

# **ECCD practices within Childhood Disability**

## ***Perspectives and Experiences of Children with Disabilities and Caregivers in Uganda***

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**FINAL THESIS SUBMITTED TO**

**THE NORWEGIAN UNIVERSITY OF SCIENCE AND TECHNOLOGY**

**FACULTY OF SOCIAL SCIENCES AND TECHNOLOGY MANAGEMENT**

**NORWEGIAN CENTRE FOR CHILD RESEARCH (NOSEB)**

**FOR THE AWARD**

**OF**

**MASTER OF PHILOSOPHY IN CHILDHOOD STUDIES**

**JUNE 2014**



# DEDICATION

*To my lovely wife Patricia,*

*and to our precious children Jordana and Jordan,*

*for the times we missed together and the moments we will share again*



## ACKNOWLEDGEMENT

I would like to extend my sincere felt gratitude to all the people who made it possible for me complete this master thesis. I acknowledge the support of my supervisors; Professor Anne Trine Kjørholt and Dr. Marit Ursin, for your tots of wisdom, commitment and guidance during this entire writing process. I appreciate the time you put a side to read through my work, and for the academic dialogue and debates that you have inspired in me. Indeed it was more than an honour being supervised by you.

I appreciate the support of the entire academic and administrative staff at the Norwegian Centre for Child Research (NOSEB); it was a pleasure learning from each one of you and thank you very much for the academic input and support that you have rendered during my study at NOSEB. To my colleagues, you were such an amazing team of people and I am so humbled to have been a great part of you all.

To my wife Patricia, for being that strong pillar when I was away, I am so indebted to you, to my children Jordana and Jordan, for each day that I have missed in your childhood moments; I share the joy of this accomplishment with you. And to my entire family, there is no day that past and I never thought of each one of you.

I also extend my appreciation to the Norwegian State Fund and NTNU, for the wonderful opportunity that you extended to me to pursue my studies here in Norway.

And finally to you my friends: Moses, Ronald, Fiona, Steve, Oliver, Aaron and my sister Susan for the time and effort you invested to ensure that this writing is a master piece.



## ACRONYMS

<b>ACPF</b>	African Child Policy Forum
<b>ACRWC</b>	African Charter on the Rights and Welfare of the Child
<b>ADL</b>	Activities of Daily Living
<b>CBR</b>	Community Based Rehabilitation
<b>COP</b>	Community Outreach Programme
<b>CoRSU</b>	Comprehensive Rehabilitation Services in Uganda
<b>CRC</b>	United Nations Convention on the Rights of the Child
<b>CRPWD</b>	Convention on the Rights of Persons with Disabilities
<b>CWDs</b>	Children with Disabilities
<b>ECCD</b>	Early Childhood Care and Development
<b>ECD</b>	Early Childhood Development
<b>ELC</b>	Early learning Centre
<b>HIV</b>	Human Immunodeficiency Virus
<b>MGDs</b>	Millennium Development Goals
<b>MGLSD</b>	Ministry of Gender Labour and Social Development
<b>MoES</b>	Ministry of Education and Sports
<b>MoH</b>	Ministry of Health
<b>NCD</b>	National Council for Disability
<b>NDP</b>	National Disability Policy
<b>NGO</b>	Non-Governmental Organisation
<b>NOSEB</b>	Norwegian Centre for Child Research
<b>NSD</b>	Norwegian Social Science Data Services
<b>NUDIPU</b>	National Union of Disabled Persons of Uganda
<b>OVC</b>	Orphans and other Vulnerable Children

<b>PWDs</b>	Persons with Disabilities
<b>SHIP</b>	Spinal Bifida and Hydrocephalus Interdisciplinary Program
<b>UCRNN</b>	Uganda Child Rights NGO Network
<b>UDHS</b>	Uganda Demographic and Health Survey
<b>UNESCO</b>	United Nations Educational, Scientific and Cultural Organisation
<b>UNHP</b>	Uganda National Health Policy
<b>UNICEF</b>	United Nations Children’s Fund
<b>UNISE</b>	Uganda National Institute of Special Education
<b>UPGIYF</b>	Uganda Policy Guidelines on Infants and Young child Feeding
<b>UPIAS</b>	Union of the Physically Impaired Against Segregation
<b>USDC</b>	Uganda Society for Disabled Children
<b>WHO</b>	World Health Organisation



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## **ABSTRACT**

CWDs are regarded as one of the most vulnerable groups of children who are marginalised by virtue of their disability status. The different ways in which childhood disability is constructed within Ugandan societies continues to reflect on CWDs as passive beings. This study was informed mainly by the Sociology of Childhood whose first stance is to regard children as active beings in their own right. The study was further informed by the rights based approach facilitated by the CRC, ACRWC and CRPWD. The argument reflected in this study from a rights based perspective is participation rights of CWDs. The study appreciated the fact that, CWDs have different capabilities and therefore, developed multiple and participatory methods for their benefit. Some of them included; drawing, recall, observation, and visual-listening. Because the study was inclusive of adult caregivers, interviews also informed part of this study. The study which combined the aspect of disability and ECCD, sought to answer the research questions of; how CWDs within community and institutionalised centres experience ECCD in regard to learning and healthcare. Furthermore, it asked the question of how children's rights to care, learning and participation are practiced within the ECCD programmes in Uganda. The findings of this study are structured into two themes of learning and healthcare which form part of the ECCD practice.

In the learning theme, it revealed that interaction facilitated children's learning processes. The social environment within the institution and home were both seen as facilitating children's learning process. It also presented the element of time as a very important factor in the learning process. It also revealed that it was critical for the home caregivers to also learn techniques and skills for caring for CWDs. It revealed that communication was a critical issue within CWDs spaces. It particularly facilitated children's agency. In regard to healthcare, the study revealed that therapy and rehabilitation processes went beyond the restoration or achievement of 'normality' of disability, as suggested by the medical model of disability. It also revealed the CBR approach as being critical to the realisation of ECCD. In the wrap up of the study, it discusses the complexities to CWDs' learning such as absence of the male home caregivers in the child's lives and then further looks at the aspects that exclude CWDs in society. It also wraps up the healthcare discussion by discussing poverty which was revealed to be a major obstacle to child disability management in the home and as such, directly reflected on the lives of the CWDs and their caregivers.



# CHAPTER ONE

## INTRODUCTION

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### **Background to the study**

This thesis explores the experiences and perspectives of Early Childhood Care and Development (ECCD)<sup>1</sup> among Children with Disabilities (CWDs) in Uganda. I discuss the roles of different social structures and institutions in extending ECCD to children with disabilities. The study also explores the children's own perspectives of disability and how relevant ECCD is in their present situation. I discuss the thematic areas of health and learning, relating them directly to how they transcend to both the needs and rights of CWDs. Throughout this research the children affected by disability have been referred to as Children with Disabilities. This categorization is in line with the provisions in Articles one and seven of the Convention on the Rights of Persons with Disabilities (CRPWD).

### **The perspective of ECCD in Sub-Saharan Africa**

It is notable that ECCD trends vary across Sub Saharan Africa. By 1990, there was a growing demand for most countries across Africa to have more focus on children and ECD. This was mainly attributed to the urgency raised by international declarations namely the CRC and the World Declaration of *Education for All* (EFA) (UNESCO 1990 in Akosua, 2008; Dawes & Biersteker, 2011). The ECD impetus across the continent continued to grow with the coming into force of the African Charter on the Rights of the Child (ACRWC) in which policy makers prioritised children issues. With the increasing need to speed up ECD issues, international development agencies such as United Nations Children's Fund (UNICEF) and World Bank invested and funded ECD activities in Africa. Countries such as Eritrea, Uganda and Kenya benefitted from World Bank credit funding by the mid-1990s (ibid 2008). By the year 2000, there was significant progress in ECD made by several African countries in the areas of education, health and nutrition among others. For instance, by 1996, Uganda had

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1 Also referred to as Early Childhood Development. Instances where ECD have been used is also to emphasis the originality of the author cited. However the ECCD and ECD are contextually the same.

launched the Universal Primary Education (UPE) programme and had also embarked on health campaigns such as massive immunisation.

The drive towards the realization of ECD in Africa was also founded in the United Nations Millennium Development Goals (MDGs). Jaramillo and Mingat (2008), point out that the MDGs tackle issues of child health, education and nutrition. All these three factors are essential in early childhood development. They should be able to check and reduce issues of under five year mortality rates, achieve inclusive education for all, and reduce the number of children suffering and dying from hunger respectively.

However despite the relevance of ECD to every child, Young and Mustard (2008), argue that ECD programmes in Africa are faced with several encumbrances. Akosua (2008), as well argues that some countries' lack of ECD national policies has affected the priority and resource allocation. Also with the AIDS epidemic that has swept across Sub Saharan Africa claiming a life of a parent or both and leaving behind orphans, some of who were also infected with HIV impacted negatively on ECD. An estimated 12 million orphans lived in Africa by 2003 with about one out of eight being under the age of six years (Fonseca, O'Gara, & Sussman, 2008, p. 93). This therefore meant that realisation of early childhood development to its full potential cannot be guaranteed for most of these children either due to absence or lack of capacity of the caregiver. Dawes and Biersteker (2011), advance this argument further by stressing such incapacitation or absence have in essence translated to low productivity and economic development all of which impinge child development in Africa.

ECCD scholars such as Akosua (2008), argue that Africa must embrace a holistic ECD approach aimed at economic growth, social change and transformation. She further points out that holistic development of the child can only be realized with an integrated ECD approach which includes health, nutrition, learning, and community empowerment.

## **Early Childhood Development and childhood disability**

Early childhood is very important as far as the child's development<sup>2</sup> is concerned because the early years have a full life impact on the rest of the child's life. It has been suggested that early childhood spans from birth usually until the age of eight years (CARE, USAID, &

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<sup>2</sup> <http://www.unesco.org/new/en/education/themes/strengthening-education-systems/early-childhood/>

Hope-for-African-Children-Initiative, 2006; UNESCO, 2006; WHO, 2012). In between this early childhood period, the child is expected to undergo and experience holistic development physically, socially, emotionally<sup>3</sup> and cognitively (CARE et al., 2006). Although most ECCD debates call for the implementation of different early childhood interventions such as education, health, nutrition and others, it is necessary that these various interventions should be able to account for the differences of childhood in time and place. This can be viewed in line with Qvortrup (2002), argument that historical dynamics of childhood are constantly changing at different levels. He argues further stating that children's status and life conditions change with time compared with the different groups or segments of society. With this regard therefore, it becomes necessary to understand the dynamics of different social structures in society in relation to implementing ECCD. Realization of good ECCD practices for children with disability would therefore necessitate an all-inclusive approach to childhood disability in which both community and family take on an active role ensuring the best interests of the child<sup>4</sup>.

Children with disability who are within the ECCD age bracket may have their development process altered by disability. These delays may result from experiencing malnutrition, disease, poverty, neglect and social exclusion due to their disability. For such reasons, Urwin 1983 in Langston, Abbott, Lewis, and Kellett (2004), suggest that the developmental needs of CWDs need to be handled with care. Furthermore, trends indicate that CWDs from poor households and families in Uganda usually suffer from either malnutrition, ill health or do not attend school because of their disability. The strong correlation between poverty and disability creates a needs and rights gap which in essence means that poor children with disability are at an increased risk for poor outcomes as far as health, wellbeing and success in life is concerned.<sup>5</sup> The inability of most CWDs in Uganda to realize ECCD at the right time has a huge significant effect on the alternative programmes setup later to try and cover up for the lost time. For instance, although UNICEF<sup>6</sup> suggests that there is still room for CWDs to catch up on skill development and behavioural adaption, this will require a lot of concerted

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3 [http://www.ecdgroup.com/pdfs/ECCD\\_Definition\\_2010\\_final.pdf](http://www.ecdgroup.com/pdfs/ECCD_Definition_2010_final.pdf)

4 See provisions of Article 3 of CRC

5 <http://www.crin.org/docs/promisingpractices.pdf>

6 [http://www.unicef.org/publications/files/Inequities\\_in\\_Early\\_Childhood\\_Development\\_LoRes\\_PDF\\_EN\\_02082012.pdf](http://www.unicef.org/publications/files/Inequities_in_Early_Childhood_Development_LoRes_PDF_EN_02082012.pdf)

effort for a country like Uganda where the policy implementation is setback by several factors such as limited resource allocation.

The support of the State, the parental role and other caregiver support remain indispensable in forwarding CWD development. Their roles, though provided for in legal frameworks such as the CRC and CRPWD, have also been reinforced by child agencies such UNICEF<sup>7</sup> which acknowledges that parents and other caregivers' active involvement are pivotal in enhancing child development such as learning. This level of involvement is very important in as far as the educational needs and rights of CWDs are concerned. The early Uganda childhood education curricula for instance incorporates the needs of special needs young orphans and other vulnerable children (OVC) under which CWDs are also categorized in Uganda<sup>8</sup>.

## **Statement of the problem**

The crippling social structures of the state have had a big impact on the family as a unit responsible for nurturing the deserved and recommended childhood in most parts of Uganda. Despite its recognition of the importance of ECCD, through its policy and legal framework on early childhood matters, the government's constrained budget allows it provide limited financial investment. It is instead the private sector and Non-Governmental Organisations (NGOs) that have become key players running ECCD in the country especially in the areas of education, health, play and nutrition. Mello, Ulkuer, and Engle (2010), argue that the healthcare system is critical in ensuring the survival and development right of every child. This is because the care and development process of every child commences from the prenatal level which necessitates high levels of interaction between the mother and the healthcare professionals. This interaction, inform of antenatal care, is supposed to be on going all through even in the early years after birth, somewhat breaks down along the way. This is due to the high costs of maternal healthcare and a poorly functional government healthcare system (cf: Ministry of Health 2010) which have continued to account for the growing number of children born with disability as well as those becoming disabled in their

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<sup>7</sup> [http://www.unicef.org/publications/files/Inequities\\_in\\_Early\\_Childhood\\_Development\\_LoRes\\_PDF\\_EN\\_02082012.pdf](http://www.unicef.org/publications/files/Inequities_in_Early_Childhood_Development_LoRes_PDF_EN_02082012.pdf)

<sup>8</sup> <http://www.crin.org/docs/promisingpractices.pdf>

early childhood. Other prevailing factors such as family poverty, the distance to health facility and nutrition have also largely contributed to fewer mothers attending antenatal or postnatal healthcare, a fact which has compromised both their health and that of their children. These inadequacies, therefore deny them the opportunity to preventive and protective healthcare (Mello et al., 2010).

Consequently, CWDs unlike other children are at a greater risk of experiencing delayed early developmental outcomes in the areas of health, learning or nutrition which is largely attributed to low levels of incomes in the home and nature of the child's disability. Some also CWDs experience a lot of stigma because of their disability from their peers, families and communities. The exclusion in community activities such as, play and learning environments weakens their morale to participate which is crucial in their cognitive and physical development<sup>9</sup>. This kind of discrimination and stigmatization has warranted that children with disabilities need special attention and care if they are to realize and develop their full potential in their initial stages of life. Over time, state and private caregiver organisations has been setup in Uganda aimed at identifying care and developmental delays CWDs experience and to also provide remedies in different forms so as to enhance their full potential physical and mental development. However, despite the existence of these institutions, there is still limited information on how caregivers can promote ECCD in Uganda.

The information generated in this study will therefore enhance the implementation of ECCD programmes for CWDs. Similarly the study will contribute to the reduction of the existing knowledge gap on best ECCD practices for CWDs that both institution and home caregivers should emphasise.

## **Study objectives**

- To understand how children with disabilities' interests are enhanced within early childhood care and development practices.
- To capture children's experiences and perceptions about the programme in regard to enhancing their care and development in the areas of health and learning.
- To understand how children with disabilities' participation is enhanced within the early childhood care and development practice

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<sup>9</sup> Refer to provisions of Article 23 of CRC and Article 13 of ACRWC

- To explore children's experiences and perspectives of community and centre based early childhood care and development practices.
- To understand how caregivers, institutions and homes promote and provide early childhood care and development to children with disabilities.

## Research Questions

- How do children with disabilities within the community and institutionalised centers experience early childhood care and development (healthcare and learning)?
- How are children's rights to care, learning and participation practiced within the early childhood care and development programmes in Uganda?
- How do institution caregivers integrate children with disabilities, their families and the local communities into early childhood care and development programs?
- How do home caregivers (including family and relatives) in the local communities experience the effect of the programmes on children's learning, health, and nutrition?

## Structure of the thesis

The thesis is structured into seven chapters; each chapter provides a short introduction of what is detailed in it. *Chapter one* is the introduction of the thesis. It entails an over view of ECCD and childhood disability. It also gives an account of why I undertook this study. It also highlights the key research questions and concerns that were raised during my fieldwork.

In *Chapter two*, I discuss the ECCD practice in Uganda. Also, the background of my study area Uganda at large and my research site in particular are discussed. In trying to bring to light how ECCD and Childhood situation in Uganda is, I use the different Ugandan policies and laws showing how they advocate for ECCD in disability but also highlighting the weakness of implementation. I also incorporate applicability of some of the international legislation like the CRC and the ACRWC in a Ugandan context. I further give an overview of early learning and healthcare practices in Uganda.

In *Chapter three*, I discuss the theoretical approaches of childhood I employed in my study. Particularly I talk about the 'emergent' paradigm of the Sociology of Childhood as the main



theoretical argument upon which I did this study. I also discuss other childhood theories and perspectives as well as approaches such as the rights based approach, the actor oriented perspective, and structural phenomenon approach. Furthermore, I use some theoretical perspectives from disability studies.

*Chapter four* entails my research methodology. I highlight my fieldwork experiences, the methods and technique of data collection that I engaged, the way in which I planned to analyse the data, and the ethical considerations and challenges.

In *Chapters five and six*, I handle the analysis and discussion of my research findings. This I do by contextualizing the data into the two themes of learning and health. The different experiences and perspectives of the CWDs and their caregivers are highlighted and discussed in these chapters.

*Chapter seven* informs the concluding discussion in which I discuss the major findings of the research data. This discussion here also creates a linkage to the theoretical and methodological approaches. I conclude the chapter by suggesting recommendations based on my research findings.



## **CHAPTER TWO**

### **THE PRACTICE OF EARLY CHILDHOOD CARE AND DEVELOPMENT IN UGANDA**

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#### **Introduction**

In this chapter, I give an insight of Uganda detailing its location, the people and their different cultures as well as other salient characteristics and traits of its population. I also discuss child disability and early childhood matters in Uganda in relation to some of the national and international legalizations and policies that are currently in place. The two themes of child learning and health which inform the basis for my research are also contextualised within the Ugandan perspective. I conclude the chapter by giving an overview the research site, and highlighting how its different structures function.

#### **Overview of Uganda**

Uganda is a sub-Saharan landlocked country in East Africa that lies in the great lakes region of Africa. It also lies within the equator latitude and is significantly known for inhibiting the source of the river Nile which is the world's longest river. Uganda is a multi-ethnic country comprising over 53 different dialects. Due to such diversity, English and Kiswahili are the officially recognised languages (Oketch, 2012). However, Luganda which is a local dialect from Central and Southern Uganda is the other commonly spoken language in several parts of the country. This ethnic variation also largely accounts for the differences in culture, tradition and norms among Ugandans. It further accounts for some of the differences in the place of childhood on the social structure and children's experience in a Ugandan society. It is estimated that the current Ugandan population stands at about 37 million people (United Nations, 2013), with over half of the population being children under the age of 15 years. With a high a fertility rate of about 6.7 children per woman, the average annual population growth rate is estimated at 3.2% per annum and is projected to reach 44 million people by the year 2020 (MoH 2010). The average life expectancy in Uganda is 51 years, for males and 53 years, for females. It is estimated that the under five year mortality rate is at about 137 deaths

per 1000 live births<sup>10</sup> a fact that denies these number of children to their right to live and experience ECCD.

Ugandan tropical climate favours agriculture which is the major economic activity of the country. The Ugandan economy is also boosted by other economic activities such as tourism, fishing and recently discovered oil mining. The public administration structure which is directly responsible for children in Uganda is the Department of Children and Youth under the Ministry of Gender Labour and Social Development (MGLSD) (UCRNN 2002).

## **ECCD legislation and policy practices for children with disabilities in Uganda**

Uganda has several documentations, legalisation and policies in place that guarantee children with disability to benefit from early childhood development. These include international legalisation such as the CRC, the CRPWD, and the ACRWC all of which Uganda has signed and ratified. These legislations are the basis upon which some of the salient ECCD practices such as learning and healthcare are built on for children with disabilities

There are also national legalisations and policy documents which take into account the different local contexts like socio-economic, cultural and political situation of Uganda and its people. Some of these include, the 1995 Uganda Constitution, the Children's statute of 1996, Persons with Disabilities Act of 2006; the National Council for Disability Act 2004; the Equal Opportunities Act 2008; and the Education (Pre-primary, Primary, and Post-Primary) Act 2008 (UNESCO, 2010). With this legal framework, it is of no doubt that ECCD and disability related policies and practices in Uganda are contextualised within local and international legalisations.

With the aim of achieving effective service delivery for persons with disabilities (PWDs), government developed the National Disability Policy. Since PWDs are considered vulnerable in Uganda, programmes such as the Social Protection Programme were also developed to

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10 2009 Uganda Policy guidelines on infants and young child feeding

address issues of direct income support for the poorest and most vulnerable population<sup>11</sup>. However Lang and Murangira (2009), argue that there are several complexities and contradictions in relation to policy and implementation of disability legalisation in Uganda. They in particular point out inefficiencies such lack of coordination within line ministries in streamlining disability issues as well as a weak statistical base of the disability numbers in Uganda which prohibit planning and implementation of disability activities. These inadequacies have equally been sighted by ACPF (2011), study of children with disabilities in Uganda particularly pointing out insufficient resource allocation as a hindrance to policy implementation.

### ***The Constitution of the Republic of Uganda***

The 1995 Constitution of the Republic of Uganda is very particular on matters pertaining different categories of children. In Article 32, discrimination on the basis of race, age, gender and disability is outlawed. In Article 34, it recognises the need for all children to benefit from an education; Article 35 recognises the need for full mental and physical development of PWDs in Uganda. It therefore bestows this duty to the state and society at large urging them to ensure that PWDs are accorded the respect and human dignity like other human beings.

### ***The United Nations Convention on the Rights of the Child***

Uganda ratified the UNCRC in 1990 and to date, it has submitted four reports to the UN Committee on the Rights of the Child (UCRNN, 2002). The government has in the recent years managed to incorporate some of the articles enshrined in this convention to its national legalisations such as, the 1995 Uganda constitution; the Children's statue and the Equal opportunities' Act, among others. By doing so, it simplified its own implementation of some of the provisions in the convention, such as education for all children, and rights of children with disabilities.

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<sup>11</sup> Uganda Demographic and Health Survey 2011

## ***The United Nations Convention on the Rights of People with Disability***

Uganda ratified the CRPWD in September 2008. By doing so, it provided an opportunity for Uganda to fast track a rights based approach to disability issues. The adoption of this convention was thus an additional support to the ready ratified and existing national and international legislation highlighting the interests of children with disabilities. In Article 1 of this convention;

Persons with disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on equal basis with others.<sup>12</sup>

The general principles of this convention of, non-discrimination, equality opportunity and respect for the evolving capacities of CWDs have in largely been implemented in Uganda by institutions and persons dealing with PWDs and children. For instance, the institution in which this research was carried out adapted this convention as one of its key working guidelines in advocacy for non-discrimination and equality of CWDs in society.

The rights of CWDs are clearly spelt out in this convention notably the incorporation of CRC's best interests of the child principle. Clause two of Article seven stipulates that the best interests of the child shall be the primary consideration in all actions concerning children with disabilities. This best interest principle therefore paves way for the implementation of other rights and obligations respectively stipulated in this convention such as the right to life, education and health. The general obligations, as provided in Article four of the convention, are therefore to be implemented with regard to the best interests of the CWD. It is therefore arguable that the disability movements like National Union of Disabled Persons of Uganda (NUDIPU), Uganda Society for Disabled Children (USDC), among others, get a lot of inspiration from this convention when advocating for the rights of the disabled.

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<sup>12</sup> <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>

## ***The African Charter on the Rights and Welfare of the Child***

Uganda is signatory to the ACRWC. In its preamble, the charter highlights how critical the situation of most African children is due to different and unique circumstances, such as their socio-economic, cultural, and developmental circumstances, among others. Due to such circumstances, the charter highlights the need for special care and safeguard for the African child<sup>13</sup>. Although there is no specific policy on ECCD in Uganda, the government recognises the importance of early childhood. It has nonetheless ensured implementation of ECCD components, some of which are campaigns to prevent early childhood disabilities. In accordance with Article five, which provides for the survival and development rights; and Article 14 which encompasses health and health services, the Ugandan government engaged in the campaign to prevent early childhood disability through the *Kick polio out of Uganda* immunisation campaign in which mass immunisation was carried out country wide. Such campaigns have continued under the Ministry of Health (MoH) programmes of *child days plus campaign*, in which children in their early childhood are given booster vaccines as well as vitamin dosages in order to reduce infant and child mortality rates. Also, the second Uganda National Health Policy 2010 in its minimum healthcare package gives priority to maternal and child health, prevention, management and control of communicable and non-communicable diseases (MoH 2010). These are some of the key components in the Ugandan health policy which reflect the provisions in the African charter and are relevant to the realisation of ECCD and management of childhood disability in Uganda.

## **Early childhood learning in Uganda**

Like other African societies, the Ugandan learning modalities were largely based on traditional values and culture that were informed by socialisation. These traditions and cultures have continued to change with a blend of both tradition and modern learning criteria which are now largely influenced by western socialisation. Meinert (2009), highlights that the child learning process in a then typical Ugandan society was highly practical and occurred in places such as fields, fireplaces or during rituals. Children as, Akosua (2008), argues, are of value to African societies and informed a great part of family life and community especially

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13 <http://www.crin.org/Law/instrument.asp?InstID=1015>

in the socialised role the *becoming* or the *incipient* child (Durkheim, 1982, p. 147) was expected to play. The constructed value of children especially in contribution to the family and community labour force deemed a child with disability an unproductive and a liability to the family and community resources.

Although the family and the community still have a significant role in the learning processes of children in Uganda, the role has largely been taken over by the education system in who views learning a more of as a school responsibility implemented by teachers. This is largely attributed to the changing socio-economic situations of most families such as parents working longer hours and children having to spend more time in learning institutions.

With the introduction of Universal Primary Education, (UPE) the school enrolment for children in Uganda increased to over 90% (Meinert, 2009, p. 4). Also the enactment of the 1997 UPE Act, has been argued as an enabling factor for children with disabilities to enrol in school because of the low cost of affordability for their families (ACPF, 2011). However, the quality of learning provided by UPE system has over time been questioned, with some parents and caregivers resorting to private schools and learning centres as the alternative to the free government education.

The Equal Opportunities Act of 2008 and the Education (Pre-primary, Primary, and Post-Primary) Act, are some of the policy documentation in place aimed at promoting learning for all children irrespective of age, sex, gender or disability. In particular the Education Act in its policy provision of education stipulates that the responsibility of educating and training a child is a joint responsibility of the state, parent, or guardian and other stakeholders<sup>14</sup>. It is also on a rights based perspective that the Uganda Children's Act of 1996, deems it necessary for early intervention in childhood disability through appropriate treatment, rehabilitation and education (ACPF, 2011).

The early learning systems in Uganda are dominated by competition for early learners. These pre-primary schools commonly known as nursery schools have incorporated in their curriculum activities such outdoor and indoor play, games and sports, music among others.

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14 [http://planipolis.iiep.unesco.org/upload/Uganda/Uganda\\_EducationAct.pdf](http://planipolis.iiep.unesco.org/upload/Uganda/Uganda_EducationAct.pdf)



These private learning centres target children between two to five years, and their holistic approach to learning has indeed enhanced early childhood learning through active child participation<sup>15</sup>. However, these early learning institutions barely admit children with disabilities. This is because their infrastructure is not developed to meet the interests of CWDs and also some of the protective practices of parents with CWDs indicate parental preferences to have their children learn from specialised learning institutions.

The basic education policy and costed framework for educationally disadvantaged children 2002, in ACPF (2011), presents that the education policy advocates for inclusive learning for all children in ordinary public schools and learning environments. It on the other hand provides that learners with severe disabilities should be assisted in specialised schools or learning institutions (Ministry of education and sports 2005, in ACPF, 2011). Based on this, the UNISE Act of 1995, mandated that establishment of Uganda National Institute of Special Education (ACPF, 2011). This institute was specially to cater for the learning interests of persons with disabilities through teacher and other personnel training in the areas of special needs education and rehabilitation (ibid).

## **Early childhood health in Uganda**

Children's healthy growth, survival and development are largely dependent on their feeding practices and accessibility to good healthcare services. Although Uganda may not have a particular streamlined policy on ECCD, there are policies and interventions in place which tackle ECCD related issues on child health. For instance the second National health policy plan of Uganda prioritises maternal and child healthcare delivery in its minimum healthcare package (Ministry of Health 2010). Disability management is also included in this national minimum healthcare package because PWDs are compounded by challenges of poverty, disease burden and are categorically regarded as a disadvantaged group (ACPF, 2011).

Child nutrition in early childhood is considered critical in the development process. One of the causes and challenges of child disability has been attributed to the issue of malnutrition in children (UNICEF, 2013). In particular, UNICEF specifies the areas of feeding challenges

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15 [http://planipolis.iiep.unesco.org/upload/Uganda/Uganda\\_EducationAct.pdf](http://planipolis.iiep.unesco.org/upload/Uganda/Uganda_EducationAct.pdf)

and balanced dieting as some of the factors reinforcing malnourishment in child disability. Some of these findings are cross cutting and were also revealed in the data I collected (discussed in chapter six). With regard to nutrition in Uganda, the Ministry of Health developed the policy guidelines on infant and young children's feeding. These policy guides are aimed at ensuring that both young children and infants benefit from nutrition and health development programs. The expected outcome from this is the enhancement of the survival of all children, while at the same time strengthening the care and support services to both their parents and caretakers (Ministry of Health 2009). The policy categorically divides children into three priority feeding groups; children in normal circumstances, children exposed to HIV and children in other exceptionally difficult circumstances. However in its implementation of ECCD, Plan Uganda acknowledges that poverty and socio-economic insecurity are still a major hindrance in as far as early childhood development is concerned (Plan, 2011). Based on this, it further argues that in spite of disadvantaged children being born with enormous potential, they require extra support if they are to achieve measurable success comparable to that of their contemporaries in areas such as, healthcare and nutrition.

Also children with disabilities born to low or average income families are usually at a great risk of not realising their full potential due to limited resources even if the families are willing to help such children. Ntale (2003), has argued that many disability conditions in Uganda are caused by poverty. Persons who are victims of poverty are usually prone to limited healthcare and good nutrition practices which situations make them susceptible to becoming disabled or failure to develop their full potential if they are disabled (ibid).

Furthermore, the issues of maternal health and literacy have continued to reflect directly on child healthcare practices. The UDHS 2011,<sup>16</sup> argues that as a stock of human capital, level of individual education had strong effects on child and family health. It is no doubt that children from educated and learned mothers have often experienced and benefitted from better nutrition and healthcare because of their exposure to information. Furthermore the spatial allocation of health facilities is in itself a threat to both maternal and child healthcare. Early childhood development trends reveal that the

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16 Uganda Demographic and Health Survey 2011

health and wellbeing of each child is highly dependent on the health and wellbeing of his/her primary caregiver and the level of household income (Early Childhood Matters 2007, p. 8).

The relatively distant of health centres, especially in rural areas, is one of the contributing reasons for women shunning antenatal care or giving birth at home (cf: Ministry of Health 2010). This has in essence not only put the mothers' lives at risk but also potentially risked the development of the child. With more than half of the country's population living in the rural areas, dissemination of information to mitigate such risky behaviour has remained a myth owing to poor institutional and structural development.

## **Fieldwork and research site**

The fieldwork was conducted in a Non-Governmental Organisation (NGO) in Wakiso district. For purposes of this study, this research site has been regarded as 'the institution'. It rehabilitates children with disabilities between 0-18 years by providing medical and social rehabilitation through innovative community based approaches with emphasis on direct service delivery. The institution has a vision of realizing that children with disabilities and their families are accepted and supported in society. Through this, they have worked towards achieving their mission of holistically providing rehabilitation services to children with disabilities and their families. Through its Community Based Rehabilitation programme (CBR), characterised by, home based care and outreach visits, the institution involves the local community in tackling challenges of childhood disability. This approach has had an impact in challenging the stereotypes and stigma associated with disability in the community and institutions. In particular, the institution has championed inclusive learning and education for children with disability through its advocacy programmes, encouraging schools to admit CWDs in their schools, and then establishing working relations with such schools, and monitoring the progress of these children in these learning institutions. The institution has different structural units which though independent, rely on the services of each to ensure prompt service delivery.

### ***The Early Learning Centre***

The Early Learning Centre (ELC) is an occupational therapy unit which uses a therapy rehabilitation and learning to enhance the development of CWDs. As an occupational therapy unit, it specializes in handling both physical and mental disability. As a unit dealing with children who have learning challenges, the ELC prioritises teaching of basic skills such as good toilet habits, tooth brushing, and dressing up, among others. This purposeful learning has been referred to as 'Activities of Daily Living' (ADL) because these seemingly simple activities are some of the key milestones during the development process of the child. They are therefore supposed to be part and parcel of the child's daily life when they attain a certain chronological age. However, because childhood disability affects children development differently, some of the children irrespective of their age are not able to carry out these ADL on their own and therefore have to rely on others for these activities. The ELC centre thus seeks to create and develop a self-dependence on the CWDs through training and teaching them ADL. The role of both the occupational therapists and the home caregivers are important and dependent on the other because the institution caregivers also engage the home caregivers to learn how to implement these activities in other places later on.

In order to achieve effective rehabilitation and learning results, the ELC takes on home setup with an in built kitchen and bathroom for the benefit of all children within the centre. It also has a therapy room and a common play room with brightly painted walls comprising different pictures, drawings and alphabetical letters. The common area is also fitted with mirrors, a television set, different toys and children's playing equipment. The ELC also has a large front veranda fitted with a ramp to easy accessibility for all the children. It is on this veranda that both children and their home caregivers sometimes share a midday meal, come out and play or participate in an afternoon activity such as painting.

### ***The catch-up class***

The catch-up class is another learning structure setup within the institution. The class is under the stewardship of a special needs instructor. The classroom has a centralised arrangement of tables and chairs so as to enhance easy mobility of all the children even those using assistive devices like wheelchairs. Like the ELC, the catch-up class, also has a television set pinned at the back corner of the classroom. The classroom is also dotted with other learning devices such as a black board, a small book shelf, and local musical instruments at the back. The

catch-up class ensures continuity of the child's learning when the child is undergoing rehabilitation at the institution. It uses a child-teacher approach in which the instructor finds out from the child which subjects he/she needs help basing on what the child has already studied at school. Also because all children cannot be attending therapy at the same time, this class keeps them occupied while waiting, engaging in activities such as drawing, singing, dancing, and watching TV, among others.

### ***The workshop***

The workshop unit does the production of assistive devices and appliances for the CWDs as well as training and monitoring their usage. This unit is made up of three sections that include the plastic, metal and carpentry section and functions in a way that allows them to complement the work of the other. As a component of the workshop, the plastic section moulds and crafts supportive devices such as splints and artificial body parts such as, limbs. The metal section on the other hand specialises in fabricating assistive devices which both enhance particular rehabilitation activity and mobility. For instance the CP chair, wheelchairs, and walking and standing frames are some the fabrications used for both occupational and physiotherapy. The carpentry section usually completes the chain of production initiated by the metal section. Specifically it will incorporate the wood fittings into some of the assistive devices like the CP chair, standing and walking frames. Besides this, they also design and make auxiliary clutches and the corner seat which is particularly tailor made to enhance the strength of the spinal.

### **Physiotherapy and psychiatric nursing care**

Physiotherapy is the other form of rehabilitation CWDs at the institution undergo. With this type of therapy, its major role is to maintain, improve or restore physical function. The physiotherapy unit therefore concentrated on helping children to adapt to the use of their physique. According to the therapists in this unit, it was their responsibility to tackle the barriers of participation restrictions to children's activities such as play, high coordination, and schooling.

The psychiatric nursing unit primarily screened for the presence of a mental challenge or disability and implemented the required interventions. It was here that the prescription for the

different drugs and medicines was undertaken to for children with mental challenges. Despite the fact that children with mental disability also benefitted from both occupational and physiotherapy, the psychiatric unit also played the complementary intervention role for such conditions. Besides this, it was common that the psychiatric nurses also took the role of comprehensive healthcare service providers. It was also because of the complementary role that all these therapy units were housed under, one block easing access and switching of units for children and their caregivers.

# CHAPTER THREE

## THEORETICAL FRAMEWORK AND PERSPECTIVES

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### Introduction

In this chapter, I discuss the major theoretical discourse; the ‘emergent’ paradigm which informs the sociology of childhood (cf. Prout & James, 1990). Furthermore, I use the actor oriented perspective and the concept of agency. I also use childhood as a structural phenomenon within my theoretical debates. This chapter also generates a rights based discussion specifically using provisions from the CRC. Prout and James (1990), argue that other sociological debates and arguments from social sciences in general cannot be delineated when theorising childhood. Based on this, I also incorporate perspectives from disabilities studies. In the final part of the chapter, I briefly discuss the concept of learning in relation to childhood disability.

### The Sociology of Childhood

The rise of the ‘emergent’ paradigm which deconstructs and reconstructs childhood has been attributed by Prout and James (1990, p. 15) to the ‘gradual growth in awareness that the meanings attached to ‘child’ and ‘childhood’ might differ a cross time or space. They stress out that these began to destabilise traditional models of child development and socialisation. As a matter of fact, they supported Danziger’s (1970, p.18), view that the ‘emergent’ paradigm ‘begins with the assumption that a child is socialised to a particular culture at a certain stage in its history’ (cf. Prout & James, 1990, p. 15).

My research process was informed by the need to understand how the different perspectives of CWDs are enhanced through ECCD. This was achievable through engaging the participation of children and their adult caregivers. Contrary to the dominant framework informed by the disciplines of psychology and sociology in which childhood was a preconceived notion of human becoming (Jenks, 1982), this research sought to explore the different social practices that surround child rearing and what they mean to CWDs.

The sociology of childhood criticises the disciplines of developmental psychology and socialisation theories because of their stance in reinforcing dominant perspectives that undermined structures of childhood. For instance, Jenks (1982, p. 13) presents the argument that the,

Unilateral manipulation of the child within socialisation theories condemns him to be an absent presence, a nominal cipher without an active dimension.

Lee (2001), shared a similar notion. He castigated how sociology for a long time had played a big role in reinforcing the *human becoming* to *human being* through socialisation. In this research, my stance is to first of all appreciate children as active agents in their own right, irrespective of their disability situations and experiences. Whereas growing up is an inevitability that every child undergoes, it was the CWDs' ability to portray their different experiences and how they impacted on the different social structures that made it worthy to study them in their own right.

As stated previously, childhood differs across time and place. Thus, childhood as a social structure is also constructed differently. In developing this argument further, Prout and James (1990, p. 8), allude that the social construction of childhood 'provides an interpretive frame for contextualising the early years of human life. Within this argument, the concept of disability as a social construction is perceived and presented differently within society. One of the common constructions of disability is the socio-cultural perspective that disability as an inability. In regard to childhood disability, such stereotyping is closely related to past perceptions that characterised childhood as a stage of immaturity and inexperience (Jenks, 1982). Similarly, such dominant constructions of childhood disability continue to affect the development of CWDs across societies. I find the notion of *becoming* as argued in sociology of childhood closely linked to the concept of 'abnormality' for CWDs. The perceived rational thinking of society is constructed within predetermined processes to correct the 'abnormality' so as to have a so-called 'normal' human being. This social construction of childhood disability is further discussed using the social model (Oliver, 1996b) of disability within the chapter. In reflecting this in the data, I highlight the different ways in which the notion of disability is constructed and perceived in society. For instance, I present the institution CBR



approach as one the institutionally driven initiatives used to deconstruct and reconstruct the becoming and normality perception of childhood disability.

### ***Actor oriented perspective***

Sociology of childhood recognizes children as social actors in their own right (O'Kane, 2000). In illustrating the meaning of this perspective when researching with children, Nilsen (1990, p.47)<sup>17</sup> argues that it 'involves an attitude where children are regarded as "whole" and "complete" human beings'. The *complete being* concept carries with it the regard with which CWDs' 'voices' need to be heard, as means to participatory research rather than patronize their vulnerability. Children are also perceived as active participants in shaping their social lives, other peoples' lives and the societies in which they live in (Jenks, 1982; O'Kane, 2000; Prout & James, 1990). Within this study, the recognition of children as complete-beings first and foremost provided ground upon which children were able to participate. The valid views of children with disabilities, have throughout been presented in the in the study alongside those of adults. As social actors, this study shows that the perspectives and experiences of CWDs are critical in enhancing good ECCD practices.

### ***Children with disability as agents***

Child agency has been defined as being 'active in the construction and determination of their own social lives, the lives of those around them and the societies in which they live (James & Prout, 1997, p. 8). Also Robson, Bell, and Klocker (2007, p. 135), have further illustrated the concept as

an individual's own capacities, competencies and activities through which they navigate the contexts and positions of their life world, fulfilling many economic, social and cultural expectations, while simultaneously charting individual/collective choices and possibilities for their daily and future lives.

Children have been argued as being dependent on others in several ways that are critical for their survival, development, protection and well-being (Boyden 2006 in Abebe, 2008). On the other hand, adults too, have been found to rely on the children's activities and skills (Kjørholt

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17 Social Studies of Children and Childhood lecture 4, 18th.10.2012: Nilsen 1990:47, Translated excerpt from article in the Norwegian journal Barn 1990, no.4, p.44-57

2005b in Abebe, 2008). Within such interdependence, the interactions espoused and manufactured provide ground for children to assert their agency. Also, Robson et al. (2007), argue that children are compelled by different circumstances to assert their agency. Such circumstances are embedded within the different social structures that are important in children's everyday life such as family. Holloway and Valentine 2000, and Kjørholt 2004; 2005b, in Abebe (2008, p. 33), thus argue that that 'the recognition of children's agency does not involve the rejections of the social structures that shape their actions, Rather it entails the need to respect their knowledge and social competencies'.

Based on my data, the children's everyday interaction with other social structure, provided ground upon which agency was exercised. One of the manifests of agency particularly related to issue of power between children and their home caregivers. The issues of child-adult power relations were often seen in relation to child participation. For children with communication challenges, they largely exerted their agency by resistance or what Ahearn (2001, p. 115), situates as 'oppositional agency'. In studying children's peer culture, Corsaro (2005), reveals that paying attention to children's multiple communicative skills is critical. Agency can thus be critical in communicating CWDs' participation interests, however, as adults, we must be able to listen to and construct meaning from children's agency Olli, Vehkakoski, and Salanterä (2012). The valid expression of agency within the child disability context therefore emphasizes the assertion that

the child is active in its own right, not simply imitatively, but as ...an agent in its own construction and as naturally an agent as adult, in the sense of agency that concerns the initiation of action by choice' (Wartofsky 1981, p.199 in Qvortrup, 2002, p. 54).

### ***Childhood as a structural phenomenon***

The sociology of childhood argues that childhood is a structural phenomenon which is both structured and structuring (Alanen, 2001, p. 13). As a social structure, childhood therefore cannot exist in totality per se but is rather informed by a combination of different variables and other social structure such as gender, class, and ethnicity (Prout & James 1990, and Alanen, 2001; Qvortrup, 2002). The interaction of childhood and gender for instance was manifested by the less involvement of men as home carers in early childhood disability issues. This was reinforced by the socio-cultural construction of disability as well as the

patriarchal structure of the society which still largely define the child rearing role as a responsibility of women. The structural debate is furthered enhanced by Qvortrup (2002), in his comparison of the structural form of childhood to the concept of class. He calls for the study of childhood should be done in relation to other groups, historical periods and among varies nations. For instance, he presents the macro structural analysis affecting both children and adults even though children most times have no control over them, they all the same have a big impact and influence on their lives. Within children's disability was the element of poverty which dauntingly reinforced disability. The evidence of poverty within the micro structures such the family and home that childhood interacts weighed heavily on the implementation of good ECCD practices for CWDs. As further discussed in chapter six, poverty was a true reflection of the class concept as presented by Qvortrup (2002). Most children with CWDs originated from humble and poor socio-economic backgrounds, which partly accounted for their disability and also put a big strain on the family economic resources when it came to caring for them.

## **The rights based approach**

This approach is developed based on the child's rights perspective as advocated for under the CRC. It categorically drifts away from conceptualising children as rights receivers who need special care and assistance (O'Kane, 2000) and instead adopts the stance of children as rights holders (Berman & Kaufmann, 2002). In forwarding the rights discourse in Sub-Saharan Africa, the ACRWC has concurrently been enforced alongside the CRC. The rights based approach is nonetheless a very broad based perspective and for purposes of this study, I will use some of the four general principles of the CRC to contextualize my discussion to early childhood and disability. These principles are also very interrelated and overlapping in their discussions of the child's rights.

### ***The Non-discrimination principle***

The different ways in which society constructs disability attracts different forms of discrimination for CWDs. In their General Comment (GC) seven, the committee of the CRC argues that the challenges of CWDs do not lie within their own disability but are rather informed by an amalgam of socio-cultural, attitudinal and physical forces (Hodgkin &

Newell, 2007). As objects of discrimination, CWDs are not only put in a vulnerable position but they also pose as powerless members of society. Freeman (1992), advances the importance of children's rights being separated from that of adults if the much deserved attention and participation of children is necessary for their full development and progress. The beginning point of tackling discrimination issues in this research was in the development of inclusive research methods and techniques for the CWDs. The socio-cultural and economic issues that reinforce discrimination and stigma also take central stage in the discussion with possible suggestions of how such discriminatory gaps can be closed up.

### ***The right to life and development***

This principle presents the precursor to the provision of other rights. In particular, Hodgkin and Newell (2007, p. 83), argue that ensuring 'survival and development' of the child to its fullest is inevitable for implementation of the entire convention. This argument is in tandem with the role ECCD plays in the lives of children. Whereas all children have the component of life by virtue of their existence, their development does vary and is influenced by several factors ranging from political, socio-economic and cultural. It is with this regard that Article 23<sup>18</sup> lays out the importance of healthcare, education, and psychological development for CWDs' full development. My study with CWDs highlights how important each of these aspects is in achieving early childhood development among CWDs. In addition to being a right, inclusive education for instance was significant in enhancing the learning and development of the children. Similarly discriminatory tendencies also impinge on CWD development. In general comment 7, for example, discrimination is presented as an obstacle to early childhood development among CWDs.

Discrimination against children with disabilities reduces survival prospects and quality of life. These children are entitled to the care, nutrition, nurturance and encouragement offered other children. They may also require additional, special assistance in order to ensure their integration and the realization of their rights (Hodgkin & Newell, 2007, p. 19).

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18 UNCRC Rights of children with disabilities

The state and parents are seen as playing virtue role in the survival and development of the child. It is this question that my research sought to answer particularly the role caregivers played in enhancing CWDs' rights and welfare in their early childhood.

### ***The right to be heard***

This principle is founded on the basis of Article 12 of the CRC, which agitates for the respect of the views of the child. The expression of children's views should come along with the possibility of adults being able to listen and take decisions based on these views. Lee (2001), argues that adults cannot always be relied upon to speak on children's behalf and neither do adult interests always coincide with those of children. As CWDs, the right to be heard was provided for in this research as they were able to use several ways to express themselves. In being heard, comes the aspect of participation which played a pivotal role in CWDs inclusion to participate in the research. Also concerned with having CWDs being heard, Tara (2013), argues that children's views and concerns of children with disability have to be taken into consideration and not rely only on accounts from their caregivers, family or teachers. The actualization of children being heard in my research was thus based on the understanding that for CWDs' experiences can be communicated using the non-verbal language or symbols. The right to be heard as facilitated using children's symbolic interaction within the study spatiality equally provided ground on which child agency was exerted.

## **Disability Studies**

The raise of PWDs' movement in the 1970s is largely believed to have contributed to the development of disability studies (Oliver & Barnes, 2010). Dominant among these movements was the Union of the Physically Impaired Against Segregation (UPIAS). Disability studies present the social model and the medical or individual tragedy model as the two major models in disability. Tara (2013), points out that these models have contributed to the varying discourses in understanding the phenomenon of disability. The social model of disability was particularly developed as a critique of the medical model. Holt (2004), points out that due to the socially constructed barriers associated with impairments which also limited their participation and citizenship, disability was refined and redefined as well as

differentiated from impairment. To this effect impairment and disability have been respectively defined as,

Impairment - lacking all or part of a limb, or having a defective limb, organism or mechanism of the body. Disability - the disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have physical impairments and thus excluded them from the mainstream of social activities (UPIAS, 1976, in Holt, 2004, p. 221).

However despite the existence of these two approaches in understanding disability, three other subsidiary principles of equality, inclusion and autonomy are particularly presented from literature of disability studies, and politics of the disability movement (Shakespeare & Watson, 1998). These principles are geared particularly towards conceptualizing and analyzing disability from a CWD's perspective and not solely rely on ideas developed from the disabled adults' political practice.

### **The medical disability model**

The medical model of disability also known as the traditional model portrays disability as a deviant condition which necessitates medical attention to rectify the condition for the individual to become 'normal' in society (Oliver, 1996a). In this model which is illuminated as the dominant frame work of disability, French and Swain (2004), argue that to be 'normal' was regarded as desirable and therefore people with disability desired to be normal and this therefore called for impairment to be normalized by treatment. This model specifically views impairment as the problem causer of issues faced by people with disability and it hence becomes the center of service provision (Shakespeare & Watson, 1998, & Oliver, 1996b). The medical model is also individual oriented because it places emphasis on altering the individual's disability rather the social process. By doing so, Shakespeare and Watson (1998, p. 15), point out that 'restoration or generation of normality is prioritized: consequently PWDs are presented as a tragedy because of their inability to conform to this normality'.

The conformity to normality can also be equated to the Parsonian sick role model in which illness is defined as incapacitation to perform normal social obligations (Segall, 1976). Illness is then taken as deviance which (ibid), describes as inherently undesirable thereby calling on

person to take on the sick role in which recoverable is obligatory. The end point therefore is both the sick role and the medical disability model challenge the individual to seek medication to correct the bodily abnormality which is responsible for different levels of disability or functional limitation (Barnes et al. 1999, cited in Strømsø, 2008).

The healthcare of CWDs in ECCD is one of the concerns I raise in my research. Whereas therapeutic action is one of the strategies I discuss as way of addressing the healthcare concerns of CWDs, it is not discussed in isolation but is compounded within other aspects such as, nutrition and poverty all which have a direct effect on healthcare. In bringing to light some of the children's disability experiences, I challenge the concepts of 'correction' and 'normality' fronted by the medical model. This is by portraying that disability therapeutic action goes beyond normalising the impairment but advocates for children to have some level of independence within their disability.

Some of the different health seeking practices discussed in this research is a direct reflection of this model. For instance, the practice of some home caregivers seeking the services of different disability rehabilitation institution is reflection of the stance argued out by the medical model. Furthermore, the discrimination and stereotyping CWDs experience in their everyday life also suggests that home carers seek alternatives that can facilitate realisation of normality. As shown in the discussion later on, normality pushes home caregivers to seek both medical and local alternatives that facilitate normality.

### **The Social disability model**

This model defines disability as the social restriction placed on people with impairments by society (Shakespeare & Watson, 1998, p. 14). Unlike the medical model which focuses on the individual body per se, this model situates disability to result from prejudice and discrimination and not the individual's body. The blame here is removed from the individual's impairment and placed on the society as a whole for its failure to address the needs of PWDs, more so service delivery and social organisation (ibid). The social model therefore advocates for the removal of social barriers in society which not only cause problems for people with impairments but also limit their participation in society

( Shakespeare & Watson, 1998, and Ansell, 2004). Some of the barriers raised in the model include inaccessible physical environment, welfare policies, segregated education, stereotypes or prejudiced attitudes.

In essence, because disability in this model is ‘a socially constructed form of exclusion’(Ansell, 2004, p. 216), Shakespeare and Watson (1998, p. 16) argue

That it is important to balance an understanding of the individual experience, particularly in terms of identity, agency and the body, with an analysis of the structural origins of the disadvantage.

In using this model, I discuss how society constructs disability and what it means to be disabled to the children. I also discuss why it is still hard to achieve the removal of barriers which promote child disability prejudice within the different social structures such as schools and home. Particularly within the home place, I discuss how the physical environment impinges on continued learning of children citing my reflections from different cases during my fieldwork process.

## **The principles of disability**

The three principles of disability are developed from the social model of disability and they take into account the experience of CWDs and young people in particular (Shakespeare & Watson, 1998). The discourse entailed in the equality, inclusion and autonomy principles have semblance to particularly specifics such as participation, equality and best interests of the child among others as enshrined in the CRC. However despite this observation, these three principles are particularly developed with a preference to the interests of the CWD.

### ***Principle of inclusion***

In the principle of inclusion, the disability movement drew attention to the several ways in which PWDs have been excluded. Particularly they argue that environments and policies have been planned, formulated and developed, and these not only exclude the PWDs in society but also do not take care of their needs (Shakespeare & Watson, 1998). The principle further argues out that PWDs do not have ‘special needs’ but rather have ordinary needs like



any other people but these needs are usually not met. A balance in society can therefore be created if structures and systems are established which are not to harmonize the so called special needs of the disabled but rather open to a wide range of citizens (*ibid*).

### ***Principle of equality***

In the equality principle, Shakespeare and Watson (1998), highlight that the vast inequalities that Persons with Disability (PWDs)<sup>19</sup> experience does not result from physiological, anatomical or psychological difference but rather from social policies, economic priorities and physical barriers. The challenge is thus for upon modern day societies to remove these inequalities. The debate is further heightened beyond just economics but to also include full citizenship rights as well as equal treatment with non-disabled people (*ibid*).

### ***Principle of autonomy***

The third principle is that of autonomy (Shakespeare & Watson, 1998, p. 17), ‘suggests that PWDs are experts on their lives’ and that the different stakeholders such as professional and therapists among others can be an obstacle to the self-development and actualization of the PWDs. The principle therefore proposes that PWDs should rise to the helms leadership and power in society when possible. Shakespeare and Watson (1998), point out that PWDs should be asked what they want, rather than provide them with what we think they want. They further argue that the experts and professionals cannot be completely disregarded in the lives of PWDs but rather than them dictating issues, they should instead allow the disabled themselves to set their agenda and have a real voice in matters that concern and affect their lives.

## **Learning**

The concept of learning is widely used in academic debates to contextualise the different ways in which children learn. Learning has been regarded as ‘a complex activity that is situated between thinking as a capacity and development as a process (Cullingford 1993 in Tchombe 2011, p. 178). As a process, learning creates interaction between mental and

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<sup>19</sup> Also to mean People with disabilities

cognitive abilities and is largely influenced by emotional and environmental aspects (Tchombe, 2011). Environment is thus situated as an inevitable that constructs part of children's learning. Gagen, 2000, p.213 in Holt (2004, p. 233), argues that '...learning environments...are often spaces through which children become aware of, and begin reproducing social identities that circulate through broader social space'.

In using the learning concept within this research, I argue that although there are certain definitive places that have been structured for learning such as the school and the classroom, (Tchombe, 2011) children still experience learning within other social spaces (Holt, 2004), such as within their peer cultures, the home and within family. Although children's learning tendencies are usually structured by adults through programming children's learning processes, the interaction of learning with other concepts such as agency in this research assert that children can use their own agency to unstructure and construct their own modalities of learning through activities such as play culture, and interactions.

# CHAPTER FOUR

## METHODOLOGY

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### **Introduction**

Research methodology explains the reasons for using certain methods and the principles of using them (Ennew et al., 2009, p. 10.11). In this chapter, I describe the procedures that I undertook to complete my study. I discuss the methodological approaches I used in the field such as, how I gained access to the research site, the rapport building process and the methods and techniques of data collection. I further discuss the ethical issues and maneuvers, my position and role in the research site as well the different expectations from both the research participants and myself. I conclude the chapter by discussing the analytical process of the data into different themes.

### **Research design**

Qualitative research is richly endowed with depth and enterprising methods which can give a researcher deep insights about a particular social phenomenon (Kvale & Brinkmann, 2009; McCracken, 1988). In my research, I adapted the qualitative approach right from the initial stages of data collection. I used qualitative methods of observation, visual-listening, interviews and researcher's diary. I also made use of participatory methods such as drawings, and recall.

I used simple random sampling when I drew a study sample of children from the different units within the institution. Since the different units within the institution housed children with different competencies and disabilities, including children from each unit would in essence bring out children's perspectives and experiences of ECCD. Particularly this inclusive child participation through randomised sampling would take into account children's healthcare and learning experiences as well as explore the rights based approaches in care, learning and participation.

Purposive sampling was also used particularly for the case of home and institution caregivers. I selected the adults on the basis of their roles and responsibilities to the children. These adults included institution carers, such as therapists, educators, and administrators and home carers including family members or relatives who were directly responsible for the wellbeing

of the child at the institution. While on the institution Community Based Rehabilitation visits (CBR), the choice of samples was determined by the number of households the institution caregivers had to visit on their outreach program and the time spent in each household determined the amount of data generated. However under this arrangement, I used observation, informal dialogue and visual-listening to realize data given the limited time factor in the households visited. Though I must note that Community Based Rehabilitation visits and methods employed during the data collection exercise were pivotal in helping me understand the post-rehabilitation status of the children and their families as discussed further in the analysis chapters.

### **Selecting field site**

The care and support for children with disability informs some of the current public health dialogues in Uganda. With several organisations in the country providing rehabilitation services for child impairments, the concerns of whether the best interests of the child<sup>20</sup> are prioritised. This has been categorically put by James and Prout (1997, p. 1; emphasis original) argument that ‘the ideology of the child-centered society gives *the child* and *the interests of the child* a prominent place in the policy and practices of legal welfare, medical and education institutions’. As issues of children continue to develop and take a central stage in a Ugandan contemporary society, my concerns are embedded in the perspectives of the minority child (cf: Abebe, 2008, p. 27). Understanding the underlying issues of early childhood within a disability perspective therefore greatly informed my decision to research with children with disabilities. Using the institutions facilitating child rehabilitation was thus my starting point of formulating this study design. With no well streamlined ECCD centers in Uganda, I particularly chose this child rehabilitation institution because it handled the emerging issues of childhood disability especially the underlying factors of early learning, healthcare and nutrition all of which are essential in early childhood care and development.

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<sup>20</sup> See Article 3 of CRC; the best interest of the child

## Accessing the research site

I went through several procedures and guidelines in ethical research. These procedures of childhood research have also been suggested by literature relating to childhood research (cf: Abebe, 2009; Ennew et al., 2009; Morrow & Alderson, 2011) and are further discussed in this chapter. The ethical clearance from the NSD<sup>21</sup> and the introduction letter from NOSEB were critical in not only identifying me as a researcher but also in getting accepted into the research site. Fine and Sandstrom (1988), argue that accessing relatively small or privately operated environments can be difficult. For this reason, they further urge researchers to avail the different gatekeepers with credible account of their presence in a particular research site. I secured an appointment prior to my maiden visit to the institution. This worked to my advantage because my first visit was progressive; I presented details of my fieldwork process highlighting what my role as researcher was, how I was going to collect the data, and the role of my would be research participants whom I also emphasised would be both children and adults from within and outside the institution.

Giving details of how I was going to conduct the fieldwork process turned out to be an ethical insight which gave rise to particular sensitive concerns from an institutional point view, such as; why I could not tape record interviews and take photographs. Flewitt (2005, p. 553), argues that ‘ethical issues arise in all aspects of research and are particularly salient when studying vulnerable members of society’. It is rather easy to assume and take for granted that such decisions solely lay within the individual’s power. However the lesson learnt from this experience as discussed later in the ethical and methodological considerations is that such taken for granted mentalities if not navigated with utmost care and regard to the several gatekeepers can otherwise jeopardise an entire research process.

During the CBR visits, I accessed the field with the help of the rehabilitation team as they made their scheduled home visits for the home based care and treatment. They knew how to trace up the households of children and their home caregivers in the different geographical locations. Masson (2004), suggests that when a researcher gets introduced to his research participants by a known person then he ceases to be a complete stranger. This being a

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21 Norwegian Social Science Data Services

sensitive topic of research, visiting the homes with persons the home caregivers and children knew gave them a sense of security as I was not completely a stranger. Although this was a methodological leap that enhanced my fieldwork, traveling with the rehabilitation team often got me labeled as part of them and not as researcher.

## **My research role**

Although I had identified myself as researcher at the initial stages of the data collection process, I reminded my research participants of my role each time I was in their midst implementing the data collection process. However this did not stop second thought opinion of who I was to some of the research participants. Whereas the institution caregivers did understand that I was a student researcher, most home caregivers thought I was another member of staff probably, a fresh recruit by the institution. Because of this, some of them referred to me as *Musawo*<sup>22</sup>. This was how they referred to all the institution caregivers. It was not any different with the caregivers in the home spaces. It took a lot of explaining to home caregivers that I was a researcher. However as time went on, I came to understand that this title did not mean a medical personnel literary, but it was also their way of showing respect to people within the institution whom they regarded as more knowledgeable than them in matters of childhood disability and the required interventions.

### ***The friendly adult***

From the start, I adapted a role of a friend to all of the participants. In this role, I learned to listen to my participants, play and interact with the children. I showed concern about how they were coping with the situation they were in. I used to pass by each unit every morning to greet and find out if all was well. It was because of this approach, that a five year old girl waited by the gate almost every morning for me to carry her. According to one of the institution caregiver, there was a sad story behind every child's disability condition ranging from poverty to negligence and stigma (cf. chapters five and six) Therefore, I found it inevitable to show some compassion not only to my participants but generally to all children and their caregivers that I interacted with. It was through this friendly adult role that I managed to increase my understanding of the life experiences of my research participants.

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22 Derived from luganda dialect literary to mean doctor but also used to refer to individuals involved in providing health services to the communities

### ***The neutral adult***

Despite their disabilities, the CWDs, like any other children, are active participants who shape not only their social lives but also the lives of other people within their societies (Jenks, 1982; O'Kane, 2000; Prout & James, 1990). As an adult, researcher and parent, I pondered on a role I should have taken while observing two children fight and argue over their toys in their play space where I was observing them.

*Upon detaching her artificial limp, a five year old girl crawled to a corner where she picked up a doll that she rocks like a baby to sleep. Within a moment she is in tears because another boy has grabbed it and when I glance to see what exactly is happening. In a reflex, all the three of us have our eyes locked together staring at each other. I hurriedly get back to my note taking so as to avoid imposing my-would be adult authority over them and secondly the approval and disapproval which each one of them seemed to seek from me.*

*(Fieldwork notes; observation and visual-listening)*

In my reflections later about what had transpired, I tried to reconstruct this scenario and wondered whether I should have acted otherwise which ordinarily meant adapting either the adult or parent role of intervening or mediating. However, the neutral role I took still turned out to be the better alternative as it was unbiased and since this was in the early stages of the research; I could not take it for granted that I could not cross paths with these children again. Nonetheless, in taking this neutral role, I also wondered whether if the girl would later resent me for not having played the adult role of coming to her rescue.

Furthermore, my neutral role was also reflected during the foot and hand print painting session with the children and their caregivers in the early learning center. As I observed this activity, I was challenged to take on the role of a judge. The caregivers' perspective was that since I was not directly participating in the activity, my opinion would be unbiased and therefore I was the best person to choose the best painting. In discussing ethical spatiality, (Abebe, 2009, p. 462) argues that 'different geographies demand different and reflexive ways of negotiating roles and ethical spaces with the researched'. Reflecting upon my role as a

researcher and negotiating whether to ascribe to my new given role, I immediately declined to assume this role because of the biases it would cause. One of the things I later reflected upon was how the children and caregivers whose paintings I would not have chosen would have felt about my decision. In essence, there was a likelihood that agreeing to this role would have complicated my relations with both children and their caregivers.

### ***The playing adult***

From my fieldwork notes, I vividly describe some of the play moments I shared with the children. Whereas these moments completely caught me unaware, I explored them as an opportunity to get closer and friendlier to the children. In one of my observation session in the Early learning Center, I took on the role of the playing adult and researcher at the same time. A young boy, whom I later discovered had suffered from mental retardation, engaged me into playing the building block board game. Whereas he was not able to talk, he patted my lap and pointed in the direction of the game. When I placed a block on the game, he did the same. The playing adult role was one of the first precedence that introduced non-verbal aspect of communication in this research. By assuming this, I further got to learn that within the children's shared spaces, facilitated interactions upon which built relations were built. The were no definite modalities of communication, however in revealing themselves as social actors (Prout & James, 1990), they manufactured their own language and symbols of interaction.

## **Data collection methods and techniques**

Research tools are instructions for using a research method with a group of research participants in order to answer one or more of the detailed research questions (Ennew et al., 2009, p. 5.39). In order to have a clear cut display of different child competencies and experiences, I employed both the traditional and tack based methods in this study. Since the research was with children with disabilities, I was very keen on using multiple methods in actualizing equal participation and representation of all children irrespective of their disability I therefore focused on reducing the biases that could result from the weakness of one method while at the same time yielding maximum results from the multiple methods (Abebe, 2009).



## ***Observation***

Ennew et al. (2009), define observation as a method of data collection where data is gathered through watching people, places or processes. I mainly used unstructured<sup>23</sup> observation with both children and adults participants. I did observation during both occupational and physiotherapy sessions, in the catch-up class during the learning, as well as during the (CBR) visits. During fieldwork, observation as method proved to be one of the strongest methods owing to the socio-spatial conditions I found in the field. As a research method, implementation of observation was done concurrently with other methods. This methodological blend of observation for instance with interviews enabled me to observe and note the bodily gestures and reactions of my research participants to different issues discussed, and also understand different phenomena when applied with visual-listening, recall and drawing. Indeed Ennew et al. (2009), point out the relevance of unstructured observation in the initial stages of the research and how it can be explored at later stages. From my diary excerpts, I noted that observation became a very pivotal tool of my research as some of the occurrences such as events, overheard comments, and behaviour that I observed and noted down formed basis for my informal dialogues with my participants later on. For instance one of my observation sessions of the feeding practices of the children in their dormitory not only reveal how CWDs exert their agency but the informal dialogue that followed this observation illustrated the different parenting practices among the home caregivers.

## ***Visual-listening***

Childhood studies demands that children be taken as active participants who deserve to be researched with and not researched on (O'Kane, 2000). Additionally Cook and Hess (2007, p. 31), argue that 'children's lives have been explored through the views of their adult caretakers'. Whereas I did get an account from institution and home caregivers on some of the children's lived disability experiences; I was still inclined to incorporate the participation of children whose disability did not allow them to actively use other methods (drawing,

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<sup>23</sup> Also called participant observation (cf: Ennew et al., 2009, p. 5.9)

recall, Journey of life and mapping) I had initially developed for the study. Christensen and James, 2002, p.2, in Cook and Hess (2007, p. 31), suggest that

Situations such as these require that an adult researcher has to go beyond his own beliefs about a situation and find alternative ways of listening to children using different ways.

I thus developed visual-listening technique as a multi-sensory technique to include the participation of children whose impairment would have otherwise left them out of my research context. These included mostly children with feeding, speech, mobility, and learning and up right posturing<sup>24</sup> challenges who had to rely on other persons for these activities. This method was informed by arguments from scholars such as Clark (2005a), who suggests the adoption and use of combined verbal and non-verbal child communication techniques in researching with children. I therefore explored this technique by focusing on the children's emotional and bodily expressions. This helped to foster child communication modalities by relating their actions, gestures, and emotions to the activity the child was involved in at that moment. The built understanding of children's actions was interlinked between their visible action and trying to listen in to what they implied. This has categorically been suggested by Prout and James (1990), in the argument that children are active in the construction and determination both their lives and that of those around them.

Through this technique, children's unspoken action always meant something and a mere observation of it could be taken for grant stance, however giving other structures such equal importance and attention help forward this technique. For instance the interaction of the child with their immediate environment, their peers and caregivers all helped in constructing meaningful action using this technique. Such critical analysis when researching younger children has also been recommended by Clark, Moss, and Kjørholt (2005, p. 176), pointing out that it is highly important to be aware of the '*unspoken words*', the huge complexity of bodily movements and emotional expression, by which children construct their identities and social practices in everyday life.

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24 Children experiencing sitting or standing difficulties

Visual-listening was also relevant in understanding the different ways in which children situated their agency. For instance some of them expressed their refusal to participate in an activity by either crying or shrugging their arms and shoulders and their home carers also reacted differently to such agency. In some of the cases I describe in the analysis chapters, I recollect the facial expression of a seven year Suubi when he was taken a photo and momentarily shown it. It was these seemingly small activities and reactions within different situations that revealed the uniqueness of this technique in bringing to light the experiences of the children through their un-spoken actions. The emphasis to include participation of all children despite their diverse disability situations also founded in the CRC's<sup>25</sup> principle of the best interests of the child and right to participation and reinforced by the. The level of participation I realized through this technique addressed the would be nonreciprocal discourse that would otherwise have raised issues of participants' rights and competences to participate in this research (Shugar, 1988).

### ***Drawings***

Whereas drawing has fondly been used when researching with children Punch (2002), argues that not only are drawings vital in guiding the researchers to understand what children consider to be important in their lives, they also avail them time to think over the research subject matter as opposed to a pressured verbal response. I used drawing with mainly physically handicapped children in the catch-up class. I asked each child to draw a picture about his or her life in within the institution. The centralized arrangement of the tables in the catch-up classroom did easy the implementation of this activity. In order to differentiate this activity from their usual classroom work, I sat with the children on the same time and did not engage in any form of supervision but rather encouraged them to ask for help if need arose.

As it turned out, drawing with the children also provided an opportunity to build further relations with me. Fargas-Malet, McSherry, Larkin, and Robinson (2010, p. 183), have pointed out drawing as task based method is a good 'ice breaker' as it helps children relax and forwards rapport building. Rather than try to understand what the children's drawings meant, I sought an explanation from each child on the meaning of his/her picture and why it

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25 Refer to Articles 3, 12 and 13

was important to them (ibid). For instance, one of the drawings showed an animal tethered to a pole. From my own perspective, it was difficult to tell whether this was a dog, cow or goat tethered to a pole and why such an animal would be within the confines of the institution. From the child's own perspective and interpretation of her picture, she had blended both her home environment and the present institution environment she was living in. She revealed that the animal in the picture was the dog at home chained and not tethered to a pole. This dog according to her was the family's source of security. Through this child's interpretation of her drawings, it actualized the argument that only children can make meaning out of their drawing and therefore should be given the opportunity to tell the story in their drawing in the best way they choose.

The drawings also established a platform for informal dialogue with the children as I probed further for insights about their life within the institution. This is an idea also presented by Hunleth (2011), where drawings provide a researcher with ground to engage the children in verbal hard to discuss issues. At the end of the drawing experience, the children asked me whether we would be drawing the following day again. This demand therefore set precedence for another drawing session the following day and even though the day's drawings did not contribute to the data directly, the observables such as behaviour and our interaction suggested that relations with children can be built over time. Based on the drawing experience I had with the children, I agree with Fargas-Malet et al. (2010), who suggest that the technique enables children to gain more control of the research process.

### ***Interviews***

The research interview is based on the conversation of daily life and is a professional conversation; 'it is an inter-view, where knowledge is constructed in the inter-action between the interviewer and interviewee' (Kvale & Brinkmann, 2009, p. 2). A research interview is also 'a site where partners meet and converse, and through their conversation they jointly construct meaning' (Gudmundsdottir, 1996, p. 295) In any childhood research, it is also important that both the voices of the children and other stakeholders are heard (Fraser, Lewis, Ding, Kellett, & Robinson, 2004). Using a key informant guide, I administered adult individual interviews for both institution and home caregivers. Through these interviews, I sought to understand the perspectives of caregivers especially their participation in enhancing

the health, and learning interests of CWDs. As part of the interview process, I used a tape recorder as storage for the conversation. General consent to record the interviews was provided first by the institution as the overall gatekeeper for the research participants and then individual consent had also to be given by the participant before I could proceed to record. Desai and Potter (2006), point out that using a recorder gives you room to concentrate on the interview process without having to worry about taking notes. Whereas I jotted observation notes during the interviews, I had to write complete interviews where respondents felt that they were not comfortable being recorded.

### ***Recall***

The recall is a task based participatory tool that is based on the child's ability to remember certain recent events and occurrence that he/she has been involved in. Through this method, the child recalls some of the activities he/she has been involved in the past few days or week and writes a sequence and an account of these activities particularly showing the date, time estimation, place and person with whom the activity was done. Ennew et al. (2009), argue that most research with human beings, including social research, is built on the memories and ability of the participants to remember things that have occurred to them in the past. Therefore like adults, children have the ability to recall events and should therefore be allowed to tell their story with minimum interference from the adult researcher (ibid).

The essence of recall in this research was basically to get insight into the children's feeding practices. I modified this tool to a picture of a puppy with a chart detailing the time, place and type of activity the child was involved in. I observed that most children could not read nor write well after I had given them the tool and explained to each one of them what they were supposed to do. I sought the help of a student intern who was in charge of the class that day and we individually helped each child using the local dialect to use the recall tool.

Also given the design of the tool and excitement it had caused among the children, I implored them to colour the picture. This kept each child busy during the entire implementation of the recall tool because while we were guiding some of the children with the tool, others kept themselves occupied by colouring the puppy. It was by using this tool, that the children revealed some of their favourite foods items, the number of times they ate daily and the persons with whom they shared a meal. In answering the questions such as 'what I eat' the

children brought to light many food options some of which were not included in their daily menu. I thus had to engage in a dialogue to generate a better understanding of some of these aspects. As a tool in this research therefore, recall provided the allowance to manufacture more information from children based on the direct short responses they gave to the direct short questions.

### ***Researcher's diary***

I used the daily diary to record in writing everyday occurrences, for instance, problems and possible solutions, and ethical issues (Ennew et al., 2009). In my diary notes, I accounted for each of my fieldwork days, writing down different activities and things that transpired. At the start of my fieldwork it was quite difficult for me to differentiate between diary notes and the observation notes I made because they seemed similar. I endeavored that this difference had to be sought and utilized and as Ennew et al. (2009), argue, my researcher's diary was very useful in as far as recording the research process was concerned. I spent 30 minutes each day after my fieldwork, reflecting on the occurrence of events, what I had done for the day and tried to make meaning of different situations and see whether they had any correlation or relevance to my study. It was through my diary notes that I built on my reflexive thinking. For instance, I rethought some of the actions and decisions that I had taken earlier on in the field and wondered whether they were justifiable. The events discussed in my role as a neutral adult were some of the key highlights of using my diary notes to build on my reflexivity experiences.

## **Ethical considerations**

Ethics are about helping researchers to become more aware of the hidden problems and questions in research, and ways of dealing with them (Alderson, 2004, p. 99). In his research with disadvantaged children in Ethiopia, Abebe (2009), argues that different research geographies present unique set of ethical challenges and dilemmas. My fieldwork with CWDs posed a number of ethical issues and considerations, some of them unique and unfamiliar to me. Most of the ethical issues required that I reflected upon my own understanding of dynamic protocols in childhood research and a number of times I

questioned myself trying to justify my path of action when handling some of the ethical concerns (May, 2001).

### ***Informed Consent***

Informed consent is one of the deciding factors for an individual to participate in a research. It involves a freely given concessional agreement by to become a subject of study in a research process (Morrow & Alderson, 2011). In my case, there was a clear cut hierarchy which I had to follow before I could realize any data from my participants. There is always a great need in seeking the support of different gatekeepers when you are undertaking a research with children because most times their vital support can determine how much success you can achieve in your research (Fargas-Malet et al., 2010; Masson, 2004). I therefore passed through the different gatekeepers explaining to them the purpose of my research and why the children's participation was very important. I further explained to them the procedures I was going to undertake and follow informed consent being part of it. The different gatekeepers who included both the institution and home caregivers were both supportive in as far as administering of both the child consent and adult consent statement.

Despite the argument of Ennew et al. (2009), that the principles and process of informed consent seeking should remain the same in whatever research or situation, the possibility of seeking direct consent from children whose disability had affected their cognition and could barely sit up right, walk or stand on their own let alone write was not practical. Faced with this situation, Cooks 2006 cited in Fargas-Malet et al. (2010), argues that where the notion of consent excludes children such as the disabled ones, a researcher should opt for assent as the alternative of including all children in a research. Masson (2004, p. 45), also points out that 'the capacity of children and young persons to consent to research may not be clear cut but depends on the researcher's assessment of their understanding'. I therefore relied heavily on the parental consent a number of times.

However during the implementation of the recall and drawing tools, the children who participated in these activities had their individual consent sought first. Since these two activities were carried out in the catch-up classroom, the institution caregiver conducting the

learning process provided the general consent for the children to participate in the activity. Taking the children through the details of the study, role differentiation and the relevance of their participation was crucial before administering the consent statement. Although it took a long time, to administer the consent statement because of the excitement caused by the smileys<sup>26</sup>, each child was given individual attention during this processing explaining to them what each smiley and statement meant on the consent form.

Similarly, all the adults who participated in this study were also provided with an informed consent form which they were required to read and sign before they could participate. However, there were some cases, especially among the home caregivers, where they preferred to give verbal consent as opposed to written consent. The argument presented by some of the adult participants included their inability to read and write well as others preferred the anonymity of a verbal statement.

### ***Building Rapport***

Rapport building is usually an ongoing process right from the beginning of the fieldwork until when the researcher is ready to exit the field. While researching with disadvantaged children in Ethiopia, Abebe (2009), refers to how he kept the rapport building process ongoing until the end of his study. I commenced my rapport building process from the onset of the fieldwork. On my first visit to the institution, I was designated a field guide whose role was very important in forwarding my entire fieldwork process. Whereas it is good to build rapport with the children, Punch (2002), urges researchers to also establish a good relation with adult gatekeepers. Establishing rapport with adults took a much shorter time than that with the children. For this reason, I started by engaging the adult research participants in the first weeks of the fieldwork as I took time to fit into the children's spaces, get to know them and be accepted. As part of the rapport creation process, I often visited the therapy units where I sat down with caregivers whom I would eventually engage in informal dialogues. These dialogues became regular in these sessions and eased the communication between me and the caregivers. They also paved way for my interaction with some of the children which

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<sup>26</sup> See appendices for Child consent form



interaction I was made to think was brought about by my continued interaction with their caregivers.

Also during my first few weeks of being in the field, I made use of a children's outing to Wonder World Amusement Park. The tour which was basically for relaxation and confidence boosting for the children also provided an opportunity for me to build friend relations with both children and their caregivers. Kjørholt (2013b), discusses the dynamics and shift in relations between researchers and children. She agitates for a move towards creating a friendlier role of the researcher with children. In this instance, I did less note taking and more observation and interaction with the different research participants' especially children. This outing also helped me open up more and built my confidence further as I managed to randomly interact with the children, helping some of them get on and off the playing toys.

Fine and Sandstrom (1988), point out that being near children cannot guarantee their friendship automatically. Having visited the early learning centre and the catch up class several times and seeing that the children were not bothered or moved by my presence, I opted to change rapport creation strategy and get more involved with the children. In the early learning centre, I took time building blocks in the common area with some of the children whereas in the catch up class, I provided children with drawing materials and practiced drawing with them. As it turned out, this became a common ground upon which a rapport was built with the children (Punch, 2002). Subsequently I noticed that a little girl was waiting almost every morning for me to arrive by the administration block. She threw her arms around me when I carried her and though she never said anything to me, the reassurance of a friendship created was evident. In the early learning centre, though most of the children could not talk, I could see the excitement in some of their faces and frantic bodily movement, with some of them pushing the building blocks to me signalling that it was time for us to play.

### ***Power differentials***

Research projects cannot erase the context of adult power that children face in their homes, schools and communities (Alanen & Mayall 2001, Punch 2002, Kjørholt 2004, & Irwin 2006

in Abebe, 2009, p. 456). Whereas most social theories speak of childhood as becoming and passage to adulthood (Jenks, 1982), the impact of some of these theories such as socialization is still evident by the way children behave towards adults and the way adult power is exercised in some situations. For instance, it appeared so strange and unusual when I opted to sit on the floor with the caregivers and the children during the therapy sessions. Despite several attempts to convince me to use the chairs in the rooms, I politely turned down the offer and said I preferred to sit down with the rest of the team down. In essence this was one of ways I balanced the power differentials which did not only exist between adults and children but also existed between the professional caregivers and home caregivers.

During implementation of the recall and drawing methods, I adopted Mandall's 1991 'adult least role' (Abebe, 2009, p. 458), in which I adopted some social skills to check my would be adult superiority. I sat among the children in their catch-up class and spoke to them in a controlled and friendly tone. Not wanting to be taken for a teacher, I challenged classroom notion that I had equally experienced as a child whereby it was the role of the child to take his/her book to the teacher for grading after completing an assignment. Therefore while implementing the drawing and recall tool, I approached each child knelt beside him or her and had a chat.

As I mentioned before, power differentials were evident even among the adult caregivers, especially among the home caregivers. The power difference created on the basis of status quo had me also a researcher placed higher than home caregivers because of the way they kept referring to me. Therefore, I carried out all the interviews with the home caregivers in open space such as the children's outer play spaces in which I sat side by side with each respondent. Prior to the interview, I engaged my respondents in casual conversations usually different from the research subject (Kjørholt, 2013b) to eliminate the formalities and lighten the mood and when the timing was good, I would slowly introduce the research discussion.

### ***Reciprocity***

Reciprocity is one of the most debatable issues in ethical research with several childhood scholars sharing mixed reactions and opinions. Whereas Ennew et al. (2009), argue against reciprocity sighting issues of high expectations from communities if items like money or any other support is rendered by the researcher. Fargas-Malet et al. (2010) and (Grenier 2000,

in Abebe, 2009, p. 461), on the other hand, counteract the above argument preferring to conceptualise research as ‘a two way street’ in which giving back something to the community for their time wasted should be a responsibility of the researcher. However going by Abebe (2009, p.462), argument that ‘different geographies demand different and reflexive ways of negotiating roles and ethical with researched’, instances of reciprocity in my fieldwork experience were practical and reflexive. In the early learning center, the afternoon activities were often out door and more of play incorporated in therapy. Of much interest and curiosity to me was the painting activity which I later learnt had not been done in a while because of lack of materials. I offered to provide the required materials which would facilitate some of the children’s painting on Wednesday afternoons.

In another situation, when someone was sought to write up a poem that some of the children would recite at the day of the African celebrations which the institution was the main organizer, I offered to help out with this responsibility because the institution caregiver had not managed to get a volunteer, and also as a former student of prose and poetry, reciprocating by doing something that I knew for my research community was something worth the time and hospitality that I had been given as a researcher.

### ***Child protection***

During the fieldwork process, I once observed one time a home caregiver smack a child. I immediately picked interest in what she was doing, I continued to listen in and observe from a distance. From a far I learnt that the child was being beaten for defecating in his pamper<sup>27</sup>. This smacking which suggested disciplining the child was done in the open with even other home caregivers and children seeing. Well as I decided not to interfere with what was happening despite well knowing that the child’s rights were violated here. Masson (2004), argues that as researchers, we have a duty of caring and protecting every person involved our research. I took another approach of speaking up to the institution caregivers about what I had observed and whether they were aware of such happenings. As it also turned out, my presence and being able to witness the situation gave me new insights about home caregivers. The institutional caregivers informed me that some of the caregivers were actually not the parents or relatives of the children and they were carrying on the role of home caregivers as a

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27 Pamper is the most popular brand of diapers in Uganda, hence their use here is to refer to diapers in general and not the brand in particular.

paid job. It was also because of the institutions responsibility to oversee the care and protection of children that they engaged the services of a counselor to closely handle these kinds of situations.

### ***Research participants' expectations***

My position as a student researcher did not stop some of my research participants from seeking for different forms of assistance from me particular during my interview sessions with home caregivers. At the end of every interview session, I would give my participants an opportunity to ask me questions and more often than not, some of them were wondering whether my research would benefit them directly. One mother in particular asked me whether I could get her a *Mzungu*<sup>28</sup> to sponsor her child as well help her get a job so that she can provide for her child after leaving the institution. I informed her and other participants that my research would not have direct benefit to them at the moment but could influence policy formulation and implementation in the near future, I also explained to this mother that it would not be possible to get her a sponsor and the issue of helping her to get a job would also make the other home caregivers to demand the same help which would in turn affect my relations with the institution administration. From my diary reflections, I situated the possibility of socio-economic hardships in implementing early childhood development interventions for children with disability. This compounded with other research findings, revealed poverty as an obstacle to good ECCD practices in childhood disability as discussed further in chapter six.

## **Methodological Considerations**

My first ethical issue arose when I hinted that I would be using a tape recorder for interviews on the first day I visited the research site. As I went through the formalities of introduction and elaborating the details of my fieldwork to the administration of the institution, the idea of recording the voices of their staff or clients was something that was against policy and therefore I could not be allowed to do so despite my attempts to argue out that such a choice would be best made by the participants. I then asked the institution caregiver to request the director of the institution for this exception. I was eventually granted the permission to use

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28 Swahili/Luganda for white person

the tape recorder but bearing in mind that I also had to seek permission of the adult research participants whose voices were to be recorded.

Although I fully took into consideration that researching with CWDs would call for the use of multiple methods, I did not foresee a situation where multiple disability rendered some of the methods and techniques inapplicable. I presumed that children with diverse disabilities would benefit from the different methods and that also the multiple methods would reinforce each other during their implementation. In particular I could not make use of Journey of life and mapping methods because they required use of verbal, mobility and writing skills which most of the children did not have or were in the initial stages of developing them. I managed to make use of the recall and drawing methods respectively. However, this was mainly with children with physical disability in the catch up class whose turnover rate was rather high, thus I could not do follow up. These kind of methodological challenges required flexibility and creativity on my side as the researcher. I had to modify and adapt to new changes in the field (Darbyshire, MacDougall, & Schiller, 2005). I hence developed visual-listening as a method and technique upon which I built focus on the children's emotional and bodily expression. This proved to be a methodological leap in covering up shortfall that had initially been created by some of the originally designed methods for the study. Additionally, I relied on the other methods especially interviews and observation. During the therapy sessions, I particularly did a lot of observation and note taking and also learnt to engage the therapists and home caregivers in informal dialogues as a way of maneuvering further the challenges that arose from methodological implementation.

## **Data analysis, interpretation and discussion**

During the buildup process of this research, I developed two major themes of health and care, and learning. These themes were later to be segmented into two chapters of analysis. However, sometimes the practical fieldwork situations demand that a researcher exercise some level of flexibility. As I got more familiar of the field, I had to make some changes such as adopting learning instead of education. Although I included education as part of learning, my decision to change this theme was based on a realization that not all children at the center were involved in schooling but everyone participated in a learning process. I also opted to

merge the nutrition theme into health and care. This was also due to the fact that there was very limited data realized from this theme and nutrition in itself was more incorporated into healthcare at the institution. In presenting my analysis chapters therefore, I used case study excerpts to generate the discussions and answer the different research questions and objectives. These case study excerpts are generated from observation and visual-listening notes, interviews and informal dialogue excerpts. I also use direct quote analysis situations in which I discuss its meaning. The analysis criteria I employ also incorporate some theoretical arguments and methodological issues raised in these respective chapters. These go a long way in informing part of the discussion within the analysis chapters. The use of this approach is to create a blend of the methodology, theory and analysis chapters which I find much interconnected in my research.

Although the discussion is developed within these two analysis chapters, I also conclusively discuss the major findings of my research in the concluding chapter seven.

# CHAPTER V: ANALYSIS AND DISCUSSION I

## CONCEPTUALISING DISABILITY LEARNING IN EARLY CHILDHOOD

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### Introduction

In this chapter, I use the different experiences from children and their carers to answer some of the research questions raised in chapter one particularly; How do CWDs within the community and institutionalized centres experience ECCD (learning); and How are children's rights to care, learning and participation practiced within the ECCD programs in Uganda. Using data from both children and adult research participants, cross cutting issues related to learning, are highlighted and discussed. For instance the role different learning structures within the institution are explored. Furthermore, the significance of the home and institution as places that facilitate learning is discussed. The data used to analyse and discuss this chapter is mainly interview data, observation and visual-listening data as well as data from children's drawings. I conclude this chapter by reviewing the different challenges to learning from the different perspectives experienced in the fieldwork.

I found it necessary to have a clear cut description of some of my research participants especially the adult. Whereas I generally referred to them as caregivers or carers, I learnt that that within the institution, the terminology *caregivers* was particularly used in reference to parents and other family relations of the children and excluded the institutional personnel. For purposes of this research therefore, I define '*home caregivers*' to include parents, guardians or other individuals with family relations to the child, and '*institution caregivers*' as the institution personnel and their partners rendering rehabilitation services to the children and their relations.

## Early learning initiatives for children with disabilities

Based on interview data, one of the key descriptions of learning I was introduced to was 'learning by copying'. The illustrated case below revealed that copying as a learning technique involved the use of visual and observable phenomenon with CWDs at the institution.

*There are so many ways of learning, but most of them learn by copying. When children come here and they live in the same place, they sit in the same place they always copy from each other... The other thing is that we always get time and give these children some activity to learn like building blocks, there's painting, and shading. So they get to learn because we sit with them, give them time and tell them what to do. We talk to them...*

*(Female institution caregiver: key informant interview)*

The data also suggests that copying was interlinked to the component of time and talking. The emphasis of time as a factor of learning suggests the need to appreciate learning as a process which is bound by a time period. Furthermore, talking to children as illustrated in the case above was informed by gesturing. This was a common trend used especially for children who had speech challenges. The visual-listening and observation data further, suggested that a combination of talking and gesturing informed part of the children's participation. This indicated that just like other children, these CWDs were actively constructing their lives within the spaces they found themselves in (Prout & James, 1990). For instance, even though Angela could not speak, her eye movement revealed that she followed the gesturing and talking of the institution caregiver during her feeding therapy session.

Also the use of suitable learning tools such as building blocks, painting and shading was both observed and explained as a learning strategy. In physiotherapy, this practice was used in helping children improve or restore physical function whereas in occupational therapy it served the purpose of helping the child develop independency. WHO (2012, p. 28), argues that the

Interventions that allow the acquisition of even basic skills, such as helping a child with a disability learn to feed or dress himself or herself can lead to a growing sense of independence and competency and reduce the burden on other family members.



In some of the children's physiotherapy sessions for instance, the institution caregivers either handed children toys in instances where the child was learning how to grip objects or placed them on these toys such on balls as a way of stimulating their motor muscles. The observation data further suggested that these same learning materials also informed the items that the children used for playing when they were among themselves or with their home caregivers.

## **Children's activities of daily living**

The Early Learning Center (ELC) was one of the learning structures established within the institution to carry out occupational therapy. The children within this center were categorized as children with learning challenges who had to depend on others for their everyday activities. The center supported early childhood development by enabling children to learn Activities of Daily Living (ADL) such as toileting, tooth brushing, feeding among others.

### ***Why social age in issues of ECCD and disability?***

Predominantly the ELC specialized in handling children with physical and mental disability. For this reason, the center handled even children who were beyond the defined chronological ECCD age of 0-8.<sup>29</sup> It is arguable that the context within which ECCD definition is universalized does not take into account individual children's experiences based on their social and political wellbeing, as well as the environmental conditions they live in (Kessen 1981, Ingleby 1981 in Clark-Kazak, 2009). With regard to this, CWDs in the ELC had in one way or another been victims of delayed or slow development due to disability. Their presence in the ELC was in essence a learning process aimed at enhancing their development irrespective of their physical age. For instance thirteen year old Eunice was undergoing ADL learning in the center. The preference using social age (Clark-Kazak, 2009) was thus based on the understanding that being at the ELC, each child irrespective of the chronological age was having a first experience of learning things that they initially could not on their own account. This rehabilitation experienced in the ELC suggested that it was first alternative that availed them the opportunity of experiencing some of the developmental milestones of early childhood. The chronological ignorance of (cf. Solberg, 1996), ECCD age of zero to eight years as reflected in the ELC suggested that vulnerable children such as CWDs would have a

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<sup>29</sup> <http://www.ecdgroup.com/setting-the-stage/>

better chance of benefitting from ECCD programmes that would have otherwise segregated them based on their age.

### ***Therapy action as a learning intervention***

The use of therapeutic action as an intervention was a major contributor to the children's daily learning. Children attending both the ELC and the physiotherapy units experienced therapy as an intervention whose practice was to enhance their development by learning. The frequency with which the children were exposed to therapeutic action enhanced their learning of a defined activity. In the case example below, I noted the participation experiences of a young boy in a therapy session in the Early Learning Centre.

*Suubi has been in the ELC since he and his caregiver arrived at the institution at the start of 2013. His mobility and mental development has been affected by cerebral palsy. The therapist stretches her hand towards him. I observe him raise his right hand with difficulty to greet the therapist. He eventually uses his other hand for more support. She gets hold of his right arm and does some stretching. From the yelling and his facial expression, there's no doubt his in pain and begging for mercy. From my interaction with his mother and therapist, I get to know that he is suffering from cerebral palsy a condition that has damaged his brain and has left him mentally retarded and also denied him his mobility. The therapist asks his mother how old he is. She says he is seven years but is also quick to add that people think he is ten years because of the way his physique looks....The therapist mummurs the alphabetical vowels and though I cannot hear his feeble sounds, I can see the movement of his lips and efforts to repeat what he is hearing. As the therapy session comes to an end, the therapist captures a picture of Suubi, whose excitement is visibly seen when he is shown his picture.*

*(Fieldwork notes; observation and visual-listening)*

In this case, child-institution carer interaction is one of the outstanding factors that promote learning through therapy. Although rights based perspectives have argued for special care such as rehabilitation and education (cf. CRC Article 23), to be extended to children with disabilities, the level of the child's participation is critical in achieving child development. One of the ways in which the child's participation was reflected here was through interaction

between the child and adult. Suubi's involvement was further shown in his murmuring of the alphabetic vowels. Although it has been argued that CWDs may require to be taught skills which other children learn spontaneously (Jones, 1998), the data suggests that doing this through interactive action that engages the child could enhance better learning outcomes

Although the learning process in the ELC may seem simplistic especially because of its use of gargets such as music, taking pictures and wall mirrors, the effects on the children's learning was far reaching. For instance Suubi's excitement at being shown his picture by the therapist would suggest a learnt ability to recognize things despite his mental retardation challenge. In a similar scenario, Paulo's wailing faded out his levels of concentration improved when the institution caregiver turned on the radio. Although I learned that music helped to stimulate the children's hearing, Paulo's case seemed to be beyond hearing. The music seemed to override the pain or dislike of his legs being stretched as reflected by his wails. His endurance and patience at therapy was heightened by the use of music to the very end of his therapy session.

## **How children experienced learning in the catch-up class**

The catch-up class was one of the learning structures established within the institution to enhance and support learning of different CWDs. According to some of the caregivers, the catch-up class particularly facilitated the learning of children who did not have learning challenges but physical disability. However, it was not unusual to find some of the children with learning challenges in this class. The catch-up class took a classroom like setup. Although the approach to learning was more similar to a normal school setting, it also incorporated other aspects of learning such as skill development. With the help of an instructor, the learning was meant to ensure that children do not lose out on their education when they were away from school due to rehabilitation or therapy. Part of the interview and data from the children's drawing suggested that the learning in this class paid attention to specific learning and education interests of different children. In this manner, the instructors managed to mentor the child's learning along the same paths. In one of the discussions with the instructors,

*When they are here and we put them in class, they continue with studies and when they go back, they join others and continue with their studies.*

*(Female institution caregiver, key informant interview)*

The time a child spent in the catch-up class depended on the rehabilitation process of each child. Throughout the research process, the class attendance varied. In particular, I learnt that some of the children who had not turned up to follow up participation in the research process had left the class and returned to their homes and schools respectively. This was because the nature of their disability required a very limited time of their presence in the center. If the concept of learning in ECCD is to be actualized further so as to have school going CWDs continue learning, even when they are temporarily institutionalized because of the rehabilitation, then it is important that their learning interests be given priority. As revealed in the data, continuity of child's learning in circumstances like this could be critical in ensuring that the child does not lose out completely in school in the time he/she was institutionalized for rehabilitation. This will not only ensure continuity of inclusive learning both within institutions and in schools but would also be critical in ensuring the continued stay of children in school<sup>30</sup>.

### ***Catch-up class as first schooling experience***

For some children within the catch-up class, this was their first experience of what school was like. They had either reached school age<sup>31</sup> while at the institution. Some had also been denied their right to education by their parents because investing in their education was socially constructed as a waste of money<sup>32</sup>. For instance, Amooti, a female home caregiver, had not only been disowned by her husband and father to her child but he had also declined to contribute to the schooling of his child. Her daughter's first experience of schooling was in the catch-up class.

A three session follow up and interaction with Amooti's daughter revealed that the child had benefitted from her experience within the catch-up class. Specifically, the observation data from the catch-up class revealed her participation in classroom activities such as drawing and singing. Furthermore, the class instructor also explained that with specific consideration initially given to the child, she had seen her learn to write her name, draw, shade pictures, and was making attempts at learning to read. Similarly, the child's participation in the

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30 The child's right to education CRC Article 28(e)

31 In Uganda, most children begin Kindergarten or nursery schooling at the age of three. They are eventually enrolled into primary schooling between the age of 5-6

32 This is discussed further in the chapter under the complexities of learning for children with disabilities.

research process, specifically using the recall tool and drawing technique further suggested the catch-up class had indeed enhanced the child's learning abilities.

The catch-up class was also one of those places that facilitated children's agency. In envisaging children as social actors, the sociology of childhood argues that children cannot be seen outside of their relationship with adults (James & Prout, 1997, p. xiii). Some of the children had used this as a way of reconstructing what they had learnt and observed their adult caregivers do within their shared spaces. During one of my observation session in the catch-up class, I listened to a conversation between two young boys seated on top of a table. With each one of them holding a teddy bear doll, they start to massage and stretch the doll's limbs. One of them says to the other, '*let me do it as it is usually done to Amos*'. Later on the classroom, another boy was building blocks with his only functional hand. He then put a doll on top of his built blocks, raising his arm and shouting, '*this is where Museveni seats*'.

Similarly, Apio's explanation that the car in her drawing was the institution van used for transporting them to another institution for surgical therapy signified that children understood and interpreted actions of adults in their own world. They had learnt to observe and pay much attention to what transpired in their surroundings. In these three cases, the arguments presented by the children are fluid. Their vivid construction of these actions suggests, that children's disability should not be an obvious taken granted assertion to perceive them as passive subjects or victims of social processes (cf. Prout & James, 1990). Furthermore, in contextualizing children as social actors, Mayall et al 1996, in Prout and James (1990), argue that children's lives are ordered within interaction with adults, but because as a minority group, children do not wield to power to determine the quality of their lives. Categorically Prout and James (1990), elucidate the concept of children as a minority group to mean practices which constrain children. With regard to this therefore, although CWDs' actions such those reflected here suggested they fully comprehended and understood what happens around them most times, for instance, their replication of the therapeutic procedures, some of their interpretation may not be seen as meaningful or be taken seriously.

It is 'unusual' that an ordinary classroom within the Ugandan setting would have a television set in it. However, this was the case in the catch-up class. The TV per se had a very strong influence in the children's learning. It was a common occurrence that the class learning

session sometime took place while the TV at the back of the class was on. The children were always well aware of this. I noticed in one incidence in which all of them turned back to watch TV when their instructor went out to pick drawing books. Based on observation, the attentiveness and silence with which the children watched TV was certainly different from the other activities, and the loudness with which the class would be in times when the TV was off and the instructor not being around. In a related incidence, I walked into the classroom on another day and Kula was singing to a song being played on TV. I kept my distance in order not to interfere with her singing. I heard her repeat after the chorus of the song *mpola...pola...* In my conversation later with her, she told me of how she loved the song even though she did not know the artiste of the song. Kula's TV moments would come to an end immediately she left the institution because she did not have a TV at home. The attentiveness while watching television as well as Kula's own experiences of it revealed that TV was a good influence here in these children's learning and relaxation.

When asked to draw a picture representation of their lives in the center, one of the things Kula drew were block numbers from 1 to 14. Although I could understand that these were block shade numbers, I could not guess what they meant to her or why she chose to include them in her drawing. In our discussion, the numbers were her way of presenting what she had been taught and learnt in the catch-up class. Relatedly, she also drew a hand. She then explained that this was her. The appreciation of her disability in her drawing was one thing that she had learned to live with but did not deter her from participating in class activities such as drawing.

## **How place reflected on children's participation and learning**

In discussing 'place', the focus is on how the different physical and social environment influenced CWDs' participation and learning. I also use the context of the home and the institution to present how they each fulfilled the learning purposes of children with disabilities.

### ***The institution-home concept***

In this study, place<sup>33</sup> was a significant aspect in conceptualizing the children's everyday learning. Like Bronfenbrenner (1979), argues that not only is the home setup critical to a child's development but also points out that the child's close interaction and relationships with other socio-spatial spaces are equally important. Through observing the institution and the CBR programmes, it became obvious how important the socio-spatial environment was to CWDs and their learning process. One of the institution caregivers noted that the institution approach they had adopted was that of a home environment rather than a hospital like setup. Another home caregiver within the centre alluded to the fact that she felt at home within the institution premises and further stressed that their children were provided with playing toys. Such material provisions that would otherwise not be afforded by all home caregivers in another environment provided the ambience, comfort with which children constructed and reconstructed their childhood in the institution.

The preference of maintaining the home setting to the medical setting was believed to have a positive impact to both home caregivers and their children. Since some of the children and their home caregivers stayed at the centre for a long time, they had come to accept the centre as their second home and had built social relations among themselves and the institutional caregivers. For this reason, it was common to see home caregivers support each other's activities in the centre such as helping each other pick up food. In another related incident, a home caregiver did not turn up for a scheduled interview session I had with her because she was collecting the mid-morning breakfast for another caregiver who was in a therapy session with her child. Significantly, this institution-home concept structured relationships on the basis of a commonality which was disability.

The constructed relations were also shown in collective activities. For instance, seating by the verandas together and eating or playing together with their children as they interacted. Holloway and Hubbard (2001, p. 77), argue that as a dwelling, the

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33 used to illustrate the different physical and social environments which the children and their carers interacted with such home, school, community and the institution

Home is often understood as a place within which only certain people and things belong; it is a place to which a person or group of people can withdraw from the outside world, as if into a castle.

It is worth noting that the interconnections within the institution-home concept also suggest that it provided a kind of certainty, and sense of belonging that constructed disability as a normality within this setting. This can be related to what Goffman (1963, p. 12), regards as ‘the routines of social intercourse in established settings allow us to deal with anticipated others without attention or thought.’

Equally the children’s representation of their physical environment was diverse. Tinka, Terence and Tito explained that their drawings were of the dormitories in which they lived within the institution. Though they each had a building of a dormitory in their drawing, Tito’s representation of the beds in it was done by shading well aligned boxes. Terence just made reference of the dormitory as having beds where they slept. Their portrayal of their dormitories mattered to them because it was their sleeping spaces and the beds revealed that each one of them had their personal or individual spaces within the dormitory.

For the children, to know that they were living in a safe environment was self-assuring for each of them. In one way or another, they found a way of reflecting the importance of this in their drawings. For instance Tito drew a fence, and gate with sharp arrows on the top. Just besides it was a dog chained to a pole. These were symbols of security at home. Tito on the other hand described a flower by the Askari’s<sup>34</sup> office. He said it was the Askari’s work to tend the flower and protect them from bad people. Through drawing, the children were able to point out the importance of the safety both at home and within the institution. The use of dogs, gates, Askari and fences were also reflective of the socially constructed aspect of individual privacy and security in Uganda. The reflection of these security symbols by children suggested that these attributes in the children’s drawings gave the assurance of their own individual safety.

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<sup>34</sup> Swahili for security person. In this case used to refer to the gateman within the institution



### ***The home as a place of care and learning***

During CBR visits, I encountered children who had previously benefitted from rehabilitation services at the institution. The institution caregivers often used these follow up home visits to monitor and evaluate home caregivers' child rearing practices in homely environments. This context thus provided the opportunity of meeting some of the children at school and at home. In particular, it provided an account of early childhood experiences of CWDs after undergoing rehabilitation from the institution. From the observation data, instances of children whose development had initially been impinged by their disability had overtime learned to feed on their own, walk or stand. This observation revealed that the home, as a socio-spatial space had thus supported the continuity of learning for children through continued participation children and with support from their families. This is also emphasised in the argument that the interaction of the environment experienced by the child and the characteristics of persons within such environments have been argued to influence the process of early learning and development (Dunst, Trivette, & Jodry, 1997, in Bruder, 2000).

Most of the children visited during CBR had previously been at the institution, learning techniques that enhanced their life quality and development. They had now been reintegrated into their home environments. This reintegration of children into the permanent environment was an institution fulfilment of its human rights obligation to the full development of the child with disability<sup>35</sup> in regard to healthcare, education and psychological development.

Although previously presented as a contributing factor in enhancing the learning process, observation and visual-listening data also suggest that homes are inhibited by spatial hindrances which are obstacles to continuity of learning for CWDs. Taking the example of the case below,

*In one of the homes we visited during CBR, we met a young girl (Marcela) with mild mental retardation. She was seated by the veranda of their house and seemed not bothered by our presence and continued to slowly eat her food. Her mother assumes that she is aware of whatever goes on around her. Within the*

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35 See CRC provisions in Article 6 & 23; ACRWC Articles 13 & 14

*compound is her walking frame device and her orthoses meant for supporting her legs during mobility. When compelled to use either of the devices, the child is reluctant and instead cries. I observe that the rugged and sloppy terrain of the compound could be the reason for her resistance...*

*(Fieldwork notes: observation)*

This example suggested that the continuity of learning for children with disabilities within their homes was not obvious. Although Marcela had initially learnt how to walk using the walking frame, the spatial hindrance presented by the appearance of the learning place at home cast a doubt in her continued development. In particular, the ruggedness and sloppy nature of the compound were risky for the enhancement of her walking activity. This has also been emphasised by Bruder (2000, p. 108), argument that ‘risk factors can impede child development and negatively impact child and family outcome’. It is no doubt that when implored to use her walker, Marcela reacted by quietly crying which was her way of asserting her agency not to participate in the walking. Garbarino, 1992 in Bruder (2000, p. 108), suggest that early learning and development varies as a function of both person and environmental characteristics and the combined influences and interactions between these characteristics.

## **The different ways of children’s communication: Examples from children’s play spaces**

Data from visual-listening and observation largely suggested that children with disabilities like all children construct their own modes of communicating among themselves and with other individuals in society. This has also been presented by Corsaro (2005, p. 145) in the argument that ‘children’s cultures are composed of a wide range of language and behavioural routines’. The discussion here focuses on CWDs’ communication within their different play spaces and how relevant it is to their learning.

*During one of the sessions in the common room area in the ELC, I sat down to observe the children who were engaged in different activities that ranged from watching TV, building blocks and completing puzzles among others. Within a few moments, I realized that neither of them could talk but with their gestures and actions there was a lot of communication happening amongst them. Their*

*constant glances at me, made me know that they had realized the presence of an adult in their space. A boy crawls to me, pats my lap and shows me a building block game. I pick one of the blocks and insert it in the puzzle; he smiles and picks a block to insert it in the puzzle. Shortly, we are joined by another boy who also picks up a block and inserts it into the puzzle.*

*(Fieldwork notes: observation and visual listening)*

Within CWDs' interaction, their communication did not always take the normative speech type of interaction. It was rather informed by an amalgam of communication techniques which they constructed within their peer culture. From the case above, it suggests that the activity of play provided the opportunity in which meaningful communication was constructed. The two boys, despite being incapacitated to talk, had constructed other means of communication among themselves and with other people. Children's multiple communication mechanisms have also been argued for by Clark (2005b, p. 46), pointing out that, to have children with different abilities share their perspectives, they need to have a chance at multisensory communication which could be different from that understood by adults.

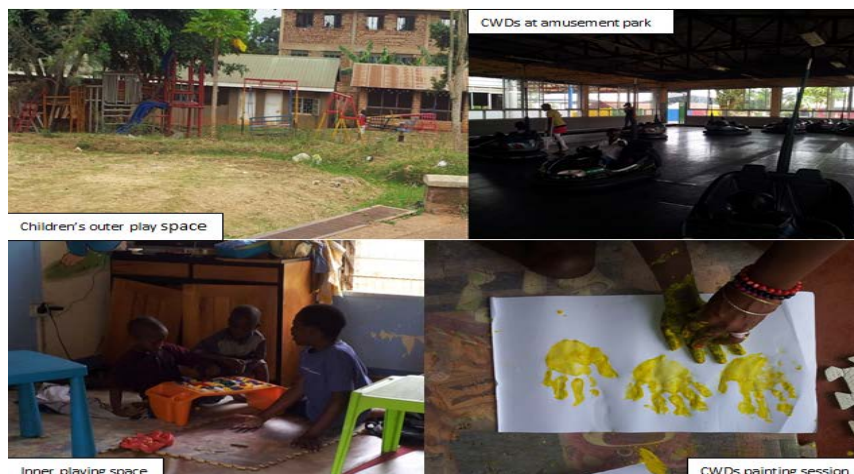
Prout and James (1990), argue that independent of adult perspectives, children's views are worthy of study in their own right. The diverse communication experience espoused by children with speech challenges suggests they had adapted to their non-verbal ways of communication. It further suggested the move to 'semiology', as critical in understanding expressive meaning in the everyday life of children through its rich vein of symbolic analyses (cf: Prout & James, 1990, p. 16). In using nonverbal symbolic expression (Hebdige, 1979, in *ibid* 1990), it revealed that adults, caregivers and all persons working with these kinds of children have to step out of their comfort verbal communication and adapt to other communication techniques espoused these children. The adaption of children's non-verbal communication by home caregivers as the children's first point of contact would in essence increase the chances of CWDs' participation in ECCD practices.

One of the activities that informed both play and learning was the weekly afternoon painting after the children's midday meal. This was an activity that was done outside on the veranda of the Early Learning Centre and all the children to participate. The institution caregiver

explained that although this was fun packed activity for the children, it was considered pivotal because it helped the children relax and improve on their concentration.

In one of the painting sessions, the children participated in hand and leg print painting together with their caregivers. Despite being both a playing and learning activity, observational data revealed that the children’s concentration levels varied from child to child. Besides the morale boosting from their home caregivers, there were mixed feelings and reactions of children towards this activity. Whereas some had the brightness and excitement in their faces, punctuated with smiles and waving of their arms or entire body movement, others seemed not bothered with this activity. One girl, Labekka, completely resisted participating. Instead she rolled on the ground, screaming, and shrugging off as well slapping off anyone’s hand who tried to approach her. This again emphasised, CWDs found alternative ways of communicating their participation rights. As shown, the use of agency within this play space validates the argument that children should not be perceived as ‘cultural dopes or passive victims’ ( Allen et al 2002 in Imrie & Edwards, 2007, p.628). This stance has also been argued for by Clark (2005a), suggesting that listening should not be limited to only the spoken but incorporate other ways of child participation which may include visual and emotional aspects. The opinions expressed by children with speech challenges must be seen as valid because they can be reflective of their participation interests in ECCD activities tailored for them.

Figure 1 Children’s play and learning in different play spaces



(Source: Fieldwork 2013)

## **Children with disabilities as right bearers**

Children with disabilities need first to be taken as children who are active agents in their own rights (Prout & James, 1990). In this regard therefore, they are right holders like other children who deserve to enjoy these rights as prescribed in the CRC and ACRWC. The focus of the discussion here is on CWD's access and acceptability in other learning places outside the institution or home.

### ***The right to inclusive education***

Education of CWDs is one of the key elements included in the learning process of CWDs within the institution. Under their education support fund, different children are enrolled to either a mainstream school or special needs school depending on the magnitude of the child's disability. The fulfillment of this education right is quite overwhelming for the institution because despite the need and right of every CWD to be in school, the budget allocation cannot make this possible for all CWDs.

During a CBR visit, we visited a five year old girl, Agatha in a small primary school in a Wakiso suburb who had benefitted from Hydrocephalus and Spinal Bifida rehabilitation. Agatha was popular in her school especially among her classmates. She sat in the middle of the classroom, and shared her desk with another girl whom she said was her friend. Every other child in Agatha's class knew her by the way they whispered her name from the moment we entered her classroom, some also said they used to play with her. During a conversation between the teacher and the therapist, the teacher raised concerns of how the Agatha did not want to be asked to do anything. The therapist told the teacher that usually children with Spinal Bifida have occasional mood swings and when this occurs, it was advisable to leave Agatha until she comes around on her own. The therapist also sought to find out from the teacher on whether they paid much attention to Agatha's toileting habits and hygiene since she also had limited control over her excretory waste. In relations to her learning process, the teacher highlighted that Agatha was a slow learner in class and the therapist alluded to the fact that children with Spinal Bifida have their spine, brain and nerves affected by the disability. Therefore Agatha's cognitive ability was much slower making it necessary for the teacher to explain everything to her in detail and much slower.

As a way of facilitating inclusive education for the benefit of CWDs, one of the institution approaches to learning was establishing partnerships with different schools. The institution did not just stop at getting the CWDs into inclusive schools but also cultivated good practices within school administrators and teachers that were reflective of the best interests of the CWD<sup>36</sup>. Such inclusive ECCD practices for CWDs have similarly been emphasised by UNICEF (2013, p. 81), in the argument that, 'improvements in ability will have greater impacts if school systems are willing and able to accept them and meet their educational needs'.

The case example presented above revealed information sharing between school teachers and institution caregivers was inevitable for continuity of CWDs learning in inclusive schooling. As Moyi (2012), suggests that for CWDs to comprehend, extra attention is required. The data suggests therefore that this extra attention should be taken with regard in all situations and places where CWDs experience their learning. Despite inadequate facilities for CWDs in most schools in Uganda, the level of interaction and involvement of institution caregivers and teachers also suggests that it is not only the facilities within the school that make it inclusive but rather begin with informed discussions about the child's participation within these schools. These discussions as presented in the data generate the capacity of teachers within schools to pay particularly attention to the agency and interests of the children with disabilities especially through inclusive approaches that inform CWDs' participation.

Also based on the institutional assessment, some of the severe disabilities cases could not be placed in inclusive schools with other children and therefore had to be placed in special needs schools. The institutionalisation of children with severe disabilities into specialised learning places and institutions such as schools is also provided for in the education and learning policies of Uganda (ACPF, 2011). The institution had overtime partnered with special needs schools and supported their education in these schools. The impact of disability on some of the children as previously discussed had caused delayed development stages in their early childhood most of the inclusive schools cannot be guaranteed to have the capacity to handle

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36 see best interests of CWDs in Article 7 of CRPWD

the needs of such CWDs. Although the placing of some CWDs into specialised learning institutions has been challenged by the social model of disability studies as excluding and limiting the participation of the CWDs in society (Shakespeare & Watson, 1998), interview data revealed that CWDs still experienced segregation when placed in inclusive schools with some even forfeiting schooling.

*There are some children who have been stopped from competent schools like a spinal bifida child whose is on a wheel chair but because that school they don't want to see someone with a disability, they chase them...*

*(Male Institution caregiver: key informant interview)*

Such tendencies do not only pose as a risk to early childhood learning for CWDs but also could also explain some resilience tendencies among their home caregivers, such as the preference to confine the child within home as a way of protecting them from social stigma. In essence, specialised learning institutions provide continuity to the child's learning as a right. CWDs that have been stopped or discriminated in inclusive schools may need such institutions as platforms to help them gain ground before they can confront the normative social setups in which their disabilities are socially constructed.

While trying to understand the different schooling patterns of CWDs within the institution, I narrowed down to a comparison of children's schooling in the catch-up class and those in the Early Learning Centre. One of the common phenomena in the catch-up class was that some children would eventually stop appearing in the classroom and this was because they usually lived for a shorter time and returned to their usual life at home and school. Unlike these children, the children at the ELC did not have a school experience and would spend their time at school trying to learn ADL. Data from some of the home and institution caregivers indicated that children in ELC often spent more time in the institution as compared to others. It is no doubt that some of them attained their school going age from the Centre. For instance in as much as she had hope that her son would learn to sit, walk or even comprehend what goes on around him, Suubi's mother was skeptical about him ever joining school. An institution caregiver equally argued that it took a lot of time and patience to help children in ELC adapt the ADL and there were no children from this center in formal schooling. Education given in such situations was therefore more than just a right, especially for children within the ELC. Despite their understanding of the relevance of schooling for their

children, the actualization of this was farfetched especially when they considered the immediate learning outcomes such as the ability of the children to sustain themselves in competitive inclusive school.

### ***How classroom structuring enhanced inclusion in learning spaces***

From Agatha's example, previously discussed, the perception of other children in other learning environments such as school suggested that accommodative peer attitudes can be essential in helping CWDs stay in inclusive learning environments. These peer attitudes in which the children incorporated Agatha, their disabled classmate into their peer cultures such as play (Corsaro, 2005) suggested that early intervention of including children with disabilities among their peers could be a strategic way of mitigating discriminatory attitudes from peers. I argue for placing the child to sit in the middle of the classroom and also sharing her desk with another classmate as having created a sense of inclusion within the learning setting. Using the example of where children with mind-body differences were set aside from their peers in a classroom with a classroom assistant, Holt (2004), argues that classroom micro-spaces can be socially excluding as well as negatively reinforce disabling difference. This arrangement promoted interaction with other peers in the classroom which interaction I also argue would probably not have been maximized from other places within the classroom setup.

Within the institution, the structuring of the catch-up classroom also suggested an element of inclusive participation for CWDs. For instance the central arrangement of tables and chairs left a lot of space at the sides of the classroom, the instructor's desk at the front corner of the classroom as well as the learning tools, playing toys and equipment at the back end of the classroom. During one of the co-curricular activities in the catch-up class that was characterised by storytelling, singing dancing and quiz event, the position of the instructor's desk at the front corner of the classroom provided enough space for children to easily access the front of the classroom to use the blackboard to participate in for example the quiz event. Similarly, during the implementation of the drawing and recall tools with the children, a young girl's participation was enhanced by her ability to work from a table while seated on her wheelchair. As observed further, she easily accessed any part of the classroom on her wheelchair. The catch-up class structuring suggested that even within inclusive learning



spaces, there is great need to pay attention to enabling practices such as ability of children to maneuver their learning spaces with their different assistive devices. For instance the example above revealed that besides have appropriate access space, the other learning equipment such as tables should also be user friendly for the child.

## **Home caregivers as learners**

In this part, I focus on skill development of home carers and why it is relevant to the children, using data from both the centre and CBR interaction with both institution and home carers. The importance of home carers learning the different rearing and caring practices for their CWDs was essential to the institution's holistic approach of disability management. The focus was not only on the child, but also the immediate relations such as the family. This as situated by the structural debate within childhood studies confirms that childhood in its structural form is in continuous interplay with other social structures such as family (Alanen, 2001). This structural argument is further supported by Bruder (2000), in the family-centred approach, in which the provision of supporting information to the family and parents in particular facilitates their ability to care and support their CWDs.

### ***Socio-economic empowerment for home carers***

The learning process was not only experienced by children but even by their adult home caregivers. Like their children, they also learned both within the institution and in their home environments. The illustrated cases below reflect how their learning was facilitated.

*We do not normally look at the child as a single person; we look at the whole family, the whole household. So we have empowerment programs whereby we train a family in for example improved farming, enterprise development, saving and credit, through these avenues the family is able to continue supporting the child.*

*(Female institution caregiver: key informant interview)*

*Ever since I came here, I have learned to knit, they are also teaching me to tailoring but the child demands a lot of my time and I sometimes cannot go to learn. We also used to learn poultry keeping but the chicken for learning are not there anymore.*

It was clear that there were several financial demands that arise from addressing the concerns and needs of CWDs in the households. Home caregivers skill developing and training addressed the issues of loss of livelihood for some of the caregivers who had spent a relatively longer time at the institution. However, as reflected in the data, it also provided them with an opportunity to acquire new skills. The skill development was to enable them develop their potential and become economically sustainable to handle the underlying challenges and concerns of childhood disability from alternative environments like home. The essence of socio-economic support has also been suggested to have a mediational and moderating influence the development as well behaviour of CWDs(Dunst et al., 1997 in Bruder, 2000).The data thus suggested that the holistic approach to disability management appreciated particularly the role the family<sup>37</sup> plays as the initial the caregiver.

### ***Home carers' skill acquisition for childcare and development***

Within the institution, home caregivers learnt different therapeutic procedures necessary for caring for their children. These procedures were and learnt by observing the actions of the therapists.

*Here now, I have learnt most of the basics on how to look after my child. In the therapy room, the therapist shows me how to help the child with exercises. I now stretch his legs on my own and even put him to stand on his standing frame. Sometimes the therapists ask us to demonstrate how we help the children with exercises and they correct us if we are not doing it very well. Like today when I take him, they may ask me to demonstrate what I learnt yesterday or how I helped him while we were in the dormitory to do his exercise*

(Fatuma, female home caregiver: key informant interview)

The experience of Fatuma revealed that continuity of the child's learning was basically the responsibility of the home caregiver. This was enhanced through practicing what the home

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<sup>37</sup> See the provisions in Article 20 of the ACRWC

carer learnt from the institution carers regularly. The teaching and the practical experience learnt from institution carers served the purpose of fulfilling the role of the home carers in enhancing the development potential of CWDs<sup>38</sup>. This course of learning action also suggested that home carers like Fatuma became experts as caregivers in places where the institution caregivers were absent such as home or in the children's dormitories within the institution. Furthermore, interview data revealed that the increasing number of children seeking rehabilitation within the institution had increased the work load of the therapists. Increasing the capacity of home caregivers to engage their children in therapeutic activities on their own therefore partially helped tackle this challenge.

During the, CBR, the learning process worked the reverse way. The institution caregivers usually asked the home caregivers to demonstrate the previously instructed activities such as urinal or faecal draining, exercise and muscle flexing. It was during these home demonstrations that they rectified and corrected what was not being done right and also applauded what was done right. This continuity of the learning process was thus an enhancement of children's care and development process at home. In this way, the professional knowledge of the institution carers also benefited the other households members found at home who had not been at the institution.

Observational data from CBR home visits further revealed that home carers took a step further to train other members of their households in these child caring and rearing skills. The balance between other responsibilities such as work and care for CWDs in the home environment demanded that experienced home caregivers train other members within the household in how to take care of CWDs. For instance, Aisha and Siima, both housemaids had learnt the feeding procedures, engaging children in their daily therapeutic exercises and excrete waste removal. For some of the households where the parent was not at home at the time of the visit, an alternative home carer was always available. The interaction between the CBR team and the home carers found within households at the time of the visits showed that the alternative carers were all well trained. In support of this, Evans, Matola, and Nyeko (2008), suggest that children's needs can be better accounted for in programs targeting

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38 see provisions in Article 23 of the CRC

families if they put focus beyond the child's parents but also consider individuals, such as family members and community resource persons, as capable carers. My observation of these alternative home carers further suggested that the care process was a shared responsibility within some of the households.

When sometimes caught up in complexities of understanding the interests of CWDs, home caregivers had different ways of manoeuvring these situations. Whereas some of these complexities called for better dialogue between the adult and the child, other situations did not seem to guarantee this.

*While observing children's nutrition and feeding practices in the dormitories, I was captivated by the struggles of Auma in feeding her child. This being mid-morning, the children had been served both porridge and milk. With a cup, Auma struggles to feed the child but she cries, and refusal to allow her mouth come into contact with the cup is a clear indication that she does not want to feed. Some of the home caregivers in the dormitory with her implore her to smack the child, so that she accepts to feed but she does not yield to their suggestions. Others suggest that she instead gives the child porridge rather than milk. All this while, I note that Auma remained calm and not bothered by the concerns of her fellow caregivers. She instead tries to feed the child on bread which she accepts and later on also allows drinking the milk.*

*(Fieldwork notes: observation)*

This scenario posed as part of the complex situations that home caregivers experienced daily in caring for their children. Although Robson et al. (2007) suggest that children have several ways of expressing their agency, this example among others suggested that home carers found it usually difficult to make a definite meaning of the child's expressed agency especially for children with speech challenges. Even in situations where the child's action would seem straightforward such as in this case by crying and refusal of her mouth coming into contact with the cup suggested refusal to feed, the reasons for refusal would often remain unknown to the caregiver. Although, Auma explained that smacking the child was not an option because it would not make her accept to feed. However, smacking a child informs some of the traditional practices of parenting within Uganda. In a situation such as this one, the data suggested that essence of smacking the child was not necessarily aimed at violating

the child's right, but was to teach the child that eating was essential for her. The course of action for refusal would tantamount to a parental smack, which also suggested a course of child discipline. The suggestion given to Auma thus revealed that home carers often found it hard to deal with such situations with their children. To handle such oppositional agency (Ahearn, 2001), they had learned different tactics and coping strategies such acting within the best interests of the children<sup>39</sup> by exhibiting patience and to act with refrain as in Auma's case.

## **The complexities of learning for children with disabilities**

In this part, I will focus on discussing the complex situations which impinge on CWDs effort to learn. Data from observation and interviews mainly suggested discrimination and stigma, as well as absent fathers in the rearing and nurturing process of CWDs as some of the challenges to the learning process of children. Furthermore, I also discuss how children's participation aimed at learning can be hindered within their play spaces.

### ***Children's experience of discrimination and stigma***

Although discrimination against CWDs is outlawed by the CRC, CRPWD and other policy and legal frameworks within Uganda, data from this research suggests that acts of discrimination based on disability are still existent within the communities. These were explained by the different caregivers as occurring in places such as the community, at schools and even within the home. The case below presents an example of how some CWDs are discriminated from within their own homes.

*What I have experienced with CWDs is that they are so neglected by their parents. Parents also don't want them, they don't take them to school, and they see them as a burden and curse... They are left at home however bright they are, they don't want to waste money... we are the ones paying schools but the parent will tell you, give me that money and I pay for the other child,... For example there was one child, I would quarrel with the mother almost every time. Whenever the mother would hear that we are visiting her, she runs away*

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<sup>39</sup> See best interests principle in Article 2 of CRC

*even if she would see the vehicle approaching she hides and then it would be the neighbour to attend to us*

*(Female institution caregiver, key informant interview)*

The poor attitudes and perceptions of parents and other home caregivers negatively impact on CWDs' learning even if they had benefited from rehabilitation programmes. In many cases such as this, it is clear that there is a strong preference of other children to the child without disability. The unwillingness of such parents and home caregivers to accept the disability situation of their children turned the home environment into a hostile space which would not support the continued learning of the child. In essence, disability is accredited to cultural beliefs such as children are linked to evil spirit in some cultures, curses, bad omen, bad luck and the parental responsibility regarded as burdensome. The worthiness of the child is measured against other children's capabilities which eventually raises issues of 'acceptance' - (Goffman, 1963, p.19). With this type of repressive social identity within their own families and households, it is doubtful that such children would yield positive learning since they are regarded as a 'spoiled identity' (ibid) which he illustrates as a stigma that is extensively discrediting, the individual is seen as being different from others because of his/her attributes. These attributes he argues cause us to discount such a person in our minds as being incomplete and less desirable.

With the campaigns to have more children with disabilities get involved in the community activities, community orchestrated stigma and discrimination still had an effect on child learning. In particular, some children had found it hard to cope in inclusive schools because of discriminating attitudes of other children towards their disability. Anna, who was physically handicapped, refused to return to school. An institution caregiver discovered that she was being abused and name called by other children at school. Anna had also the experienced being stared at by her peers and thus preferred to stay home with her mother. In addition to their own learning challenges, Anna and other CWDs have to struggle be socially accepted into new learning environments. Moyi (2012), study of CWD education in Uganda also reveals that there were significant challenges to CWDs schooling. He noted that CWDs did not enrol into school and suggested that social stigma and prejudice were main reason why parents may exclude their children from attending school. Based on the data, being

labelled as different from the rest of the children could potentially cause the loss of interest to learn and preference to choose a friendlier environment such as home.

### ***How play spaces exclude children's participation***

Well as the children's painting activity was explained a good gesture towards children's play and relaxation from their morning therapy session, the observation data revealed that the dominating role of the home caregivers negatively reflected on the children's participation. The painting activity that eventually turned into a competition showed adult caregivers present in this activity became more concerned about winning hence the desire to complete the activity in the fastest time possible. This was a contrary to some of the earlier perspectives highlighted as children being availed credible time to learn. The objective of the activity as suggested by the institution caregiver would not be fully enhanced as the activity did not appreciate the difference in disability of each child and the need for the child to participate according his/her interests. This could also act a further reminder to the children of their disability by denying them the feeling of being able to do or participate fully in certain activities. Holt (2004), raises a similar concern in his argument that disableist practices can occur within micro-spaces that aim to be inclusive.

One of the other key activities that encompassed play and learning was the children's visit of the Wonder World Amusement Park. This was an activity which completely took the children to a new environment out of the institution. The events and occurrence prior to the departure of this activity brought out lots of mixed reactions both for the caregivers and children. Significantly a mother ran out of an interview session with me when she heard her child crying because she was not one of the children going for this activity. Equally there was a 10 year old, handicapped boy quietly looked disappointed when the issues of his mobility at the amusement park were raised since he did not have mobility devices. Those who got the opportunity however, could not hide their excitement of visiting outside play space, as they sang cracked jokes and laughed all the way to the park. To the institution, these outer trips were supposed to expose the children to life outside the institution, build their confidence and also help them relax.

Figure 2: An illustration of excluding play space

Although this activity provided children with the opportunity to interact with other play spaces outside the institution, observation data revealed that not all children could play within this environment. As observed, the physical setup of the playing items suggested that they had specifically been developed for other children without disabilities.



Source: fieldwork 2013

Furthermore even though some of the play items could be used by the children, accessing them was more difficult than using them because the child had to either climb staircases or be lifted to it by a caregiver. Most of the children who were study participants for this research were reflected as confined to particular spaces with the amusement park because they could not actively participate.

### ***Men as absent home caregivers***

It was undeniable that the effects of raising a child with disability had its toll on the home caregivers although though their experiences varied. A common experience was the single parent role that many of them played in caring for their children. Both in the institution and at the CBR visits, the women's involvement was more evident compared to that of the men. Statements such as 'I am both the father and mother of my child' were common among some of these female home caregivers. The role of women as primary caregivers for children with disabilities has also been acknowledged by other studies, such as ACPF (2011).

Like ACPF (2011) revealed, the care of most CWDs in Uganda is jeopardised by higher costs which most of their carers cannot afford. In exemplifying this, I reiterate to the case in the ethical considerations in chapter three, where a female, home carer sought help from me to either get her employment or a sponsor for her child. This, among other examples suggested that not only are women and mothers in particular, the primary carers of children



with disabilities (ACPF, 2011; Prochner & Kabiru, 2011), the overwhelming role of being mothers and breadwinner pushes them to seek alternative options of survival. Similarly, such scenarios, also suggested either less involvement of or total absence of men as fathers in the caregiving role of children with disabilities.

The interview data from institution as well as home caregivers also presented vivid situations of the laxity of men and their family members in assuming their paternity roles to their children with disabilities.

*Most men have left the burden to women, in as much as women want to support the education and learning of a disabled child, most men think that they do not give birth to a child with disability; it's an outcast, it's a curse.*

*(Male Institutional caregiver: Key informant Interview)*

*If the mum and dad were together in helping this child, the dad will give up along the way or the mum will give up along the way, though it is rare for the mothers, it is commonest with the fathers. They run away...*

*(Male Institutional caregiver: Key informant Interview)*

*My child was born lame, when we visited her father's family; they rejected both the child and me....*

*(Female home caregiver: Key informant interview)*

*I do not produce children like those, go look for the man that made you pregnant....*

*(Female home caregiver: Key informant interview)*

The absence of male caregivers in child rearing role meant that female home caregivers had to apportion their time appropriately between caring for the learning and development interests of the CWD and their other daily obligations. Although women play the lead role in the care and nurturing of children in all societies and contexts (Flett, 2007), the complementary role of men especially in the context of childhood is inevitable helping both the child and mother cope with the disability. Some of the negative attitudes expressed from men would only serve to reinforce notation of stigmatisation and exclusion.

Traditionally, the gender role and interplay of social structures such as family and parenthood (Alanen, 2001; Qvortrup, 2009), have for a long time had an influence on child rearing practices in African societies. Socio-historically, the different gender roles were socially

constructed to suit the superior position of men and inferior role of women. The reproduction, child rearing and nurturing role were bestowed upon women while the men took on the bread winning role. Though still existent, these roles have been reconstructed overtime. Today more men are directly involved in rearing and nurturing of their children. However drawing from the illustrated cases above, child disability is presented as the ultimate cause for the absence of fathers in the lives of some CWDs. Although men still appreciate their social role as bread winners, the changing and overwhelming responsibility that comes with caring and nurturing for CWDs drove some of them to deny their roles as fathers. Based on the low and average economic status of most female home carers, Richter and Morrell (2008) argue that households with both supportive parents create a balanced parental role. However the absence of such social capital also revealed the unequivocal power imbalance which makes it difficult for women carers to influence the fathers of their CWDs to be a part of their development process.

In using their drawings, some of the children expressed the absence of the father figure in their lives. For instance, Tito used her drawing to reveal the absence of her father in her life. Her drawing was a representation of her life in the institution with insights of other places such as the home. One of the things she presented in the drawing was a car. In answering the question;

*Why is this picture/ the things in this picture important to you?*

*Tito said the car parked outside the dormitory was for her daddy. I then asked her whether her daddy came visiting her in car. She quickly added that he never visited her at all but she knew him.*

*(Child participant: drawing/dialogue)*

The explicit view of the child here was expressed in her drawing of an absent father who she expected that came to visit her at the institution. The faintness in Tito's voice when she spoke of him never visiting her was one of disappointment. The portrayal of him visiting her in a car might also be an anticipation of hopefulness that maybe someday he could visit her. The active involvement of fathers in the lives of CWDs especially during their early childhood gives the child a greater chance at the development stages. This is because the social capital input of the father in most times will give an allowance of emotional and social interaction between the child and its father. The positive effects of the father can thus be reflective on the developmental outcomes of even CWDs such as in learning and health (Potter, Walker, & Keen, 2012; Richter & Morrell, 2008).

## CHAPTER VI: ANALYSIS AND DISCUSSION II

### CONCEPTUALISING HEALTH ISSUES OF CHILDREN WITH DISABILITIES IN EARLY CHILDHOOD

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In this chapter, the analysis and discussion is based on the research questions; How do children with disabilities within the community and institutionalised centers experience ECCD (healthcare); and How do home caregivers (including family and relatives) in the local communities experience the effect of the programs on children's learning, health, and nutrition? Based on data from both children and adult research participants, this chapter presents perspectives on health related practices of ECCD within the disability context of children. It also goes on to discuss the burden of poverty as a major obstacle to successful ECCD realisation in childhood disability.

#### **Institution child admission policy**

In getting to know how the institution operated, I asked some of the institution carers what procedure they considered when recruiting the children. Interview data from some of the adult institution caregivers challenged the concept of child *recruitment*. They argued that the institution was inclusive because it took on all children and therefore the process was referred to as child admission.

*I could not call it recruitment but we as an institution we are mandated to admit and provide rehabilitation to children who have disabilities, all disabilities as long as we can handle as an institution.*

*(Female institution caregiver: key informant interview)*

The other key issue that was considerably highlighted by the institution caregivers was the age of the children. In order to be admitted to institution the child had to be under 18 years. The use of chronological age in demarcating the child admission boundary was emphasised by some of the institution caregivers statements such as; '*the children have to be between the ages of 0-18 years... it's only that age bracket we accept*'. Although a child by Ugandan law is defined to be a person under the age of 18<sup>40</sup>, the social construction of a child within some Ugandan contexts is influenced by culture and social responsibility that adults have towards

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<sup>40</sup> Definition of the child in the Ugandan Children's Act

children even when they attain the age of 18. It was therefore no doubt that the institution's preference to pay particular emphasis to chronological age was a mechanism of having its rehabilitation services rendered to only children defined by chronological age.

The admission system also relied on the Community Based Rehabilitation programmes as well as the self-referral strategy. Interview data revealed that the CBR programme<sup>41</sup> through its activities provided ground for examining and assessing new cases of child disability prior to admission. On the other hand, self-referral system was based on information clients provided to other community members. This usually involved instances of people wanting to benefit from a similar service of rehabilitation after witnessing promising results from clients who had previously attended the institution.

## **Conceptualising childhood disability**

In this part, I use data from key informant interviews and informal dialogue to portray how carers constructed child disability. I also use children's perspective to reflect on their own construction and understanding of their disabilities using data from children's drawings, visual-listening and observation notes as well as from narratives from their carers.

### ***Caregivers' understanding and construction of childhood disability***

The institution caregivers highlighted that the disability conditions both within and outside the institutional setting ranged from intellectual disability, cognition and neurological disability as well as physical disability. One condition which was common was Spinal Bifida, which is caused by lack of folic acid and was locally defined as having a sac at the back. Others included Autism, Mental retardation, Hydrocephalus, Osteoarthritis, club foot, Down syndrome, Post burn contractures, and Cerebral Palsy, which one institution caregiver highlighted as the most common case in their unit.

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<sup>41</sup> CBR approach to healthcare is further discussed in the chapter under healthcare practices related to CWDs in early childhood

**Figure 3 A representation of childhood disability in the community and at the institution**



(Source: Fieldwork 2013)

Interview data from institution carers further emphasised that the level of disability among the children varied with some of the children having multiple disability conditions. Although some of the children did have the same kind of disability such as cerebral palsy, there was still a variation in each of their condition which required that each child be looked at in its own right not only in rehabilitation but also within this study (Prout & James, 1990). I also noted that despite similarity in the disability condition, the therapy and rehabilitation process also differed according to the magnitude of the disability and commitment of both the child and the home caregiver.

Although, as noted above that cause of the different disability conditions among these children varied, one of the institution carers explained that some of the disabilities were genetically oriented. Genetic conditions such as Down syndrome and epilepsy were highlighted as being chronic and incurable. Hence repeated therapy action was thus used as an enabling practice that would see children with such conditions adapt to certain activities necessary for their early childhood and for the bigger part of their livelihood later on.

On the other hand, interview and observation data from the home caregivers found them to instead construct child disability according to the part of the body which was impaired by the disability, or by relating it to the way it affected the child. For instance, the Hydrocephalus condition was commonly referred to as having water in the head, spinal bifida as having a wound and a sac on the back whereas, cerebral palsy meant the child's senses were not

functional. The other disability conditions which could not fall into their local description were generally referred to as *obulemu*<sup>42</sup> a description to mean disability locally.

Within their local and cultural contexts, the home carers perceived the concept of disability to be the same as impairment. This similarity has also been reflected within some disability study debates that have strongly affirmed that disability is caused by impairment (Bury 2000 in Thomas, 2004). The rehabilitation process therefore undertaken by institution caregivers and the optimism shown by the home carers in the therapeutic process suggested that some impairments can be normalised or improved (Oliver, 1996b) through such interventions.

Instances from home carers also revealed that their own understanding of disability was based on the constructed definition of disability within the social dominations. For instance, the effect of impairment had to be seen as disabling before it could be asserted as a disability. Some of them argued that they measured their children's developmental stages according to the activities they learnt to do within a specific time frame. In situating incidences of how they got to know of their children's disability, some home carers explained that some of the children were not able to sit, walk or talk at certain ages as compared to their peers. These were some of the visible and recognisable developmental milestones that parents would use to assess the early development of their children.

However, some developmental delays were rather harder for the home carers to monitor. Ornitz, Guthrie, and Farley (1977), argue that since child development is monitored by observing multiple aspects, it is easy to overlook a developmental delay which could be an indicator of an early disability. This was the case with one of the home carer whose son had cerebral palsy. Since her first two children were girls, Maria had been told that girls unlike boys experienced developmental stages faster. So when her son could not sit on his own by six months, she thought it was normal and that it was only a matter of time before he could sit. It was not until he was about one year that she realised that his development was not progressive as she had been told.

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<sup>42</sup> From local luganda dialect for disabled, used within this context to refer to children with disabilities

### ***Children's construction of their disability***

The children had their own perspectives and understanding of their different disability conditions. This was revealed through different activities and ways of communication that informed their everyday life. As discussed in the previous chapter, Kula's inclusion of a hand in her drawing did not only reflect her ability to participate, but it also asserted her own social construct of her disability within her childhood (Prout & James, 1990). Furthermore, it was a reflection that disability did not always cause restriction of one's participation in an activity (Holt, 2004).

The daily course of action within children's socio-spatial spaces also built on the children's own understanding of what it meant to be disabled. In his study with children of mind-body differences, Holt (2004), acknowledges the existence of greater exclusion and stigmatisation levels within children's own cultures. An interview with an institution carer revealed Amina's refusal to go to school because she was abused and ridiculed by her schoolmates. Such exclusion within children's own cultures serves as reminder of a child's disability especially how different she was from the rest. It is within such context that the social model in disability studies situates prejudice and discrimination to be the cause of disability in society (Shakespeare & Watson, 1998). As social agents, children's course of action can be reflective of how they feel they are being treated. In Amina's situation of dealing with social exclusion, she chose forfeiting school as an immediate coping strategy. This action relates to what Boyden and Mann (2005), state that children in different ages, contexts and abilities understand and make meaning out of their experiences in several ways.

Therapy was one of those activities that informed the lived experiences of every child either at home or within the institution. It was the activity that was a true reflection and reminder to each child of their abnormality and the need to normalise some of their activities. Therapy was thus a true reflection of the dominant medical disability model that paved way for restoration (Shakespeare & Watson, 1998). These regularised therapeutic activities usually accompanied by assistive devices sort of created an understanding within children that they had to learn to do certain things such as walking in order to move away or improve upon their present situations as illustrated in the case below.

*Namata has both her legs disabled due to polio. In the due course of her therapy session, I observe her limbs being flexed and I ask the therapist whether she will be able to walk again. She says no, but the therapy action here is just to help her become flexible and enable her use her wheelchair easily. She is put on the floor and instructed to crawl before she is asked again to rise and support herself on her knees....She is commended for this action and the therapist quickly adds that if her upper leg muscle support is good, then it becomes easy for her to transfer from the wheelchair to any other place...*

*(Field notes: observation)*

From this case, Namata's ways of experiencing her disability were shown. Her understanding of her disability was rooted in her acceptance to participate in the therapeutic activities asked of her. The end goal was that she would be able to become independent in some of her activities. The effort with which she struggled to support herself on her knees could momentarily be regarded as her own desire to be independent and an attribute of the Parsonian sick role interplay (Segall, 1976). This was further reinforced by her mother who acknowledged that she was even able to help herself to get into her bed alone.

## **Healthcare practices related to CWDs in early childhood**

In delivering healthcare to the children, the institution adopted a two way approach; one was the Centre based healthcare in which the service was provided to children within the proximity of the institution and the other being the Community Based Rehabilitation (CBR) approach in which the institution carers took the service to the community. A combination of these two approaches as interventions to childhood disability management is also emphasised by WHO (2012). In this part therefore, I discuss some of the healthcare practices exhibited by carers using both of these approaches and how they emphasise ECCD practices for CWDs.

### ***Centre based healthcare approach***

As mentioned in the previous chapter the preference of the institution was to maintain a home environment for its clients. This was also achieved through collaborative healthcare provision. In particular, it partnered with two other institutions that carried out orthopaedic and hydrocephalus surgeries. However, after these surgical procedures, the children were still



referred back to the institution for post-surgical therapy and rehabilitation that included, among others learning to use an assistive device.

In healthcare practices such as therapeutic activity, the reliance of assistive devices<sup>43</sup> was a very important aspect of child development. For instance, in physiotherapy, which primarily worked towards achieving mobility, some of the institution caregivers were quick to point out that since different disability conditions manifested differently in each child, it was difficult to achieve results with minimal use of appliances. The appliances in essence helped the child do things that it would have otherwise not been able to do on its own. In two visual listening sessions, I witnessed two different children's efforts in using their appliances to walk and stand respectively.

*In case one; a two year old Matyia makes an effort to use his walking frame in the compound, with his shoulders fixed on walker to support his standing posture, he takes one stride and with the other leg shaking and struggling to gain support, he makes another stride. All this while, he is crying and pleading with his mother. However, the determined mother encourages him that he can do it and does not let him stop until his made a few more strides.*

*In case two; a four year old girl is being helped with weight bearing on her legs so that she can be able to stand on her own. She can neither walk nor talk due to the cerebral palsy. The therapist encourages the child to stand up on her own. The child makes four attempts to stand on her own.*

*(Field notes: Observation and visual-listening)*

In these two cases, though they present different situations, they reveal the use of different assistive devices highlighting the ways in which children participated and experienced these devices. Both these children were seen to make an effort in using their devices. Like I presented in the previous chapter, repeated practice and the appreciation of time was an important learning element which would enhance use of such devices. In Matyia's case, his mother revealed further that within the two months she had spent with him in the institution, the walker had enhanced his standing, something that he previously could not do on his own. Also within their use, some children such as Matyia were expected to use the walking frame

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<sup>43</sup> Appliances used in by CWDs to facilitate their livelihood. Also used in their rehabilitation processes, they include but are not limited to crutches, wheelchairs, standing and walking frames, orthoses, and prostheses.

for a while until he experienced walking on his own. However, other children had to depend on these appliances for the rest of their lives which suggested that the appliance had to be continuously redeveloped according to the child's physical growth and development patterns.

Also in relating these cases to the CBR cases where two of the children had refused to use their devices raises concerns of possible delayed outcomes expected without the help of assistive devices. Observation data during CBR highlighted that reluctance from some home caregivers to facilitate the children's use of their assistive devices regularly or try to establish reasons why the child resisted using the appliance at home. This suggested that, inconsistent use of the appliance would put a strain on the child's efforts in experiencing ECCD.

The need to balance the child's interaction with other socio-spatial spaces was reason advanced for the rehabilitation breaks for some children within the institution. In elaborating this, one of the carers at the institution alluded to the fact that for children who spend over six months in rehabilitation within the institution, they often gave them some time to return to their homes before their eventual return to commence the next stage of rehabilitation. This interaction with the home environment was considered essential because it allowed both institution and home caregivers to assess how the child made use of his/her developed skill.

The use of this strategy in the centre based healthcare approach could possibly be one of the reasons why some of the children reflected both the home and institution environment in their drawings. For instance, in Tinka's drawing, she reflected both her home and institution interaction experiences. She explained that the girl with a kite was a representation of her cousin at home whom she played with. Also within her drawing was her representation of her and her family sharing a meal at home. This revelation portrayed the importance of the home environment to Tinka, particular her social networks, the things she loved to do and the moments she shared with her family. The rehabilitation breaks would thus be argued to facilitate the children's resilience to experiencing rehabilitation because they are not subjected to being in one place for long. In his argument about child development, Bronfenbrenner (1979), suggests that child development is better understood from within a socio-cultural context of family, the community and larger society. The argument reflected by this rehabilitation break strategy therefore, moves away from the medical model perspective of viewing normality as the end result of disability rehabilitation (Oliver, 1996b). It instead appreciates the fact that children's social relations with are built on the basis of interaction

with other structures (Qvortrup, 2002). The child's interface between these two places, would suggested that the institution did not want to structure the child's development based on only its social processes but rather mentor the child based on its interaction with other spaces outside the institution.

### ***Community based rehabilitation approach***

Community Based Rehabilitation approach is one of the fast track developing interventions to addressing health concerns within the community in Uganda. This approach involves healthcare service providers using home-to-home visits, and community sensitization programmes to address the health challenges and concerns of the community. In Uganda, this approach has been used widely in mass immunisation campaigns, and the Human Immunodeficiency Virus (HIV) counseling and testing. The data from institution caregivers presented CBR as health intervention approach which the institution relied on very much in addressing the concerns of CWDs and their home carers. This approach worked in two ways; the Community Outreach Programmes (COP) and then client follow-up strategy.

### ***Community outreach Programme***

The interview data from institution carers presented Community Outreach Programme (COP) as being implemented through community campaigns in which teams of institution carers used community gatherings to sensitise and educate communities on issues of childhood disability. These community dialogues and meetings were also presented as a good strategy for enrolling children with disability into the institution's initial center based healthcare rehabilitation. Through the community parent support groups<sup>44</sup>, and community local leaders, the community was informed and mobilised for these kinds of activities.

At another level, the COP strategy worked through media programming and partnerships. In media programming, the concept of radio and television talk shows was used by the institution carers to give information on child disability, as well as urge community members with CWDs to bring them to the institution.

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<sup>44</sup> A group of parents each having a child with disability who have been trained to help implement and dress community concerns related to child disability

The partnerships also informed part of the bigger CBR approach. Data collected from institution carers further revealed that institution partnered at a professional level with two other child rehabilitation institutions. It was these two partners that carried out all the surgical medical procedures before the children were returned to the mother institution for post-surgical therapy. Furthermore community partnerships were also established and built at individual and institution levels. Individuals and corporate institutions such as banks, and telecom companies supported the institution community activities, sponsored the rehabilitation of children or made financial contributions to the institution.

The three levels of the Community Outreach Programme, pointed out the importance of community participation in child disability programmes. The data about community campaigns and media programming in particular suggest that these strategies were an effective way of mitigating community perceptions and attitudes that excluded CWDs from community activities and gatherings. This finding is also presented in the descriptive goal of CBR by WHO 2013b in Hansen, Chaki, and Mlay (2013, p. 3 of 7), as ‘enhancing the quality of life for people with disabilities and their families, meeting basic needs and ensuring inclusion and participation’.

The recollections of the significance of the individual and corporate institution partnerships were reflected in a mid-morning scenario, in which a mother, who had been robbed off all her belongings, arrived at the institution with only a shawl she had used for wrapping her child. The mother and child were immediately presented with other items which included beddings and clothing. These items formed part of the contribution made by individuals and corporate institutions. This therefore emphasises the argument that CBR is a joint responsibility and effort of persons with disabilities, their families, and communities, organisations among others (WHO 2013b, cited in Hansen et al., 2013).

Based on this institution strategy of engaging the community, it can be argued that this holistic approach pays special consideration to the interests of the child. In particular the community campaigns advocate for change of the perceptions and attitudes constructed within communities in which CWDs could have been portrayed as incomplete *beings* (Jenks, 1982) due to their disability. Since the institution barely received support from the state, the

partnership on the other side availed the much needed socio-economic support to facilitate the improved growth and development of CWDs.

### ***Client follow- up strategy***

This CBR strategy was built on institution carers carrying out home visits to households with children who were initially enrolled in the institution's center based healthcare programme. During these visits, the institution carers provide home based care and support to the home carers. It also depended on the existence of the parent support groups. Although the parent support groups are best suited to be categorized in the Community Outreach Programmes, I also found their role being indispensable in the client follow-up strategy. The case example below illustrates the relevance of these groups.

*We also went ahead to train parents who have CWDs as community volunteers and mobilisers. In each Sub-county in Eastern, Western and Central Uganda, in these districts at the Sub-county we have a parent support group. These support groups are the ones that sensitize communities and villages; they mobilize children who have disability...*

*(Female institution caregiver: key informant interview)*

During one of the CBR visits, a parent support group member involvement in the day's activity could not be underscored. Observation data revealed that Hajira, had a vast understanding of the communities we visited, knew how to trace up hard-to-find households that were to be followed up and also inform the institution caregivers of new disability cases within the community. With her own experience of caring for her CWD, she often shared her own experiences with other home caregivers we visited, showing them what they had to do and encouraged them not give up on their children because of their disability. The role of support groups for parents with CWDs is equally argued for by WHO (2012), as providing ground for experience sharing, and peer support through which they can learn from others in similar situations.

Though child healthcare was the main concern, the maternal health concerns were also addressed particularly those that were seen to reinforce childhood disability. It is no doubt that proper maternal health in itself reflected positively on the early childhood healthcare and

development. Presented with situations of continued new cases of early childhood disability, the concern of checking disability raise was incorporated in both CBR and centre based health approach. For instance, one of the institution caregivers explained that most children who presented the Spinal Bifida condition were result of lack of folic acid in the bodies of their mothers during pregnancy. Therefore in rehabilitating children particularly with this condition and that of hydrocephalus, the underlying causes of these disabilities were also tackled particularly by providing mothers and all women of child bearing age with folic acid. These women were also encouraged to eat folic acid rich food which would help increase the level of this nutrient in their bodies.

In CBR, information dissemination was based on community out-reach programmes and home visits. It was in the home visits that I observed some of the mothers recruited in to the SHIP<sup>45</sup> program which handled both preventative and curative interventions.

**Figure 4 Spinal Bifida & Hydrocephalus information as shown on a wall in one of the households visited during CBR**



(Source: Fieldwork 2013)

In other instances, some of the home carers also did seek that alternative healthcare intervention as an approach to managing early childhood disability. This was revealed in two situations one being within the institution and the other during CBR activity. In the CBR incidence, an infant with both hydrocephalus and spinal bifida had traditional beads tied around her waist area. As the institution carer examined the child, she also realised that some

45 Spinal Bifida and Hydrocephalus Interdisciplinary Program

herbal medicinal cream was also applied on the child's back a fact that was acknowledged by the home carer found in the household. In the other situation, the grandmother of a four year old boy with Cerebral Palsy revealed to me that she had contemplated on placing her grandson in pit as a mechanism of correcting his spine when it started curving out, but was only stopped by some community members.

In these two illustrations, it was evident that they both advocated for the medical model of addressing disability although the former revealed the attempt to blend the traditional and modern rehabilitation procedures. Hartley, Ojwang, Baguwemu, Ddamulira, and Chavuta (2005), research on child disability in Uganda revealed that the continuous search for a cure for the child impairment led home carers to seek for remedy from both formal medical practitioners and traditional healers. Though these two incidences may have seemed to be farfetched and could probably not address the issues of these children's disability, the act of engaging alternative rehabilitation in the first incidence suggested the socio-cultural beliefs within which disability was constructed, did not only construct disability an abnormality but also provided remedies within which normality would be realised.

On the other hand, the thoughts of using local therapeutic procedures suggested that limited socio-economic situations of home caregivers to afford recommended care for child disability drove some of them to seek alternative and cheaper healthcare processes. Although this can be argued further as being done on the home carers' perspectives of the best interests of the child, the data revealed that some of these alternative practices are continuous being challenged as shown by the intervention of some community members in the grandmother's case.

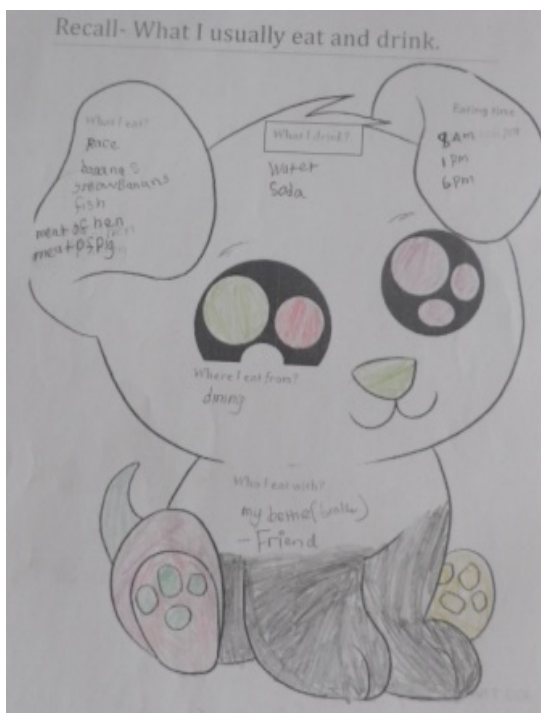
## **Nutrition and feeding practices of CWDs in early childhood**

The discussion in the first part analyses children's food choices and feeding patterns using the recall tool. In the next part, I discuss the feeding practices for CWDs; I focus on children with feeding challenges. Using visual-listening and observation supported with informal dialogues, I present some of the patent issues such as agency which the data showed was used mostly by CWDs with communication and feeding challenges. The nutritional aspect is very important element of the growth and development of children. Within the institution,

nutrition therapy<sup>46</sup> was incorporated in other forms of therapy and rehabilitation activities. An institution caregiver highlighted that some of the children's immediate needs were nutritional therapy before they could even engage the child in other therapies. For children with extreme nutritional deficiencies, nutritional supplements were often recommended from *Muwana Mugimu*, a food supplement company.

### **Children's reflection of their feeding**

I found it necessary to understand the different components that formed the nutrition and feeding patterns of these children. Some of the features that I sought to understand were the feeding practices such as, what children ate and drunk, their eating time and places where they had their meals from. Through the use of the Recall tool in the catch-up class, some of the children revealed that they averagely ate between 3-4 times daily.



**Figure 5 Children's representation of their feeding time patterns using the recall tool**

- Philo:** 8 am, 1 pm, 6 pm
- Amos:** 8am- porridge time, 1 pm- lunch, 6pm- supper, 9pm- Tea
- Molly:** 10am, 01:00pm, 01:30pm, 06:00pm.

The reflection of children's feeding time according to the recall tool suggested that the children had on average three to four major meal times. This was reflective of the food practices within Ugandan societies in which

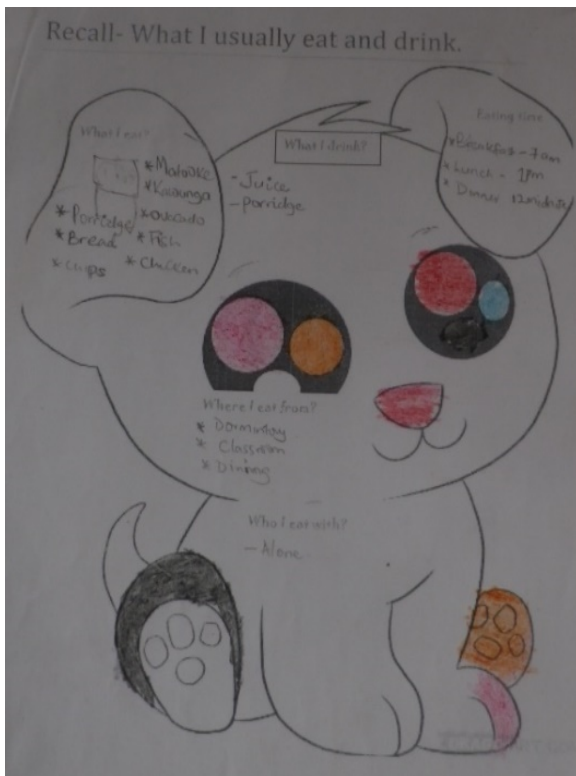
the average number of major meals one has a day is between three and four. Based on this, it suggested that the children's major feeding time patterns was reflective of their current physical health and wellbeing which according to observation data revealed that they were healthy.

46 A therapeutic approach used to redress the nutrition deficiencies in CWD that have initially resulted from malnutrition and poor feeding



In answering the questions ‘*What I eat?*’ and ‘*What I drink?*’, the children wrote down a variety of foods and drinks they had. Intrigued by their options, I sought to understand from them moments when they had some of the foods they listed below.

**Figure 6 Children's representation of their food choices using recall tool**



**Agatha:** *Matooke, Kawunga, ovacado,*

*Porridge, fish, bread, chips, chicken*

**Molly:** *bread, rice, beans, pineapple, cassava, subuusa, fish, Matooke*

**Philo:** *Rice, yellow banana, fish, meat of hen, meat of Pig*

**Faisal:** *Juice, soda, Tea*

**Amos:** *Porridge, water, passion juice, safi Juice, oranges*

Agatha told me that her mother always bought avocado from the market to spice up her food every day. As for Philo, the yellow bananas, and fish were always brought by his aunt when she

came visiting on the weekends. From the excerpts and follow up discourse with these children, what they had their own preferences of what they liked to eat and drink. Therefore besides the food that the institution provided them, some of the enjoyed a variety of other foods either bought from the nearby market or brought in by visiting relatives.

The children’s food choices also reflected that their feeding comprised both solid and fluid foods. The foods reflected by the children such as *Matooke* (Green banana), *Kawunga* (Maize flour), yellow banana, cassava among others inform part of the nutritious food basket of Uganda. Their preference of such foods suggested that children as active agents are capable of informing important decisions such as making food choices which can be directly reflective of their health and physical wellbeing.

The children's reflection of porridge and milk in some of their recall tool further confirmed that both porridge and milk, inform part of the daily and regularised foods that are considered nutritious for children in Uganda. This reflection was based on the observation that porridge and milk were served as a daily beginning meal for the children within the institution in the morning and mid-morning. Based on the cultural feeding practices in Uganda, porridge and milk are also commonly served as a daily first meal within schools in Uganda.

### ***Feeding practices for children with feeding challenges***

The feeding pattern of some children was also greatly affected by their disability condition. This was the case with children who had the cerebral palsy condition. Their ability to feed on their own was one of the things that they had been denied and the condition posed chewing and swallowing challenges for the children as reflected in the case below.

*Angela is one of the few out-patient cases at the institution and has the cerebral palsy condition. She has been attending physiotherapy here for over three weeks now. A car accident, left her with a brain damage when she was 3 months which then resulted into her mental retardation, inability to sit, walk or have cognition. Physically though Angela looks healthy, her mother says that she does not want to eat and smashed food has to be forcefully pushed down her throat. The therapist feeds Angela on milk using a rim slanted feeding cup and a small plate placed right below her chin to collect the dripping milk. Through this feeding process is slow, I observe that Angela is actually drinking up the milk. During this therapy-feeding session, the therapist urges the mother not to rush the feeding process so that the child is able to realise that it's actually feeding. He further tells her that it takes time for the child to learn to feed and that positioning Angela upright is important so that she does not choke but rather swallows easily. He further instructs her that the sitting position of the child has to be at 90 degrees and with support from a bed sheet, or a pillow on the head, the feeding can be done. Once this has been learned, he recommended feeding to be done using a CP-chair. He tells her to bring a banana for the next feeding session and recommends that the best feeding time for the child is 30 minutes and should she take less time, then probably something wrong must have happened.*

*(Field notes: observation/ visual-listening)*

Once again, the importance of time is revealed in this feeding process of Angela. Throughout this feeding process, I observed that the child drank a large quantity of the milk, a fact that was equally acknowledged by her mother. The child's acceptance to take milk could possibly have meant several key aspects needed to be considered during the feeding process. Like revealed by the therapist, enough time to feed allowed the child in this condition to exercise her agency by showing more interest in feeding. Having to force food through her gut would only serve to build on her resilience but not enhance her feeding. Angela had younger siblings who equally demanded their mother's time which partly explained why she possibly never got enough feeding time due to her mother trying to balance her motherly obligations.

Also in helping children with feeding challenges, there were a number of techniques revealed as in the demonstration of Angela's situation. Another institution carer highlighted the issue of them having to continuously design various methods and techniques to help children feed. In this case therefore, the feeding gargets such as cups and plates sometimes have to be improvised to enhance the feeding of the child. The home caregiver here could even locally modify an ordinary cup into a rim slanted feeding cup. Similarly, since most of the children with feeding challenges are not usually able to sit up or support themselves when made to sit, Angela's feeding demonstration revealed the essence of positioning the children in comfortable feeding positions that can enhance their feeding and eliminate choking related incidents for the children. This possibly contributed to Angela's reluctance to feed despite her mother's futile attempts.

In observing the feeding patterns of some of the children with feeding challenges within the institution and in the home place, their home carers endeavoured to feed them on smashed soft foods. The concern of some home caregivers was on the on the amount of food that each child took in. During my observation of the feeding patterns of children in the ELC, I noted that some of the children fed on their own, and others had to be fed. Both these feeding criteria were reflective of quantity of food eaten by each child. Gideon only managed about five spoonfuls of mashed rice and beans. When given a few more scoops of food, he momentarily took it into his mouth before spitting it out. With eyes focused on his mother, he communicated his not wanting anymore food further by sideways shaking of his head when presented with the next spoonful of food. When I later talked with his mother on his feeding

pattern, especially on the amount of food he took in, she confirmed that on average, Gideon took five to eight spoons in a meal. And in as much as this was little, she had to feed him in interval of about two hours. It was therefore this regularised frequent feeding that was her feeding technique for her child to measure up for the less food he ate during a meal.

## **The influence of poverty on childhood disability**

The aspect of poverty was a very eminent subject of discussion throughout this entire research. The occurrence and recurrence of poverty as a significant hindrance to attaining ECCD for CWDs is discussed in this part. Graham, Moodley, and Selipsky (2013, p. 329), argue that poverty compounds the challenges faced by people living with disability. The interview and observational data highlighted the poverty situation of home carers and how it compromises the health and development of the CWD and the entire family. Also the CBR visits revealed the daunting socio-economic status of the different home carers and their CWDs especially their living conditions.

The effects of poverty were reflective on child development. From the data I present here, I argue that it very difficult to delineate poverty from childhood disability. WHO (2012), also highlights the link between child disability and poverty raising concerns that poverty may not only further disability but could also be a consequence of disability. The case below is an illustration of poverty from an institution caregiver's perspective.

*When I get clients, our conversations are so broad, we talk about poverty... Poverty and disability are inseparable because even when you are not poor from the start, this child's condition will drain you. But majority of them are already poor, most of our disabled children come from very poor families, you will realize that a mother from a village in Kamuli, is a citizen type who will not go for antenatal, will not deliver from a hospital... So you realize that cerebral palsy and those pre and postnatal child factors are inseparable, at the very back of them all, there is poverty. when you look another family, let's say maybe from Kampala that is not poor, they were able to do all the right things, go to the right hospitals, right doctors, a simple mistake can also have that child with cerebral palsy from those same factors of birth injury, early*

*infection, they will also get poor because this child will always need therapy and devices that are pretty expensive.*

*(Male institution caregiver: Key informant interview)*

In order to understand the background of a child's disability, institution caregivers had to seek a little more information on the family background of most of their clients. This argument is also emphasised by Hansen et al. (2013), pointing out that a therapist working with a child with disability must look beyond the child and also explore family and home context. It was these kinds of background checks that brought to light different socio-economic situations of home caregivers' households and their efforts to survive amidst their poverty situation.

The illustration in this case, brought out the fact that some of the disability conditions resulted from risky maternal health behaviour, such as irregular antenatal and postnatal care. Interview data from home carers suggested that the distance of the health facilities and the cost of reaching such the facilities were relatively high. Similarly, other home carers argued that the antenatal visits became more frequent necessitating them to visit the health unit about twice every month during the third quarter of their pregnancy. This regularized visiting to some could not be afforded despite the services in the health units being free. The public health concerns regarding maternal health raised by the institution carer and also reflected in interviews with home carers raised suggested that maternal healthcare was essential in checking child disability. Poor maternal health and a restricted diet due to poverty have been argued to directly affect fetal development (WHO, 2012). Ordinarily some of the preventable disability conditions such as cerebral palsy result from lack or limited medical advice related to nutrition and general wellbeing of the mother before birth.

Like elaborated in the case example above, even fairly stable households succumb to pressure from poverty when family resources such as incomes begin to dwindle. Examples from the observation and interview data showed that most fairly placed home carers seek early interventions for their CWDs. For instance, the case of four year old Angela with mental retardation revealed that her family had sought a number of early interventions right from the time when she was just a couple of months old. These included, hiring a private physiotherapist thrice a week for one year, and undergoing two major surgeries. This therefore suggests that the pressure exerted on the family income here is quite high

considering the fact that there is little or no support from state health facilities. The families thus, have to sacrifice whatever incomes they have to facilitate full recovery of their children.

As highlighted in the case above of how poverty drains family resources, WHO (2012), equally points out that pressure of having to meet extra costs associated with disability, such as healthcare bills depletes family resources thus escalating their poverty situation. As home carers continue to inject their limited incomes into healthcare processes such as therapeutic and rehabilitation services, positive results cannot always be guaranteed. For instance, even with the services of a private therapist, and the aftermath of the second surgery, Angela's mother revealed that even the few development milestones such as sitting, and trying to raise her head were eventually lost.

Furthermore, Angela's example also confirmed a stance in which home carers sought interventions from the next institution if the previous one did not yield positive results. This was driven by the desire and need to have the child improve, thus, home carers, risk almost all their resources and incomes for the benefit of their CWDs. Hartley et al. (2005) study on child disability in Uganda also noted such occurrence preferring to regard it as a behaviour among parents of CWDs. They noted that the motive of curing a disability had pushed parents to move from one hospital to the next if they did not see positive results.

During the CBR visits, the observational data suggested that family wellbeing was also greatly affected by limited income levels within households. This directly trickled down to the CWD in terms care. From the different households, the housing, and nature of healthcare all suggested a needs gap in acquiring these services because of cost and affordability. The case highlighted below is a reflection of the escalating wellbeing of some CWDs and their home carers within their households.

*Two year old Amos was born without any deformity, but when he was burnt by hot boiling milk six months back, his developed several complications including cerebral palsy. I visibly see him breathe with difficulty, and his steep neck is constantly tilted to the left side. His mother's experience of caring for Amos has seen her in and out of Mulago hospital and has benefitted from some therapy action. With fresh wounds on his head due to effects of cannula medicines, Amos' mother has been blamed for his present situation..... The*

*CBR team recommends that Amos needs a CP-chair, a standing frame and shoes to avert the developing club foot....*

*(Field notes: observation)*

In this incidence, Amos was a new case of disability to the CBR team. The physical state in which Amos was warranted that he be admitted for medical rehabilitation immediately. However despite the fragility of his state, the cost and affordability of both the recommended appliances and the therapeutic proceeds was something that was out of context for Amos' mother. The CBR team had hinted on the fact that she would have to meet the costs of the therapeutic appliance although she had already alluded to the fact that she had virtually spent most of her financial resources in the time she had been at Mulago hospital. This further confirmed that parental ability to undertake interventions to enhance children's development are met by poverty hardships. Similar findings such as the ACPF (2011), CWDs study revealed that raising CWDs in Uganda came with an extra financial cost. This burden was all placed on the families who have to seek several alternatives such as work, trade and donations. For home carers, unless the institution caregivers offered the service at completely zero cost sharing, it was unlikely CWDs coming from poverty stricken would meet the objective of ECCD.

In my observation data, the description of the several households visited also built on my analysis of the social wellbeing within households. Failing political, social and economic conditions have arguably been analysed as undermining family ability to render the deserved care and support for their children (Evans et al., 2008). From the onset of CBR, some of the households visited were located within the slum areas of Kampala and Wakiso districts. From one of the homes which was a single room house, I noted that the access staircase to the house was so high that it could not be used by the five year old Agatha, recently rehabilitated for Hydrocephalus and Spinal Bifida. In the household of Amos whom I discuss in case above, though not located in the slum area, it was also a single room, semi-permanent house, with un-plastered walls. The observation data further suggested that such limited shared space for all family activity including cooking posed as a risk to the CWDs and their family members. As revealed by Amos' mother, his disability resulted from an accident in a cooking place which was part of the family shared space in their one room house.

The limitation posed in these kinds of situations would definitely limit child development. Even if the child had initially been exposed to other socio-spatial spaces such as in the institutional setup, the continuity of the child's activities within such a restrictive home environment cannot be guaranteed. Hartley et al. (2005), argue that poverty affects coping behaviour because it reduces the external resources available for facilitating such behaviour. Raab, Davis, & C Trepanier, 1993 in McBride and Peterson (1997), argue that a family's lack of resources impinges on its ability to fulfill its childrearing functions for child development. From this data, it suggested that despite home carers having best interests and good intentions for the development of their children, their poverty situation made it hard to actualize it. Disability child development within a poverty context thus continues to compromise the enjoyment of other rights such as health and child participation in activities such as education and learning.



# CHAPTER SEVEN

## CONCLUDING DISCUSSIONS

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### Introduction

In this final chapter, I discuss some of my major research findings by relating them to the research questions I raised in chapter one. The discussion is cross cutting between the two major themes of learning and healthcare. I also discuss good ECCD practices based on examples from children's agency and how place facilitates good ECCD practices for CWDS. I conclude this chapter by suggesting recommendations based on my fieldwork experience and study findings.

### Good ECCD practices for children with disabilities:

#### Examples from children's agency

Children with disabilities have continuously been constructed as a vulnerable group who need care and special attention. For instance, the CRC<sup>47</sup> and the CRPWD, assert the special care deserved by CWDs. The vulnerability reflected above has been argued by the social model of disability as setting a precedence where the interests of CWDs are categorized as special needs rather than having inclusive structures that cater for the needs of PWDs like other citizens (Shakespeare & Watson, 1998). Some of the data presented from the previous two chapters has contested the concept of vulnerability by way of CWDs' agency across time and place. As reflected further in the data, it is important to note that when James and Prout (1997), speak of children as being active agents, this is inclusive of all children. Within the different contexts under which I have situated children's agency, I find it necessary to highlight again that interactions of CWDs with other structures provided breeding ground for child agency within this research (Qvortrup, 2002).

The many unique ways in which children are said to communicate have been presented by Clark (2005b, p. 46) through the 'question of hundred languages'. From the children's interaction among themselves and with their carers, it confirmed that CWDs manufactured

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<sup>47</sup> See CRC Article 23 and ACRWC Article 13

their own language of communication. Through children's construction of their communication which was both verbal and non-verbal, suggested that their everyday life experiences were partly informed by their agency. With particular regard to the non-verbal communication, children revealed alternative ways of asserting their agency. From the case examples of Amina's refusal to go to school because of being discriminated, to Marcela's refusal to use her walking frame all revealed resistance agency to participation (Ahearn, 2001). Within the dominant arguments such as socialization theory, which data also revealed as strongly existing in the Ugandan child rearing practices, child resistance to participate would simply be constructed as immaturity, and incompetence of the child to communicate (Prout & James, 1990). However, like Spitzer 2003 in Olli et al. (2012), suggests, that even though the child's action may seem meaningless to an adult, seeing it as meaningful to the child can help us understand from the child's perspective. From the findings, negotiated communication between adult carers and the CWDs can be stated as inevitable for implementing good ECCD practices for CWDs.

Furthermore, the degree of persistence reflected in some of the children's resistance such as that of Labekka revealed that as agents CWDs could make informed choices regarding their participation. It further raised the question of whether these choices were vehemently respected by their adult carers. It has been argued that being both a child and a disabled person are risky factors towards the realization of child agency (Olli et al., 2012). In this case, I relate this to the difficulty with which most carers especially home carers found it hard to interpret the children's actions or interests expressed non-verbally. For instance whereas the institution carer's argument for Angela's reluctance to feed was compounded in the aspects of time taken to feed her, and the way she was positioned while feeding, her mother's inability to comprehend this and take course of action caused her a lot of frustration. In this regard, the likelihood of home carers giving up on facilitating the interests of CWDs was likely especially if they did not understand the implied meaning of the asserted agency.

The notion of being disabled is one that rose questions of competencies of CWDs even among their own carers. Although all children are defined as deserving care and provision by right, the different occurrences suggested that CWDs' competencies to decide on their choices of care and provision were sometimes undermined by their home carers. It was

assumed that a child's disability seemed to have spoiled the child's taste for choice, and therefore the adult home carer was better placed to decide for the child. As reflected from the data, some instances of agency were also treated as a matter of child stubbornness, or vulnerability caused by the disability. This vague understanding of child agency mostly expressed non-verbally has also been argued by Robson et al. (2007) as generating a power struggle between the home carers asserting their adult provisional role and children wanting to exercise their rights.

However, the profoundness with which the institution carers' appreciated and respond to children's agency confirmed that CWDs more of active participants and not passive recipients of different processes (Prout & James, 1990). As Olli et al. (2012), point out, interaction provides grounds upon which child agency is expressed. Agency will thus only be realized if the child's influence is taken into account and responded to. From the several ways cited in which child agency came into play, I find the above argument convincing enough because all situations of child agency discussed previous were fuelled by interaction. The interpretation of the different children's agency suggested that it fitted within the children's concerns for instance the four year old boy's refusal to use his walking crutches.

Though I argue that for institution caregivers, they were professionally accountable for healthcare interventions for their clients, the level and frequency of interaction they had with the children helped them build a bonding relationship. They exhibited professionalism with compassion and this possibly explained why they often understood children's agency expressed differently. This argument is also suggested by Olli et al. (2012) arguing that since CWDs spend more time in special institutional spaces, such as healthcare and rehabilitation centers, professional carers must actively play the role of facilitating their agency. The continued interaction of institution carers with children and their home carers was thus inevitable whose continuity I argue as forthcoming in achieving early childhood development for children with disabilities. CWDs with development challenges in their early childhood have higher chances of continued progressive development if institution carers continued to listen to the voices of the disabled (Clark & Moss, 2011; Shakespeare & Watson, 1998). By doing so, they will continue to facilitate child participation through their agency. The CWD's construction of their own ideas, and the ability to express them is a recognition of the child's

own competencies which in reality can give carers meaningful insights in understanding of lives CWDs (Clark & Moss, 2011) in relation to their early childhood concerns.

## **How place can facilitate ECCD practices for CWDs**

From the analysis data, the aspect of time and place was of great relevance in the implementation of ECCD for CWDs. These two were synonymous and their interplay was strategically used by carers in helping children realise developmental goals brought about by delays in their disabilities. In showing how place can be reflective of child development, it has been argued that,

The processes that influence early learning and development are produced by the interaction of the environments experienced by a child and the characteristics of the people (including the developing child) within these environments (Dunst, Trivette, & Jodry, 1997, in Bruder, 2000, p. 108).

Based on this, the findings revealed that the concept home was considered to be the best place to enhance child rehabilitation alongside ECCD practices. As evidenced from institution preference to adopt a home setup within its premise, 'home' meant the best place for a child to grow and development. The provisions of amenities such as children's toys in play spaces, and televisions were a reflection of what a child would mentor a child's development within their own home surrounding. These amenities as I have discussed previously did not only facilitate child development but also nurtured their comfort. Thus, if the home per se is the beginning point of a child's comfort, then it is right to argue that this institution-home setup initiative served the best interests of the child because it facilitated interactive development of the child.

Furthermore, the institution as place of rehabilitation was reflective of good ECCD practices for CWDs. These practices as reflected in the data considerably pay attention to issues of childhood care and development. The all-inclusive approaches reflected by the actions of the institution caregivers such as, mentoring children to learn ADL, restoration or achievement of functional mobility all suggested that efforts to empower children to become independent.

This rehabilitation aspect has also been defined by child and disability rights legal frameworks<sup>48</sup> as enhancing child development.

The perspectives documented by the children also reinforced why the structure of home was important in their development. As reflected in some of the children's drawings, the place of home was considered important as a point of their identity. One of the children showed the home as a place where they shared a meal together with the rest of the family. Another revealed it as the place where she played with her sisters and cousins. The traits of family collectiveness that is sharing and play would point to the fact of their own acceptance that their presence within the institution was temporal. The attributes of family sharing and play confirmed the home as that social structure where they were accepted despite their disability.

## **Children's rights within ECCD practices**

The question of child right is one which cannot be separated from matters of early childhood. Some of the prominent ECCD campaigns such 2000 Dakar *Education for All* saw the need to have the 'rights question' answered by several ECCD interventions in the developing world (Penn, 2004). The rights based debates also continue to define children as *rights holders*, who deserve support from caregivers and state parties if they are to fully develop (Hodgkin & Newell, 2007; Prochner & Kabiru, 2011). The data generated has revealed that early childhood development within a disability context requires a participatory approach in which both carers and children negotiate their roles. The rights concept within learning and healthcare all of which are pivotal in good childcare are very much built on a needs perspective especially from the home caregivers' point of view. This has equally been highlighted by Tine and Ennew (1998), as children's rights in Africa been categorized as needs.

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<sup>48</sup> See Articles 13,14 of ACRWC; Article s23, 24 of CRC, and Article 26 of CRPWD

## Childcare practices for Children with disabilities

Childcare as a practice of child rearing is defined within the socio-cultural aspects of societies. In parts of sub-Saharan Africa, childrearing practices were informed by socialization theories and traditionally tailored to suit the human *becoming* (Qvortrup 2009, in Kjørholt, 2013a) role that the child would adopt in adulthood. Children were and are still an investment especially with the regard to the reciprocal role they are expected to carry on in adult adulthood (Kenyatta and Kariuki 1984; Kilbride and Kilbride 1990; Mwamwenda 1996, in Prochner & Kabiru, 2011; Tine & Ennew, 1998). The social construction of good childcare with regard to an African setup involve certain role expectations such helping with domestic chores within the home. This has also been emphasised also in the ACRWC<sup>49</sup> in the duties and responsibilities of the child. Although the dynamics of culture have paved way for diversity in childrearing practices among African societies especially with the first growing influence of western models of childrearing, Prochner and Kabiru (2011) argue that certain traditions still inform a great deal of childcare practices in Africa.

The beginning point of childcare was seen in the carers' own appreciation of the relevance of life to each and every child. For the institution caregivers, the right of every CWD to live was informed by their moral and ethical obligation to implement the institutional child protection policy as well as the CRPWD<sup>50</sup>. These both informed an important legal framework which the institution used as a yardstick for implementing child rights. However, among home carers, the concept of *care* was more of a responsibility that every parent owed to their child. Home caregivers explained that they had to provide care for their children if they were to survive. The bid to seek rehabilitation for their children was therefore a manifestation that home carers exercised their rights obligation to child protection and care. Childcare was thus constructed more as a need than a right. This concern has equally been highlighted by Tine and Ennew (1998), pointing out that the inadequacy of children's culture causes the fulfillment of rights as needs.

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49 See Article 31 of ACRWC; The responsibility of the child

50 The convention on the Rights of Persons with Disabilities

The component of nutrition also informed part of the child healthcare. In analysing the essence of nutrition care in early childhood disability, it revealed that home carers needed to adapt different feeding interventions for children who had feeding challenges. Basing on visual-listening and observational data, children with feeding challenges use their agency in nutrition determine how their feeding interests should be practiced. I find such child participation as very critical in guiding home carers to make informed decisions crucial in nutritional care such diversifying the feeding mechanism of the child.

Within some of the child care practices, the data pointed out the single mother role of caring and nurturing CWDs as being overwhelming to the female home caregivers. Similar arguments of men involvement in the caretaking role of CWDs have been advanced as not only lessening the burden on the women but also enhances family abilities to care for CWDs through competency building (WHO, 2012). The absence of men in the caring process was reflective on the wellbeing of the children and their female caregivers. The discussed examples reflected further that the socially constructed breadwinner role of the man within a Ugandan society was taken over by the women in cases where male caregivers were absent. Further examples from children's perspectives revealed that absence of their fathers was detrimental to their development. It was further revealed that besides struggling with the role of being the sole providers within their families and households, the daunting levels of poverty further hindered the advancement of good caring practices for CWDs.

Also one of the major findings from this study was that poverty greatly affected child care and rearing practices. As revealed in the data, the home caregivers' desire to provide for their children was hindered by the aspect of poverty which was reflective of both study participants in the institution and at home. The poverty effect highlighted situations where it hindered children's participation in the home environment because of the nature of the family dwelling.

Also within childcare practice, the CBR approach was revealed as one of the viable alternatives to disability management. Hartley et al. (2005), suggest that CBR programmes can be effective in addressing CWDs' concerns if they aim at empowering community and family with knowledge on disability. The efficacy of CBR as shown by the data enhanced continuity of child learning and healthcare processes. It closely monitor how children were

coping and within the home spatial spaces. Within the community structures, data has shown that it was an effective strategy to use in changing negative attitudes and perceptions about children with disabilities.

## **Learning and health**

The concept of learning and education are relatively used within Ugandan perspective. It is a common trend that activity of learning for children is more defined and connected to education. The data on learning, however, has challenged some of this thinking first by asserting that education is a component of child learning. Although education is vital for early childhood development, children with disability demonstrated that there is more to learning within early childhood than just schooling. Like Tchombe, (2011), suggests that development is much influenced by learning, the data from the learning and health chapters revealed that the two are interconnected. The children's health and care was very much dependent on the activities that the children had learnt themselves. Children's resistance to participate in some learning activities did suggest that children were not necessarily negative about learning but rather that, more attention needs to be paid to their learning interests.

The relevance of home caregivers in learning process was therefore paramount for the achievement of good healthcare practices for such as feeding and nutrition CWD in early childhood. Similarly rights based debates championed by the CRC suggested that caregivers can facilitate positive child development if they are fully involved (WHO, 2012). The care and support demanded by CWDs is far beyond that of other children. Instances such as longer feeding time, appropriate learning space and non-verbal communication showed that it was inevitable for home caregivers to also be part of the learning process because they usually remained as the constant in the children's everyday lives after the institution carers exited.

The several variations in the learning patterns of children were also influenced by the nature of the effect of the disability on the child. This was the basis upon which children were placed in different rehabilitation units. In the ELC which basically handled the children with learning challenges, the main concerns addressed were children's own ability to develop some level of self-dependence. Through learning ADL, children would learn among other



basics things such as toileting practices, and tooth brushing. Many children from the ELC could not be enrolled in formal schooling. Besides schooling being a human right, a Ugandan perspective of school lies in the role it plays in helping improving an individual's socio-economic status. Across the board, growing need to realise economic growth and achieve national development has been acknowledged as reason for investing more in the future of children through education (Kjørholt, 2013a). The denied access of such children to go to school thus raised the realities of porous learning structures which cannot meet the rights of children with learning challenges.

## **Recommendations**

One of the revelations from the interview data was that there was little input from government in regard to supporting ECCD activities for children with disabilities. This was particularly noted in the area of none government participation in funding ECCD initiatives for CWDs run by the institution. This therefore meant organisations such as this institution where the study was carried out solely relied on good will and donor funding to implement ECCD related activities. One of the relevant strategies suggested for developing ECCD activities across sub-Saharan Africa is for national governments to build partnerships with civil societies, NGOs and development partners (Akosua, 2008). For countries like Uganda, such partnerships can be important in supporting the bid of private institutions and government organisations in the actualisation of good ECCD practices not only for CWDs but for all children.

Furthermore, the data revealed that most cases of early childhood disability were a result of poverty and poor maternal health seeking behaviour. The poor health seeking behaviour was mainly facilitated by a weak healthcare system in which some mothers were reluctant to seek antenatal care because of distant healthcare centres or cost of the service. These findings thus suggest that combating incidences of childhood disability should be a government priority through early intervention first and foremost by building capacity of the decentralised healthcare infrastructure to combat cases of disability such as, Spinal Bifida which is closely related to maternal health. Secondly the early intervention programmes of child disability require support from government. In particular this can be through budget support for early intervention programmes that can facilitate child development and participation. Early

intervention strategies are continuously been advocated for as the best alternative for enabling CWDs to experience ECCD. For instance key international agencies note that children with disability or developmental delays have a better chance of achieving full development if the disability or delay is identified at an early stage (UNICEF, 2013; WHO, 2012).

As previously highlighted, the lack of an ECCD national framework has solemnly the role of ECCD implementation to private individuals, organisations and NGOs. Like pointed out by Akosua (2008), national ECCD policy not only promote the best interests of young children but also streamline the modalities for the implementation of these policies. For the case of Uganda, different government ministries such as Health and Education have well streamlined policy documentation which would otherwise facilitate effective ECCD implementation. However policy implementation of developmental progress in the country is grappled by issues of bureaucratic procedures and duplication of activities. The starting point of achieving well streamlined ECCD practices that address the interests of CWDs in Uganda should be in the amalgamation of the different policy frameworks of children into one consolidated ECCD national framework.

In regard to child nutrition and feeding practices,WHO (2012), suggests that prioritising health issues for CWDs can ensure their growth and development. The data revealed that the component of nutrition and feeding practices informed greatly the wellbeing of children. Nutrition therapy for malnourished CWDs was initiated as the first intervention in the rehabilitation process. However the data also showed that home caregivers with children with feeding difficulties experienced a lot of challenges in exercising good feeding practices. One of the reason noted for this was that the available institution caregivers handling occupational and physiotherapy or nursing care were overwhelmed by the number of children the attended to daily, let alone participate in the CBR activities. Nutrition therapy as a major component of child development was therefore not given the due attention it deserved. Although the data suggests that most of the nutrition and feeding practice intervention recommended by the institution caregivers seemed to work, specialised input from a nutritionist was inevitable to boost the efforts of other institution caregivers and to further develop the home caregivers' skills in the feeding practice necessary for their children.

In using Community Based Rehabilitation approach, the data gathered showed that there was continuity of promoting ECCD practices such as learning and healthcare at home. Since this strategy facilitated interaction between the community, the home caregivers and the institution caregivers, it can be recommended as one of the best strategies of building male home caregiver support. It could be easier to break negative dominant male home caregiver attitudes towards their children with disability. The support of both parents in the development of their children is mandated as a right that every child must enjoy. Support from both parents in essence reduces the pressure of only mothers having to work towards meeting the best interests of their children which interests as revealed by the data have been a challenge to meet because of their socio-economic as single home caregivers for their children.

Conclusively despite striving so hard to implement interventions aimed at improving CWDs' realisation of ECCD, institutional approaches must with regard pay attention to the different ways in which CWDs can participate in their own development. As revealed in the data, children with disabilities continuously find ways of raising issues related to their participation through their agency. It is important therefore that both home and institution caregivers not take for granted the notion that children within a disability context are a mere passive subjects whose experiences can only be determined by social structures and processes they interact with (Prout & James, 1990).

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# Appendices

## Appendix I: Child informed consent



My Name is **David Okimai**



I am here because my school and I would like to learn from you how you live your life here

The ways in which you learn, the things you do here

The care and treatment you get

The foods that you usually eat



I promise, everything that you tell will remain a secret between you and me

You do not have to tell me anything you don't want me to know



There are no wrong answers.

You know more than I do

You can ask me to stop if you don't want to continue

You can circle the tick if you want to participate

OR

You can circle the Cross if you don't want to participate



**YES**



**NO**

## Appendix II: Adult Consent Form for Caregivers

Hello,

My name is David Okimait and I am a student of Childhood Studies at the Norwegian University of Science and Technology. I am here because I am undertaking a research with children of ..... The topic of my research is **“The role of caregivers in promoting early childhood care and development among children with disabilities in Uganda.”** The research also involves the participation of adults like you as outlined in the research o below;

1. Understand how Early Childhood Care Development (ECCD) enhances interests of Children with Disabilities (CWDs)
2. To capture children’s experiences and perceptions about the ECCD programme in regard to enhancing their care and development in the areas of health, education and nutrition
3. Assess how special needs children experience Home based and Centered based Early Childhood Care Development projects
4. To understand how caregivers, both institution and home promote and provide Early Childhood Care and Development to children with disabilities.

The purpose of this communication is to request your participation in this study through answering some questions related to this research topic. The decision to participate or not is purely yours; however your participation and completion is very important to this study. All your answers and opinions are paramount and confidential and will be used purposely for this study. You can choose to end the interview at any time and you don’t have to answer certain questions which you feel you are not comfortable with.

Also for purposes of clarity and data analysis, with your permission, the conversation will be tape recorded and at your discretion, the tapes will be destroyed once all the information has been retrieved from them.

The information you will provide to me may also be accessed by my immediate project supervisor, however all information you provide will be coded differently and pseudo names or identification will be used so that nobody can identify you as the provider of the responses.

Do you grant permission to be audio taped?

Yes \_\_\_\_\_ No \_\_\_\_\_

I consent to participate

Respondent \_\_\_\_\_ Date \_\_\_\_\_

I agree to the terms:

Researcher \_\_\_\_\_ Date \_\_\_\_\_

Should you have any questions or inquires about this study, please contact me or my supervisor at the address below

Norwegian Center for Child Research  
NTNU  
N-7491 Trondheim NORWAY  
David Okimait

Anne Trine Kjørholt  
Director, Professor  
Norwegian Centre for Child Research  
NTNU  
7194 Trondheim, NORWAY

### **Appendix III: Parental/ Guardian Consent form**

Hello,

My name is David Okimait and I am a student of Childhood Studies at the Norwegian University of Science and Technology. I am here because I am undertaking a research with children of ..... The topic of my research is **“The role of caregivers in promoting early childhood care and development among children with disabilities in Uganda.”** The research also involves the participation both children and adults as outlined in the research objectives below;

1. Understand how Early Childhood Care Development (ECCD) enhances interests of Children with Disabilities (CWDs)
2. To capture children’s experiences and perceptions about the ECCD programme in regard to enhancing their care and development in the areas of health, education and nutrition
3. Assess how special needs children experience Home based and Centered based Early Childhood Care Development projects
4. To understand how caregivers, both institution and home promote and provide Early Childhood Care and Development to children with disabilities.

Your child has been randomly selected to participate in this study. The purpose of this communication is to request your permission to allow your child participate in this study. Since participation is voluntary, your permission for the child to participate will be followed by request from me to the child to participate in the research process. You have the reservation to either accept or refuse your child to participate in this study, and the child also has the right to either accept or refuse to participate. However the child’s participation and completion is very beneficial to this study. All answers and opinions provided by the child are paramount and confidential and will be used purposely for this study. The child can choose to end the interview at any time and he/she does not have to answer certain questions which you feel you are not comfortable with.

I will be using participatory methods such as drawing, remembrance, the child’s journey of life, and mapping to collect data and understand the child’s perspective of the research issues. The research may not have immediate and tangible benefit to the child but will be used to formulate policies which could improve the care and development of disabled children in different institutions. I take upon myself to guarantee the physical safety of the child during

the research process and also protect the identity and information provided by the child. All information that could link the personal identification of the child in this research will be removed or altered through use of pseudo names and identification.

I do consent to my child's participation

Parent/ Guardian \_\_\_\_\_ Date \_\_\_\_\_

I agree to the terms:

Researcher \_\_\_\_\_ Date \_\_\_\_\_

Should you have any questions or inquires about this study, please contact me or my supervisor at the address below

Norwegian Center for Child Research  
NTNU  
N-7491 Trondheim NORWAY  
David Okimait

Anne Trine Kjørholt  
Director, Professor  
Norwegian Centre for Child Research  
NTNU  
7194 Trondheim, NORWAY



## Appendix IV: Adult Key Informant interview guide

### General issues

1. Tell me about your role at Katalemwa Cheshire home?
2. Could you describe your experiences with Katalemwa Cheshire home, and why you are interested in children with disabilities (*probe for general insights about the home, and how it operates*)
3. What are the different forms of disability that one would find at this Centre and in the community (*Also generate further discussion based on the observed disabilities.*)
4. Could you describe how you recruit children at Cheshire home. What do you think about the recruitment criteria?
5. Does the center incorporate the UNCRC in its work with children? If No why? If yes, how is the UN convention on the Rights of the Child incorporated in the implementation and rolling out of your ECCD programs? (*Reflect on particular articles such as the 4 principles, also probe for national children documents like the Children's statute of Uganda*)
6. Do children have a voice in decision making within the Cheshire home? If yes, how is their participation reflected.

### Learning/ Education

1. Could you tell me what children with disabilities learn at your institution?
2. How do children with disabilities learn in this institution?
3. How learning for Children with disabilities is rolled out through your home based and center based programs?
4. Are there any policies reforms Cheshire home is undertaking to improve early childhood education?
5. Tell me about the challenges you face in implementing early childhood education among CWDs? (*Also probe for some solutions or measures taken to overcome these challenges*)
6. Who are the personnel involved in providing early childhood education to CWDs? (*probe for details on the trainings and how the institution outsources them, does it go a step further to enroll staff for training programs*)

7. What activities children with disabilities living outside the Centre involved in? (*probe for level of involvement of the center in these activities*)
8. Apart from formal education, is there any other form of learning provided for disabled children who are not able to study in terms giving them skills to engage in informal sector

### **Health & Nutrition**

1. Could you describe how health care is provided to CWD by your center?
2. Are there any physical structures and aids that support the disabled children (*Probe for items like mobility kits, access to buildings, toilet facilities among others*)
3. Are the parents and community integrated in supporting the health and nutrition interests of CWDs?
4. Are there any differences between the care and support of CWDs here in the Centre and those in the community? (**Observation, houses, toilets, play space, clothes children wear, food served, level of interaction, general atmosphere- happiness etc.**)
5. What are the strategies in place to reduce discrimination\stigma against CWDs in community and Centre?
6. What is the role of both the central and local government in regard to ECCD among CWDs? (probe for government policy and role, and that of local governments)

#### **Appendix V: Drawing tool**

1. Can you draw a picture of your life here in the center?
2. Can you tell me about the picture you have drawn?
3. Why is this picture/ the things you have drawn in this picture important to you?
4. What does the picture you have drawn mean to you?

Appendix VI: Recall- What I usually eat and drink



## Appendix VII: Ethical clearance form

**Norsk samfunnsvitenskapelig datatjeneste AS**  
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

**NSD**

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

Anne Trine Kjørholt  
Norsk senter for barneforskning  
NTNU  
Loholt Allé 87, Pavillion C  
7491 TRONDHEIM

Vår dato: 24.05.2013      Vår ref:34543 / 3 / HIT      Deres dato:      Deres ref:

### TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 14.05.2013. Meldingen gjelder prosjektet:

34543      *The Role of care Givers in Promoting Early Childhood Care And Development (ECCD) Among Children With Disabilities; A case of [redacted] in Uganda*

Behandlingsansvarlig      NTNU, ved institusjonens øverste leder  
Daglig ansvarlig      Anne Trine Kjørholt  
Student      David Okimait

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

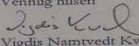
Personvernombudets tilrådning forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

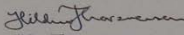
Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre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

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 15.06.2014, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

  
Vigdis Namtvedt Kvalheim

  
Hildur Thorarensen

Kontaktperson: Hildur Thorarensen tlf: 55 58 26 54  
Vedlegg: Prosjektvurdering  
Kopi: David Okimait, 1653 Herman Krags veg, 7050 TRONDHEIM

Avtalingskontorer / District Offices  
OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47 22 85 52 11. nsd@uis.no  
TRONDHEIM: NSD, Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47 73 59 19 02. kynn-soar@skbvt.ntnu.no  
BIRKBEK: NSD, SVF, Universitetet i Tromsø, 9017 Tromsø. Tel: +47 77 64 43 36. usd@iuhd.uib.no

## Personvernombudet for forskning



### Prosjektvurdering - Kommentar

Prosjektnr: 34543

According to the notification form there will be obtained verbal and written consent based on verbal and written information about the project and the processing of personal data. For children under the age of 18, consent will be obtained from parents or guardians as well.

The Data Protection Official for Research finds the letters of information satisfactory according to the Personal Data Act, as long as information about when the project will be completed and personal data will be anonymized is added.

There will be registered sensitive information relating to health, cf. Personal Data Act § 2, no. 8 c).

The information will be registered on a private computer. The Data Protection Official for Research presupposes that the use of a private computer is in accordance with the routines for data security for NTNU.

When the project is completed, by 15.06.2014, the data material will be made anonymous by deleting directly and indirectly identifying variables and audio-recordings will be deleted. In order for the data to be fully anonymised, all directly identifying data, such as names/reference numbers must be deleted, and indirectly identifying data in the remaining material must be deleted or changed.

## Appendix VIII: Introduction letter

NORSK SENTER FOR  
BARNEFORSKNING

THE NORWEGIAN CENTRE  
FOR CHILD RESEARCH

To whom it may concern

Our consultant:  
Line Hellem  
Higher Executive Officer  
Telephone no.: +4773596357  
E-mail: line.hellem@svt.ntnu.no

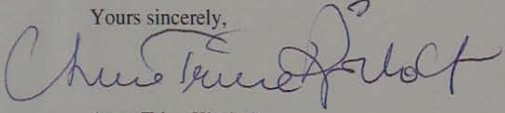
Dated: 2013-05-28      Our ref.:      Your letter dated:      Your ref.:


**LETTER OF INTRODUCTION**

We hereby confirm that David Okimait, born 7 May 1982, is a student in the programme *Master of Philosophy in Childhood Studies* at Norwegian Centre for Child Research, Norwegian University of Science and Technology, Norway. He will undertake his fieldwork and data collection from 4 June to 5 August 2013, in Kampala, Uganda, on the topic:

*The Role of Home Caregivers in Promoting Early Childhood Care and Development among Children with Disabilities in Uganda: A case of [REDACTED]*

We would be grateful for any assistance given to him during this process. This includes granting interviews, assisting him in making appointments, handing out materials and making information accessible to him. We ensure that the information collected is treated confidentially, and that the fieldwork bears no costs on the institutions and persons visited.

Yours sincerely,  
  
Anne Trine Kjørholt  
Supervisor/Professor  
Director of Norwegian Centre for Child Research

  
Line Hellem  
Higher Executive Officer

NORWEGIAN CENTRE FOR CHILD RESEARCH  
NTNU  
NOSEB is organized as a department at The Faculty of Social Sciences and Technology Management, Norwegian University of Science and Technology (NTNU)  
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Page 1 of 1