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**Growing up with disability in Ethiopia: The Perspectives and Experiences
of physically disabled children**

Master's thesis in Childhood Studies (MPhil)

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Abstract

Although disabled children have long been subject of research and policy attention, their situation in the Global South including Ethiopia largely remained unimproved. Societal attitudes about disabled children have been negative. The majority of these children face enormous socioeconomic barriers, lack access to basic needs such as health and education, and subject to multiple deprivation within their family (ACPF, 2011a). Policies and intervention programs also have been less appropriate. Most studies about disabled children have been focusing on documenting the number, the causes and consequences of disability, and the societal attitudes about disability, saying little about the children's lived experiences. Researchers have been hearing from parents and professionals, leaving the children's perspectives and experiences largely unexplored. My study aimed to explore the perspectives and experiences of children with physical disabilities based on a two month fieldwork in one of the rehabilitation centers in Ethiopia. Data were collected through participant observation, semi-structured interviews and neighborhood walk with ten children of ages 12 to 15 in the rehabilitation centre; focus group discussions with four social workers and interviews with four parents.

The results show that the children in my study tended to hold a relational view about their disability situation in which they live. They viewed their disability situation as a 'difference' from able-bodied children basically in terms of physicality/body, in terms of mobility and everyday activity performance. The children also made a point that growing up with disability has rendered them powerlessness, marginalization and lower social status among their able-bodied peers, in family and community. They reported negative societal attitudes and environmental challenges/poor infrastructure as the major barriers to their everyday lives. There was a widespread negative societal attitudes about disability, which the children themselves also tend to reproduce, although their perspectives of the disability situation in which they live were changing and varied based on various factors. Disability was viewed by most people as God's punishment or as caused by elders' curse or evil spirits. The children were considered as having cursed or sinful family background or as caught by evil spirits and were subject to segregation and marginalization and experienced limited social interaction with able-bodied children as a result. Negative attitudes about the children's ability were also held in community.

However, various accounts of these children in my study were evidences that not only were these children objects of challenges; they were also active agents who created various adaptive strategies and remain resilient amidst challenges. They play important role in their household through engaging in various activities ranging from home chores to herding cattle and working on farm fields, which demonstrates their agency, despite their disability.

The various rehabilitation services provided in the center have brought a significant improvements in the children's physical and social wellbeing. However, the negative societal attitudes and poor infrastructures remain unresolved and challenging. Working on the attitudes of community and building enabling environment through facilitating infrastructures would be important measures to improve the wellbeing of the children in addition to providing rehabilitation services in institutions.

Acronyms

ACPF- African Child Policy Forum

ACRWC- African Charter on the Rights and Welfare of the Child

CBR- Community Based Rehabilitation

CRPD- Convention on the Rights of Persons with Disabilities

CSA- Central Statistics Agency

ILO- International Labor Organization

MOLSA- Ministry of Labor and Social Affairs

NGO- Non-governmental organizations

NOSEB- Norwegian Centre for Child Research

NTNU- Norwegian University of Science and Technology

UN- United Nations

UNICEF- United Nations Children's Fund

UNCRC- United Nations Convention on the Rights of the Child

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CHAPTER ONE

1 INTRODUCTION

1.1 Background of the study

Many children in the Global South live in the circumstances that would generally be considered “difficult” in the North (Ansell, 2005). The Global south in my study refers to those countries other than Europe and North America that are socially and economically less developed or developing (Rigg, 2007), also called the majority world in another term (Punch, 2003). The Global South - North division is based on economic inequalities and the global signifies that the division is not a strict geographical categorization, but that both North and South are, together, drawn into global processes (Rigg, 2007: 3). Most children in the Global South live in extreme poverty and many are affected by war, forced migration and exploitation (Ansell, 2005; Boyden & Mann, 2005). These adversities have deepened concern internationally for the protection and promotion of wellbeing of the children (Boyden & Mann, 2005). UNICEF, for example, identified some group of children which it called “Children in Especially Difficult Circumstances” (CEDC), consisting street children, children in armed conflicts, children affected by HIV/AIDS, sexually exploited children, children with disabilities and those in institutions, and employed an umbrella term “child protection” to provide assistance appropriate to their situation largely in relation to survival, health and education (Ansell, 2005). The first four groups of these children have been given considerable coverage by researchers from the North, while the last two groups (children with disabilities and those living in institutions) relatively attracted less attention (Ansell, 2005). My study focused on exploring the perspectives and experiences of children with disabilities.

Millions of children with disabilities are living in the world, most of whom are in the Global South (UNICEF, 2006; Maulik & Darmstadt, 2007). The high incidence of childhood disabilities in the Global South is attributed largely to poverty and the environmental factors that underlie high levels of illness and accidents; the prevalence of unattended home births, the fact that selective abortion, which has reduced the number of children born with disabilities in the North, is seldom available (Ansell, 2005: 215).

Many policies and programs have been adopted to improve the situation of children with disabilities worldwide. For example, the United Nations adopted the Convention on the Rights of the Child (CRC) and Convention on the Rights of Persons with Disabilities (CRPD) and many countries in the Global South also has ratified these conventions and taken

responsibilities of improving the wellbeing of children with disabilities (UNICEF, 2013). However, the situation of children with disability in the Global South remains largely unimproved (Ansell, 2005). The societal perspectives and attitudes around children with disabilities in these countries are largely negative (Ibid). In much of African countries, including Ethiopia, children with disabilities are seen as burdens of care, and negatively perceived as unnaturally conceived, and therefore neither fully human nor part of the community (Kabzems & Chimedza, 2002). The majority of these children face enormous economic and social barriers and many of them do not have access to the most basic needs such as health services and education, and experience multiple deprivations even within their family (ACPF, 2011a).

Policies and intervention programs available to the children with disabilities in the Global South have also been less appropriate (Ansell, 2005). The dominant provision for disabled children in these countries largely relies on the medical model which conceptualizes disability as an individual impairment that requires rehabilitation, neglecting the social factors playing a major role in the construction of disability (Ansell, 2005). Having originated in the North, the medical model has become naturalized to the extent that it has created the standardized treatment for disabilities (Holt, 2004). Moreover, children in the Global South have been understood from the North imagination of childhood (Boyden; 1990). In the North childhood has been constructed as a period of school, play and work-free; and children should be safe, happy and protected from circumstances that interfere with their development (Boyden, 1990). These values of childhood ideal to the wealthiest nations of the North have been exported to the South under the colonial rule and more recently through the United Nations international legislations on children's rights (Boyden; 1990: 197). These notions of childhood have become the point of departure for international and national child rights and welfare policies in many countries of the world; creating an idea of global model of childhood (Ibid).

However, it has been criticized by contemporary research that policies and intervention models that have been formulated in the North according to the globalized model of childhood were inappropriately exported to the South to serve the children in different socioeconomic situations (Boyden, 1990; Punch, 2003; Woodhead, 2003; Montgomery, 2003; Boyden & Mann, 2005). The various images of children from the South raised a question whether the world's children enjoy the same childhood (Montgomery, 2003). It should be noted that the world's children live in significantly varied socioeconomic circumstances that

expose them to different life consequences (Punch, 2003). Comparatively speaking, a substantial number of the world's children reside in the Global South (Punch, 2003), and as such, many children in these countries live in the circumstances that exhibit childhood disability (Ansell, 2005). Numerous children suffer from chronic and periodic illnesses and a sizeable number of children are working at an age when children in the North play and go to school, for instance (Ansell, 2005: 192). Children in the North, on the other hand, experience more privileged and protected childhoods compared to the South (Punch, 2003). They live in improved socioeconomic situations that exhibit less vulnerability to the circumstances that cause disability. States' support to children also considerably varies among the North and South. For example; while countries in the North like Scandinavian focus on family planning, income maintenance, day-care services and public housing, the Global South countries like Ethiopia, for example, still struggles to reduce or end infant and child morbidity and mortality (Boyden, 1990: 195). Boyden (1990) further argues that the fact that the social policies are informed by the global standards of child rearing and child welfare has the effects of penalizing or criminalizing the children of the poor, for a simple reason that poor families could not reach this standard (p. 202). The present Convention on the Rights of the Child (CRC) comes closer to this effect focusing on standard welfare and rights of the child and playing down the impact of wider social, economic, political and cultural conditions the lives of the world's children. The unequal distribution of resource, poverty, unemployment, ill health makes it impossible for many children and families to achieve these goals (Ibid).

These inappropriate views about children's wellbeing in the Global South were partly resulted from the neglect for children's perspectives and experiences in research and policies (Boyden & Mann, 2005). In the particular case of disabled children, there has been a greater tendency to neglect the children's own perspectives and experiences in most research about them both in the South and North despite varied degrees (Robinson & Stalker, 1998; Shakespeare & Watson, 1998; Ytterhus et al., 2015). As some disability scholars argue, research with disabled children has been characterized by a "legacy of neglect" (Standford & Stanford; 1996 in Ytterhus et al., 2015: 15). The main reason for this neglect has been the perceived assumptions about the difficulties of researching children with disabilities (Bailey et al. 2014). Researchers also tend to hear from adults based on the general tendency that adults know about children because they were once a child, what Mouritsen (2002: 35) calls the "childhood baggage" of adults and because they often see or nurture children (Mouritsen, 2002; Punch, 2002; Qvortrup, 2002). The lives of disabled children have largely been seen

through the eyes of adults as researchers choose to hear from parents, teachers, social workers (Ytterhus et al., 2015). When researchers have involved disabled children in research, they have typically been preoccupied with impairment, vulnerability, services provision and the burden of presumed dependency at the expense of a more nuanced account of children's everyday lives (Ibid:15). The children's perspectives, their everyday experiences and agency have widely been neglected (Klocker et al, 2007). The issue becomes critical in the Global South as most research lack attention to the children's perspectives and lived experiences (Miles, 1996; Kabzems & Chimedza, 2002; Ansell, 2005; Msall et al., 2007; Parnes et al., 2009). It is important that these children's lived experiences are understood (Ansell, 2005). My study therefore sought to explore the perspectives and experiences of children with physical disabilities in Ethiopia based on the fieldwork in one of the rehabilitation centers for physically disabled children.

1.2 Statement of the problem

The voices of children including those with disabilities living in the North have relatively been accounted for in research, policies and programs, firstly because most studies which argue for the inclusion of children's voices were conducted in the North, and secondly policies and conventions promoting children's voices like CRC and CRPD are formulated in the North according to the culture of the children growing up there (Woodhead, 2003). In the Global South, however, little accounts of disabled children's perspectives and lived experiences were documented in research and their needs have been neglected in policies and programs related to them (Miles, 1996; Kabzems & Chimedza, 2002; Ansell, 2005; Msall et al., 2007; Parnes et al., 2009). In the particular context of Ethiopia, most research with disabled children (for example; Moore et al., 2001; Tirussew, 2005; Fitaw & Dorsma, 2005; Lewis, 2009; ACPF, 2011a; ACPF, 2011b; ACPF, 2014) largely focus on documenting the number of children with disabilities, the causes and consequences of disability and the societal perspectives towards disabled children, leaving widely unexplored or saying little about the perspectives and experiences of the children themselves. Not only were these children neglected in research; they also have been conceptualized as weak, unable and vulnerable beings (ACPF, 2014; Tirussew, 2005). The children's accounts of everyday lives, their aspiration, capacity, agency and resilience amidst everyday challenges have been neglected by focusing on the aspects outside the children's lives.

As a result of a reconceptualization of children as active human beings in society inspired by social studies of childhood and children, children have begun to be studied from their own rights irrespective of adult perspectives and concerns (Prout & James, 1990). According to this research paradigm, children including disabled children need to be seen “not just as passive subjects of the social structures and processes,” but as “active in the construction of their lives and the lives of those around them and of the societies in which they live” and children’s social relations and cultures must be studied in their own rights independent of the perspectives and concerns of adults (Ibid: 8). It is therefore important that these children’s lives are understood from the circumstances in which they live (Ansell, 2005). Understanding their situations requires understanding their perspectives and everyday experiences, by which one can explore the actual realities in which these children are living. My study explored the perspectives and experiences of children with physical disabilities in Ethiopia in light of this changed paradigm through a two month fieldwork with these children in one of the rehabilitation institutions in the country.

The main objective of my study was to explore the perspectives and experiences of children with physical disabilities. More specifically, it was aimed to:

- Explore the children’s own perspectives of growing up within disability situation
- Explore the children’s experiences of their everyday lives, the challenges they face in their everyday lives and the ways they negotiate these challenges
- Explore the children’s experiences of institutional life

1.3 Research questions

The main research question that my study sought to answer is: ‘*what are the perspectives and experiences of children with physical disabilities about their disability situation?*’ The specific research questions include;

1. How do children with physical disabilities view growing up with disability?
2. How do children with physical disabilities experience their everyday lives?
3. What challenges do they face and how do they negotiate these challenges?
4. What are the children’s experiences of institutional life?

Based on these research questions, a two month intensive fieldwork was undertaken in one of the rehabilitation centers for physically disabled children. Participant observation, semi-structured interviews and neighborhood walk were made with ten physically disabled children in the institution whose ages range from 12 to 15. Semi-structured interview and focus group discussion were also made with four parents and four social workers in the institution respectively. Several task-based methods (Punch, 2002) like storytelling, sharing childhood memories and sport activities were also employed with the children to build a rapport with them during the fieldwork.

1.4 Significance of the study

My study may have academic and practical significance. Firstly, it may contribute to the theoretical and methodological knowledge in research with disabled children in the context of the Global South. The children's perspectives and experiences documented in my study may give insights for future research in similar areas especially in the context of Ethiopia in particular and Africa at large. The fieldwork experiences, the methods, the socio-ethical dilemmas in the fieldwork and the ways I negotiated them might be a lesson for researchers who are interested in this area.

Secondly, I hope my study may also have a policy implication in the field of children with disabilities in Ethiopia. The children's accounts of everyday life in community, their experiences of institutional life and perspectives of the intervention programs in the center may provide insights for the government and non-government organization (NGO) working with disabled children in the country.

1.5 Organization of the thesis

This thesis is organized into eight chapters. The first chapter introduces the study; presents the objectives and research questions that my study sought to address. The second chapter provides an overview of my study context, in which data pertinent to the fieldwork area are presented and discussed. The third chapter provides the theoretical perspectives and conceptual frameworks that informed my study. Chapter four presents the methodology employed in my study and discusses my fieldwork experiences. Chapter five, six and seven presents the major findings of my study, analyzes and interprets the field data. The last chapter discusses the major findings of my study, provides concluding remarks and recommendations based on the findings.

CHAPTER TWO

2 THE STUDY CONTEXT

My study was conducted in one of the rehabilitation centers/institutions for children with physical disabilities in Ethiopia. I hereafter use the terms ‘center and institution interchangeably to refer to the residential home care. Physical disability in my study refers to all kinds of disabilities which limit children’s mobility and function that includes the impairment of one or more limbs, legs or arms according to the definition of WHO (2001). Children with physical disabilities therefore include those children who experience one of these disabilities. In this chapter, I will highlight the contexts in which my study was conducted so as to make a clear direction towards which my study travels. Included in the chapter are an overview of the fieldwork site and the specific social, economic and cultural situations in which children with disabilities in Ethiopia are living, and policies and laws related to children with disabilities in the country.

2.1 The fieldwork institution

The institution, where I conducted my fieldwork, is located in Oromia regional State (shown in the map below), one of the semi-autonomous regional states in Ethiopia. Ethiopia is administratively sub-divided into nine semi-autonomous *kililoch* (regional states) and two chartered cities (Addis Ababa and Dire Dawa), divided along ethno-linguistic lines (see the map below).

There are a number of institutions working on children with different kinds of disabilities in Ethiopia. The institution where I conducted my fieldwork has been working to enhance the social functioning of children with physical disabilities through a provision of comprehensive rehabilitation services (see also chapter seven). The center was established with a vision of preventing avoidable disability and changing the attitudes of society by promoting equal opportunities for people with disabilities in the country through the provision of rehabilitation services. There had never been such institutional care for children with disabilities in the country before 1960s. Since early 1990s, the institution has enabled more than 35,000 children with different kinds of mobility difficulties to walk and live independent life. The center has professional workers like physiotherapists, nurses, especial need teachers, orthopedic technicians and social workers. It provides rehabilitation services for up to 70 residential children at a time and also provides outreach services for children with physical

disabilities in the local community. The center works in a network with medical institutions to provide medical services for children with disabilities.

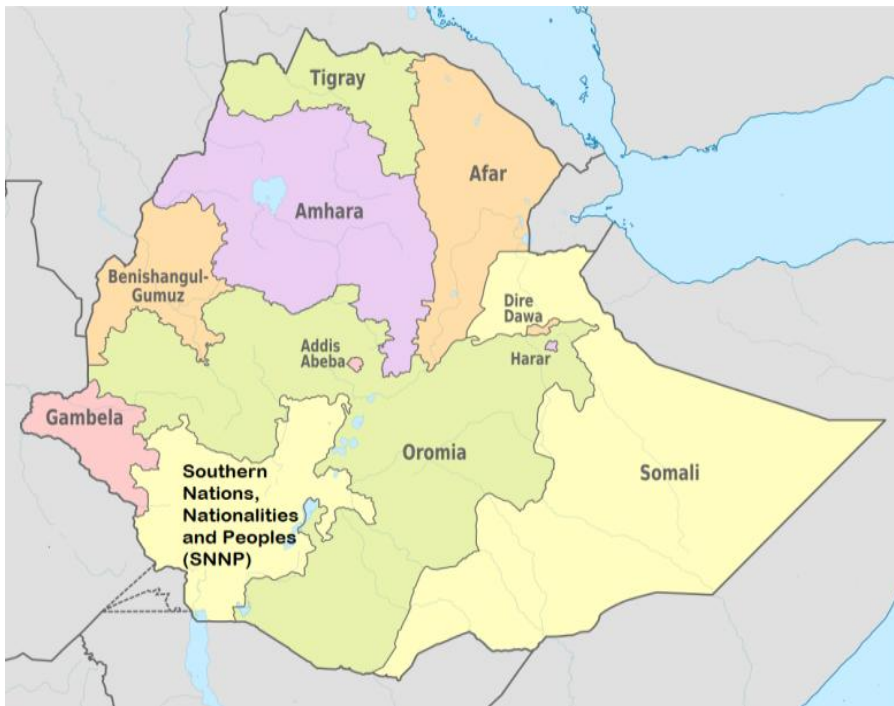


Figure 2.1: the administrative map of Ethiopia

Retrieved from: <http://www.ethiovisit.com/ethiopia/ethiopia.html>

In addition, there are a number of related institutions and organizations working with disabled people in the country. Most of these organizations are domestically developed by the joint efforts of disabled persons, civil societies, governmental and non-governmental organizations. Organizations formed by people with disabilities in Ethiopia include the Federation of Ethiopian National Associations of People with Disabilities (FENAPD) and the Ethiopian National Association of the Blind, the Deaf, Blind-Deaf, Persons Affected by Leprosy and Intellectual Disability (ILO, 2013). There are also other associations working for the equality of the persons with disabilities such as the Ethiopian National Disability Action Network (ENDAN), the Ethiopian Centre for Disability and Development (ECDD) and the Ethiopian Women with Disabilities National Association. These organizations, mainly work in the area of rehabilitation, health, rights, social affairs, and public awareness about disabled people.

However, the services provided by these organizations are affected by a problem of urban bias, the most commonly observed problems in a provision of development services and

facilities in Ethiopia. That is, most of these organizations are concentrated in the urban areas of the country where infrastructure is relatively better. A vast majority of people with disabilities, however, live in the rural areas where access to basic services is limited (ILO, 2013).

2.2 An overview of childhood disabilities in Ethiopia

In Ethiopia, children below the age of 18 constitute more than half of the population. The country's population pyramid is characterized by a broad base and narrow top showing that a significant proportion of the population is children below the age of 18. In a 2007 housing and population census, a population of the country was counted to be more than 73 million out of which 42 million (about 57%) were children (CSA, 2008).

The majority of children in Ethiopia live in an extreme poverty that may lead to disability. Children in the country are obliged to live in poor socioeconomic situations characterized by high level of illiteracy, inadequate health care, high prevalence of HIV and AIDS and harmful traditional and cultural practices (Committee on the Rights of the Child, 2005). According to a 2005 report by the Committee on the Rights of the Child, a large number of populations engages in the livelihood strategies that abuse and exploit the children. The presence of diversified pre- and post-natal factors like the health of prospective mothers, home delivery, childhood infectious diseases, malnutrition, civil strife and periodic episodes of drought and famine have also brought a phenomenal increase in childhood disability (Tirussew, 2005; Fitaw & Boersma, 2005). Diseases like polio and leprosy, and accidents (vehicle and others) were also mentioned as the causes of disability by the 2007 census.

Studies show that data pertaining to a figure and situation of children with disability in Ethiopia are fragmentary and sometimes misleading (for example: Tirussew, 2005; ACPF, 2011a; ACPF, 2011b; ACPF, 2014). Ethiopia lacks statistics relating to disability in general and most of the numbers are just estimates (Lewis, 2009). It is only during the third, the 2007 housing and population census, that a complete enumeration of the household was made in Ethiopia in which disability and orphanage were included. The census estimated the overall prevalence of disability in the country to be 1.09%. The estimates made by the census were however far lower than those estimated by other organizations. For example, the 2011 World Report on disability jointly issued by the World Bank and World Health Organization indicated that children, adults and elderly persons with disabilities in Ethiopia represent 17.6

percent of the population (ILO, 2013). If WHO estimate is used, which puts the disabled population at 10 percent of the total population of the country, the number of people with disabilities would be more than 7 million out of which the majority is children (ACPF, 2011b). Social stigmas and ignorance also prevent disabled children and their families from self-identifying (Tirussew, 2005; ACPF, 2011a; ACPF, 2014).

2.3 Disability and society in Ethiopia

There is a widespread negative societal attitude towards persons with disabilities in Ethiopia despite recent improvements in public awareness. Disability is attributed to traditional or religious factors and people wrongly perceive disability as originating from curse, a consequence of past misdemeanors or evil deeds by parents, ancestors or by the disabled persons themselves, and other supernatural forces (Tirussew, 2005; ACPF, 2014). Children with disabilities are marginalized because of these cultural beliefs and practices, and their voices are rarely heard in families and schools (ACPF, 2011a, ACPF, 2014). In some cases a birth of the child with disability has become a source of shame, disagreement as well as divorce among families (Rhamet, Metasibia & Selamawit, 2000 in Tirussew, 2005: 6). Most families with disabled children experience stigmatization and social exclusion in the community in which they live and hide children with disabilities at home arising from fear of stigma (Tirussew, 2005; ACPF, 2011a). There is also a general tendency to think children with disabilities as weak, dependent and unable to learn and work, and generally burdens of care and subject of charity (Tirussew, 2005). Children with disabilities experience emotional and social deprivation. They face neglect and rejection within their family, and are put at a social distance within their peers and neighborhoods. Most of them also do not attend schools.

These misconceptions of causes of disability added to the misunderstanding of the capabilities of persons with disabilities have affected their participation in the family, neighborhood, and the community at large. It has also created a limited provision of public services like education, health, transportation, information and legal protections for the disabled persons and restricted the involvement of disabled persons in different socio-cultural and recreational activities, and employment opportunities (Tirussew, 2005; ACPF, 2014). These socio-cultural constructions about disability and disabled children and the impact they had on the children's lives have largely been discussed in the analyses chapters.

Most care for children with disabilities in Ethiopia is provided at a family level as most children do not have access to rehabilitation services (Tirussew, 2005; ACPF, 2011a; ACPF, 2014). Family functions as an important social unit in the country, where a social welfare is non-existent. Family based care is the most prevalent early child care in the country and most of the disabled children are cared at the family level (Tirussew, 2005). However, most families, lack the support and resources to support their children.

2.4 Policies and laws related to people/children with disabilities in Ethiopia

Disability is mandated to a department of rehabilitation affairs, under the ministry of labor and social affairs (MoLSA) in the country. Although the rights of persons with disabilities are not given independent focus in the constitution, they are upheld within the rights of different groups in article 41 (5), which reads “the State shall, within available means, allocate resources to provide rehabilitation and assistance to the physically and mentally disabled, the aged, and to children who are left without parents or guardian.” The constitution also upholds the best interest of the child in article 36 (2) of the constitution which states “in all matters concerning children undertaken by public or private welfare institutions, courts of law, administrative authorities or legislative bodies, the primary consideration shall be the best interest of the child.”

The constitution guarantees all international agreements ratified by the country, including those related to persons with disabilities to be an integral part of the law of the land (Art. 9(4)). These include international conventions on the rights of the children in general and children with disabilities in particular like UNCRC ratified in 1991, the Convention on the Rights of Persons with Disabilities (CRPD) ratified in 2010 and others like the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993, the Salamanca Statement and Framework for Action on Special Needs Education, 1994, ILO Convention concerning Discrimination in Respect of Employment and Occupation, 1958, (No. 111) ratified in 1966 and ILO Convention concerning Vocational Rehabilitation and Employment (Disabled Persons), 1983, (No. 159) ratified in 1999 and their subsequent optional protocols (ILO, 2013; Lewis, 2009).

Ethiopia has also formulated a number of laws, policies and standards pertaining to people with disabilities. Some of these policies and laws include the following (ILO, 2013, ACPF, 2011);

- Proclamation concerning the rights to employment for people with disabilities (no 568/2008), which focuses on ensuring equal employment opportunities to disabled people.
- The federal civil servant proclamation (no 515/2005) which focuses on the need to provide special attention to candidates and employees with disabilities.
- Building Proclamation, No. 624/2009, this focuses on the accessibility in the design and construction of any building for physically disabled persons.
- Framework Document 2009, which provides for Special Needs Education (SNE) in Technical and Vocational Education and Training (TVET).
- Growth and Transformation Plan (GTP) 2010-2015, which establishes disability as a cross cutting sector of development where focus is given to preventing disability and to providing education and training, rehabilitation and equal access and opportunities to persons with disabilities.
- National Plan of Action of Persons with Disabilities (2012-2021) aims at making Ethiopia an inclusive society.

However, although the country has formulated a bunch of domestic policies and adopted important international conventions like CRC and CRPD and other disability acts, it has failed to endorse and implement them effectively. Poverty and corruption has been the source of the inadequate implementation of policies and programs designed for disabled people/children in the country (ACPF, 2014).

2.5 Education and disabled children in Ethiopia

In Ethiopia, most of the children with disabilities are found outside schools (ACPF, 2011b; ACPF, 2014). According to Ethiopia's third education sector development program (ESDP iii), the country has about 1.7 to 3.4 million children with disabilities who have special needs (MoE, 2005), out of which only one percent has access to education (ACPF, 2011b). Those who attend school also suffer a high risk of dropping out (Tirussew, 2005). Inadequate policy frameworks and funding, lack of access to physical environment and information, school distance, limited special schools and lack of trained teachers and negative societal attitudes have created barriers to disabled children's schooling (AFCP, 2011b; ACPF, 2014).

Although Ethiopia has adopted international proclamations advocating for the rights of children with disabilities to education and endorsed the National Framework for special needs

education (SNE) in 1994, children with disabilities are mostly excluded from education (Lewis, 2009). Discrimination and stigmatization is common in inclusive schools. The special need education plan in Ethiopia has not been effectively practiced because of different factors. Teachers lack special skill. Schools are mostly confined to urban areas and technical and vocational training programs have predetermined rules imposing restrictions on candidates with special educational needs (Ibid). However, in the rehabilitation center where I conducted my fieldwork, the children were given education and vocational training during their stay in the center.

CHAPTER THREE

3 THEORETICAL PERSPECTIVES AND CONCEPTS

For a long period of time childhood has been studied from the perspectives of developmental psychology which sees children as unfinished human ‘becomings’ focusing on child development and socialization (Prout & James, 1990; Woodhead, 2003). In developmental psychology, children have been seen as incompetent and irrational beings that cannot decide and act on their own rights, and simply awaiting temporal passage to the full stage of human beings – adulthood (Prout & James, 1990). The biological facts of life were constantly used to explain the social facts of childhood with little account taken of cultural components. Children’s present childhood; their role in determination and construction of their social lives and their participation in family and society has been overlooked (Ibid).

However, over the past three or four decades there have been changes in the study of childhood inspired by the social studies of childhood and children, also called the sociology of childhood, which shifted the conception of childhood from human ‘becoming’ to a new understanding of children as independent human beings and actors, and childhood as socially constructed (Prout & James, 1990, James et al, 1998). The social studies of childhood and children is based on six (but not limited to) central tenets (Prout & James, 1990: 8-9). First, childhood should be understood as socially constructed. Childhood is neither a natural nor universal feature of human beings; rather it appears as a specific structural and cultural component of many societies. Second, childhood should be understood as a variable of social analysis. Childhood is understood in relation to other factors like class, ethnicity, gender, disability, poverty, etc and as such there is a variety of childhoods worldwide. Third, children’s social relations and cultures must be studied in their own rights independent of the perspectives and concerns of adults. Rather than hearing from adults, researchers should study children’s own perspectives and lived experiences to understand various circumstances in which children live. Fourth, children are and must be seen as active in the construction and determination of their own lives, the lives of those of around them and of the society in which they live. They are not just passive subjects of social structure and processes. Fifth, ethnography is an appropriate method for the study of childhood as it allows children’s direct participation in the process of research than survey and experimental methods that have been practiced in developmental approach. As childhood is a socially constructed phenomenon, it is best understood through engaging in children’s everyday life. Finally, the social studies of

childhood engage in the process reconstructing childhood in society. This research tradition reconstructs the children's social status by presenting them as full human beings and actors in society (Prout & James, 1990). However, although the social studies of childhood set out these epistemological and methodological features to study childhood, it is essentially a hermeneutic paradigm that engages with these features and also invites new explorations (Prout & James, 1990; James et al., 1998).

These changes in the study of childhood have been coincided with a paradigm shift in disability studies from medical perspective to the social and cultural understanding of disability (Shakespeare & Watson, 1998; Ytterhus et al, 2015). The social model of disability which sees disability as discrimination faced by people with different forms of impairment has been taken as point of departure among disability scholars (Oliver, 2009).

My study is primarily informed by the social studies of children and childhood. I used the 'minority group child' approach (James et al, 1998) and the notions of children's agency and resilience to back up my study with relevant theoretical perspectives and concepts. My study also brought into usage the 'social model of disability' from disability studies to interpret how disabled children are understood in society. Perspectives in disability intervention have also been considered as my study also sought to examine the children's perspectives of intervention programs available to them in the institution where I conducted my fieldwork. I will first introduce childhood and children, disability and the 'disabled childhood' before proceeding to these perspectives.

3.1 Childhood and children

Childhood has been understood differently among different societies and at different times. Aries (1983) claimed that the idea of childhood did not exist in the medieval Europe. According to Aries (1983), childhood as a distinct human condition gained recognition during the seventeenth century and culminated in what he called sentimentalization of the childhood and child-centered family in the nineteenth and twentieth century. As noted at the outset of this chapter, the study of childhood and children has been dominated by the developmental approach provided by psychology (Prout & James, 1990). A key feature about children in developmental psychology is the development of the child. According to Piaget, a well-known developmental psychologist, childhood is seen as a natural stage of development where children gain a state of rationality through successive growth towards adulthood (Woodhead, 2003). In sociology as well, things were also not better. The socialization

theories have been presenting children as asocial, incompetent human beings and passive representatives of the future generations who through the process of socialization turn into competent social beings (Prout & James, 1990). Children should be socialized and integrated into the social system of society through formal education and parental teachings. Childhood has therefore been a “feature of parental discourse” and the “currency of educators” (James et al., 1998: 3).

The developmental approach has been dominating the understanding of childhood in the North and informed many child related policies and practices (Prout & James, 1990). The concept of childhood has widely been defined in terms of development, both in academia and policy instruments. For example, the UNCRC defines childhood as anyone below the age of eighteen (Art. 1). Furthermore, in the North, childhood has been constructed as a period of care, play and school, and these images of childhood have been exported to the Global South through the process of globalization, especially through schooling system and international conventions like UNCRC (Woodhead, 2003; Punch, 2003). Most childhood research has been based on the lives, experiences and expectations of children growing up in the North according to the theories and methodologies adopted by the researchers living within those societies, but they have been widely applied to the lives of the children living in very different circumstances (Woodhead, 2003). However, the socioeconomic realities in which children in the Global South grow up significantly vary from children growing up in the North. UNCRC has also been criticized to have been formulated on the basis of these understandings of childhood peculiar to the North (childhood as period of development through schooling, protection and leisure) which has been said to have created the difficulty of applying the principles of the convention to the cross-cultural differences (Burr & Montgomery, 2003). It is in this light that the African Union adopted an alternative convention for African nations, the African Charter on the Rights and Welfare of the Child (ACRWC) which stresses not only child rights and parental responsibilities, but also the duties and responsibilities that children have towards parents (Art. 31).

In Ethiopian context for example, like in many African countries, children grow up working and performing various responsibilities in family rather than just play and schooling (Abebe & Kjörholt, 2013). Childhood in Ethiopia is understood by what Abebe and Kjörholt (2013) call a “generational age,” “a set of relationship –junior or senior than- in which authority, right and obligation achieved rather than naturally attained” (p. 17). Age is socially defined rather than chronologically counted (Clark-Kazak, 2009) and as such children are assumed

with different roles, responsibilities and duties within their household at different ages. Children are the sources of labor and active actors in most livelihood activities of the households in Ethiopian society (Abate & Abebe, 2013). It therefore creates a difficulty to generally define childhood as a period under the age of eighteen and as a period when the child enjoys schooling and protection from work. It has to be clear that school is a major feature of children growing up in the North while work is still a normal part of childhood for most children in the Global South (Woodhead, 2003).

In recent times, there is an increasing awareness within the social studies of children and childhood that the meanings attached to the childhood might differ across time and space, which began to destabilize the traditional models of child development (Prout & James, 1990). Many accounts of the world's children living in significantly varied social, cultural, economic and political circumstances have drawn attention to the new way of looking into childhood - childhood as a "social construct" (Montgomery, 2003). As Jenks (1982) argues "the idea of childhood is a social construct constituted in particular socially located forms of discourse" (p. 23). Some scholars like Qvortrup (2002) also view childhood as a structural form; as a constitutive and distinct form of any society's social structure. It has therefore become a point of departure in the social studies of children and childhood that childhood is socially constructed and that many childhoods exist across the globe. Children should therefore be studied within the contexts in which they live with the emphasis given to their lives.

3.2 Disability

WHO (2011) argues that disability is part of human life that almost everyone will temporarily or permanently be impaired at some point in a life but indicated that children and old age, mainly in the Global South, are more likely to experience it. While there is a general agreement that definitions of disability should incorporate both medical and social aspects, disability has been predominantly understood in a medical perspective, with a focus on specific physical or mental impairments (UNICEF, 2013). However, disability is a "multidimensional concept" and different factors ranging from the person's physiological characteristics to the social ones interplay in its construction (WHO, 2011). As Shakespeare & Watson (2010) argue,

"Disability is the quintessential post-modern concept, so complex, so variable, so contingent, and so situated. It sits at the intersection between biology and society, and

agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality” (p. 19).

According to Shakespeare and Watson’s view, disability is a multifaceted phenomenon that cannot be reduced to the individual health (biological) issue. It is rather an interaction between the individual and the society in which aspects of societal structure and individual agency interplay.

Over the past decades, researchers from social and health sciences have identified the role of social and physical factors in the construction of disability (WHO, 2011). A shift has been made from a medical model to a social model in which people are viewed as being disabled by society rather than by their bodies (Oliver, 1990). Most studies and policy frameworks tended to focus on the social barriers and show the institutional and social discrimination of people with impairments. One of the frameworks for definition of disability is the International classification of Functioning, Disability and Health (ICF), developed by the WHO (2001), which defines disability as “an outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers that he/she faces” (3: 19). That is, disability is about people and their social relationships and, as such, it is about the lives of people with disabilities and their interaction with community and environment (Parnes et al., 2009). The Convention on the Rights of Persons with Disabilities (CRPD) also stresses attitudinal and environmental barriers that hinder full and effective participation of persons with disabilities in society. The convention defines disability as;

“The long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder the person’s full and effective participation in society on an equal basis with others” (Art.1).

As elaborated in the CRPD, disability is discrimination on the basis of a person’s impairment. Disability is sometimes equated with impairment. However, the two are distinctive. Individuals are impaired if they experience or are perceived by others to experience physiological or behavioral statuses which are socially identified as problems, illnesses, disorder, while disability exists when people experience discrimination on the basis of perceived functional limitations (Kasnitz & Shuttleworth, 2001 in Reid-Cunningham, 2009: 101). According to the CRPD “discrimination on the basis of disability” is any exclusion or restriction on the basis of impairment which restricts/deprives the person’s full participation in society and exercise of his/her human rights and fundamental freedoms in the social,

economic, political, cultural, civil and any other fields (Art. 2). It includes all forms of discrimination, including denial of reasonable accommodation. The convention holds the States Parties responsible to take all the necessary measures to ensure the rights of persons with disabilities including children protected and promoted (Art. 4).

3.3 The ‘disabled childhood’

While most Global South countries have adopted CRPD and other international instruments and many domestic laws to promote the wellbeing of children with disabilities, disabled children in these countries face plenty of discrimination and barriers in a society in which they live (Parnes et al., 2009). Although attitudes towards persons with disability vary historically and culturally, most disabled children in the Global South experience negative societal reaction (Ansell, 2005). Shakespeare and Watson (1998) argue that a major problem for children with disabilities is that they live in a society which views childhood disability as a problem. Shakespeare and Watson argue that the origin of the problem lies in the fact that we human beings believe in normalcy and our approach to childhood impairments is also entrenched in the principle of normalcy.

We may no longer follow the traditional route of abandoning or killing the disabled children (in most cases), but we are keen to invest immense amounts of money in developing techniques to prevent them from being born. If by any chance an impaired child slips through this screen, an array of techniques is available to intervene surgically and attempt elimination of the physical abnormality (p. 20).

This is in the context of the North. However, in the Global South the birth of an impaired child is mostly unavoidable through mechanisms such as selective abortion or surgery, but children with impairments simply become the recipients of different cultural beliefs that attach many prejudice and stereotypes to their circumstances. Disabled children end up in social stigma, segregation and discrimination in their everyday lives and deprived of their human and democratic rights and effective participation in society. In much of African countries, disabled children have been seen as unnaturally conceived, neither fully human nor part of community. Disabled children are characterized as a ‘needy population’ and subjects of charity through the medical and charitable models of disability employed by the governments, NGOs and donors (Ansell, 2005). Disabled children are denied access to the same early, primary and secondary education or life-skills and vocational training that are available to other children. They either have no voice or their views are discounted and are

more vulnerable to abuse and violence (Parnes et al., 2009: 1176). They are considered unable to perform tasks in a socially acceptable way and burden to their families and communities (Kabzems & Chimedza, 2002). However, these children are not given enough chances to freely do things, to participate in society and to learn and work and live independent life. They are just disabled. This is what Shakespeare and Watson (1998) calls “disabled childhood” (p. 19). They argue that “...the potential problems of disabled childhood are not caused by their impairment, but are the outcomes of social relationships, cultural representations and the behavior of adults” (p. 22). As Ansell (2005) argue, it is important that these children are given unbiased consideration both in society and policies related to them.

3.4 The ‘minority group child’ approach

Although there are several theoretical perspective and approaches in the sociology of childhood/social studies of childhood and children, my study employed the ‘minority group child’ approach, an approach which sees childhood and children as affected by an “unequal and structurally discriminatory society” (James et al., 1998). In the social studies of children and childhood, James et al (1998) provided a series of four approaches to sociologically study childhood; namely, the social structural child approach, the socially constructed child approach, the minority group child approach and the tribal child approach. Before proceeding to the ‘minority group child’ approach, it is important to overview the rest of these approaches.

The social structural child approaches views childhood as recognizable components of all social structure across space and time; vary from society to society but uniform within particular society. They are not only a component of social structure but also are social actors and as citizens, they have needs and rights. The socially constructed child approach sees childhood as a discursive phenomenon constructed according to specific social, cultural, political, historical and moral contexts of a particular society and, therefore, there are many childhoods. The tribal child approach sets out from the commitment to making the children’s social world as a real place and province of meaning in the children’s own right and not as precursors of adult state of being (see for detail James et al. 1998: pp. 26-34; 195-218).

The ‘minority group child’ approach is the politicized version of the social structural child approach. It views children as having a marginalized position in a structurally discriminatory

society (James et al, 1998). The study of children as ‘minority group’ arises from the parallelism between the politics of women studies and childhood studies.

.... Women and children are of course, linked socially, but the development of these specialist academic studies also poses methodological and political questions about the relationship between the status of women and children as social minority groups and their constitution as objects of academic gaze (Oakley, 1994 in James et al., 1998: 30).

Children are viewed as a minority group status in a similar way women have been seen. Historically, the study of childhood has been coincided with the study of women characterizing both as marginalized group in society. Charlotte Hardman (1973) in her work on anthropology of children characterized both women and children as the “muted group,” to explain that they are marginalized in the study of a society (p. 85). Prout and James (1990) argue that the term “muted” is indeed appropriate to describe the fact that children and women have been neglected in the study of society. This term may also explain the status of children and women currently in the Global South.

The very notion of ‘minority’ here refers to moral rather than demographic or population size, that conveys the relative powerlessness or victimization of the children (James et al., 1998). It would, however, be difficult to generalize that all children occupy a minority group status. As James et al. (1998) argue an approach to study children as a ‘minority group’ begins, not from the intrinsic interest in childhood, but instead from the place of children in the social structure and the paternalistic ideology that deprives children of their power. It is not childhood in itself which is emphasized as having the minority group status, but the social structure which marginalizes the children and as such the degree of marginalization varies from society to society. The approach recognizes that children are structurally differentiated within the societies and, as such, they experience the exercise of power differently. Globally, all children are to different degrees exploited and their rights are under-expressed and inappropriately exercised. However, practically this occurs across a spectrum of degrees of liberation marked by differences in gender, age, ethnicity, ability and disability, for example (James et al., 1998: 211). It means that children are marginalized to a minority group status on the basis of certain characteristics such as ethnicity, gender, race and disability. As Qvortrup (2002) argues ‘minority group’ is defined by its subordinate relationship in terms of some characteristics of a group of people in society.

Any group of people who because of their physical or cultural characteristics are singled out from the society in which they live for differential and unequal treatment, who therefore regarded themselves as objects of collective discrimination. Minority status carries with it the exclusion from participating in the society (Wirth, 1945 in Qvortrup, 2002: 72).

As elaborated in this definition, although childhood would be regarded as a minority group as far as the power relations between children and adults is considered, marginalization exhibits on a basis of certain characteristics of children (physical or cultural). Race, ethnicity, disability, poverty and other socioeconomic characteristics of children would be a ground for discrimination and minority group status. So it means that certain group of children is more marginalized in some societies on the bases of these characteristics. There is also a varied degree of children's liberation from society to society.

Taking this into the situation of children with disability in the Global South may give useful theoretical insights. As I have been discussing in the previous section, studies show that children with disabilities having a minority group status in countries of the Global South (Ansell, 2005; Parnes et al., 2009; ACPF, 2011; ACPF, 2014). Negative societal attitudes marginalize children with disabilities to the minority status and deprive them of their rights and power to exercise their everyday lives. As Qvortrup (2002) argues marginalization is located on the varied degrees of factors. Disability, especially in the Global South, is one key feature by which children are placed to the minority group status and exposed to marginalization.

The weakness of an approach which study childhood as a 'minority group' in society derives from its generalization of any social group as a "group for-itself" instead of just "in-itself," through imposition of politicized uniformity that neglects the differences within. The global universal child becomes a minority group with a demand that have to be heard; but the fact that the group is fractured and faceted is less often remarked (James et al., 1998: 31). The problem is that it compares childhood with adulthood or children with adults as women have been compared with men in terms of power relation. Both children and women have been considered the minority groups and much emphasis are made to redress these inequalities. Children and women are presented as the "group for-itself," who demand justice. The internal diversity within childhood is neglected this way. I would argue that although looking into the power relations between children and adults is one way of scrutinizing childhood, but

childhood would better be studied in its own rights. What then does it mean to study children in their own rights? “It means that focus is directly on the targeted group or category; as far as children or childhood are concerned, that we directly observe these entities,.... that they are at the center – not anyone else related to them or person whom they allegedly depend on” (Qvortrup, 2002: 65-66). It is to give children/childhood a “conceptual autonomy” (Thorne, 1987 in Qvortrup, 2002: 65).

Nevertheless, the ‘minority group child’ approach not only sees children as a minority category in society, but also as conscious and active beings. That is, children are seen as essentially indistinguishable from adults but as active agents. Through ascribing to children the minority group status, this approach seeks to challenge rather than confirm the existing set of power relations between adults and children (James et al., 1998: 30). Most studies in the Global South countries tend to study children from the minority group child approach because most of them focus on child work and conceptualize these children as victims (Punch, 2003). This kind of collective judgments ignore these children’s individuality, personal capacities and their constructive ability (Qvortrup, 2002: 73). Children with disabilities in the Global South are subject to these kinds of constructions in studies and in a society in which they live. As I have discussed earlier in the notion of ‘disabled childhood’ in this chapter, disabled children are presented in many societies of the global south as victim, unable and weak and their capacities and agency are downplayed (Ansell, 2005; Parness et al., 2009). However, they are not provided equal chances with other children (Parness et al., 2009). According to the minority group approach, children are not only constricted by the social structure in which they live, but they also exercise some sort of agency. While this approach seeks to show how childhood is subject to the process of discrimination that is hierarchically distributed through age, gender and disability, it also sees children as conscious and active beings. This approach gives a theoretical perspective that children such as disabled children have their needs and rights and that their aspirations, agency and capacities need to be given appropriate weight through research.

3.5 The social model of disability

Disability has been theorized in two models: the medical model and the social model of disability (Oliver, 2009). The two models have been presented as dichotomous; one evolved in reaction to the other, but for many decades disability has been a province of the medical model (Llewellyn & Hogan, 2000). The general framework of the medical model, also

referred to as the individual tragedy model, emanates from the disease model used in medicine, which predisposes practitioners to think of disability as a condition which needs appropriate 'treatment' (Llewellyn & Hogan, 2000). Having been originated in the North, the medical model has dominated disability policy and service provision for many decades (Oliver, 2009). However, since the 1970s, disability understanding has been shifted to the new model – social model of disability – which claims people are disabled not by their bodies but by society (Shakespeare & Watson, 1998; Oliver, 2009).

The understanding of disability began to shift to the social model in 1970s when one of the earliest disability movements, the Union of Physically Impaired Against Segregation (UPIAS), united against a social exclusion of the physically impaired people in UK came up with a new definition of disability (Oliver, 2009).

In our view, it is the society which disables the physically impaired people. Disability is something imposed on the top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore oppressed group in society. To understand this is necessary to grasp the distinction between the physical impairment and the social institution called disability, of people with such impairment. Thus we define disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairment and excludes from participation in the mainstream social activities (UPIAS, 1976, in Oliver, 2009: 42).

This turned the understanding of disability, shifting the source of the problem from the person's impairment to discrimination in society (Oliver, 2009). The problems that disabled people face are not the result of their impairment but the result of a society that fails to address their needs both in the delivery of services and its social organization (Shakespeare & Watson, 1998). As Oliver (2009) argues "it is the society not people with impairment that should be targeted" to solve the problem of the disabled people.

.... The social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment. The barriers disabled people encounter includes inaccessible education system, working environments, inadequate disability benefits, discriminatory health and social support services,

inaccessible transport, houses, public buildings and amenities, and the devaluing of the disabled people through negative images in the media (Oliver, 2009; p: 12).

As elaborated in the above definition, the social model holds the view that it is the social and physical environment which ‘disables’ the disabled people than their impairment. Unlike the medical model of disablement which focuses on the impairment as the root cause of problem, the social model calls for the removal of barriers faced by disabled people which may be physical, attitudinal, institutional or legal, to the participation of disabled people (Shakespeare & Watson, 1998; Ansell, 2005). These may be inaccessible physical environment, discriminatory employment or welfare policies, segregated education or transport, negative stereotypes or prejudiced attitudes (Shakespeare & Watson, 1998).

Nevertheless, there has been a tension among disability scholars that neither of the two models has adequately addressed the issue of disability and that people with disabilities would have not been understood in a better way (Shakespeare & Watson, 1998; Llewellyn & Hogan, 2000; Holt, 2004; Oliver, 2009; Parnes et al., 2009; WHO, 2011). The medical model sees disability as a purely medical issue, ignoring the social barriers that disabled people face. Despite significant contributions to the rights and well-being of the disabled people, the social model itself has been criticized to have neglected to consider the issue of impairment and physicality (Shakespeare & Watson, 1998; Holt, 2004).

WHO (2011) emphasized that disability should be viewed as neither purely a medical nor purely a social phenomenon and that a balanced approach which gives appropriate weight to the different aspects of disability is needed. Many scholars argue that the two models could work together. Oliver (2009) argues that the endorsement of the social model does not mean that individually based interventions in the lives of the disabled people such as rehabilitation, are always counterproductive. Emphasizing the social model of disability does not reject the necessity for medical and professional services; nor denies the importance for interventions to reduce or alleviate impairments. Provision of technical aids, medical intervention and professional support are all important ways of promoting empowerment and independence and are an integral part of the social model (Parnes et al., 2009).

Understanding disability from the perspectives of the social model as a social phenomenon where different factors are interplaying in its reproduction is important to do justice to lives of disabled children; to study them from their own rights and to appropriately address them in policies and programs. The children’s accounts of everyday lives in my study; the way they

navigate their everyday lives, the challenges they face and the ways they negotiate those challenges demonstrates how the use of this model is appropriate to understand disabled children. The perspectives of the medical model also helped me see the children's accounts of the institutional life and their perspectives of the intervention programs available to them in the center.

I would argue that it is, in fact, desirable to improve the potential of a physically impaired child through medical treatment and provision of assistive devices, for example. However, professionals should work to improve the children's potential to participate in the society not to restore normalcy of the impaired body, which is mostly impossible. Disabled children can lead their everyday life as anyone else if not for the disabling social and physical environment. Children with disabilities, for example, face segregation through negative societal attitudes, handicapped by inaccessible roads, buildings at school and other public spaces. It requires building enabling environment to improve the situation of the disabled children. This on the other hand entails listening to disabled children themselves, accommodating their needs and respecting their rights to live independent life and participate in the society. For example, Shakespeare and Watson (1998) suggest the incorporation of three basic principles of the social model in disabled children's everyday lives, in policies and practices related to them. These include; equality, inclusion and autonomy (p. 16). If, implemented correctly, these principles would improve the wellbeing of disabled children in the Global South. The principle of equality means that disabled people are treated equally with non-disabled people. This includes removal of any kind disadvantages and restriction to disabled people and settling fair and equal treatment of disabled people with non-disabled ones. The principle of inclusion draws attention to the ways in which environments and policies have been developed which exclude disabled people. The structures and systems need to be developed which do not single out the disabled people. Inclusive education not special need education is needed, for example. Inclusion is regarded as being more appropriate than integration. The latter implies that society does not change but the individual is normalized or slotted in; while inclusion implies the system is designed to accommodate for all. The third key principle- autonomy- suggests that disabled people are experts on their lives. The influence of other people (professionals and family) in their lives has been obstacles to self-development and liberation of disabled people. People with disabilities should be heard in all matters concerning them (Ibid). That is because disability is the issue which impinges not

only on health and social welfare, but it also needs to be understood in relation to politics, economy, development and human rights (Ansell, 2005).

3.6 Perspectives in disability interventions

Disability interventions have generally been practiced along three different programs. These are the institution-based rehabilitation, the community-based rehabilitation and family-centered care (Imrie, 1997). The most known model of intervention for the disabled children has been the institutional based rehabilitation, which is based on the perspectives in the medical model. Institutional based disability interventions were first originated in the North (Miles, 1996). People with impairment have been perceived as requiring long-term institutional care and intensive rehabilitation services are provided in a centralized institution by professionally trained rehabilitation teams (Mitchell, 1999).

With the changed understanding of disability from the medical model to the social model since 1970s, disability intervention models also began to change in the North towards working on the inclusion of the disabled people (Miles, 1996). There also has been a failure to meet the needs of the majority of disabled people through institution based services in the Global South. As a result, greater attention is paid to the community support networks and indigenous practices (Miles, 1996). These resulted in the WHO developing an innovative approach to the delivery of rehabilitation services called community based rehabilitation (CBR) in 1980s (Miles, 1996; Mitchel, 1999).

Community based rehabilitation, developed as an alternative to the institution based rehabilitation, is a strategy for providing rehabilitation services in the community in a more equitable, sustainable and appropriate way than can be provided in the institution (Miles, 1996). It was believed that community based rehabilitation would facilitate knowledge transfer in the field of rehabilitation to disabled people, their families and community. There was also an expectation that the local community would be actively involved in planning, decision-making, and the evaluation (Ibid). As Mitchell (1999) said one might call community based rehabilitation a “democratization of rehabilitation” (p. 459).

Family-centered service is a philosophy of health care service provision based on the idea of family empowerment (Wuart & Darrah, 2002). It is assumed that parents know their children best and that family can function well with adequate social support and resources. Family is recognized as constant in their child’s life and service providers collaborate with families to

identify the needs and abilities of the child, provide information to families about options available to them and work in partnership with families to implement intervention strategies. The intervention is defined by the unique needs of each family not by the framework of existing programs (Ibid).

Although the social model of disability has been adopted by the Global South countries as part of improving the situation of disabled people, most interventions for disabled children are trapped by the dominance of the medical model (Ansell, 2005). Institution based rehabilitation, which once has been a dominant intervention model in the North, has been adopted and is serving as a dominant model of intervention in most countries of the Global South (Whyte & Ingstad, 1995). However, this model of intervention has been criticized to have failed to adequately address the problem of disabled children in the context of the Global South. Institution based rehabilitation in the Global South is expensive, often inappropriate and unlikely to be of benefit to the majority of disabled children. Most of the institutions are located at the urban centers, beyond the reach of the majority and unaffordable for impoverished families (Miles, 1996). Institutionalization has also resulted in the isolation of disabled children from the mainstream of community life which further reproduces stigmatization and leaves the societal perceptions mostly unresolved (Ibid).

Although community based programs have recently been working on the children's access to education and employment, most intervention programs prioritize the process of rehabilitation (Ansell, 2005). Institution based rehabilitation are also supported by the donor agencies who like to be seen as giving to the 'less fortunate' (Kabzems & Chimedza, 2002). These ways, disabled children have been constructed as the needy and subject of charity; and disability has been shifted from the mainstream government agenda to a personal tragedy to be addressed by voluntary organizations and charities (Ansell, 2005).

Even in the presence of good intervention programs, there are many constraints to effectively implement them. In African context for example, poverty, institutional barriers, corruption and little or no accounts for the children's needs are some of the bottlenecks (Miles, 1996; Kabzems and Chimedza, 2002, ACPF, 2014). The institutional loopholes persist in phrases such as 'funds permitting' (Kabzems and Chimedza, 2002). Different stakeholders have different interests. Disability professionals have institutional power and can mobilize resources; government is reluctant and bureaucratic; disabled people's organizations (DPOs) often seek to promote the social model rather than the medical model; families and children

are mostly neglected. Families are criticized to have neglecting, overprotecting and discriminating children. All the processes are generally dominated by adults who show little interest in children's issues (Miles, 1996; Kabzems and Chimedza, 2002).

3.7 Linking the social studies of childhood and the social model of disability

By attempting to combine the perspectives in the social studies of childhood and social model of disability on childhood and disability, one can see similarities among these paradigms on how they need to study disabled children. On the other hand, one can also figure out that the developmental approach and the medical model of disability also share commonalities in this regard. As previously noted children have been viewed as passive, incompetent and therefore need to be controlled and socialized by adults (parents, pediatricians) in the traditional approaches of developmental psychology. Evidences of what is 'normal' or 'typical' became standard to judge which children were physically and intellectually 'subnormal' or 'retarded' (Woodhead, 2003). On the other hand the medical model of disability also presents disabled children as having physical, mental or intellectual problems and therefore need treatment by adults through medical treatment or rehabilitation to be active to lead their lives (Shakespeare & Watson, 1998). These classical theories of child development established frameworks of what it means to be a 'normal child' marking the boundaries of deviating from developmental norms creating a view of disabled children as having 'abnormal development.' These discourses of 'normal child development' and 'normal life course' have had a significant impact on the lives of disabled children and help to understand why they continue to be identified as social problem in many contexts (Ytterhus et al., 2015: 16-17).

The redefinition of childhood in the social studies of children and rethinking of disability as a socially created discrimination in disability studies have challenged these traditional approaches of individualized and biological understanding of childhood and disability (Ytterhus et al, 2015). One thing that unifies these new approaches is a rejection of ways that solely focus on what is lacking with the individual. In childhood it is lack of rationality and in disabled people it is lack of normal body or mind (Ibid, p. 20).

The social studies of childhood and children redefined children from passive human "becomings" to active human "beings" who have needs and rights.

Children should no longer be seen as passive objects owned and controlled by their parents but as social actors contributing in various ways to their families and communities. This view was extended to disabled children and, instead of viewing them primarily as object of medical or psychological interventions, they were looked up on as active agents negotiating their everyday interactions with peers, adults, services and communities. These perspectives encourage professionals to take the children's own perspectives and experiences more seriously than has been done previously (Ytterhus et al., 2015: 17-18).

This approach sees childhood as socially constructed and as such there are many childhoods based on different factors such as age, gender, race, ethnicity, (dis)ability and poverty, for example (Prout & James, 1990). Disabled childhood therefore is one of many childhoods that exist in the structure of every society despite the different incidence of impairment and degree of disablement.

It is also emphasized in the social model of disability, similarly as in social studies of childhood, that disability is a socially constructed problem faced by children and adults with impairments rather than the inherent problem of their bodies or mind (Shakespeare & Watson, 1998; Ytterhus et al., 2015). Emphasis is on the social processes and cultural meanings that greatly influence the disabled children's and adults' lives and opportunities. By moving the focus of attention from individual impairment to the environment and social arrangements, new dimensions in disabled people's lives become visible (Ytterhus et al., 2015). Although the link between childhood studies and disability studies have not been concretely developed, scholars studying disabled children from the social studies of children endorses and uses the social model of disability to understand the situation of disabled children (Ibid). By combining the perspectives of the social studies of children and social model of disability on childhood and disability, we can understand more about disabled childhood (Shakespeare and Watson, 1998). These paradigms see disabled children as actors/agents and experts in their lives and recognize disabled children's agency in the production and reproduction of their lives. They advocate for the study of the disabled children in their own rights irrespective of the adults perspectives.

3.8 Children's agency

The idea of agency arises from the dichotomy of agency and structure that exists in sociological understanding of what constitutes society (James et al., 1998). From the structural point of view, the individual is relatively passive in society and the social structure is an objective and external condition which determines the conduct of societal members as they enter into different forms of social relationships. On the contrary, the second dichotomy, the agency account, views society and its social structure as manufactured through the actions of individuals in concert; these individuals are the creative agents of their own subjectively meaningful courses of action and develop their social relationships through their agency (p. 201). Although these dichotomies continued to be a relatively antagonistic tension within the social theory, in reality, the real social relationships exist at the hinterland between these extremes (James et al., 1998). "The social action continuously and reflexively creates and is produced by both agency and structure at one and the same time" (Giddens, 1984 in James et al., 1998: 202).

For a long time, the study of childhood has been subject to discussion through the dichotomy of agency and structure. The questions about the children's competencies, rights, responsibilities and needs have been located in these poles (James et al., 1998). In traditional theorization of childhood, as noted before, children have presented as passive beings that are shaped by the structure of the adult society (Ibid).

In the social studies of children and childhood/the sociology of childhood, the notion of 'children as agents' is taken as a point of departure in studying childhood and children (Prout & James, 1990; James et al., 1998; Mayall, 2002; James, 2009; Corsaro; 2005). The key feature from which this paradigm emanated was the idea that:

Children are and must be seen as active in the construction of their lives and the lives of those around them and of the societies in which they live; they are not just passive subjects of the social structures and processes; their social relationships and cultures are worthy of study in their rights, independent of perspectives and concerns of adults (Prout & James, 1990: 8).

This idea which constitutes the social studies of childhood holds in it the idea that children are not passive beings; they are 'actors' and 'agents' in society. So what does agency and children as agents mean?

Agency is understood as individuals' own capacities, competencies and activities through which they navigate the contexts and positions of their life world fulfilling many economic, social, political and cultural expectations while simultaneously charting individual/collective choices and possibilities for their daily and future lives (Klocker et al. 2007: 153).

Agency is therefore individual's own competencies to define and decide on his/her lives – individual being an actor of his life while also being shaped by the social structure in which he/she lives (James et al., 1998). Conceptualizing children as 'agents' means viewing them as "competent social beings," "thinkers" and "doers" rather than simply passive recipients of the processes and structures imposed up on them by the society in which they live (Klocker et al. 2007: 135). To study children as agents means to see them as active actors in the construction of their own lives, to regard them as having a part to play in the lives of those around them, the society in which they live and contributors to the wider process of social and cultural reproduction (Mayall, 2002).

The study of children as agents is therefore a call for children to be understood as social actors shaping as well as shaped by their circumstances (James et al., 1998), a change in perception that has brought a reconceptualization of the role of children as active participants in society (James, 2009). As Corsaro (2005) argues, it is the change in perception of the role of children in the wider social reproduction. The process of social reproduction is not a process by which children passively internalize society and culture; instead it is a twin process of children actively contributing to cultural production and change on the one hand, and their being constrained by societies and cultures of which they are members on the other (p: 19).

As noted before, children have been viewed as "human becomings" awaiting change to adulthood, not just as "human beings" in the developmental psychology (James, 2009). They have been viewed as weak and victims of different life situations and their capacities, resourcefulness and active roles in construction and determination of their lives has been neglected. Particularly, children who are considered to be in 'especially difficult circumstances' like disabled children have been more labeled as victims and seeking help (Ansell, 2005). However, little or no accounts of these children's perspectives, rights and capacities are taken into consideration. The most forefront characteristics of these children presented to the media and viewed by the public were their vulnerability and their need of

help; while the children's active roles to overcome adversities and their capacities to stay resilient in the situation have been forgotten. Klocker et al. (2007) argued that children with some kind of disabilities are denied their agency by powerful actors such as teachers, social workers, parents and the community at large. Holt (2004) also argues that children are social agents and their practices must be explored to question how disability is reproduced /transformed. In her fieldwork conducted with children with learning and intellectual disabilities, what she called "children with mind-body differences," Holt demonstrated that disabled children are not mere cultural dupes, but can respond to the opportunities and constraints provided by adults. She pointed out that these "children can transform the adults' expectations and norms," which she said "highlights the importance of children's agency even in the contexts where they have little power" (p. 232-233). These children should be viewed as individuals having capacities to act and shape their lives rather than passive and innocent dependents or victims (Klocker et al., 2007). This also calls for the greater attention to the children's own experiences of their lives (Boyden & Mann, 2005).

3.8.1 What mediates children's agency

Children do not enjoy their agency straightforwardly. As Klocker et al (2007) argue children's agency is mediated by a host of factors like the social contexts such as intergenerational relations, the children's positions within social formations like family, the cultural discourses like discourses of childhood, the personal factors like age, gender, (dis)ability, family background, and the spatial relations such as the child's identification with specific spaces like school and home (Klocker et al. 2007: 137). The agency of disabled children in the Global South can be discussed in relation to these factors. As studies show disabled children in the Global South experience a childhood that is generally marginalized (Ansell, 2005; Kabzems & Chemedza, 2002; ACPF, 2011a; ACPF, 2014). As noted in several parts of my study, disabled children in Ethiopia in particular experience social stigma resulting from cultural constructions about their disability situation. Some families prevent disabled children at home because of fear of stigma, which deprives children of their participation in school and community (Tirussew, 2005; ACPF, 2011a). These would exemplify the social and cultural discourses that deny the children their agency.

Children's intergenerational relations with adults at different level may also affect their agency (Punch et al., 2007). Children are entangled in a range of generational relationships with adults, including their parents, relatives and neighbors and teachers. The influences of

adult power in children's lives may be supportive or disciplinary and controlling (Ibid). Punch et al. (2007) argue that most parents in the Global South tend to control the children's everyday activities by exercising their authoritarian power over the children's own needs and desires. Bringing this into the lives of disabled children, it would also be argued that their lives are almost controlled by the powerful adults, such as parents, teachers and professionals.

However, children are not simply passive recipients of the social structures but they exercise their agency amidst restrictive situation (Punch et al., 2007; Klocker, 20017). Punch et al. (2007) used a concept of "situated agency" to argue that children are not merely figures of the social structures; they rather exercise their agency through their actions, resistance and innovation amidst the adults' control over their everyday activities (P. 136). Klocker (2007) also used concepts of "thin" and "thick" agency to show that factors like age, poverty, gender, ethnicity and (dis)ability can enhance or reduce ("thicken" or "thin") children's agency. Klocker used the concept to portray that children in marginalized situations do not simply lack agency, but they exercise some amount of agency (thin agency) often mediated by different factors. The concepts of "situated" and "thin" agency might be used to conceptualize children's agency in the marginalized situation, in contexts where children lack power to exercise their agency (Punch et al., 2007), as in the case of disabled children in the Global South.

Fingerson (2009) also used another concept, "embodied agency," to see how bodies themselves can be an object and a source of agency for children. Fingerson (2009) argues that body is both a direct source of agency and can be drawn on as source of agency. The body negotiates children's agency through factors like race/color, illness/disability or age/puberty, for example. The agency of disabled children, for example, is negotiated by their disabled bodies in terms of social interaction and activity performance. Fingerson, presented how children's social interaction is negotiated by their bodies.

When some changes occurred about our physical bodies, it changes the way we interact with others. We all are 'embodied social agents.' We are immersed in a world where our lived meanings and experiences have bodily dimension. This approach to understanding of social action, called embodiment, recognizes the body's corporeality and materiality as well as the social interaction and interpretation with which it is shaped and given meaning (Fingerson, 2009: 217).

As Fingerson (2009) argues “individuals are constrained by the conditions in which they live and it is through embodied practices that they become subjects, participate in the practices of the construction of their conditions and act upon their world” (p. 217). In order to understand the children’s social lives, we must understand their embodied lives (Ibid).

3.9 Child Resilience

The fact that childhood has been studied from the perspective of development, which sees childhood as a biological stage characterized by both physical and mental immaturity (Prout & James, 1997) has pictured children as ‘vulnerable beings’ that are subject to many life challenges that affect their development. Children like disabled children, who are considered to be in ‘especially difficult circumstances,’ are presented by social research as leading the life that is considered generally ‘difficult’ (Ansell, 2005). However, researchers from social studies of childhood and children are going beyond this conventional wisdom to studying lived experiences of these children. Not only are the vulnerability of these children, but also their ability to remain resilient in face of adversity focused (Boyden & Mann, 2005).

The notion of resilience seems to have been used in health science to characterize the recovery of patients from physical trauma such as accidents and later adopted to psychology to refer to person recovery from mental illness. It is now understood to indicate an individual’s capacity to recover from, adapt to, and remain strong in the face of adversity (Boyden & Mann, 2005: 6).

Since 1970s the idea of the world’s children has come to the public showing the North audiences and researchers the consequences that war, famine, poverty, child abuse, etc. have on children across the world. These circumstances in which children in different parts of the world, mainly of the Global South, live raised awareness that some children do not inhabit the idyllic world of ‘happy, safe, innocent, protected childhood’ (James, 2009). These images of radically different childhoods began to challenge the North images of childhood and began broaden this narrow view of childhood. Research began to place emphasis on children’s experiences of these adverse circumstances. The ways in which children in diverse settings learn to respond to adversity and extreme hardships are began to be understood as critical components of child development. Many scholars have shifted their focus to the factors that enable children to remain competent in the face of adversity (Boyden & Mann, 2005).

Boyden and Mann (2005) argue that the notions of childhood vulnerability, development and wellbeing should be contextually studied. Children's development is mediated by a host of internal and external factors that are inseparable from the social, political and economic contexts in which the children live. It is desirable to focus on factors that put children in difficult circumstances and highlight the responsibility of the concerned bodies to improve children's wellbeing. However, children should not be characterized as passive and defenseless in the face of adversity. Emphases should be given to the dynamics of children's experiences of adversity (Ibid).

CHAPTER FOUR

4 METHODOLOGICAL UNDERPINNING OF THE STUDY

The selection of research methods depends on a specific theoretical /research approach from which one analyzes the research population (James et al., 1998). In research with children, how childhood and children are understood in different discipline has implications for how they are researched (Punch, 2002; Clark, 2005; Lundy & McEvoy, 2011). For example, children have been seen as objects of research; and experimental and survey methods have been used to understand what it means to be a child in developmental approach (Prout & James, 1990; Woodhead, 2003). This approach to study childhood and children has deprived children of their voices in research (Prout and James, 1990).

As noted earlier in the theory chapter, the social studies of childhood/the sociology of childhood sees children as actors in their own rights and that their social relationships and cultures should be studied from their own perspectives and lived experiences (Prout & James, 1990; James et al; 1998). Scholars from this research tradition emphasize children's agency and reposition children as subjects and participants rather than objects of research (Woodhead & Faulkner, 2008) and see children as having the rights to be properly researched (Ennew & Plateau, 2004; Beazley et al., 2009; Ennew et al., 2009). They employ methods that help to produce knowledge from the children's own experiences and perspectives such as ethnography and several child-centered participatory methods (Prout & James, 1990; Punch, 2002).

In my study, I used qualitative research design to produce important data about the perspectives and everyday experiences (Greig, Tylar & Mackay, 2007) of children with physical disabilities. In particular, ethnographic and participatory methods like participant observation, semi-structured interviews, focus group discussion and neighborhood walk were used during the fieldwork to document children's perspectives and experiences on their disability situation and how they navigate their everyday lives, what factors intermedate their everyday lives and how they negotiate these factors. In addition, some task-based participatory methods (Punch, 2002) were used during the fieldwork mainly to develop a relationship with the children. In this chapter, I will present and discuss my fieldwork experiences: how these research methods were applied in the field and the methodological and socio-ethical challenges occurred during the fieldwork and how I negotiated them.

4.1 Selecting the fieldwork site

My study was conducted in a residential home care for physically disabled children. Access to vulnerable children like children with disabilities for the research in the community where they live is mostly difficult. Not only are these children hidden from view, but information about them may also be kept secret (Ennew et al. 2009). As noted, In Ethiopia most parents prevent children with disabilities at home arising from fear of stigma (Tirussew, 2005). Conducting a research in the residential home care helped me not only solve the problem of access, but also allowed the children's active participation in the research process. There are a number of institutions providing rehabilitation services for people with disabilities in the Ethiopia. The selection of this institution amongst a number of related institutions is determined by the fact that the institution provides residential home care exclusively for the children with physical disabilities, which are the primary participants of this research (unlike some other institutions which provide care for both children and adults with different kinds of disabilities in the country). My familiarity with the local culture and the geographic area in which the institution is located also rendered me an advantage to overcome the language and culture related barriers during my fieldwork. Ethiopia is a country of diverse ethnic groups with distinctive language and culture.

4.2 The process of access

In the initial stages, I had to change my fieldwork site, because the institution where I had initially planned to undertake my fieldwork did not fit the objectives and fieldwork practicalities of my research. The institution I first contacted provides rehabilitation services for both children and adults with physical disabilities. The number of the children in the institution was also small. The purpose of my research was, however, to work with the children in a wider children's space to document their perspectives and everyday experiences. I intended to observe a sizeable number of children with physical disabilities in the institution. Over time, with the help of the workers of the institution, I was able to find another institution. Unlike the former one, this institution is a residential home care which provides different forms of rehabilitation services only for children with physical disabilities, which was an ideal for my study. I spent two weeks to secure the permission to conduct my research in this institution. Upon the submission of the letter of introduction from the Norwegian Center for Child Research (NOSEB) along with my project description on the basis of their request, I finally secured permission to conduct my study in this institution.

4.3 The fieldwork

The fieldwork lasted for about more than two months. Being in the field was a turning point for my research as it was a transition period when I translated the project description into practice, a juncture at which theories were translated into practice. The fieldwork was overwhelmed with a variety of activities (both planned and unplanned), ranging from preliminary observation to withdrawal from the field. It includes, in order of increasing, early visit of the research site and consent of the participants, building rapport and data collection through different methods. Each stage of the fieldwork consumed a different length of time based on the activities that were undertaken.

4.3.1 Obtaining consent

Researching children in the institutional care can be quite complex in terms of gaining access and seeking consent because of the potentially large number of gatekeepers involved and the stricter institutional rules, operating within them (Fargas-Malet et al. 2010; Ennew et al., 2009). I went stage-by-stage process of obtaining consent. I submitted the letter of introduction from my study institution along with my project description and subsequently made a written agreement with the project manager of the center. In addition, I had to get consent from child care workers who are frequently identified with the children. They were the ‘professional gatekeepers’ (Cree et al., 2002), who by the virtue of their profession, went beyond giving consent to providing me their professional support in the various stages of my fieldwork. I made a written consent with them as well, which created a good working environment for my fieldwork.

After passing through the aforementioned stages, I finally sought the informed consent of the children. I went through the child care workers to be introduced to the children as children are more likely to consent to participation in the project when the researchers are accompanied by a trusted professionals like social workers or child care workers (Cree et al., 2002) or people Ennew et al. (2009) call ‘intermediaries’ or ‘go-betweens.’ With the help of the childcare workers, I collected the children in a class room and explained to them an overview of my research along with my personal information. I informed them that I seek their participation, but that this is absolutely based on their voluntarism and that they have a right to withdraw from the research at any point they wish.

In my fieldwork, the issue of parental consent raised some sort of dilemma. Although parents are important gatekeepers (Alderson and Morrow, 2011), I did not seek parental consent on behalf of the children, mainly because most of the parents were not available during the fieldwork. The parents often come to the center when they first bring their children and when the children have completed their treatment to take them back home. While doing so, I had taken into account the evolving capacities of the children (Alderson and Morrow, 2011). I also discovered that the absence of the parents had given the children the autonomy to decide on their own about their participation in the research. The risk of relying on the children's consent alone was also insignificant in my fieldwork as the childcare workers acted as the 'residual parents' in the center. They were the ones who control the children's activities in the center and act as a 'professional parents.'

I asked the parents to give their consent to participate in the interviews. Three of the parents were not willing to sign the document; they gave me an oral consent to participate in the interview. They refused not to engage in a written agreement because of skepticism associated with signing the document (Abebe, 2009). Most of the children in my fieldwork, however, wanted to have a written consent, regardless of their ability to perfectly write and read. Based on their interest to sign the document, I then used a finger signature, where a person presses his/her painted finger on the document and the sign which appears on the document is used to represent a person's signature. This method is traditionally used to sign documents in Ethiopia among the uneducated people. The name of the person signing the document is often written next to the finger signature just to make identification. The children took the original copy of the consent form on which their finger signature was settled. They enjoyed this method as it was partly fun. In fact, it resembles drawing.

4.3.2 Building rapport

In my fieldwork, I spent the first two weeks building a rapport with the participants. In an attempt to develop a rapport with the children, I organized social activities such as storytelling, sharing my childhood memories to the children and different physical activities and games among the children, which helped me build the relationship of trust with the children (Ennew et al., 2009). The informal dialogue also helped me develop a good relationship with the children, especially in the early stages of my fieldwork (Abebe, 2009).

I used storytelling to engage with the children in communication, mainly through sharing the stories in a small group. In Ethiopia, storytelling is generally a communal cultural practice

transferring cultural notions, norms, and values across generations and is used as a mechanism of socializing the children (Jirata, 2011). Parents tell folktales to their children in order to teach survival skills and cultural norms and the children also share the tales among themselves. The children gained pleasure from hearing and telling folktales during my fieldwork. They expressed their sentiments and opinions and pose questions to clarify points, make meta-communicative comments on the proper ways of narrating (Jirata, 2014). Through storytelling, I was able to build a relationship of trust with the children, which eroded the feelings of shyness on the part of the children and made them active participants in the fieldwork.

I also used telling my childhood memories to the children as another method of practicing communication with the children. The children were very eager to listen to my memories. Sharing my childhood memories to the children had enormously helped me develop a trust with them. I was very aware whether this could provoke any harm to the children and deteriorate their relationship with me. However, it appeared less harmful in this regard as I do not have exceptional childhood memories than those experienced by most children in Ethiopia.

I also organized different games and competitions among the children, which mostly focus on physical activities like football games, table ball, running race, different physical exercises and play activities like slides. These activities were designed to make the children active participants in the fieldwork as they are participatory and child-friendly (Punch, 2002). Besides the enjoyment, the children showed that they are capable of playing these activities regardless of the physical disability with them which limited their mobility. I created the football match between one team who uses crutches and the other which consists of children who do not use the crutches. I called the match '*the two legs versus the four legs battle*,' representing the children with mobility difficulties who do not use crutches and those who use crutches respectively. It was very interesting to see children with the crutches (the 'four legs' team) playing quickly with those without crutches but have mobility difficulties. I was a referee of the match. These activities helped me easily develop a relationship with the children. However, the activities were observed to be non-inclusive in some regards as some children did not want to participate.

4.3.3 Recruitment of the participants

The participants of my research were school age (aged 12-15) children with physical disabilities who live in the residential home care (see the appendix). My study also included adults who were thought to have a stake in the lives of these children, such as parents and social care workers. Generally a total of 18 participants; ten children with mobility difficulties of both genders between ages of 12 and 15, four parents/guardians of the children and four social workers of the center participated in my study. I focused on children of this age category, assuming they are relatively well experienced to share their lived experiences in the study. They were recruited in the center towards the end of the first two weeks of the fieldwork. The data produced with the parents and the social workers would not be representative of the parental and social workers' perspectives about the disabled children, as the number involved is small.

The parents were included in my study to see the parental perspectives and experiences of raising up a child with disability. As the parents were not always in the center, I contacted them according to their visit. The social workers were contacted through negotiating the time of their work in the center, as they were most of the time engaged in the service provision to the children.

The children were selected through purposive sampling based on their age and sex. The selection of the final sample has gone through a multiple process. I firstly identified myself with a group of children who have shown interest to engage in a variety of activities used to develop a relationship with them. I then tried to build a rapport and relationship with them. I did not want to push in those children who did not show an interest to engage in those activities. I wanted to use this as a default mechanism of opting some of the children out. I then registered the age of those children who have engaged in the pre-selection activities and subsequently identified those who fall in my age category (12-15 ages). I finally selected 5 boys and 5 girls who were found in 12-15 age categories for interviews. I used the pseudo names in my notes to keep the anonymity of the children. The children who were not selected for interviews have also been participating in different activities and participant observation.

4.4 The process of data collection

I employed multiple methods of data collection which helped me gather a good amount of data and offset the weakness of one method by the strength of the other (Abebe, 2009).

During the fieldwork, I used Participant Observation, Focus Group Discussion (FGD), Interview and Neighborhood walk. In addition, task-based participatory methods discussed previously were used mainly to build rapport. Below is the discussion of the main methods used in my study and how they were used to gather important data.

4.4.1 Participant Observation

I conducted participant observation to learn about the children by participating in and observing their daily lives (Ennew et al., 2009). Participant observation is more particularly important to understand children's everyday lives in institution (Warming, 2005). I had been observing the children's interaction with adults, the opportunities and obstacles they may face amidst the interaction and the way they negotiate these factors. The participant observation was conducted in two consecutive phases. In the initial phase, I made an observation without participation. In this phase, I had been identifying how the children spend their days and spaces that they frequently occupy which helped me identify the temporal, spatial and situational factors that may affect my fieldwork. I combined informal dialogue with participant observation at this stage. That is, I had been making an informal dialogue with the children while observing their everyday lives.

In the second phase, I conducted an observation with participation/participant observation. This was the main part of participant observation and aimed to build a rapport with the children and collect important data. During this stage, different task-based activities like football, some physical exercises and play activities which I discussed earlier were made with the children. I engaged myself in almost every day activities the children were doing in the center. I had been taking field notes after the end of participation and normally throughout the observation to record important data.

During the early observation, the children tended to be respectful and shy. Over time, informal dialogues and interactions and activities developed into a relationship. I used Informal dialogue as a double-purpose method: to build a rapport with the children on the one hand and record important data on the other. I was able to learn about the children's background, how they come to the center and their relationships with one another and the social workers in the center through informal dialogue.

4.4.2 Focus Group Discussion

Focus group discussion is useful for identifying the ideas, attitude and values of a group (Ennew et al., 2009). I conducted a one hour focus group discussion with four social workers in the Centre. The focus of the discussion was '*the interventions available to the children in the center and the children's perceptions towards them.*' I chose to make focus group discussion with the social workers because it was difficult to make an individual interview with them as they were most of the time busy treating the children. The focus group discussion was time-effective. It helped me to hear a diversified viewpoint on a particular topic within a short period of time. In the discussion, it was sought to explore the social workers' experiences of serving the children; their relationships with the children and their experiences of how the children perceive the intervention services provided to them in the Centre. The childcare workers talked both about their professional expertise and experiences of serving the children.

I made the focus group discussion in the social workers' office in a round table setting. I created an exercise to stimulate a discussion using what I called '*discussion cards,*' a paper which contains certain word or phrase related to the point of discussion and put it the middle of the discussants and heard everyone's point of view on it. This made the focus group discussion more interactive and participatory and helped each of the members participate effectively. Everyone in the discussion was asked to raise idea about the topic turn by turn and then the group reflected their respective idea. The discussion was recorded. The child care workers appreciated the use of the discussion cards.

4.4.3 Semi-structured Interview with the children

I conducted individual semi structured interviews with ten children with physical disabilities in the center. I preferred semi-structured interview to extract in-depth knowledge about children's perspectives and experiences (Ennew et al., 2009) regarding their disability situation. Semi-structured interview gave me a chance to hear from the children based on the interview guides (see the appendix) while also giving the children more chances to elaborate. It was an interactive process where information and interpretations flew both sides (Gudmundsdottir, 1996). The children enjoyed the interview as it gave them the opportunity to openly discuss their ideas (Ennew et al., 2009).

The interviews were conducted after I spent time and developed a good relationship with the children, which helped me conduct the interviews without communication barriers. The children were encouraged to narrate their lived experiences and tell their life histories. The interviews were recorded to capture the full dialogue. I had been asking for the children for consent about recording the interview.

It seemed easy generally to interview, but it was hard to do it well (Kvale & Brinkmann, 2009). During the initial stages of the interviews, I faced a problem to arrange the interview schedule and find suitable interview space. The children were most of the time busy with their treatment, which made inconvenience for me to set interview schedules. I negotiated with the social workers and facilitated schedules for the interviews on the time when children were free of services. On the other hand, most spaces in the center were occupied by the adults and the children, which also created a difficulty to identify private interview space. I began the first interview behind one of the buildings in the center. Non-participant children and childcare workers were joining the interview and the sound of the children playing around the building was also disturbing. I therefore had to quit the interview and look for private interview spaces. As demonstrated by Abebe (2009) finding interviews space requires both flexibility and a “degree of planning and preparedness in terms of being ready to take opportunities as they arose” (p: 457). On the next day, I found a large tree in the center, which was away from children’s views and sound, more suitable for interview. I conducted the rest of the interviews with the children there. This created better condition not only to avoid the interferences of other children and childcare workers but also preserved privacy and confidentiality of the children and reduced power imbalance, which I will discuss in the following section. However, weather will disturb such interview spaces as a rain once relocated us in the middle of the interview.

I also experienced some problems related to the children’s understanding of the interview questions. For example, the account of one boy is worth sharing here. A twelve year old boy, answered the question “how do you see disability?” saying, “*I see it with my eyes.*” The question was presented in Afan Oromo, one of the two local languages in which I conducted the interviews. The version in this local language, which appears as “*qaama midhamummaa akkamitti ilaaltaa?*” misled a child as it connotes more direct meaning. I then asked the question in a different ways as “how do you explain disability?”, “what does disability mean in your perspective?” I understood that this challenge arose from the way questions were formulated and asked. The boy came to the track when I asked the interview question in a

more clear way. This gave me an opportunity to reconsider and redesign my interview guides. Interview is not only a process of collecting data from the participants; it is just a “craft” where one learns through experiencing challenges and opportunities as Kvale and Brinkmann (2009) pointed.

4.4.4 Semi-structured interview with the adults

I also made semi-structured interviews with four parents of the children. Interviews with the parents were designed to know the parental perspectives regarding children with physical disabilities and experiences of raising up disabled children in the community. The interviews with the parents were made when the parents visited the Centre. They were undertaken in a free room in a face to face communication around the table. During the interview, the purpose and subject of the interview was properly explained to the parents and each parent was asked for consent to participate in the interview. The parents talked about their experiences of raising up a disabled child in their community. In particular, they were encouraged to explain their perspectives of the phenomenon of disability, their view of the everyday life of their disabled child, how their relationships with disabled child and the relationships among the disabled child and his/her able-bodied siblings were negotiated and how the phenomenon of care for the disabled child looks like.

4.4.5 Neighborhood walk

A one hour neighborhood walk was made with a group of six children who participated in the interview, four boys and two girls. The walk was made to the farming owned by the Centre in the local environment. It was used both as a method and a recreation, hitting two birds with one stone. The children enjoyed the environment on the one hand and various conversational interactions were occurred during the walk on the other, out of which important data were extracted. The neighborhood walk helped me strengthen the social relations with the children and explore experiences of their everyday lives (Abebe et al., 2013). The children talked their life histories and experiences related to their disability situations in their community and how they negotiate the challenging factors they encountered. The walk was helpful to hear children’s life histories without fearing to cause emotional distress, which was found to be somewhat challenging through interview. The walk diverted the children’s emotion while telling their histories and experiences as they were enjoying the natural environment.

The neighborhood walk was also child-friendly and fun method that made the children active participants in the fieldwork (Punch, 2002). Besides, I also understood that the children played out their agency through the neighborhood walk. They were not only active walkers, but also capable of negotiating some challenges of the landscapes, given the mobility difficulties with them.

4.5 Socio-ethical dilemmas during the fieldwork

I experienced several socio-ethical dilemmas during my fieldwork with disabled children in a rehabilitation center. Employing participatory methods by itself had generated a number of methodological and practical dilemmas during my fieldwork (Abebe, 2009). Working with disabled children, on the other hand, exhibited some ethical and practical dilemmas (Kirk, 2007; Bailey, et al. 2014). Children with disabilities can easily be exposed to discrimination simply because they are disabled and physically different from the researcher (Kirk, 2007); which partly contributed to the ethical issues that arose during my fieldwork. The prevailing social and moral values of Ethiopian childhood have also created some difficulties to manage power imbalance, and safeguard anonymity, privacy and confidentiality of the children during my fieldwork. Although negotiating all these ethical issues was not an easy exercise, I had been abided by essential ethical principles to overcome those challenges, which have been presented as follows.

4.5.1 Managing power imbalance

During my fieldwork, the issue of power imbalance between me as a researcher and the children as the participants was noticeable. Many factors might have contributed to the power imbalance; but I noticed two factors exacerbating the problem of power inequality between me both as an adult and a researcher, and the children as the minors and the researched. The first factor and related to the children in my study was the children's physical difference – their disability – which made them think of themselves as less powerful. The children tended to prevent themselves from participation in the fieldwork, which affected their relationship to me, especially during the early observation. There was also a feeling of empathy about these children on my part at the initial stage. As Bailey et al. (2014) argued working with disabled children may create a feeling of empathy on the researchers and that researchers should avoid personal feelings and study the children's childhood from their own rights.

The other factor is the cultural trap of what is called normal/good childhood in Ethiopia. Cultural traditions and inter-generational relations in Ethiopia generally tend to perceive children more as part of family collectives not as independent rights holder (Poluha, 2004; Abebe, 2009). The normal/good childhood is determined by the rule of seniority prescribes children's high respect for adults. Children are culturally encouraged to be respectful to the elders and not to discuss on equal terms with adults, what Abebe (2009: 458) called '*tihitina*', which means *politeness or respectfulness*. This would deprive the children, their rights to freely express their views and their views seriously taken in matters concerning them in their everyday lives (Ibid). This 'cultural trap' contributed a significant part in the power imbalance between me and the children. The children tended to respect me over and be shy in our relationships during the early stages of the fieldwork. As Abebe (2009) narrated his experience of working with Ethiopian childhood, breaking this 'cultural trap' and making the children got use of the new idea of active participation took time and required working on the children's empowerment.

In an attempt to rectify the problem of power imbalance during my fieldwork, I played a "friendly-role" (Abebe, 2009). Through identifying myself with the children in their everyday activities, I repositioned my status of the adult researcher by friendship role. I interacted with the children socially and emotionally by participating in everyday institutional chores and shared with them varieties of daily routines in the center. My account of one day would best illustrate how I engaged in the children's everyday lives to develop a friendly-role. One day childcare woman was serving the children a boiled bean for a supper while I was chatting with the children. The children wanted me to have a supper with them. I took some beans and ran out of them before the children did. The children invited me to have some of their own as they recognized that I have run out of the beans. I took some beans from the children who were sitting on my right and left sides. Such intimacy helped me develop strong relations of friendship and trust with the children.

On the other hand, the methods I employed to build rapport and friendship with the children helped me break this trap. I had been encouraging the children to be freely and friendly engage with me and to freely express their ideas. As noted earlier, conducting the interview in a field under a large tree sitting on the grass and talking to them in a very relaxed situation also helped me reduce the impact of power imbalance during the interviews. Making the interview in such a natural setting, where there was no formal seating arrangement (Klave and Brinkmann, 2009) made the children consider me not as a researcher, but more as a friend.

4.5.2 Protecting anonymity

In my study, I refrained from using the names, both children and adults and that of the institution to protect anonymity of the research participants (Morrow, 2008). I used the naming method with the children. I asked the children to name themselves with the anonymous names they preferred. Some children chose the name of the animals they like most. There were replications in some instances when children were interested to use the same names, but I employed the first-come, first-serve principle in such cases. The children enjoyed the naming method as it was fun. It was helpful to protect the anonymity of the children, during the interviews. However, I used not these names in the analysis chapters, but other anonymous names to identify quotes and dialogues. The names used in quotes and dialogues in the analysis chapters for both the children and adults are therefore all pseudo names not the real names of the children and adults involved in my study.

I took the pictures of the children and the spaces during participant observation just to record the important activities made with the children and the context in which they were undertaken. The pictures used in the analysis chapters were those taken in a manner that would not expose the identity of the children like, for example, from the back and the distance. Most of the pictures reflect the situation and the setting in which the activities had undertaken rather than who had been participating in the activities. They were taken on the basis of the children's consent. I will discuss below how the pictures served to reciprocate the relationship between me and the children during the fieldwork.

4.5.3 Preserving privacy and confidentiality

Respecting the privacy and confidentiality of the participants became a vital ethical concern in my study, although ensuring them was far from straightforward (Alderson and Morrow, 2011; Ennew et al., 2009). Especially, during interviews with the children, it was challenging to secure privacy and confidentiality. In addition to difficulty to find a private interview space in the center, which I have mentioned earlier, the children are highly mobile in the center, such that they occupy every space and they were highly interactive with one another. In addition, the prevailing socio-cultural norms and generational relations in Ethiopian society also encourage collective lives rather than individualism, contrary to the western societies where individualism is the leading way of life. It was really difficult separating one boy or girl from the crowd for the interview. They suddenly came by the interview setting and started to join the interview situation. The child care workers also sometimes passed by the interview

setting. This means that the other children and the child care workers could identify the child who was participating in the interview. I began to call children for interviews when most children were not around. The tree under which I conducted interviews was also obstructed from the children's view.

The children also unintentionally talked of their private stories during the interviews; although I informed them not to do that. It was really difficult to stop interviewing or change the point of interview during such times. Doing this may even cause feelings of distress on the part of the children as the children would have talked about their private matters partly because of the trusting relationships they built with me (Abebe, 2009). I heard the stories to the end and work on the possible ways of diverting those feelings. As Beazly et al. (2009) argue the ethical decisions are, most of the time, situational. That is, different socio-ethical dilemmas would arise during the fieldwork and the researchers need to negotiate those challenges and act according to the importance of the dilemmas that have occurred (Ibid). I tried to do the best way of collecting important data without infringing on the privacy of the children involved. As Abebe (2009) narrated in his fieldwork experience with children, I was going back and forth, encouraging the children to tell me their stories and yet trying to protect them from telling me something they may not have wished. I understood that it requires the joint efforts of the researcher and the participants to protect the privacy during such times, although the primary responsibility falls on the shoulder of the researcher. Although it was not easy to work on the feelings of the children in such moments, I unintentionally shared the children's feelings. For instance, I had been hugging the children, as my instinctive responses, and providing them some important advices about how they could overcome those feelings as someone who is professional (at least have basic knowledge in the field of research with the children). This may probably demonstrate the fact that the theoretical separation of self from others and the research itself is not so easily accomplished in qualitative research with vulnerable respondents as the research, the researcher and the researched are tightly bound together and the boundaries become redefined and continuously blurred during fieldwork (Katz 1994 in Abebe, 2009:460).

4.5.4 Negotiating reciprocity

It is increasingly agreed that reciprocity needs to be understood in the context (Alderson & Morrow, 2011). Most of the reciprocal relationships during my fieldwork were negotiated through the exchange of non-material aspects. There were in fact no concrete grounds for

compensating the children directly for their participation in the research as the children live in a residential home care, where there was adequate provision. The reciprocal relationships between me and the children were mostly constructed and reconstructed based on the exchange of relationships of trust. Alderson & Morrow (2011) argue that the reciprocal relationships between the researcher and the researched should not simply be a contractual; they should last in the formation of relationships of trust, where the researcher and the participants engage in a shared relationship to produce a good quality of data and avoid doing harm to the participants. That is, reciprocity should result in the pragmatics of collecting good quality of data as well as doing an ethical research (Ibid).

I shared various social interactions and emotional feelings with the children during the fieldwork, which were mostly moderated by the friendly role that I established (Abebe, 2009). Some activities that I designed to build a friendly role with the children unintentionally resulted in reciprocal relationships. I would like to remind here how sharing my childhood memories to the children resulted in reciprocity. I told the children my primary school memory that I used to walk long distances to attend school and that this had not stopped me from my education. This had sown feelings of courage and inspiration among the children. Indeed, cultural practices do not encourage disabled children to go to school in Ethiopia. Disabled children are seen as unable to learn (Tirussew, 2005). They seemed they were inspired by my story although it was not similar to their life experiences. I had been encouraging them not to cut hope in their endeavors amidst various social and cultural barriers they may face. The children on their part became reciprocal to me wishing me further success in my future endeavors. These relationships of trust and friendship went beyond the immediate fieldwork purpose, although it was a short term. I had been helping the children to be active participants in their daily lives, not only in the residential care, but also in their community, although this would not change the prevailing structural and cultural factors in the community.

Up on my departure I distributed them their photos as they asked me to give them the photos I took during the fieldwork. They claimed the photos were memories of their lives in the residential home care in general and their memories of my fieldwork in particular. They may remember those times they spent; the laughs, the plays, the games and the lessons that came out of all those endeavors during the fieldwork when looking into those photos. The photos served as one way of reciprocating, although this may raise another question whether the pictures could serve as reciprocity or how this would be negotiated. It was a great happiness

for them having those pictures along with themselves when returning back to their community. They told me that they will show the pictures to parents and friends.

4.6 Post-fieldwork: the process of analysis and interpretation

After the fieldwork, it seemed like most work has already been done, but most work was left actually. Transcribing the interviews, categorizing data and writing up and rewriting were a hard working time. In ethnographic research, there is no recipe for analysis and the process of analysis is not a distinctive stage of the research process. It may begin from the pre-fieldwork phase and continues to writing report (Hammersley & Atkinson, 2007).

I informally began to generate ideas of analysis and conceptual frameworks while reading to figure out relevant theoretical perspectives and concepts based on my research questions. As soon as I started the fieldwork, I began to develop some analytical ideas while observing the children's accounts of everyday lives in the center. These endeavors have laid some foundation for my further analysis ahead of the fieldwork.

4.6.1 Transcribing data

After the fieldwork, I started transcribing the interviews and the focus group discussions. The interviews with the children and parents were made in two local languages; Afan Oromo and Amharic, as some children and parents speak Afan Oromo and some others speak Amharic. The focus group discussions were conducted in Amharic. I chose to transcribe the interviews and the focus group discussions by directly translating them into English as it was time consuming to transcribe every record in each language. I therefore did both transcription and translation at the same time. I frequently listened to the interviews and the focus group discussions to translate and transcribe them in English. I was listening back to the interviews and focus group discussion several times even while writing up to check back if had still important data to include.

4.6.2 Writing up: analyses and interpretations

After I completed transcription of data, I began to categorize data based on my research questions. I categorized the data into three major themes and several sub-themes which were constructed according to the research questions. The major themes include; the children's perspectives of their disability situation, the children's experiences of growing up with disability and the children's institutional life, which later developed into chapters.

I began the process of writing by scaling up these major themes into the chapters. I followed the mixed approach of analyzing, in which I employed both the bottom-up and top-down approaches (Nilsen, 2005; Hammersley & Atkinson, 2007). I have been navigating back and forth between the data and the theoretical perspectives while writing (Nilsen, 2005). I did not work to necessarily develop new concepts from own data, but concentrated on how I can analyze and make meanings form empirical data by employing relevant theoretical perspectives and concepts, and compare and contrast them with previous studies.

CHAPTER FIVE

5 THE CHILDREN'S PERSPECTIVES OF THEIR DISABILITY SITUATION

Most studies conducted about children in Ethiopia in general tend to neglect their perspective. Abebe & Kjærholt (2013) in their book "*Childhood and local knowledge in Ethiopia*," which covers a wide range of issues about Ethiopian childhood argue that "most studies with children are silent on how children think about their lives" (p. 9). As noted earlier, the situation is critical in the case of disabled children. There exists striking research gap in the perspectives and experiences of disabled children as most studies sought to examine the perspectives of the adults on behalf of the children, neglecting the perspectives and experiences of the children themselves (Moore et al., 2001; Tirussew, 2005; Fitaw & Dorsma, 2005; Lewis, 2009; ACPF, 2011; ACPF, 2014). However, disabled children have their own perspectives and lived experiences about their situation.

In my study, much had been learnt through the fieldwork about the children's perception of growing up with disability. To generally present the overview of the children's perspectives of their disability situation in my study, children explained their disability situation as a subject of 'difference.' They compared their situation to the non-disabled children and tended to see disability as a substance of 'difference' mainly in terms of physicality/body and in terms of mobility and activity performance. Being disabled was believed as God's punishment for doing sin, as cursed by elders or being caught by evil spirits. Disabled children were therefore viewed as having sinful or cursed family background or as having been possessed by evil spirits and as a result were excluded by able-bodied children in the school and in villages. Growing up with disability was also seen by children as subject of powerlessness, marginalization and lower social status. Nevertheless, the children's perspectives about disability were changing and varied based on ranges of factors. In this chapter, I will discuss these perspectives of the children about their disability situation based on the data from the fieldwork with physically disabled children in one of the rehabilitation centers in Ethiopia. The chapter also includes how the children think about the traditional causes of disability mentioned above and how these perspectives of the children were changing.

5.1 Disability as a ‘difference’

As I have already mentioned above, the children in my study viewed their disability situation in which they live as a ‘difference’ from other children and people who are non-disabled. They compared their life situation to that of able-bodied children and explained the disability situation in which they live to have rendered them a ‘difference’ in their everyday lives. The children figured out differentiation in terms of physicality/body and in terms of mobility and ability to undertake everyday activities. I will discuss in separate how the children in my study experienced differentiation in terms these components.

5.1.1 *Difference in terms of body*

There were tendencies among the children to focus on their physical body and explain themselves as different from other children and people who are able-bodied. They saw themselves as lacking what they think ‘normal’ human beings need to be – being able-bodied. As a result, it was apparent in the children’s interview that they tended to see disability as ‘abnormal’ and non-disability as ‘normal.’ Gemachu, a 13 year old boy, tended to consider what it means to be disabled in this regard.

“A disabled person is different from normal people. I am different from my friends because I am not able-bodied like them. I am handicap.” (Gemachu, boy, 13)

In the above extract, the boy conceptualized a disabled person as different from the people he called “normal” people, people who are able-bodied. There were concerns among the children to consider their disabled bodies as not normal or problematic. The children construed their disabled body as a handicap, not ‘normal’ and therefore different from that of the able-bodied children. Some children explained this situation in cultural expressions. Chaltu, a twelve year old girl, used a cultural expression to express what it means to be disabled.

“A disabled person is Nafa, (a person who is handicapped, paralyzed or unattractive).” (Chaltu, girl, 12).

The above expression is used among the Oromo ethnic group in Ethiopia to refer to disabled body. As presented in the extract, the term carries out the meaning that physically disabled child is physically disfigured or unattractive and functionally handicapped or unable. Able-bodied children use this kind of expressions to bully and insult the disabled children. Birra, a fifteen year old boy, told me his experience that able-bodied children insult him saying *Okola*

(*Okoltu* for girls) among the Oromo ethnic group, also called *Ankasa* among the Amhara, connoting that the child is slow, can't walk and unable to perform things. There are many of such cultural expressions of disability among different cultural groups in the county which convey the unattractiveness and inability of disabled children, which I will discuss in the next chapter.

These reactions from the able-bodied peers combined with the children's feeling of difference affected the children's social relationships with able-bodied children. The children reported that they have limited social interaction with non-disabled children. In the interviews, they narrated that they experience frustration and fear in their relationship with others because they feel they are different from other children in terms of their body. Chaltu, the above girl, further said,

"I most of the time do not interact with other children at school. I feel I am different from them. I am not able-bodied like them. I can't play; I can't run like them."
(Chaltu, girl, 12).

As can be seen from extract, there were feelings of difference, marked by incompetence and inability on the part of the children in the interaction with able-bodied children. The girl narrated that she feels she is not as able as other children to play and run; and as a result tend to limit her interaction with able-bodied children. Fingerson (2009) argues our social interactions are embodied and the changes to our physical body influence our social interaction.

When some changes occurred about our physical bodies, it changes the way we interact with others. We all are 'embodied social agents.' We are immersed in a world where our lived meanings and experiences have bodily dimension. This approach to understanding of social action, called embodiment, recognizes the body's corporeality and materiality as well as the social interaction and interpretation with which it is shaped and given meaning (Fingerson, 2009: 217).

As noted above the reaction from able-bodied children also had an impact on their social relationship. Bira, a fifteen year old boy, told me his experience.

"You will be subject of discussion among friends. You will be verbally or physical abused. Even a little child will beat you and escape, because they know that you

cannot run and catch them. I just fear to play around with other children except those who are close friends. Even they sometimes bully you.” (Bira, boy, 15)

Haile, a fourteen year old boy also said,

“I mostly do not play with my friends at school. They laugh at you... they insult you. Even my siblings do not want me to go with them when they go to school and other places.” (Haile, boy, 14)

As elaborated in these narrations, the children face insult and bullying and even physical violence from the able-bodied children in school and in village. In some cases their siblings also tend to neglect them. As Fingerson (2009) argues individuals are constrained by the conditions in which they live (like disability, for example) and it is through embodied practices that they become subjects, participate in the practices of the construction of their conditions and act upon their world. As can be seen from the children’s narrations, the children’s relationship with other children is mediated by their (dis)ability situation. The children in my study experienced limited or unhappy social interaction with able bodied children. They were also to various degrees deprived of their agency to make friends and produce and reproduce their social relationships. Fingerson (2009) called this analytic way of understanding how bodies can be used for negotiating power relations in daily lives among all ages and groups “embodied agency.” “Bodies can be both an object and source of agency in the social process. They can be used in an agentic manner as they help to shape the course of social interaction” (p. 218). Children experience their bodies in terms of the social consequences they have on their lives; they emphasize their actions and interactions in terms of their bodies (Christensen, 2000). Fingerson (2009) concludes that by understanding the ways in which children socially experience their bodies, we can learn the ways in which they construct their social world; the ways in which they, for example, define themselves as gendered, raced, aged or disabled beings. That is, bodies can negotiate children’s agency through what a child possesses or what may happen to the child’s body like illness, disability, puberty and color/race, for example.

5.1.2 Difference in terms of mobility and activity performance

On the other hand, the children also explained themselves as different from able-bodied children in terms of their mobility and everyday activity they were perceived to undertake. They focused on their physical ability to perform everyday routine life like work, school and

play and compare their performance to able-bodied children. They explained themselves referring to their ability to walk/run, work and help their parents and go to school in relation to able-bodied children. In virtually every interview with the children, phrases such as “I can’t walk,” “I can’t run” and “I can’t play,” “I can’t work” were common when discussing what it means to live with disability. The following extracts from interviews with two of the children illustrate this view of the children.

“Disabled person cannot walk or run like others do. I do not play as I wish with my friends at school. I can’t work like other children.” (Tirunesh, girl, 14)

Gemachu, a thirteen year old boy also said,

“I am disabled to perform my everyday lives. I stopped going to school. I do not work and help my parents.” (Gemachu, boy, 13)

Comparing his situation to able-bodied children he said;

“My friends and my siblings go to work. They help their parents with many activities. But, I seek help from my parents instead of helping them.” (Gemachu, boy, 13)

However, this view of the children may not signify that these children are unable, incompetent to work and help their family and contribute to the socioeconomic spheres of the society. There are many accounts of these children working and contributing to their household in my study, which I will discuss in the next chapter. The children tended to compare their performance with the able-bodied children and think themselves as less competent in terms of activities they undertake or perceived to undertake. The children’s focus on their ability to perform their everyday lives seems to have related to the prevailing social expectation of children in Ethiopia. Children have a responsibility to work and help their parents in addition to going to school (Abebe & Kjörholt, 2013; Abate & Abebe, 2013). Less performance or inability to attend to these expectations may create feelings of difference on the part of the children. Being able-bodied is also of great importance in agrarian societies like Ethiopian where children are sources of labor (Qvortrup, 2002). This social expectation about the children may present disabled children as problems. As Tirussew (2005) argues, this can be seen as the perception of society in the framework of their physical limitation or strength, to work and help family, to learn and live independent lives, form a family, and their role in the socio-cultural aspects of society and their contribution in the nation building. In

this perspective, being disabled seems to be considered problematic not only in terms of the impaired body, but also in terms of the social expectations of the society.

It is, in fact, not deniable that disabled children's performance of their everyday lives and their contribution to their household may vary from the able-bodied ones. It is also true that even able-bodied children may contribute less to their household than some disabled children. That is because children's performance of their everyday lives and contribution to their household is negotiated by range of factors. This also invites us to also consider children's agency and how it is negotiated by socio-cultural, personal, spatial and temporal factors (Klocker et al., 2007). The prevailing socio-cultural constructions in Ethiopian society about disabled children's ability are largely negative. Disabled children are viewed as weak, unable to work and learn (Tirussew, 2005). The children also reported that they are viewed as weak even by their family members. For instance, the following boy was accusing parents to have regarded him as weak.

“They (parents) tell you that you can't do this or that. They see you as a weak person. But, I think I should try although I am not as good as my siblings.” (Abebe, boy, 14)

These perceptions of the family and society may influence the children to think of themselves as less active in terms of their everyday lives (like helping their parents) when compared to the able-bodied children. Parents in my study however acknowledged that disabled children support them through many activities, but said that they prevent their disabled children from engaging in hard works in order to care for them. One of the parents said;

“We mostly order his siblings to do many things. We care for him (a disabled child) not to engage in hard work that would harm him.” (Kedir, father, 45)

This account also reflects the dual practices of power relations and children's agency, as the children's everyday lives are negotiated by the adults who control and restrict their action. As the above boy mentioned, it seems that the children are restricted to play out their agency independently. The boy was accusing his parent for their control over his activities. The parents on the other hand, said that they tend to prevent the children from the work/activity they think may hurt or be heavy for the children to undertake in order to care for them. This account would also interfere with the practice of 'care' and the principle of “the best interest of the child,” enshrined in the UNCRC and CRPD. It raises a question of to what extent the parents should care for the children and how much the rights of the child to participate in

different socioeconomic activities in the family is respected and what factors intermediate this practices. To look to this account from the perspective of the children's agency, Robson et al. (2007) uses a concept of "situated agency" to explain children's actions, resistance and innovations in the situations where children faces much control from adults. They argue that "children are not merely figures who experience obligations and restrictions, but they actively define, produce and reclaim space as well" and suggested that "notions of agency challenge the view of children as essentially powerless, changing the emphasis from weak minors to active empowered young people" (p.136). Clocker (2007) also uses a more expressive concept of "thin agency" arguing that factors like age, gender, (dis)ability, ethnicity and poverty could enhance or reduce (thicken or thin) the children's agency. In the above extract for example, the boy was complaining that he should be allowed to do the activities he wanted to do. The parents, however, resist the boy's interest through the disguise of care or protection. Parental control of the children from participating in different activities might 'thins' the children's exercise of their agency.

5.2 Disability as a subject of marginalization, powerlessness and lower social status

Being disabled or growing up with disability was also viewed by the children in my study as being subject of marginalization, powerless and having lower social status among their friends and in family. The children in my study explained that disability is considered by many people in their community as resulted from God's punishment for wrongdoings or as caused by elders curse or as having been possessed by evil spirits. The children reported that they were perceived by other people and able-bodied children as having bad family background like a sinful or cursed family or as having been caught by evil spirits; and as a result faced segregation and marginalization from their able-bodied children at school and in village. Although I will discuss in detail about the socio-cultural constructions of disability in the section that follows, I will mention some accounts of the children and show how the children are subject to marginalization in their everyday lives. The following narrations from two of the children illustrate this phenomenon.

"People perceive you as having a bad family background.... like cursed or sinful. Your friends at school talk negative things about you. They exclude you in many school activities." (Bontu, girl, 15)

Abebe, a fourteen year old boy, also had the same experience about his disability situation.

“You are viewed as an offspring of a cursed family or caught by the evil spirits. People gossip about you and your family. Some parents tell their children not to interact with you. The village children tell you what their parents talk at a back stage.” (Abebe, boy, 14)

It is apparent from the children’s narrations that they were subject to marginalization among their able-bodied peers in school and in village because of these stereotypes and prejudiced assumptions about their disability prevalent in their community. The able-bodied children talk these negative assumptions about them in school and in village. As also noted earlier, they exclude them in school activities. Some parents of able-bodied children also do not want their children to interact with disabled children.

On the other hand, some parents also keep disabled children in home because of fear of social stigma. The story of Abdi, a twelve year old boy who was kept in home for several years without contact with a social world, is an important story to consider. Abdi, was disabled when he was two years old. He told me that he spent most of his life in home without contact with other children in the village. He said:

“I had been kept in home by my parents. I was most of the time left with my younger siblings at home. I never attended school nor had I been to the social events in the village. My parents brought me to this center after they heard from the local people about the treatment for people like me” (Abdi, boy, 12).

This story indicates that disabled children in some cases were subject of severe marginalization to the point that they were kept in home for several years. Abdi spent about ten years without much contact with the wider social world except his family. He never attended school. This may indicate that some disabled children were obliged to live a childhood that is ‘generally marginalized’ or detached from the community in which they live. As has been demonstrated in this story, this deprives the children of their participation in the social world and marginalizes them from many aspects of the society including access to education, their rights to live independent lives and their agency to construct their social world.

The children also viewed growing up with a disability in terms of social status and power relations among their peers and within their family. They said disability has rendered them

powerlessness and lower social status among their peers and in their family. Birra, a fifteen year old boy, narrated the following about what it means being disabled.

“Being disabled means many things: powerlessness, having lower status in relation to your friends, for example. You are cast out in school and in village.” (Bira, boy, 15)

A twelve year old girl on the other hand described what how it feels to be disabled.

“Disability disgraces you. It makes you below everyone. You are considered weak in family. You are not good at work nor are you at school. You are just simply lost.”
(Chaltu, girl, 12)

As can be seen from these narrations, disability was viewed by the children as powerlessness disgrace and weakness among their friends and their family members. The children tended consider their social status among their friends and in their family and tend to view themselves as powerless, weak and occupying lower social status. This perspective of the children was related to their reactions from their able-bodied friends and their family members as also noted before. The children were segregated in the school by their able-bodied peers. They were considered as weak in their family. These negative reactions resulted in lowering of the children social status among their able-bodied peers and their family and tended them to consider themselves as powerless and marginalized and generally occupying lower social status.

James et al. (1998) argue that children are structurally differentiated within the societies and, as such, they experience their rights and power differently. Although all children are to different degrees structurally differentiated and subject discrimination in society, practically this occurs across a spectrum of degrees of liberation marked by differences in gender, ethnicity, ability and disability, for example (James et al., 1998). Children are subject to the processes of discrimination that are hierarchically distributed through factors like age, gender, ethnicity and disability, for example. It means that some group of children (for example; disabled children) may be subject to a discrimination in the social structure and experience a lack of power that renders them a lower/ marginal social status in the society. It would be argued from these perspectives that disabled children occupy a minority group status in a society like Ethiopian, where cultural constructions marginalize and deprive the children of their power to construct their social world and live independent lives. Nevertheless, James et al. (1998) contend that these children are also conscious and active beings. They exercise

agency amidst the social structure in which they live. They are not only constricted by the social structure in which they live, but they also exercise some sort of agency. There are many accounts of the children in my study playing out their agency discussed in this chapter so far and will be discussed in detail in the coming chapter.

5.3 Children's perspectives about the traditional causes of disability

As I have discussed above, there were negative societal attitudes about disability and disabled children. As noted, the children frequently raised that these negative socio-cultural constructions affected their everyday in various ways. I asked the children to elaborate more on this topic to explore how disability was traditionally viewed in their community and how they perceive these cultural constructions of disability. According to the children, knowledge about disability is reproduced through generational relations. The children learn about what causes disability from their parents, neighbors and community. In most of the interviews with the children, they highlighted different cultural and religious views about the causes of disability. The following narration from a fourteen year old girl is an interesting illustration.

“You know, it is the will of God. You need to go to the church fathers that interpret the work of God and plead your sin. My parents took me to church and purified me with the holy water several times. They pledged to dedicate me to serve the church if I get improved. But it is by the will of God that you will be healed.” (Tirunesh, girl, 14)

This story holds both the cause and treatment of disability, and attributes both to the divine source. Disability was viewed as bestowed from God and would also be healed by God's will. In Ethiopia not only the source of disability is attributed to cultural or religious sources but also the treatments are made in the traditional rehabilitation (Tirussew, 2005). For example, parents use traditional medicines like herbs, holy water and religious healing system. They take their children to religious fathers or the witch/sorcerers to seek a relief from illness or disability. Parents also promise to sacrifice something as a tribute to the services of the religious fathers; a process which is locally called “*silet*,” (Tirussew, 2005; Kassahun, 2012) a promise to undertake something in return to God's favor. According to Kassahun (2012) in Ethiopian Orthodox Church, *Silet* is a religious contract between an individual and a church in which an individual or his family make promise to pay tribute or sacrifice in response to something good happened in the individual's life which may be a relief from illness or other achievements. *Silet* includes practices like serving church, slaughtering cow or sheep to feed the local people or church community, for example. It is the church fathers or the traditional

religious men or the witches/sorcerers who briefs the source of disability/illness and orders the parents to do this or that in order to effect a relief. The religious fathers sometimes order expensive *silet* like building a church.

Some children also attributed disability to the evil spirits and the curse of elderly people on family. Abebe, a fourteen year old boy narrated how he got impaired as follows.

“It was when I was two years old. Both my feet were impaired. It was a “likift,” (invasion by the evil spirits). I was caught by an evil spirit while I was playing with my siblings on the spot where a fire ash was poured, my mother said. But, the neighbor told me that it is because my grandfather was cursed by the local elder. My grandfather is not alive. I know that a family in our neighborhood has lost four of their children as a result of a curse of their grandfather. If your parents or your grandparents or even your kinship was cursed, it would be transferred to you or to your son or daughter. You should take care not to do wrong to others, especially the elders as they would curse you” (Abebe, boy, 14).

Disability was also attributed to the evil spirits and a curse of the notable elders. As Tirussew (2005) found, the individual would be cursed by the elders if he/she has offended others or has done wrong to people like for example, killing and stealing property and subsequently denied the offense. It is believed that the curse would result in impairment, death or illness of the offenders themselves or their children.

There is also a belief that disability would be caused by the evil spirits locally called called ‘*Likift*,’ ‘*invasion*’ by bad/evil entity. The boy in the above story said that he was told by his mother that he was caught by the evil spirit while he was playing in the field where a fire ash (a residue that remains when something is burned) was poured. There is a belief that the children would be caught by the evil spirit if they are found to play on the spot where the ash is collected. The assumption is that the waste, especially the ash is a home for the evil spirits. Children who play over or wander around the ash would be caught by the evil spirits because they are interfering with the spirits’ entitlement, which would cause illness or impairment. In another interview with a fifteen year old boy, the cause of disability is also narrated in the same way.

“It was when I was too young that my foot was impaired. My mom told me that I left the house to follow her when she went to fetch water from river some kilometers away

from our house. My mom told my grandma to look after me. My grandma thought I would go nowhere. I couldn't arrive at my mom and ended up in the empty field. There, I encountered a devil. I believe it could happen because everyone tells me the same." (Gemachu, boy, 13)

Disability is also believed to be caused by a devil. It is believed that individuals, especially children and woman who walk unaccompanied in a silent and unoccupied field or forest would be exposed to a devil.

It can be seen from the stories of the children that the children learn about the causes of disability from their parents and local people. The interviews with some parents show that the parents also attribute disability to the traditional and religious sources. Girma, a 47 year old father of a disabled boy, narrated the following.

"Illness, disability... all is from above. All is God's will. God punishes us for our sin by destroying our property, killing our cattle or sickening or impairing our beloved ones or even taking their life so that we would realize his majesty." (Girma, father, 47)

People believe illness and disaster as God's punishment (*Yegzabiher Kuta*) in local language (Tirusew, 2005). It is believed that everything including disability happens by the will of God and that God does everything for good, what is locally called '*Le Bego New*,' (it is just for good). As can be seen from this narration, the parents believe that they should take whatever happened for granted as it is God's will and should remain faithful as God is testing their faith by sickening their beloved ones.

However, the children's perspectives about the phenomenon of disability vary based on different factors, which I turn to in the following section.

5.4 The changing perspectives of the children

The children's perspectives about their disability situation vary based on different factors like the child's knowledge about the phenomenon of disability, the educational status of the children and their family, their residential area (whether they live in urban or rural areas). There were instances of differential understandings of the phenomenon of disability among children who were from urban and rural communities. For example, Bontu, a fifteen years old girl who lives in urban area and who is from educated family said;

“Disability is not inability. We can do things as others do. We can even do better than others” (Bontu, girl, 15).

I asked Bontu to explain how she comes to understand disability in this form following her response and she told me that she hears about disability and the issue of disabled people from her parents, media and school. She raised the story of a pilot woman with impaired arms who flies a plane with her legs, which she saw from a television. She said that her parents always encourage her in her education and that she wants to be a doctor in the future and treat persons with disabilities. She added:

“The disabled people even do things better than others if the conditions are facilitated for them. The bad thing is, however, our society does not encourage the disabled persons. They just consider disability as inability, but it is not!” (Bontu, girl, 15)

It is apparent from this story that the children’s knowledge about the phenomenon of disability was one important factor that influences the children’s understanding of their situation. Parents’ educational background and level of awareness about disability also had a great role in shaping the children’s perspectives. As ACPF (2014) also found, in most urban areas and among the educated family disabled children are treated well despite the underlying negative societal attitudes towards disability. School and media also play vital role in creating public awareness.

The children also reported changing perspectives over time after they come to the rehabilitation centre. Most of them have changed their perspectives about the phenomenon of disability as a result of disability education in the centre and blamed the existing negative societal perspectives towards disability and disabled people to have influenced their everyday lives. Moreover, they showed their ambition to change the existing status quo in their community. Although I will discuss this idea in detail in the coming chapter, where I deal with the children’s institutional life, I would like to use the case of a fourteen year old girl here to illustrate changing perspectives of the children.

“My mom had been telling me that I was caught by an evil eye while I was too young. Here, I was told that I was caught by polio. I will tell people that disability is normal and [...] that disabled person can do anything he wants.” (Chaltu, girl, 15)

The above story is a portrayal of how the children’s perception about their disability situation has come to be changed in the rehabilitation centre. As conveyed by this girl’s narration, there

is also a belief among the parents that people with an evil eye will inflict harm or impairment. The girl has shown that she has come to hold a different perspective after she came to the centre. That is, impairment as a health issue and that it will not impede a person from performing everyday lives. As also seen from this narration, the children were inspired to fight against negative attitudes about disability.

In most rural areas, where formal education and health facilities are rare, the traditional and religious beliefs play a major part in the construction of disability. As already noted, the sources of disability were attributed to factors other than medical like spiritual or traditional. Children who grow up in these communities tend to understand disability from the traditional and religious perspectives.

CHAPTER SIX

6 THE CHILDREN'S EXPERIENCES OF EVERYDAY LIVES

Children with disabilities have lived experiences of their everyday lives. As I experienced in my fieldwork, the children in my study have their own needs, aspirations, desires, roles and responsibilities to play. They also have personal and social resources to undertake these activities and various factors intermediate their everyday lives. This chapter explores what the everyday life experiences of the children in my study looks like based on what was learned from the fieldwork with these children. The chapter widely discusses the activities the children undertake in their everyday lives, the children's schooling, the challenges they face in their everyday lives and the strategies they employ to negotiate these challenges. The chapter also covers how the children's inter and intra-generational relations with parents and their non-disabled siblings respectively and the phenomenon of parental care for the children were manifested and negotiated. The chapter begins with the everyday activities the children engaged in.

6.1 The children's everyday activities

The general structural and social definitions of childhood in Ethiopian society attach many roles and responsibilities to children and seek children to be active actors in the socioeconomic roles of their households, like many other African countries (Abate & Abebe, 2013). As also forwarded in the African Charter on the rights and wellbeing of the Child (ACRWC) children in African societies not only enjoy rights, they also bears responsibilities to care for their parents (Art. 31). As Abebe and Kjørholt (2013) documented the contributions and challenges during childhood in Ethiopia, "the majority of children in Ethiopia are contributing actors who work for the well-being of family collectives and to obtain gainful employment plays an important role in their future life" (p. 24). Children are source of labor in the family and play many roles, responsibilities and duties in their household.

Children with disabilities also undertake different activities ranging from their individual everyday activities to the familial responsibilities on an individual basis or in the collection with other children or adults. However, studies are largely lacking in this regard, except some recent developments like ACPF (2011a, 2014) which began to include the children in research. ACPF (2011a) found that most children with disabilities in Ethiopia are involved in

household activities like preparing meal, washing clothes, cleaning house, fetching water and taking care of their younger siblings.

Children in my study also reported that they engage in the activities documented by the ACPF (2011a) mentioned above. In addition, the children also listed to have engaged in such activities as farming and herding cattle and helping the parents through running different errands like delivering things to neighbors and going to shop. The children's involvement in these activities tended to vary based on factors like gender, whether they live in rural or urban areas and socioeconomic background of their household. For instance, girls reported that they mostly perform home chores while boys reported they engage in outside work. The extracts from the interviews with the following two children (a boy and a girl) illustrate these differences.

“I look after the cows in the field with my siblings and other children in the village before and after school. I also go to farming with my parents and siblings” (Gemachu, boy, 14).

Tirunesh, a fourteen year old girl, on the other hand, narrated that she undertakes home chores.

“I undertake home chores after and before school. I make coffee and Enjera (a pancake like Ethiopian food dished with a souse called ‘wot’). I clean house, dishes and wash clothes. I also look after my younger siblings” (Tirunesh, girl, 14).

The children's interviews indicate the prevalence of gender based division of labor. As elaborated in these extracts, girls help their parents undertaking home chores like preparing meals, washing clothes, cleaning dishes and house and taking care of their younger siblings, while the boys engage in farming and herding cattle. This gender division of labor is not different from the one prevailing in Ethiopian society in general. Children's participation in household's livelihood is negotiated through gender based division of labor and generational relations (Abate & Abebe, 2013; Abebe; 2007). A measurement of boyhood is active engagement in economic activities like farming and raising cattle while girlhood is determined by the mastering of home chores.

In the rural areas, herding cattle and working on the farm field are common childhood activities. The majority of Ethiopian population lives in the rural areas and engages in agriculture, which typically mixes up farming and raising animals, as the main economic

activities. Children also engage in these activities as part of their household sources of livelihood. Abebe, a fourteen year old boy who lives in a rural village, narrated the following about his everyday activities.

“I look after the cattle in the field some kilometers away from our home with my siblings and friends. I also work on the farm with my parents and siblings. We cultivate maize” (Abebe, boy, 14).

Cowboy, called ‘*Tikse*’ in Afan Oromo or ‘*Eregna*’ in Amharic, the two most spoken local languages, is a communal child activity/work in rural areas. Children start herding sheep, goats and cows approximately when they are as young as five years old and start working on farm fields some ages later. Farming and rearing cattle are not only the most important means of livelihood in rural areas; but also define the social position of the household in a rural community. Children are therefore used as a source of labor and encouraged to be active participants in these activities. They learn how to conduct them through generational relations. These activities also serve as the marker of the children’s social position in their community. As noted in chapter three, childhood in Ethiopian society is defined through “generational age,” a set of relationships as senior or junior than – in which rights, obligations and roles are achieved rather than ascribed naturally (Abebe & Kjørholt, 2013: 17). Whether a child is a ‘child’ or achieved the ‘adulthood’ stage or a stage at which a child can assume economic responsibilities in family, is defined through the child’s social position and economic importance rather than through natural ages. Herding is left to the younger children in family and the older ones perform farming. Farming is a common adult work. Younger children are trained by their seniors and parent how to do farming through complementing their seniors on the farm fields. When a child acquired important skill to engage in farming, then a child is perceived as an ‘adult’ and began to take some broader responsibilities. Young men are classified as “adult” if they have achieved the level of economic importance that would permit them to acquire certain roles like having wives and becoming economically viable agents (Abebe & Kjørholt, 2013). This social positioning creates a status and serves as a marker of social transition to adulthood (Ibid).

On the other hand, children who were from urban areas in my study, reported that they engage in income generating activities or businesses like shoe-shining and handworks. I will discuss the accounts these children in the following section in relation to the factors that drive the children to engage in different activities in their household. Although responsibility to help

family was the main reason for engaging in household activities, the children reported several reasons, which I will turn to in the following section.

6.1.1 Why the children engage in their household activities

Children in my study mentioned several reasons to engage in various activities in their household. Familial responsibility, poverty, shortage of labor in household and the need to be independent from others help were mentioned as the main factors. Abebe, the boy in the previous narration, explained why he works.

“I have a responsibility to help my parents. We are poor family. They (parents) also want me to work as we do not have enough labor. My siblings are younger than me. My big sister mostly works at home. My mom most of the time falls sick” (Abebe, boy, 14).

The responsibility to help family is the main factors to engage in household’s socioeconomic activities. Children have a responsibility to help their parents. As elaborated in the story, the shortage of labor in the family as a result of family composition and sickness of family members also triggers the children’s involvement in the activities of their household. However, working and helping the household is the prevailing culture of childhood in Ethiopia as most of the African society (Abebe & Kj rholt, 2013). Children learn through generational relations that helping their household is a symbol of good childhood. ACPF (2011a) found that most children enjoy and take as an obligation working and helping their households. This kind of childhood goes in contradiction with the North model of childhood that constructs childhood as work-free, period of care, play and schooling (Woodhead, 2003; Boyden, 1990). Woodhead (2003) argues that studies are largely lacking about the place of work in child development in the Global South.

Although most studies are carried out in global north where school is a major feature of growing up, work is still a normal part of childhood in the Global South. Everything from carrying out simple domestic chores, caring for younger siblings, working in fields and plantations, fetching water and firewood, fishing to trading in streets and markets right through to the most harmful and exploitative child labor in backstreets and bonded labor are the major feature of growing up in the Global South (Woodhead, 2003: 92-93).

The child responsibility to help the family in Ethiopia and in Africa in general, which also has given a legal ground in the African Charter on the Rights and Welfare of the Child (ACRWC), also contests the idea of child rights and parental responsibility enshrined in the UNCRC (Burr & Montgomery, 2003). Article 31 of the ACRWC reads “every child shall have responsibilities towards his family and society, the State and other legally recognized communities and the international community.” The child, according to his age and ability, “shall have the duty to work for the cohesion of the family, to respect his parents, superiors and elders at all times and to assist them in case of need” (a) and “to serve his national community by placing his physical and intellectual abilities at its service” (b).

According to ACPF (2011) although it is “encouraging and positive emotional ramification of familial inclusion, given that assisting family is an inherent aspect of Ethiopian society, most children work for long hours, up to four hours a day” (ACPF, 2011: 52-53), which may pose a question of child labor.

Poverty in the family also drives children to work to help themselves and contribute to the livelihood of their household. In the above story, the child explained that he should work to contribute as his family is poor. Some disabled children in the urban areas engage in income generating activities to help themselves and contribute to their family’s livelihood. Bira, a fifteen year old boy, who lives in small town, worked a shoe shining to earn money to buy his school materials and to support family. He said he returns back to home with bread and charcoal from his work. Bontu, a fifteen year old girl, who also lives in town, narrated how she helps her parents.

“I work handmade clothes like scarf and hat in the home, which I learned from my mom. My mom takes them to the market and also sales to the local people. She buys coffee and sugar with it. She also buys me clothes and shoes” (Bontu, girl, 15).

The stories of these two children indicate that disabled children also work to contribute to the wellbeing of their household in addition to fulfilling their personal needs. Poverty is closely associated with disability in Africa as both a cause and a consequence of disability (ACPF, 2014). The majority of children in Ethiopia live in extreme poverty that leads to childhood disability and children are engaged in the livelihood strategies (Committee on the Rights of the Child, 2005). Poverty also exacerbates the situation of the disabled children through making hard access to adequate health care and assistive devices. Families may not have the

resources to pay for assistive devices, medicine, or school fees for their children (ACPF, 2014). The welfare services for children and family are also non-existent in Ethiopia (Committee on the Rights of the Child, 2005).

On the other hand, the children also reported that they work to be independent from the help of family. Bira, the boy who works a shoe shining in the above story, said,

“.... It is better to work rather than becoming dependent on your family. I am supporting my family besides fulfilling my school expenses” (Birra, boy, 15).

It would be reminded from chapter five that disabled children are considered by the people as weak and unable to work. However, the various accounts of the children in my study elaborated so far show that these children play a significant role in the socioeconomic wellbeing of their household, which challenges this view of the society. As Boyden and Mann (2005) argue this calls for the greater attention to the children’s own experiences of their everyday lives. As can be seen from the children’s stories, these children are active agents in their lives and the lives of those around them like families (Prout & James, 1990).

6.2 The children’s schooling

As it has been apparent in the interviews with the children in the previous section, the children also combine helping parents with school. School is divided into shifts in Ethiopia. Children help their family through engaging in different activities after and before school. Work is a normal part for children in Ethiopia and school is most of the time combined with work (Abate & Abebe, 2013), as for most children in the global south (Woodhead, 2003; Punch, 2003),

Children with disabilities in general are less likely to start school and have lower rates of staying and being promoted in school (WHO, 2011). As stated, most children with disabilities in Ethiopia are found outside schools. Those who attend school also suffer a high risk of dropping out (Tirussew, 2005). Despite the launching of free and compulsory primary education policy for every school age child, there exists the shortage of primary schools in the country, especially in the rural areas. The special need education plan in Ethiopia has not been effectively implemented (Lewis, 2009). According to AFCP (2011b, 2014) lack of access to the physical environment and information, inadequate policy and budget, lack of trained teachers within schools and negative attitudes create barriers to disabled children’s schooling.

Almost all children participated in my study showed very low educational status. Although disability has been mentioned as the main factor for the children's school dropouts, several factors have complicated this situation. School distance, inadequate school facilities, lack of support, negative societal perceptions about disabled children's education and fear of social stigma were the main factors mentioned by the children in my study.

6.2.1 School distance and poor infrastructure

School distance and poor infrastructures were mentioned by the children as the main factor for school dropouts and inability to attend school. The majority of the children who participated in my study live in rural areas where schools are in critical shortage and located at far distances from the children's residence. Gemachu, a thirteen year old boy, shared his experience.

“There is only one school in our kebele and it is too far from my home. I dropped out when I was grade two” (Gemachu, boy, 13).

ACPF (2014) also found that long distances between school and home as the reason for not going to school for most children with disabilities in rural Ethiopia. Schools are sparsely distributed in the country. In my knowledge, one primary school per Kebele (neighborhood association) and one high school per woreda (district) town are normally built. A single high school in one Woreda (district) serves children from several kebeles (neighborhood associations). Sometimes children in the remote areas move to their relatives around schools to attend their education. Children who complete their primary education should travel to towns to attend high school usually many kilometers away from their family. Most of the time young people need to rent and live away from their family in towns to attend high school education. This means that it would be challenging for poor and disabled children to continue their education.

Besides school distance, infrastructures are poor both in the rural and urban areas. Roads are not built in the rural areas. Most public schools, both in rural and urban areas lack accessible environment and special facilities for children with physical disabilities. Only very few children get access to the rehabilitation services and assistive devices. Special need schools are few in the country and most of them are concentrated in the urban centers (Lewis, 2009). Public school construction does not take into consideration the issues of children with physical disabilities (ACPF, 2014).

6.2.2 Negative attitudes about disabled children's educational achievements

There is also a widespread negative societal perception about disabled children's educational achievements. As stated so far, people consider children with disabilities as weak, dependent and inactive at education, which influences them to have low academic achievements. The interviews with the children reveal there were negative attitudes about their educational achievements. The following narration demonstrates this.

“People think you as weak at education. Most people think like it is worthless to send disabled child to school” (Tirunesh, girl, 13).

Among communities, especially in rural areas, educating a disabled child seems to be considered as a worthless investment. The society holds the view that disabled children are not good enough at school and therefore less successful in their education (Tirussew, 2005).

In addition, there were also discriminations from able-bodied children at school. The children were marginalized in schools by their non-disabled peers in most school activities. Tirunesh, the above girl, continued;

Your school friends react to you in unpleasant ways. They do not want to be along with you in group activities and classroom exercises, for example. They neglect you even when the teachers arranged group work” (Tirunesh, girl, 13).

Interviews with the parents in my study revealed that parents were also not willing to send their disabled child to school because of fear of stigma. Sara, a 42 years old mother of a disabled boy, told me that she preferred to keep her son at home than letting him face another pain at school. The story of Abdi, a twelve year old boy, who was kept in home for several years without attending school, would be reminded from chapter five.

6.2.3 Lack of support

The children also lack social, economic and moral support from the government and other concerned bodies. Most families lack economic power to support their children (ACPF, 2014). As elaborated by the children there was significant lack of support from the government in the children's education. The following story would be an example.

“No government body helped me. My school gives me exercise books, pens and pencils once a year and sometimes clothes” (Abebe, boy, 14).

The children reported that they have received material support from schools and other non-governmental organizations. There has been no or little support from the government for the children to attend school and continue their education. Most supports for education of disabled children have been made by the NGOs (ACPF, 2014). The ACPF (2014) concludes that while most African countries signed most human rights treaties that uphold the educational rights of children with disabilities, implementation of these legislations and policies has been very slow. Most policies go unimplemented with the loophole like ‘funds permitting’ (kabzems & Chimedza, 2002).

6.3 Generational relations

The children in my study engaged in a two forms of generational relationships in their family – relationship with parents (intergenerational relations) and with non-disabled siblings (intra-generational relations). According the children’s interviews, their relationship with parents tends to vary between father and mother. Most children said that their mother is the one who frequently interact with them, especially in home than other members of the family. On the other hand, the parental relationship to the children also tends to go along the gender based division of labor previously discussed. The girls said that they are mostly identified with their mother while boys are associated with their father. The following extracts from interviews with two of the children illustrate this situation.

“I mostly ask my mom for help while I am doing something. My siblings sometimes neglect me when I ask for help. Mom always helps me and shows me how to do things” (Konjit, girl, 15).

A fourteen year old boy said he mostly participates in what his father undertakes.

“I mostly work with my father on the farm. My Dad taught me how to do plough and cultivate. He most of the time took me with himself while going to farming” (Abebe, boy, 14)

The parent-child relationship tended to follow the gender based division of labor existing in the family. As can be seen from the children’s extracts, boys mostly spend their time participating in outside work with their father and girls are affiliated to their mothers through undertaking home chores.

According to the parents in my study the intra-generational relationship between the disabled children and their non-disabled siblings in family tend to be characterized by some form conflict. Kedir, a father of a disabled boy, narrated the following.

“The children most of the time quarrel over the issue of doing this or that. We (parent) mostly order the able-bodied ones, but they complain we discriminate against them. As a result, they sometimes abuse him (a disabled boy). But we care more for him. His siblings can do things as they want. It is he who is unlucky” (Kedir, father, 45).

According to the parents, the relationship between disabled children and their non-disabled siblings is characterized by conflicts arising over different interests, especially role division in family. The parents mostly assign different tasks to the non-disabled children and tend to free the disabled child of different task in family. As can be seen from the narration of the above parent, the non-disabled children tend to complain this parental discrimination among the children. The parents also disclosed that the able-bodied children tend not to support and care for their disabled sibling. It would also be reminded from chapter five that the able-bodied children sometimes abuse and bully their disabled sibling.

6.3.1 Parental care for the children

The parents in my study explained that the care for the disabled children depends on some factors like the child’s overall health status, age, the severity of impairment, the support they have from siblings and a kind of work they engages in and their ability to undertake. Two of the parents narrated their experiences of caring for their disabled children.

“Children with disabilities in fact need different attention than others. But it depends on the child’s ability. The age matters as well. We were a little bit burdened when he (a disabled boy) was younger, for example. Now he stays outside with his siblings. His siblings will also help him. We still fear for him as he does not take care when doing things. But the good thing is he is healthy despite his disability” (Galane, mother, 42).

Girma, a father of a disabled boy, also told me his experience of raising up a disabled boy.

“In fact, he needs our support than the healthy ones. But he most of the time undertakes things by himself. He seeks support from us when he is doing something challenging. I mostly show him how to do things and become independent” (Girma, father, 47).

As can be seen from these narrations, the parents contended the view that the disabled children are burden of care and explained that the care of disabled children depends on factors like the child's health, age, and ability to undertake activities and support from siblings. The parents tend to think disabled children as not simply burden of care but as the care depends on circumstances and that they rather focus on socializing or teaching a disabled child on how to do thing. In this regard, the perspectives of the parents in my study tend to vary from that of society in relation to the disabled child's care. As repeatedly stated, society views disabled children as weak, dependent and therefore burden of care (Tirussew, 2005). As can be seen from the stories of the children so far, they help their household by engaging in varieties of economic activities. These stories also, to various degrees, demonstrate the children's independence and agency in their everyday lives.

6.4 Challenges in the children's everyday lives

So far in this chapter, I have been discussing how the children in my study navigate their everyday lives – the everyday activities they undertake, their schooling, how the generational relationships and phenomenon of parental care for the children were manifested. The children's reported that their everyday life experiences explored so far were negotiated by varieties of factors that affected their life and their participation in community. The major challenges reported by the children in my study were negative societal perceptions and environmental challenges which are discussed as follows.

6.4.1 *Negative societal perceptions*

Disability scholars from the social model of disability see disability as a social problem arising from a structural relationship between people with impairment and a discriminating society (Shakespeare & Watson, 1998; Oliver, 2009). As Shakespeare and Watson (1998) argue the major problem for disabled children is that they live in a society which views childhood impairment as problematic. Tirussew (2005) who has conducted a large study on 'disability and society in Ethiopia,' argues that disability is understood in terms of the prevailing societal understanding of its cause and consequences; and that there is a widespread negative societal perception about disabled children in Ethiopia. As it has been discussed in chapter five, disabled children in my study reported that they were marginalized in their everyday lives in school and villages and discriminated in family. The children also reported that there were negative beliefs about their ability and that they were victimized in their everyday lives.

1. Negative beliefs about the children's ability

As previously stated, the children's capacity to work and learn, live an independent life, form family, their role in socio-cultural and recreational organizations and their contribution to the nation building is downplayed by society (Tirussew, 2005). Associated to this is a variety of cultural expressions that are attached to disabled children which carry over negative assumptions about their ability. As also discussed in chapter five, figurative cultural expressions were used to describe the children's bodies and their ability to perform tasks. Tirussew (1998) in his study on the public attitudes about disabled people documented several figurative expressions commonly said in Amharic language to convey inability of disabled person to perform tasks. For example; the hearing impaired were addressed as *Donkoro* and *Duda* (one who cannot understand and tongue-tied), the visually impaired as *Ewir*, *Denbara*, *Libu ende ayenu yetawere* (one who is disorganized and not bright), those with motor/physical impairments as *Dewe*, *Komata* (highly disfigured or mutilated) and *Shibba*, *Ankassa Kulem* (curved or bent or lame) and children with mental retardation as 'you with 44 devils, *Ganel Am*, *Likift Am* (possessed by evil spirits) (Tirussew, 2005: 13). These kinds of constrictions are deeply embedded across different cultural groups in the country (Tirussew, 2005). However, these expressions do not represent the reality of the disabled children. As can be seen from the children's stories so far, the children undertake various activities in the everyday lives and contribute to their household's livelihood. These expressions illustrate the prevalence of negative and stereotypical assumptions in the society that downplay very efforts of the children to live independent life and deprive the children of their agency to participate in different everyday activities and their role in the various aspects of the society. These are dehumanizing and misleading terms which wrongly characterize the capability of disabled children (Tirussew, 2005).

When disabled children are involved in work or certain activity, there is a belief that they may make wrong or create destruction. They are believed as not having wisdom or skill to do something. Abebe, a fourteen year old boy, told me his school experience of working in teamwork.

"We are building a basket container as part of training for our handwork subject. One of my able-bodied friends told me that I have to rest because he told me that I will cause destruction in the work and then our grade will be poor" (Abebe, boy, 14).

Besides, the mistakes or faults of disabled children are attributed to their disability. For example, Abebe, the boy in the above story, further elaborated,

“When you, for example, unfortunately destroyed certain furniture, people become hot. They say to you... wayifu bofa mila dhogate” (‘God made a snake legless because He knows it is dangerous’). (Abebe, boy, 15)

The above extract shows that there is also belief that disabled children are originally having certain bad or dangerous personalities and that God disabled them to control their actions. As can be seen from the boy’s narration, it is ironically resembled to a snake. Like snake is made legless to control its dangerousness, physically impaired children (children with leg and arm impairments) are disabled to control their actions or heal them of the believed bad personalities. The children also said that family members also become abusive while they are found to have done wrong or committed even simple faults.

“My mom becomes hot and sometimes beat me even when I accidentally poured water. My siblings also tend to bully me while doing something.” (Konjit, girl, 14).

As can be seen from this narration, the children are subject to verbal and physical abuse in family. In Ethiopia, children are subject to abuse and violence among family (Committee on the Rights of the Child, 2005). Parents use corporal punishment of children as measure to discipline children towards good behavior (Poluha; 2004). Disabled children however might be more abused than the able-bodied as they are also subject to verbal abuses through these cultural construction and expressions.

2. *Victimization of the children*

On the other hand, people also view children with disabilities as victims and vulnerable. As children in my study narrated people tend to help them through different means. They give the children money, for example because there is a belief that disabled person/child is unable and therefore needy. The following extract from the dialogue with a fifteen year old boy illustrates this situation.

“I used to walk to school on my hands as both my feet are impaired. I have no assistive devices. The people feel pity when they see me walking like that. Some give me money. I actually earn money by shining people’s shoes after school. After I recognized that people will help me, I overtime continued begging as an alternative

means of income. I quit polishing people's shoes the day I got sufficient money from begging” (Haile, boy, 14).

The reaction of people when they see disabled children often goes along pity and compassion. As can be seen from this boy's narration, people tend to see children in need of help or charity and give them money even when the child does not need help. The boy in the above narration earns money by polishing people's shoes on the road after school. He began to use begging as an alternative means of income after realizing that people will give him some and quits his shoeshine job when he gets money from people. ACPF (2014) also found that there is a general tendency among the public to think of children with disabilities as weak, helpless and in need of help. A parent of disabled child was quoted in ACPF (2014) saying;

“Sometimes when I go out with my son, people consider us beggars, and just want to throw some coins. It is really upsetting and hurting.” (A parent of child with a disability, ACPF, 2014: 30).

Ansell (2005) argue that such societal reactions have reinforced the view that disability is a subject of charity rather than part of a government development policy agenda. I would also argue that this phenomenon would have created ‘dependency symptom’ on the part of disabled people/children by diminishing their capability, resourcefulness and agency to change their lives. Haile, the boy in the above story from my study, said that he began to use begging as an alternative source of income while he also works a shoe-shining on street. As to my personal experience, begging is widely seen among disabled children and people in urban parts of Ethiopia. Disabled children sometimes used as objects of charity by adult families or other agents.

6.4.2 Environmental challenges

The other factor reported by the children was environmental challenges. The children reported that they face enormous environmental challenges to undertake their everyday lives. Especially those from the rural areas said that the environment is mostly natural with variety of challenging landscapes and the infrastructure is almost non-existent. Most children with physical disabilities in the rural have no accesses to the rehabilitation services and assistive devices (ACPF, 2014). They face enormous challenges to undertake varieties of everyday

activities and to attend school. Gemachu, a thirteen year old boy sharing his experience of everyday lives in the rural village.

“It is challenging to go herding and schooling especially during a rainy season as the roads become muddy. It is also makes difficult to use Ule/Dulla (a wood made walking support) as it goes down and gets stuck.” (Gemachu, boy, 13).

In the urban areas as well, most roads and buildings such as schools are not accessible by the physically disabled children, who constrained the children’s everyday activities such as schooling and their participation in different community lives such as leisure and sport activities. Children in the urban areas have better chances of accessing rehabilitation services and assistive devices. Nevertheless the physical environment and the construction do not take the problem of people with physical disabilities into the account (Tirussew, 2005). Most buildings lack lifts and ramps for the wheelchair users (Ibid).

ACPF studies show that societal attitudes towards disabled children are gradually improving and becoming more supportive in Africa. For example, the majorities of households are including their disabled children in different socio-economic activities and there is also an increasing involvement of the children in school and other community lives (ACPF, 2014). Nevertheless, ACPF (2014) suggested that there is a wide gap in infrastructure development and the policy making and implementation. Policymakers tend to ignore the needs of citizens with disabilities and fail to ensure that policies are relevant, adequately inclusive, enforced and budgeted (kabzems & Chimedza, 2002; ACPF, 2014).

6.5 The children’s strategies to overcome everyday challenges

The children in my study were not only victims of the social and environmental challenges; they also had their own strategies to overcome these challenges. The interviews with the children and parents in my study show that the children use different local resources and have various special adaptive skills to the challenges they face in their everyday lives.

6.5.1 The use of local resources

Environmental challenges have been identified by the children as one of the challenges they experience to undertake various everyday activities. As noted so far in this chapter and in chapter five, mobility problem was reported by the children to have constrained their everyday activities like working, play and going to school. The use of various local resources

to overcome these environmental challenges and to undertake various everyday life activities with ease was reported by the children as one of the strategies to navigate their everyday lives. Most of them said they use locally made walking support and animals back to move to move. One of the children in my study told me the following.

I use Dulla to walk, which my father prepared for me. I also ride a donkey when I go to herding” (Abebe, boy, 14).

In rural areas, where the children cannot get assistive devices, families prepare homemade walking supports for the children. Children in my study reported the use a wood made walking support called ‘*Ule*’ in Afan Oromo or also ‘*Dulla*’ in Amharic. “Dulla” or “Ule” is a wood made stick used to support a person with leg impairment. Animals like donkeys are also used by children including those with physical disabilities to travel to work in rural areas. Most children go to farming and herding being on the back of the donkeys. Although parents play a major role in preparing these materials for the children, the children’s skill and readiness to get use of this locally made assistive material and animals back was an agentic skill. Some of them said they also fix the walking support or make another one if it is broken and that they do not need help to ride donkey.

6.5.2 *Special adaptive skills*

Apart from the use local resources to assist their mobility, the children in my study also had special skills such as mastery of doing things, problem solving abilities and being resilient and patient amidst challenges they face from the physical environment. Gemechu, a thirteen year old boy, who lives in a rural village, told me how he navigates his everyday life.

“You know, you will learn a lot of skills when you know that you do not have any choice than adapting. I know how to handle the obstacles I face in my everyday lives. I use Ule (a walking support). But still I face many challenges. I am patient and resilient though” (Gemachu, boy, 13).

As noted earlier, the children in my study engage in different activities with able-bodied siblings and friends despite their disability. Abebe, a fourteen year old boy, compared his situation to his able-bodied sibling and friends; and argued that he had his own especial skill although he is not as able as the able-bodied children.

“It is like a story of ‘the Rabbit and the Tortoise.’ I stay outside herding the cows with my able-bodied sibling and friends although I am not as agile as them. In fact, they also help me when it turns so challenging” (Abebe, boy, 14).

The children’s engagement in similar everyday activities with their able-bodied sibling and friends, would demonstrate the children’s competitiveness and agency besides their contribution to their household. Abebe, the boy in the above extract, metaphorically expressed he works with his non-disabled counterparts, referring to the story of the Rabbit and the Tortoise. According to the tale of these animals, which most children in Ethiopia have in their mind, the tortoise and the Rabbit once up on a time made a running race. In the race the rabbit ran fast and slept in the middle of the race because she wanted to take a rest until the tortoise come closer. However, the slow tortoise finally won the race as the Rabbit was a slept. He relates the non-disabled children to the Rabbit, which is very fast than the Tortoise and the disabled children to the Tortoise, which is slower. He used the story to demonstrate that although the disabled children face more challenges than the non-disabled ones they are still active and resilient. They have their own capabilities and agencies to undertake their everyday lives. As far as the meaning of the tale is concerned, it is not the mobility or ability or disability which should be concerned but the children’s resilience and determination to navigate their everyday lives amidst the challenges they face.

The parents in my study also argued that the children are resilient to the challenges they face in their everyday lives. They admired the children’s contribution to the household by participating in different productive activities. Galane, a mother of a disabled boy, explained the everyday experiences of her son.

“When you see most disabled children, they are strong, active and undefeatable by the challenges they face in their everyday lives. He (my son) for instance, helps us by working on farm field and herding the cattle with his sibling in the pastureland.” (Galane, mother, 42).

According to the parents the disabled children are not only the victims of the challenges they face in their everyday lives, but also can outshine everyday challenges. The children actively participate in different productive activities despite their disability. Boyden and Mann (2005) argue that children like disabled children have been presented as vulnerable beings that are subject to many social and environmental challenges that would interfere with their development and as a result, high attention is given to protection and care of the children.

Children who are in especially difficult circumstances are loudly presented by social research as leading the life that is considered generally difficult (Ansell, 2005). The accounts of children in my study however show that these children are not only subjects of the everyday challenges they face; they also have various adaptive skills and they use their agency and responsiveness to negotiate these challenges.

CHAPTER SEVEN

7 THE CHILDREN'S EXPERIENCES OF INSTITUTIONAL LIFE

The care of children with different forms of disabilities in Ethiopia has been the responsibility of family for a long time (Tirussew, 2005). Family, especially the extended one, plays a significant role in taking care of its members in Ethiopian society despite the impact of emerging changes in the family structure. As also discussed in chapter five, children with disabilities are intervened by their families through different traditional and indigenous mechanisms such as herbal medicine and holy water prescribed by traditional healers, people who are claimed to have knowledge about diseases and their cure, indigenous psychotherapy provided by a person called *Qalecha* (a religious man or a person with special spirit alleged to have a healing ability) and *Wogessa* (a person who gives physiotherapeutic services mainly for injuries and physical disabilities) (Tirussew, 2005: 25-27).

Nevertheless, disability intervention has been taking a new feature in the country for the past decades with the adoption of institutional rehabilitation (Tirussew, 2005). In Ethiopia, disability rehabilitation institutions have been established and are providing different rehabilitation services for children and people with different forms of disabilities. As stated, children in my study lived in the rehabilitation centre where they were provided different intervention services on a residential basis. The children live in the rehabilitation center for a period of up to five to six months on average. In this chapter, I will explore the children's experiences of institutional life in which I will discuss the intervention programs given to children in the center, the children's perspectives of these programs, their perspectives and experiences of living in the institution in relation to their lives in community.

7.1 The intervention programs in the centre

The institution provides a range of rehabilitation services to children with different forms of physical disabilities which include physical, social, educational and vocational rehabilitation and recreational services and various assistive devices. An overview of these programs is presented as follows.

7.1.1 *Physical rehabilitation*

The centre provides different physical rehabilitation services to improve children's physical wellbeing and mobility. These services include physiotherapy, orthopedics, massaging and

mobilizing, various body exercises and muscle strengthening through activities of daily lives. The centre also provides the children with various assistive devices such as wheelchairs, crutches and artificial limbs.

The institution also implemented different environmentally contextualized services like demonstrative farming and Animal-assisted therapy (AAT), particularly, Donkey-assisted therapy (DAT). According to the focus group discussion with the social workers, Donkey-assisted therapy (DAT) is aimed to use the benefits of positive animal-child interactions and relationships. The purpose of Donkey-assisted therapy is to improve a child's social, emotional, physical and cognitive functioning. The Donkey-assistive therapy relies on the physical and emotional qualities offered by the nature of donkeys. Donkeys can develop strong social and emotional bonds with children; and they are readily trainable, manageable, accessible and affordable. The assumption in the Donkey assisted therapy is that the children with physical disabilities ride donkeys and get a therapy through riding. Riding will give the children therapy and enhance their mobility. Furthermore, the Donkey-assisted therapy is fun and child-friendly.

Children are also taken to the farm and encouraged to work on farming. According to the social workers, the demonstrative farming is aimed to improve the children's mobility through participating in locally known economic activities. The children are familiar with these activities and do not need training. The social workers argued that demonstrative farming helps the children improve their mobility and learn the skills of local economic activities at the same time.

7.1.2 Social rehabilitation

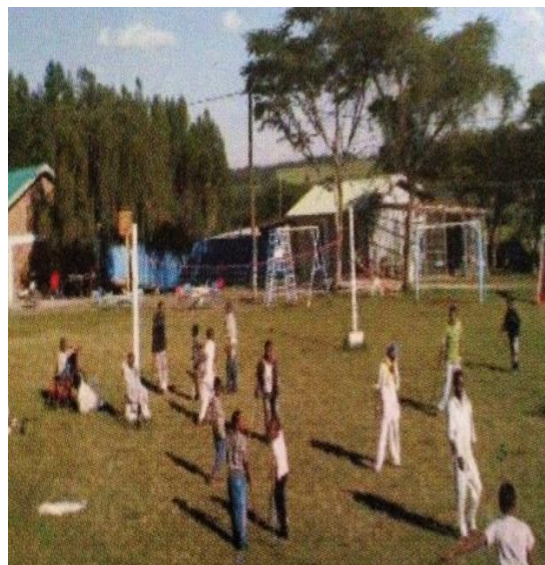
The social rehabilitation program provides counseling, advice and necessary information and service opportunities for children and their parents. Children are given different disability education and training that would develop their self-esteem and improve their participation at school and in community. Different social events such as coffee program and social talks are organized by social workers to teach children how to participate in community. Different awareness raising programs are also organized through outreach rehabilitation services to teach the local community about disability and the issues of children with disabilities. Necessary information on disability and rehabilitation service opportunities in the centre is also provided for children with disabilities who are in community and their parents to facilitate admission procedures. It was partly through such outreach program that many

children with disabilities in different communities were brought to the center for rehabilitation while others came to the centre through dissemination of information by children who have benefited from the centre.

7.1.3 Education and recreation

The center also gives educational services to the children to prepare them for school upon their return to their community. The teachers at the center teach basic subjects like Mathematics and English language and basic everyday life skills like keeping personal hygiene, for example.

In addition to education, the center also provides varieties of recreational activities that give children leisure. Children spend their everyday lives in the center playing different activities like table ball, tennis and football, and various physical activities. It would be reminded from methodology chapter that I organized a football match among the children and that the children actively participated in the activity. These activities are believed to also enhance the children's physical wellbeing, in addition to entertainment.



Picture 7.1: children's activities

7.1.4 Vocational training

Another program offered to the children in the center is a vocational training, which teaches children different vocational skills. According to my observation, the children practiced different vocational skills like making clothes such as hats, capes, small bags, and decorations

and other handcrafts. The purpose of the vocational training is to train children with different vocational skills that would help them engage in different income generating activities when discharged from the center and to further integrate them into community. I observed the children doing different handworks. The social workers said that the handcrafts are sold and the income is used by the centre.



Picture 7.2: children's handworks

7.2 Children's perspectives of the intervention programs

The children were asked their perspectives of the intervention programs provided for them in the center and they reported that they have seen improvements in their physical and social wellbeing. They also said that they have learnt many vocational skills in the center. They said they were also happy about the life in the center. I will discuss these improvements and their impact on the lives of the children in the center and in their later community life in this section.

7.2.1 Improvements in the children's physical and social wellbeing

According to the interviews with the children improvements have been brought in their physical and social wellbeing as a result of ranges of intervention services in the center. The most commonly reported changes by the children were improved physical health and mobility, and educational and vocational skills. The children were provided with assistive devices like crutches and wheelchairs which they said have improved their mobility. They also emphasized that the educational and vocational trainings will help them improve their life in community. Gemachu, a thirteen year old boy, was talking about being in the center.

“I am very happy to be here. My mobility was improved. Now I can walk fast using crutches. I also have learnt to do handworks, which I will do and make money by selling when I go back to my village. I will also be better at my education as I am taking training here.”

As elaborated in this narration, educational training may prepare the children to continue their school when they are back to their community. The children also learned several handwork skills in the center as a result of the vocational training given to them (see picture 7.2 above). It was believed that the vocational skills enable them to create their own business/income generating activities when returned to their community although it would raise a question about how much support the children may get from parents and the local government bodies to engage in such activities.

7.2.2 Changes in the children’s attitudes

As also noted in chapter five, the children reported that their attitudes about disability were changed since they came to the center as a result of the social rehabilitation given to them in the center. While they were in community they tended to view disability as god’s punishment or as a curse or as caused by evil spirits, which have largely been discussed in chapter five. After they came to the center, they began to understand that those assumptions are simply prejudice and stereotypes by people. A narration of a fourteen year old boy illustrates the children’s changing perspectives about their situation.

“I was thinking a disabled person as a ‘backward person’ who cannot perform things. Now I understood it is my identity which I am proud of. People do not have education about disability. They think disabled people are weak. I also have been thinking the same while I was in community. Now I have changed my mind. Disability is my identity and it does not prevent me from doing what I want. Here I see the manager of this centre is a disabled man like me, for example” (Abebe, boy, 14 year old).

Birra, a twelve year old boy, also said,

“People should stop discrimination against disabled children. We are equal to other children. We can work and learn like others do.”

According to the focus group discussion with the social workers, children are taught about the causes of disability and that negative societal attitudes about disability have been a major

barrier to the children's school attendance and participation in their community and that this has brought positive changes in the children's understanding of their situation. The children's improvement in this regard means a significant change in their everyday lives. As explained in the above narrations, the children's perspectives about disabled people are also shaped by interaction with disabled workers of the Centre. Experiencing disabled people who work in the center seem to have given the children courage and optimism about their future, which may change their attitude about the capability of disabled people. Some children showed their determination to fight against the negative societal perceptions about disability, although the question rises here is how much the children are heard in the society. Konjtit, a fourteen year old girl, for instance, expressed her readiness to teach the local people about disability.

“I will teach people in my area and my school friends that disability is nothing but a health problem and that a disabled person can live the life like other people” (Konjtit, girl, 14).

However, it would also be important to raise some issues in relation to what might be the shortcomings of these programs based on the children's perspectives about the intervention programs in the center. Although the children's attitudes about disability have been changed, social factors that 'disable' the disabled children may remain to persist. In the center, the children are separated from society, which makes them identified from the everyday lives of their community. This would have negative consequences of reinforcing social stigma in community. In fact, the center also works on public awareness through social rehabilitation services such as outreach program with local community. Such kinds of community based works are promising initiatives that need to be capitalized.

In addition, most institutions in Ethiopia are also located in city centers. Majority of children with disabilities however live in the rural areas and lack access to rehabilitation services (ACPF, 2014). This caused families of the children high cost of transportation as the parents in my study also reported. Kedir, a father who came to take his son, told me the following.

“I have not visited him since I left him here five months ago. He finished his treatment fifteen days ago. I even could not reach for him on time. I should pay for hotel besides a transportation fee” (Kedir, father, 42).

As it is apparent in the above complain, the parents from far areas were subject to many expenses to bring their children to and take back from the rehabilitation center. Whyte and

Ingstad (1995) argue that the rehabilitation institutions in the Global South countries are established by huge resources but they serve only small proportion of the population as they are located in urban areas.

7.3 Institutional life versus community life

The children's life in the institution is negotiated by range of aspects that make up their everyday life in the centre, like social life and generational relationships that is exhibited between the children and the social workers, and among the children themselves. Data from my observation, the children's interviews and the focus group discussion with the social workers indicate that most children are happy about living in the institution. The children saw living in the center better when compared to their community life in terms of the following aspects.

7.3.1 Better facilities

Apart from the treatment that is given in the center, the children also experienced a better life. The Centre has better facilities like living rooms, meal and water, which the children could not enjoy in their community. Abdi, a twelve year old boy, narrated how it feels to be in the centre.

“It is really good to be here. I got treatment. I sleep on a good bed and eat good food. There is no lack of water.” (Abdi, boy, 12)

As can be seen from this narration, the children were happy about the facilities in the center when compared to their life in their community. They were happy about the food, water and the living room.

Although the children reported that they are happy about the institutional life, I fear that they would experience problem of 'post-institutional integration' when they return back to their community. Although it is for a short period of time, mostly up to half a year, the children learn different life that varies from their conventional life in their home communities. This may have its own impact on later lives of the children when they returned to community. Most children in Ethiopia live in an extreme poverty (Committee on the Rights of the Child, 2005). Especially in rural areas, where most of the children in my study came from, children's life is characterized by poor socioeconomic circumstances such as lack of basic facilities like clean drinking water, electricity, and roads, healthcare and schools (Tirussew, 2005). Most

families live an impoverished life mostly characterized by the lack of /inadequate basic needs. This paradox might create integration crises when they return back to their community.

7.1.1 Autonomy and liberation

On the other hand, liberation from the adult power and social stigma was also mentioned as another advantage of being in the centre. In the centre, the children are more autonomous and independent from parental control. The homogeneity of the children in the center has also given them independence from the social stigma, segregation and discrimination that has been reported by the children as common experiences of their everyday lives in community. Abdi, the above boy continued;

“I play with children like me. There is also no worry about parental control.” (Abdi, boy, 12)

Haile, a fourteen year old boy also said;

“Here, I play as I want. It is not like school. We all are the same children. No one disturbs.” (Haile, boy, 13)

Being in the centre gave the children chances to experience their agency without barriers. They engage in a variety of play and sport activities in the center (see picture 7.1 above). In addition to serving leisure and physical wellbeing, children’s participation in these activities demonstrate that the children are active beings, who can participate in leisure and sport activities. As Clocker et al. (2007) argue children’s agency is negotiated by socio-cultural contexts, personal biography and spatial relations. This account of the children in the centre was a demonstration of the fact that the children use better social and spatial opportunities to play out their agency.

7.1.2 Social life and friendship

Another experience the children narrated about living in the institution was the social life and friendship they experienced in the institution. According to the interviews with the children and the focus group discussion with the social workers, the children enjoyed the social life in the centre. One of the girls narrated her experience of living in the centre.

“We think like the children of one family. We eat together, live in a common room and spend a day together. We play together. We think of each other about our treatment. I think, I gonna miss my friends when I left this center” (Bontu, girl, 15).

As I also observed, the children lead a collective life in the centre which developed a high degree of interaction and cohesion among them. They live together, eat together, and gather together, chat, play and make a lot of fun. The children’s social life in the centre seems to have been strengthened by the fact that they share a common identity. The children’s everyday life in the centre is characterized by senses of belongingness, togetherness and solidarity. The social life in center seems to have exhibited a friendship that would go beyond the space and time limit of the centre. As elaborated in the above narration, some children expressed that they will miss each other when they left the centre.

7.2 Relationships with the social workers

The children also talked about their relationships with the social workers. They revealed that they experience little power from the social workers and that the social workers engage with them in their everyday lives. Bontu, a fifteen year old girl, described her relationships with the social workers.

“The social workers show us love and affection. They are kind and supportive. They help us move, push our wheelchair. They treat us like friends... they talk to us and sometimes engage with us in play activities. They advise us to be strong at our education, show us hope... I am really happy with their treatment.”

In the focus group discussion, the social workers also discussed that they exert little amount of power over the children. They mostly tend to control the children in times of treatment. According to the social workers, although most children were less interactive upon their arrival and some felt home sickness and unfamiliarity to a new environment, they began to adapt to the institutional life within a short period of time. They argued that the less authoritarian relations they have with children has created good environment for children to actively integrate into the institutional system and play out their everyday lives without more barriers.

CHAPTER EIGHT

8 DISCUSSION, CONCLUSION AND RECOMMENDATIONS

My study explored the perspectives and experiences of children with physical disabilities in one of the rehabilitation centers in Ethiopia based on a two month fieldwork. In this chapter, I will make a brief discussion of the major findings in my study and forward concluding remarks and recommendations based on the findings.

8.1 Discussion

Much has been learned about the children's experiences and perspectives of their disability situation through the fieldwork. I will reflect on the major findings of my study based on the research questions that my study sought to address. These research questions were:

1. How do children with physical disabilities view growing up with disability?
2. How do children with physical disabilities experience their everyday lives?
3. What challenges do they face and how do they negotiate these challenges?
4. What are the children's experiences of institutional life?

The first research question that my study planned to answer was '*how do children with physical disabilities view growing up with disability?*' This question was addressed through exploring the children's perspectives of their disability situation in which they live. As such, the children in my study viewed growing up with disability as subject of 'difference' from other people especially from their able-bodied peers. The children viewed being disabled as being different from their able-bodied peers in terms of body, mobility and ability to undertake everyday life tasks. The children tended to compare their disability situation to that of the able-bodied children and see their disabled body as a problem. It was apparent from the children's interviews that disability was viewed as abnormal while non-disability/being able-bodied was seen as normal. The children also reported that they feel difference in terms of mobility and activity performance from able-bodied children. In most interviews with the children, phrases like "I can't run," "I can't play or work as able-bodied children" were common. The children also viewed growing up with disability as being subject of marginalization, powerlessness and occupying lower social status in family and among able-bodied children.

These perspectives of the children about their disability situation were primarily influenced by socio-cultural construction about disability prevailing in their community. As the children and the parents in my study narrated, people view disability as God's punishment for doing sin or as caused by elders' curse or evil spirits. It was believed that God's anger or elders' curse on parents will result in illness or disability of the children. Disabled children were therefore viewed as having cursed or sinful family background or having been possessed by evil spirits. These assumptions about disability were reproduced through generational relations. The children hear from their parents and local people. Able-bodied children reproduce these stereotypes in school and villages. Most disability treatments were also made in traditional rehabilitations such as the use of holy water, called '*Tsebel*' in local language) and various herbal medicines. Parents also take disabled child to local church men and traditional healers.

As a result of these stereotypical assumptions about the sources of disability prevalent in their community, the children were segregated in school and in the village by able-bodied children. They experience limited social interaction with their able-bodied peers in schools and villages. This limited social interaction was also negotiated by negative reaction from able-bodied children who tend to bully and abuse them. The children were marginalized even in their family through these negative assumptions. For example, they were viewed as weak, unable to work and learn. Some parents hide disabled children in home for several years without schooling and contact with social world because of fear of social stigma. It was generally apparent from the children's accounts that they tended to live a childhood that was marginalized in many forms and experience less power and occupy lower social status in their family and community. They were deprived of their rights and agency to live independent life and make their social world.

It was however, apparent that the children's perspectives about their disability situation were changing. The children's understanding of disability varied based on social, cultural, personal, temporal and spatial factors. As noted, the socio-cultural perceptions about disability in their communities were powerful factors that shaped the children's view of disability along certain lines of understanding (cultural, religious or scientific). Furthermore, parental knowledge about disability, socio-economic backgrounds like educational status of their parent and whether they live in rural or urban areas also affected the children's perspectives of their disability situation.

The second and the third research questions were addressed together as they both focus on the children's everyday life situations. These questions were *how do children with physical disabilities experience their everyday lives, what challenges do they face and how do they negotiate these challenges?* These questions were addressed by exploring the children's everyday activities, their schooling, relationships with parents and siblings, the challenges they face in their everyday lives and how they negotiate them.

Children in my study reported that they engaged in different livelihood activities of their household. They engaged in various activities ranging from home chores like cooking, cleaning, washing and looking after young children to herding animals and working on farm fields. There were no differences between the kind of activities children in my study engaged in and those activities commonly undertaken by able-bodied children in most communities in Ethiopia. Home chores, herding cattle and working on farm fields are common childhood activities in many communities in Ethiopia. However, there would be differences in the extent of their involvement, the challenges they face and how they negotiate these challenges. Some children engaged in income generating activities like shoe-shining and handworks and support their household with income. Gender based differences were seen among the kind of activities that children in my study were engaged in as boys mostly reported outside activities like herding and farm fields, while girls on the other reported home chores. These gender based division of labor were not different from the one prevailing in society. The main reason the children reported for taking part in their household's livelihood/activities were their responsibility to help their households, shortage labor force in their household, poverty and the need to be independent from parental help.

The children combined schooling with these activities. Almost all children in my study had lower educational status. One of these children had never attended school as he was hidden in home for several years because of fear of social stigma. The children's schooling was affected by school distance, poor infrastructure, negative societal attitude about disabled children's educational achievements, social stigma and limited support from parents and government.

It was apparent that parents and siblings were the significant others in the everyday lives of the children in my study. According to the children and the parents, parents provide the children support and control their everyday lives on the other. The parent took the role of socializing the children through teaching them societal rules, roles and responsibilities, and how to undertake different everyday activities and prepares them for future lives. The parents

in my study revealed that they tend to care more for the disabled children when compared to the able-bodied siblings. They also argued that although disabled children seek more care from their parents than the able-bodied ones, the care for disabled children depends on circumstances such as the wellbeing of the child, child's age, a kind of activity the child undertakes and the amount of support from siblings. The relationship between disabled children and their non-disabled siblings is characterized by some sort of conflict basically based on division of labor in family. The parents in my study reflected that they mostly tend to order the able-bodied children to undertake most tasks in the family while they tend to make the disabled child free of responsibility. Some disabled children in my study on the other hand considered this exemption from family responsibilities as a marginalization from family affairs. This account tends to conflict with the ideas of child care/protection on the one hand, and the principle of the best interest of the child enshrined in the UNCRP and CRPD on the other. As also has been seen from some children's claim in my study, parental exemption of the children from some tasks in the name of care/protection also deprived of the children their agency to undertake the activities they wished to undertake.

The major challenges the children reported in their everyday lives were negative societal perceptions and the environmental barriers. As mentioned earlier, segregation and marginalization were common in school and in the village from able-bodied children. Negative attitudes were held about the children's ability and they were victimized. Many cultural expressions were used in their communities to explain that disabled children are weak and unable to work and learn. On the other hand, the children indicated that the physical environment was challenging to go about everyday lives. The children reported that the infrastructure was poor in their communities, especially in rural areas. Moreover, children in my study said they had less access to the rehabilitation services and assistive devices before coming to the center. The construction of the schools and other public buildings, mostly in urban areas does not take the issues of disabled into account.

Nevertheless, the children in my study were not only passive subjects of the challenges they face in their everyday lives; they also created various opportunities, strategies and made use of the resources at their hand to navigate their everyday lives. They used homemade assistive devices used to support their mobility called *Ule/Dulla* in local the languages. They also used animals like donkeys to travel to work, for example. They had various skills that help them navigate their everyday lives amidst challenges like special mobility skills, mastery of doing things and creativity. They were also resilient to the challenges they face while also using

their agency to mobilize existing opportunities such as social support from their family and friends.

The last research question - '*what are the children's experiences of institutional life?*' - was focused on the children's institutional life. This question was addressed through exploring the varieties of children's institutional life experiences such as rehabilitation services available in the center, children's perspectives of these services, the children's relationships among themselves and the social care workers, and the social care workers' experiences of serving children in the center.

The children were provided with different intervention services such as physical rehabilitation, social rehabilitation, vocational training, education and recreational services in the rehabilitation center. The children were happy about the services provided for them in the center. They reported many changes since they came to center which include improved physical wellbeing such improved mobility through treatment and the use assistive devices, improved social wellbeing through education and recreational activities. The children argued that education in the center will prepare them to continue their education and that the vocational training will also help them develop skill to engage income generating activities when they return back to their community. The children also have brought attitudinal changes about the phenomenon of disability after they joined the Centre as a result of the social rehabilitation given to them in the center. The center also works public awareness with the local community through outreach programs.

The children also reported that they enjoyed the institutional life. They argued that the center had better facilities, and gave them liberation from social stigma and autonomy from parental control. They also revealed that they enjoyed the social life exhibited among themselves and the relationships with the social workers. It was observed from various activities of the children in the center that they children gained autonomy and independence to exercise their agency. They engage in various sport and leisure activities despite their disability situation. As noted above, the children were deprived of their rights to live independent life and exercise their agency. They were marginalized in the family and at school and in their village by their able-bodied peers.

According to the social workers, some children tended to experience home sickness, problem of adapting to a new environment for some time but gradually began to adapt. The social workers pointed that they exercise less power control over the children and argued that the

children's autonomy and independence in their everyday lives in the center opened up opportunities for the children to adapt to the institution and integrate to each other.

8.2 Conclusion

The perspectives and lived experiences of disabled children in Ethiopia have been neglected in many research conducted about them. Most studies rather tended to document the prevalence, the causes and impacts of disability and the perspectives of society about disabled children. My study has tried to explore the children's perspectives and everyday life experiences.

The children in my study have their own lived experiences, perspectives, aspirations and needs through which they navigate their everyday lives and construct their social world. The children think the situation of disability in which they live as a subject of difference in various ways from able-bodied children and that it has rendered them marginalization, powerlessness and lower social status in their family, among their peers and in their community. Although they were constrained by negative societal beliefs prevailing in their communities and poor infrastructure, these children contributed to their households through engaging in various activities. It was discovered that these children were engaged in similar kind of activities that able-bodied children in many communities of Ethiopia perform like home chores and herding and working on farm, for example. This would indicate that these children are part of their communities and play productive role, although their level of involvement varied and negotiated by various factors. This also calls for the public/the communities in which these children live to give accounts for these children's endeavors and empower them. It also calls for the researchers to understand the disabled children's lived experiences and the role they play in their family and community as well. As Boyden and Mann (2005) argue:

There is a deal more research needed in this field, especially in the Global South context and with children whose lives do not conform to the images perpetrated by the existing literature. These children have much to teach us in terms of broadening our understanding of wellbeing and coping in extremely difficult situations. Given the diversities of issues under consideration and the diversity of children's lives in different circumstances, it is crucial that we do justice to these children's experiences and perspectives. Doing this means increasing our knowledge while avoiding

simplistic policy recommendations aimed at reducing risk and enhancing protective factors (p. 21).

The children in my study have different strategies to negotiate various everyday challenges. They have their own agency to create various skills and opportunities and mobilize the local resources. Although children in my study had various coping strategies amidst challenging social and physical environment, there was substantial lack of support and policy neglect from the government. Moreover, although poverty is a nationwide problem in the country, children with disabilities are among the poverty stricken population (ACPF, 2014; Tirussew, 2005). My study has not explored these aspects of the children in detail. In therefore recommend future studies to explore more about these accounts of the children. It was also not reflected on how the children negotiate the negative attitudes that they face in their everyday lives despite the fact that there were just subject of these negative attitudes.

In addition, as my study was conducted with children who were in the rehabilitation center, I could not get the chance to engage in these children's everyday lives in community, which would have been interesting. I will recommend future studies to also include the children who are in community and to contrast these two groups of children. I also came across an account of a child who was kept in home by parents because fear of stigma. These might also invite another attention to discover similar accounts of the children.

It was apparent form the children's experiences in my study that the rehabilitation institutions play a significant role in empowering disabled children. Improvements in the children's physical and social wellbeing like mobility improvements and attitudinal changes about the phenomenon of disability as a result of the various rehabilitation services in the center were in fact promising. However, these children's 'post-institutional integration,' might also need to be considered.

8.3 Recommendations

In this part, I will finally forward some of the recommendations that might be considered by relevant stakeholders in the lives of these children.

1. **Public awareness creation:** it is important to create public awareness about disability and disabled children. The government might work with other agencies; NGOs and

rehabilitation institutions to initiate series of community development works to change the attitudes of the public about disabled children. In this regard, rehabilitation institutions may work more on community through outreach programs or other means to change the attitudes of family and community.

2. **Towards better rehab services:** rehabilitation services might work not only on institutionalization of children, but also consider shifting their model of services to community based rehabilitation so that they could work on the source of the problem (the community) rather than the victims (the children).
3. **Better infrastructure:** The government needs to first give attention to the children's needs. Basic facilities like health centers and school should be fulfilled for the children in their communities. Constructions should be inclusive that they can accommodate children with disabilities.
4. **Towards better community:** community should understand the children's everyday endeavors. The children in my study reflected that they work and engage in various activities and contribute to their households. Some even support their household through working different income generating activities. These are the best examples to see the disabled children's ability. Change should start at the family and schools through empowering the children. This might entail collaborative work of the government, the media, the rehabilitation institutions and schools on public awareness. NGOs also need to invest on community development works rather than institutionalization of disabled children.

Finally, I would like to end with a piece of advice from Shakespeare and Watson (1998) regarding how we need to think about disabled children.

While becoming aware of the ways in which children are isolated and oppressed, we must not end up thinking of them as victims or tragedies; while understanding that the disabled children are a social group, we also remember that they are individuals; while understanding the similarities, we must recognize the differences, including issues such as gender, race, class, and particularity of impairment itself. The social model should guide our analysis and the principle of disability equality should inform our values, but our ultimate commitment must be to the views of the disabled children themselves. As researchers or social workers, our task becomes clear; to listen to what disabled children say about their lives, respect their wishes and support their choices (pp. 25-26).

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APPENDICES

I: The participants

Table 1: child participants

Children				
Gender(Boy /Girl) (B/G)		Age (12-15)	Education/ class grade	Rural/Urban (R/U)
Boys	B1	14	4	U
	B2	14	2	R
	B3	15	6	U
	B4	12	0	R
	B5	13	0	R
Girls	G1	14	3	R
	G2	12	1	R
	G3	15	4	R
	G4	15	4	U
	G5	14	5	R

Table 2: adult participants

Adults				
Gender (Father/mother) (F/M)		Age	Education/class grade	Rural/Urban (R/U)
Fathers	F1	47	Basic	R
	F2	42	7	R
Mothers	M1	39	8	R
	M2	45	Basic	R

II: The research tools

Project title: *Growing up with disability: Exploring the perspectives and experiences of children with physical disabilities in Ethiopia.*

Research questions

The main research question: ‘what are the perspectives and experiences of children with physical disabilities?’ The study, more specifically planned to answer the following research questions.

1. How do children with physical disabilities view growing up with disability?
2. How do children with physical disabilities experience their everyday lives?
3. What challenges do they face and how do they negotiate these challenges?
4. What are the children’s experiences of institutional life?

I. Interview

a. Interview guides for the children

Number of children: **10**

i. Personal information

1. Age: _____
2. Gender: _____
3. Educational status: _____
4. Residential area: Rural/Urban: _____

ii. Children’s experiences of everyday lives

1. What activities do you do every day?
 - a. How do you perform these activities?
 - b. With whom?
 - c. Why are you engaged in these activities?
2. What obstacles did you face in your everyday life?
3. How did you manage to overcome these obstacles?

iii. Children’s perspectives about their disability situation

1. How do you perceive your disability situation?
2. Explain what disability means for you from your point of view?
3. Tell me how other people think about /talk of your disability?
4. Tell me what do you think about others’ thinking of your disability?

iv. Intervention programs available to the children and Children's perceptions of the programs

1. Tell me how it looks to be in this center?
2. What are services provided to you in this institution?
3. What are your perceptions about these programs?
4. What does the relationship between you and the person who treats you in this centre look like?

b. Interview guides for the parents

Number of parents/guardians: 4

i. Personal information of the parents

1. Age: _____
2. Gender: _____
3. Educational status: _____
4. Occupation:
5. Place of residence: Rural/Urban: _____

ii. Parental perspectives of their child(ren) with disability

1. What do you feel about your child's disability situation?
2. Tell me how other people think about the situation of your child?
3. What supports do you give for your child in his/her everyday life?
4. How does the care for your disabled child look like?

II. Focus Group discussion with the social workers

Number of participants: 4

Focuses of discussion

1. The services or interventions provided to the children in the centre
2. Social workers' experiences of working with children with physical disabilities
3. The relationship between the children and the social workers

NB: The interview and focus group discussion guides outlined above were simply the guides and starting points during interviews and the focus group discussion. Based on these guides detailed dialogues were made with the children in which the children narrated their experiences, perspectives and life histories.