years of age. The majority of students in primary education is between 15 and 20 years (Kan and Klasen 2018, 3-4). A study of Essama-Nssah et al. (cited in Kan and Klasen 2018, 5) shows that the UPE policy influenced the age-appropriate entry positively.

### Children with disabilities/ Special Needs Children

As presented in the previous chapter, the definition of CwDs is not consistent and is unclear in different legal documents. The term 'Children with disabilities' is in the Children's Act got an amendment in 2016 to add 'Special Needs Children'. The phenomenon of 'Special Needs Children' also appeared in the findings of this research. SNE teachers and teachers assigned for the general school population, were asked in the interviews if they have 'Children with Disabilities' (CwDs) in their class. All teachers came up with examples and the answers varied

largely. During the first and second interview, I found out that ‘Special Needs Children’ is a more utilised term in schools. Therefore, I asked in the following interviews: ‘Do you have CwDs or special needs children in your class?’. It was hence more accurate to mention both.

### **Impairments**

With asking this question, an interesting twist occurred: Special Needs Children is an umbrella term for a very large group of children with many different characteristics. Teachers gave examples of children with physical problems: ‘hearing/speaking problems’, ‘sight problems’, other ‘physical problems’ were mentioned e.g. ‘lameness’ or ‘missing an body part (arm or leg)’.

Another category of CwDs were the ones with mental problems. Examples of these were ‘mentally disturbed’, ‘autism’, ‘a problem with the brain’ or ‘mentally retarded’. In the special needs class there are 26 children that are registered with ‘mental retardation’. This term drew my attention, because of the stigmatising character of the word ‘retardation’. Increasingly, the word ‘mental retardation’ has been replaced by ‘intellectual disability’, however it covers the same group of people (Schalock, et al. 2007, 116). The term used for this impairment, has been through many different changes in the last 200 years: ‘*idiocy*’, ‘*feble-mindedness*’, ‘*mental deficiency*’, ‘*mental disability*’, ‘*mental handicap*’, and ‘*mental sub normality*’. The reason for the recent changes is that the term ‘mental retardation’ results often in devaluation of people with this disability and does not reflect respect and dignity. The current used term of ‘intellectual disability’ is in line with the WHO’s focus on behavioural and contextual factors that influence the person’s functioning as was presented in the theoretical framework. It is seen as a less offensive term towards people with the disability and more in line with the international terminology. Finally, it is a consistent term for individual support in the social-ecological framework (Schalock, et al. 2007, 120). The negative labelling is further explored in the chapter environment, explaining how the social barriers play a role in disability.

### **Orphaned children**

When asked about ‘CwDs / special needs children’, teachers gave examples of children that are orphaned. Teachers, as well as the national housing census differentiate between ‘single orphaned children’ that lost one parent, or ‘double orphaned children’ that lost both parents. In the special needs class this is registered in the book: there are six children that lost one parent and one that lost both. A large problem for orphaned children is nutrition. An example was



given by a teacher: a boy that lost his parents at a young age, started stealing food of other children at the school and was banned from school for being a thief.

The national housing census report of UBOS 2014 shows that between 2002 and 2014 the trend level of orphan hood has declined from 13% to 8% respectively (UBOS 2014a, 21-22). A small calculation shows the following: the total population of Uganda is 34.6 million persons in 2014. Of these, nationally 55.1% Ugandans are between the age of 0 and 17 which is 19 million. Of the children in Uganda 8% lost one or both parents, which is little over 1.5 million children (UBOS 2014a, 8-14-21).

### **Ill health**

Children with 'ill health' were categorised as CwDs or 'Special Needs Children'. This means that a child is often sick and its absenteeism rate is high. Diseases that often affect the children are measles, malaria and HIV/AIDS. One teacher mentioned that the medication for HIV/AIDS makes them sick. HIV itself is an immune system disease, which makes the impact of diseases for HIV children extra strong. In the interview with a teacher from the first grade, appeared that 7 children of 90 have HIV/AIDS in the class. In Uganda, a number of 1.4 million adults and children were living with HIV/AIDS according to UNAIDS report 2016. (UNAIDS 2016, 1). The housing census does not assess the number of people with HIV/AIDS. Therefore, we must rely on other sources that do not specifically count for the Kabarole district and not specifically for children.

Half of children are orphaned because of HIV/AIDS. The HIV/AIDS pandemic had its highest rates in the 90's when around 15% of adults had HIV/AIDS. In 2001, the prevalence was down to 6% because of effective government campaigns. However, rates went up in 2004 to 6.1% and in 2006 to 6.4% of the population (Dalen, Nakitende and Musisi 2009, 2).

### **Children from low-income households**

Many teachers gave examples of children from low income families, in Uganda defined as children missing the basic needs. How poverty effects children's daily life will be explored further in the chapter 'commodities'.

Some teachers mentioned that disabilities might appear due to malnutrition. Other disabilities may appear due to heavy lifting when children are young. Some children have to carry jerrycans

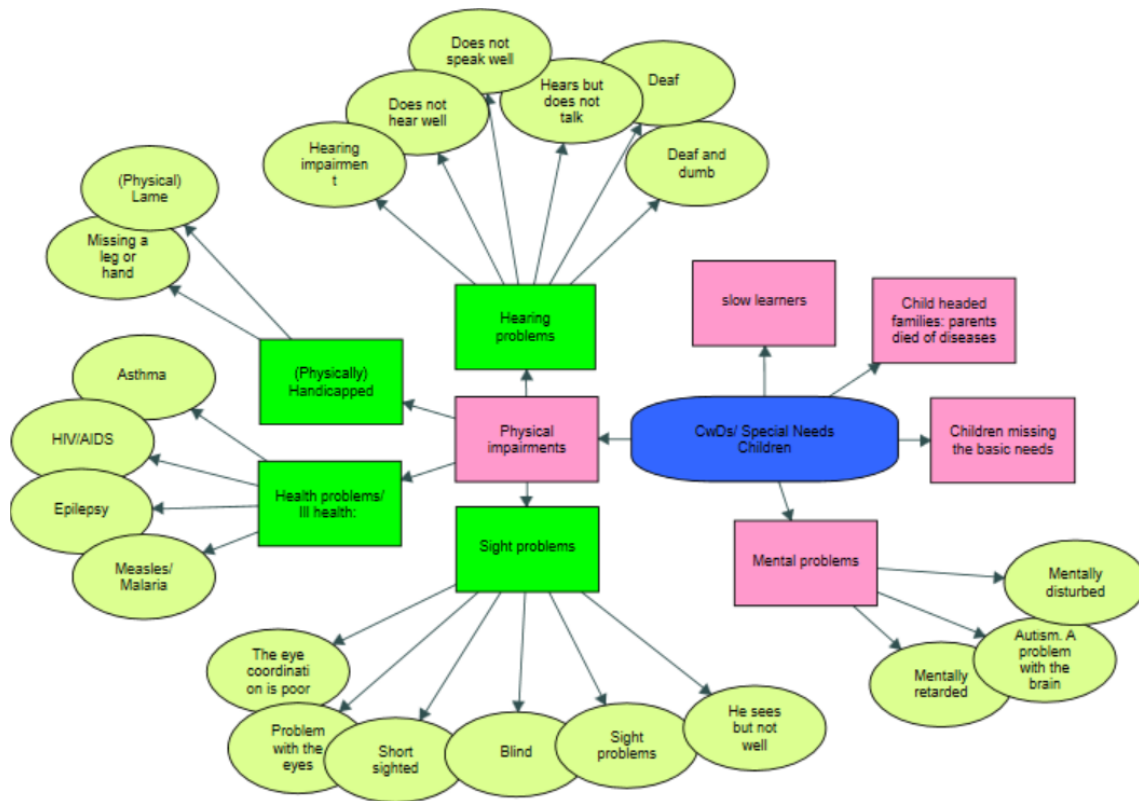
of water or firewood from far. This can damage their spine or chest. Correspondingly the way to get water or firewood can be hazardous due to the slippery slopes in the rain season. A teacher in school A expresses this problem in the interview: *‘Nothing to do, water is very far. And the families [...] they cannot manage to buy. For us, we don’t have the national water, the water that comes from the pipes. But the children have to fetch water at the well. Some wells are very far. I don’t know, on slopes, it sometimes has to go down to get the water from the well. So they end up spoiling their spines and now they are disabled. [...]. It is there, and very many. And for others it is their chest that is damaged. Carrying firewood. From far. So they do a lot of work here.’* (Teacher 5 School A).

### **Slow learners**

There was a last and even more complex group that is defined as CwDs or ‘Special Needs Children’ are called the ‘Slow Learners’, which was often mentioned in the interviews. I asked as a follow up question: ‘Why they are slow learners?’ and the answers were very diverse. Answers included: ‘bad sight’, ‘physical lame’, ‘do not fully attend’, ‘they don’t have parents’, ‘the children with HIV’, ‘neglected children’, ‘children that suffer from malaria or measles’, or ‘intellectually challenged children’. One teacher states that of every 10 children, about 3 or 4 are ‘slow learners’. The same teacher explains that it is just a matter of different levels in the class and that every child goes through different phases. Summarising the group of slow learners brings together all the previous mentioned groups of ‘children with disabilities’ or ‘special needs children’. It can be any child that does not optimally perform in school due to individual or environmental reasons. The complexity of the definition, reflects the complexity of the problems of these children. They are interrelated and often occur together or as a result of one another.

In the figure below is shown how the CwDs/ special needs children are categorised, with examples from the interviews:

Figure 6 Disability in the educational context



The concept ‘CwDs’ or ‘Special Needs Children’ according to the interviews is presented in the figure. The pink squares show the five main categories that were found and the green squares present the sub-categories of the physical impairments that were found. The different categories are illustrated with the light green circles attached according to the categories.

Answering the question ‘how is ‘disability’ conceptualised in the educational context’ appeared to be multifaceted. Causes for disability appear to be interrelated: often the HIV pandemic leads to orphans and orphans find difficulties financing their basic needs, like food and clothing. Orphans rely on the family or the community to cover their basic needs and their education. When nutrition is a problem, children have difficulty concentrating in school, which makes them slow learners.

## 6. COMMODITIES

Traditional economic utility approaches consider a person with more commodities better off and does not concern disabilities of a person. Sen (cited in Mitra 2006, 240) agrees with this and mentions that due to the larger basket of primary goods a disabled person has a higher chance of living a 'normal' life compared to a non-disabled person with a smaller basket of primary goods. The capability approach can be used to analyse how the individual uses the individual goods and how choices are made to achieve a functioning. For participation in education, children need certain commodities, and this chapter presents the (in) availabilities of different commodities. The aim of this chapter is to find answers to the question: 'How does the (in) availability of commodities affect the participation of children with disabilities in primary education in Kabarole district?'.

The previous chapter shows that 'children with disabilities/special needs children' are not only the ones with physical or mental impairments, it also includes the children from low income households and miss the basic needs, children with ill health and orphans. Children with physical impairments might need assistive devices and technology to function in the education system, as is pointed out by Mitra. The effects of (in)availability of these devices and technology will be explained. Then we will look into the role that poverty plays for children. As presented in the policy review, through UPE education is provided for free, however uniforms, pencils and exercise books are to be provided by the parents. Another expense that is needed for education is a contribution for PTA. Although it is a small contribution, it can be an economic barrier.

### **Assistive devices and technology**

Assistive devices and technology can help the individual to participate in society and function with the impairment. According to the WHO definition 'assistive devices and technology' have the purpose to maintain or improve an individual's functioning and independence to make participation easier and improve overall well-being. *'Examples of assistive devices and technologies include wheelchairs, prostheses, hearings aids, visual aids, and specialised computer software and hardware that increase mobility, hearing, vision, or communication capacities. In many low-income and middle-income countries, only 5-15% of people who require assistive devices and technologies have access to them.'* (WHO, Assistive devices and technologies n.d.). Access to education can be improved by providing assistive technology and is recognised in the CRPD as needed for full and equal enjoyment of human rights (Borg,

Lindström and Larsson 2009, 1863). In school A, few assistive devices and technology were present. There was one girl in a wheelchair and she had crutches. She got it from an American traveller, who donated the assistive devices. Other than that, no assistive technology was available in the school.

In the special needs class, a boy with bad vision participated. The size of the letters and numbers that he wrote were very large, and when he had to read something he looked as close as possible at the paper. He often he walked up to the blackboard to see what the teacher wrote and looked at a short distance at the words. The teachers told me that an NGO had once given him glasses and it helped. Unfortunately the glasses are now lost. I observed that in the school with over thousand students not one child had glasses. Children find ways to adapt to their visual impairment by sitting in front of the classroom, or keeping the paper close to their eyes to be able to read. To help the children with bad eyesight, teachers adapt seating for the children. *'[...] I can put the ones that are blind in the front, or the lame ones I can put them where they can write properly. Special pens we give them to them. The resources are not enough, but we try'* (Teacher 2 School A).

On the government's website, it shows that the special needs and Inclusive Education's objective is *'To deliver Special Needs & Inclusive Education services in a coordinated and adequately resourced manner.'* One of the department's responsibilities is *'Providing adequate special instructional materials and equipment.'* (MoES n.d.). The reality shows that there is a lack of resources, meaning that this is a shortcoming of the Special Needs and Inclusive Education Department.

### **Poverty**

As presented in the previous chapter, children living in poverty are defined as 'children missing the basic needs', which is food and clothing. According to the World Bank, people live in poverty when there is a lack of insufficiency of money to meet basic needs (food, clothing, shelter). Poverty is measured based on the monthly or annual expenditure of an individual. The so called 'poverty line' which is in 2011 set at \$1.90 per day (World Bank 2015). Poverty is described as much more than the lack of money. Moreover, deprivation of other important areas of wellbeing are considered such as education, health, water and housing. In Uganda, the population living under the national poverty line declined from 31.1% in 2006 to 19.7% in 2013 (World Bank 2016, 5).

One basic need measured in the National Housing Census of 2014 by the number of meals per day. It mentions: ‘On average more than half of the household members aged 5 years and above consumed 2 meals a day, about 35 percent had three meals, and only 12 percent had one meal a day’ (UBOS 2014a, 40). These numbers are very high, but compared to previous years a decline. In the Kabarole district specific report the percentage of household members of the age 5 years and above, 5.9% consumes less than 2 meals per day (UBOS 2014b, 44). In the report on Uganda’s Millennium Development Goals it is shown that malnutrition remains an important challenge (UNDP, Millennium Development Goals Report for Uganda 2015 2015, 15-16).

Other basic needs that were assessed in the national housing census were: soap for bathing, sugar and salt consumption, ownership of two sets of clothing, at least one pair of shoes and a blanket. These are shown in the table below.

*Figure 7 Households consuming basic needs by residence and sex of household head.*

	Sex of Household Head		Residence		
	Male	Female	Rural	Urban	National
Soap for Bathing by household members	95.3	93.1	93.9	97.5	94.7
Sugar consumption (at least once a day)	70.7	69.4	64.6	88.1	70.4
Salt Consumption	94.7	93.0	93.9	95.7	94.3
Ownership of at least two sets of clothing	88.1	87.0	85.3	95.9	87.9
Ownership of at least one pair of shoes	70.0	67.5	62.9	89.4	69.4
Ownership of a blanket (i.e. all those under 18 years)	54.5	58.0	50.1	73.3	55.4

(UBOS 2014a, 41).

As the table shows, many families lack basic needs. In the observations I see that there are children that always wear the same clothes or wear no shoes in school, or very old and broken shoes.

In the observations and interviews appeared that not all children get enough food to function in school. Especially the children that live in villages far away, come from poor families. Teachers explained that children that did not eat breakfast and come from far away, are often tired in class. When they come from far, they have to walk for more than an hour to school. Some children did not have food all day and are therefore not able to focus and feel tired. In the school, this is visible: many children look undernourished and some children were sleeping

on their benches. Teachers know which children receive little food at home, and sometimes they give them food or other children to give them something to eat. A teacher expresses problem this in the interview: *'Some parents, they cannot afford food, cannot afford a uniform, even they cannot afford PTA'* (Teacher 2).

### **Educational expenses**

Officially school fees were banned with the implementation of UPE, however parents pay a term fee towards the PTA. The fee differs per class and per school. The fee for the Special needs class at School A is 40.000 shilling per term (approximately 85 NOK). This is slightly higher than the fees for grade one to four, which is 35.000 shilling. For grade five to seven the fee is 65.000 shilling. In school B the PTA fee is lower: In the first and second grade, the PTA fee is 19.500 shilling, grade three to five is 23.500 shilling and grade six and seven is 32.500 shilling per term. In school B the fee for CwDs is according to their grade fee.

It is important to see the amount of PTA fee in the economic context of Uganda. In the mid-western region of Uganda, where the Kabarole district is, an average monthly income per household is 185,000 Ugandan Shilling (UBOS 2014c, 97). Considering the fact that a the fertility rate lies at 5.8 in the Kabarole district (UBOS 2014b, 4) and parents have to pay for an average of 5.8 children. Therefore, the PTA fee can be a burden, especially for poor families. Teachers often have to ask repeatedly for the PTA fee. Sometimes only a part is paid or nothing at all. The consequences of not paying the PTA fee is not specified in either of the interviews.

The boarding section is available for children that live far away. The fees for the boarding section are mostly paid by the parents. Both schools have a boarding section for special needs children and the term fee in school A is 300.000 shilling, which is about 650 NOK. The HM says about this: *[...], in this school, we have the boarding section for the special needs children. [Basically] it was started by the church to help the children to access school, to access education. Especially those from far-away places. We have the deaf children in the boarding section. Their parents also contribute money to their feeding for their welfare, [...]* (HM school A).

In some cases, foreign resources contribute the PTA fee or the boarding section fee. An American traveller pays the PTA fee for the child in the wheelchair and students from the UK sponsor a boy in School B for the boarding section.

In addition to the PTA fee, parents need to provide uniforms, pencils and exercise books. When children are very poor, teachers sometimes support children with mathematic set, pencils or exercise book and state that they sacrifice some of their own salary to support children. Some children are from poor families and do not have a uniform. In school A, this problem was visible; some children did not have a uniform and come to school in normal clothes or did not wear shoes. This is accepted but actually not allowed. Some children, especially in the special needs class, have old uniforms with holes in it or missing a sleeve. Other children only had a part of the uniform, and missed for example the jumper.

### **Orphaned children**

In Kabarole district, many children are orphaned as previously mentioned. Being an orphan brings other problems. These children are also categorised as ‘special needs children’ both in the policies and in the interviews. Orphaned children are often more affected by poverty, which is illustrated in the interview with a teacher in School A: *‘Were there any children with disabilities that dropped out of school that you know of? Teacher: Yeah, they do. Especially those ones who don’t have parents. So maybe children have been to school, then the parent dies and so he has not anybody to support their education, so he or she decides to leave the school.’* (Teacher 3 School A).

A study in the Rakai district of Uganda shows that child headed families often are concerned about their basic needs like food and shelter and shows that they enjoy going to school, but the inability of paying school fees often causes dropouts (Dalen, Nakitende and Musisi 2009, 3-4)

### **Insufficiency: desks and school materials**

In this school few books are available. Only in the 3<sup>rd</sup> and 1<sup>st</sup> grade about 50 books are available for English class, for approximately 90 children and there are not enough pencils for all of them. As presented in the policy analysis, due to UPE a problem occurred to provide sufficient textbooks and pencils. This appeared to be still a relevant problem in school A: the lack of school materials lead to less participation of especially the poorer children. A teacher in the first grade explained that there are children that repeated the first grade several times, because they did not have exercise books or pencils. At the beginning of the term, parents are asked to provide pencils and pens. Children bring them to school and the teachers keep control of them. The pencils are in a bucket in a locked cabinet in the classroom. However, teachers mention



that many pencils disappear. Children do not give the pencils back after using them. I could confirm this problem, both with pencils, erasers and sharpeners. In the local supermarket, I bought these materials several times. However, after giving them to the children, they disappeared in a day or two. It did not matter if I brought it again, the materials would disappear. There is often discussion between the students, because there are not enough pens for all students and they fight about them.

### **Commodities**

This chapter showed the answer on the question: ‘How does the (in) availability of commodities affect the participation of children with disabilities in primary education in Kabarole district?’. Children appear to miss commodities in all facets and the capability set varies enormously between the children. There are children that are hungry or tired, children that miss a uniform or school materials. Some children get help from peers, teachers, NGO’s or foreign resources. UPE gives the individual the opportunity to choose the option ‘education’. The child’s school attendance strongly depends on the child’s ability to find help and its capability to overcome the barriers.

## **7. ENVIRONMENT**

In this chapter the findings are presented for the question ‘How does the political, economic, physical and social/ cultural environment influence the participation of CwDs in primary education in Kabarole district?’. In the theoretical framework, it is shown that functioning is strongly related to environmental factors. The CRPD definition of disability, states that long term impairments in interaction with various barriers may hinder participation in society.

The environment chapter is divided into different facets of the environment. First the political influence education system and the education infrastructure are presented in the paragraph ‘political environment’. Then then economic environmental factors are presented, which is strongly related to the commodities presented in the previous chapter. Then the physical environment and finally the social environment are highlighted.

### **POLITICAL ENVIRONMENT**

To find out which stakeholders play a role at the local government level, both HM’s were asked about the stakeholders for education, specifically for CwDs. A further exploration on the role of the local government was done in an interview with the SNE officer of the Kabarole district.

The local governments play an important role in providing education for CwDs in the Kabarole district. The education officer is the head of the district’s department of education and everything connected to education is the responsibility of the education officer. There is also an education officer in charge of the municipality of Fort Portal.

There is a district inspection body for the municipality and one for the Kabarole district. The School Inspection analyses what the needs are of the school, through regular inspections. When I was present at the school, the inspection noticed that students were missing exercises. The reason for that was that children miss pencils and exercise books. This has to do with parents not being able to afford books and pencils, as presented in the chapter ‘Commodities’. Teachers mentioned to me that this might be a good outcome, so the government could possibly do something about it. However, as previously mentioned, the lack of provision of educational resources, which lays by the Special Needs Education and Inclusive Education department, is lacking.

The Headmaster of School B mentions that community leaders are stakeholders in case a child has dropped out of school. Schools can contact the community leader and ask what the reasons are for the absenteeism.

The HM mentioned the Centre Coordinating Tutor to play a significant role in the provision of education. The tutor supervises the school and makes a report on the situation of the children. The Centre Coordinating Tutor is in close cooperation with the teacher training college. The teachers have different types of education and they have different grades of certificates: some have a so called 'grade 3 certificate' others a 'grade 5', a 'diploma' or a 'bachelor degree'. Some teachers have done an additional workshop for special needs children. One SNE teacher did the Special Needs Education study at Kyambogo University. Special Needs Courses are not so widely available: there is the Kyambogo University in the capital, Kampala. There are small courses in the Kabarole district. These focus for example for basic sign language skills or braille.

The last stakeholder that was mentioned by the HMs to play a role is the SNE officer. She is in charge of all matters concerning special needs education, both in the district and the municipality. The SNE officer monitors and supervises quality education for children with special needs. The role of the SNE officer is to look at the needs of the children and the needs of the teachers. In the interview with the SNE officer, she described her tasks: the coordination of schools and the education activity of children with learning disabilities and how those difficulties are mitigated. Furthermore, the SNE officer is in charge of identification, categorisation and assessment of CwDs, in order to provide appropriate support. Furthermore, the SNE officer claimed to be responsible for sensitisation of teachers, head teachers, parents, CwDs themselves and the community. The need for that task was expressed: *'A child with a disability, they feel unwanted, then they begin isolating themselves, then they have that negative attitude, so we have to do the sensitisation to them first, to have them accept themselves, with those challenges, and then to come to meet other people in the society.'* (SNE officer). This relates to a study that shows sensitisation to the parents and community is done through radio talks to change the mind-set of the people and to create a positive attitude towards the children. Sensitisation was promoted by 82% of the local government, through meetings, seminars and other opportunities that arise and aimed for sensitisation of head teachers, teachers, parents, local leaders, peers, and the community (Kristensen, Omagor-Loican and Onen 2003, 198).

Summarised, the SNE officer looks at the needs of the children and aims to make it possible that all children learn together and coordinates education through planning, management and mobilisation of resources. The Ugandan government assigns the education services to the districts and a specific position of the education officer of special needs is created to ‘coordinate assessment, provision and monitoring of Special Needs Education at local government level’ in the decentralisation act of 1997 (CSBAG 2013, 20).

As presented in the chapter ‘policy analysis’, the PwDs Act states that the government is responsible for awareness raising and sensitisation of the community. The SNE officer does regular radio talks to promote the rights of CwDs.

### **Schools**

Education in Kabarole district is available at 124 government aided primary-schools (Kabarole District Local Government Five Year Development Plan 2011/2012-2015/2016 2010, 59). In Fort Portal, school A is the only public school that has a special needs class. In the Kabarole district, there is one other governmental primary school that provides special needs education: school B. According to the interview with the SNE Officer, there are 28 SNE teachers in the Kabarole district. There are two SNE teachers in school A and three in school B. The other teachers are employed at other schools in the district.

School B is a ‘demonstration school’, meaning that the school is connected to the Primary Teaching College. In the past, the school was only for blind children. After UPE in 1999, the school was taken over by the government and with this intervention other children could participate in the school, including children with different impairments. According to the headmaster, the policy of ‘Inclusive Education’ is valid for this school since then. This means that children with special needs, study in the same class with ‘ordinary children’ in order to avoid stigmatisation. In some cases, children cannot learn with the other children. For them, there is a Special Needs Class where a SNE teacher teaches them individually a part of the day. Children in the Special Needs Class are tested regularly, so that when they reach a level of academic performance, they will be promoted to the ordinary classes. The HM states that the school gives priority to CwDs to enrol in education.

### **Examinations**

At the end of every year, there is an end of term test. The tests are graded with percentages, and the children need at least an average of 40% to pass to the next grade. When a child does not pass, he has to re-sit the grade. At the end of the term in the seventh grade, all students make the Primary Leaving Examination. With a high enough score, the children can continue to the secondary school. All tests are developed by the Uganda National Examination Board (UNEB). UNEB has special attention for children with special needs. The HM reports to UNEB how many special needs children will participate in the examinations, and what the special needs are. UNEB adapts the exam to the individual needs of the child and grades differently when the child has a disability. There is an opportunity for the blind to participate in the PLE, and UNEB provides the exams in braille. Other children that are intellectually challenged or slow learners, get extra 45 minutes to finish the exam. The children with bad eyesight are provided with a large print of the exam, so the child is able to read it. For a deaf child, someone that can sign from UNEB assists the child during the Primary Leaving Examination. The SNE Officer is to be informed about the number of special needs children at the school. After her permission, the school can apply to UNEB for special adaptations of the Primary Leaving Examination.

### **Administration**

In school A, the administrator of the school registers daily how many children are at school. In the SNE class, this is written on the blackboard and in a book. Some days the teacher calls all the names of the children separately and children answer 'present teacher' or 'absent teacher'. However, this happens rarely. In the regular classes the registration is different: when the administration is done, the teacher asks separately the boys and girls to raise their hand and the teacher counts them. The counting goes fast and is not done very precisely: some children are walking around in the classroom and others have gone to the latrines. The teachers tell the administration an approximate number of boys and girls that are present.

Teachers register every day, when they come into school. They write their name and the time in the administration book in the guards' office. The punishments for being absent without a valid reason, is to write an apology letter to the HM. This letter will be kept in a file and can be used against you later. The SNE teacher mentions to me that she could lose her job for being absent without permission of the depute or HM.

In my presence at the school, teachers were absent a few times for several days. On my question where they have been they answered most times that there was a funeral. They explained that when a person dies, family and friends pray for several days and there are ceremonies. One time a teacher had a traffic accident and was not able to work for a few days.

The relevance is shown in the literature. A survey of absenteeism of teachers by the World Bank showed that in Uganda, teachers are absent one out of five days. Other problems shown in this report were that especially in Uganda teachers were found drinking tea, reading the newspaper or talking to colleagues while they were supposed to teach (Banerjee and Duflo 2011, 74). This is in line with my observations. In my presence, teachers were reading the bible, watching videos on their phones or were even sleeping in the classroom.

### **ECONOMIC ENVIRONMENT**

Most facets of the economic environment are presented in the chapter ‘Commodities’. In this paragraph about the economic environment, the financial resources of the school will be presented, including UPE grant, subvention grant, PTA and income from foreign resources.

The two schools that are included in this research receive two government releases every term; the UPE grant for every public primary school in the country and a subvention grant. The UPE grant is used for school materials, cocurricular activities, management, administration, official duties of head teachers and other expenses. The subvention grant for schools that involve CwDs, however the amount differs per term and the HM from school B states that sometimes this grant is not released at all. The amount of the amount of UPE grant depends on how many children are registered at the school in total, and the amount of the subvention grand how many CwDs are enrolled in the school. The subvention grant is spent on meals for the special needs children (children receive a cup with porridge in the break time), school materials (books, pens, pencils), teaching materials and first aid both in school A and B.

The interviews of the HM and the headmaster of the schools are the source of this information, since no official information on these grants is published by governments’ sources.

According to the interview with the HM, there are 28 teachers at school A. The financial situation of the school does not allow the HM to employ more teachers and there is not enough money to build more classrooms.

The children that are in the school need to pay a small fee per term, towards the PTA. Some teachers said it is for teachers' salaries, and the Headmaster of School B mentioned that PTA is to support the school. The school provides some school materials with this money. School B supports children with a poor background and is flexible with the PTA fee.

The HM of School B writes to volunteers (foreign NGO's) to request money and writes regularly proposals to the ministry requesting money for special needs children. An Australian visitor donated the bicycles for the children in the SNE class. Other foreign organisations spend; wheelchairs, a water tank for the school, a fence for the school and lavatories. There is an NGO from the United Kingdom, that does weekly sport activities with the children. Additionally, missionaries come from a church close by to talk with the children about religion every week.

## **PHYSICAL ENVIRONMENT**

In this paragraph, the physical environment of the education system is presented. The accessibility of (special needs) schools and the overcrowded classrooms are barriers for children to access education.

### **Accessibility of schools**

Not many schools provide special needs education in the Kabarole district. School A is the only school for deaf children and School B is the only school where blind children can enrol. Both schools have possibilities for children with other disabilities or special needs. Many children have to travel far to go to school, or have to live in the boarding unit, which is expensive. Some children walk to school, others take a so called 'boda-boda': a motorbike taxi. The expenses for the transport is paid by the parents.

A problem mentioned in the interviews is the road to school. Few roads are made of asphalt, and most roads are dirt roads. When it is dry, it is possible to use the roads, but with the rain, the road turns into mud. A teacher confirms this problem in the interview: *'There are children that come from very far, from villages outside to go to school. Now the road is impossible to use, because of the rain season. So the other one that must take the boda-boda, cannot go. They cannot manage to go here.'* (SNE Teacher School A).

In the National Housing Census of 2014, it shows that in the Kabarole district for 11.8% of the households the distance to the nearest to a public primary school is 5 km or more (UBOS 2014b, 25). The housing census does not present the accessibility of special needs schools. However, we can conclude that the distance to school is a barrier for children. Especially children from poor families, that often have to walk far on an empty stomach, as is presented in the chapter 'Commodities'.

### **Overcrowded classrooms**

As presented in the policy analysis, there is a problem with overcrowded classrooms since the implementation of the UPE program. This is seen in the observations. School A has seven grades and a nursery school and in the third term of 2017, when I was at the school, there were 981 students in primary school and 26 children in nursery school. The number of children per class varies between 109 and 177 children. Most children of the same per grade are taught in one classroom. The third, fourth and fifth grades have two classrooms per grade. A problem resulting of overcrowded classrooms is that children have very little space at the desks, and sometimes children have to sit on the floor to do their exercises. According to the interview with the HM, the school has 160 desks. She expresses that government rules state that there are supposed to sit 3 children per desk. An example of my observations was in science class of the seventh grade. Around 110 children were present and attend class at approximately 30 desks. This means that around 4 children sit at one desk. I observed this problem in the regular classes. The windows are open and fresh air comes in, but it feels still very warm since it is about 25 degrees. According to a literature the pupil-teacher ratio is 54:1 but the average number of students per classroom is 121 and only 57% of the learners have adequate seating space (Kristensen, Omagor-Loican and Onen 2003, 196).

### **SOCIAL ENVIRONMENT**

In this paragraph the role of the social environment for children's enrolment in education is presented. First the importance of the relationship of CwDs to peer students is described. Then the need of individual attention from the teachers is pointed out and to explain the difficulty of the individual attention, the teaching methods are described. The teaching methods and overcrowded classrooms limit the teachers in their ability to give individual attention. The paragraph will conclude with the attitudes towards CwDs, and how this creates a social barrier.



### **Peer students**

Children talk, socialise, interact, play together and find friendships in school. This seems a motivation to go to school. Teachers point out that interaction helps children to develop language. Moreover, children help each other with their exercises or daily routines, a girl in a wheelchair gets pushed around by classmates or they help her to get seated at her desk. In School B, children help the ones that are blind to go to the lavatory. Some children give each other food when they do not get anything from home. Students control each other when the teacher is absent. Children that misbehave get beaten by other children that are older. In the observations I see that children laugh together, play together and find friends in school and children help each other with school work.

### **Individual attention**

The large number of children per class creates another problem: it does not allow the teacher to give individual attention to the children, or to develop individual learning plans or special exercises for the children. In regular classes, teachers try at times to give individual attention, while leaving the other children unattended. This is mentioned by several teachers as well as by the HM: *'[...] the challenge is, those teachers handle many children and they don't have time to attend an individual.'* (HM School A).

The HM and teachers try to enrol special needs children in the regular classes, nonetheless there is no time to teach the children individually. The HM mentions that the ideal situation would be if the children of the special needs class could be in four different classrooms with at least four different teachers: lower primary, middle primary and higher primary, and the extreme cases in another room, so says the HM.

Teachers adapt seating of the children to the needs of the children. If there are children with bad sight, they let them sit in the front. They group children with similar levels in the same area in class, so they can repeat the information to the 'slow learners' after they have taught the whole class. *'Actually, for the slow learners, after teaching, we go back, we sit with them and we guide them. We guide what we have told. And we can make some groups, for example, we divide them. The way you see this, they are not the same. These ones they are high level, these ones they are in the middle and those ones there (teacher points) they are low level. So that's how we make the seating order.'* (Teacher 3 School A)

Literature shows that inclusive education is most likely to be achieved when teachers and learners are assisted in inclusive classrooms. To effectively implement education for CwDs the family and the community needs to get support (Kristensen, Omagor-Loican and Onen 2003, 194).

In the special needs class in school A, individual attention is given, however there are only two teachers for 40 children between the age 4 to 19, and from nursery school level to the seventh grade, with different disabilities in one classroom: hearing disabilities, physical disabilities and intellectual disabilities (called 'mentally retarded children'). Two teachers for forty children of different age, level and disabilities is a lot of work for the teachers, as they say themselves as does the HM. Mostly, the children get individual exercises in their exercise book and sometimes on the blackboard. The other children sit at their desks and talk or play.

### **Teaching methods**

To understand the children's possibilities of enrolment, the methods that are used for teaching need to be explained because it influences the children's participation in education.

The main teaching method in the special needs class is to copy the letters, words or numbers that the teacher tells them to do. In the exercise books, it shows that only once every few weeks or every month, every child from lower grades gets exercises. The children from higher grades are working every day on their exercises. The SNE teacher in School B takes individual children out of regular classrooms to teach them individually.

Teachers of SNE classes, both in School A and School B try to teach children academic skills they point out the importance of teaching them life skills. SNE teacher of School A tells me that some children have learned to go to the toilet, (which before wore diapers) and wash their hands, make friends, make food, etc. *'Aah! Ah they can socialise. Very important. They can go for a short call, Just to talk, just to have friends here, that is very important. It is also a lesson it is all! [...] But at least we do a lot of work. Can't you see: They can write, they can play, they can go for a short call, you can share!'* (SNE Teacher School A). Teachers follow up on children that are absent. Ask for a letter form the parent when a child has been absent. Teachers try to reach parents when a child is absent, or went to a local council to apply some force to the parents to send the children.

In regular classes, teachers use repetition as a teaching method. The teacher in front of the class teaches the children about different topics. Often the teacher leaves out the last words of a sentence and the children have to finish it. To illustrate this with an example:

*(Teacher explains time differences around the world)*

*Teacher: 'When we go east we ....'*

*Children together: 'Add time'.*

*Teacher: 'When we go west we ...'*

*Children together: 'Subtract time'*

The teacher would repeat these sentences a few times. Most children participate actively, however the ones in the back of the class do not always pay attention. I often have the feeling that the children actually do not understand what they are saying. It seems that children in the back of the classroom mumble something and do not really know what the information is about.

Sometimes teachers do stretching exercises and dancing with the children to give the children new energy. Teachers encourage children in class, clap for them, praise them and say 'try again' instead of 'wrong answer'. Teachers motivate children that are academically weak to perform in other activities, like agricultural activities or sports. A teacher states in the interview that children feel responsible and feel that they cannot absent themselves: it keeps them in school. Teachers include teaching life skills in their curriculum, like housekeeping, health issues etc.

In every class the teacher has a stick with him/her. This is meant to beat children that do not listen/participate or behave badly. It seems necessary because children are used to this method of punishment, and there are so many children in the class (one teacher for 90 to 120 children) that corporal punishment is the only way to keep control of the large number of children. Yelling is also a way to control and motivate the children. Teachers express that they do not punish the special needs children as bad as others. Teachers let CwDs (Of special needs children) clean the blackboard instead of beating them, especially the ones with HIV/AIDS, so mentions a teacher in the interview. Often children do not understand an exercise or make a mistake. Children get yelled at that they fail in front of all other children. In my attendance, the teacher yelled at a child after making mistakes at the blackboard: '*shame, shame, shame on you!*'. Children are often crying in class after the teacher has yelled at them or beaten them. Sometimes children are beaten in front of many other children, parents and teachers, in the

classroom or on the football field, where everyone can see it. Reasons for beating appear to be bad behaviour, sinning (like stealing or lying) and performing badly on tests.

### **Teachers experience of the profession**

Teachers are happy to work for the school and they express unanimous that they enjoy their profession. School A has staff housing and lunch for the teachers and they get tea, coffee and porridge. School B has no staff housing. They build friendships with colleagues and some teachers express that the salary is good. In the interviews, teachers express their experience of the profession: *'Actually I like it, because I have gained knowledge I have more friends from here and at least my income has also increased.'* (Teacher 3 School A). *'In a way, I love teaching, and I have [always] loved teaching, especially the young ones. I enjoy my profession. I like to see people growing, [...] that is my experience.'* (Teacher 4 School A). All teachers express that they enjoy their profession in a different way: some mention the friendships, the income and the passion for the job.

The SNE teacher of school B expresses the burden of the job. *'It is tiresome, it is less payed, he or she uses his money to go for studies. So all of that. So for us who are studying, [...]. And the devotion is different. It is accorded. I am devoted, you may not be devoted. I'm committed, the other one may not be committed. So according to the personality. So that is the problem. But teachers are many.'* (SNE teacher School B). Similarly, the SNE teacher of school A expresses that it is a difficult job, because they get paid like other teachers, but doing extra work. They have to give individual attention. They express that they feel that the government does not recognize them. They have the feeling that other teachers look down on them, because they think that the CwDs know nothing. I will illustrate this with a quote from the interview: *'For us we just want the government to recognise us. We are teaching a special class, and we are special teachers. [...]. And give special attention! We get payed like other teachers, but we are doing this job. Other people they tend to say that those teachers who are teaching SNE class, those pupils with disabilities, they know nothing.'* (SNE teacher school A)

### **Attitudes**

SNE Teachers do the same teachers training college as other teachers, followed by a specialization or a special needs course, which is possible at different levels (degrees and diplomas). Teachers pay this additional course with their own money. According to the HM of

School A, SNE teachers are present in the Kabarole district, however they do not teach in special needs classes

Teachers and the HM mention in the interviews that teachers have no interest in teaching children with special needs. According to the SNE Officer, there are 28 SNE teachers available in the district. The SNE teacher at School A thinks that others have no interest in the job and these children have a lot of problems that you have to care about. The HM of School A explains that teachers want degrees, but do not want to face the reality: *'Hmmm. getting them is not easy. There are few [teachers] trained in that area. [...] And those who are trained, they don't want to come and handle those children. Just trying to get papers. Diploma in Special needs. Degree in special needs. That is all. They don't want to come and face the reality. That is what you find now. Because in the municipality there are teachers and other schools, but they refused.'* (HM School A).

The Special needs education and inclusive education department states that a responsibility of the department is to *'Ensuring adequate recruitment and deployment of SN&IE personnel in consultation with the relevant bodies.'* However, in reality it is seen that not enough teachers are specialized in special needs education, and even less are employed as SNE teachers. This shows that SNE and IE is ineffectively implemented.

### **Parents' attitude**

In the interviews and observations, the negative attitude of the parents appeared to be a social barrier to education for CwDs. When parents have several children, they often prefer the children without disabilities to go to school and pay money for them instead of the child with a disability. Some parents see it as a curse that they have a child with a disability and deny the existence of the child. Many parents and people in the communities cannot imagine that CwDs have a future. Parents do not know that children with impairments can excel like any other child. Some think that they cannot talk and therefore not learn or work. They label them useless and they see them as a burden to the family. The HM of school A expresses that some parents see the school as a dumping place for the CwDs and they can dump them there, but not with the intention to educate them. When CwDs live in the unit of the school, sometimes the children are not picked up at the end of the term, and teachers have to wait for days until the parents come.

Some parents do not want to pay the PTA fee for the CwDs. Although they do pay for their other children that are not disabled. The HM expresses that poverty is not always the issue. They have the money, but they do not value the child with a disability like other children that are not disabled. It is therefore that some parents do not want to pay the PTA fee. The SNE teacher of school A expresses this in the interview: *'And another problem the children have, the parents of these people, they take them like they are not like other children. They don't need to go to school. And on top of that, they don't pay the school fees. For us teachers, we end up not getting our money. Because of the parents, they are home. Are you getting me Rosaline? They take them to be home, they are [nasty]. You can find a parent that has like 3 children here. One in p.1, p.7 and SNE. The parent can come here and pay the one that is in P.7, the one that is in p.1 and just walks away without saying hello to the teachers and they just walk away. [...] And on top of that, they end up not paying. Yeah!'* (SNE Teacher School A). This quote shows the expression of the SNE teacher about how she experiences people's attitude towards the children and towards her. It seems difficult for her that people do not greet her and do not want to pay her the PTA fee.

The SNE Officer points out the problem of the parents' attitude: *'[...]Then we talk to the parents, because as parents they have such children they get disgusted, because they look at them like a burden. So they feel like even paying less attention they feel like these people are a waste, because they cannot achieve anything, they look at them as a curse in the family, so our sensitization for the parents has to change their mind-set and have a positive attitude towards the caring of these children. [...]* (SNE officer).

To change the attitude of the parents, is a long and difficult process, so states the SNE teacher of school B in the interview. The SNE officer does radio talks to sensitise the people in the community. Radio is a main source of information for most people. According to the housing census of 2014, in Kabarole district 74.2% of the households owns a radio and for 72.8% of the households, the radio is the main source of information (UBOS 2014b, 26-27). This relates to the Persons with Disabilities policy that states that the government is responsible for awareness rising and sensitisation in the community.

School B organises every term a day where the parents come to school and they are informed about the situation of the school. In between the official talks, the children sing, dance and do games. Special attention is given to the children with impairments. The school does this to

show parents how the children develop, aiming to change attitude of the parents (HM School B).

### **Environment**

This chapter aimed to answer the fourth sub-question of this study: ‘How does the political, economic, physical and social/cultural environment influence the participation of children with disabilities in primary education in Kabarole district?’. Summarising the findings in the chapter ‘environment’ shows that there are barriers for enrolment in education at different facets of environment: political, economic, physical, social.

The education infrastructure appeared to be a political environmental barrier, since the government of Uganda provides free primary education, but is in practice not accessible for all children. The adaptation of the government to the large increase of the pupils in the schools is not appropriately implemented, which results in a physical barrier: the classrooms are classrooms, there are insufficient (SNE) teachers and (exercise) books, pens and desks are not available for all children. Physical restrictions for children are the few schools that provide special needs education and the roads to schools that are poorly maintained. The units where children can live are expensive and is an economic barrier.

The MoES organises special needs education for teachers. Although SNE teachers exist, they are not all willing to teach children with special needs. Reasons appeared to lay in the social environment. A negative attitude exists in the community towards CwDs, resulting in stigma and discrimination. SNE teachers experience the attitude of the parents that refuse to greet them and are not willing to pay PTA fee for CwDs. The SNE officer aims to sensitise the community with radio talks, and schools organise parent days where special attention is given to CwDs to change the attitude of the parents. The attitude of the parents appeared to be difficult to change.

The different environmental factors are thus interrelated. Together, the environment strongly limits children in their participation in education, especially CwDs.

## **8. DISCUSSION**

This chapter presents how the findings relate to each other and how they answer the research questions of this study. The main question is: ‘What could explain the discrepancy between education policy and the implementation of education policy for children with disabilities in Kabarole district?’ To answer this main question, four sub-questions are answered, which include: ‘policy’, ‘the definition of disability in education’, ‘commodities’ and ‘environment’.

### **Policy**

Chapter four presents the global and national policies, to answer the first sub-question: ‘How do policies aim to include children with disabilities in primary education in Kabarole district?’. It appears that there is no consistent and clear definition of ‘children with disabilities’ throughout the legal framework. In addition, there is a lack of data on CwDs, because of the lack of adequate national surveys. Together with the exponentially growing population, this leads to the inability to adequately target policy.

The international policies aiming for education for all, need resource and funding for implementation. The lack of adequate funding in addition to the lack of resources lead to the discrepancy in policy and practice.

### **Definition of ‘Children with disabilities’ in the educational context**

Chapter five presents the definition of CwDs in the educational context in Kabarole district and answers the second sub-question: ‘How is disability conceptualised in the educational context through the lens of the capability approach in Kabarole district?’. The results of this study indicate that disability in the educational context in Uganda is very complex and factors of personal characteristics, commodities and environment are interrelated. In interviews CwDs were described as ‘special needs children’. It appeared to include children with physical disabilities, which means impairments of hearing and seeing, missing a body part, or chronic failure of body systems necessary for everyday living (e.g. muscle dysfunction). Mental impairments are mentioned and examples were given of children with autism or mental retardation. The term ‘mental retardation’ is criticised in the literature, because of its stigmatising character. Currently the term ‘intellectual disability’ is preferred in most countries. The utilisation of the term ‘mental retardation’ shows that the social environment disables children, rather than the impairment.



The term 'special needs children' became synonymous with the term 'children with disabilities'. This made me understand that teachers and the people in the community have an expanded definition of CwDs. Children included in this group were children with diseases such as measles, malaria and HIV/AIDS. In Uganda the HIV pandemic is a large problem and many children have HIV. There are no numbers on the prevalence of HIV/AIDS for children specifically, but in Uganda, 1.4 million people in Uganda had HIV in 2016.

Another category of 'special needs children' are children who lost one or both parents. Both in policy and in interview data, the terms 'single' or 'double orphaned' children are mentioned. Single orphans are children who lost one parent and double orphans are children that lost both parents. The loss of a parent often leads to other problems, because they strongly depend on the social safety net of family and community. Orphans often struggle with basic needs, like food and clothing, which make school attendance more difficult. Correspondingly, financial problems occur, because they are not able to meet the demands of the school.

The interviews revealed that not only orphans are struggling with basic needs. Many children in the school are from low income families, often from villages far away. Children without proper nutrition and lacking reliable transportation, face a barrier to education. Children come to school hungry and weak. Low energy intake and high energy expenditure of walking to school, reduces the ability to pay attention in class. Often children share food between them and sometimes teachers give them food. According to the capability approach, this shows that children find alternative ways of functioning. Children appear to have a higher chance of finding food, by going to school.

Finally, the most complex group that was often mentioned by teachers are the 'slow learners'. This group appeared to involve all previous described groups. As well as children that just do not pay much attention in class or children that are just slower than others. One teacher explained that of ten children, three or four are slow learners. The term of 'slow learners' is the most accurate, however has a very negative connotation. The term 'Slow learners' refers to the outcome of all the barriers that were described above.

### **Commodities**

Chapter six presents the commodities that are needed for children to function in education, but are often absent. The third sub-question is answered: 'How does the (in) availability of

commodities affect the participation of children with disabilities in primary education in Kabarole district?'.

Legally, public primary education is free, but in reality it is not. The costs on education exist in the form of a contribution to the PTA, the contribution of school material and a uniform. Parents and teachers agreed on a fee that is paid per term for every child in the school. The cost of the PTA fee differs from 35.000 Ush (approximately which is 100 NOK) in the first to the fourth grade, and is higher in the special needs classes: 40.000 Ush. In the sixth and seventh grade it costs 60.000 Ush per term. The PTA fee equals 10% to 20% of an average Ugandan monthly salary. In 2014 in Kabarole, the fertility rate was 5.8. With the high number of children per family, the financial burden could be problematic for low income households. In Uganda in 2013, 19.7% of the population lived under the poverty line, which is 1.90\$ per day. Some children's education is partly financed by foreign aid, or NGOs. This allows them to participate. For those who do not receive such aid, a financial barrier can occur.

The lack of commodities appeared to be a disabling factor for many children. As previously mentioned, poverty plays a role for categorising children as 'special needs children' because their basic needs are missing. Due to the budget constraint of low income households, buying the necessary school material is not always prioritised. The children often solve this on their own by borrowing from their classmates. This is another compensating ability that children find, and is related to the previous mentioned ability to receive food in school of other children.

Another challenge low income households face, is the lack of assistive devices. Most children who need a small adaptation like glasses, are not able to have their needs met, due to limited household income but also because there is a large shortage of assistive devices and technology. Lacking these devices, small impairments become a disability.

### **Environment**

The seventh chapter answers the fourth question: 'How does the political, economic, physical and social/cultural environment influence the participation of children with disabilities in primary education in Kabarole district?'.

The environment limits CwDs in their functioning capabilities. The environmental factors were grouped in political, economic, physical and social/cultural factors. The economic barriers are

described above. One can look at the education system as a political environmental barrier. Universal Primary Education was introduced in Uganda in 1997, education is officially free (however, in reality it is not) since then, enrolment of children increased largely. However, the school system was not adapted to the major increase. As a result, classrooms are overcrowded, children are squeezed in at the same amounts of desks and the pupil-teacher ratio became enormously high and 20 years later it is still around 110:1 in reality. A social barrier exists because of the overcrowded classrooms; teachers do not have enough time to give individual attention.

The teaching methods are limited when the classes are so large. The only teaching method that is used, is to explain the information in front of the classroom and let the class repeat the information. In regular classes, children who need extra attention do not get that and depend on others that are willing to repeat the information for them. The teaching method is especially unsuitable for children with special needs, who need to have the information repeated. Teachers are not able to adapt to the diversity of learners in the classroom, because teaching methods are not sufficient to let all children participate fully in class.

Nationally, there is a special needs education and inclusive education department, as a part of the ministry of education. This department sends grants per term to schools that provide education for children with special needs. The Uganda National Examination Board uses adaptive methods to examine children with impairments. Children that are 'slow learners' get 45 minutes extra during the exams, children with bad eye sight get large prints of the exam and deaf children get help from a translator that knows sign language. NGO's and foreign resources, support CwDs to enrol in school.

In the special needs class, children are taught individually. Nevertheless, there are only two teachers for forty children of different ages, on different levels (between nursery level and the seventh grade) and with different disabilities. SNE-Teachers express that they teach children not only academic skills but additionally life skills are taught e.g. socialising, build friendships, use the lavatories, food preparation, do the laundry and other activities like gardening. SNE teachers have knowledge of special needs education: one teacher completed a bachelor degree in special needs education at Kyambogo University in Kampala and others did workshops or courses, for example, in sign language.

The attitude towards CwDs and towards SNE teachers are exposed in the observations and interviews. SNE teachers express in the interview that they want the government to recognise their efforts. Their work requires special skills, and they need recognition both financially and socially. Besides recognition from the government, they feel underappreciated by their colleagues who believe special needs children cannot learn. This attitude is also found in the community and with parents. Some parents refuse to greet the SNE teachers and often do not pay the PTA fee. Especially the children with intellectual disabilities are stigmatised and are seen as a burden on the family. Villagers often do not know these children can learn. Children with impairments are often dumped at school, to get rid of the heavy burden they put on the families.

The SNE-officer of the local government often does radio talks to sensitise the community, to destigmatise CwDs in the community. SNE teachers have a positive attitude towards CwDs and play an important role to enable the children to go to school. They do their job with passion and commitment and express high satisfaction for working for the school. They love the children and enjoy working with them. Some teachers express that especially this school is nice to work for; they receive a decent salary, they have the opportunity to live in staff housing, and they build friendships at work.

### **Potential and actual disability**

For this study, 'disability' is presented through the lens of the capability approach. It is complex and the factors that disable a person's functioning are interrelated. Mitra (2006, 241) differentiates between actual disability and potential disability. Potential disability is when a person has an impairment or other special needs and almost inevitably lead to a reduction of the capabilities of the person. A person might need more adaptations to function as someone without the impairment. A person is actually disabled if the person experiences restrictions in functioning and when the beings and doings of the person are affected. If a person can be and do what he or she wants to be and to do, according to the capability approach a person is not actually disabled. So if a person is actually disabled depends on the values of the person.

An example of the difference between potential and actual disability is a child that is not able to walk. When the person values to move around, the inability to walk is a disability. However, if we look at the mobility of the person that is affected and is the valued by the person, there are several ways to adapt. A wheelchair can improve the mobility of the person and the actual

disability changes into a potential disability. This example shows that a person can adjust to the impairment and find a different way of achieving what he or she values to be and to do.

Another term used by Mitra (2006, 241) is ‘compensating abilities’. The individual can find other ways to achieve, to be and to do, what the person values. When an impairment is a characteristic of the person, an assistive device or technology can help the person, though in the case of Uganda these are rarely available. Here it depends rather on the creativity of the person to find ‘alternative functioning’.

Other potential disabilities result from barriers in the environment. Children that are orphaned or miss the basic needs face an extra barrier to access education because their capability set is smaller than others, because of their need for adaptive capabilities to function. The findings show that disability might result of the social and physical environment. The environmental barriers appear to be more disabling than the impairment itself. Stigma and discrimination are barriers in the social environment for the child with the impairment, specifically a mental impairment. Parents and the community, especially in the rural villages often lack the knowledge that these children can learn. Often these children are kept at home and are not able to access the education system. Here we speak of a more complex disability, and looking at the capability approach; it is difficult to find alternative functioning or compensating abilities.

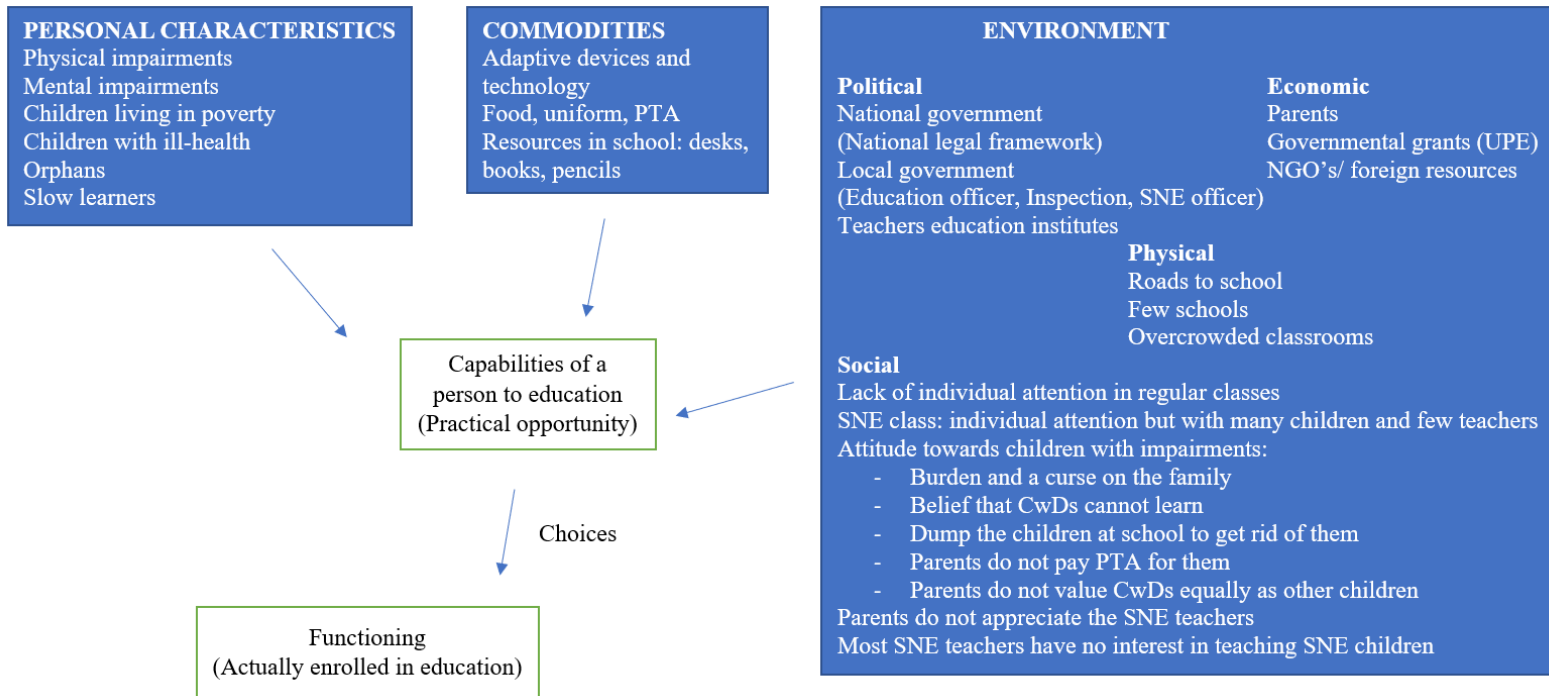
Some ‘needs’ appear to be more disabling than others, because they require more compensating capabilities than others. Physical impairments are therefore less disabling than mental impairments, because the children with mental impairments face more complex barriers. It is the system that disables the children, more than the impairments themselves.

The actual disability of restrictions in functioning is reduced because of the ability to cope with barriers. Children appear to be creative with solutions to the barriers they face. They often find what is described in the capability approach as ‘compensating abilities’ to achieve ‘alternative functioning’. Children’s choices to prioritise education enables them to participate.

In figure 8, the scheme of Mitra (2006, 239) is applied to the findings of this research. The personal characteristics, the commodities and the (political, economic, physical and social) environment together result in the capabilities of the children to education. The individual

choices and compensating abilities of the children lead to the functioning in education. According to the personal beliefs, preferences and values, the functioning is achieved.

Figure 8 Findings applied to capability approach

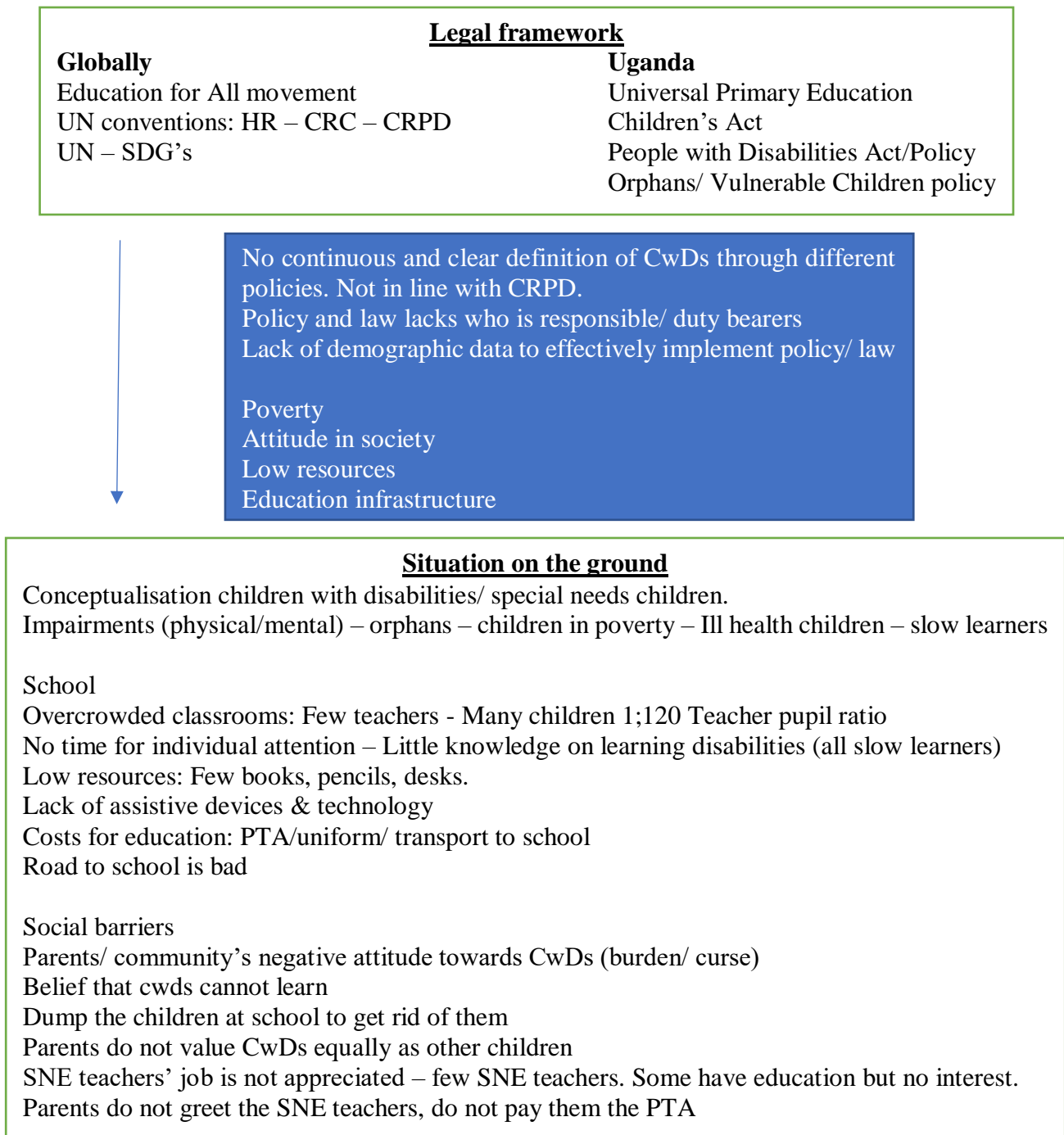


In this study, we looked only at the children that are enrolled in education and are in this theory only the children with potential disabilities, not with actual disabilities. The enablement of school enrolment strongly depends on the individual motivation to go to school, to be surrounded by friends and participate in a social environment. Additionally, the teachers express their devotion and commitment to keep children in school. These social constructions enables them despite all the barriers to enrol in schools. Additionally, policy plays a role in enablement, however it is less strong than the social role.

As presented in the theoretical framework, functioning in the system depends on internal and external factors. With policy, external factors can be influenced, which crates capabilities for the person to utilise the commodities and convert it into functioning. Shortcomings are found on the ground. Implementation of education for children lacks resources in education, especially for those with impairments: the lack of materials, large classrooms, few teachers, the lack of individual attention, the few SNE teachers available. Additionally, there is a social barrier: the negative labelling of CwDs in the community. All create the barriers to education.

In figure 9, the implementation gap is illustrated, showing the policy (legal framework) and practice (situation on the ground) and the complications that affect the implementation.

Figure 9 The implementation gap: policy and practice



## 9. CONCLUSION

With this research, I aimed to find answers to the question: ‘What could explain the discrepancy between education policy and the implementation of education policy for children with disabilities in the Kabarole district in Uganda?’ There appears to be an implementation gap between the legal framework and practice. The legal framework for education for CwDs in the form of policy programmes, laws and acts does not effectively apply. With the help of the capability approach this study explains that both internal and external factors play a role for the individual to function. Findings show that the external factors limit the capability set, and that enrolment in education strongly depends on internal factors.

In the findings is shown that the needs of CwDs are not met in the educational infrastructure. The needs of the children lay in the provision of education, which for public schools mainly are the government’s responsibility. Children with special needs face challenges to participate in the education system, because of their need for adaptive devices which are absent or unaffordable. Adaptation to the individual needs is limited, because the classes are overcrowded and there is little time to give individual attention. There is little knowledge about the impairments, which makes it difficult to use a suitable teaching method. Furthermore, few SNE schools and the low quality infrastructure makes it difficult to physically access school. The inability to function fully in the education system through the barriers that CwDs face, lower their chances to fully participate in society.

In addition to the barriers in the infrastructure of education, at a national level, there is a lack of data on the exponentially growing population: between the last two housing censuses (in 2002 and 2014) the population grew from 24.2 to 34.6 million people. The distribution of the population consists of approximately 52% of children (age 0-17) in 2014. Data is limited on the prevalence of disability, so the extent of the problem is not really known. For measuring ‘disability’, a problem occurs, since there is no consistent definition of disability throughout the different policy documents and within the different laws. The absence of a clear and consistent definition of disability in the legal framework, and the absence of data on the population and on disability and make it difficult to target policy.

In reality, the findings show that the term CwDs is synonymised with ‘special needs children’ which enlarges the group. Firstly, physical and mental impairments are categorised in this



group. In the Kabarole housing census is stated that 4.4% of the population has some kind of impairment including hearing, seeing, concentration/remembering and walking/climbing steps. Other 'special need children' are: Orphans (in 2014 8% of the children in Uganda), children with ill-health (6.4% of the Ugandan population had HIV/AIDS in 2006), children from low-income households (19.7% of the Ugandans lived under the poverty line in 2013, and 5.9% of the children in Kabarole have less than one meal per day). Finally also children that are 'slow learners' are defined as special needs children. The cause of the slow learner could be any of the previous mentioned reasons. Given this definition, illustrated with numbers, we see that the group of CwDs or special needs children is complex and large.

The capability approach focuses also on the internal factors, which are highlighted in this research. The compensating capabilities to achieve alternative functioning that children find, and the individual choices that are made enable them to function in the system. Findings show that children are able to receive food in school from others, borrow pencils and choose to go to school although they are often hungry and weak because of undernutrition. These are the conversion factors that are central in the capability approach. The well-being of the individual depends on the values, beliefs and preferences of the individual, are achieved through the choices made by the individual.

It appeared that the environment in all various facets disables the person, more than the impairment itself. The ineffective education system, poverty and social environment appeared to be the complex and interrelated causes that limits possibilities for CwDs, but the individual compensating capabilities choices, the devotion and love of the teachers, are the enabling factors, to achieve alternative functioning. This research shows that the causes for the implementation gap are the external factors, rather than the internal factors.

### **Recommendations**

As presented above, the enrolment of CwDs in primary education now strongly depends on the ability of the individual to find alternative abilities. The choice of children to go to school is not always the most obvious one.

The choice of education is less attractive, because of barriers in all facets. The government's aim should be to make the choice of education more attractive and profitable. A few

suggestions appeared in the interviews: If education would be entirely free, and children would get a meal in the break time, sending children to school would be more attractive for parents than leaving them at home. The attitude towards disability must change, through more sensitisation. Physical accessibility of schools could be improved through improvement of infrastructure. Additionally the number of schools and teachers should improve, so that the classes are smaller and teachers have the opportunity to give individual attention. Due to the movement of inclusive education, more teachers should have knowledge of special needs teaching methods, as well as the job of SNE teachers should be more attractive. A way of doing this is making the salary of SNE teachers, higher and lower the demands for the specialisation.

For more effective policy implementation through the lens of the capability approach, Trani et al. recommends to assess the beliefs, preferences and values of the community. To accomplish effective implementation, policy makers can look at the (in)available resources, and how they can be improved in low resource countries.

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## **Appendix I: Interview guides**

### **Interview guide teacher**

#### **1. Introduction**

Please tell me about your class:

Which grade/ classes do you teach?

How many children are in your class?

What do you think about the number of children in your class?

What do you think about the teacher-pupil ratio?

How long have you been working here?

How do you experience being a teacher in this school?

What makes this school different than other schools?

#### **2. Children with disabilities**

Do you have CwDs / slow learners/ special need in your class?

Can you tell me about the disabilities/ slow learners/ special needs they have?

If previous experience with CwDs / slow learners/ special needs, what were they?

What kind of CwDs could be/ could NOT BE in your class?

#### **3. Teaching**

Have you received any special training to assist students with disabilities/ special needs/ slow learners?

If yes, what kind of training?

Do you think you had the appropriate training to teach CwDs ?

Is there any special training you would like to receive?

What kind of children are particularly difficult/challenging to teach?

Why do you find that difficult/ challenging?

#### **4. Support**

How do you support the special needs of the children?

How do you get help to support children with special needs in class?

*(school, district, national government)*

Do you face any obstacles teaching them? How?

Do the CwDs face any obstacles in your classroom, or in your school?

#### **5. Drop outs/ absenteeism**

Are there children in your class that are often absent?

Do you know the reasons behind the absenteeism?

Were there any CwDs that dropped out of school that you know of?

Do you know what the reasons were for the drop out?

How does the school deal with absenteeism or dropouts?

And the community?

What is done/ could be done to prevent absenteeism or drop outs?

How is it for you as a teacher when children drop out of school?

#### **6. Final**

Is there you would like to add, things you find that we haven't talked about?

Do you have questions?

## **Interview guide HM**

### **1. Introduction**

How many children are in the school?

How many of them have some kind of disability?

How long has the school been involving CwDs?

How many teachers are working in this school? And who decides the number of teachers?

What is the pupil -teacher ratio?

Since when does the school exist?

What is the background of the school?

What kind of CwDs can/ can not be in the school?

Which other schools provide Education for CwDs in the Kabarole district? (or Fort Portal)

### **2. Finances**

What are the financial resources of the school?

*(the role of government (UPE), PTA, SNE/IE, NGO's, other financial resources)*

Which financial resources are most important for the school to involve CwDs?

PTA:

How much is the PTA costs per student?

Who is involved with the PTA rates?

What happens if parents don't pay PTA?

What is payed from the PTA?

UPE and SNE/ IE grant:

What is payed from the grants?

How much are the grants?

When is it paid?

Other financial resources:

Which other grants does the school get?

NGO's?

### **3. Stakeholders**

- DIS (District inspector of Schools)
- DEO (District Education Officer)
- SNE officer (special needs education)
- UNEB (Uganda National Examinations Board)
- DEO/ Education department

Can you tell me about the different stakeholders and their relation to the school?

Which stakeholders are missing?

Which ones are most important to the school? And why?

### **4. Absenteeism/ drop outs**

What are causes for absenteeism or dropouts?

(ask specifically for)

- Parents'/ people's negative attitude towards CwDs
- Accessibility
- Large classes/ few SNE teachers
- HIV/ Malaria/ other epidemics



- Underfeeding
- Teen pregnancy
- Poverty

Which of these is the biggest problem for CwDs and their enrolment in education? Why?  
 What must be done to make it possible for CwDs to benefit education? And by whom?

### **5. Policy**

Which of the following policies affect the school? And how?

- SNE & IE policy 2011
- National policy on disabilities 2006
- Uganda Children's Act 1997
- People with disabilities act 2006
- Uganda pre-primary, primary, post-primary act 2008
- National Orphans and Vulnerable Children act 2004
- Local Government Act 1997
- National Development Plan 2010
- UN Sustainable Development Goals 2015
- Ratification of the UN rights of people with disabilities 2006

### **6.Final**

Is there you would like to add, things you find that we haven't talked about?  
 Do you have questions?

### **Interview guide SNE officer**

Can you tell me a about your job? What tasks do you have? What does it mean to be a special needs education officer?

When we look at education for CwDs, which stakeholders play an important role?

Which policies play a role for including CwDs in education?

What is your role in improving quality of education for CwDs?

What do you recognise as barriers to education?

What is your role in carrying out the policies for CwDs?

What would be the ideal situation for providing education for CwDs? What is needed and how could this be achieved?

## Appendix II: NSD approval



Randi Wærdahl  
Postboks 4 St. Olavs plass  
0130 OSLO

Vår dato: 13.09.2017

Vår ref: 55071 / 3 / LB

Deres dato:

Deres ref:

### Tilbakemelding på melding om behandling av personopplysninger

Vi viser til melding om behandling av personopplysninger, mottatt 07.07.2017.

Meldingen gjelder prosjektet:

<i>55071</i>	<i>Exploring School Dropouts for Children with Disabilities in Fort Portal, Uganda</i>
<i>Behandlingsansvarlig</i>	<i>Høgskolen i Oslo og Akershus, ved institusjonens øverste leder</i>
<i>Daglig ansvarlig</i>	<i>Randi Wærdahl</i>
<i>Student</i>	<i>Rosaline Cost Budde</i>

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

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

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget [skjema](#). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en [offentlig database](#).

Personvernombudet vil ved prosjektets avslutning, 01.10.2018, rette en henvendelse angående status for behandlingen av personopplysninger.

Dersom noe er uklart ta gjerne kontakt over telefon.

Vennlig hilsen

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