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‘Raising our Voices’

The perspectives of stakeholders on the challenges present within the service provision towards disabled children in Kabarole district, Uganda, and their suggestions for improvement

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Abstract

The service provision towards disabled children in the global south is often far from optimal, despite the fact that when a child has a disability, the health and welfare system around the child should be strengthened so that it is possible for the child to live a life as similar to children without a disability as possible. This case study aimed to gain an understanding of the perspectives of the stakeholders on the challenges that are experienced when providing services towards disabled children within the setting of Kabarole district, Uganda. As well as suggestions from the stakeholders on how these challenges could be addressed.

To collect these challenges and suggestions for improvement, 15 semi-structured interviews have been conducted in the last three months of 2017. These interviews were held among the various stakeholders, and included parents of disabled children, workers from community-based organizations, rehabilitation center. Two focus groups were organized afterwards which focused on sharing results from the interviews, gathering extra information on the challenges and suggestion on how to address the challenges

Eight main challenges were identified in the data; stigma surrounding disability, a knowledge gap about what disability entails among the stakeholders, lack of transparency which stakeholder is providing which services, inefficient use of resources due to overlap within the service provision, challenging communication and collaboration between the stakeholders, limited resources available to provide every disabled child in the district with those services that they need, missing a coordinating body due to low engagement from the local government in Kabarole district and cultural differences between Ugandan and 'Western' stakeholders leading to friction. These different challenges are interacting with one another and are together causing the service provision towards disabled children being less from optimal given the local circumstances

To address these challenges, the stakeholders suggested to focus on creating awareness about disability and to improve the coordination and collaboration between the stakeholders. Programs and approaches such as community-based rehabilitation and inter-organizational relations could be beneficial to organize the service provision in a locally efficient manner where as many disabled children as possible are benefitting from the services provided by the various stakeholders.

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Abbreviations

ACPF – African Child Policy Forum

CBO – Community Based Organization

CBR – Community Based Rehabilitation

CRC – Convention on the Rights of the Child

CRPD – Convention on the Rights of Persons with Disabilities

DID – Disability Inclusive Development

DPO – Disabled People Organization

ICF – International Classification of Functioning, Disability and Health

IDDC – International Disability & Development Consortium

IOR – Inter-Organizational Relationship

MGLSD – the Ministry of Gender, Labor and Social Development

NGO – Non-Governmental Organization

NDP – National Development Plan

UBOS – Uganda Bureau of Statistics

UN – United Nations

WHO – World Health Organization

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Definitions

Various terms are being used within this research, terms that can be understood from different perspectives. The list below provides an overview of the most important terms used and the way they are being understood for the purpose of this study.

Challenge: An issue experienced by one or several stakeholders while providing services towards disabled children in Kabarole district.

Disability: physical, mental, sensory and/or an intellectual impairment on a long-term basis, which may, due to the interaction with various barriers, hinder full and effective participation within society.

Service Provision: The provision of those services that are necessary to meet the needs of disabled children. These include both:

- *Mainstream services*: services that should be available to every person in Kabarole district. Such as general health- and education services.
- *Specialized services:* Those services that are needed because of the disability of a child, such as rehabilitation services, assistive devises and social support.

Specialized service provider: Providers of the specialized services. These are the employees of the community-based organizations, rehabilitation center and the disabled people organization.

Stakeholder: Individuals, organizations and institutions that are involved in the service provision towards disabled children in Kabarole district. These include, family members, the community, workers from main-stream services such as education and healthcare, the local government and specialized services such as rehabilitation- and community-based workers

1 Introduction

Within this study I aimed to grasp and understand the various challenges stakeholders experience while delivering services towards disabled children in Kabarole district, Uganda, as well as their views on how these challenges can be addressed. In this introduction chapter I intend to answer the question; Why is it necessary and relevant to study the experiences of the stakeholders regarding service provision towards disabled children in Kabarole district, Uganda? An introduction on the topic from relevant literature, reports and from 'on the site', as well as the relevance of the study will be presented. This will be followed by the purpose of this particular study and the presentation of the research question. In the last part of this chapter a reading guide will be presented which will outline the structure of this document.

1.1 Service delivery by stakeholders towards disabled children in low-resource settings

A person who has a disability has a physical, mental, sensory and/or an intellectual impairment on a long-term basis, which may hinder full and effective participation in society due to interaction with various barriers (UN 2016). Within this study I chose to focus specifically on the situation of children. When a child has a disability, the health and welfare system around the child should be strengthened so that it is possible for the child to live a life as similar to children without a disability as possible. Different steps should be taken by involved stakeholders to provide the services necessary for the child to meet their needs. These services include the facilitation of early diagnosis, sensitizing the parents and teachers about disability, as well as the provision of therapy, assistive devices and psychosocial support (Shrivastava, Shrivastava, and Ramasamy 2016, 29-30).

There are different people, organizations, and institutions that should be providing those services. These include the parents of the disabled child, workers from main-stream services such as education and healthcare, the community, the local government and specialized services such as rehabilitation- and community-based workers (WHO 2010). Next to stakeholders, the term of specialized service providers will also be used. These are the organizations that provided specialized services to meet the need of disabled children, such as rehabilitation. Together these people, organizations and institutions are in this study called the stakeholders. Further on in this report, a more detailed description will be given on the term's disability, services and stakeholders.

1.2 Perspectives on challenges within service delivery towards disabled children

Service provision towards disabled children in the global south, can be viewed from various perspectives. Numerous reports have been written and literature studies have been performed on disabled children in low-resource settings. These reports and articles, for example the reports from the World Health Organization (WHO), have outlined a number of issues that are interesting to study and which made recommendations for change to improve the service delivery. However, relevant and prevailing issues on micro-level or on the ground, might vary from area to area. The background of this study combines both micro- and macro perspectives, including issues that made me put emphasizes on service provision towards disabled children in the first place, as well as the issues found 'on site' when I started my fieldwork in Kabarole district.

I entered the field of research, Kabarole district in Uganda, with the following question: which issues are particularly present when considering disabled children in Kabarole district, Uganda and make an interesting study? Following the approach of Corbin and Strauss (2008, 21-23), I used the general topic of issues regarding disabled children in a preliminary research. By doing some initial interviewing and observations during the first weeks of my fieldwork, I discovered issues that were of interest to the stakeholders involved in the service provision towards disabled children in Kabarole district. I used these areas of concern as input for the focus of this study, aiming to assure relevance of the study for the respondents.

"*We don't know what they are doing"* was the phrase that I heard from the staff of the rehabilitation center where I was volunteering, when I asked about the activities of the other Non-Governmental Organizations (NGOs), Community-Based Organizations (CBOs) and the local government in the district. There was, according to the staff of the rehabilitation center, a lack of transparency about which services where provided in the district by the various organizations and the local government in Kabarole district. This lack of transparency was, to their opinion, leading to inefficiency and other challenges in the service provision towards disabled children. As an illustration of this inefficiency, I was told that some families in the district, 'were being seen' by at least four different organizations, without these organizations knowing from each other who exactly was providing which service, and at which frequency. This despite the fact that there are other disabled children and their families in Kabarole district that do not receive any services.

I found the lack of transparency about which organization is providing which services, potentially leading to inefficiency in service provision, an interesting issue. Especially since I was told that various organizations in disability service provision already collaborate in several ways. Because of this collaboration, I would assume or expect that they do have a good understanding of each other's service provision in the district. This due to the need to communicate when collaborating and to know who they can refer to for certain services when they identify a child with a disability.

Since the preliminary research only focused on one of the specialized service providers, I could not say if these challenges of lack of transparency and inefficiency were also experienced by the other stakeholders in Kabarole district, this required additional research. I therefore decided to focus this study on identifying which challenges are experienced by the various stakeholders, and how the stakeholders experience these challenges when providing services towards disabled children. I consider grasping the experiences of the stakeholder as essential when aiming to improve the situation of disabled children in a context as Kabarole district. It is important to identify what the 'real' issues are and to consider the views of the persons involved to create understanding and support for improvement.

Challenges in service delivery towards disabled children were also identified from reports and studies. Various challenges are reported regarding the provision of services towards disabled children and their families in developing countries. In the World Report on Disability, the WHO reports various barriers in the participation of people with disabilities in daily life. One of those barriers is the lack of provision of services. Persons with a disability are especially vulnerable to insufficiencies in services such as the lack of rehabilitation, support and assistance (WHO 2011a, 9).

Riche and Anyimuzala (2014, 3) performed a situation analysis on the rights of disabled children living in Uganda. Social norms of disability that are leading to discrimination are the first bottleneck outlined in their report. There is ongoing presence of stigmatizing attitudes towards disabled children, leading to, among other things, neglect and abuse. The negative attitudes towards disability often lead to problematic situations, where disabled children are hidden away, or where the mother and her disabled child are abandoned by the family. Stigmatization and negative attitudes are not only present at the level of the family and the community, but also at institutions, health care facilities, within education and at the level of the government (Riche and Anyimuzala, 2014, 78).

The second issue presented by Riche and Anyimuzala is that, though Uganda has several constitutional, legal and policy legislations in place for disabled people, it fails to implement these policies effectively and efficiently on the ground. This can be seen as an implementation gap of the policy. Reasons given for this implementation gap are processes and policy formulations that are too ambitious. Being too ambitious makes it difficult to implement the policies afterwards. Another reason is the lack of financial resources and budget allocated to execute the actual implementation. Limited budgets also result in the limitation of staff being able to force action (Riche and Anyimuzala, 2014, 78).

The third issue outlined in the report, the weakened institutional framework, can be attributed to two underlying causes; a lack of coordination among the key-stakeholders and a gap in knowledge and capacities among those stakeholders. The weak coordination is being seen between the various government institutions in Uganda, and other bodies that are concerned with matters that relate to disabled children. On government level, there are three different ministries designing and implementing policies that directly affect disabled children. These are the Ministry of Gender, Labor and Social Development, The Ministry of Education and Sports and the Ministry of Health. It is evident that the fragmentation among the various ministries is leading to fragmentation and duplication of efforts, on government level this results in flaws in the collection of data regarding disabled children. Among the stakeholders in the institutional framework, there is limited knowledge about disability and minimal capacities to mainstream disability in the already existing programs. The lack of understanding of the needs of disabled children, restricts the full realization of the rights of disabled children regarding inclusion in mainstream health services and the right to receive specialized rehabilitation services. (Riche and Anyimuzala, 2014, 82-83).

The weak institutional framework contributes to a fragmented programmatic approach and the design of small-scale initiatives from both government as well as non-government stakeholders, that lack long term vision and sustainability. They often focus on addressing practical issues, like building an accessible classroom, rather than focusing on structural changes for disabled children in Uganda, that will make a considerable impact on their lives. The programs that exists furthermore tend to focus on the 'easy-to-reach' children.

The fragmented approach results in the basic needs of disabled children not being met, which is especially seen in the health, rehabilitation and education sector (Riche and Anyimuzala, 2014, 85-86).

From a right based perspective, the service provision towards disabled people is named in the Convention on the Rights of Persons with Disabilities (CRPD), which Uganda ratified in 2008 (United Nations 2017). One right of the CRPD, that is especially relevant regarding the provision of services towards disabled children and their families is article 25, lid a, b and c, regarding health. According to this right, disabled people have both the right towards health care as provided to any other person as well as to those services they need because of their disability. In the concluding observations on the state report of Uganda on the CRPD (CRPD/C/UGA/CO/1), the committee reports on article 25, that it is concerned about the lack of information that is available on accessible health-care facilities for persons with a disability (Committee on the Rights of Persons with Disabilities 2016, 10).

Convention on the Rights of Persons with Disabilities - Article 25 – Health

"State Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. (…). In particular State Parties shall:

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons

(b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.

(c) Provide these health services as close as possible to people's own communities, including in rural areas. (UN 2006)

Summing up the perspectives presented in this paragraph, the reports and the situation 'on the ground' show both challenges regarding the service provision towards disabled children, despite that these children do have the right to sufficient services to meet both their regular health needs, as well as the special needs they have related to their disability. To be able to address the challenges that are specifically present in Kabarole district, it is important that they are understood well from the perspective of those who experience it first hand, which are the stakeholders.

Within this research, I gathered a bulk of data which was rich of information about the service provision towards disabled children in Kabarole district, the challenges experienced by various stakeholders and what the stakeholders themselves see as possible solutions to these challenges. The data collected has been analyzed to identify what stakeholders, with long experience of providing services towards disabled children, believe are the main challenges regarding the service provision in the district, and their views on how these issues related to the service provision towards disabled children in Kabarole district could be addressed.

1.3 The relevance of studying experiences within service provision towards disabled children

Disability is a condition that concerns many children and people and shows to be even more disadvantaging to those living in the global south. In general, scholars note a lack of research on disability, especially in the global south, and including Uganda (Grech 2016, WHO 2011a, Riche and Anyimuzala 2014). Disability does not seem the be ‘on the radar’ as a research topic due to other key-development issues within the global south, such as high mortality rates in women who give birth and in children under five, as well as issues within governance, education, poverty and climate change. This results in disability also not being not within the interest and priority of donors, policy-makers and practitioners (Grech 2016, 9).

In a report on global services and support to children with developmental delays and disabilities, Collins et al. (2017, 7) present various goals relating to research gaps within the identification and care of disabled children. One of these goals is improving programs and policies. The research priority should be put on evaluating programmatic and policy approaches targeting disabled children and monitor their coverage and results, analyzing to what extent programs that serve a broader population can be made equally available and beneficial to disabled children and their families. At last it is also essential to evaluate what can be done to improve the implementation of policies and programs as well as to learn from implementation successes.

The results of this study could be beneficial to the stakeholders in service provision towards disabled children in Kabarole district. Within this research several challenges, as well as suggestions for addressing these issues will be presented and discussed. This could be used by the stakeholders to improve the collaboration and the service provision towards disabled children. A study on the collaboration between stakeholders in Kabarole district could also be useful for other districts in Uganda, using the experiences in Kabarole district to understand and improve their own service provision. On a larger scale, this research will contribute to a broader understanding of the provision of services towards disabled children in a low-resource setting.

1.4 Aim and study objectives

The aim of this study is to get a better understanding of what stakeholders, involved in the service provision towards disabled children in Kabarole district, identify as the main challenges regarding the service provision and to understand in which ways these challenges are being experienced. The potential causes and consequences of these challenges will be examined and suggestions for improvements proposed by the stakeholders will be presented.

The study objectives for this research are:

- To identify which challenges are experienced by stakeholders involved in service provision towards disabled children in Kabarole district, Uganda.
- To understand which causes and consequences these challenges have according to the stakeholders.
- To explore what the stakeholders suggest as potential improvement to address the challenges present and how this could lead to improved service provision towards disabled children.

1.5 Research Questions

Within this study I aim to answer the following two research questions;

1) *Which challenge do stakeholders experience in the service provision towards disabled children in Kabarole district and how do these challenges influence the service provision towards disabled children?*

Within this question I will try to understand which challenges are being experienced by the various stakeholders, how they are being experienced, and what, according to the stakeholders themselves, are the causes and consequences of these challenges. I will also analyze the data to investigate if and how these challenges are related.

2) *Which suggestions do the stakeholders make to address the challenges and how can these contribute to improvement of the service provision towards disabled children?*

Within the data collected, many suggestions have been made by the stakeholders for improvement of the service provision towards disabled children in Kabarole district. Many of these suggestions are a response to the challenges experienced. I will focus on what the stakeholders see as improvements and how they think these suggestions can be implemented within Kabarole district.

1.6 Reading Guide

This report is split in seven individual chapters. In this first chapter, the introduction chapter, I introduced the research topic of challenges experienced by stakeholders regarding service provision towards disabled children in Kabarole district, from both reports written about disabled children, as well as 'from the ground' in Kabarole district. These formed the incentive for this research on which I presented the research aims and questions.

In the second chapter I will set the scene of this study. I introduce the concept of disability from various perspectives, as well as the relation that disability has in relation to the demographics of Uganda and specifically Kabarole district. I will also outline the legal framework of disability in Uganda.

Within the third chapter I outline the topic of challenges within service delivery towards disabled children from the literature. I also give attention to approaches that are proven to be effective when organizing disability service provision in low-resource settings. I will discuss the use of community-based rehabilitation and the concept of inter-organizational collaboration as methods to effectively (re-)organize the service provision towards disabled children. In this chapter the concepts of stakeholders and service provision towards disabled children in the global south will also be discussed.

The fourth chapter will be used to outline the methods used in this study. Focusing on the study design, sampling- and data collection strategies, as well as the methods used for analyzing the data. I will also discuss the ethical considerations and the ways in which I accounted for the quality of the research.

In the following, fifth chapter, I present the results from my research. These results are presented in two individual parts. Within the first part I will focus on the various challenges experienced by the stakeholders in Kabarole district, before I move on to their views on how these challenges can or should be addressed.

In the sixth chapter I will discuss the results of my study in relation to the literature presented in the first three chapters. I will compare the challenges experienced by stakeholders in Kabarole district, and the suggestions made for improvement to the literature presented in the chapters one till three.

The conclusion will follow in the last chapter, where I focus on the meaning of the outcomes of this research and the use of it in Kabarole district and on a broader perspective. I will also give suggestions for further research to be done as a response on this research.

2 Setting the Scene of Disability in Uganda

In the following chapter, I will give a brief overview of the history, culture and demographics of Uganda and Kabarole district and in which ways this interacts with the service provision towards disabled children and disability in general. I will touch upon those points that are important to address when researching the challenges experienced by stakeholders within the service provision towards disabled children in Kabarole district.

2.1 Defining the Concept of Disability in Sub-Sahara Africa and Uganda

There are various definitions used for disability, both in Uganda, in low-income countries and in the world in general. Next to these differing definitions, there are varying individual and cultural understandings of what disabilities imply (Riche and Anyimuzala 2014, 2). Looking at the definitions of some of the key players in the field of disability in low-income countries and Uganda, we see that the government of Uganda uses the term 'person with disabilities'. They define persons with disabilities in the Ugandan Persons with Disabilities Act 2006 as; *"having physical, intellectual, sensory or mental impairments which substantially limits one or more of the major life activities of that person"* (The Government of Uganda 2006).

To identify people with a disability in Uganda, the Ugandan Bureau of Statistics (UBOS), uses four different questions related to disability in their household surveys. In their latest household survey, from 2014, a person is classified as having a disability whenever they have at least some difficulties on one of the questions. Someone was reported as having multiple disabilities whenever they reported difficulties on at least two of the questions. These questions asked whether a person or child has difficulty in either hearing, seeing, walking or climbing steps and remembering or concentration (UBOS 2017).

The United Nations (UN), in the Convention on the Rights of Persons with Disabilities (CRPD), adopts a rather broad definition, and includes 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*" (UN 2016).

When conceptualizing disability, there is the question about who to include, and who to exclude. According to Marks (1997, 85), one of the challenges is that the capacities and values given to bodies, learning abilities and emotional capacities are contested and to a great extend changeable. The 'system' expects disabled people to meet a fixed list of functional capacities, which can be measured. However, individual disabled people belonging to a certain 'impairment category', such as mentally, visually or physically, have very differing characteristics.

In the literature and reports I studied for this research, terms as impairment, handicap or physically and/or mentally challenged were used alongside disability. Next to these different terms that are being used, the definition of disability can also vary among individuals, societies and countries. This makes it challenging to give a unified explanation of the concept. Since this study concerns individuals from different organizations, cultures and backgrounds, I therefore choose to focus on explaining different ways how disability can be understood in the following paragraph, rather than focusing on giving a set definition of disability for the purpose of this study.

Marks and other scholars distinguish between a medical model and a social model of disability; The medical model focuses on the individual and finding an accurate diagnosis. It aims to find ways of preventing, curing and caring for disabled people. The social model, on the other hand, focuses on the role of disability within a certain social environment, such as family, community or even beyond that. Policy-makers tend to focus on the medical model in order to address disability related issues such as prevalence, treatments, services and benefits (Marks 1997, 86-88).

According to the WHO, neither the medical nor the social model of disability are adequate but are both partially valid. The WHO therefore attempted to provide a standard language and framework about disability with their *International Classification of Functioning, Disability and Health* (ICF). Within the ICF, disability is seen as *"an umbrella term for impairments, activity limitations and participation restrictions* (WHO 2002, 2). It is a conceptual basis that can be used for definitions, measurements and policies related to health and disability. It can be used on the individual level, such as for assessment- and treatment planning, at institution level, for, for example, education and training purposes and on the social level for policy development, and needs assessments (WHO 2002, 2-6).

Within the ICF, disability is understood as a complex phenomenon, which is both in interaction with the level of the individual body, as well as on the social level. For this reason, the ICF opts for a different model, including what is valid about both the medical and social perspective. This '*biopsychological model'* (see figure 1) includes different perspectives of health; namely the biological, individual and social perspective (WHO 2002, 9).

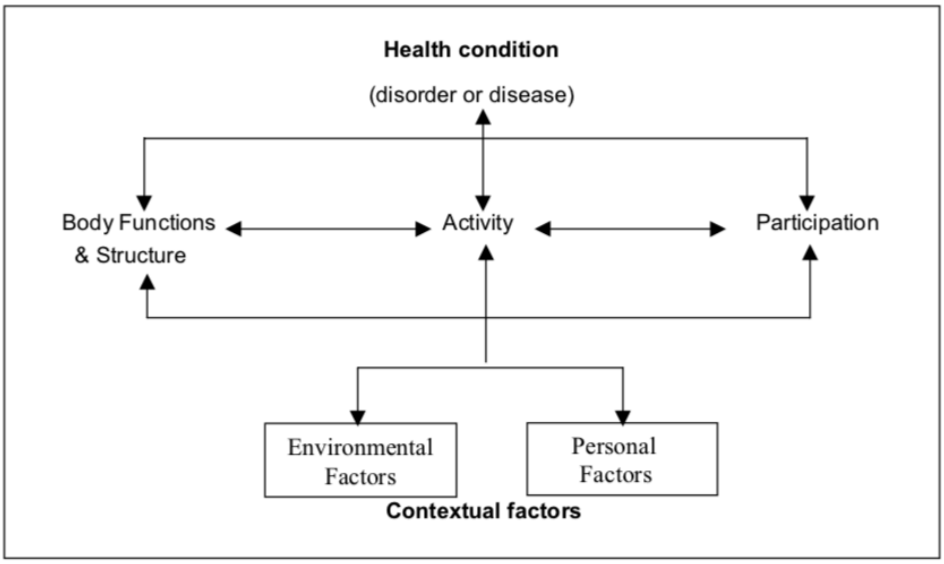

Figure 1: ICF Biopsychological Model

The model indicates an interaction between health conditions and contextual factors. The health conditions include the medical side, such as disease, disorder and injuries. The contextual side is split in two; The environmental factors focus on the external aspects, such as social attitudes, structures but also climate. The personal factors focus on the internal aspects such as gender, age and coping styles. The middle part of the diagram, includes the three levels where disability can occur: impairments in body functioning & structure, limitation in activity and restriction in participation (WHO 2002, 10).

The WHO would like to see that the ICF is used as a universal model for understanding disability, both to identify the needs of a disabled person, but also as for data gathering and policy uses within health and health-related sectors (WHO 2002, 19).

Considering disability in low-income countries as Uganda, there are a few aspects that should be taken in to extra consideration. Stone-MacDonald and Butera (2014) argue in their article on cultural believes and attitudes about disability in East Africa, that definitions and concepts of disability vary across countries and communities, even only looking at East Africa. It is therefore difficult to establish a set concept in this area. In countries in East Africa, you are considered to be disabled or not, based on the functional capacities of individuals to complete life tasks without help from others. Therefore, something might be seen as a disability in East Africa what is not seen as a disability in the developed world. Their literature review showed that individuals in East Africa are more likely to experience stigma and discrimination when they cannot participate in aspects of normal life, rather than because of obvious physical deformities or diagnostic labels (Stone-MacDonald and Butera 2014).

Parnes et al. (2009, 1171) adds on this by arguing that disability in low-income countries is interrelated with many other cross-cutting issues. For example, poverty is linked with disability, and both poverty and disability are linked with gender and health, and all are related to discrimination and stigma. Therefore, Parnes et al. (2009) argue that disability cannot be seen in isolation, it is interwoven with all aspects of an individual's life and has different implications at different stages of someone's life, which is in line with the ICF model from the WHO. How these different cross-cutting issues influence the life of a person with a disability is best understood from the social model, which can provide a framework for understanding the nature of the cross-cutting issues. This does, however, not mean that the medical model is not important, sometimes a disability can be easily addressed with medical aid.

Language used to describe disability has been rapidly developing over the last century. The most common way to talk about disability these days, for people in high income countries, is the so-called people-first language. Where in the case of disability you speak about 'people with a disability' or 'children with a disability'. The reason behind this is to avoid defending a person on terms of his or her disability (NCDJ n.d.). However, others opt for using another approach, which is called the identity-first language. This terminology is preferred by various disability groups because they consider their disability to be inseparable parts of who they are, they embrace their disability as their identity (NCDJ n.d.). Both approaches were seen in the literature used, and in the data collected throughout this research. Therefore, followed the approach suggested by Dunn and Andrews (2015, 261), using both identity-first and person-first language interchangeably to acknowledge to role and perspective of both disabled people, the insiders and people without a disability, the outsiders.

To conclude this section, it is important to acknowledge the different views that people might have on disability, depending and in interaction with culture, personal views and cross-cutting issues. It can influence how and to what extent services are provided towards disabled children. Since this study is focusing on the stakeholders who provide services towards disabled children, and only targeting the children indirectly, this study concerns those children with a disability that have been identified by the stakeholders as having a disability and need some form of specialized services because of their disability. I acknowledge and respect that these stakeholders all have their own individual view on disability.

2.2 Uganda's demographics and the influence on disability

Uganda is a landlocked country in the east of Africa. It borders South Sudan, Kenya, The Democratic Republic of Congo, Tanzania and Rwanda and has a total area of 241.511 square kilometers (UBOS 2016, 1). On administrative level is Uganda divided in districts, which are further divided in counties, sub counties, and parishes. The local governments in these administrative units have the tasks to monitor and implement government programs at the respective level (UBOS 2016, 1). This includes the planning and delivery of rehabilitation services towards disabled children and ensure that government programs targeting disabled children are implemented in the district.

Kabarole district, the district to be studied in this research, is located in the southwest of Uganda, close to the boarder of the Democratic Republic of Congo. Kabarole district is one of Uganda's 112 districts in the household survey from 2014. However, these numbers have changed since then. By an act of Parliament in September 2015, it was decided that 23 new districts were to be created over the next four fiscal years. These new districts also effect the area of interest in this thesis. Kabarole district, previously consisted of three sub-counties, Bunyangabu, Fort Portal Municipality and Burahya. Since the 1st of July 2017, short before the data collection of this research, Kabarole district only consists of Fort Portal Municipality and Burahya county, Bunyangabu county became an individual district (Envision 2016). This research used the 'new' Kabarole district as research area.

2.2.1 Population & Disability

In the most recent National Population and Housing Census from the Uganda Bureau of Statistics (UBOS 2016, 8) the national population size was 34.6 million with an average annual growth rate of 3.0%. The Ugandan population is characterized by a young population with 55 percent of the population under the age of 18. This age distribution is a reflection of fertility and mortality in the past (UBOS 2016, 14). The high population growth can, among other things, be contributed towards the decreased childhood mortality rate. In 1991 there as an infant mortality of 122 per 1000 life births, this decreased to 53 in 2014. The under-five mortality rate decreased from 203 per 1000 life births in 1991 to 80 in 2014. The rapid growing population can also be contributed to the increased life expectancy. In 1991 the life expectancy was 48.1 years at birth, where it is currently 63.3 years (UBOS 2016, 17).

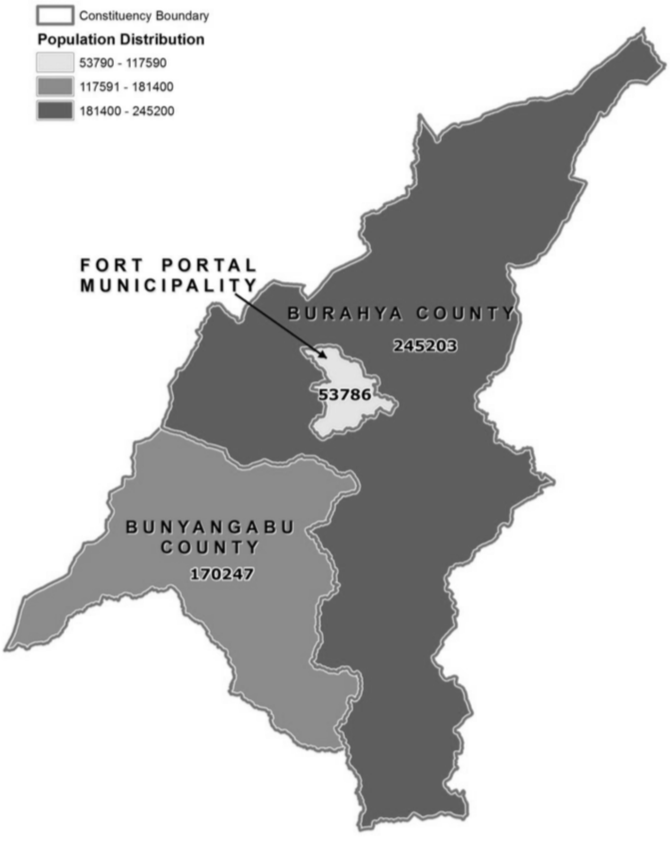

Figure 2:Population Sub-Counties Kabarole District

In Kabarole district, under the old district distribution, the total population size in 2014 was 470.000 inhabitants, with a percentage of 52.8 percent between 0 and 17 years. Looking at the new distribution where only Fort Portal municipality and Burahya county are included there is a total population of nearly 300.000 (see figure 2, (UBOS 2017, 8)). The increasing population and over half of the population being under the age of 18, makes children an interesting scope for this research. An increased population and decreasing mortality will, assumable, also mean more children with a disability that are in need of a form of specialized services.

According to the World Report on Disability from the World Health Organization (WHO) (2011a, 7), there are more than one billion people in the world, who live with some form of disability. This is about 15% of the world population. Disability is disproportionally affecting vulnerable populations; the prevalence of disability is higher in low-income countries, than in high-income countries. In Africa, the prevalence of moderate and severe disability among the age group 0-14 years is 6.4%, compared to 2.8% in high income countries and 5.1% in the whole world (WHO 2011b, 30).

In Uganda, the percentage of the population that is 2 years and above, with a disability is in the most recent housing census 12.4 percent (UBOS 2016, 22), in Kabarole district, 12.3 percent of the population aged 2 years and above has a disability. This lies just under the national average (UBOS 2017, 23). Specific numbers of people and children with a disability are available for the different districts and counties. In Fort Portal Municipality, there were a total of 717 children aged 2-17 identified with a disability and in this number was Burahya 5.216. Children under the age of 2 were not included in the counting. This brings the estimated total children with a disability within the age of 2 – 17 in the 'new' Kabarole district on almost 6000. With a total amount of almost 132000 children between the age of 2-17, it brings the disability rate among children in Kabarole district on 4.5% (UBOS 2017, 2016). 6000 children that have a form of a disability shows, to my opinion, the need for well-organized and sufficient service provision to meet the needs of all these children.

It is important to note that data relating to disabled children in low-resource settings and specifically in Uganda is scare, and to an extent unreliable (Riche and Anyimuzala 2014, ACPF 2011b). According to the ACPF (2011b) there are three reasons for this; there is low investment in systems that gather such data, the stigma surrounding disability, which likely results in surveys leaving out significant numbers of disabled children and that that the definition of disability is still contested. Riche and Anyimuzala (2014) note that the measurement of the prevalence of disability is problematic due to the differing individual and cultural perceptions of what a certain disability implies and inadequate data collection tools where the wording and number of questions differ in different surveys and questionnaires.

2.2.2 Economy, Development & Disability

The largest part of the population of Uganda is working within agriculture, with a total of 64.7 percent of the total population that is working (UBOS 2016, 29). Agriculture is also the most important form of work an income in Kabarole district, with 80.3 percent of the household engaged in crop growing (UBOS 2017, 27). In the past years, Uganda's national development index has increased, partly because of the initiative by the Government to provide free primary and secondary education (ACPF 2011b, 4). According to the poverty assessment from the World Bank, Uganda has at a rapid rate reduced poverty. The part of the Ugandan population living below the national poverty line (ranging from US$0.88 to US$1.04 (2005) per person per capita depending on the region) declined with 11.4% from 31.1% in 2006, to 19.7% in 2013 (World Bank 2016). This decline in poverty and the economic growth can be attributed to increasing export, nearly 50 percent of the total export earnings of Uganda comes from agriculture, with coffee, tobacco and fish being the main export products. The rise of industry and service sectors also contributes to positive growth.

However, it can be expected that this decline in poverty is less applicable on people and children with disabilities. According to reports on children with disabilities in Africa, a lot of disabilities that occurred can be traced back to poverty. Poverty induces diseases and a lack of resources to establish proper nutrition and preventive and curative health care contributes to an even higher number of disabilities (ACPF 2011a, UNICEF 2013, Grech 2016). Poverty can also increase and intensify disability, while the onset of disability increases or leads to poverty. Next to the higher risk of becoming disabled, the children are also more likely to be denied basic resources to mitigate and prevent getting deeper in to poverty once they are disabled. Poverty and disability seem to strengthen each other, which increases vulnerability and exclusion (UNICEF 2013, 7)

2.2.3 Culture & Disability

Uganda has a diverse culture, which include different religions, tribes, ethnicities, believes and languages. Despite some recent changes in traditional values due to migration and intermarriages, do these different culture characteristics still play an important role in the behavior and daily life's of Ugandans (UBOS 2016, 4).

In Uganda, the largest religious group is Catholics, consisting of almost 40% of the population, followed by the Anglicans with 32% and Moslems with almost 14%. These three religions account for more than 80% of the total population. Other religions are Evangelical, Seventh Day Adventist and Baptist. Only 0.2 percent of the population is registered as 'Non-Religion' (UBOS 2016, 19).

Culture and religion have a strong influence on the way disability is viewed upon in Sub-Sahara Africa. Parents and others that have a close connection to the child with a disability are often aware of their challenges and needs, but socio-cultural believes and attitudes constraint the support given to disabled children and the realization of their rights (Riche and Anyimuzala 2014, 39). According to UNICEF (2013, 4) are children with disabilities among the most excluded and marginalized in the world. The reason for this is widespread violation of their rights, caused by the negative cultural and religious believes about disability. A recent article by the BBC outlined how mothers of disabled children are encouraged to murder their child, because their children were considered "cursed, bewitched and possessed" (Soy 2018).

2.3 Uganda's legal framework regarding disability policies

Uganda has been praised by their advocating for the rights of people with disabilities (Abimanyi-Ochom and Mannan 2014, 1). Their rights are fostered in several laws of the national legal framework of Uganda. In the Constitution of 1995, disabled people are mentioned under article 35: *"persons with disabilities have a right to respect and human dignity, and the State and society shall take appropriate measures to ensure that they realize their full mental and physical potential"* (Republic of Uganda 1995).

Next to the strong legal framework, Uganda also has a high number of elected people with a disability in different political levels, from village, to parliament. Other positive progresses that Abimanyi-Ochom and Mannan (2014) mention are; Uganda's commitment to provide education to disabled children, a strong training focus on community-based rehabilitation, the inclusion of disability questions in household surveys for better data collection and programs to improve the social-economic opportunities of vulnerable people, including people with a disability.

At district and sub-county level, it is the Department of Community Development who handles disability issues and is responsible for social rehabilitation. This is regulated in the Local Government Act from 1997. On paper, the district councils are responsible for aid and support towards disabled people (The Government of Uganda 1997). The Local Government Act embodies the decentralization of the governance system (ACPF 2011b, 4).

Local governments are supposed to ensure descent service provision toward disabled people and the implementation the Community Based Rehabilitation program in their district as part of the national strategy for planning and delivery of rehabilitation services (ACPF 2011b, 7).

2.3.1 National Legislations and Policies

The four main legislations, policy and strategies that I consider to be relevant when studying the challenges experienced by stakeholders providing services towards disabled children, are the National Development Plan, The National Action Plan for Children with Disabilities 2015/16-2019/20, The National Council for Disability and The Persons with Disability Act 2006. A short overview of these legislations and their relevance for this study will be outlined below.

National Development Plan

The future development of Uganda is guided in the National Development Plan (NDP) which focusses on the development of Uganda towards 2040. The NDP is implemented through several other plans, from different sectors, ministries and local governments. In the current NDP, which is the NDP II, there is specific attention for disability. They note that during the NDP I, negative attitudes were tackled through advocacy, networking, awareness raising, and reviewing policies to make them 'disability sensitive'. The current government strategy for interventions towards disabled people is the Community Based Rehabilitation (CBR) method. At the time of writing the NDP II, in 2015, there were only 26 districts that accessed funding for CBR. Kabarole district is not included in these 26 districts. The limited amount of districts assessing funding for CBR is noted to be a big gap (The Government of Uganda 2015, 69). The CBR method and how it can be beneficial for disabled children will be touched upon more in detail in the next chapter. Remarkable is that the NDP II does not give any specific plans on how to improve the lives of disabled people in the coming years. Though noted along other vulnerable groups such as women, children and elderly, there is no specific attention for disability.

The National Action Plan for Children with Disabilities

The National Action Plan for Children with Disabilities 2015/16-2019/20 from the Ministry of Gender, Labour and Social Development (MGLSD) is one of the leading documents regarding the future agenda for disabled children in Uganda. It builds upon the outcome of the research from Riche and Anyimuzala (2014) on the rights of disabled children in Uganda.

The goal of the National Action Plan is to: "*Foster the holistic inclusion of children with disabilities in protection and participation for responsive and responsible growth for national service and development"* and focuses on four action areas: performance enhancement, which includes capacity enhancement, motivation for work and the creation of an enabling environment. The second area is participation and inclusion, concentrating on the holistic and inclusive development of disabled children in collaboration with all stakeholders. The third area, coordinating and networking, is specifically targeting the scattered programmatic approach, by improving coordination and networking at all levels. The fourth and last area focusses on the development and enforcement of the legal and policy framework on children with disabilities (Ministry of Gender Labour and Social Development 2016).

Both National and Local government have a key role in the implementation of the National Action Plan. The MGLSD is the overall coordinator for the implementation of the activities mentioned within the different areas. On local level, it is the Senior/Community Development Officer that is responsible for disability and elderly affairs who is responsible for the local implementation (Ministry of Gender Labour and Social Development 2016, 25).

The National Council for Disability

The National Council for Disability was established through the National Council for Disability Act, 2003. The objectives of this council include: "*to advocate for and promote effective service delivery and collaboration between service providers and persons with disability;* (The Government of Uganda 2003). The practical implementation of this objective is however not included in this act. The ACPF (2011b, 8) reports that this body also acts as a linking body between the state, the non-state service providers and the disabled people for coordination of services. The act itself, however, does not report how they implement their regulation or objectives. The concluding observations on the CRPD state report from the UN also notes this lack of strategy from the National Council for Disability to coordinate public policies (CRPD/C/UGA/CO/1, UN 2016, 13).

The Persons with Disabilities Act, 2006

The objectives of the Persons with Disabilities Act are focused on the participation and inclusion of disabled people in all sectors and aspects and to promote positive attitudes towards disability (The Government of Uganda 2006). Article 10 does provide a framework towards rehabilitation. In this article, the government assures to *"adopt measures of rehabilitation to help persons with disability regain functional ability to enhance participation in social and economic life"* (The Government of Uganda 2006, 6). In article 28 of the act, regarding the right to supportive services, the government promises to provide different supportive social services to disabled persons through assistive devises, personal services, specialized training, counseling and rehabilitation. The act recognizes that disability is a multisectoral issue, and needs therefor be addressed with the help from all sectors (The Government of Uganda 2006, 11).

2.3.2 The gap between policy and practice

When talking about Uganda's Legal Framework regarding disability services, it is important to note the gap between policies made by the government and the implementation of these policies. Abimanyi-Ochom and Mannan (2014, 5) in their research on the progress and challenges in Uganda's disability journey, concluded their paper by the statement that Uganda has 'exceled' by establishing a legal framework for people with a disability, but that a gap continues to exist between laws, policies and practice. This implementation gap makes monitoring progresses that are being made difficult and discourage prioritizing resources towards disability.

Katsui and Kumpuvuori (2008) found a similar gap between policy and practice in their study on disability in development in Uganda from a human-rights based approach. Their study shows the same gap but calls it a gap between political space and social space. This gap leads to that the needs of the people on 'grassroots level' are not met. Reasons given for this gap relate to the failure of the disability movement to challenge the government, and the competition between state and non-state actors over resources and recognition (Ibid, 2008, 232). The only disabled people that seem to benefit are the once with the right pre-conditions, such as being equipped with the right assistive devises, and being skilled in sign language, but the majority of disabled people does not manage to get these preconditions fulfilled, and can thus not benefit from the available political space (Katsui and Kumpuvuori 2008, 232). It can therefore be concluded that despite the political space, actual intervention does not seem to be reaching PwDs at grassroots level, which limits their social space (Ibid, 232).

The ACPF attributes the gap between policy and implementation to a lack of resources available to invest in disability services, such as health, education and rehabilitation. The majority of disabled children are, just like the rest of the population, living in rural areas. Although services are available from the government, NGOs and the private sector, the family remains the main provider of financial and emotional support towards their disabled child. The services that are being delivered by actor's other than the family, then to focus on specific needs, such as surgery, assistive devises or sponsoring of education (ACPF 2011b, 59). Most of these service providers do not target families in a holistic manner, although disability is affecting the whole family. The ACPF study showed that, despite there are many disability-focused service providers, they are not making a massive impact on the lives of disabled children and their families (ACPF 2011b, 59).

2.4 The scene of Kabarole district and the relation to this research

Within this second chapter I presented the scene of Uganda and Kabarole district in relation to disability. Considering the way disability is conceptualized within a setting as Kabarole district, how certain demographics relate to disability, which policies are present in Kabarole district relating to service provision towards disabled children and how these policies function in practice is valuable information within this research. What has been outlined in this chapter can be related to the challenges experienced on the ground and also regarding the suggestions made to address these challenges. What has been presented in this chapter will therefore be used in the discussion section of this study.

3 Service provision towards disabled children in low-resource settings

How should the service provision be organized among the various stakeholders involved to provide disabled children, within a defined area, with those services to meet their needs? Many different suggestions have been made in literature and reports around the topic of service provision towards disabled people in low-resource settings, such as various approaches, models and programs, which will be presented and discussed in this chapter.

The topic of service provision towards disabled children in low-resource settings touches on different research areas within the social sciences. Disability research, organizational research and social development research are three of the research areas on which this study touches. These different fields of research will all be used within this literature review and later on be used in the discussion section as a comparison with the situation in Kabarole district.

3.1 Organizing service delivery towards disabled children

In regard to the bottlenecks and barriers that hinder the realization of the rights of disabled children, Riche and Anyimuzala (2014, 117), give several recommendations on how to address these bottlenecks and barriers. Though most of these recommendations focus on changes within higher, national government level, there are several recommendations that are related to service provision on local level, and therefore interesting for this particular study.

First of all, knowledge should be built about the needs of disabled children and the capacities of stakeholders should be strengthened. To realize this, the perspectives of disabled children should be mainstreamed in all programs and services. Programs relating to prevention, health and rehabilitation and increased access to education should be realized, as well as changes in social norms and awareness-raising. However, Riche and Anyimuzala (2014, 116) note that these recommendations are not ‘of-the-shelf’ solutions to the problem and that further research needs to be conducted to address issues within the various sectors and on different levels. They note that a stronger programmatic approach is needed to realize the rights of disabled children and that all these programs, should be designed, implemented and evaluated in close collaboration with all stakeholders.

Though there are no definite solutions to the challenges faced by disabled children and their families, several approaches have been suggested to address issues in organization, collaboration and coordination of service delivery towards disabled children. Reports and studies on disability in the global south suggest various approaches on how to organize the service delivery directed towards disabled people. These strategies, and what they contribute will be outlined in the section below.

3.1.1 Approaches for service delivery towards disabled children

According to UNICEF the support and development of children with disabilities needs a so-called twin-track approach. This twin-track approach recognizes in the first place that disabled children and their families have ordinary needs and must therefore be included in mainstream programs and services like health care and education. The other side of this approach consists of specialized care that is specifically targeting disabled children (WHO and UNICEF 2012, 21). Which type of specialized care they need, depends on the type of disability. These services include rehabilitation, surgical interventions, assistive devices or mobility aid such as wheelchairs and modification of the environment such as ramps or accessible transport (UNICEF 2013, 13).

The WHO recommends in the Global Disability Action Plan 2014-2021 different support mechanisms to improve the continuation of care experienced by people with disabilities across their lives. These support mechanisms include: discharge planning, multidisciplinary team work, development of referral pathways and service directories (WHO 2015, 12). This requires, a multi-sectoral approach, with effective coordination between the sectors. This can ensure adequate support, improved service outcomes and reduced vulnerability (WHO 2011a, 14-18) This multi-sectoral approach to provide care to disabled children and their families requires collaboration across the health system as well as collaboration among the different sectors that are involved (Collins et al. 2017).

Development initiatives in general, are often being implemented from a top-down method. Initiated and designed by policy-makers that are located far away from the community level. It is being recognized that involvement of the community and individuals is the essential element of development (Axelsson 2008, 42). According to WHO (2010, 21) does this, so called, community-based approach, help to realize that development reaches all layers of the community and facilitates initiatives that are more inclusive, realistic and sustainable.

The ACPF argues that, regarding the service delivery towards disabled children in Africa, there should be a shift from a charity-based approach, towards a human rights-based approach (ACPF 2011a, 53). From a right-based perspective, there are two main conventions that come in play when addressing the situation of disabled children. These are the Convention on the Rights of Persons with Disabilities (CRPD), which Uganda ratified in 2008, and the Convention on the Rights of the Child (CRC) which was ratified in 1990.

The human-rights based approach can be seen in opposite with the charity-based or welfare-based approach. These approaches have traditionally been predominant in development interventions within the field of disability. The charity-based approach focusses on fulfilling the material needs of disabled people, which in practice means technical aid, nutrition and health services. Charity-based approaches often fail in empowering disabled people in making decisions about their own lives and to take active ownership of themselves. The charity-based approach can be drawn back to the medical model of disability, as outlined in the previous chapter. The human rights-based approach, on the other side, has been arising together with the social model of disability.

Though the human-rights based approach might sound interesting, there is critique on this approach, especially on the implementation of the approach in the Global South. As Grech (2016, 8) argues; *"While rights and policies may look good on paper, they mean very little in practice for the poorest who struggle to eat, who have more immediate and practical needs, who may not even know what their rights are and who do not have the means to seek redress."*

This leads to human-rights, including the CRPD and CRC, often only being good intentions, rather than hard improvements in welfare for disabled people. Examples given by Katsui and Kumpuvuori (2008, 230) include the implementation of new programs that are based on human rights, where human-rights are not mainstreamed, but only implemented in a limited context. Another example is development cooperation claiming that they have contributing to human rights all along. Uvin (2004) concludes that, regarding the practice of the human rights-based approach, vagueness dominates. The conversation about human rights stays at theoretical level and is not reaching the practical level. Disabled people seem to prefer a charity-based approach, where they receive material benefits like food and blankets, rather than skills and knowledge (Katsui and Kumpuvuori 2008, 233).

3.1.2 Community-Based Rehabilitation

The WHO developed a model for the organization of service provision towards disabled people in low-resource settings, which is known as Community-Based Rehabilitation (CBR). The WHO underlines that CBR includes many of the above presented approaches (WHO 2015, 5), with a focus on the twin-track, community-based and human-rights approach and the recognition that multi-sectoral collaboration is needed to secure sustainable CBR implementation.

CBR was initiated by the WHO and originally started as a strategy to improve the access to rehabilitation services for people with a disability in developing countries, to provide a form of rehabilitation or support services through the local community, using local resources (Kuipers and Sabuni 2016, 453), but has developed further in a multisectoral strategy to address the different needs of disabled people, ensuring their participation, inclusion and improving their quality of life (WHO 2010, 1).

Together with different non-governmental organizations, disabled people's organizations and other stakeholders within the support for people with disabilities, the WHO wrote guidelines and created the CBR-matrix, which provides the scope and structure to the CBR guidelines (WHO 2010, 13). This matrix is built up consisting five key components: health, education, livelihood, social and empowerment. Within each of these five components there are five elements (see figure 3). The health, education, livelihood and social elements relate to sectors that are essential to the development and are reflecting the multidisciplinary and multisectoral scope of the CBR. The last element, empowerment, refers to the empowerment of people with disabilities, their families and communities (WHO 2010, 24).

Individual organizations or programs are not expected to cover all the different elements of the CBR-Matrix within their scope. The different programs can select which of the elements covers the present local needs, resources and priorities. The CBR programs need to develop partnerships with other programs and services providers it can be ensured that people with disabilities and their families are able to access all the different elements of the CBR-matrix (WHO 2010, 24). CBR can be implemented locally, regionally or nationally. This depends on who is implementing the program, what the resources are and what the area of intervention will be (WHO 2010, 35).

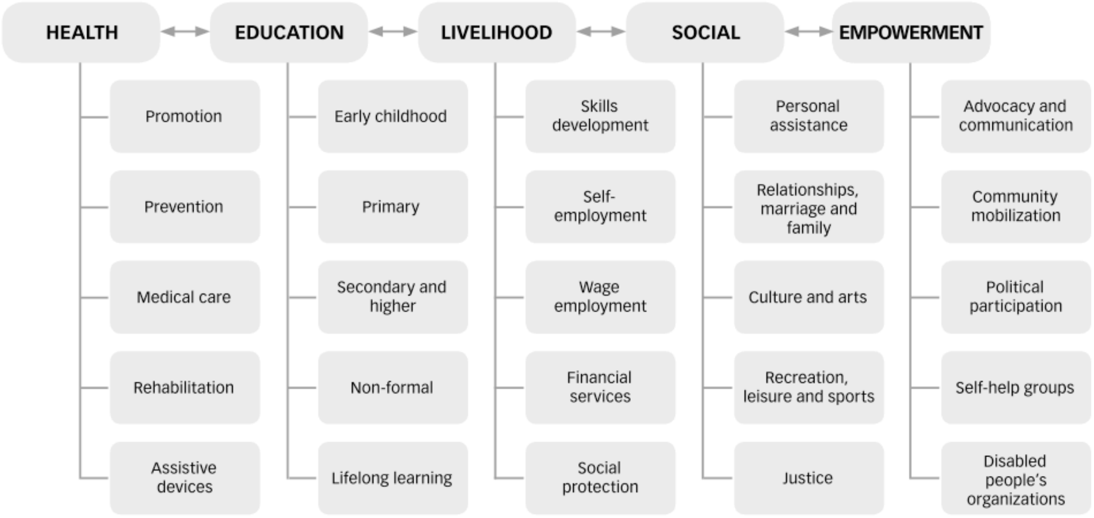

Figure 3: Community Based Rehabilitation-Matrix

The matrix also provides a basic framework for the development of new CBR programs. It is important to note that the CBR-matrix and its guidelines do not provide a set framework for the provision of CBR within a certain area. Every CBR program contains its own unique elements because of physical, socioeconomic, cultural, political and other factors within its scope (WHO 2010, 33).

The implementation of CBR is usually initiated by someone outside of the community, such as the government or an NGO. Whoever initiated the implementation, it is important to guarantee that the necessary resources are available and that the community is ready for the development and implementation of the program. Participation of people with disabilities and their families is very important throughout the whole process of implementation. Their experiences, observations and recommendations provide valuable information and inputs for the design of the program and will help to adjust to the needs that are present among the disabled people, their families and the community (WHO 2010, 36).

In recent years, there has been, next to the CBR method, also attention for Disability-Inclusive Development (DID). This move was initiated by the idea that service provision towards disabled people should move beyond traditional rehabilitation and emphasize inclusion and rights, related to the earlier presented twin-track approach. DID is initiated by the International Disability & Development Consortium (IDDC). Which is a network of 23 DPOs and international NGOs who support the inclusion of disabled people in over 100 countries (IDDC 2010, 1). With DID the IDDC promotes: *"respecting the full human rights of every person, acknowledging diversity, eradicating poverty and ensuring that all development processes are inclusive of- and accessible to all persons with disabilities"* (IDDC 2010, 1). It focusses on inclusion of disability within all phases of the development cycle (design, implementation, monitoring and evaluation) and that people with disabilities are meaningful and effectively participating in the development processes (IDDC 2010, 3)

It is being argued that DID can be seen as the goal, and CBR as the method to reach that goal. DID can then be seen as the end result, where disabled people are included in development, community and society and CBR functions as the key to achieve this end result (Kuipers and Sabuni 2016, 464). Kuipers and Sabuni (2016, 455-463) argue that both CBR and DID have positive and negative sides. In the case of CBR, cost-effectiveness and evidence of outcomes have not been demonstrated. It is also being criticized for not including the voice of disabled people and that it is too much of a Western model, which results in insufficiently considering of religion and gender differences in the global south.

Though Kuipers and Sabuni (2016) agree that the importance for CBR in the global south is clear, they question whether the various methods provided, such as the CBR Guidelines, The CBR matrix and adoption of DID, will give enough support to address these limitations. It is important that there is not only a focus on 'upstream' agendas, where there is being looked at the big picture of conceptual and human rights issues and management concerns. But also focus on a 'downstream' agenda, focusing on the needs of the disabled people and their individual inclusion and social participation. It is further important to note that 'western' models cannot be replicated on every situation. The social and cultural histories of the country need to be taken in to an account when assessing the possible implementation of a western model (Parmenter 2008, 130). Looking at service delivery models for people with a disability, it is suggested by Kishore (2017, 201) that program and policymakers understand and consider the cultural notions of disability by the community and that the goals of the service delivery model should be compatible with the needs within the community. CBR is recognized as an international model for the organization of service provision towards disabled children in low-resource settings. In the discussion section of this study the method of CBR will be discussed as potential tool to address the challenges present in Kabarole district, and to investigate if it can contribute to the implementation of the suggestions made to address the challenges.

3.2 Collaboration between stakeholders

What becomes clear out of the introduction of the various approaches regarding the service provision towards disabled children, and the introduction of the CBR method, is that all these various approaches and the CBR method require collaboration or partnerships between stakeholders. The question that follows is, who are these stakeholders? And how can collaboration be established between these stakeholders?

3.2.1 Stakeholders

To answer the first question, we need to look at the concept of stakeholders. The term ‘stakeholder’ comes from the management literature and touches upon strategic planning, system theory, corporate social responsibility and organization theory and can be used with the development of strategic management. Freeman (2010, 49) conceptualizes stakeholders as *“those groups who can affect or are affected by the achievement of an organization’s purpose.”* In this research, the stakeholders are those individuals, groups or organizations that are involved or targeted in the provision of support towards disabled children in Kabarole district.

The ACPF (2011b) provided a list of stakeholders that could be active in service provision towards disabled children in Uganda, and their roles and responsibilities. This list of stakeholders included the ministries, departments and institutions from the government, NGOs and foreign missions. The majority of these stakeholders are involved in the medical and rehabilitation services provision, where fewer are involved in other components of disability care such as the provision of assistive devises, education, vocational training and employment (ACPF 2011b, 15).

The CBR touches upon the importance of including all stakeholders when planning and executing disability services. It is important that all key stakeholders are being identified and are involved from the beginning of implementing CBR, to ensure the establishment of ownership. Figure 4, adopted from the WHO CBR introductory (WHO 2010, 42), provides an overview of which stakeholders are

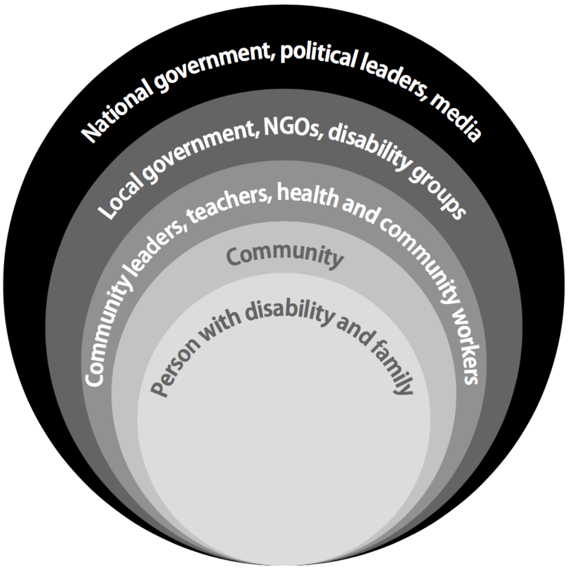

Figure 4: CBR Stakeholders

involved in (CBR) service provision towards disabled children. As a rule, the closer a stakeholder is placed to the inner circle of ‘person with disability and family’, the more contact they have towards the disabled person.

Kabarole district has her own unique mix of stakeholders related to the service delivery towards disabled children. Table 1 includes the various stakeholders that I identified in Kabarole district, and an overview of the various tasks they have. This table is built up with information from the various stakeholders themselves and is neither complete nor exhaustive.

Level	**Service Provider**	**Roles**
Village	Disabled Children & Their families	Daily caregiving towards their children, taking them to the service providers.
Commune	Children Homes	Providing a home for disabled children who are not able to stay with their families
Commune	Schools/Teachers	Educating the children with a disability.
Commune	Community Health Centers, VHTs (Village Health Teams)	Identifying children with a disability, referring them to specialized care, providing medical care.
Commune	Community Based Organizations (CBO)	Identifying children with a disability, providing a variety of services; income generating activities, basic physiotherapy, medical care, assistive devises, family strengthening, vocational training
District	Orthopedic Workshop	Manufacturing Assistive Devises
District	Rehabilitation Centre	Physiotherapy, occupational therapy and speech therapy. Early intervention training, provision of assistive devises, special education support, income generating activities.
District	Local Government	Designing policies. Focusing specifically on the health and education policies

District	Disabled People Organization (DPO)	Having a network throughout the district of disabled people groups, income generating activities, vocational training, provision of assistive devises, advocating for disabled people at local government.

Table 1: Stakeholders in Kabarole district

An interesting aspect in Kabarole district is that it includes both foreign, 'western' lead NGOs as well as Ugandan NGOs, which brings different cultures within the collaboration. A recent study by Vangen (2017) outlines the importance of considering the cultural diversity within collaborations between stakeholders. Culture is typically considered within collaborations relating to norms, values, (interpersonal) behavior, organizational practices and language (Vangen 2017, 307). Vangen and Winchester (2014, 687-688) note that culture within a multi-cultural collaboration forms a paradox. This 'cultural paradox' means that the diversity of culture can bring both advantages as well as disadvantages to the collaboration.

Three types of culture should be considered within culturally diverse collaborations: the national, organizational and professional culture. National culture can be associated with individuals' behavior and focusses on characteristics as being polite, friendly or reserved. Organizational culture refers to attributes of the organization as a whole and in which way they carry out their work, such as which procedures they use while working. Professional culture is related to the specific skills, experiences and expertise that individuals bring to a collaboration, such as means of communication and language (Vangen 2017, 314).

Managing culturally diverse collaboration should focus on two different aspects; the development of cultural sensitivity and the development of working communication processes. For the stakeholders within a collaboration this means that they need to contribute to making trade-offs and compromises, this will open up the possibility to yield advantages out of the cultural diverse collaboration rather than disadvantages (Vangen 2017, 314-317).

Providing care to disabled children and their families requires collaboration across the health system as well as collaboration among the different sectors that are involved (Collins et al. 2017). For the successful and sustainable implementation and execution of the CBR method in a certain area, there are a few 'essential ingredients' that should be in place. These are; *Effective leadership*, where program managers are responsible for the motivation, inspiration and support of the stakeholders. *Partnership* between the stakeholders to make optimal use of the available resources. *Community ownerships* by including the community in the implementation and execution of the CBR program. the *usage of local resources* to ensure greater sustainability. *considering cultural factors* means that local customs and tradition are considered when implementing and executing the CBR program. *Building capacity* of stakeholders through awareness-raising and training is essential in the whole process. At last *financial support* through different sources and *political support* to guaranteed wide spread use of the CBR method are both important for the success of CBR (WHO 2010, 36-37).

What all of these components seem to have in common, is that they require collaboration between various sectors to establish these various ingredients. If the different stakeholders do not work together there is a risk of competition, duplication of services, wasting valuable resources and unsuccessful implementation of the program. Formal arrangements such as a memorandum of understanding can help to start, secure and sustain partnerships (Ibid).

3.2.2 Inter-Organizational Relationships

A concept used to understand the collaboration and relations between and among organizations is the concept of inter-organizational relationships (IORs). IORs can be interpreted from different perspectives; It can be interpreted in terms of a working relationship that is established between one or more people from each of two or more organizations, or from the perspective where the organizations themselves have the relationship (Cropper et al. 2008, 3). It seeks understanding in the character, pattern, origins, rationale and consequences of such relationships (Cropper et al. 2008, 2). The organizations active within an IOR can be of different kinds. They can be public, business or non-profit and the relationship can vary in scope of just two organizations, or an extensive network of organizations.

IORs are especially relevant where different actors gather in a certain policy field and address the issue jointly. The study of IORs is therefore also concentrated on ‘policy coordination’, the processes and dynamics in which the different actors try to address a certain problem more effectively (Biermann and Koops 2016, 4).

Names for inter-organizational entities

an alliance
an association
a cluster
a coalition
a collaboration
a consortium
a constellation
a cooperation
a federation
a joint venture
a network
a one stop shop
a partnership
a relationship
a strategic alliance
a zone

Descriptors for inter-organizational entities

collaborative ...
cooperative ...
coordinated ...
interlocking ...
inter-organizational ...
inter-professional ...
joined-up ...
joint ...
multi-agency ...
multi-party ...
multi-organizational ...
multiplex ...
trans-organizational ...
virtual ...

Names for inter-organizational acts

bridging
collaboration
contracting
cooperation
franchising
networking
outsourcing
partnering
working together

Figure 5: Terminology for IORs

The terminology for these partnerships or relationships varies. Cropper et al. (2008) give an overview of the most used terminology within the field of inter-organizational relationships (see figure 5). They underline that it is often not so much the ‘relations’ that are spoken about, but more about the inter-organizational entities, that lay on the manifestation of the existence of these IORs. As seen in Figure 5, adopted from Cropper et al. (2008, 3), there are many different terms that are being used for such relations and relationships. All of these terms are being used with different meanings, and there is not one term that is universally accepted (Cropper et al. 2008, 2-3).

From the sociological perspective, which is relevant to this study, IORs are often related to as a network (Biermann and Koops 2016, 4). According to Mandell and Keast (2008, 716) do networks have their unique characteristics compared to other organizational models. Within a network the interpersonal relationship is a core component and must therefore be identified in order to be able to say if performance measures are useful or not. The main purpose of a network is to link members of the network to resources, organize joint actions and learning, and by doing so creating new and innovative ways in addressing a certain issue (Ibid).

Geddes (2008) focusses specifically on IORs within local and regional development partners and shapes a more realistic view on these partnerships. Local and regional development partnerships include actors from different sectors. Such as community and civil society, as well as organizations within the public, for profit and non-profit sectors. When it comes to IORs within local and regional development there are a few key issues where discussions concentrate on, these are; building partnerships and the issue of trust, inequality and difference in partner contributions, managing partnerships, governance and accountability and identifying the added value. These lead to theoretical perspectives for analyzing partnerships in local and regional development (Geddes 2008, 204).

The building of partnerships between actors is often considered to be time consuming. Both in amount of time used and the duration of the partnership. Trust is essential for effective partnerships but is difficult to achieve. This due to lack of understanding, varying interests and different objectives within the partnership. Trust can be built by strong leadership and a common goal within the partnership. However, Geddes (2008, 217) also emphasizes that, despite trust being considered to be an ideal basis for a partnership, many partnerships function on very limited trust and is in many cases a 'pragmatic necessity'.

Geddes (2008, 217) recognizes that within IORs, there is often great inequality and difference in contribution of the various partners. Within different settings the various stakeholders can have varying involvement. Where in the developed world, it is often the national government or large businesses being the leading role, in the developing world it can be a powerful NGO or even a small community or voluntary organization.

Local partnerships are often consisting of small institutions and other stakeholders, with limited management skills. Because these partnerships are often voluntary, it is challenging to manage performances. This is closely related to issues regarding accountability and governance of the partnerships. Within partnerships it is the question how a partnership is accountable to its partners vice versa. Identifying the added value of an IOR is often difficult. There is little evidence that these partnerships actually have an added value. This is due to the difficulty to measure if the same outcomes would have been achieved if the partnership was not established.

Despite these challenges regarding local IORs, according to Benington (cited in Geddes 2008, 215), local partnerships can definitely have a number of potential positive outcomes; The first benefit is that it can assist in problem-solving. by bringing together different partners that have different perspectives and knowledge. The second potential benefit is that it can produce innovation. Individuals and organizations are being exposed by new ideas and new ways of working. This can trigger innovations to happen. Local partnerships are also potentially beneficial in making better use of resources, because resources can be used in a more sustainable way, and partnerships may open up new resources. Bringing together different actors can also contribute in the reduction of the risk of policy failure and distributes the work load of executing the policy of the different actors. These different actors can contribute to the legitimacy of government processes by building a collaboration behind a policy.

Most of the literature written about IORs focusses on high income countries. There is only limited literature available about these kinds of relationships, within the delivery of social care, in low- and middle-income countries.

One study by Rein and Stott (2009) assesses six cross-sector partnerships in Southern Africa, focusing on South Africa and Zambia. Collaboration showed to be advantaging regarding the direction of resources, the resources were directed towards those places where it was most needed and added value in these partnerships was noted in the ability to improve social services and to give attention to relatively weak members of the society.

However, Rein and Stott also give some critical notes to the partnerships. Although the fashionable status partnerships have these days, there is no model that applies to each and every situation. The partnerships should be built on good practices and consider the local conditions. Regarding building on good practices, emphasizes should be put on transferring learning, rather than ‘copying’ activities (Rein and Stott 2009, 86).

Out of the section above it becomes clear that there seems to be confusion over what outcomes should come forward out of these IORs. One major reason for this, is that evaluation of these relationships is complex. It is hard to measure the outcomes of IORs when you don’t know what would have happened if the IOR was absent (Provan and Sydow 2008, 2). Although the complexity, evaluating IORs is being seen as essential to provide a benchmark for determining success, which is useful for the stakeholders within the IORs to decide whether the relationship is worth maintaining. Next to the benefits for the stakeholders, does it give researchers valuable information to compare different IORs (Provan and Sydow 2008, 3).

Greer (2017, 42-77) introduces elements for successful inter-organizational collaboration, where joint identification and resolution of complex problems is the central aim. These elements of success are: committed members, resources, time, communication, trust, shared goal, defined process and collective identity. These elements are split up in two sections. The first category are those elements that are needed to start collaboration, which are time, resources, communication and committed members. The second category are those elements that are essential for member interaction and includes the elements collective identity, trust, a shared goal, defined processes and communication.

The elements needed to start collaboration, what Greer calls the ‘initial elements’ are committed members, time and resources.

Committed members understand the problem and have commitment in solving it. They have the ability to provide time, resources, energy and have adequate communication skills. They are able to deal with uncertainties and the lack of organizational structure.

The second initial element is *time*. Time is needed to overcome inefficiencies and challenges in the collaboration, to form relationships. Time is built in many of the different elements and steps within collaboration. It is essential for successful outcomes.

The varying stakeholders in the collaboration need to invest *resources* for the development of outcomes, such as time, materials and expertise. They are required both before, during and after the collaboration. It includes a whole set of resources, for example, among others, the possibility to send members of the individual stakeholders to meetings, funding and knowledge to facilitate the collaboration.

The ‘emergent elements’, as described by Greer, are those elements that emerge during the development of the relationships among the stakeholders, within their social context and include the elements trust, a collective goal, collective identity, trust, defined processes and communication.

Communication is a fundamental element for successful collaboration and can happen in a variety of ways; in person, email or via other communication strategies. The goal of communication within IORs is the exchange of information and ideas, resulting in better outcomes. (generalized and particularized conversations).

Trust is the second emergent element and is a factor that develops over time through interaction and successful conflict. It is the process of consistency in words and actions leading to shared respect and understanding by others. (three separate processes trust development Le Ber and Branzei 2010). Trust as an element for successful inter-organizational collaboration is noted to be an important aspect for managing challenging situations such as conflicts and varying interests.

A *shared goal* creates a feeling of connection between the stakeholders and willingness to act to achieve that outcome. Stakeholders in an interorganizational collaboration often formed this collaboration around a preliminary goal. However, this goal is not yet internally approved and validated. The share goal develops on the other elements of collaboration. The goal must be realistic and needs the contribution and support of all stakeholders in the collaboration.

The members of the collaboration need to have a *defined process*, about the actions to be taken to reach the shared goal. A defined process offers structure to the collaboration when there are conflicts or when there is pressure from outside.

The last element, *collective identity,* refers to the manners in which the individuals and stakeholders behave and demonstrate their commitment to the collaboration, the processes within the collaboration and the shared goal.

3.3 Conclusion

Many suggestions have been made on how service provision towards disabled people and children specifically should be organized in order to meet their needs. These include various approaches as the twin-track approach, the human-rights based approach and a multi-sectoral approach. The WHO develop one overlapping strategy which combines these approaches, which is the method of community-based rehabilitation (CBR). CBR can be seen as a method to reach the eventual, local, goal in service provision.

Within the use of the CBR method, much emphasizes is being put on collaboration between stakeholders that are involved in the service provision towards disabled children. This chapter presented various of these stakeholders and their role within service provision in Kabarole district, and the influences the various cultural backgrounds. I finally introduced the concept of inter-organizational relations to understand means of collaboration between stakeholders.

In this chapter I presented the literature that is relevant when researching the experiences of stakeholders regarding challenges and suggestions for improvements regarding the service provision towards disabled children in Kabarole district. By reviewing literature regarding suitable and evidence-based approaches when organizing disability service provision and how these approaches can be brought implemented and managed by reviewing literature on stakeholders and the collaboration between them I frame the background of this research. What has been presented in this literature review will be used in the discussion section of this report as comparison and justification of my findings.

4 Methods: Studying the Experiences of Stakeholders in Kabarole District

"Here we do not distinguish between quantitative and qualitative methodologies, nor do we differentiate which development agency or funder supports the research. The research methodology does not drive the research, but is a tool used to meet the needs of the research questions." (Rioux et al. 2016).

Within this chapter I will provide an overview and discussion of which methods I have been using while conducting my research. Within the different sections I will describe the certain methods being used, and the way I have implemented them. I will also discuss which challenges and limitations they bring and how I accounted for these.

The aim of this study is to get a better understanding of what the stakeholders in service provision towards disabled children in Kabarole district, Uganda see as the main challenges regarding the service provision, and in which ways these challenges are experienced. The potential causes and consequences of these challenges will be examined and potentials for improvements suggested by the stakeholders will be presented.

4.1 Study Design

I used a qualitative design for this study, where I focused on words or meaning when it came to data collection and analysis, rather than, as in qualitative methods, on quantifications (Bryman 2016, 32). It is an approach where individuals or groups attribute meaning towards a social phenomenon. The complexity of situations are being explored and understood (Creswell 2014, 32). In this case, the social phenomena are the experiences of stakeholders regarding challenges present in the service delivery towards disabled children, and their views upon how the service delivery can be improved.

Within the qualitative approach, I used case study as research design. A case study is a research design that *"entails the detailed and intensive analysis of a single case*" (Bryman 2016, 688). A more detailed description comes from (Creswell 2013, 97), who specifically focusses on case studies within qualitative design, conceptualizing it as *"a qualitative approach in which the investigator explorers a real-life, contemporary bounded (a case) or multiple-bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information."* This study is focusing specifically on the case of stakeholders that are involved in the service provision towards disabled children in Kabarole district. Focusing on their experiences regarding challenges in service delivery towards disabled children and their views upon potential improvement.

4.2 Sampling

The context in this research is Kabarole district in Uganda. Kabarole district makes an interesting site for my study due to a lack of research available from this area of Uganda. The introduction chapter showed a clear need within Kabarole district for a better understanding of the current state of the service delivery towards disabled children, the present lack of transparency, potentially leading to overlap and gaps in the service delivery, resulting in the consequence that disabled children in Kabarole district are not receiving the help they need.

Out of the preliminary research it showed that Kabarole district already had an established network of service providers and other stakeholders in the district. Kabarole district is, compared to other districts, among the more developed once. Since there are many districts in Uganda where there is not such an established network, these districts can learn from the processes in Kabarole district and avoid facing the same challenges.

I chose to focus on the whole district of Kabarole district over a smaller focus due to most service providing stakeholders working over several sub-counties, as well as the local government being organized on district level. Together this makes Kabarole because it demonstrates aspects of interest (Bryman 2016, 409).

Within this research, participants have been selected because they are expected to be of significant value and contribution to the research. This strategy of sampling, where participants are chosen because of their relevance to the research, is what Bryman (2016) identifies as purposive sampling.

I used two different purposive sampling approaches; generic purposive sampling and snowball sampling. It is common to use multiple sampling techniques within purposive sampling, especially in combination with snowball sampling (ibid, 419).

Generic purposive sampling includes several purposive sampling approaches, but does not include theoretical sampling, because sampling does not occur with regard to creating theory or theoretical categories. Within generic purposive sampling, criteria that are needed to be met to become a participant, are selected based upon the research questions. Within this research, the criteria for becoming a participant were; being a stakeholder within the service provision towards disabled children in Kabarole district. Stakeholders are individuals, groups, organizations and government institutions involved or somehow connected to disabled children and their families, as well as family members from disabled children. The participants needed to be 18 years or older.

Generic purposive sampling is also used to select the non-Ugandan volunteers that have been participating in the research. These participants were selected because of their connection to a certain stakeholder. I considered it to be valuable to include their perspective on the service delivery in Kabarole district. These volunteers have been working closely to the stakeholders and have seen what is going on within the organization on a day to day basis.

Within snowball sampling the researcher initially identifies a small group of participants relevant to the topic. They can be relevant because of a certain experience, knowledge or other characteristics. The first participants will recommend other participants that can contribute relevant knowledge to the research, and so on. Snowball sampling is proven to be very useful when sample populations are hard to reach because of the absence of a sampling frame (Bryman 2016, 415). This absence of a sampling frame was the case in my study, I arrived in the sampled area, Kabarole district, with limited background knowledge about the area, the circumstances and which stakeholders were active. This made snowball sampling a relevant method.

4.3 Recruiting

I recruited participants through a number of different channels. The first participant that I identified was the clinical director from a rehabilitation center for disabled children in Kabarole district, this is also the location where I did my first initial identification of a topic for this research. She provided a list with contact details from other potential participants. During the following interviews, at the end of each interview, I asked if participant knew anyone else could contribute with their knowledge or stories to this research.

The first contact with the potential participants was normally initiated by the program manager from Knowledge4Change. He knew a lot of the desired participants personally and therefore he was able to introduce me to them and this made the boundary for participation lower. For most interviews, I would meet the participants one time before the actual interview. This meeting gave me the opportunity to hand out my information sheet, which can be found in appendix 5. This information sheet contained the necessary information about my research, so the potential participants would get informed about the background of my research and would be able to make an informed decision whether they wanted to participate or not. When they agreed to participate, an appointment was made to meet them at a later time that was convenient for the participant.

4.4 Sample Size

In total their where 25 different participants included in this research. These participants participated in either one of the 15 interviews, in one of the two focus groups, or in both. The participants form a heterogeneous group which included family members, staff from various organizations such as from a rehabilitation center, community-based organizations (CBOs), disabled people organization (DPO), local government and western-volunteers. With the participants coming from different stakeholder groups, I collected a rich data set.

However, there are also various limitations to the stakeholder group. Due to limited time and resources I was not able to collect more data. This meant that I was not able to interview all proposed participants that where suggested to me through the snowballing method. I was also not able to include community members and representatives from the national government in my research, meaning that I am not able to include their perspectives about their views upon service provision towards disabled children. Next to the limitations regarding participants, there was also limitation regarding the context. I conducted most of my data from stakeholders that are active in the main city of the district, Fort Portal, or the sub-counties just outside Fort Portal. Due to the limited time, I was not able to investigate if there are more organizations active in the sub-counties far away from Fort Portal.

4.5 Data Collection Strategies

"The choice of research method should be determined by the research interests, the circumstances of the setting or people to be studied, and practical constraints faced by the researcher (Taylor, Bogdan, and DeVault 2016, 104)."

This section will provide an overview of the strategies I used to collect my data. I applied two main techniques; semi- structured interviews and focus groups. Next to a discussion on these techniques, I will also comment on the way I used these two methods within this research. The data has been collected in Kabarole district, Uganda in the period of the 25th of October until the 6th of December 2017, the whole study included 15 interviews, and two focus groups. Together including a total of 25 unique participants. An anonymized list of participants can be found in appendix 1, including information which stakeholder group the participant belongs.

4.5.1 Semi-Structured Interviewing

Within this study I carried out 15 semi-structure interviews, together accounting for most of the data collected in this research. Most of these interviews were face-to-face interviews with one participant. Some of the interviews were with two informants at the same time. In the case of two participants per interview, in most occasions this was pre-discussed if the informants came from the same stakeholder group and from the same organization. In one occasion this situation occurred naturally by the second participant being at the location at the time of interview and willing to participate and able to contribute knowledge.

Some of the interviews were collaborative interviews together with fellow student R, who performed her study in the same field as me. We pre-discussed who was going to ask which questions and how we would manage the time between us. These interviews were transcribed as one big interview, where we were able to use each other’s questions as data. In these collaborative interviews, the participants consented to both my research, as well as R her research.

I choose the strategy of in-depth, semi-structured interviewing to get an understanding of the informant’s experiences and views on the specific experiences regarding the challenges within service provision towards disabled children in Kabarole district. I found it important to get a grasp of the way that the different stakeholders experience the challenges within service provision, on the ground in a district where previously not much research has been done (Bryman 2016).

Interviewing is found to be a suited technique were the research interest are relatively well defined, were settings and people are not otherwise accessible, were the researcher has time constraints and were the researcher has an interest in understanding a broad range of people or settings (Taylor, Bogdan, and DeVault 2016). These reasons to choose for interviews as a strategy are all applicable on this research, making interviews a useful strategy within this study.

The interview technique being used within this research is a combination of two types of interviews being described within Taylor, Bogdan, and DeVault (2016, 103). The first type is where the informants act as the observers. This technique includes that the informants share their views on a situation, what happens within this situation and how they experience it. The second type focusses on yielding a picture of situations or people. Here interviewing is used to study a large group of people in a relatively short time.

The negative aspect of this strategy is that observations are not made out of first hand. Using the experience and observations of the participants brings in their personal interpretations of the situation. It is important to realize that the data is therefore not completely objective. I put extra emphasizes on the experience of the stakeholders in my research question, to let the reader understand that it is the informants own, subjective, experience.

Within the approach of in-depth semi-structured interview, I used an interview guide with specific questions and topics to talk about in the interview. I used two basic interview guides, one for the family members of the disabled children and one for the other stakeholders. These can be found in appendix 2. Before every interview I adjusted the questions so that they would match the specific stakeholder and/or informant. During the interviews, there was room for flexibility, following the flow of the interview and building on the answers of the informants (Bryman 2016, 469). It depended from interview to interview to what extent the questions of the interview guide where used to direct the interview. During all interviews I assured that we touched upon all topics that were of interest to me.

Within all the interviews, I first started with an introduction of myself and the research I was conducting in Kabarole district. After that I moved on to the consent forms or, in some cases, the verbal consent and gave the informant the possibility to ask question about the consent from. After consent was given by the informant I also gave the opportunity to make comments or ask questions before the start of the interview. This possibility was used by some of the informants to indicate how much time they had for the interview.

My interviews touched upon three different themes. In the case of the first interview guide, which I used for the staff members of the various organizations, the local government, the western volunteers and stakeholders active within education, I first focused on the tasks of the specific stakeholder. I asked question relating to their activities directed towards disabled children, the scope of these activities within the district, and their opinion about the activities they provide. As a tool to talk about the various services, I used the CBR-matrix as presented on page 26. I also brought a map of Kabarole district, so they could point where in the district they provide their services. The information from these questions have been used to get a good understanding of the services a certain stakeholder provides and in which setting challenges are experienced.

After the activities of the specific stakeholder, I moved on to questions about the service provision within the whole district and the collaboration with other stakeholders. I focused on which challenges they experience while providing these services, and within the collaboration between other stakeholders.

In the last part of the interview I focused on the future of the service provision towards disabled children in the district. I gave the opportunity to the informants to present their ideas on how the challenges they mentioned in the previous section of the interview can be addressed. As well as how they see their and other stakeholders' responsibility in this. Before the end of each interview I checked if we touched upon all topics and gave the possibility to the participant to add information that they thought was of interest to my study.

The interview guide for the family members of the disabled children also consisted of three different topics. The first topic focused on their story about their disabled child, and to understand which needs the child has. The second topic was devoted to the services the families receives, the opinion of the family members about these services. The last topic focused on the thoughts the family members had about how the service provision in Kabarole district could be improved.

Most of the interviews were conducted in the work- or living situation of the informant. In some cases, it was on 'neutral' terrain, as for example a restaurant. This was up to the preference of the informants. The length of the interviews varied greatly and lasted from twenty minutes to two hours.

All interviews have been conducted in English, which is one off the official languages in Uganda. I made the decision to conduct the interviews in English to avoid loss of information which can occur when using a translator. All participants recruited through the snowball method were able to speak a sufficient level of English, they were able to express their thoughts on the subjects in the interview.

4.5.2 Focus Groups

Next to the interviews, two focus groups took place. Focus groups are an interviewing technique where several, usually at least four, interviewees participate. Within the focus group there are two aspects. The first aspect is the discussion on specific topic or questions and the second aspect is the interaction within the group and the construction of meanings (Bryman 2016, 501). The focus groups were organized after the interviews. In total, there were 15 participants during these focus groups, some of them participated in the interviews as well, others did not.

The first focus group was organized for the organizations, the local government and the Western-volunteers. All the participants from the interviews were invited to this focus group. If the participant of the interview could not take part, the stakeholder had the possibility to send a colleague. There were in total of seven participants during the first focus group, of which six participated in the interviews and one participant was a colleague of one of the informants. Unfortunately, not all informants from the interviews were able to join, which resulted in no participants from the family and local government stakeholder group.

The second focus group was conducted with the staff from the rehabilitation center. This was on the request of the rehabilitation center itself, to get informed about the outcomes of the research I did during the past months. This focus group included eight participants. Though this focus group was originally not intended to be held, it made a great contribution to the rest of the data.

Both focus groups had three different aims. The first aim was to deliver knowledge back to the informant stakeholders that had been participating during the interviews in the form of early findings of my research. The second aim was to validate my results, to check whether what I found, was corresponding with the thoughts of the stakeholders in the district and also to provide the participants the occasion to react on the outcomes, have a discussion on the challenges in the district regarding the care to disabled children and give new perspectives. The third aim was to generate more data, by specifically asking for suggestions for improvement of the service provision towards disabled children in Kabarole district, to address the challenges that were named during the interviews.

I designed a guide for the focus groups that has been followed to structure the meeting. This guide can be found in appendix 3. The focus groups were structured in the following way; After an introduction of what my research entailed and how I have been conducting my data during the prior weeks. I presented a copy of the CBR matrix with the information on which components of the matrix the different stakeholders were active, and in which part of the district they were providing these services, according to what I have been told in the interviews. The participants in the focus groups were asked to comment on these two documents. Afterwards, there were group discussions and general feedback on various challenges regarding the service provision towards disabled children and collaboration between the stakeholders in the district. These challenges were selected through preliminary analysis of the data. The content of the discussion included if the participants agreed or not with the challenge presented, what they think can and should be done about the challenge, and who should take responsibility. After discussing these various challenges, the participants had the possibility to make final additions and comments on the collected data.

4.6 Recording & Transcription

All the interviews and focus groups were audio-recorded with permission of the participants. I have used the audio-files to later transcribe the interviews and focus groups. Audio-recording the interviews and focus groups gave me the possibility to fully focus on what was being said, rather than making detailed notes. It also allowed me to analyze not only what has being said, but also the way it had been said (Bryman 2016, 479).

I transcribed all the interviews and focus groups myself, and as literally as possible. If a word or part of a sentence was unclear, this was clearly marked in the transcription. Transcribing the interviews have contributed in great deal to identify the first key themes and challenges that have being used during the focus groups. The quotes that are being used in the results and discussion part of this thesis are directly quoted, without adjusting the flow or word order to make the sentence easier to understand for the reader. I decided to use to original quotes to keep the quotation as authentically as possible and to be able to interpret the quotations in the right way.

4.7 Analyzing Strategies

In the following section I will justify the strategies that I have used for analyzing the data within this research. I will both explain the way I coded my data as well as the analyzing of the coding afterwards. For the analysis, I made use of the digital qualitative analysis tool Nvivo.

4.7.1 Coding

After transcribing, I first turned my data in to individual fragments and after that I coded them through the open and axial coding strategy as described by Strauss and Corbin (cited in Bryman 2016, 574).

Within open coding, I went over the various interviews, and fragmentized the transcribed interviews in to four different categories. The first category was *service provision*. In this category all fragments were collected that said something about the activities of the various stakeholders. Including which services, the stakeholders provide to disabled children, within which geographical context and on what scale. The second category was the category *challenges*, including all the challenges being faced by the informants regarding disability. Within the third category, *management*, I included all fragments that said something about the management of the services, including collaboration. The last category, *future*, included all fragments that said something about the future of service delivery towards disabled children, including suggestions for improvements.

After the open coding, I discovered that I had been too ambitious with my research question. With the data I had gathered I was not able to answer my original research aim to create transparency about the service provision towards disabled children in Kabarole district. I discovered that the organization of the service provision was too complex to map. I therefore decided to shift the aim of my research and focus on the way the stakeholder experience and understand the challenges present in the service provision towards disabled children and their suggestions for improvement.

I moved on to axial coding where I put the data back together in new ways after the open coding, creating connections between categories and connecting codes to each other. During the axial coding I focused on categorizing the different challenges, aiming to link different fragments that said something about the same challenge. I also analyzed the data for connections between the various challenges named, to identify how these are inter-linked, and to investigate whether one challenge can either be a cause or a consequence of another challenge. Analyzing the challenges, the stakeholders mention, I was able to discover what the underlying causes were of this challenge and which consequences the stakeholders experienced out of the challenges.

To answer the second research question, about the suggestions for improvements, I used both data from the interviews, where I ask participants specifically for their ideas on how to address the issues they named during the interview, as well as data from the focus groups where specific attention was given to the ideas of the stakeholders on how to address the issues present in Kabarole district.

4.8 Ethical Considerations

Due to this research being a social research, where fieldwork used to collect data, involving direct contact with other human beings, it is important that I justify the considerations I made regarding ethics. Ethical approval for this study has been requested and obtained from the Norwegian Centre for Research Data (NSD), see appendix 4.

4.8.1 Confidentiality and the Issue of Harm to Participants

To avoid harm, it is essential to minimize the disturbance on both the participants themselves, as well as the participants relation with their environment, maintaining confidentiality is critical to avoid harm to participants (Bryman 2016, 127). This has been a challenging issue within this thesis, because there are only limited organizations active in the district, and it is therefore relatively easy to identify who has been participating, especially since the different organizations know each other personally. Therefore, the content of the interviews and the quotes used in the analyzing part of this study, are completely anonymized, making it impossible to trace the quote back to the concerning informant.

To guarantee confidentiality as much as possible I anonymized the list of participants and also categorized the various organizations to stakeholder group, so it is less easy to identify who exactly said what. I also made sure that the audio files, the notes taken during the interview and the transcriptions and other documents on the computer did not contain any information that would make it possible to link what has been said, to an individual informant. All files with raw data were stored on the computer in a locked file. The only file that does contain the full names of the participants, a table where it is possible for me to see which interview belongs to which participant, was stored in a separate locked file. All raw data and the list of participants will be deleted after the completion of this research.

4.8.2 Informed Consent

Informed consent means that the desired participants in the study should be given as much information as possible to make an informed decision whether or not they would like to participate in the study (Bryman 2016, 129). I took several steps to let the participants be as informed as possible before they gave consent to participate.

An information sheet has been used to inform potential participants about my study. This information sheet held details about the content of the research such as a short summary of the introduction, background, research question and methods of this study (see appendix 5). This information sheet was given to the potential participant, after which the participant was given time to decide whether they wanted to participate or not, before making an appointment for the interview.

In most cases written informed consent was obtained prior to the interview. This consent form can be found in appendix 6. This consent form contains information about the digital recording, the use and storage of data and about the possibility for the participants to opt out of the study at any time, without giving an explanation.

In some cases, verbal consent was obtained instead of written consent. This was done where it was expected that the consent form would raise concerns rather than taking them away, which could lead to the participants not wanting to be involved. For those participants, the same points as on the consent form were used to inform verbally, on which the participants were asked if they agree on these points or not.

4.8.3 Privacy

Privacy, or the invasion of privacy, is closely linked to confidentiality and informed consent. An invasion of privacy has been as much as possible avoided in this study by giving the participants the option to not answer certain questions and stop the interview or withdraw from the research at any time. An effort regarding privacy was also made by conducting the interviews in a separate room or location were interruptions were least likely to happen.

4.9 Quality of the Research

The most common criteria to evaluate social research are reliability, replication and validity. Reliability is about whether the result of the research can be repeated and is concerned with the measures and concepts used. Replication is closely related to reliability but is more occupied with whether the study itself can be replicated. The last criteria, validity, is concerned about the integrity of the conclusions forthcoming out of the collected data (Bryman 2016, 41). There have however been critiques whether these evaluation criteria are relevant for qualitative research (Bryman 2016, 383). For this reason Lincoln and Guba (cited in Bryman 2016, 384-386) present two alternative, primary criteria, for evaluating qualitative research; trustworthiness and authenticity. I will use these two criteria to evaluate this research.

4.9.1 Trustworthiness

Guba and Lincoln argue that, within qualitative research, there are multiple ways to look at social realities, while reliability and validity focus on just one social reality. Trustworthiness focusses on putting emphasis on these multiple accounts of social reality and can be split up in four criteria; credibility, transferability, dependability and confirmability.

Credibility is being established by carrying out the research according to the principle of good practice and checking whether the results are being acknowledged by the participants of the research. Carrying out the research according to good practice has been secured by using acknowledged research methods and considering the ethical principles. Acknowledgement of the results has been secured through the use of multiple data collection methods, also known as triangulation (Bryman 2016, 386). In this research both semi-structured interviews, as well as focus groups were used. The later method functioned to a great extent to check whether the preliminary findings were recognized by the participants, which is called respondent validation (Bryman 2016, 385). As mentioned in the data collection strategy section above, the focus group focused on the presentation of the various challenges that the informants mentioned in the interviews. The participants in the focus group had the chance to confirm or refute this challenge and to make additional comments on it.

Qualitative research often entails an intensive study of a small group and results are oriented to a unique context. In this research, I focus on a small group with unique characteristics, which is common within qualitative research. It is an empirical issue whether the findings are transferable to another context or to the same context but during another time. That is why qualitative researcher are encouraged to produce a thick description (Geertz, cited in Bryman 2016, 384), this is a detailed description of the culture, which makes it possible to make judgements whether it is possible to transfer the finding to another environment, the *transferability*. I adopted this strategy of thick description in the 'setting the scene' chapter.

Dependability can be seen as a the parallel to the quantitative reliability. Dependability can be established by adopting a so-called auditing approach. The auditing approach entails that an audit trail is kept, this audit trail includes all phases of the research process, such as fieldwork notes, data analysis approaches, and the problem formulation. Though an actual audit has not been done, this report accounts for which approaches have been used and how this research was established and executed, which can be seen as the audit trial.

The last criterium is *confirmability.* Confirmability is concerned with, although complete objectivity is not possible within social research, it is important to assure that personal values and theoretical inclinations influence the research and outcomes the least as possible. This has been challenging within this research since I bring my Western views towards a Non-Western setting. I aimed to be as objective as possible by putting focusing on the perspective of the stakeholders. I included many quotes in the analyzing part of this study, to put extra emphasizes on their perspective.

4.9.2 Authenticity

Authenticity is concerned with the broader political impact of the study through several criteria, which are fairness and authenticity on ontological, educational, catalytic and tactical fronts (Bryman 2016, 386). *Fairness* is concerned with the question if the research included different viewpoints of the members in the social setting of the research. This research aimed to include a heterogeneous group of participants from different stakeholder groups, to consider and include their different views. *Ontological authenticity* it is the question if the research helps the members of society to get a better understanding of their social milieu. This research has a strong focus helping the stakeholders in service provision towards disabled children understand which challenges are experienced. *Educational authenticity* stresses the importance of giving the members of society a better understanding of each other's perspectives. This research includes many different perspectives and puts extra emphasizes on the different perspectives of the stakeholders regarding culture and priorities of different stakeholders within the service provision. *Catalytic authenticity* is concerned with the question whether the research acted as a stimulus for the members of society to act. This research has a strong focus on triggering action by including suggestions for improvements in the study. Though the stakeholders themselves need to take the step to act, knowing what needs to happen can serve as an incentive to act. The last criterium, *tactical authenticity,* focusses on the question whether the research empowered the stakeholders to act. By putting the main focus of this research on the perspective of the informants in this study, and their views on improvements, I aimed to make the informants feel as the key to change.

The authenticity in this research is accounted for by including the multiple perspectives of the different stakeholders in disability services in the district. It aims to give the stakeholders a better understanding of the challenges that are currently present in Kabarole district, and what the different stakeholders perspectives are on this. I hope that this research eventually will trigger the stakeholders to improve the service provision and that it empowers the stakeholders to take action (Bryman 2016, 386).

4.9.3 The quality of this research in practice

Though this paragraph gives account for the ways in which I aimed to guarantee quality within this research, the eventual research that has been done involved some limitations that influenced the quality of the research. These will be outlined in the discussion section of this report.

Dear supervisor, secretly I have no fucking clue what I have been doing!

5 Challenges in Service Provision and Suggestions for Improvement

Within this chapter I will present the results of the analysis done on the collected data. I will first focus on the presentation of the challenges experienced by the stakeholders in Kabarole district, before moving on to the suggestions made to address the challenges.

5.1 Challenges experienced by stakeholders in Kabarole district

Many different challenges are being experienced by the various stakeholders. Through analyzing I combined some of the challenges that were closely related to each other and had similar causes. I selected all challenges that, to the opinion of the stakeholders, have a major impact on the service provision towards disabled children.

What is important to realize, that these challenges are not isolated. They interact with one another and might be the cause or consequence of another challenge. The most profound challenges experienced by the various stakeholders in the service provision towards disabled children, that were distracted from the data, will be presented in the section below. I will structure the results in the following way. I will present one of the challenges experienced, and for each individual challenge I will outline the potential causes and consequences as outlined by the informants.

5.1.1 The Challenge of Stigma

Stigma about disability is observed by individuals in all layers of the stakeholder circle. In the direct circle of the disabled child, which is the family, there are often strong beliefs about what caused the disability of a child. It is seen as a curse, or the devil. Several informants have mentioned situations where the father left the family because of the disability of the child. The father leaving the family has a big impact, due to the income generating role most fathers have in Uganda.

Lack of direct support from those people closest to the family can lead to situations where being a single mother and having a child with a disability can be very challenging and also have an impact on the siblings of the disabled child. Mothers that are abandoned by their husbands and are not supported by the rest of their family need to find a form of income. However, leaving the house to work has consequences for the disabled child. Within some family's siblings are not going to school to look after their sibling with a disability during the time that the mother is away.

"You get to this point where you have maybe an eight-year-old child with severe disabilities, you are a single mom and you need to go out and work (...) what do you do? you can't really carry them on your back and take them with you, so do you leave them alone in the house? Locked in the house alone, incredibly vulnerable, they are not able to toilet themselves, feed themselves get themselves a drink. Or do you pull your other children out of school to look after their sibling?"

Within the community it is seen that families are isolated who have a child with a disability. The belief that disability is a curse or the devil within the community, leads to families being excluded from community life. Being a member of a church is an important aspect in community life in Kabarole district. Informants mentioned situations in which the families that have a disabled child where not welcome in church anymore, or were uncomfortable situations were occurring in cases where they would still go to church.

"People are just scared to go to church because of people staring at their child, they say come come come and see, of that stigma, people talking about you, in front of you, staring at your child and talking a lot of bad things. You are like, why should I bother going."

Next to the family and the community, lack of awareness and stigma is also observed among service providers. Regular primary schools often refuse to include disabled children because of the present stigma, and health workers within local hospitals often don't have the knowledge to act adequately when they are confronted with a disabled child. Some of the stigma among the families and communities is being raised and maintained because of the health workers stigma. The mothers are told that it is their fault that their child has a disability.

"We hear from families: "the nurse at the health center told me that my child has a disability because I was disrespectful to my mother-in-law" (...) if somebody like that tells you that it is your fault and it is because of a curse, you are not going to question it.".

It is being suggested by several informants that there is also stigma about disability within the government, both on local level as well as on higher, national level. Which leads to lack of actions from the local government, both in creating the awareness that is lacking, as well as in other aspects, which will be discussed later in this chapter.

Stigma around disability is being observed among all layers of stakeholders. It is often caused by cultural believes among the community that disability is a curse. The consequence of the stigma is that disabled children and their family members are in cases being abandon by their husband or family and excluded from community life.

5.1.2 The Challenge of the Knowledge Gap

Among several stakeholders in disability service provision there is lack of awareness about disability. This can partly be contributed by the challenge of stigma, but also to scarce education about disability and a limited amount of role models that have a disability. The lack of awareness leaves a knowledge gap among public education and health care workers. Disabled children are in many cases not able to go to school and are not receiving sufficient care within health care facilities.

There are cases known among the informants, where, despite the disability of the child, they are being told by workers at the public health care facilities that there is nothing they can do. The health personal having limited knowledge about disability, leads to families not being referred to the necessary services. It is often the local health centers where families first go to when they are concerned about the development of their child. Health workers play in this sense an essential role in identifying disability and including new families in the system, and therefore attention should be given to this knowledge gap to make sure the desired services reach all families.

Another issue relating to a knowledge gap of what disability entails, among family members and the direct community around disabled children is that families don’t know when and where to look for help when they discover that their child is ‘different’ than other children. This leaves a big gap in the early identification of disabled children, which could also lead to the disability getting worse.

People often don’t understand the added value of services such as physiotherapy or speech therapy until it is explained to them what it means and how it could benefit their child.

This is according to the informants an explanation why the families of disabled children, but also health workers like nurses, prefer the provision of goods, such as food, a new roof on their house and money over services as rehabilitation. They lack the long-term vision of what rehabilitation can contribute to the eventual well-being of the disabled child and the family as a whole.

> *"For example, there is a nurse at K. She used to take us to a family where there is a disabled child. I think the child has speech impairment, and of course they are hiding him which is not good. But the only thing she [the nurse] could tell us, not to train the child better ways of communication, but she would say: "this family is very poor, you look at the housing. I wish you brought the bed", every time she would talk about the bed and the mattresses (...) and the moment you buy the mattress, you have done something and then for the training they [the family] don't come to the training. 'We have got what we wanted, we don't need it'."*

The data gave various implications on the difference in prioritizing certain services among Western and Ugandan service providers. Where the Ugandan service providers often focus on meeting the materialistic needs of the families of the disabled children, by providing goods such as scholastic materials, clothes or food, Western lead or funded organization focus more on providing those services that should be beneficial in the long run, such as physiotherapy and education.

Looking at which services the two mothers interviewed would like to receive for their family and child with disability, they mention that they would both like services as therapy or education for their child but are also requesting material goods or money.

A consequence of the knowledge gap is that there are limited number of workers in the district that have the knowledge about disability to provide those services that are needed. Such as rehabilitation therapy and medical services. As a result of that, the workers that do work with disabled children, and also invest time and money in that specific area, sometimes provide services that they are not specialized in, which could sometimes do more harm than good.

> *"These organizations won't employ a physio, an occupational therapist or a speech therapist, but they want to provide such services. So, we find that they do stretching exercises, but they have done it in a wrong way, so they end up doing things not right (...) a few months back, there was an organization which had social work students, and this social work student was advising them a lot on physiotherapy, so the mother told us about what the social worker had told them about physio, and it was so so so much hurting for the child."*

5.1.3 Challenging Communication & Collaboration

The stakeholders currently collaborate in a number of ways. They refer disabled children and their families to each other when they see that the disabled child is in need of a service that they themselves not provide. There are also various forms of collaborative service provision, where several stakeholders team up to provide services to disabled children within different settings, such as education and health care.

The stakeholders who are providing specific services to disabled children, which are the CBOs, the DPO and the rehabilitation center, are communicating in a number of ways, to organize and maintain this collaboration. This communication includes multi-agency meetings, text messages, communication books and phone calls. This communication has several aims. To notify each other about a family that could benefit from a certain service, to notify each other about the progress a child is making or to check which service provider is delivering which services.

A group of stakeholders, who are from the rehabilitation and CBOs stakeholder group, hold so-called 'multi-agency meeting' These meetings were started by one of the organizations out of the urge to have a better overview of which organization is preforming which tasks. Because they found that some families are being seen by three or four organizations and providing similar services, which leaves other families on the waiting list. The multi-agency meetings are used to discuss the children that are being seen by two or more of the service providers. These meetings take place every three months, they rotate the location, every meeting is at one of the organizations who is joining the meetings. During these meetings, they review on different subjects.

However, some difficulties are experienced regarding these meetings, especially regarding the frequency of the meetings. The meetings are now organized every three months, where previously it was tried to hold them every month. The experience with monthly meetings was that is that most of the participants were able to make it, due to a high work load. Some organizations still suggest organizing the meetings monthly, due to the gap of three months in between the meetings,

> *"The multi-agency meetings which is fine, but if they are only every three months, that means there is three months with no communication and then it all happens in one go. We tried doing them more frequently, but we are all so busy that trying to get that group together, is too much, like we tried doing it monthly, people were not making it, that actually became too difficult, so we reduced the amount down."*

Because the multi-agency meetings mentioned in the paragraph above, only take place every three months, the stakeholders are compelled to communicate in other ways in between the meetings. Over the past years they have tried various communication strategies. One of these ways is by using communication books. These communication books were left at the different families that are being seen by several organizations, the concerning organization can fill out what they have done when they are performing a visit. This method had, however, not much success due to the organizations forgetting to fill out the communication books when visiting the families, or because families would lose the book.

> *"As much as we tried to introduce books in those families and updating when you come and what you do with the client, and in some cases, it was not really being done very well, because sometimes the caregivers could not tell where the book is and even sometimes they are not there, so does not give us the information about when the last visit was."*

Another form of communication that is being used is by the messaging application WhatsApp. In this app, the different stakeholders share information in a joined group chat. The positive side of this method is that everyone can be informed directly at the same time. Though this method is not being used optimally, because valuable information is getting lost due to messages that are not directly related to the service provision. This leads to people being less engaged in the groups or even leaving the chat. The cultural element plays part in this as well. Where there is a difference between the Ugandan service providers, who are often religious, and the Western service provider who is not.

> *"So, we have tried, and we are trying to have a WhatsApp group, but Ugandans… I just end up leaving so many WhatsApp groups because you set them up and then people start sharing pray requests and you start getting so much stuff that your inbox gets full. So, you just end up ignoring it because you just think it is so full of rubbish and then people end up leaving the group because they are frustrated with all the crab that people send. […] So, you ignore it and then the one important message that you needed to get through you have ignored because you are so frustrated with everything else."*

Currently, the most used method is by making phone calls to individual stakeholders. The stakeholders call each other when they need their services. The positive aspect of this communication method is that you are able to contact someone directly and make sure that the message is being received and that direct action can be taken. However, when multiple stakeholders need to be informed it is a time-consuming method.

> *"Direct communication, we will call somebody if, I need you to call this person, I need this to happen, I will phone you but that does not necessarily tell anyone else. So, when you got seven or eight organizations it is difficult to keep the communication going."*

One of the organizations is keeping a database file where all families are registered that are being seen by more than one organization. The aim of this database is to increase transparency and to 'put everyone on the same page'. The database consists of an excel document and is being owned and updated by the rehabilitation center. This document includes details about the organization who referred them to the rehabilitation center, which other organization is seeing them and details about which intervention is being done by the rehabilitation center and 3-monthly updates. The document is shared by the rehabilitation center to the other organization before the multi-agency meeting. However, this document seems not to be under the attention of all organizations, who request the use of such a database.

> *"We are missing a database where we have clients which [stakeholder 1] is also visiting and who [stakeholder 2] is also visiting and we all know we have gone in working together in that family. So, we actually looking at working, creating a database where we can always have*

> *copies of the same database that are being updated, it is something that is still missing in our communications, but I hope that is being worked on."*

It seems that regarding communication, the old fashion way of phone calls and direct communication is currently the most effective.

What the causes are of the inefficiency in communication is not clearly identifiable out of the available data. Causes that are named are related to the various stakeholders being too preoccupied with their own service provision, the cultural difference between Ugandans and Western stakeholder which leads to irritations in the communication and collaboration

A potential consequence of the lack of communication mentioned by some of the stakeholders that when families in need of a service don't get what they want from one organization, that they go to one of the other service providers.

> *The problem is that you get conflicts, you have one organization saying: no this is not our priority you can't have this. So, they try again with another one, and another one, and another one and I understand."*

Inefficient communication leads to lack of transparency about who is providing which services to which family, this will again lead to overlap and gaps in the service provision and the waste of resources.

5.1.4 The Challenge of Low Engagement from the Local Government

Various of the informant point out that they only see limited engagement from the local government of Kabarole district, regarding the service provision towards disabled children. Limited engagement from the local government is seen by stakeholders within various situations.

It is agreed by these service providers that the local government is not providing enough services towards disabled children. Reasons given for this lack of actions from the government are that there might be a lack of 'interest' and 'passion' for this group in the society, and that the local government chooses to prioritize other issues that are present in the district.

"I think it is a bit of a challenge, because especially our government, that has priorities elsewhere. It is hard for them to give funds or support for people with disabilities"

Several of the CBOs and the rehabilitation center have tried to invite the local government to meetings or events, but with only limited response. This leads to an attitude from these organizations to not invest their limited time in motivating the local government. Instead they focus on the provision of their own services. The consequence of this attitude from the other service providers is that they advocate less at the address of the local government, leading to maintenance of the inactivity of the local government.

Another reason for limited involvement of the local government, is that the local government sees that various NGOs and CBOs are providing different services towards disabled children. They are encouraging these service providers to continue with their work. It is assumed by informants that this is so that the local government resigns from their responsibility to provide such services.

"I think some of it is: -you are already doing it, I am not going to get involved because then you are wanting something from me. But you have already done it, you carry on doing what you are doing, it is great, as long as I don't have to take any responsibility for it -. (...) We are all so busy, so it is just easier to just get on and do what we are doing, without sort of this, it is like a sealing, you are sort of banging on the sealing to get through to the local government and it is just nothing there"

One of the service providers calls the relation between the government and the families 'very poor'. The service providers see a difference between the policies being designed by the local government, and the actual implementation of these policies towards disabled children and their families.

"I think they are only designing the policies, in books and on paper, they are writing programs for people with disabilities, but they are not implementing anything."

It is mentioned by the informants that it is hard to find families who have been visited by government officials to check on them and see if they need any form of support. One of the mothers who has been interviewed has been visited by the local government once, to 'check' on her child. When they came they mentioned to her that they were 'inspecting' and that she could expect assistance, but she has not heard anything since. The mother calls the local government 'not reliable'.

The consequence of the government not visiting these families is that they don't know what is 'going on, on the ground'. So, they will not see the need of service provision and will therefore presumably not improve or extent their services.

> *"It is policy, they remain in books, they don't come on the ground".*

This lack of action from the local government, and therefore the lack of trust among the other stakeholders, leads to a far from ideal situation for the service provision towards disabled children. The local government is the stakeholder responsible for implementing policies and programs that are applicable to disabled children and are being initiated from the national government.

As a response to a question about the policy gap, a representative from the local government mentioned in his interview that they don't receive the necessary tools to implement the policies from the national government, such as knowledge and resources. With the resources the local government of Kabarole district has, they focus on special needs education when it comes to disabled children. The local government is, on paper, also providing rehabilitation services at the local hospitals. However, these rehabilitation services are often not executed.

> *"If there was good governance, then the therapists in the hospitals would actually do their work. Some of the families have been there once, but there were no therapists there because they did not turn up for work, and you know the families, that is a lot of money for those families, they are not going to come back again."*

Many of the stakeholders recognize that the local government should have a coordinating role in the service provision towards disabled children in the district. They should establish proper service provision towards disabled children within the public service provision, which is within health care and education, and should function as a regulating body to organize the service provision over the rest of the district.

5.1.5 The Challenge of Limited Resources

Stakeholders are facing the challenge of limited resources. This lack of resources not only includes financial resources, but also the availability of health, education and rehabilitation workers that are trained in working with disabled children and the availability of suitable assistive devises. This lack of resources occurs at all stakeholders' levels.

The availability of resources, or the lack of it, influences too what extent services can delivered. Many of the CBOs and the DPO are not able to deliver the same services continuously to the same families.

> *"Every organization of operation might find someone is in Fort Portal but cannot really go to Busoro because of limited funds or the big distance. Someone can be working in that area where the offices are located, it is a challenge. But what I see is that it is all about resources. If you have recourses, you can get everywhere"*

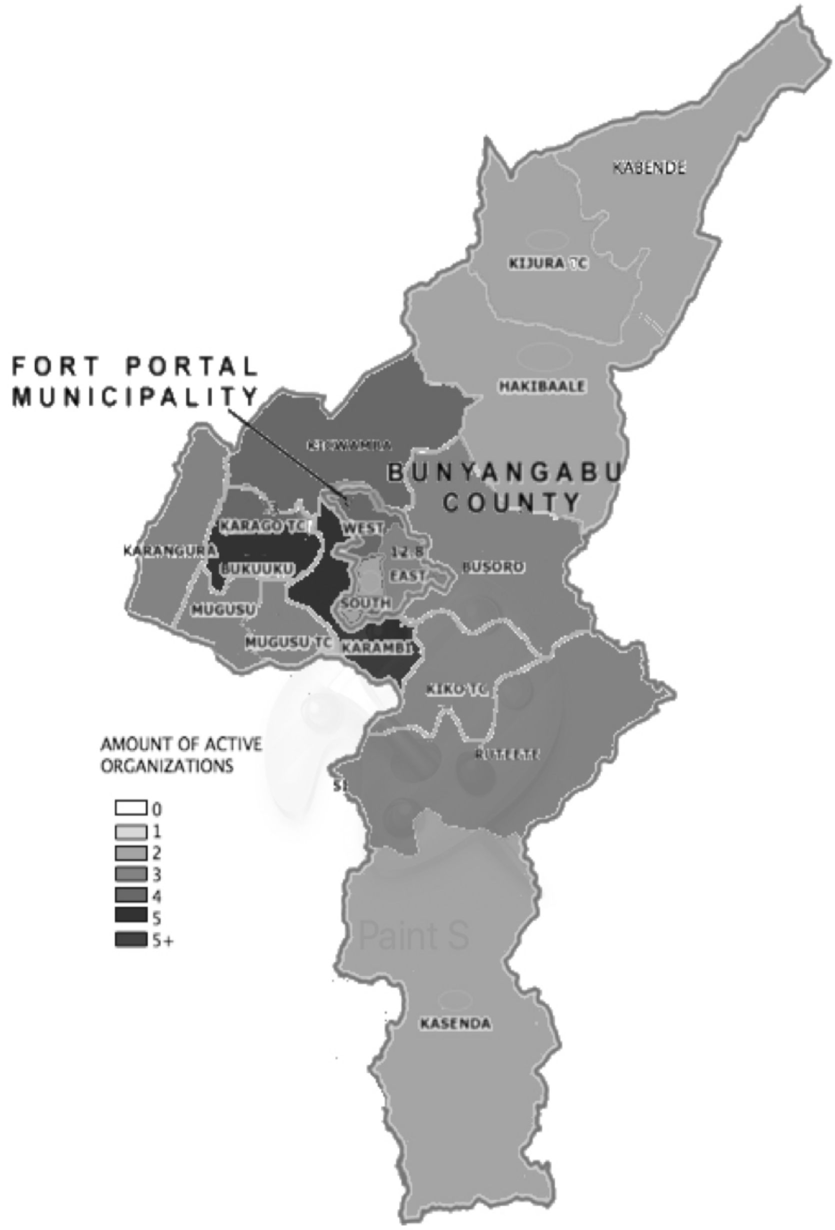

Figure 6: Service Distribution of Interviewed Organizations

The map in figure 6 shows where the interviewed CBOs, the DPO and the rehabilitation center provide their services in the district, based on information gathered in the interviews. As can be seen on the map, the services are mainly located in the sub-counties on the west side of the district around Fort Portal an in Fort Portal municipality.

> *"People concentrating to areas which are near the town, near their offices, they are easier accessible than going deep deep deep, very far in the village."*

This map was presented during the focus groups and the participants were asked to comment on whether this map gives a realistic picture of the current situation. The participants agreed that there is an imbalance in the service provision in the district; Some families benefit from the services of five different organizations, where others can only benefit from two.

Looking on the ground, on parish and village level, the stakeholders note an even greater imbalance. Though some of the organizations do provide service in the sub-counties far away from Fort Portal, such as Kabende in the north and Kasenda in the South, they do not have the resources to reach every parish and village, and therefore most likely not every family that has a child with a disability.

> *"The result of that is, you got some families benefitting from three or four different organizations, and the other families are having absolutely no input, we know that we need to go deeper in to Kasenda, and we know the challenges that are stopping us to do that."*

The imbalance of service distribution over the district, has the consequence that organizations that are active in a certain sub-county, might not be able to refer disabled children with specific needs to an organization, because they are not providing services in that part of the district.

> *We could be in Busoro and want to make a referral to someone because of something that we can't do, but another organization can't, because that organization is not working in that part of the district. So, the family is not getting the benefits."*

Another outcome of this imbalance of service provision, is that this is disproportionally affecting poor families. The families that are most in need in Kabarole district, are the once that are hard to reach. These are the families that are among the poorest in the district and live in rural areas, far away from the services in and around Fort Portal.

> *"There are high levels of poverty here, whit a severe disability this often leads to inability. Because families are living deep in the village, it is difficult for them to access health care. They don't have money to travel by transport, so they are then left to walk five kilometers and If you have got this sick kid and have to carry them five kilometers on rough roads, you can really understand how it becomes inaccessible to reach basic health care"*

Families being poor could potentially lead to many other problems. First, they are not able to access the health services, which could increase the disability. Increased disability could mean less mobility and not being able to attend school and taking part in other aspects of community life. Which leads to the child being left alone in the house, because the mother needs to earn money to buy food for the rest of the family. As illustrated in the next quote…

> *"When we ask; what is the problem? they say; I can't stop working for this child, I have other children to take care off. So, I can't be here, giving all my time and attention to one child. So, when these children are in poor families, the situation becomes worse. So, economic empowerment of these families is also needed."*

Many of these organizations try to serve as much disabled children as possible. However, Due to the limitation of their resources, they are not able to provide constant care to families.

> *"I think it depends a little bit from time to time, like [name stakeholder] sometimes can focus on one of the services and then sometimes not because of like resources or something (...) so, I think it depends a lot on what resources are available at that moment."*

Unfortunately, this leads to families with a disabled child losing trust in these organizations, because they notice that the organizations are not able to meet the promises they make.

More organizations active within a certain sub-county, does not necessarily mean that families are benefitting more, or making more use of the services…. of the family members of the disabled children are more engaged and are overall more present on the outreaches the rehabilitation center provides than parents that live in a sub-county where there are more services available. This issue is attributed to the provision of material goods by some of the organizations. Families are getting used to get money, or goods such as mattresses and don't understand the added value of therapy.

> *"Why in Kyombia, where there are not many organizations people will come? Where there are not many organizations, people will come. Kabende, where there are not many organizations, people will come. But when you are in Karambi, where people get more services, people are not coming.", "maybe these clients are getting used to get mattresses, food or money. So, for us, we are going there to provide therapy and they think we are not helping (...) I think it is due to that, they don't appreciate the medical help we are providing, they want money or mattresses."*

One of the areas where the lack of resources was mentioned most, was within the area of assistive devises. Suitable and affordable mobility aid, such as wheelchairs or artificial limbs, is very limited in the district. A majority of the children with a disability in Kabarole district needs an assistive device, such as wheelchairs, splints or hearing aid. However, these assistive devises are often not available or are too expensive. Even if they are available, there is the issue that the assistive devise is not suited to either the person, or the environment. This has to do with well-meant donations being send from western countries. Containers with assistive devises are shipped to Kabarole district in the believe that this will make a great difference. However, these assistive devises are often electrically powered, fitted to the body of a person or in general not suitable for the Ugandan physical environment.

There is an orthopedic workshop in the district, which manufactures and maintains assistive devises. However, the workshop requests a lot of money for the wheelchairs and for maintenance. These fees are often not within the research of the families that have a disabled child and are only available for those families that have a little more to spend.

> *"The wheelchairs we have gotten from Europe, most of them were old and needed spares, and also they keep breaking down. (...) But when we take it to the orthopedically workshop it is expensive, it becomes expensive to maintain the wheelchair (...) and then of course our terrain is not so good for wheelchairs."*

Other areas where the limitation of resources was present was within specialized health care. There are, for example, no specialized hospital or hospital services for disabled children. When disabled children need specialized care, they now need to be referred to other health centers outside the district, which adds additional costs that most families are not able to afford.

Various examples of limited resources and their consequences have been presented above. But what are the underlying causes of this limitation of resources? One of the reasons according to the informants is that the organizations should fundraise together, instead of individual. Currently the various CBOs and the rehabilitation center all have their own fundraising events. Some of the informants believe that fundraising together would increase the total income because it would potentially reach more people.

However, other informants see fundraising together as another task they would need to take on where they already have so much to do.

5.1.6 Summing up the challenges

This original incentive for this research which came forward out of the preliminary research was the appearing lack of transparency regarding the services provided towards disabled children by the various specialized service providers in Kabarole district. This lack of transparency was potentially leading to gaps and overlap in the service provision. The fact that the stakeholders do not have a clear overview of who is providing which services and activities towards disabled children, with what frequency and on which scale suggests that the service provision towards disabled children in Kabarole district forms a complex whole.

During the execution of this research it became clear to me that there are numerous stakeholders involved in Kabarole district. Some of these stakeholders have service provision towards disabled children or disabled people as their core business, but most of the stakeholders only have service provision towards disabled children as a part of their service provision or provide those service that should be available to disabled children as they should be available for every other child, such as regular health and education services.

Next to the large number of stakeholders, the involvement varies great from stakeholder to stakeholder. In Kabarole district is seems to be the private sector that is providing the specific disability services, where the local government provides the mainstream services such as health care and education to disabled children. The stakeholders are not able to provide every service on the same scale all the time. Due to the unpredictability of the availability of resources, the service providers are not able to say in advance when they are able to provide which service. All together it can be concluded that there is indeed a lack of transparency in Kabarole district regarding the service provision towards disabled children provided by the various stakeholders.

Next to the challenge of lack of transparency leading to inefficiency in the use of resources, the informants of this research named five challenges which are experienced by stakeholders that provide services towards disabled children in Kabarole district. Stigma about disability, a knowledge gap regarding disability, challenging communication and collaboration between the stakeholders that provide specialized disability services, low engagement from the local government leading to the absence of a coordinating body and limited resources available, lead to the service provision towards disabled children not being as optimal as possible within the given circumstances in Kabarole district.

Reading between the lines of the interviews and the focus group there is next to these seven challenges that have been outlined above, another challenge present and experienced by the stakeholders. This is the challenge of cultural differences between the stakeholders. This is a challenge that has not been named directly by the stakeholders but has been identified by analyzing the data for secondary challenges. An example of this cultural difference can be found in which services are prioritized to provide. Where western organizations focus more on the provision of services that could benefit on long-term basis, such as physiotherapy, do Ugandan organization focus on the provision of direct services, such as the provision of food. There seems to be a lack of understanding among the specialized service providers why they are exactly prioritizing certain services. The difference in culture is also seen within the challenge of communication and collaboration. Where the use of WhatsApp groups does not seem to work due the large number of messages that are not related to the service provision, leading to frustration among some of the stakeholders. This difference in culture seems to be leading to misunderstanding and irritation among the stakeholders.

5.2 Suggestions for improvement of the service provision

Based on the challenges, the stakeholders named various potentials for improvement of the service provision in Kabarole district. Most of these improvements were suggested during the focus groups. During these focus groups the challenges named in the section above where discussed and the participants of the focus group were asked what they think are possibilities to address the challenges.

5.2.1 Address stigma and the knowledge gap; create awareness

Addressing the issue of stigma and lack of awareness requires a slightly different approach according to the informants at the focus group. They see potential in using stakeholders that are more closely related to the family. Such as community- and church leaders. These are the stakeholders that often have a good relationship with the family, and the rest of the community, and are the persons that are trusted by the community.

In many churches there is time during the service for health workers and other medical people to talk about health. This could be an opportunity to talk about disability and the services the various organizations provide so that the information is spread among the community.

> *"Creating awareness among a selected group of stakeholders closely related to the disabled child, would help to spread the word among a larger community (...) because this mother has a child who is disabled, it is easier to communicate with another mother, who has another child with a disability, that would connect much easier naturally than the one who is not"*
>
> *"Everyone who has the knowledge, has the chance of creating that awareness. If you come here, maybe a parent can tell another parent."*

Another form of reaching the community is the use of media. TV, newspapers and radio could be used to spread the message about disability. As well as through the use of posters in public places as health centers. In line with this recommendation the informants also suggest that role models should be used more. These role models could show disabled children, their families and the community that they have potential and educate about the added value of services as disability and getting education, even if you have a disability.

> *"If we had a role models, like real disabled person ... we give them more hope when someone is disabled"*

Next to creating awareness among the community as a whole. The informants also note that training is needed among health workers, teachers and other workers that provide ordinary services that disabled children should be benefiting from as well. The health workers are often the service providers which the family of the disabled child will first go to when they note difficulties within their child and they play an essential role in the first diagnosis and the process to refer the disabled children on to other service providers.

> *"I think we need to focus on training health care workers as well" "I think there is a lot of work need to be done on training health care workers in better compassionate understanding of disabilities and actually allowing health care centers to know about the different organizations and support necessary for children with disabilities" "it is not only the resources that are needed when you are dealing with the children, sometimes you need to create awareness to the parents, so we can go there and do the sensitization "*

5.2.2 Improve Coordination, Collaboration and Communication

To be able to improve the service provision towards disabled children in Kabarole district, the informants considers it necessary to improve the communication between the various service providing organizations: the CBOs and the rehabilitation center.

Many forms of communication have already been tried between the stakeholders, but with varying success and the most successful form of communication so far is making phone calls. But this is inconvenient when a larger group of stakeholders needs to be informed. Suggestions to improve the communication included more frequent multi-agency meetings and an online database with those families that are being seen by more than one of the organizations. This database should include who is providing which service to this family and should be updated when the organization in question has performed a visit.

“*What it should be is that we say: okay let’s look at who is going where, who can cover which family, so one can do one family each, rather than three doing one family, who then is getting double what they should get.*

Another approach to address the issues present in Kabarole district is improvement of coordination among the various service providing stakeholders, such as the CBOs and the rehabilitation center. Coordination needs to come in place to improve the collaboration and to divide the resources available equally over the district. The question that remains is who is going to do the actual coordination? According to some of the informants this should be the local government.

“I am thinking of a regulating body, for instance by the local government, that registers these NGOs, maybe if they can allocate the NGOs appropriately. Say if you want to come, and you want to offer those services. Maybe the local government can direct you that this is where you can go, where the services can be utilized most. So that you don’t see the same services being offered in the same place, and other areas not getting it.”

However, various informants also raise the question whether the local government is able to step in to this role and actually full fill such a regulating and coordinating role within the district. If the local government is not able to full fill that role, the NGOs and CBOs themselves need to coordinate the services among them to be able to address the other issues present in Kabarole district.

“The local government is not going to fill any gaps that you have identified. So, it is a case of we need to look at what is the priority of what is missing, it might be where we got four or five people doing the same thing, we just need to shift a little bit, just change focus slightly or change area slightly so that we are helping more people”

Asking a staff member of the local government about how the issues in Kabarole district could be improved, they themselves also gave the suggestion to establish partnerships with existing NGOs to improve the service provision in the district.

“if we developed partnership with some existing NGO’s at least it would also give support”

In order to establish such a relationship and improve the relationships they already have, it is, according to the informants, important that they work together as a team and have a common goal to work on.

> *"We as organizations who are working with the same work can come together, that is one of the strengths we have, that we can speak as a voice of the voice less"*

The question who should take responsibility for implementing these suggestions for improvement, is a difficult one to answer. Some suggest that it is a joint effort, where everyone should take their responsibility, others name the local government as the one who should take responsibility. According to the stakeholders there is need for more organizations that work together with each other, so that they can reach more children and carry out more work.

> *"Right now, [sums up stakeholders], and other organizations where we are partner with, we have been sitting as a block, see what we can do to help these children, but more organizations need to come on board (...) and since it is just the planning face, we have been implementing little. So, we also need to follow up on the recommendations we have made, to that these recommendations get implemented."*

The informants note the need for the establishment of a common goal for all who are involved within the service provision towards disabled children. This will provide a framework on which all stakeholders can build, which can contribute to the improvement of the collaboration, establish better relationships with other stakeholders as the local government.

> *"I think we need a common goal, I think all these organizations need to have a common point of what they are working towards"* and *"Raising our voice, we as the organizations are working with these clients, if we can team up our voices high, and also looking for a way how we can establish good relationships or looking for how we can enact more closely with the government people or the government of Uganda."*

During both the interviews, as well as the focus groups, much emphasizes was put on collaboration between the various organizations to address the challenges that are present in Kabarole district. The informants see increased collaboration as the key to address many of the challenges present in the district. Whether it is on the lower level of using community leaders to raise awareness or on the higher level of the local government, stakeholder groups need to work together in order to make significant changes regarding the challenges occurring in Kabarole district and in the lives of disabled children in Kabarole district.

6 Discussion on the Challenges and Improvements

In the analysis chapter, I presented the challenges experienced in the service provision towards disabled children, from the perspective of the stakeholders and included their views on the possible improvements that could be made to address these challenges.

Within this chapter I aim to discuss the meaning of these challenges, focusing on ways the challenges interact and reinforce each other and how this influences the service provision towards disabled children in Kabarole district. I will also discuss the suggestions made for improvements and relate them back to known models regarding the organization of service provision towards disabled children. I discuss my findings with the use of the literature presented in the first three chapters, and relate them to the research questions as stated in the introduction chapter; *Which challenges do stakeholders experience in the service provision towards disabled children in Kabarole district and how do these challenges influence the service provision?* And *Which suggestions do the stakeholders make to address the challenges and how can these contribute to improvement of the service provision towards disabled children in Kabarole district?*

6.1 Challenges in Kabarole district and their influence on the service provision

This study identified eight challenges present in Kabarole district that hinder the service provision towards disabled children. These challenges are; stigma surrounding disability, a knowledge gap about what disability entails among the stakeholders, lack of transparency which stakeholder is providing which services, inefficient use of resources due to overlap within the service provision, challenging communication and collaboration between the stakeholders, limited resources available to provide every disabled child in the district with those services that they need, missing a coordinating body due to low engagement from the local government in Kabarole district and cultural differences between Ugandan and 'Western' stakeholders leading to friction. In this first part of the discussion I will place these challenges in a broader perspective and identify in which ways they are related with one another.

The 8 challenges experienced by stakeholders regarding the service provision towards disabled children in Kabarole district:

1. Stigma surrounding disability
2. A knowledge gap about what disability entails among the stakeholders
3. Lack of transparency which stakeholder is providing which services
4. Inefficient use of resources due to overlap within the service provision
5. Challenging communication and collaboration between the stakeholders
6. Limited resources available to provide every disabled child in the district with those services that they need
7. Missing a coordinating body due to low engagement from the local government in Kabarole district
8. Cultural differences between Ugandan and 'Western' stakeholders leading to friction

6.1.1 The challenges in a broader perspective

The eight challenges identified in Kabarole district, are not original challenges bounded to this specific district, when compared to the challenges named in the literature.

The challenges experienced by the stakeholders are to a large extent similar to the challenges found within the situation analysis on disabled children in Uganda by Riche and Anyimuzala (2014). The first challenge they discovered, the discriminatory attitudes and behavior towards disabled children, is present in Kabarole district as the stigma around disability and in the gap in knowledge regarding disability.

The gap in implementation of the Ugandan regulatory framework was also named by the informants as a policy gap and lack of actions from the local government. The local government is supposed to ensure decent service provision toward disabled people and is obliged with the implementation of the CBR program in their district as part of the national strategy for planning and delivery of rehabilitation services (ACPF 2011b, 7). The stakeholders in Kabarole district note limited actions from the national and local government when it comes to the implementation of policies and involvement in disability service provision as a whole. The policy stays 'on paper', according to the informants, and is not implemented on the ground. This situation occurs due to other priorities of the local government (ACPF 2011b, 59), scarce resources the local government receives from the national government to provide the services and limited knowledge about disability among government workers.

The third issue Riche and Anyimuzala (2014) reported is the weakened institutional framework, by a lack of coordination among key-stakeholders and gaps in knowledge and capacities among the key-stakeholders. Lack of coordination and collaboration, as well as gaps in knowledge were found as challenges experienced by the informants in the data. Though there is quite an extensive network of specialized service providers, disability is only minimally mainstreamed in general health- and education services that should be available to all children. The lack of coordination was found on several levels, the local government does not function as a coordinating body for the various service providers in the district, and the specialized service providers do not seem to manage and coordinate the services themselves. This due to being too occupied with their own goal to provide as much help as they can to disabled children. The weak communication and the lack of a coordinating body between the stakeholders is also prove of a weakened institutional framework.

The study of Riche and Anyimuzala (2014) concluded that a weak institutional framework contributes to a fragmented programmatic approach, where small-scale initiatives are designed, which lack long-term vision and sustainability and tend to focus on the easy-to-reach children. This picture is also seen in Kabarole district. There are serious gaps found in the distribution of the services over the whole length of the district, due to challenges within coordination, communication, and inefficient use of recourses leading to overlap and gaps. This leads to families living far away from Fort Portal town, in rural areas, being less likely to receive support compared to families in Fort Portal or on the West-Side of the city.

That the challenges experienced by the stakeholders in Kabarole district are similar to the challenges found in the literature gives the evidence that Kabarole district is not unique in its situation and that these challenges are experienced in similar situations. This case study on the specific area of Kabarole district can therefore function as an example of how the situation is found on the ground, and vice versa can suggestions made in the literature to address the challenges named there be of help when addressing the challenges in Kabarole district. This will be discussed more in detail in the next paragraph

6.1.3 Interaction between the challenges

Together these eight identified challenges clearly hinder the service provision towards disabled children. The challenges experienced by the stakeholders are not exclusive. The challenges are related to one another and as previously noted in the analysis chapter, can in many cases either be seen as a cause or a consequence of another challenge. in figure 7, I aimed to visualize the way the challenges, experienced by stakeholders in service provision towards disabled children, interact with one another.

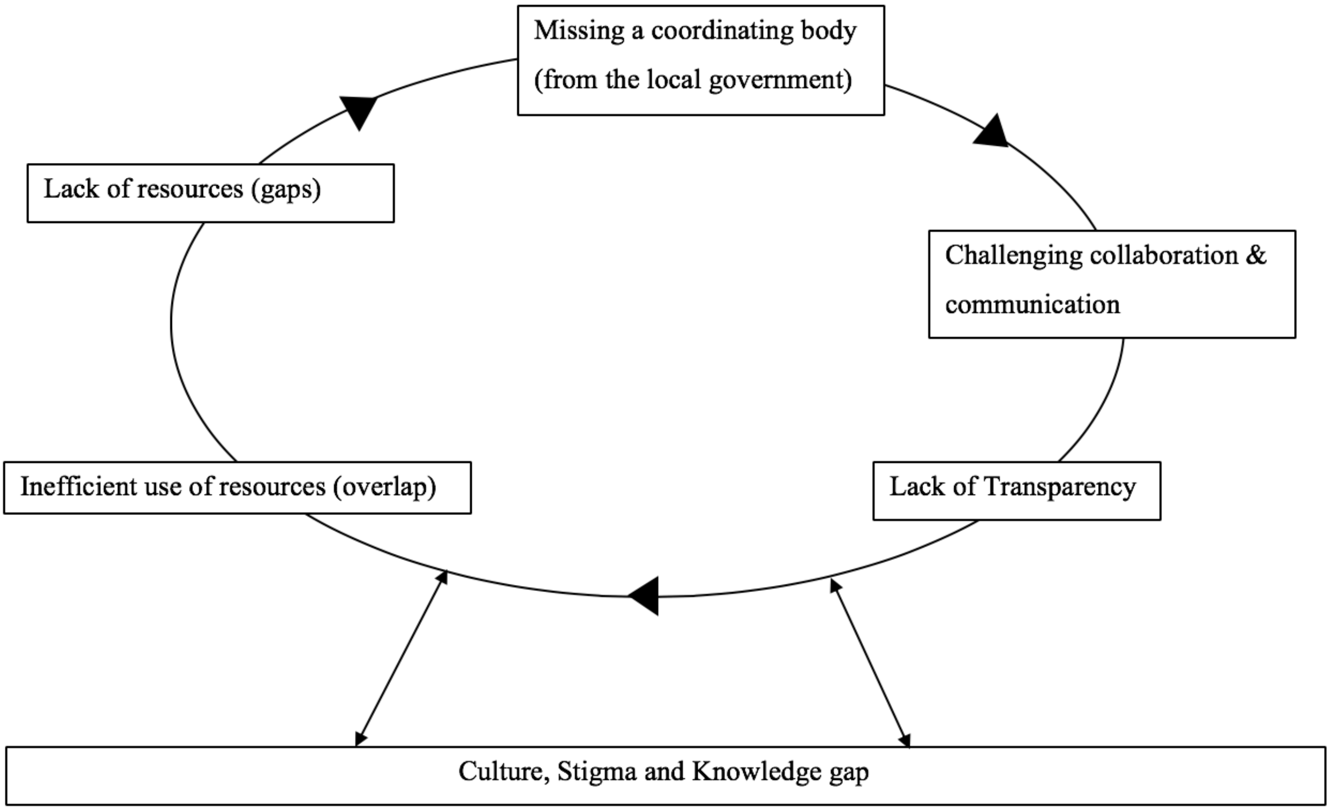

Figure 7: Interaction between the challenges experienced by stakeholders in Kabarole district regarding service provision towards disabled children

The absence of a coordinating body, whether that is the local government or a coordinator within the private service provision, makes it challenging to collaborate and to communicate. Though various stakeholders already collaborate, there seems to be lacking a framework where within the various service providers communicate and collaborate. This leads to a lack of overview of who is providing which service, which can be seen as the lack of transparency. The lack of transparency makes it difficult for the various stakeholders to understand where they can refer to for which services, when they identify a child with a disability. This lack of transparency hinders efficient service provision, and thus inefficient use of resources. Clear examples where given where there was more than one organization providing the same services to one family. Overlap leads, due to limited resources, equally to gaps in the service provision. Because the various service providing stakeholders try the best they can to provide as many services as possible to the disabled children in the district or are occupied by providing services to others in need, they are more occupied with fulfilling their daily tasks, rather than collaborating and coordinating with other service providers to improve the distribution of services over the district. The lack of resources therefore leads back to the lack of coordination.

The difference in culture, stigma and the knowledge gap can be seen separately from the other challenges. These occur among all stakeholder levels, but are not directly involved in the actual planning, organizing and execution of the service provision. However, the other challenges are influenced by culture, stigma and the lack of knowledge. The lack of knowledge has influence on what should be prioritized regarding service provision towards disabled children (the use of resources), efficient use of the referral system (communication), coordination from the government and though not directly named as a challenge, on the quality of the service provision towards disabled children as a whole. Stigma around disability influences how many children are actually included in the service delivery due to the willingness of parents and relatives to seek help, and too what extent general services are provided towards disabled children. Cultural differences are leading to frustrations within communication and collaboration and is leading to misunderstanding and friction.

These challenges, and their interaction, hinder the effective service provision towards disabled children. It can be assumed that due to these challenges, the service provision is less from optimal and that more children with a disability in Kabarole district could benefit from services. If there is improved coordination, collaboration and communication, it could be assumed that there is less overlap and gaps in the service provision leading to possibilities to serve more children and increase the services to those who are already receiving services.

6.2 The way towards locally efficient service provision

The data presented in the previous chapter showed various suggestions for improvement regarding the challenges named by the informants of the interview. Stakeholders themselves have come up with these improvements, which is a great first step regarding implementation of the improvements, since the improvements have been suggested from a bottom-up approach.

The improvements suggested focus on two different areas; the first suggestion was creating awareness among the whole community in Kabarole district, including the family, the community, health- and community workers, primary education, health centers and local government. The second suggestion was the improvement of coordination and collaboration between the stakeholders. The suggestions made by the informants in this study are to a large extent in line with the recommendations made by Riche and Anyimuzala (2014, 116) within their study on the rights of disabled children in Uganda. There two main recommendations are building knowledge about disability and strengthen capacities among the stakeholders. This should be realized by the inclusion of disabled children in mainstream programs, changes in social norms and awareness raising. There should also be a stronger programmatic approach which is built in collaboration with all stakeholders. These recommendations are similar to the suggestions made by the stakeholders in Kabarole district on how to address the challenges present there. Riche and Anyimuzala note that there are no 'off-the-shelf' recommendations and that it is essential to take the local circumstances under consideration.

Within the following paragraphs, I will discuss these recommendations, considering the situation in Kabarole district and including suggestions and approaches from reports and literature.

6.2.1 Create awareness

The informants made several recommendations about how there could be created more awareness about disability among the community in Kabarole district. These recommendations included the use of role models, speaking in churches and putting up posters in health centers to reach the broader community. As well as the training of health care workers and other stakeholders regarding the needs of disabled children.

One of the recommendations of the WHO in the World Report on Disability is the increasing of public awareness and understanding. They see a role for governments, voluntary organizations and professional associations to run social marketing campaigns to change attitudes and see the involvement media and the use of role models as a vital part (WHO 2011a, 19), which are in line with the suggestions made in Kabarole district.

Rohwerder (2018, 3), in her study on disability stigma in developing countries, suggests interventions on three different levels regarding the addressing of stigma and the creation of awareness. On intrapersonal level, which include the disabled person and the family, interventions should include self-help, advocacy and support groups. Interpersonal interventions focus on the creation of awareness within education and the use of CBR to create awareness among the larger community. The last intervention level is the governmental/structural level, where the focus should be on media campaigns and the inclusion of addressing stigma in the legal framework. These interventions are useful for Kabarole district, as awareness needs to be created on these three levels.

6.2.2 Coordination & Collaboration

Due to the lack of involvement of the local government as a coordinating body, and limited coordination among the other service providers themselves, the service provision towards disabled children in Kabarole district is organized less from optimal. This leads to gaps and overlap in the services provided, both in kind of services as well as the distribution of services over the district. Several of the stakeholders are already collaborating within the service provision towards disabled children. The CBOs and the rehabilitation center collaborate to make use of each other's services with the goal to reach as many disabled children as possible. However, challenges are being experienced within the collaboration and communication, which, as outlined in the previous paragraph, are again caused by the lack of coordination.

The path towards successful coordination and collaboration seems to be a challenging one. With little involvement from the local government, strong cultural differences between the specialized service providers and the influence of the other challenges outlined in this report. In the following sections I will discuss various suggestions that have the potential to contribute to improved coordination of service provision and collaboration between the stakeholders. These recommendations build on the suggestions made by the informants in this study, as well as on literature and reports. Eventually the stakeholders in Kabarole district themselves need to take the essential steps towards improved coordination and collaboration. There is not one definite solution to the issues within collaboration and coordination these suggestions can serve as tools for the stakeholders in Kabarole district for the actual process to improved coordination and collaboration.

The recommendations made by the stakeholders in Kabarole district focused on the improvement of partnerships, including more stakeholders within this partnership and to focus on a common goal regarding the service provision towards disabled children. The literature purposed several suggestions to obtain and implement these suggestions.

One of the purposed approaches to organize the service provision towards disabled children, which underlies the need for improvement of collaboration, is through the so called, multi-sectoral approach. This approach can ensure adequate support, improved service outcomes and reduced vulnerability (WHO 2011a, 14-18) The multi-sectoral approach, to provide care to disabled children and their families, requires collaboration across the health system as well as collaboration among the different sectors that are involved (Collins et al. 2017) and is therefore a suitable approach to reach the goal of increased partnership between the various stakeholders in Kabarole district.

The earlier introduced concept of inter-organizational relations (IOR) is relevant when willing to improve collaboration and coordination and establish a multi-sectoral approach. The stakeholders in Kabarole district should focus on the further establishment, maintenance and improvement of IORs, since IORs are relevant where different actors gather in a certain policy field and address the issue jointly (Cropper et al. 2008, 3), which is applicable to the situation of Kabarole district. The further establishment of collaboration within Kabarole district by the establishment of IORs can also potentially be beneficial in making better use of resources, it can produce innovation and can assist in problem-solving (Benington cited in Geddes 2008, 215). Challenges named in the literature regarding IORs include the lack of trust between the participants of the IOR, inequality in contributions and challenges to manage the partnership due to the voluntary character of the IOR. It is essential for a successful IOR in Kabarole district that these challenges are recognized and accepted by the various actors in the IOR and that strong leadership and a common goal are established within the IOR (Geddes, 2008, 217).

It is essential that individuals from all different stakeholder groups are included in this multi-sectoral approach and within the collaboration, such as the parents and the community. Involvement of the community and individuals is the essential element of development (Axelsson 2008, 42). According to WHO (2010, 21) does this, so called, community-based approach, help to realize that development reaches all layers of the community and facilitates initiatives that are more inclusive, realistic and sustainable.

Riche & Anyimuzala (2014) advocate for the human-rights based approach in their study, where they focus on establishing service provision towards disabled children based upon the principles of the CRPD. However, other scholars note that meeting the practical needs of disabled children and their families in the low-resource settings are also desirable (Uvin 2004, Katsui and Kumpuvuori 2008). Kabarole district seems to have a combination of stakeholders focusing on the direct needs, such as the provision of food, scholastic materials and mattresses Other stakeholders focus on the provision of services that focus on the long run, such as vocational training and rehabilitation services.

Families of disabled children in Kabarole district seem to prefer their direct needs being met, over services as rehabilitation that focus on benefits in the long-run. The family members that were interviewed within this study named practical services they would like to receive, such as a goat, or a new floor in the house because the dust is bad for the lungs of their child. However, many family members do not see the added value of human-rights based services such as rehabilitation.

When organizing the services, the stakeholders need to be aware of both the human-right needs, as well as the practical, charity-based needs. Currently both approaches are already being used in Kabarole district. It is important that all stakeholders have a good understanding of the various approaches and see the added value of both of them.

In general, the stakeholder in Kabarole district should give extra attention to gain mutual cultural understanding of each other’s norms, priorities, work processes and goals. As suggested by Vangen (2017, 314-317) should the IOR consider develop cultural sensitivity and develop working communication processes. All stakeholders should be willing to contribute by making trade-offs and compromises, this is essential for the IOR to be successful.

This research shows a paradox when it comes to the question whether the local government should be involved or not. Earlier attempts to collaborate with the local government were not experienced as fruitful by the specialized service providers. However, many of the informants note the importance of the government acting as a coordinating body for the optimal distribution of service provision towards disabled children in Kabarole district and see a shared responsibility for the implementation of the suggestions for improvement. Addressing the issue of involvement of the local government seems to be the most challenging within this research. As noted by the informants in this study, it is essential that the organizations providing services towards disabled children collaborate in their attempts to get involvement of the local government.

The two improvements, creating awareness and improvement of collaboration and coordination are strongly inter-related with each other. Increased and improved collaboration and coordination gives the opportunities to create more awareness due to better use of resources and more equal distribution of services over the district. When there is improved coordination and collaboration the stakeholders have opportunities to discuss how to organize the awareness raising and are able to plan and organize jointly. However, to be able to increase the collaboration and coordination and improve the communication, awareness and knowledge about disability and the needs of disabled children is needed to mobilize stakeholders to act.

6.2.3 Community-based rehabilitation the model for service provision in Kabarole district?

Community-Based Rehabilitation (CBR) was introduced by the WHO as an effective multisectoral strategy to address the needs of disabled people. The focus lies on their participation and inclusion in society and the enhancement of their quality of life (WHO 2010, 1). Considering this goal for CBR, there are links towards the improvements suggested on how to address the challenges experienced in Kabarole district. A multi-sectoral approach is in line with the collaboration between various sectors and stakeholders. Whereas the - participation and inclusion in society – part is related towards the creation of awareness about disability and addressing stigma. The WHO claims that CBR programs have several benefits. It can help to ensure collaboration between stakeholders, engagement in advocacy for disabled people and coordination between various levels (WHO 2010, 26), which are all three related to the two suggestions of improvements made in this study.

The CBR method is seen as the method to provide sufficient support towards disabled children in low-resource settings. There is currently no CBR program in Kabarole district. Despite policies being present where the design and implementation of the CBR method within the district of Uganda is being fostered. Several of the informants in the interviews named the CBR method as a method that could be beneficial in Kabarole district. The literature study showed the CBR method was developed to give stakeholders in disability service provision tools to develop and maintain sufficient services for disabled people.
In the case of Kabarole district, the CBR method, or parts of it, do have potential to be beneficial regarding the organization of service delivery towards disabled children.

As suggested in the literature, CBR could be used as a method to reach the goal of sufficient service provision towards disabled children in the whole of Kabarole district (Kuipers and Sabuni 2016, 464). The method itself could be of use when establishing relationships and considering the various services that should be established when organizing service provision towards disabled children. When the stakeholders in Kabarole district decide to use the method of CBR, it is important that they consider the voices of all stakeholders, and especially those of the disabled children themselves, as well as their family and the community around the family. Extra attention should also be given to the cultural and religious notions present in Kabarole district (Kishore 2017, Kuipers and Sabuni, 2016).

For successful use of CBR method to reach the goal of sufficient service provision towards all disabled children in Kabarole district to meet their needs, the stakeholders who initiate the use CBR method, whether this is the local government, a CBO, the rehabilitation center or a joined effort. The initiators need to consider the ‘essential ingredients’ for successful CBR programs. Which include effective leadership, partnership, community ownership, usage of local resources, considering cultural factors, building capacity, financial support and political support. These essential ingredients are to a large extent related to the outcomes of this research and the suggestions made for improvements. Such as effective leadership by the improvement of coordination, partnership through the establishment and increasement of collaboration and considering cultural factors.

6.2.4 The way forward

In this paragraph I discussed the two main suggestions made by the stakeholders in Kabarole district. Creating awareness and the improvement of collaboration and coordination are both essential for the establishment of locally efficient service provision towards disabled children in Kabarole district. Though the use of CBR cannot be seen as a definite 'off-the-shelf' solution for the improvement of service provision towards disabled children in Kabarole district, it has the potential to serve as a method to reach that goal. Together the stakeholders need to see which elements of CBR could be useful within the service provision in Kabarole district.

6.1 Critical views on this research and limitations

While writing this report, it is essential for me to realize as a researcher, is to what extent I am trying to implement my western views, norms and values on the challenges and implications for improvement. Though I studied the challenges from the perspective of the stakeholders, including their views, opinions and understanding of the challenges present in Kabarole district, I am, with my western view, biased in how I examined the data from the interviews, and which material I used to answer my research question, and which I left out.

An important point to note regarding this research is that it specifically focusses on the perspective of stakeholders from a specific area, namely Kabarole district. It is therefore difficult to generalize the results of this study to other settings. Further research should be done in comparison to this research to be able to say if the challenges experienced and the suggestions made for improvement are also applicable on other situations.

For this reason, I also decided to not use a general framework in which I placed the results of this study. I focused on grasping the perspective of the stakeholders and presenting their views on the situation, in an attempt to give a realistic view of the situation on the ground, in which the informants would feel that they are taken seriously and providing them with information which they can use to improve the services

7 Conclusion

In this research I aimed to grasp the perspective of stakeholders in Kabarole district, Uganda on the challenges experienced in the service provision towards disabled children in Kabarole district, as well as suggestions from the stakeholders on how these challenges could be addressed. After analyzing the data collected through the semi-structured interviews and the focus groups and discussing the outcomes in relation to the literature, there are some final conclusions that can be made, which will be presented below.

Nearly 6000 children are reported to have a disability in Kabarole district (UBOS 2016, 2017). Despite this number being unreliable to a certain extent, it is evident that there is a large number of disabled children in Kabarole distric. For these children, it is important that they receive those services that are needed to live a life as optimal as possible. These services should include both mainstream services, such as health- and education services, as they should be available to everyone, as well as specialized services such as rehabilitation, assistive devises and social support. These disabled children have, on paper, the same rights towards sufficient (specialized) service provision to address their needs, both the practical needs, such as food and housing, as well as the needs that need to be in place to meet the rights from the CRPD.

There are many different stakeholder's active in Kabarole district who are or should be providing these services. These stakeholders include family- and community members, workers from mainstream health- and education services, specialized service providers as community-based organizations, rehabilitation services and the local government.

On the ground there are various challenges experienced by the stakeholders in regard to the provision of services. Challenges as stigma surrounding disability, a knowledge gap about what disability entails among the stakeholders, lack of transparency which stakeholder is providing which services, inefficient use of resources due to overlap within the service provision, challenging communication and collaboration between the stakeholders, limited resources available to provide every disabled child in the district with those services that they need, missing a coordinating body due to low engagement from the local government in Kabarole district and cultural differences between Ugandan and 'Western' stakeholders leading to friction. These challenges hinder the service provision towards disabled children.

7.1 Final remarks on challenges and improvements

Despite the challenges, Kabarole district seems to have many of the ingredients to provide decent support and services to disabled children and their families in place. Several engaged stakeholders are providing a variety of services and are willing to improve the service provision in the district. There are two main points that Kabarole district needs focus on to improve the service provision towards disabled children. Awareness needs to be created among all stakeholders about disability to tackle stigma and to improve knowledge about disability. Awareness also need to be raised among the stakeholders regarding the different views they have on disability and regarding service provision towards disabled children, they need to understand and respect each other's culture.

The second improvement that needs to be made is coordination and collaboration between the stakeholders who are providing services. Coordination and collaboration are needed to improve the communication in regard to the service provision. Increased coordination and collaboration, and with that the communication are expected to lead to more transparency and more sufficient use of funds. In this way, the various organizations supplement each other rather than overlapping and leaving gaps in many places. More sufficient use of funds in a well-managed system of stakeholders could contribute to the possibility to serve more children with disabilities and serve those that already receive services more frequent. Increased collaboration could be established through the establishment and improvement of the inter-organizational relationships (IORs).

A method that could contribute to the implementation of these improvement is the method of community-based rehabilitation. Though CBR should not be seen as the end goal in this situation, the method as introduced by the WHO contains many tools and features that could support the stakeholders in Kabarole district to reach the common goal of providing efficient services towards disabled children in Kabarole district. It is essential that all different stakeholder levels are included in the implementation of the improvements, whether or not the CBR method is used as a tool. Attempts also need to be made to understand each other's culture and values.

The question is whether the (local) government should be involved in this or not. What becomes clear out of the research is that the local government is currently not very active, and that the service providing NGO's and CBOs don't see that changing within the near future. If the local government is not going to act as the coordinating body that functions to direct service and resources to the right locations in the district, the service providing NGOs and CBOs that currently collaborate have to take responsibility and coordinate among themselves. It is important that the various stakeholders respect differences in culture and understanding about disability and use the differences in knowledge they have to provide as many services towards disabled children as possible.

As a final conclusion, stakeholders in Kabarole district seem to be able to organize the service provision towards disabled children in a manner that is effective within the local circumstances in Kabarole district. When the stakeholders manage to collaborate and coordinate the services among them and extra attention is given towards the creation of awareness among all stakeholders, it is expected that more disabled children in Kabarole district could be benefitting from the services present in Kabarole district which contributes to their quality of life.

7.2 Implications for further research

This research gave various implications and suggestions for further research. Because of the outcomes of this research, but also due of the limitations of this study.
Due to the scope of this research I was not able to include representatives from all stakeholder groups. To get a better understanding of the challenges these stakeholders experience, additional research needs to be done. These include community members and community leaders such as church leaders and local leaders. Also, representatives from the general health services and disabled children themselves should be included. The largest group of informants within this research were stakeholders from the group of community-based organizations, which lead to this group being over-representative compared to the other stakeholder level, this meant that other stakeholder groups that were included in this research, education workers and the local government, being less representative which could give a skewed image of the actual situation.

Research should be done on the cultural differences between the various stakeholders. This study showed that the cultural aspect plays a big role in regard to the means of interaction between the various stakeholders in Kabarole district. Especially the cultural difference between Non-Ugandan ‘Western’ workers and Ugandans. The cultural difference was a secondary finding, meaning that it was not directly named by the informants from the interviews and focus groups, but this was identified by recognizing the different views of the stakeholders on, for example, the services that should be prioritized and means of communication. Therefore, more research is needed on the ways cultural differences in working influences the service provision.

Additional research should be done on the involvement of the local government in Kabarole district regarding service provision towards disabled children. This research should focus on the question why there is limited involvement of the local government, the role the national government and the general structure and execution of the governance in Uganda plays in this.

Finally, as part of this research, ideas of improvements were collected among the informants on how the challenges in Kabarole district could be addressed. However, it was not possible to do research on to what extent these suggestions of improvement are feasible to implement. Additional research is needed on how these suggestions can be translated in to actions. It is important that all different stakeholder levels are included in this research to secure support from all stakeholders.

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Appendix 1: Interview List

Nr	Stakeholder	Number of participants	Ugandan (U) or Western (W)	Date	Focus group
1	Rehabilitation	1	W	25-10-2017	Yes
2	Rehabilitation	1	U	31-10-2017	Yes
3	Vocational School/CBO	1	U	31-10-2017	Yes
4	CBO	1	U	01-11-2017	No
5	CBO	1	U	01-11-2017	Yes
6	CBO	1	U	02-11-2017	Yes
7	CBO	1	U	08-11-2017	No
8	School	1	W	13-11-2017	No
9	CBO	2	W	17-11-2017	Yes
10 (C)	DPO	1	U	20-11-2017	Yes
11 (C)	School	1	U	21-11-2017	No
12	Family: Mother	1	U	23-11-2017	No
13	Vocational School/CBO	2	W	23-11-2017	No
14 (C)	Local Government	1	U	28-11-2017	No
15	Family: Mother and Sibling	2	U	3-12-2017	No
FG 1	CBO, Rehabilitation, DPO, vocational school	7	4U + 3W	5-12-2017	-
FG 2	Rehabilitation (8 participants)	8	7U + 1W	6-12-2017	-

(C)= Collaborative interview with fellow student R

FG = Focus Group

Appendix 2: Interview Guides

Interview guide: Stakeholders in disability specific care Kabarole	
Conditions	Person - 1 interviewer - 1 translator in the case the interviewee does not speak English Location - The location is chosen by the interviewee. Preferably at the working place of the interviewee Equipment - Recording equipment - Pen + Paper - Interview guide - CBR-matrix + component explanation - Map of the district
Introduction of the interview	
Introduction	First of all, thank you for willing to participate within this interview. (interviewer shortly introduces him/herself)
Aim	The aim of this research is to get an overview of the services that are currently available in Kabarole district for disabled children, to see if there is need for improvement and investigate ways to achieve this improvement You are one of the stakeholders in the district and therefore your information is very valuable. The aim of this interview is therefore to see what your organization is doing regarding service provision towards disabled children and how you see the service provision towards disabled children in Kabarole district in general.
Topics	We will talk about the following topics in this interview - Topic 1: Your organization - Topic 2: Current situation of service provision towards disabled children in the district

	- Topic 3: Future of service provision towards disabled children in the district
Introduction question	Do you have any questions/comments before we start the interview?
Topics	
Topic 1 Your organization	Question: Can you tell me a little bit more about your organization? Possible follow up questions - Which services do you provide to CwD and their families? [use CBR matrix] o Is there anything your organization provide that does not fall under the matrix? o To who do you provide these services? - Where do you provide these services within Kabarole district? [use map]
Topic 2 Current situation of service provision in the district	Question: How do you see the current service provision to children with disabilities and their families within the district? Possible follow up questions - Do you work together with other organizations or government institutions that provide services to CwD and their families in the district? o Which organizations/institutions - How do you work together? How is this going? - In which ways do you communicate with other organizations? - With which organizations do you work together in the district? - Do you see any problems in the current provision/coordination/organization in the district? o If yes, which problems do you currently see in the provision of care to children with disabilities in the district?
Topic 3 Future of service provision in the district	Question: How do you see the future of service provision towards disabled children in the district?

	Possible follow up questions - What do you think is needed to achieve these plans? - What can be improved regarding the service provision/organization/coordination to CwD and their families? o How can this be improved? o What is your organizations role in this? o What is the other stakeholders' role in this? - Regarding the problems, you mentioned earlier, how can these be adequality addressed?
Conclusion	
Closing the interview	Do you have any further comments regarding this interview? Relating to this topic, who else do you think I can interview for this research? [get phonenumber/contact]
Follow up	I would like to organize a focus group in the beginning of December [date] at Knowledge4Change to discuss the results from the interview with different stakeholders. Would you be willing to participate in this focus group?
Word of thanks	I would like to thank you for participating in this interview.
Contact details	Please feel free to contact me the same way we corresponded before if you have any questions or comments after the interview.

Interview guide: Parents of children with a disability	
Conditions	Person - 1 interviewer - 1 translator in the case the interviewee does not speak English Location - The location is chosen by the interviewee. Preferably in their own living situation and without the presence of any other persons Equipment - Recording equipment

	- Pen + Paper - Interview guide
Introduction of the interview	
Introduction	First of all, thank you for willing to participate within this interview. (interviewer shortly introduces him/herself)
Recording	If you agree I will record this interview. This gives me the opportunity to focus on what you say during the interview and it is more reliable afterwards when I transcribe it. Do you give permission to record this interview?
Topics	We will talk about the following topics in this interview - Topic 1: Your family - Topic 2: Current Support and Services - Topic 3: Future Support and Services
Introduction question	Do you have any questions/comments before we start the interview?
Topics	
Topic 1 Disability	Question: Can you tell me a little bit about your child? Possible follow up questions - Is there a difference between your kid and other kids from his/her age? And if yes, what? - What do you see as the cause for his disability? - What kind of help does your child need during the day?
Topic 2 Current support and services	Question: What kind of help does your child need during the day? Possible follow up questions - Who is giving this help? - How is giving this help going? - Which organizations are helping you with that? o What do you think about these organizations? o How did you get to know these organizations? - Which help is available for you and your child, as far as you know?

	o Which organizations do provide these services? o How did you get to know about these services? - How does this support help you and your child? - Is there any help you don’t receive at the moment but would like to receive? o If yes, what kind of help and from which organization?
Topic 3 Future support and services	Question: How could the help to children with disabilities and their families be made better? Possible follow up questions: - What do you think is needed for that? - How would you like to receive this support/services? - How would these support/services benefit you and your child?
Conclusion	
Closing the interview	Do you have any further comments regarding this interview? What did you think about the interview?
Word of thanks	I would like to thank you for participating in this interview.

Appendix 3: Focus Group Guide

Duration: 2 hours

Set up: The office will be used as a venue. Drinks will be provided, as well as snacks. Chairs will be put in a half circle.

Part 1: Welcome

- Introduction of myself
- Introduction round of the others
- Explanation what I have been doing the last weeks
- What we are going to do today

Part 2: The current services

Overview of the CBR-Matrix, who is providing which services (according to themselves) and a map of the district where the organizations are providing their services.

Discuss with neighbor:

- What are the things that pop out for you?
- What do you think about that?
- What is good?
- What can be better?
- Was this how you expected it to be?

Part 3: Bottlenecks and possible solutions

On paper, different bottlenecks are written out, every couple gets one bottleneck and discusses the following with their neighbor for a few minutes:

- Do you agree that this is a bottleneck or not?
    - Why, why not?
- What can be done to make this bottleneck go away or make it less big?
- What is needed for that?
- What can the different stakeholders do?
- Who should take responsibility?

After discussing in groups, the different groups will be sharing their outcomes

Part 4: Any other comments

Regarding the services to children with disabilities in the district, are there any other comments you want to make?

List of bottlenecks

- Every organization is working on its own, it is unclear who is doing what
- There is a lot of overlap in the services, which leads that other families are being left out
- There is not enough available and suitable mobility aid, which leads to many other problems for the child and the family
- Communication between the different organizations can be better, the quarterly multi-agency meetings are not enough.
- There is not enough awareness among the community about what disability is and there is still a lot of stigma
- The local government is not doing much and there is very little trust in their services, we do not advocate enough for the CwD at the local government.
- We are missing a database where we can see who is seeing which families and that is being updated
- We are lacking a specialized medical center in the district for children with a disability
- We are missing fundraising together and organizing events together.
- There is only primary education, there is no secondary education available after that

Appendix 4: Ethical Clearance Sheet NSD

Randi Wærdahl
Postboks 4 St. Olavs plass
0130 OSLO

Vår dato: 14.08.2017 Vår ref: 55094 / 3 / BGH Deres dato: Deres ref:

Tilbakemelding på melding om behandling av personopplysninger

Vi viser til melding om behandling av personopplysninger, mottatt 10.07.2017.
Meldingen gjelder prosjektet:

55094	*Empowering Parents of Children with an Intellectual Disability in Uganda: Meeting the Needs of Both Parents and Children*
Behandlingsansvarlig	*Høgskolen i Oslo og Akershus, ved institusjonens øverste leder*
Daglig ansvarlig	*Randi Wærdahl*
Student	*Emma van de Wetering*

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, 15.11.2018, rette en henvendelse angående status for behandlingen av personopplysninger.

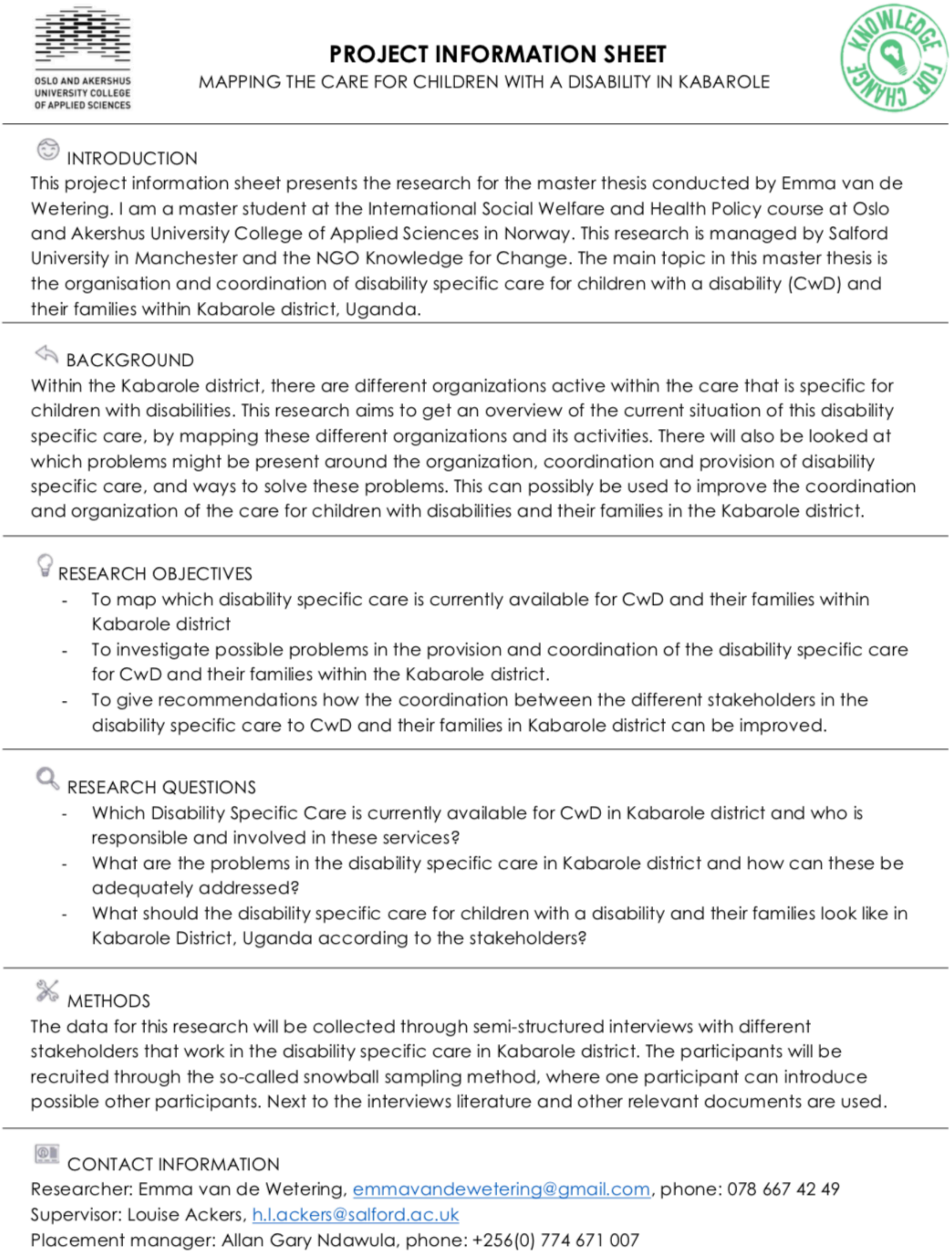
Dersom noe er uklart ta gjerne kontakt over telefon.

Vennlig hilsen

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

NSD – Norsk senter for forskningsdata AS Harald Hårfagres gate 29 Tel: +47-55 58 21 17 nsd@nsd.no Org.nr. 985 321 884
NSD – Norwegian Centre for Research Data NO-5007 Bergen, NORWAY Faks: +47-55 58 96 50 www.nsd.no

Appendix 5: Information Sheet



OSLO AND AKERSHUS
UNIVERSITY COLLEGE
OF APPLIED SCIENCES

PROJECT INFORMATION SHEET

MAPPING THE CARE FOR CHILDREN WITH A DISABILITY IN KABAROLE

INTRODUCTION

This project information sheet presents the research for the master thesis conducted by Emma van de Wetering. I am a master student at the International Social Welfare and Health Policy course at Oslo and Akershus University College of Applied Sciences in Norway. This research is managed by Salford University in Manchester and the NGO Knowledge for Change. The main topic in this master thesis is the organisation and coordination of disability specific care for children with a disability (CwD) and their families within Kabarole district, Uganda.

BACKGROUND

Within the Kabarole district, there are different organizations active within the care that is specific for children with disabilities. This research aims to get an overview of the current situation of this disability specific care, by mapping these different organizations and its activities. There will also be looked at which problems might be present around the organization, coordination and provision of disability specific care, and ways to solve these problems. This can possibly be used to improve the coordination and organization of the care for children with disabilities and their families in the Kabarole district.

RESEARCH OBJECTIVES

- To map which disability specific care is currently available for CwD and their families within Kabarole district
- To investigate possible problems in the provision and coordination of the disability specific care for CwD and their families within the Kabarole district.
- To give recommendations how the coordination between the different stakeholders in the disability specific care to CwD and their families in Kabarole district can be improved.

RESEARCH QUESTIONS

- Which Disability Specific Care is currently available for CwD in Kabarole district and who is responsible and involved in these services?
- What are the problems in the disability specific care in Kabarole district and how can these be adequately addressed?
- What should the disability specific care for children with a disability and their families look like in Kabarole District, Uganda according to the stakeholders?

METHODS

The data for this research will be collected through semi-structured interviews with different stakeholders that work in the disability specific care in Kabarole district. The participants will be recruited through the so-called snowball sampling method, where one participant can introduce possible other participants. Next to the interviews literature and other relevant documents are used.

CONTACT INFORMATION

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Supervisor: Louise Ackers, h.l.ackers@salford.ac.uk
Placement manager: Allan Gary Ndawula, phone: +256(0) 774 671 007

Appendix 6: Consent Form

Consent Form

Research on disability specific care, provided to children with disabilities and their families within Kabarole district.

I, the undersigned, have read and understood the Project Information Sheet provided by the researcher.

I understand that taking part in the study will include being interviewed and audio-recorded for transcription and analyzing purposes.

I have been given adequate time to consider my decision and I agree to take part in the study.

I understand that my personal details such as name, and employee address will not be revealed to people outside the project.

I understand that my words may be quoted in the research outputs, but that my name will not be used.

I understand that the data will only be used for this specific project, and that the data will be deleted when the project is finished (November 15th, 2018).

I understand that I can withdraw from the study at any time and I will not be asked any questions about why I no longer want to take part.

I have read the forgoing information, or it has been read to me. I have had the opportunity to ask questions about it and any question I asked, has been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Name of Participant_____________________________________

Date ____________________________

Signature of Participant _________________________________

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