# Unfolding the Realities of Family Care: The Experience of family members caring for a child with disability

By: Woynishet Kerebih

College of Social Science

School of Social Work

Addis Ababa University

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By: Woynishet Kerebih

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Advisor: Debebe Ero (PhD)

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School of Graduate Program

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## A thesis submitted to school of social work

Approval of board of examiners

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| Advisor | Signature | Date |
| Examiner | Signature | Date |
| Examiner | Signature | Date |

## Declaration

I the undersigned, declare that this thesis is my original work, has never been presented in this or any other university, and that all resources and materials used here, have been well acknowledged.

Name: Woynishet Kerebih Desta

Signature: ___________________________

Place: Addis Ababa University, Addis Ababa, Ethiopia

Date of Submission: __________________

This thesis has been submitted for examination with my approval as a university advisor.

Name: Debebe Ero (PhD)

Signature: __________________

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## Acronyms

WHO- World Health Organization

CBR- Community Based Rehabilitation

HIV- Human Immune Virus

AIDS- Acquired Immune Deficiency Syndrome

PWD- People with Disability

CRPD- Convention on the Rights of Persons with Disability

UN- United Nations

ILO- International Labor Law

NGO- Non Governmental Organization

CWD- Children with Disabilities

## Abstract

*Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. The challenge of facing disability is not only the problem of children with disability rather it becomes a problem of primary care givers because they are in one way or another becomes a part and parcel of the caring process. By using qualitative research design with the method of case study, the study explored and described the experiences of mothers who are responsible for caring of children with multiple disabilities generally and exploring and describing the feeling of mothers, the challenges they faced and how to take care their responsibility specifically. Five mothers (clients of BGW), two FGDs and two key informants were interviewed and tape recorded. 9 themes and 34 sub themes were identified and based on these themes, the research identified that mothers as a primary care giver involved in every activity to take care of their children so their ample time was taken by their children due to the demanding nature of caring. Social isolation, high level of stress, burden, occurrence of health problems, not able to engage in income generating activity simply, abandon their marital life and are always very much worried about the future fate of their children when they may face sickness, problem or death . Mothers also experience wrong societal belief and have negative impact on care giving beliefs like: disability is occurred as a result problem in kinship, curse and sin, children with disability are useless and they should be raised in human service organization. Regarding coping mechanism, strength of mothers, high level of attachment to their religion, strong level of support from BGW and not listening negative sayings forwarded from their surrounding environment were identified. Involvement of all stakeholders and integrated interventions at all level from policy, social work education and research is important in order to alleviate the challenges faced by children with multiple disabilities and their family care givers.*

***Key words: multiple disabilities, children, mothers, experience, policy, societal beliefs***

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# CHAPTER ONE:

# INTRODUCTION

## 1.1. Background of the Study

Generally human beings living in this world face so many challenges. One of these challenges is dealing with disability at individual level and its effect at family level. Such challenge can occur anywhere in the world irrespective of sex, gender, race and ethnic affiliation in any cultural and social setting. According to WHO (1980) on the context of health experience, disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being and disability is characterized by excesses or deficiencies of customarily expected activity performance and behavior, and these may be temporary or permanent, reversible or irreversible, and progressive or regressive.

Literatures say disability has so many causes. As Maxwell, Belser, and David, (2007) said, poverty is one of the biggest causes of disability. Poor people are most vulnerable to disability because they are forced to live and work in unsafe environments with poor sanitation, crowded living conditions, and with little access to education, clean water, or enough good food.

The challenge of facing disability is not only the problem of an individual living with disability rather it becomes a problem of the family as a whole because each member of a family in one way or another becomes a part and parcel of the caring process. Cuzzocrea1, Larcan1 and Westh,( 2013) research results showed differences in family functioning, parenting stress, and parenting style in the two types of families(a family caring a person with disability and a family without a person with disability) with differently aged parents. The results confirmed that the need to better examine family functioning in contexts in which each component inevitably dynamically contributes to ensure a proper fit and to reduce the vulnerability of the family system. They proposed a solution of family adjustment, stress, and parenting style seem relevant factors in ensuring that families can better adapt to children with disabilities.

Sandra and Abdelrahim, (2016) stated that learning that a child has a disability can have a significant impact on the family. When a disability is confirmed in early childhood, unique challenges arise as parents, siblings, and other family members shift their perspectives on what they envision for their child and for themselves and they propose a solution that efforts must be  increased in the inclusion of the whole family in treating and assisting children with disabilities. Moreover, O'Hanlon, (2013) empirical literature, focused on the needs of families of children with disabilities, stresses the importance of successful family coping to better support the child with a disability, the role of social support as a means of successful coping, and in particular, religion, as a positive means of support for families raising a child with a disability.

Majority of research papers were conducted in western countries and they mainly focused to explore the negative consequences of disability on family members who have directly or indirectly involved in care and support of a child with disability. However my study focused on searching the problem at household level, exploring family experiences, who involved in caring of a child with disability especially multiple disabilities, seeing in social work perspectives in our social and cultural setting. Thus this study explored about experiences faced by family members who were directly involved in care and support of a child with multiple disabilities in Brother of Good Works Counseling and Social Service Center, a faith based organization under Ethiopian Catholic Church, particularly department of Community Based Rehabilitation (CBR).

## 1.2. Statement of the Problem

More than one billion people in the world live with some form of disability, of whom nearly 200 million experience considerable difficulties in functioning. In the years ahead, disability will be an even greater concern because its prevalence is on the rise. Across the world, people with disabilities have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than people without disabilities,(WHO, 2011).

Due to the increasing occurrence of disability, stress experienced by family members who involved in care giving also becomes part of their life. In my work place while we tried to engage mothers of children with multiple disabilities in income generating activities, we have been facing those challenges in day to day work activity and the researcher believed that such family care giving experiences need to be further explored from care givers point of view under their social, cultural and economic setting. Understanding caregivers’ experiences may be useful in prompting governments and service providers to invest in education and support programs aimed at helping caregivers to cope with this stress and deal with the behaviors associated with the problem of multiple disabilities.

I came across with research papers in relation to my research topic. According to Ayenalem, (2014) worked in families living with a child diagnosed with autism:

challenges and coping mechanisms said that the functional family system is experiencing a challenging situation due caring a child with autism which further affects family members and the community at large and the study unraveled the challenges in relation to psychological, social, economic, marital and sibling aspects and coping mechanism of families living with a child diagnosed with autism. Hiwot,( 2002) also did research on experience of mothers of children with mental retardation with a finding of the overall challenges they faced and the community, including that the family had to bear all the experiences in upbringing, supporting to educate, employ, & guide the Mentally retarded children to lead sustainable & appropriate life. Another researcher was Berhanu, (2004) on the issue of psychosocial experiences of parents with mentally retarded children and he well stated about the social and emotional experiences families faced and the coping mechanisms in order to tackle the challenges.

In addition to the above researches Sandra B. & Abdelrahim, (2016) on their summarization of review of literature said that, most of the studies examining the impact of supporting a child with disabilities have focused on the negative effects; however, several studies have considered the positive effects on the family. Although small in number, these studies are important as they help provide a balanced view of the impact of disabilities on families. Other than negative consequences, parents experience high levels of quality of life in raising a child with disability positively, framing their child’s disability within their religious and spiritual beliefs, caregivers derive greater satisfaction and fulfillment in supporting their children and siblings also learned how to take care of others and to be more accepting of others with differences, with several siblings reporting intentions to pursue careers with caretaking or protective roles.

Additionally, this positive experience linked with facing disability within the family while they had been giving care for their beloved ones given little attention even globally; in Ethiopia, family members who are responsible in caring a child with multiple disabilities in psychological, social, physical and economical dimensions had not received much research attention. As shortly presented above, most researches in Ethiopia focused on investigating the issues pertaining to children with disabilities rather than on care givers. This research however, intended to assess and explore the negative and positive experiences faced by family members who were involved in caring a child with multiple disabilities.

This gap in our understanding of the care-giving experiences and the challenges faced by family members of children with multiple disabilities in Ethiopia and the day to day observation of challenges at my work place were the motives behind for conducting this study.  Generally, the study focused on the care-giving experience in different life dimensions, the influence and impact of experiences on their life, exploring feelings of family members on the issue of multiple disabilities.

## 1.3. Research Questions

Main research question:

What are the experiences of family members who are responsible for caring children with multiple disabilities in psychologically, socially and economically?

Specific research questions:

How do family members feel about and give meaning to their experience of caring for a child with multiple disabilities?

How do they handle the responsibility of care giving for a child with multiple disabilities?

How do the care giving experiences for a child with disability affect family member's life?

How do families explain their experiences of caring for children with multiple disabilities?

## 1.4. Objectives of the study

### General Objective

The general objective of this research is to explore and describe the experiences of families who are responsible for caring of children with multiple disabilities.

### Specific Objectives

To explore the feeling and meaning of their experiences in care giving for people with disabilities

To describe how care-givers manage their care giving responsibilities

To describe the effects of care giving, for a child with disability, on the lives of family members

To explain family members experiences who are responsible for caring a child with multiple disabilities

## 1.5. Significance of the Study

The significance of this study is to explore the challenges faced by family members who engaged in care giving of a child with multiple disabilities in their own cultural and social setting. By explaining and exploring family members experiences while they were involved in care and support , the study added to the body of knowledge to other families facing the same problem and gave valuable experiences to social work professionals to consider the needs of caregivers in the intervention process, the nature and context of their care giving experience, and other family member's issues could be taken into account when interventions has being devised for their children facing disability.

This study added the body of knowledge by clarifying and exploring the experience of family members in providing care for their relative with multiple disabilities. By exploring the problem from the family caregiver's perspective, the study aimed to add to the advancement of empirical knowledge regarding the experience of care-givers and mapping comprehensive nature of care giving for a child with disability relatives in the organization in particular and in Ethiopia in general.

The study also informed social work practitioners about the experience of family members caring for children with disabilities particularly multiple disabilities. This could further initiate intervention programs and policies by responsible bodies. The study also may assist other researchers in giving empirical information about the issue and become a starting block for further studies that would be planned in our Ethiopian cultural and social setting.

## 1.6. Scope of the Study

The study was focused on the experiences of family members caring a child with disability and who were clients of Brothers of Good Works Counseling and Social

Service Center particularly Community Based Rehabilitation department. The organization is currently working at Arada Kifleketema particularly at Woreda 2, 3 and 4 whose beneficiaries are people living with HIV/AIDS, orphan and vulnerable children, commercial sex workers and children with disability. This study was undergone on clients who lived in Arada sub city and the sub city is one of the densely populated sub-cities in Addis Ababa, which have ten Woredas and having nine hundred point seven hectares in dimension.

## 1.7. Operational Definitions

**Family** – Family for this particular study is an entity that deals with caring of a child with multiple disabilities.

**Child** - A child for this particular study is a child who lives with his/her families and whose age is under 18.

**Child with multiple disabilities** - Child with multiple disabilities is the one who faces two or more disabilities, living with family care givers and whose age is under 18.

**Experience** – Any perception, thought, feeling, activities, lived situations etc. of family members who are responsible for caring a child with multiple disabilities.

# CHAPTER TWO

# REVIEW OF LITERATURE

This chapter consists of reviewed literatures about understanding and defining disability,  models of disability , disability and family caregivers , experiences of care-giving for a family member with disability , care giving challenges and impacts faced by family members involved in care giving and conceptual framework.

## 2.1. Understanding and definitions of disability

The definition of persons with disabilities (PWD) which is accepted and currently in use is of the UN Convention on the Rights of Persons with Disabilities (CRPD). Accordingly, “persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’’

Over a billion people, about 15% of the world's population, have some form of disability. Between 110 million and 190 million adults have significant difficulties in functioning. Rates of disability are increasing due to population ageing and increases in chronic health conditions, among other causes. People with disabilities have less access to health care services and therefore experience unmet health care needs (WHO, 2007).

Concerning data and statistics, different literatures across the world say different figures. According to ACPF (2014), credible or reliable data and statistics on children with disabilities are not available, not appropriately disaggregated on the basis of disability, gender and age where needed, and do not accurately capture the number of children with disabilities or their needs. ACPF further said that there are between 93 and

150 million disabled children aged less than 14 years. Disability in Africa is largely attributable to war, poverty, and inadequate access to health and rehabilitation services. For example, it is estimated that 75 per cent of blindness in Africa can be prevented or cured. In Ethiopia, 60 per cent of children with visual impairments acquired them through preventable illnesses. In South Africa, the main contributors to childhood impairment and disability, in order of prevalence, are illness; pre- and peri-natal problems such as genetic disorders and birth trauma; injuries; accidents; and violence. Disability must be permanent in order to qualify a person as disabled. In addition, the impairment must affect the person’s participation in society in an equal basis with others. In fact, the physical, mental, intellectual or sensory impairment must prevent his or her full and effective participation in all aspects of life.

Due to incomplete data collection and inaccurate statistical results and difficulties relating to standardized definitions, the prevalence of disability among children in Africa is very difficult to assess accurately. Available data tends to differ considerably from country to country due to divergent classifications, definitions, and thresholds in categorizing disability. Ethiopia is an example of a country that has a high threshold for categorizing a person as disabled, and therefore estimations do not necessarily represent the entire population of those who are disabled.  Ethiopia estimates that 1.09 per cent of its population is disabled. However, that data excludes persons who are homeless, persons with temporary impairments, and persons with sensory impairments who are deemed to perform activities within the “normal” range. Other estimates put the prevalence of disability in Ethiopia at 7.6 percent (ACPF, 2011).

When we come to Ethiopia, according to the Central Statistics Housing and population census (2007), the number of persons with disabilities was 864,218. The disability population size is still debatable which is, partly attributed to the loose definition of disability and the 2007 Population and Housing Census excludes the following persons from being classified as disabled for they are being capable of performing activities that other healthy persons could do. Persons with one eye or one ear as long as the person is able to fully perform activities in the manner or within the range considered normal for a human being, even if his/her other eye or ear is blind or defective, he or she is not considered as disabled person. Unlike in the 1994 Census Leprosy, Epilepsy, and Mental problem (except mental retardation) were not considered as disability. However, they could be causes of disabilities.

## 2.2. Classification of disability

According to the document produced by Nepal government (2006, p.2), the classification of disability is based on the nature of the problem and difficulty in the parts of the body and in the physical system, disability has been classified into the following seven categories.

> **Physical Disability**: Physical disability is the problem that arises in operation of physical parts, use and movement in a person due to problems in nerves, muscles and composition and operation activities of bones and joints. For example: polio, cerebral palsy, absence of a body part, effect of leprosy, muscular dystrophy, problem with joints and spinal cord, club feet, rickets, weakness produced due to problem related to bones etc. are physical disability.

**Disability related to vision**: Disability related to vision is the condition where there is no knowledge about an object's figure, shape, form and color in an individual due to problem with vision. This is of two types: The blind and low vision is under this category.

**Disability related to hearing**: Problems arising in an individual related to discrimination of composition of the parts of hearing and voice, rise and fall of position, and level and quality of voice is a disability related to hearing. It is of two types: The deaf and Hard of Hearing under this category.

**Deaf-Blind**: An individual who is without both hearing and vision is a deaf-blind disabled.

**Disability related to voice and speech**: Due to difficulty produced in parts related to voice and speech and difficulty in rise and fall of voice to speak, unclear speech, repetition of words and letters is disability related to voice and speech.

**Mental Disability**: The inability to behave in accordance with age and situation and delay in intellectual learning due to problems arising in relation to implementation of intellectual activities like problems arising in the brain and mental parts and awareness, orientation, alertness, memory, language, calculation is mental disability. Intellectual disability/Mental retardation and Autism are under this category.

**Multiple disabilities**: Multiple disabilities are problems of two or more than two types of disability mentioned above in one person.

## 2.3. Service provision to children with disabilities in Ethiopia

ACPF studies showed that children with disabilities continue to face significant barriers to access to public spaces, community, recreation and religious centers, and even their own homes. They are usually marginalized due to the challenges and barriers in the environment they lived and as a result they are not fully and effectively participate in a range of social and economic activities. Moreover, they are usually victim of social injustice or deprived of equal enjoyment of rights because of their disabilities (ACPF, 2014).

According to ACPF, (2014) most buildings in Africa are largely inaccessible and present a huge challenge, and the newly built ones make only partial accommodations for the needs of persons of disabilities. In addition negative parental attitudes to disability pose a tremendous challenge to some children with disabilities in their own homes. Families usually isolate, hide or essentially imprison children with disabilities in the family home. As a result they are denying them to access education and social interaction compared to their siblings without disabilities. Ethiopia is one of the African countries who share the burden of challenges in relation to disability. JICAPED,( 2002 ) stated that, the major current problems in Ethiopia concerning disability are lack of public understanding, lack of information on the number and status of disabilities, shortage of basic needs, such as vocational training placement, health facilities etc. and inaccessibility to assistive devices.

In Ethiopia, there are nine regional states, one special administration (Dire Dawa), and one capital city of the Ethiopian Federal Democratic Government. To alleviate the problems of disability the Ethiopian Federal Democratic Government has organized a Rehabilitation Department under the Ministry of Labour and Social Affairs (MOLSA). Each regional council also has a Labor and Social Affairs Bureau, which handles all social affairs matters, including disability-related welfare. The structure at the regional level is more or less similar to that of the federal government. Rehabilitation, integration, prevention, and placement are handled by bureaus at the regional level, headed by a team leader (JICAPED, 2002).

The Government of Ethiopia has adopted and implemented a number of laws, policies and standards pertaining to people with disabilities, including their right to productive and decent work (ILO, 2004). ILO further stated that in 1999, the Ministry of Labor and Social Affairs prepared a National Program of Action for the Rehabilitation of Persons with Disabilities. The main objectives of the Program are: to take disability prevention measures by promoting community participation, to enable persons with disabilities to achieve a better standard of living by building their capacity and to ensure their equal rights and full participation in society. The focus areas of the program are: disability prevention, medical rehabilitation, educational rehabilitation, vocational rehabilitation and employment services, accessibility, awareness-raising, strengthening and expanding disabled persons' organizations, religion, culture sport, recreation, and family life.

ILO, (2004) further stated that the National Program of Action focuses on promoting equalization of opportunities for and full participation of persons with disabilities by implementing rehabilitation measures. The vocational rehabilitation process is understood to encompass vocational guidance, vocational training and appropriate placement which enable persons with disabilities to engage in occupations which generate an adequate income. This process includes follow- up and evaluation procedures which are undertaken after placement. In addition, the Program of Action addresses the needs of disabled persons in rural areas who do not have access to vocational rehabilitation centers, by promoting community-based rehabilitation services.

Even though Ministry of Labor and Social Affairs prepared a National plan of Action for Persons with Disabilities, (2012) and Ethiopian social protection policy, (2012) in order to take disability prevention measures, ensure their equal rights and full participation in society, misconceptions about the causes of disability prevents people to access the service. According to ACPF, (2014), in Africa misconceptions about the cause of disability are deep rooted in cultural beliefs and traditions that causes of disability include witchcraft; a curse or punishment from God; anger of ancestral spirits; bad omens; reincarnation; heredity; incestuous relationships; and the misdemeanors of the mother. These misperceptions not only lead to not using of the available service but also create negative attitudes about children with disabilities with their families in the community. Even family members themselves are also sharing the misconceptions as a community member; as a result, children with disabilities becoming invisible or hidden from society. So, in Ethiopia, without effective access to adequate habilitation and rehabilitation services, children with disabilities may not be able to work, go to school, or participate in cultural, sports, or leisure activities.

According to ACPF (2014) about 15 per cent of children with disabilities surveyed in Ethiopia live in areas where there are no health services in their communities at all. Health services remained inaccessible for the majority of children with disabilities.

The main reasons included expense (28 per cent) and a lack of accessible transport (12 per cent). NGOs provide the majority of health care services, including 87 per cent of CBR services; 65 per cent of specialized rehabilitation services; 88 per cent of occupational therapy; 84 per cent of speech therapy; 69 per cent of audiologist services; 62 per cent of ophthalmologist services; 81 per cent of counseling services; and 80 per cent of dietician services.

Isabel Egüez,(2008) prepared NGOs and UN Agencies Assisting Persons with Disabilities and in that document eventhough it was non-exhaustive, only four organizations were identified namely Center for the Victims of Torture, Christian Blind Mission International (CBM), handicap international and inclusion international with the service of community based rehabilitation, medical service , education and the first organization for health care for refugees who suffer from torture.

ILO, ( 2013) in its publication also identified organization and associations that gives services to people with disability like:

> *” under the umbrella of a Federation: Federation of Ethiopian National Associations of People with Disabilities (FENAPD), Ethiopian National Association of the Blind, Ethiopian National Association of the Physically Handicapped, Ethiopian National Association of the Deaf, Ethiopian National Association of the Blind-Deaf , Ethiopian National Association of Persons Affected by Leprosy and Ethiopian National Association on Intellectual Disability. In addition other disability associations playing a key role in the disability equality movement are: - Ethiopian National Disability Action Network (ENDAN), Ethiopian Women with Disabilities National Association, Tigray Disabled Veterans Association and The Ethiopian Centre for Disability and Development (ECDD)”. (p.3).*

## 2.4. Disability and Family Caregivers

In general children with disability and with multiple disabilities in particular are in one way or another dependent on their family members starting from fulfilling their basic needs up to other advanced needs. So the burden is not only limited to the child her/himself but also goes to family members especially mothers. According to ACPF (2014),

> *“Many children with disabilities and their families are severely deprived of the basic resources and services that could enable them to develop to their full human potential. Most have very limited access to healthcare, clean drinking water, and sanitation, and nutritional deficiencies are widespread among children with disabilities. African tradition often blames the child’s disability* on the mother. *When she is blamed, she is expected to assume all responsibility for the child’s welfare. It is common for fathers to reject responsibility for a child with disabilities because of this belief, leading to total abandonment or divorce.” (p.15)*

According to Bass, (1990) cited in Hall and Brown, (1998),” Provision of care within the family has long been, and continues to be, the main form of care for individuals in need of care giving. Individuals with disabilities are no exception to this form of care giving. However, the existence of a family member with disability generally means that care giving goes beyond assumed lengths of time, level and roles (p.2)”. Becoming the mother of a child with disabilities is demanding and time taking because their needs are complex as compared to a child without disability. So the development of services for children with disability has been contextualized in relation to the family home and resources (Clarke, 2006).

According to N. C. Van Wyk and R. Leech, (2016), the transition to motherhood of children with disabilities takes place in the inside world at home, the outside world external to home and the ‘going-between’ world of travelling between the two worlds. The mothers are challenged at home to integrate basic infant care with technical care of their children. In the outside world they often struggled to ensure that their children got the necessary professional care. Travelling between their homes and healthcare services posed many problems.

Family members who are responsible in caring of a child with disability face so many challenges as presented in different literature. Unlike these challenges there are also positive experiences of family members who are responsible in caring of a child with disability. According to Sandra B. and Abdelrahim, (2016), although small in number, there are studies which are important in helping to provide a balanced view of the impact of disabilities on families. Other than negative consequences, according to these studies the occurrence of disability within the family may have positive effects.

Furthermore, Reichman, Corman and Noonan, (2008) also explain about the negative and positive effects of having a child with disability in the family. It is well stated as follows:

> *Living with a disabled child can have profound effects on the entire family–parents, siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning. On the positive side, it can broaden horizons, increase family members'*

> *awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a child with disability can have far-reaching effects. (P. 1)*

So because of the existence of many problems in relation to disability particularly in relation to family care givers, a wide range of sectors should be involved in and share responsibility for identifying children with disabilities, providing care and support services for the family as a whole (WHO and UNICEF, 2012).

## 2.5. Care giving Challenges and impacts faced by family members involved in care giving party

In Ethiopia as different literatures said and my day to day observation at work area while dealing with children with disabilities and their family care givers, there are so many challenges faced by family members especially mothers who are responsible for caring children with disabilities specifically multiple disabilities. As CRPD, (2012) stated that, the major challenge of persons with disabilities in Ethiopia includes wrong attitude and low-level awareness of the society towards them that usually hampers their inclusion, limited knowledge about the causes of disabilities that could have increased the disability population size. Limited support service in education training, access to education and other basic services, poor physical and technological accessibility that hinders independent mobility and adversely affect their overall inclusion in society and low coverage of rehabilitation services and discrimination in employment.

Even though the above mentioned challenges are subjected to children with disabilities, mothers who involved in care giving also shared those challenges. According to Marcenko and Meyers, (1991), most mothers of children with severe developmental disabilities, majority took on most of the day-to-day responsibility for the care of their children with handicaps. Even though they are involved in the day to day lives of their children with disabilities and face different challenges, most mothers did not receive much instrumental, emotional, or informational support. Family members who are involved in care giving activity of a child with disability face so many challenges as stated in the following literature:

In relation to economical challenge, according to Anderson, Dumont, Jacobs and Azzaria, (2007) there is evidence in the literature that parents of children with disabilities face unique financial challenges and meeting their child's needs and making financial ends meet is difficult for most. Anderson and et al., (2007) further showed that not only is the child with the disability affected in such matter, but also is the entire family. These families are more likely to be single-parent families (single income families with lower quality jobs), live in poor quality housing, require more time off work and are more likely to work reduced hours that results decline overtime. According to Gottlieb, (1997) it will be even more challenging for practitioners to support non partnered mothers who are also primary providers, not usually work in full potential, and these women may be less often connected to the human services systems.

Psychologically, according to Singer & Farkas, (1989) mothers reported a high degree of stress related to caring for their young children with developmental disabilities, as indicated by their responses to the impact on family. The study further suggests that social class, financial status, and severity and chronicity of a child's disability may affect maternal experience of stress.

Due to the stress experiencing in relation to their children’s disabilities, they are not in a position to work fruitfully to secure their family’s economical needs. According to Gottlieb, (1997) it will also be important to determine the extent to which these mothers are working out of personal choice or job commitment, as opposed to a sense of financial necessity. In the case of mothers who are experiencing stress as primary providers, practitioners should help them pursue additional income sources because the level of stress makes them economically disadvantageous. Families whose children have conditions that change or worsen over time are affected by worry about their child’s physical and emotional health (official journal of the Association of Rehabilitation Nurses , 2008).

Most literatures said that, most of the time mothers are primary care givers for their children with multiple disabilities and as a result the level of stress on them is high. The study conducted on Saudi mothers by Aldosari and Pufpaff, (2014) said, Saudi mothers of children with intellectual disabilities experience more stress than fathers in relationship to both child and parent characteristics. According to the study, the contributing factors are: being the primary caregiver, experiencing the restrictions on women in the Saudi culture, and the lack of social support provided to mothers of children with disabilities.

Socially, Children with disabilities in Africa comprise one of the most neglected groups. The majority of these children and their families face enormous economic, political, and social barriers. As a consequence, the strengths and abilities of children with disabilities are invisible, their potential in social contribution is consistently underestimated, and inadequate resources are allocated to social services for meaningful inclusion of children with disabilities (ACPF, 2014). Swanepoel, (2003) also said that, It is usually difficult for a primary care giver of a child with disability to maintain the family as a unit. It is common for families to lose family friends or to isolate themselves because of public criticism towards them and being with a child with autism in public places.

As Cant, (1992) said that, "the routine rules for friendship obeyed as parents offer each other emotional support and resources in the form of mutual help. Families who want support to meet the needs of their children with disabilities may be isolated from the extended kin network, but are more commonly isolated from the local community, because neighborhood and friendship ties are disrupted by tending responsibility." Hiwot, (2003) in her finding also said that how mothers are in a terrible state in relation to their social life, how people do leave them alone; staring at them, look at them fiercely, talking about them, which makes them to feel worst.

According to Ayenalem, (2014) as compared to families normally developing economic wellbeing families caring a child diagnosed with autism is disrupted with imposed additional cost. She further said that, for those who are dependent on one bread winner, providing balanced diet for children with disability is very difficult. In addition families are forced to resign, engage in part time work, and unable to take part in labor market. Berhanu, (2004) also stated that family care givers with mentally retarded children experience different negative emotions. The parents also go through different negative social experiences as well and if the child with disability is in a position to demand the care from his parents, they become very much deprived of the outside activity like job.

## 2.6. Models of Disabilities

### The Medical Model of Disability:

The medical model is presented as viewing disability as a problem of the person, directly caused by disease, trauma, or other health condition which therefore requires sustained medical care provided in the form of individual treatment by professionals. In this model the main purpose of the intervention is cure and individual's adjustment and behavioral change. To effect this change, at the political level, principal response is that of modifying or reforming healthcare policy (Langtree, 2015).

### The Social Model of Disability:

Langtree, (2015) stated that, the social model of disability sees the issue of "disability" as a socially constructed problem and a matter of the full integration of individuals into society. In this model, disability is not an attribute of an individual, rather a complex collection of things which are created in the social environment. Social model approaches have been developed and applied to understand the experience of disabled people in relation to personal autonomy, including access to public space and public roles (Clarke, 2006).

### The Bio-psychosocial Model:

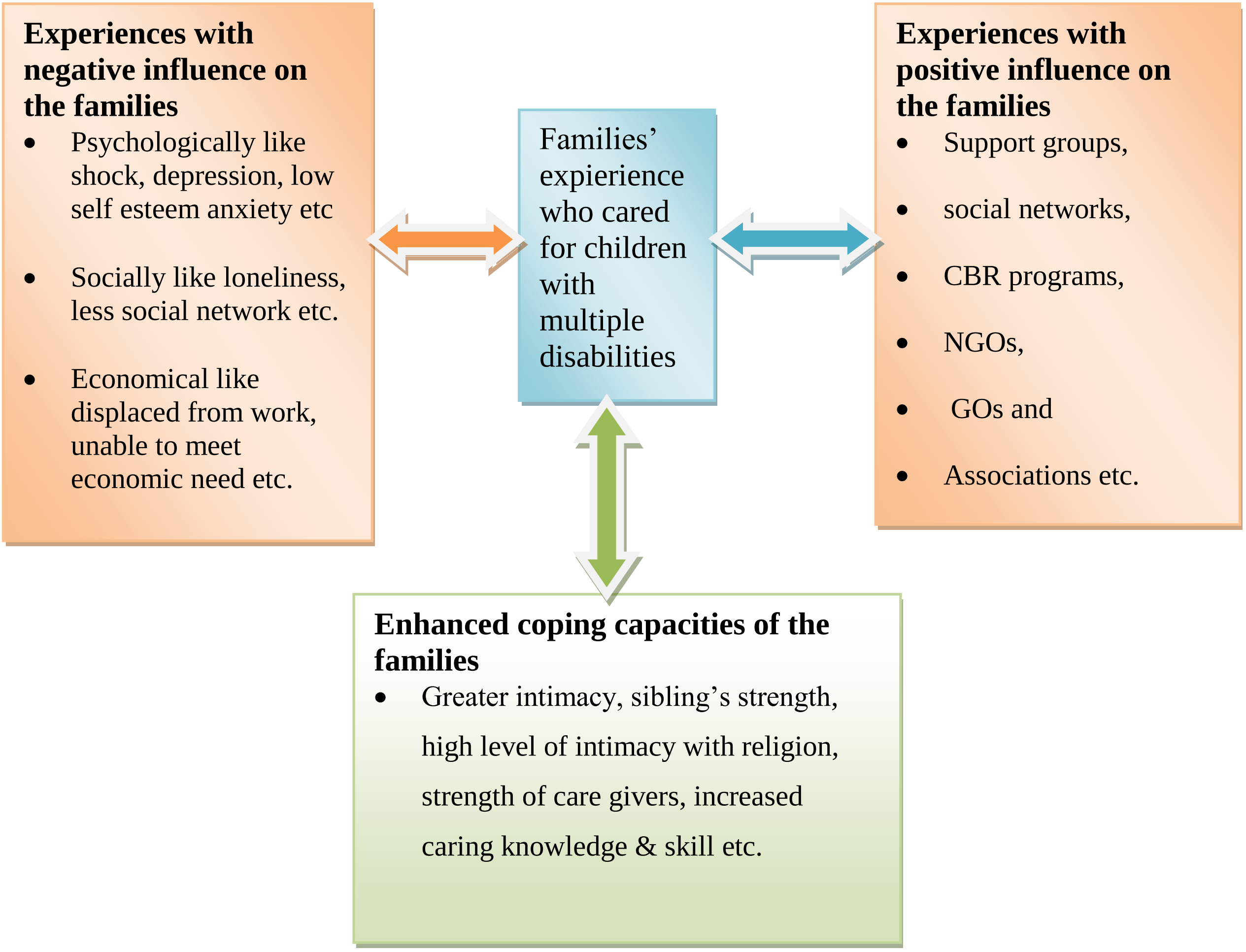
On their own the medical and social models are partially valid but not adequate. So a synthesis of both models is the most useful approach. The latest International

Classification and Functioning from the World Health Organization is based on the bio-psychosocial model which is an integration of the medical and social models and provides a coherent view of different perspectives of health: biological, individual and social (Langtree, 2015).

Based on the assessment of literatures, there are few studies conducted in Ethiopia in relation to care giving experience of a child with disability. Those studies are not comprehensive enough and did not examine the issue from different dimensions of life. Therefore, the studies conducted did not fully reveal the multidimensional aspects of family care giving experiences for a child with disability. The proposed study attempts to contribute to the understanding of positive and negative experiences of family members who are responsible in caring a child with disability.

## 2.7. Conceptual Framework

The conceptual frame work of the study is the system of concepts, assumptions, expectations, beliefs and theories that supports and informs your research and is a key part of research design (Miles & Haberman, 1994). According to Maxwell, (2005), conceptual framework for the study is something that is constructed, not found. It incorporates pieces that are borrowed from elsewhere, but the structure, the overall coherence, is something that you build, not something that exists readymade. Accordingly, the researcher understood the connection of relevant concepts and ideas from the literature as diagrammatically presented below and used the framework to inform the development of tools for field data collection.



**Experiences with negative influence on the families**

- Psychologically like shock, depression, low self esteem anxiety etc
- Socially like loneliness, less social network etc.
- Economical like displaced from work, unable to meet economic need etc.

Families' expierience who cared for children with multiple disabilities

**Experiences with positive influence on the families**

- Support groups,
- social networks,
- CBR programs,
- NGOs,
- GOs and
- Associations etc.

**Enhanced coping capacities of the families**

- Greater intimacy, sibling's strength, high level of intimacy with religion, strength of care givers, increased caring knowledge & skill etc.

# CHAPTER THREE:

# RESEARCH METHODS

## 3.1. Research Design

The study followed a qualitative research approach. Qualitative research approach is an approach that study participants are enabled to represent their views and perspectives. It also gives us a chance to cover contextual conditions, the social institutions and environmental conditions within which peoples' lives takes place (Yin, 2011). In this regard a qualitative research approach is considered appropriate as the focus is on the experiences of target groups. The method becomes useful in order to explore and describe the life experiences, the factors that revolve around the issue, the challenges they faced and the recommendation they proposed while they were in a position to involve in the care giving activity of a child with disability particularly a child with multiple disability.

Qualitative research methods also helps to uncover the various factors and challenges affecting the situation of care giving activity of a child with disability by family members and helps to explain the context and meaning of the situation to the people experiencing it. It further enables the researcher to explore the general situation of care giving for people with disabilities within the particular context of experience by the family in in-depth wise and brief. Qualitative researches conducted in the "field," where the participants live and work-these are important contexts for understanding what the participants are saying and to understand the historical and cultural settings of the participants (Creswell, 2007).

## 3.2. Specific method

Methodologically, the research followed qualitative case study approach. According to Yin (2003), case study is "an empirical inquiry that investigates a particular phenomenon within its real life context and produce contextually rich and meaningful interpretation." In addition "case study research is a qualitative approach in which the investigator explores a bounded system (a *case)* or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving. Moreover, it is stated that a case study is a good approach when the inquirer has clearly identifiable cases with boundaries and seeks to provide an in- depth understanding of the cases or a comparison of several cases" ( Creswell, 2007,p.73) .

The study used case study and gained predominant advantage of describing the existing situation from different cases perspective to provide an in-depth understanding of the issue (Yin, 2003). It is useful for the researcher to choose a case study to examine a "case," bounded in time or place, and look for contextual material about the setting of the "case." Gather extensive material from multiple sources of information to provide an in-depth picture of the "case" (Creswell, 2007).

From the previous literatures, the experience of family members who were responsible for care giving a child with disability had not received much attention. Case study research design enabled the researcher to got an in depth picture of the situation and it was a preferred design in exploring the unique experiences of family care givers in different life dimensions in their social and cultural setting. In this particular research a case refers to a family unit whose members were responsible for caring a child with multiple disabilities.

## 3.3. Study Area and Target Group

The Counseling and Social Services Center which is being managed by the Congregation of the Brothers of Good Works has been in operation in Addis Ababa since September 1992. It was organized under the Ethiopian Catholic Church in response to a request by the government for the Churches and NGO sector to cooperate with them in the fight against HIV and its effects. The Center began as a referral centre, receiving clients from hospitals and other agencies in Addis Ababa to provide on-going counseling, social services, and home and terminal care of persons living with HIV. At present the Center is providing comprehensive services to deal with problems related to HIV/AIDS and disabilities through four well structured departments- Counseling and Social Services, Orphan support, Education and CBR (Community Based Rehabilitation) program for Children with Disability.

CBR program is a strategy used to address the problems of persons with disabilities through rehabilitation and psychological integration. Its holistic objectives are implemented with the combined action of parents, persons with disabilities, communities, and health, educational and social services.  Currently the department is giving different services for 148 children with disabilities. This research focus was on family members who were responsible for caring a child with multiple disabilities.

## 3.4. Participants of the research

According to Yin (2011), in qualitative research, the samples are likely to be chosen in a deliberate manner known as purposive sampling. The goal or purpose for selecting the specific study units is to have those that will yield the most relevant and plentiful data, given your topic of study. Creswell, (2007) also said that there is a challenge in qualitative case study development which is the researcher must identify his or her case. The case study researcher must decide which bounded system to study, recognizing that several might be possible candidates this selection and realizing that either the case itself or an issue, which a case or cases are selected to illustrate, is worthy of study.

Yin, (2003) said that, the evidence from more than one case is often considered to be stronger than evidences from a single case. The researcher must consider whether to study a single case or multiple cases. So this non-probability purposive sampling technique was very useful in choosing respondents or cases who fulfill the inclusion criteria and that best fitted in answering the objective of the study.

In order to find suitable cases for the study, the researcher made a kindly request to the coordinator of CBR department to facilitate for identifying immediate family members (as literatures say most of the time are mothers), who would be capable of articulating their experiences, expressed themselves very well and could told their practices in an organized manner. The sources of data for this study could be family members who were responsible for care giving of their children with multiple disabilities. The researcher was conducted the study in the organization as well as at their residence for the sake of their convenience. Most qualitative studies focused on in-depth understanding of the phenomena and it should be compatible to small sample size so the researcher was used cases until data saturation or occurrence of redundancy in data collection than employing statistical criteria. By considering the issue of data saturation, a sample of five cases (study participants) were selected using purposive sampling for the detailed open-ended interview structured in line with the objective of the research.

## 3.5. Criteria for participant selection

The identification of clients with multiple disabilities (study participants) was made with the support of staff members of CBR department staffs who have been supporting the families. Research participants' inclusion criteria were: Families who cared for children with multiple disabilities; the family must be a client of Brothers Good Works Counseling and Social Services Center because of having a child/children with multiple disabilities. These families were represented by mostly mothers of the disabled child/children or others who were mostly and directly involved in the day to day caring (irrespective of blood relation to the child/children with multiple disabilities) relative to other family members, and are adults and willing to be part of the study.

From the day to day observation of mine at work place, most of the time caring of a child with multiple disability is the responsibility of their mothers and the researcher chose mothers with an assumption of majority of experiences of the entire family is well known and told by mothers. Moreover, mothers most of the time are closely attached to their children so that the researcher believed, they knew about the issue in an elaborative and detailed way.

## 3.6. Tools and process of Data Collection

As a qualitative design, the study involved assessing, the deep feelings and views of families, who were responsible in care giving for their child with multiple disabilities. Thus, in-depth interviews, focus group discussions, key informant interview and a non-participant observation are major techniques, which were applied for collecting information. I got the permission from the deputy administrator of Brothers of Good Works Counseling and Social Service Center so that I was used both primary and secondary data in this study to obtained basic and relevant information. The primary data collected through in-depth interviews, focus group discussion with family members who have primary responsibility for providing care to a child with multiple disabilities and from key informants. Interview guides, observation guide, as well as focus-group-discussion guide were used as instruments to collect relevant information for the study. It consisted of demographic questions about care givers, questions that answered the research questions and explanation and elaboration of the care givers experience in caring of a child with multiple disabilities.

### In-depth Interview

While doing qualitative interviews, a researcher tried to understand a participant's world, which was likely to include concentrated efforts at mastering the meanings of the participant's words and phrases. The line of questioning is not controlled by a questionnaire but requires the researcher to exert continual mental energy (Yin, 2011).

In-depth interviews provide an opportunity for the researcher to got a detailed investigation of individual personal perspective, deep understanding of the personal experience in relation to the research topic in different dimensions of life with in their social and cultural setting. According to Ritchie& Lewis, (2003), interviews are the only way to collect data where it is important to uncover the perspectives within the context of personal history or experience; where delicate or complex issues need to be explored at a detailed level, or where it is important to relate different issues to individual personal circumstances.

**Focus Group Discussion (FGD)**

According to Kitchen and Tate (2000) as cited in Hiwot Moges, FGD has been proven instrument to illustrate and explore the inter-subjective dynamics of thoughts, speech and understanding of the members of a group. FGD may be consisted of six to ten individuals discussing on a particular topic under a guidance of a moderator who promotes interaction and directs the whole discussion process (Kitchen &Tate, 2000 as cited in Hiwot Moges).

FGD supplemented the data generated from an in-depth interview apart from being useful in triangulating the data from different sources. The FGD helps to get information on individual and shared experiences of participants as well as if there was support mechanism among families who have similar problems of caring a child or children with multiple disabilities.

The researcher conducted two FGDs with the groups of mothers who were responsible in caring a child with multiple disabilities. 13 participants in two focus groups ( first 6 and second 7) participated based on the prepared guide, the researcher tried to get relevant information, and the groups expressed their views about disability, the care giving experience in relation to caring of their beloved children with multiple disabilities, how to manage their responsibility, the effect of care giving in social, psychological economic dimensions and what are the possible recommendations proposed by them in order to improve the situation of their children living with multiple disabilities.

### Non –Participant observation

The purpose of the observation is to gain additional information about what is going on and what are the activities of family members in supporting their children with multiple disabilities. The observation was allowed documenting the experience of care givers in different dimensions of life within their social and cultural setting.

In terms of secondary source, in order to get clearer pictures of the issue an attempt was made to assess relevant studies carried out by other scholars both in Ethiopia and abroad. Moreover, various publications of agencies who work on the issues of disability, books, magazines, different published and un-published materials and journals were assessed in order to gain comprehensive information about the issue.

## 3.7. Data management and Analysis

After the successful completion of data collection the next task was analyzing the collected data strictly following the data analysis steps. Finding from the in-depth interviews, FGD and key informant interview give a number of themes that explains and explores about the experience of mothers who were directly involved in caring process for children with multiple disabilities. Issues in relation to policies also have themes.

According to Creswell, (2007), analyzing data texts and multiple other forms of data presents a challenging task for qualitative researchers. In order to manage and analyze the data properly and to catch all ideas and sayings of the interview, the respondents were tape-recorded based on the consent of the participants. All data obtained from the interview were processed in a confidential manner, anonymously and all the data that gained from the study participants were managed by the researcher and always closed by passwords.

The analysis process was started with transcription of audio records collected from an in depth interview of study participants, key informant interview and focus group discussion in Amharic language. Transcriptions of audio record were followed by compiling note taken in the interview session with transcribed audio record. And then translation of all the data gathered through interview and focus group discussion to English language was done by the researcher. Then the translated data and the transcribed data was checked and rechecked by the advisor and peer debriefing who were previous graduates.

Organizing the data; coding the data; immersion in the data; generating categories and themes; offering interpretations through analytic memos; searching for alternative understanding; and presenting the study were the steps followed (Patton, cited on yin 2003). The translated data was sorted and coded according to the categories. Categories yield thematic areas in which the researcher formulated it and in a way it became easy for analysis and data was recorded under them.

Finally, the researcher moved to report writing by giving meaning from thorough reading and the critical thematic analysis of the primary data in relation with the literature and conceptual frame work. Moreover, direct quotes, common and typical responses from the interviews were presented in order to get the clear picture of the situation.

## 3.8. Trustworthiness of the Study

Trust-worthiness is one of the questions asked by many persons while a researcher undergone qualitative research. According to Stake (2010), researcher bias, and respondent biases are the major challenges for trustworthiness of qualitative studies. Becoming a researcher, especially for a person doing qualitative research, is partly a matter of learning how to deal with bias. In order to ensure the trustworthiness of a study in this regard, I was self-aware about my feelings about the subject area and well aware about the possible biases occurred in the study participants before the actual data collection procedures was employed.

To enhance trustworthiness, the study used multiple sources of data or triangulation from in depth interview, focus group discussions, non-participant observation and interview of government officials and experts in the study area. The primary data was collected from in depth interview of study participants, focus group discussion for two groups, interviews with government officials and observation. Using rich and thick description to convey finding was a strategy to enhance trustworthiness of a study (Creswell, 2007). To enhance trust worthiness, I used rich and thick descriptions including sayings and illustrations of the study participants. I also undergone peer review or debriefing to the administrator of the organization and my colleagues as an external check of the overall research process.

## 3.9. Ethical consideration

The study was conducted after getting support letter from Addis Ababa University, school of social work to respective organization. In addition informed consent was obtained from the study participant to confirm willingness for participation after explaining the objective of the study. The respondent notified that they have the right to refuse or terminate at any point of the interview. The questionnaire was formulated in anonymous way (they were not in a position to call by name). The information provided by each respondent was kept confidential.

> *The qualitative research in a good study is ethical. This involves more than simply the researcher seeking and obtaining the permission of institutional review committees or boards. It means that the researcher is aware of and addressing in the study all of the ethical issues through all phases of the research study( Creswell, 2007:P.47).*

## 3.10. Limitations of the study

This study was designed and aimed to explore and describe the experience of primary care givers (mothers in this research) who were responsible to taking care of children with multiple disabilities. However there were limitations in this study. First study participants were not representing all care givers from different backgrounds like ethnicity, family background, cultures and norms. Even all the study participants had been living in Addis Ababa. Second limitation was at the time of interview, the respondent’s attention frequently destructed by their children’s situation. At that time, I forced to wait until they come back to the interview and this thing demands frequent reminder where they stopped and so time taking.

# CHAPTER FOUR:

# FINDINGS OF THE STUDY

## Introduction

The findings chapter starts with a brief socio demographic background of study participants. Substantive elements of the finding are shown under the 9 themes and 33 sub-themes that were identified by analyzing the field data. Moreover, authenticity of the fining is further substantiated by direct quotations taken from statements of research participants. On the finding, pseudo names were given to the study participants in order to assure their confidentiality.

## Socio Demographic Profiles of the Study Participants

In table one, the study participants consists of five mothers who are directly involved in the day to day activities of children with multiple disabilities. These mothers' age ranged from 30 to 33 years. All study participants lived in Addis Ababa and of all the mothers1 is married, 3 divorced, and the other one 1 widowed. The report confirms that mothers living with 2 to 6 family members in their household. According to the data gathered through the interview, three of the mothers were orthodox Christianity follower, Beletu was a protestant and the remaining one (Merem) is a Muslim by her religion. Educationally; four of them were at grade 5 to 10 levels while the remaining one was not able to read and write.

Out of five participants two were engaged in cloth and *Injera* selling business and the rest three did not have job. Regarding duration of years involved in care, all of them were involved from the beginning of birth of their children and all were children's mothers. Two of the participants heard about the organization (BGW) from their friends, one from other clients, one from kebele and the remaining from staff of BGW.

Table 1: The socio demographic profiles of study participants

| | Merem | Beletu | Aster | Tsehay | Lemlem |
|---|---|---|---|---|---|
| Age | 32 | 30 | 33 | 30 | 33 |
| Sex | F | F | F | F | F |
| Educational Status | 5th | 5th | 8th | Not able to read and write | 8th |
| Marital status | Divorced | Widowed | Divorced | Divorced | Married |
| Religion | Muslim | Protestant | Orthodox | orthodox | Orthodox |
| Family size | 2(1F,1M) | 6(5F,1M) | 3(2F,1M) | 3(1F,2M) | 4(2F,2M) |
| Employment Status | Trade(small scale) | No work | No work | Trade(small scale) | No work |
| Relationship with the child | Mother | Mother | Mother | Mother | Mother |
| Years in care giving | 4 | 7 | 8 | 14 | 2 and 8 months |
| How they heard about the organization (BGW) | Other clients | Staff of BGW | Her friend | Kebele/ Woreda | Her friend |

Accordingly in table 2, children that are subjected to caring aged ranged from 2 and 8 months to 14 years. With respect to their gender, four of them were males and the remaining one was female. Regarding disability type, all of them have more than one disability. Five of them have cerebral palsy (a group of permanent movement disorders that appear in early childhood), movement and speech problem. Out of five, three of them (children of Beletu, Aster and Tsehay) have epilepsy and two out of five( children of Aster and Tsehay) have visual problem.

Table 2: The socio demographic profiles of children with multiple disabilities

| | Merem's son | Beletu's daughter | Aster's son | Tsehay's son | Lemlem's son |
|---|---|---|---|---|---|
| Age | 4 | 7 | 8 | 14 | 2 and 8 months |
| Gender | M | F | M | M | M |
| Type of Disability children have | Speech partially<br>Movement<br>and cerebral palsy | movement, speech, cerebral palsy and epileptic | Visual, movement, speech, cerebral palsy and epileptic | Visual, movement, speech, cerebral palsy and epileptic | Speech , movement and cerebral palsy |
| Disability happened congenital or after birth | Congenital | Congenital | Congenital | After birth | Congenital |

From a total of 103 pages of transcripts, a total of 148 key concepts and statements of participants were extracted and from these concepts 9 themes and 34 sub-themes were identified. The findings are presented in this section in order to answer the research questions about, How did family members feel about and gave meaning to their experience of caring for a child with disability?, How did care givers handle the responsibility of care giving for a child with multiple disabilities?, How did the care giving experiences for a child with disability affected family member's life?, and How did families explained their experiences of caring for children with multiple disabilities?

## 4.1- Participants' Knowledge of Disability and Attributes to their Children's Disability

Under this theme there are three major Sub themes; (a) Participants' attribution to their children's disability, (b) Knowledge about disability, and (c) How parents know their children's disability were identified.

### 4.1.1- Participants' attribution to their children's disability

All study participants lived in Addis Ababa when they gave birth to their children. According to their response, all of them had follow up at health facility. Although all of them had follow up, they gave different reasons for their children's disabilities. Merem and Lemlem told the investigator that the causes of their children disability were suffocation or lack of oxygen during birth. Merem said that,

> *"The disability of my son started during birth. After birth, they immediately put him in incubator for 15 days. I went to there now and then for breast feeding then I always questioned that: why he was not became active like other children? What is the reason behind not to cry like other children?"*

On the other hand Beletu said that the cause of disability goes back to her pregnancy time and she said:

> *"The doctors told me that your daughter was hurt during pregnancy. The reason behind is, during the 8th month of pregnancy I fall down with my buttock and the doctors told and explained to me the reason may be that. Even though I fall down two times, I was not going to health facility because I felt my baby's movement inside the womb".*

One participant of FGD said that, *"for me I thought the cause of disability is by using drug during pregnancy, falling down accident and absence of oxygen during delivery."* Aster viewed the issue that, her son's disability was due to the mistake committed by the health professional during delivery. She claimed that:

> *"During my labor, the midwife's phone was ringing so when she went to there, the baby expelled and hit by something. She gave me my baby and at that time I didn't knew the consequence. After six days his color changed to yellow and I was going to hospital to seek medical help and the doctor told me that the baby was hurt during labor so consequently in the future walking, seeing and hearing may be delayed and late in every aspect."*

From FGD participants, one of them said that, *"my baby's disability was due to instrumental delivery during labor"* while the other said that," *I faced prolonged labor."* Another participant also said that," *I delivered not at health facility. I thought the cause* *was due to the traditional birth attendant's lack of skill, she continuously massaged my abdomen."* On the contrary, for Tsehay, the reason for her son's disability was falling down at the age of one year and nine months.

### 4.1.2- Knowledge about disability

The interview response shows that all of the study participants didn't have any knowledge about multiple disabilities prior to their children birth up to the time of knowing their children's disability. Not only mothers but also the entire family didn't have any knowledge. One of the participants said; "*there was no knowledge within me and my families"***.** Merem in particular articulate that the need of such information on the care giving process and she said,

> "*I have no knowledge but I wish I had that kind of knowledge. I lost the chance already. During labor, I put myself in a bad position. If I knew the outcome of that position, I was taking care of everything."*

### 4.1.3- How parents know their children disability

Although all of the participants had different experience concerning how they knew their child was disabled for the first time, they still share some common experience like, their children were not done but what other children without disability did. Regarding this Beletu said" *You know why? I didn't know the reason but I thought she could stand up, she could walk and talk. I didn't knew the reason why she couldn't perform these things by her own.*" Furthermore Merem also said;" *before I knew his situation, I was very much suspicious about my son. Why did he continuously cry? I was afraid, I always asked myself*." Even though all participants heard their children disability from health professional, the time of diagnosis was different among mothers. Regarding the notification of disability, Beletu also said that: *"….lately after going to disability organizations, sawing other families with disabilities, I started to understand her disability."*

## 4.2-Care Giving: Source of knowledge, and Participants' Feelings

Under care giving process, reflection and experience four major Sub themes; (a) Source of knowledge for care giving and care givers reflection(b) Why mothers become primary care giver (c) Parents care giving process and (d) Participation of other family members for caring were identified.

### 4. 2.1- Source of knowledge for care giving and care givers reflection

Knowledge and skill are very important for care givers who are responsible for caring children with multiple disabilities because as compared to children without disabilities, they need special care, time, energy and patience. Regarding the source of knowledge, Merem learned about caring from the situation. She said: "*We passed plenty of time for feeding and we suffered a lot in order to take care of him, feed him and fulfill his needs. So I was alone to do that and I learnt from the situation and adapt."* For Beletu, she acquires knowledge for care giving process from the situation and staffs of BGW and she said:

> *" I learnt from the situation and after joining the organization, staffs teach me and trained me how to took care and they trained us about how to did work and earn money and I became reassured and strong and wanted to work and live."*

For Lemelem and Tsehay, they got the lesson about care giving from the organization. Tsehay stated:*" First, I learnt at the organizations, the staffs showed me about what is* *needed from me and in what way I was going to gave physical exercise (especially hands and legs). After I learnt from them, I can do it by myself even at home level."* Aster further said that*, "I knew from health professionals and BGW. Before that, I didn't know. So from these I knew what to do for my son."*

When we come to the general reflection about the care giving process, all participants had no negative feeling about the care given to their children with disabilities rather they feel happy about that and they considered it as fulfilling responsibility as a mother. For Aster, she expressed her feeling in one sentence in this way: *"Me? I am very much happy to do these things for my son."*Other respondent, Lemlem stated her feeling about the care giving that,

> *"For me I thought that more care and attention is needed by them because they didn't ask their interest, they are not able to talk, and children like him are not expressing their feeling. So I always keenly observed and tried to fulfill his needs. In my view I am always ready to serve him*."

Regarding the feeling and reflection on the care giving process given to children with disabilities, Merem stated her feeling as follows:

> *"I feel happiness about the care given to him. This has been my responsibility and even foreigners support us in this regard. I am the mother of him so there is no other person come for him… in my view my son caring responsibility is not by an organization. Nobody in this world cares him better than me because I give care with love."*

### 4.2.2- Why mothers become primary care giver

As the day to day observation of mine for the last three years dictates, mothers are mostly involved in caring of a child with multiple disabilities. Towards the question why they became primary care givers of their children is being a mother and all of the respondents shared this idea. As Lemelem stated that:” *I have no work my work is him. I want to make him a better person and I always wanted to keep his wellness. My husband is always at work so I am his mother and responsible for caring of our son.”* Furthermore Merem expressed her view in this way,

> *“Here, I am his mother I am the one to held in my womb and suffered by labor so due to this I must be a primary care giver for him no other person……Generally mothers like us were not supported by relatives of themselves and other family members.”*

### 4.2.3- Parents care giving process

Care giving process by mothers to children with multiple disabilities includes many activities because children with multiple disabilities are not in a position to take care of themselves. Study participants involved in every activity like changing diapers, feeding them, washing them and the likes based on their children’s demands. Merem, one of the study participants, expressed:

> *“Early in the morning, he needs potty so I put him on it. He may urinate or not urinate and then he asked me to lift up and then asked me water immediately. He always experiences aspiration while he is eating and drinking. He can’t able to swallow like other children so I am always in a state of worry to become dead due to aspiration and always looking in to his eyes. Sometimes he asked me to lift up in fact it is a chance; there were children with disability who didn’t say anything to their mother. My child*

> *is not able to use potty by himself so there is always my guide. To change clothes, to feed him, to change his diapers and to fulfill his needs is our responsibility. I passed the whole day to take care of him."*

All FGD participants also confirmed that the following activities mentioned by five respondents were true and shared by them. One of FGD participants said that: *"I am washing her, change her clothes, feed her, change her diaper and play with her when she demands so the care includes all these things."*

### 4.2.4- Participation of other family members for caring

The study also assessed care giving to children with multiple disabilities by other family members other than the primary care giver. Three respondents; Beletu, Aster and Lemelem acknowledged that most family members supported them in the care giving process. Lemlem said,

> *"His sister always takes care of him. She takes more time with him and his father also share her burden, take care of him and support him in every aspect when he is out of work for example during Sunday. During week days when my husband is at work, I am responsible to give care to my son."*

Aster also further said that:

> *"All family members have good feeling towards him for example they supported him in buying of diapers even some times they wash him and support in this way. My elder daughter always gives him his drugs, she does not want to listen him cry she hold him and sit down with him. When he wants to lift up, both of us (me and my daughter) knows about his feeling we lift him, hold him and play with him. When I am out of home for*

> *a social purpose, she is in charge of giving his medication so she supported me."*

On the contrary, the participation of other family members in the care giving process for Merem and Tsehay is unthinkable. Tsehay said: *"I almost have no support from other family members. At first my husband gave me small support, later on he and his mother asked and blamed me about the disability was occurred because of my kinship origin and curse."* For Merem lack of support from other family member so far made her to decide not to accept anymore even though it will be offered in the future and said:

> *"Other family members didn't care about him and I am not willing to accept any support from them if there is any (she was in a state of anger). They said "give him to organization" and they develop negative things that causes expel us from their house. For me instead of taking support from them, I prefer to beg from people of Ethiopia."*

Concerning the feeling of being the primary caregiver of children with multiple disabilities in relation to the role played by other family members, all participants believed that they have been the one responsible for the day to day care giving of their children. They also claimed that as compared to other family members, they are the one that understands their children interest and communicated with them unlike other family members. One of the respondents, Beletu said that:

> *"Whether family members giving care to her or not, I consider myself as a responsible person to take care of her. As far as I existed I am responsible for her but when I faced sickness, nobody takes care of her, feed her and look after her. When I saw such situation, I became angry and in a state of sadness (she is crying). I felt angry when I saw that nobody looks after*

> *when I was in a state of sickness. Otherwise as far as I am healthy, I am very happy to feed her and take care of her."*

Merem also considers and compares her duty with her husband's responsibility and the issue of accountability towards the child with disability said that:

> *"I am the one accountable to give care to my child and God gave me the ability to take care of him otherwise it is hard. At least if his father is with me, he can able to work and earn money outside the home but he left both of us alone. He not only left us alone but also took my valuable resources. Nobody is responsible to accuse them and ask them about their responsibility. Now I am not in a position to run here and there to work hard and earn my own income because I am occupied by my son and always with him."*

## 4.3- Understanding and Managing Care Giving

Under this theme there are five major Sub themes; (a) Parent knowledge level about complication on children with disability, (b) How parents communicate with their children with disability , (c) How parents identify strengths of children with disability, (d) resource mobilization and (e) What is the care looks like, were identified.

### 4.3.1- Parent knowledge level about complication on children with disability

All parents have limited knowledge about their children disability and all of them are well aware of complication faced by children with multiple disabilities in the day to day activities and needs of children. All respondents became emotional, crying, depressed and burst in to tears while we were dealing with complications resulted from disability. One of the respondents, Beletu reflected that:

> *"As far as my understanding, don't let them to stay in one position is very important. They don't express their ideas, they never say I am hungry, thirsty or other. So we mothers are responsible to understand (she struggle with her tears). I understand! I have an obligation to understand this (long silence and head down). When we came to knowledge, I have no enough knowledge about her disability. I hope one day God make her standup, have a chance to eat and can sit by herself or she may ask 'I am hungry, thirsty and want to urinate.' I am eager to see that. The complication is not only on her but also on me; but my daughter doesn't know anything (she struggle with her tears). Those described impacts are increasing from time to time* ***ሲጋ ነሽና ትከፊያለሽ.****"*

Tsehaye further said about this issue in her own words that: "*my son is unable to move, feed, to wear, urinate and defecate by himself. These are the problems occurred due to the disability he has. You know, I am responsible to do these things myself. (She becomes emotional and doesn't talk about this issue any more……silence)."* Merem also expressed that the complication is not only on him but also on her life,

> *"For my part the level of knowledge about my child's disability is less because nobody teaches me about the issue. I observe that he becomes happy, when I gave love. The impact of disability is experienced not only on him but also on me. My son is unable to feed by himself, not able to play with mates and unable to do anything like children with the same age. As a mother seeing a tantrum child is a source of happiness instead of seeing a child like this."*

### 4.3.2- how parents communicate with their children with disability

All respondents tried to communicate to children with disability by their own instinct and all of them are consensus of identification and understanding of children's way of expression. This is very important in order to make the care giving process simple and complete. While expressing her level of communication with a child with disability, Beletu said that:

> *"Thank you God. When she becomes hungry, there is a sound from her tongue (she showed me by producing sound from her mouth) and when she feels thirsty she cried loudly. For the last 3 years she started to communicate with me like this. When she has a pain, I immediately understand by seeing her face like when she experience abdominal cramp, I know it by seeing her so hold her and go here and there or go to health facility. when she became awake at the middle of the night, I thought may be due to absence of light so I put on the light and if insomnia persists, I thought she may be thirsty so I provide her water."*

Furthermore Lemelem said that:

> *"I understood his interest very well. For example when he wanted to urinate, he produced a sound like eeeeee so at that time I let him urinate. Other family members didn't understand this sign. When he feels hungry, his eyes are steering at lunch utensils so I provide him food. I understand and communicate with my son. His strength is expressing his feeling and interest with non verbal communication. Nobody understands him but I do."*

### 4.3.3- How parents identify strengths of children with disability

All respondents tried to identify their children strength by observing children's way of expression. This gives input in order to make the care giving process a bit easy. One of the respondents, Aster said:

> *"It is important to know the strength of the child. For example when my son became hungry, there is a sign, he showed me his tongue out repeatedly (She show me practically). When his diaper is not changed*

> *timely, he started to cry over nothing. These signs for me are signs of strength. When he wants to picked up, he picked his upper body out of the pillow (*the child tried to lift upper body and sometimes laugh- she showed him to me*).* And the researcher asked her about his feeling at that time? *She replied, he is happy now and I understand each activity of my son."*

In identifying the strength of her son and used as an input for the care giving process, Thehay said that:

> "*I understand his feeling very well. Sometime I understand that his feeling is not full filled for example: now the way he is laying is not comfortable to him that is why he cried for nothing. He is not happy with the food because it is repeated. When I hold on my back, it is not comfortable for him and if he feels no comfort, he shows me with movement so I search for other place and change position. To show me this signs for me is a sign of strength."*

### 4.3.4- Resource mobilization

Regarding internal and external family resources mobilization for the care of their children, two respondents, Tsehay and Merem do not believe in the organizational support rather they want to self support and need favorable conditions to work in order to be self sufficient. In this regard Tsehay said:

> *"As compared to healthy children, they need more care and resource like clothe, soap, food, fruits, and diapers to provide care to him. For other healthy child, he/she can eat the available food in the house but a child like him was not eating available food in the house simply. He is unable to chew so his food is most of the time fluid so I am responsible to search all this and always try to work and become self sufficient for both of us. Now I am doing Injera baking and selling of spices and when I got some profit, I buy things to full fill his interest."*

Merem further said that:

> *"I do not believe in an organization, because the organization of this type is not long lasting. My interest and believe is, if government prepares a place for our children (daycare) and prepare an income generating activity for us, we can work and become self sufficient and I think this satisfied us. Support from organization may be discontinued and is not always a source of happiness. Everybody is happy when he/she did jobs by him/her selves and develops a moral of being sufficiency."*

Three of the respondents, Beletu, Aster and Lemelem always tried to search for internal and external resources and they also appreciate the support provided by organizations and associations. For example, they search for an organization (BGW) for physiotherapy and other service.

> *"For me, most people around us say* ***ጸጸ(ከንፈር መምጠጥ*** *means lip sucking), at that time I said to them, 'instead of saying like this why don't you provide her food, soap and diaper to keep her cleanliness.' Until now there are no individual or organization that provided diaper for her I wish somebody will provide her diaper permanently. Due to shortage when one diaper put this morning, I will change tomorrow morning and I feel very sorry to see this. Sometimes I want to change her diaper in half day basis but I do not afford the cost of diaper. Sometimes I thought and give prior to diaper than food but the cost of diaper is very expensive as 10 pieces costs 75.00 birr. I used this for 10 days and always feel pity always."*

In seeking and getting support from home, school, community, neighborhood, peers, associations GOs and NGOs, all respondents agreed that they do not get lots of help as such so far. One FGD participant said, *"There was no enough support provided for our children. We feel enough when our children entertained according to their needs.*

*Example when they get clothes, wheel chair, diaper; especially wheel chair and crunches based on their size."*

Aster said that*:*

> *"So far I got support from Brothers of Good Works. The organization provided us with wheel chair, medical support and coverage and we are engaged in income generating activity. It is true that, it is hard to get support from neighbors and is unthinkable (with dead sure facial expression). From family members, we got a daily support for me and my children."*

Concerning the necessity of support, they all agree that stakeholders should involve in the provision of care for their children. Tsehay expressed her idea as follows:

> *"When people gave me money, I invested on him. Regarding associations and organizations, I got not only financial but also clothe support and knowledge about the disability. Especially I thank to BGW for it provide us with the necessary knowledge about my child's disability situation. Moreover, BGW engaged me in income generating activity after giving basic business skill training. In addition the organization made me to know what was needed and what to do for my son."*

### 4.3.5- What is the care looks like?

The central point of giving care by almost all study participants focused on full filling their children's need and also caution about their security. All mothers are willing and they are in a position to understand and communicate with their children with disabilities. One of the respondents, Tsehay said that:

> *"I always take care of him not to fall down, not to be soaked in urine and feces, hungry and starved and not to be neglected and being alone. My son is not able to move by himself. If I left him in the house, nobody take care of*

> *him, nobody fed him and supported him in defecation. He is not able to say' I am thirsty, hungry, give me this and that' so unless and otherwise we take care of him, he will be harmed."*

Regarding the type of care given to her child with multiple disabilities, Lemlem said that:

> *"As I said to you, I knew his interest very well and I always gave the type of care that created pleasure for him. I always prevented him from falling down by keeping him on mattress instead of at bed. Even in the mattress, I always put my eyes on him in order to prevent collision with the floor. I always tried to communicate with him. I put him in different positions and I tried my best that is why there is change."*

## 4.4- Parental feeling and reflection about care giving

Under the theme Parental feeling and reflection about care giving there are three major Sub themes; (a) Feeling and meaning of care giving (b) Family belief system and care giving and, (c) Care givers feeling, worries and hopes were identified.

### 4.4.1- Feeling and meaning of care giving

When we come to the description of care givers personal feelings towards a child with disability in the family and as primary caregiver to the child, three respondents, Aster, Tsehay and Beletu had negative feeling. According to them people around them made them feel like that. Aster said," *People around said that he is without legs, without hands and unable to see and honestly when I heard these things I feel petty and it affected my feeling. (Head down with deep emotion and feeling)."* And Tsehay also expressed her feeling that,

> *"I appoint to do a kind of work for some body, if he becomes sick I am not going their; I became in a state of anger and said to myself that, 'it is because of him and if he is not in the house, I am able to work outside like my friends'."*

On the contrary, Lemlem said she had no negative feeling and meaning in relation to having of a child with multiple disabilities. She said: *"I am not feeling anything. God gave him to me. I do not complaining anything towards God. I could not have the will to change anything so I patiently provided the care needed by him."* When we came to the fifth respondent, Merem expressed the challenge she experienced and the way how to cope up with the problem and accordingly she said:

> *"I am alone and the only care giver of my son. All my family members discriminate me and even his father abandon us, family create distance from me. Despite all these things, I live in rental house and live our lives. The feeling is very hard because think of being alone and every family member left you. If I was not strong in religion as such, the response or reaction of people around me makes me crazy."*

When we come to care giver's meaning towards caring of a child with disability, almost all respondents consider themselves as responsibility taker what their God entrusted them by giving such children. One of the respondents, said: "*The meaning I gave is* ***አበሳዬን እዚሁ ጨርሼ ሂዱሁ ነው የምለው ከፈጣሪ ጋር*** *God gave and entrusted her to me and involved in her daily care giving and I thought after death I will go to heaven."*

Regarding their personal life experience in relation to having children with multiple disabilities, all the respondents were very much happy and they dedicated their life to their children. Aster in this regard said that:

> *"Me? (By putting her hand on her chest) I am sure! I am so happy. This son is a gift from God like other healthy children. I am not comparing him with his sister, I love him and I am not in a position to discriminate and neglect him. "*

*On* the other hand Merem expressed her fear in the future about her son in such a way,

> *"My personal life? My personal life was abandoned because of him. .... From now on wards I want to waste my time for my son not for other person. My fear in the future is, I started to feel pain in my back and kidney problem so, I am in deep fear of being sick because nobody takes care of him."*

### 4.4.2- Family belief system and care giving

When we come to the description of care givers on the family's belief system about having a child with multiple disabilities, How is this belief system reflected in the interaction among family members, and in collaborating or otherwise for providing appropriate care for the child with multiple disabilities, for Beletu and Aster, there was no wrong belief in their family system but the negative effect comes from outside their home that is from neighbors. One of the respondents, Aster said that,

> *"There is no wrong belief within the family. My family members always believed in, 'one day he will walk and become healthy' so in this way they make me stable. Hence family belief can create a very good environment in communication wise and have a positive impact on caring."*

On the contrary, regarding family belief system, Lemlem, Tsehay and Merem said that there is belief system in their family that multiple disabilities is a result of bacteria, sin or curse and its solution for Tsehay's families is from witchcraft and these beliefs had a negative impact on care giving. Lemlem, said that: *"Family members (relatives) believed and asked me that, is there a curse that the result is like this?"*Tsehay also said that: **"***Some family members and neighbors thought that taking her child to church is not a solution for the problem rather 'why don't you go to witchcraft to get a solution'."* Merem further said that: *"In our family there is no knowledge and awareness concerning disability because my sister told me the cause is transmitted by bacteria and others say that he is useless and give him to any organization."*

### 4.4.3- Care givers feeling, worries and hopes

Respondents also asked about their feeling while they were in public with their children with multiple disabilities, three respondents, Beletu, Aster and Tsehay said that, we are not feeling comfortable while we were living with the public. Tsehay said that (with deep emotion) :

> *"I always take care of exposing ourselves in front of many people because they always stare us and asked me many questions like: what is wrong with him? I always in a state of worry whether there is odor from him or not …. So I am not comfortable while I am out to the public with him."*

Moreover Aster explained that:

> **"***I have a negative feeling when I am out home and joined the public, most of the time he cried now and then without a point. I always worried about whether he urinates or not, he passed stool on his diaper or not, there is odor or not. When I am with him in the public, I always worried whether*

> *people are disturbed or not because he cried in a strange manner (he produce unique and strange sound). Due to this I feel pity more than thinking of his disability."*

Unlike the above three, Lemlem and Merem were not worried while they were in public with their children with multiple disabilities. In this regard Lemlem said that: "*I don't care. I have no negative feeling at all."* Merem on the other side: *"I have no negative feeling in this regard. I give value and care to my son. For me giving priority for my son with disability creates a sense of humanity."*

When we come to worries of care givers in relation to caring of children with multiple disabilities, Tsehay, Merem and Beletu worried about the future fate of their children. Beletu said that:

> "*When she starts grown up, I get more and more worried (she struggle with her tears). When she reaches at puberty stage menstruation is common. And at that time if I get sick, who will be responsible for giving caring to her? I always ask this question. Now she is 7 years old and tooth extraction started, I am very much worried about her future."*

> **"***My son's age is increasing so the burden is also increasing time to time (struggle with tears) and my living situation is changing time to time. Especially now due to the situation with my neighbors, the extent of worry I experienced is big."* Tsehay added.

For Merem, *"I always worried about the future fate of my son. I always think that if I die first who is going to be responsible for him and this is the source of my worry."*

On the contrary, Lemlem and Aster previously were worried but now things get changed. They accessed organizations like BGW and this normalize the situation. On this account Aster said that:

> **“***Previously, I was worried a lot about him. I was continuously crying and at the verge of developing psychiatric problem. Now that I got enough awareness about my son’s disability and go to BGW, I started to normalize my son’s situation. And when saw  I saw other children with disability come to my mind thinking and  understand that I am not the only one who experiences this situation and there are also worst cases serious than my own case.”*

Regarding the future hope of children, Aster, Lemlem and Merem have a good hope in the future; they believe that by the help of God their children condition will be improved. “*I always have hope in God and now the technology is in state of advancement so, one day things may change and my son like other children can walk, go to school by himself and play with other children.”* said Aster. On the contrary, for Tsehay and Beletu, do not have a good hope in the future. Beletu said : *“no hope at all, it is death. ……I always pray for God to do a right thing for us.”*

## 4.5- Challenges care givers encountered

Under the theme challenges care givers encountered, there are six major Sub themes; (a) Challenge in relation to child**,** (b) Health problem (c) Social isolation (d) Economic impact (e) Psychological impact and (f) Challenge in relation to societal belief were identified.

### 4.5.1- Challenge in relation to child

All the respondents revolved around the challenges of care giving and these challenges were connected to the impact of disability on children's life. Accordingly not able to ask their interest, unable to feed and drink by themselves, unable to control urine and feces, danger of aspiration, unable to talk, unable to sit, stand and walk by their own etc. are the challenges mentioned by all the respondents. In this regard Merem said that,

> ”*he is nothing to do as compared to his age groups. For example at the age of four, he still eats like a small baby, he is unable swallow solid food and he is always in danger of losing his life because of aspiration. Babies like my son having a very narrow throat feel very difficult to feed him but easy to provide drinks.***”**

Lemlem further said that:”*he doesn't ask me about his interest like asking me for food, water, and wants to defecate and he is an able to talk at all.”*

### 4.5.2- Physical Health problem

As a care giver, all respondents said that, there is a health challenge in relation to the burden created on them while providing caring for children with multiple disabilities. All respondents pointed out that they started to complain back ache and fatigue resulted from carrying of their children from place to place and carrying out the day to day activities to their children. Here is the case of one mother, Aster, said,

> *“Regarding my health, first I am in a state of worry because of his situation, I developed hypertension. Now a days, Where ever we go, I hold and carry him on my back for longer period of time; as a result I feel pain on my back (putting her hand at her back in a depressed feeling and exhausted looking).”*

### 4.5.3- Social isolation

Respondents also faced social problems because of being a mother and primary care giver of children with multiple disabilities. All respondents describe that they are not freely participating in social life not only due to the burden but also because of people using negative and non inviting reaction towards them. One respondent Beletu said,

> *"I am not in a position to go to weeding, mourning etc. freely. Even when I went to these occasions people didn't show me good face. For example one day I went with my daughter to my friend's house for celebration, at that time I felt sorry due to my friend's view towards my daughter. I said to myself 'I am not ashamed because of having her, why other people make me feel like that? She is clean, wears neat clothes; I was not asking them to kiss her, I felt sorry and caused me anger'."*

Merem on her side," For *I don't want people see me as a unique person I do not go to in public gatherings. I do not want to go to my relative's house because they don't show me good looking. I have no interest at all in all social life."* On the contrary, Tsehay said she is relatively active in social life as compared to other respondents but it is at the expense of her son's time with her. *"I leave him alone in the house and go and involve in social activity like mahiber, mourning etc."* said Tsehay. *One* participant in FGD said that, *"our neighbors invite my elder daughter for birthday party but after my son's existence; they were not asking him for birthday with her. They invited her alone and they said 'dressed her and send instead of dressed them and send'."* Another FGD participant said that, *"I go to my friend's son birth day but they are not allowed my son to have photograph with their children and even they were not happy by our presence."*

Most FGD participants also support this issue; similarly one participant of FGD said that*, "my neighbors stigmatized us. They didn't consider my child with disability as a human being. Some neighbors said when we saw him, we wanted to vomit. Hence nobody around us wanted to talk with us."*

### 4.5.4- Economic impact

Economically, all respondents claim that either they are not involved in work activities or problem of market for their work. My observation and office evidences showed that, mothers took excess time for caring children with multiple disabilities, due to this the income generation activity of these mothers are relatively poor as compared to other mothers caring without children with multiple disabilities. One respondent, Aster said,

> *"People around me thought that because of my son's continuous salivate and incontinent of urine and feces, the Injera prepared by me is not clean. They said 'she is the one who bake it'. Due to this I forcedly stopped the business. Regarding engaging myself in type of work, for I give care to him, I have no time to work and earn my own income."*

Being a primary care giver of children with multiple disabilities, two of the respondents Lemlem and Aster, the former became dependent on her husband and the latter other on her family members respectively. As a primary care giver Lemelm said that," *It is true that because of being a primary care giver of my son, I wait the hand of my husband and I am economically totally dependent on him."*

## 4.5.5- Psychological impact

Mothers directly involved in caring of children with multiple disabilities faced so many psychological problems, Being in a devastated situation, feeling bad due to forwarded ideas from other persons, feeling of hopelessness, becoming alone, lack of support and abandoned by husbands and other family members were psychological impacts almost faced by all respondents. Thus Aster said, *"Psychologically, previously I was so devastated but now I am strong and okay."* Furthermore, Tsehay said that,

> *"I am not feeling good when I think of my husband, though he is an educated person, he abandoned his son, and the way he said to me about our son's situation was unforgettable. I was not expecting such words especially from my husband."*

Psychological problems of mothers who are involved in caring of children with multiple disabilities may not always come from external; it may also arise from their children's condition. One respondent, Beletu said, "*When my daughter feels even minor sickness, I feel she will die. If this happens, people around may say 'I murdered my daughter' this is the extent of my worry."*Aster also said that, *"My fear is in relation to feeding. He always experience of food passing to trachea and due to this in am in continuous fear of losing him."*Moreover Merem said that,

> "*I always ask a question to myself up to when things go like this? During time of his sickness, nobody accompanies me when I go to hospital. Just I am going alone and at this time I feel loneliness, helplessness and psychologically affected."*

### 4.5.6- Challenge in relation to societal belief

Every society has its own culture, norm and belief towards any incidence within it. When we come to societal belief towards children with multiple disabilities, all participants said that, there is societal belief of; children with disability are useless and they should be raised in human service organization and care givers should be free of worry in fulfilling their needs. Aster explained about societal belief and her reaction saying,

> “*When I hold him with my back, he always wears shoes. When people meet me, they said ‘***አንቺ ጉደኛ ደግሞ ብለሽ ብለሽ ጫማ አደረግሽለት ለማይሄድ ልጅ ምነዉ ለድርጅት ብትሰጭዉ***?’ I confront them and said, ‘What is your problem I only take care of him, why don’t you say give him to an organization? Can I tell you I am in a state of give up? Can I ask you any support, diaper, soap or other thing? I said don’t talk to me like this otherwise I am not greeting you anymore’.”*

Three of the respondents, Lemelem, Merem and Tsehaye said that society believed that such type of disability is occurred because of kinship problem, curse and sin. Merem said that, *“people believe that such problem is occurred due to kinship relation (through blood relation).”* Furthermore Lemlem said that, “*even though I am not accepting such type of thought, people believe that such type of disability is the result of curse or sin.”*

## 4.6- Positive aspects of caring, coping and adaptation

Under this theme there are two major Sub themes; (a) Level of satisfaction and increase of sibling responsibility and (b) Coping and adaptation were identified.

### 4.6.1- Level of satisfaction and increase of sibling responsibility

Despite negative impacts on mothers and their families while they are being primary care providers of their children with multiple disabilities, there are also positive impacts mentioned by respondents like increase of sibling responsibility and psychological satisfaction on mothers. All respondents were happy and feel satisfied about the care provided to their children with multiple disabilities. On this issue Beletu said that, "*I feel happy when she started to laugh and tried to communicate with me and try to utter out words. I feel always being a strong person and greater satisfaction."* Aster also said that, "*I feel very much happy being a care giver of him. I sometimes observe changes on him. When I see these changes, I sometimes forget about the issue of disability. Hence I feel satisfied."*

When we come to sibling responsibility, three respondents, Lemlem, Tsehay and Aster said that sibling's level of responsibility is increasing from time to time. One of the respondents, Aster said,

> *"The level of responsibility of his sister towards him is increasing and it is unexpected. She always takes care of him and she always gives him his medication on time. When I forgot his time of medication, she always reminded me or gave him by herself at a right time and dose."*

### 4.6.2- Coping and adaptation

Regarding coping and adaptation mechanisms towards the challenges resulted in caring a child with disability, strength of mothers, strong level of attachment towards their religion, strong level of support from human service organization like BGW and not listening negative sayings etc. were mentioned as a way of coping towards the situation. One respondent, Beletu said that,

> *"I always have hope with God and always try to avoid and not listening other's negative idea or view in relation to her. God gave me health in order to feed, wash, hold, carrying and others to my children. I myself did these so I don't care what others told about us and I always close my ears for such things."*

Lemlem further said that*," I already learnt from the situation, staff of BGW supported me to know and I also learn from Television programs."*Merem also said in this way,

> *"The best coping mechanisms I had are my own strength and my hope towards God. I always said, God created both of us and we believed on him that there is no way to left us like this. The level of attachment to my religion made me strong enough in taking care of my son."*

## 4.7- Expectations of Participants from Different Actors for a Positive Influence on Care giving

Under this theme there are three major Sub themes; (a) Effective and betterment of the service, (b) Support from family members**,** neighborhood peers, society, community, professionals and (c) Support from government and organizations were identified.

### 4.7.1- Effective and betterment of the service

The most effective way to give care for children with multiple disabilities and the recommendations for the better provision of service to children with multiple disabilities was also assessed in this study. For Beletu*," the effective way of care giving is to be* *strong if there is no views, insults and ideas come to me which is very abusive and irritative, every mother of a child with disability can properly taking care of her responsibility."* On the other hand Aster said that, "*for children like my son there must be special needs education and day cares like other healthy children. More over we need psychological and counseling support because most care givers are left by their husbands and the situation of our children is like this (she pointed to her son)."* Tsehay claims food and sanitary materials support but for Merem, care will be better and effective:

> *"When we have our own house with intact marriage, spouses can support each other in dealing with problems and both parents must avoid selfishness. Husbands must live with the family instead of leaving their children like any material in the house. Fathers of these children should be accountable and government must give attention for us."*

### 4.7.2- Support from family members, neighborhood peers, society, community and professionals

Even though families of those children with multiple disabilities' needs are different from significant others , all respondents agree on the importance of support for effective and better care. They said:  professionals, family members, community and neighbors should be responsibility to take care of their children. One of the respondents, Lemlem said, "O*ther family members must take a responsibility of feeding him, providing water for her and should take the care giving task during our absence and not to discriminate her."* For Aster, "*people and kebele officials should develop their level of awareness. People better not to say 'she holds a useless son' and, I expect good advice and counseling from professionals."* One of the respondents, Merem said,

> *"I expect more from educated people to coordinate things in order to prioritize the services needed for children with disabilities. The impact of disability on these children should be explained in media. ...... It is hard for a care giver who is always taking care of a child who is not self sufficient in every self care."*

### 4.7.3- Support from government and organizations

All respondents expect support and recommend ideas for government and human service organizations. Beletu said that, "*From government I expect inclusive education and environment for our children. I wish there is a school for them around us and for organizations,' it is better to diversify services instead of providing the same kind of service'."* Aster also said that*." government should give great attention to create organizations established like in the case of cancer and HIV."*Lemlem recommends,*" food and sanitary material support from organizations and government."* On the other hand Merem said that, *"We expect from government to organize and coordinate day care for our children so that we can work and we have our own income."* One respondent from FGD in this regard also said that, *"what is the responsibility of the government? This question must see critically. Our children are growing and they have a right to get sustainable care and support. "*

## 4.8-Common Challenges and Coping Mechanisms

Under this theme there are two major Sub themes; (a) Day to day care and lack of support and (b) Shared experience to cope up were identified.

Challenges:

### 4.8.1- Day to day care and lack of support

In the focus group discussions, participants were asked about the common challenges encountered as a result of caring for children with multiple disabilities. All participants said that, they face danger of aspiration while they are feeding their children and those children are not in a position to do activities by themselves as compared to their age groups. Regarding aspiration problem, one FGD participant said that, "*I always holding him in my thigh when I feed him but he always experience aspiration and I am alone at this time nobody allows water to me in order to give him"*

When we come to the problem of asking what they want, one participant said that,

> "*My son doesn't say I am hungry, thirsty and he cannot talk with me. So I served by guess. There is a problem of asking what he wants like other children without disability. Moreover, I am not allowed to go with taxi or bus while I am with him because drivers were not willing to serve us. Oh! It is really a problem."*

In addition all participants face psychological challenge because of having children with multiple disabilities. Psychologically, one participant said that, *"I always in a state of worry because he always cried over nothing."*Moreover another participant explained that*," When I am out of home with her, people always stare at us and pointing to us frequently as if I am with a different creature."* And all participants agreed with her idea and they said they were not comfortable about people's reaction towards them while they are with their children in a public place.

### 4.8.2- Shared experience to cope up

When we come to the shared experiences in terms of coping with challenges of caring children with multiple disabilities, all participants discuss on an idea like, in addition to their strength, there should be a kind of union or support group organized by themselves. They all said there was an experience of organizing such group and it was useful for them in every aspect. One of the participants, Beleu expressed her experience to confirm group's idea as follows:

> *"We, mothers of children with disability, organize a kind of union that gives response to our problem. We contribute 10 birr per month and when problem arises in one mother, we support each other in every aspect. When we meet each other, we started to normalize the situation that we are in and create a sort of happiness. This type of union creates awareness within our neighbors. The problem of our children makes us one so we support each other in every social aspect."*

## 4.9- Policy issues and Implementation

Under this theme there are five major Sub themes; (a) - policies and programs on disability (b) Resource mobilization, participation and accountability of stakeholders (c) Institutional structures, resource allocation and commitment for implementation, (d) Gaps for implementation of policies so far and (e) Monitoring and evaluation of policies about disability were identified.

### 4.9.1- policies and programs on disability

Like other countries, Ethiopia has policies and programs on the issue of disability. Ato Amha Berhe( Policy and Programming Team Coordinator) and Ato Damtew Alemu(Capacity Building Team Coordinator), both worked at the Federal Ministry of

Labor and Social Affairs (MoLSA**).** About the department, Ato Amha said, *“Mainly deals with employment and social issues handle all social matters, including disability-related issues, under the policy framework established by MoLSA and also understanding of the wide variety of social protection policies and program that presently exist throughout.* Furthermore, Ato Damtew said that,

> *“There is a general social protection policy taking as a national frame work that emanated from outdated developmental Social Welfare that stems from charity model thinking. The strategies prescribed include: creating an accessible, promoting positive attitudes towards disability. An understanding of the central challenges and opportunities facing social protection systems can help us to inform current and future efforts to extend social protection. Similarly, the National Program of Action for Rehabilitation of Persons with Disabilities intends to put in place measures to prevent disability, empower and promote equity and their participation in the societies. There are a number of legal and policy instruments designed for the future as a policy direction and it includes persons with disabilities and their families.”*

Social protection policy mainly formulated to address the problems faced by parts of the society who needs protection. Ato Damtew said that,

> ” *well under the social protection policy we identified thirteen socio-economic problems that are regarded as exposes to the increased vulnerability. From the 13 socio economic problems disability manifested itself in marginalization/exclusion from resources and encounter different forms of abandonment or neglect and sigma they are rooted in negative assumptions and ignorance. Therefore, in responses to situation the policy document incorporates a policy direction giving priority is a crucial factor*

> *in responses to the problem by what is needed to their futures to the benefit of all."*

### 4.9.2- Resource mobilization, participation and accountability of stakeholders

Regarding resource mobilization, participation and accountability of stakeholders, my key informants from MoLSA said that,

> *"Well one thing primarily needs to know in addressing disability problem can not only be practical by the government alone. Our society had created structures which is community care coalition movement. The movement originated from the community to help vulnerable households and was started before fifteen years ago. Resource is mobilized from community members for children with disabilities. Family and care-givers receive assistance in cash or in kind like crop to support their families as a child grant. When we try to look at a fund from external sources our government doesn't give much emphasis on it. The primary focus area is to strengthen the local capacity to generate income. Dependency on foreign aid due to many reasons isn't a wise strategy. After the international economic crises, the foreign aid shows a reduction/cut in the amount. The stakeholders for the support of the programs are Government, NGOs and the Private Sector."*

Furthermore, W/o Genet Peteros (Children Care and Support, Inspection Directorate Director) at Addis Ababa Women and Children office said that, they are not in a position to entertain children with disability separately from children without disability. The directorate director said, *"Concerning this there are projects and there are NGOs working with us. So we mobilize resources and coordinate them in order to give services to children."*

### 4.9.3- Institutional structures, resource allocation and commitment for implementation

Any country must have institutional structures, enough resource allocation and stakeholder's commitment for the implementation of policy and programmatic issues. In this regard, Ato Amha said that:

> *"When we say institution, we mean governmental institutions. The nature of disability is mainly multi-originated. When we implemented these multi - originated problems we need to have multiple solutions. In order to implement this policy, the different institution of the federal arrangement is able interplay with their own business mentioned in article 916/2008.*
>
> *Under the role and responsibilities, the Ministry of Labor and Social Affairs (MoLSA) is the main governmental organ at federal level responsible for the provision of social rehabilitation for people with disabilities. BoLSAs at regional level is responsible for the implementation or handling of all social matters, including disability-related issues, under the policy framework established by MoLSA. These structures are meant to plan, facilitate, implement and monitor programs aimed at realizing the rights of persons with disabilities."*

W/o Genet in this regard said that, *"For me disability is a possibility for everyone. Today we are ok but we don't know what will happen tomorrow. So every sector office must consider disability issue as part of their plan and implementation. The responsibility is not only given to one sector but for other sectors."*

## 4.9.4- Gaps for implementation of policies so far

Another area assessed by the study is gaps occurred in the implementation of the existing policies and programs in relation to the provision of care to children with disabilities and their families. Ato Ameha said that;

> *"Regarding the implementation we are on the bottom line. Well one of our problem is low level of public awareness creation. There is also a problem on all beneficiaries and the implementers towards the policies and guidelines. There is no clear understanding on it. Moreover there is a resource limitation and inadequate trained personals on the issue of disability. In addition, there is a high turnover in experienced staffs in governmental organizations; for experienced staff they prefer to go to international organizations so we are forced to do with junior staffs. This is a prime issue that hindered us from implementing the policy on issue under the public institutions. "*

Concerning the level of policy implementation, W/o Genet said that,

> "*Even though it needs research based empirical data, when we observe the existing situation of children with disability, there is change when we compared it with the previous time. When I say there is change. I don't mean that it is implemented at the level of Ethiopian constitution says about disability. The misconception is so deep rooted in our culture and hence it needs time. Things have changed a lot but this is not enough, we should work hard in the future."*

## 4.9.5- Monitoring and evaluation of policies about disability

Concerning monitoring and evaluation of policies and implementations, Ato Ameha said that, *"The monitoring and follow up activity is in a good condition. As usual we work with different partners hence we always invited them from policy initiation up to implementation, review and appraisal. Thus we meet with those NGOs and the public wing in every quarter for policy implementation and review. All stakeholders are participated in every aspect of implementation processes in order to ensure that there is a match between what is offered and what is needed that are critical component of quality assurance in the program. We work through collaborative partnership."*

# CHAPTER FIVE: DISCUSSION

## Introduction

The main objective of this research was to explore and describe the experiences of families who are responsible for caring of children with multiple disabilities. The discussion tried to answer the following specific research questions; How did family members feel about and give meaning to their experience of caring for a child with disability?, How did care givers handle the responsibility of care giving for a child with multiple disabilities?, How did the care giving experiences for a child with disability affected family member's life? And how did families explained their experiences of caring for children with multiple disabilities?

This chapter includes discussion of the findings in relation with different researches in the literature. The issues which are going to be discussed are experiences faced by mothers who are primary care givers of their children with multiple disabilities. We pick major findings and discussed with reviewed literatures. Most of them are supported by pervious researches while others are not well discussed in relation to the reviewed literature. A number of findings in this research supported previous research. For example, challenges faced by primary care givers of children with disability, how mothers become primary care givers, care giving process, complication on child, societal belief system, positive aspects of caring and others. While the others literatures partially support the research finding. The discussion that synthesizes field data and literature knowledge along the researchers view is presented in the following paragraphs.

## Services to Prevent Congenital Disability

Regarding the health service given to mothers who are in anti-natal, peri-natal and post- natal, the health policy produced by Ministry of Health (2010) said that,

> ‘*Quality of Health Care’ is a measure of the degree to which health services for individuals and populations increase the likelihood of the desired health outcomes consistent with current professional knowledge. The delivery of quality health services is central to improving the health status of the population. The Federal Ministry of Health has built an impressive framework for improving the health for all, including maternal and neonatal health (MOH, 2010).*

Even though ministry of health launches the above strategies to improve the health service system, regarding condition at pregnancy, birth and post natal care as majority of the study participants said that, suffocation and lack of oxygen during birth, negligence of health professionals, hurt during pregnancy, mismanagement of prolonged labor, excessive use of instrumental delivery and falling down of children after birth were the main contributors for their children’s disability. The participant’s idea was supported in the reviewed literature in that: ACPF (2014), “disability in Africa is largely attributable to war, poverty, and inadequate access to health and rehabilitation services (pre- and peri-natal problems such as genetic disorders and birth trauma; injuries; accidents).

## Knowledge about Disability

In the finding concerning knowledge about disability and community awareness, most study participants said that community should be supportive and well aware about disability is nothing to do with the misconceptions raised by our community. The respondent's idea is also supported by: Phuong, Depasse, Khanh, Hang and Erickson (2009), said that, "the positive perceptions of families and the community are key to trigger in a broad and significant communications strategy to help drive change and impact knowledge, attitudes and perceptions at an individual and community level."

On the contrary of the above idea, all the study participants confirmed that, they didn't have any knowledge about disability, before they knew the diagnosis of their children with multiple disabilities. Not only mothers but also the entire family didn't have any knowledge. The literature also supports that in Africa particularly in east Africa, instead of having scientific knowledge about disability, misconceptions are predominant as ACPF (2014) and Mbah-Ndam (1998) as cited in MacDonald said that in Africa misconceptions about the cause of disability are predominant in cultural beliefs and traditions that causes of disability include witchcraft; a curse or punishment from God; anger of ancestral spirits; bad omens; reincarnation; heredity; incestuous relationships; and the misdemeanors of the mother.

## Caregiving Responsibilities

Care giving process by mothers to children with multiple disabilities includes many activities because children with multiple disabilities are not in a position to take care of themselves. For all study participants, they involved in every activity like changing diapers, feeding them, washing them etc. based on their children demands and all agreed that their ample time was taken by their children with multiple disabilities for caring as previous researches by N. C. Van Wyk & R. Leech (2016), mothers are challenged at home to integrate basic infant care with technical care of their children. More over my field notes also confirmed that, their time was mostly occupied by the types of care needed by their children with multiple disabilities and they had no enough time to do their income generating activity efficiently.

One of the critical issues facing mothers of children with multiple disabilities is most of the time they are the primary care givers and this makes them responsible and loaded by everything concerning of children with multiple disabilities. All respondents said that, they are after all mothers of their children and there was no one like them to take responsibility to take care of their children with love based on children’s interest.

Even though all the respondents consider themselves as a primary care giver, they had positive view on the importance of support from professionals, family members, community and neighbors for effective and better care for children with multiple disabilities. They said:  these bodies should assume responsibility to take care of their children by any means. This response is also supported in the research, the UK Contact a Family (2011) that families of children with disabilities face an overwhelming combination of financial, emotional and practical pressures and, without information and support, they find it difficult to cope. Council of IASSID (2012) further confirms on this issue that, “with better funding from agencies that recognize the importance of family context and international collaborative efforts, we may be better able to support and intervene with all families supporting an individual with disabilities, regardless of their location, socioeconomic circumstances".

## Societal Belief about Disability

As presented in the finding, regarding societal belief in the caring process, all participants said that, there is societal belief of; disability is occurred as a result problem in kinship, curse and sin, children with disability are useless and they should be raised in human service organization and care givers should be free of worry in fulfilling their needs and this type of societal belief have negative impact on the care giving process as study participants said. Most literatures supported the cultural beliefs that disability is a result of sin, punishment from God, witchcraft and the like in most east African countries. This is also supported by the literature ACPF (2014) stated that, in Africa misconceptions about the cause of disability are deep rooted in cultural beliefs and traditions that causes of disability include witchcraft; a curse or punishment from God; anger of ancestral spirits; bad omens; reincarnation; heredity; incestuous relationships; and the misdemeanors of the mother.

## Meaning of Care giving

In the finding, care giver's meaning about care giving to their children with multiple disabilities, majority of participants said that the meaning they gave about care giving is abandoning of their personal life meaning their focus is only their children. Most of them except one are not living with partners and do not have a plan to have marital relationship in the future. All participants are occupied by the day to day care giving of their beloved ones and even one of the participants expressed her meaning towards her care giving in an expressive way “**አበሳየን እዚሁ ጨርሼ ሂድሁ ነዉ የምለዉ ከፈጣሪ ጋር**”( Such type of expression in our society incorporates many things like pity, hopelessness, exhaustion, lack of support etc.). The challenge and the demanding nature of care giving resulted from the care giving of children with multiple disabilities supported in the literature ACPF,(2014), Marcenko & Meyers,(1991) and Hiwot,(2003) stated that family care givers face challenges in different life dimensions. The challenges resulted from care giving dictates the meaning care givers given to that.

## Worry about the future of Disabled Children

As indicated in the finding, almost all study participants worried about the future fate of their children. Since all of them were primary care givers of their children with multiple disabilities they always think and worried about who will be responsible to take care for their little loved ones other than them when they may face sickness, problem or death. This finding is also supported in literatures, Council of IASSID (2012) and the UK Contact a Family (2011) said that, “in many contexts family involvement extends over the life span of parents, with siblings and extended family members taking on caring roles, especially when parents are no longer able to and the constant worry is there for their children with disability for the future if they are not around to care any longer.”

## Impacts of Care giving on Caregivers Lives

The finding of this research concerning the challenges faced by care givers of children with multiple disabilities are very much supported by previous researches in literatures. In the research finding caring and dealing with children with multiple disabilities affects different dimensions of participant’s life because these challenges were connected to the impact of disability on children’s life like not able to ask their interest, unable to feed and drink by themselves, unable to control urine and feces, danger of aspiration, unable to talk, unable to sit, stand and walk by their own. Social isolation(lack of participation in social events), high level of stress, burden, occurrence of health problems, not able to engage in income generating activity simply were the challenges mentioned by participants of this study. This result was also supported by the literature reviewed in Thwala and et al.(2015), swanepoel (2003), CRPD(2012), Anderson and et al. (2007), Singer and Farkas (1989), Gottlieb (1997), Hiwot (2003) and Ayenalem (2014), said about the challenges faced by family care givers in health wise, psychologically, socially and economically.

Unlike negative impacts on mothers and their families while they are being primary care providers of their children with multiple disabilities, there are also positive effects mentioned by respondents like increase of sibling responsibility and psychological satisfaction on mothers. All respondents were happy and feel satisfaction about the care provided to their children with multiple disabilities as literatures also supported this result in Reichman, Corman and Noonan(2008) and Sandra B. & Abdelrahim (2016) , that it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions and increasing of sibling responsibility.

## Coping Mechanisms of Families Caring for Children with Multiple Disabilities

Regarding coping and adaptation, even though coping with the situation as stated by Tracy Wilkins (2007), hindered by lack of normalization of the situation, lack of appreciation of the existence of children with disabilities, stress raised from providing support and family has been in constant change, this research participants have their own ways of cope up like: strength of mothers who are involved in care giving, strong level of attachment towards their religion, strong level of support from BGW and not listening negative sayings forwarded from their surrounding environment.

Most literatures so far were not focused or concerned about the relationship between the level of being religious and the care provided to children with disability. In this study, the most important coping mechanism towards the challenges as a result of caring is hoping towards God. Most of our participants, regardless of the type of religion they follow, they said being a religious person made them to accept their children's situation and gave appropriate care to their loved ones with hope and love. This idea is supported by Tracy Wilkins(2007), that families, who are caring a child with disability that have faith in something is more able to cope up than who do not have.

Moreover, almost all study participants appreciate the advantage of support group they organized so far and had been regular meeting to do with challenges encountered as a result of caring a child with disability by them. When families of children with multiple disabilities meet each other, they started to normalize the situation that they are in, create a sort of happiness and awareness within their neighbors. This idea is also supported by Solomon, Pistrang, Barker(2001) said that: that members of the group found the groups as very helpful and satisfied with the support they received from their groups, the groups also is a source of cohesion, expressiveness, task orientation, and self-discovery.

## Legal Frameworks on Disability

When we come to policy issues and implementation, according to the Ethiopian social protection policy (2012), Ethiopia has ratified international conventions, rights and instruments concerning children in general and children with disabilities in particular and based on that the social protection policy developed to underpin actions necessary to fulfill constitutional requerments. Article 41/5 of the FDRE Constitution states ‘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.’ Constitution of the federal democratic republic of Ethiopia (December 1994)

In the finding, key informants of the government bodies confirmed that, in order to improve the service given to children with multiple disabilities and to make the social protection policy implementation effective, all government sectors must consider persons with disabilities in to consideration, elevate community awareness about disability, resource should be mobilized both from internal and external resources and efficient monitoring and evaluation program should be in place.

Even though government launches the social protection policy as a policy framework with the aim of as key informants from ministry of labor and social affairs said,” *putting measures in place to prevent disability, empower and promote equity and participation in the societies.”,* the services implemented for families of disabilities, all participants said that there is inadequacy of support from government and community. They further said, they are deprived of economic and social rights, low level of awareness about disability in the community, the services given by government bodies were not user friendly, still experience stigma and discrimination, predominant existence of wrong beliefs and ignorance about disability, office holders or expert’s wrong attitude towards children with disabilities and their care givers. They expect and recommend more support for them in order to overcome the above mentioned challenges faced by children with disabilities and their care givers and in general for children with disability and children with multiple disabilities in particular.

Regarding the implementation of the social protection policy particularly for children with multiple disabilities, the key informants also said we are on the bottom line as compared to others but it doesn’t mean we are at zero level as this study participants (mothers who are responsible to care children with multiple disabilities) said. The reasons behind the low level of implementation are, the misconception is deep rooted in our society, low level of awareness creation, no clear understanding on policies for beneficiaries and implementers, resource limitation and high turnover of trained personnel. They further said things in relation to disability started to change but it was not enough, more work, activity and commitment are left in the future. So we should work hard and different stake holders must also cooperate with us to effect change in the lives of families of children with disabilities.

### Relating findings with Models of disability

There are models of disabilities that see disability from different perspectives or angles. The medical model of disability view disability as a problem of the person, directly caused by disease, trauma, or other health condition which therefore requires sustained medical care provided in the form of individual treatment by professionals. While the social model of disability see disability as socially constructed problem and a matter of the full integration of individuals into society. In this model, disability is not an attribute of an individual, rather a complex collection of things which are created in the social environment. So this study takes synthesis of both models as the most useful approach that is the Bio-psychosocial Model.

In relation to medical model of disability, purpose of the intervention is cure and individual’s adjustment and behavioral change. To effect this change, at the political level, principal response is that of modifying or reforming healthcare policy. This main assumption of the model was better described in the experience of mothers participated in this research. They said the predominant cause of disability for them is suffocation and lack of oxygen during birth, negligence of health professionals, hurt during pregnancy, mismanagement of prolonged labor, and excessive use of instrumental delivery. So to decrease its magnitude, proper health policy implementation should be a must.

When we come to social model of disability, disability demands multi-sectoral response, since the problem is created by an unaccommodating physical environment in which children with multiple disabilities and their families are living and unhealthy attitudes and views from the larger social environment.  This main assumption of the model was better described in the experience of mothers participated in this research. People do leave them alone; staring at them, look at them fiercely, talking about them isolate them from social events, giving unproductive comments are common from the social environment they have been living. So giving them space for social environment and interventions at political level is mandatory.

On their own the medical and social models are partially valid but not adequate so this study takes the Bio-psychosocial Model. The assumption in this model is best explained in this research finding. Participants faced health problems of children with multiple disabilities that need medical intervention and also faced problems in relation with denied social inclusion. So involvement of all stake holders in the intervention is unquestionable.

# CHAPTER SIX:

# CONCLUSION AND IMPLICATION

## Introduction

In this chapter the conclusion and implication are presented in reference to the data from the participants of the study, the literature review and the researcher’s view in line with the title of the research.

## Conclusion

The study participants consisted of five mothers, age ranged from 30 to 33, who were directly involved in the day to day activities of children with multiple disabilities. The participants of this study are clients of BGW who were volunteered to share their care giving experiences.  Concerning knowledge, this study finds, instead of having scientific knowledge about disability, misconceptions are still present in the cultural belief of our society even though there are improvements. So people who heard about it considered disability as a private business of the family that faces the problem. As a result, a family of a child with multiple disabilities is always facing psychological, social, and economical problems in the context of research participants.

Caring for a child with multiple disabilities is an experience that is embodied both personally and in all systemic structures of family relationships. This research finds the care givers challenges in these systemic relationships in health, psychological, social, and economical dimensions. Despite the above all challenges in different life dimensions, the research finding showed that, almost all responsibility is on the shoulder of mothers who are taking care of their children with multiple disabilities. So professionals and implementing institutions working with these families equip family caregivers with appropriate skills to manage strong emotions and supporting mechanisms in order to overcome their challenges.

It is essential that professionals including social workers, health professionals and others concerned bodies including government officials to understand the challenge from the mouths of primary care givers of children with multiple disabilities. This study has documented the real and ongoing challenges of family caregivers of children with multiple disabilities. From the finding, the availability of support for families with multiple disabilities was insignificant starting from family members up to the government at large. On the contrary, government offices claim that, there is good policy based on the constitution of Ethiopia, there are implementation institutions up to kebele level, involvement of all sector offices, resource mobilization and have good monitoring and evaluation activities. So the policy makers and implementing institutions must understand the existing gap, use care giver's experience as an input, sure about policies implement at grass root level and must find a way to fulfill it.

This study has also recognized that the most important (agreed by all study participants) coping mechanism to overcome the challenges as a result of caring is hoping and believing by God, the support group families  organized so far and the level of strength care givers have.  In addition, all participants have positive view on the importance of support from professionals, family members, community and neighbors for effective and better care for children with multiple disabilities. So concerned bodies work on this families can use this coping mechanisms as an entry point for effective support and efficient policy implementation.

## Implication

This research finds that, psychological, social, emotional, physical and economical challenges are predominant in care givers who are responsible to taking care of children with multiple disabilities. In order to overcome these challenges, interventions at micro, mezzo and macro level must be in place. The following are implications for policy, social work practice and further research in order to result positive and effective care giving experience by families who involved in care giving for children with multiple disabilities.

### Implication for policy

At the federal level, Ministry of labor and social affairs developed a general social protection policy, can be taken as a national frame work formulated based on the Ethiopian constitution and international rights of children and disability accepted and signed by our country. In addition the revised family code also formulated with the Preamble of “it has become necessary to amend the existing law in such a way that it gives priority to the well-being, upbringing and protection of children in accordance with the Constitution and International Instruments which Ethiopia has ratified” (P.1). The social protection policy was formulated for social and economical vulnerable groups and people with disability are one of them. However when we come to implementation according to my key informants, we are at the bottom line and this fact also confirmed by study participants. Having such policy formulated on paper is not enough rather government bodies must work on more capacity building to increase the number of skilled manpower, work on more resource mobilization activities, to increase benefit packages for staffs who work on disability in order to prevent turn over and create a clear understanding about existing policies among different stake holders work on the issue of people with disability.

In policy formulation, the key informants from MoLSA said that, the monitoring and follow up activity they work with different partners and invited them from policy initiation up to implementation review and appraisal. However in the grass root level, all the study participants didn’t know about policy matters so the concerned government body must listen and incorporate the ideas of families who are involved in caring of children with disability.

Regarding capacity building of care providers and program managers, the concerned body must review the knowledge and competencies of staff in disability issue because it can provide the government bodies to develop appropriate measures to improve them. More over the special needs education must be accessible to the needy, not far from their residence and must be staffed by skilled manpower including health professional, psychologists, counselors and social workers. In addition the started inclusive approach in many sector offices including in health care setting must be widened and the environment must be disability friendly.

On the issue of awareness about disability, the misconception is still present in the cultures of our society so government must increase public awareness through social campaigns by using or work with voluntary organizations, informal social organizations like *idir*, *mahibers*, *iquibs* and professional associations. More over support groups organized by family care givers of children with disability should be strengthened by information, income generating activities and professional support. Policy makers must consider support groups as an entry point to get the necessary inputs for their work, to know the level of awareness and the gaps in implementation so far.

Advocacy work should be done by professional associations, media at national and regional level, mini media at school level, influential people, civil societies, artist, organizations and government agencies in order to mobilize resources and to overcome economic marginalization.

## Implication for social work education and practice

The social protection policy of Ethiopia considers people with disability as vulnerable groups who need intervention to ensure socio economic wellbeing of them. Social work is also a profession that works towards improving the life of vulnerable groups of people and to promote social inclusion in the lives of people. From the finding children with multiple disabilities with their family care givers faced many problems in different dimensions of their life so school of social work and social workers have a home work to deal with such problem in order to make these people become economically self-sufficient and liberate from the challenges they faced.

From the finding, key informants said that there is shortage of empirical researches to show the magnitude of the problem of disability. As AASW (2016) said that, "social workers develop evidence based assessments, planning and interventions within a client empowerment framework. Social work interventions take in to account the impact of health, psychosocial or other needs of the individual and their support system". Based on this fact,  school of social work in general and social workers who study in this subject matter in particular must provide empirical researches for policy input and as an evidenced document in planning interventions and strategies focused on children with disability and their families.

Social workers look at the person-in-environment, including all of the factors that influence the care giving experience of family members for children with multiple disabilities. The respondents of this research paper experience challenges within their environmental setting and have their own coping mechanism so social workers must consider these things in to consideration in order to give user friendly service. In this case social workers can intervene in many aspects of the individual i.e. beginning from the individual to the family, community and the wider society to improve the wellbeing of children with disability and their family members.

Social work researches in many social problems like in case of issue of disability as key informants said were put in the shelf, so the school of social work has a responsibility to make them practical and to be used in inputs for policy formulation. Social workers must involve themselves in institutions that work in disability issue in order to play their part like in problem solving, counseling, networking etc. hence the lives of children with multiple disabilities and their family care givers becomes improved.

## Implication for further research

Social work research in different social problems is mandatory to know the extent of the problem in evidenced manner. Further research could be needed to know the magnitude of the disability problem and KAP survey in the issue of children with multiple disabilities. Furthermore regarding the level of implementation of the programs of children with disability, the concerned governmental offices said that there was no a single research so far so it needs research. In addition all respondents said that as a coping mechanism, religion and support groups played a significant role so far. So the religious institutions role and the extent of support from support groups for children with multiple disabilities with their family care givers as a coping mechanism needs further study.

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## Annex I

## In-depth Interview Guides consent form

My name is Woinshet Kerebih, a post graduate student at Addis Ababa

University, College of Social Sciences, School of Social Work. I am planning to conduct a study on the experiences of family members who are responsible for caring for a child with multiple disabilities. The purpose of the study is to understand, explore and explain about, How do family members feel about and give meaning to their experience of caring for a child with disability?, How do care givers handle the responsibility of care giving for a child with multiple disabilities?, How do the care giving experiences for a child with disability affect family member's life? And how do families explain their experiences of caring for children /child with multiple disabilities?

For the successful accomplishment of the study, the cooperation of caregivers who are responsible for caring children with multiple disabilities is crucial and I would like to ask your permission to participate voluntarily in this study. Your participation enables me to know what I am supposed to investigate.

The procedure to be used is an in-depth interview and the time and conditions required to participate in this project will favor the convenience of study participants. The researcher will clarify any questions that are not clear for you during the interview. During the whole process of the study and after that, I would like to assure you that your identity will not be disclosed to anyone. In this case the information you provide will be processed by using only pseudonym or other codes during analyses and report writing of the research. This is to protect your privacy and confidentiality of the information you provide.

I will use tape recorder to correctly record the conversations we do, and the recordings will be locked in a safe place and will not be exposed to anyone. I assure you for any data collected are to be used in the process of completing my Masters in Social Work. The notes and tapes will be destroyed after the study is completed and approved by the School of Social Work. By participating in this study, you will contribute not only for the success of my studies but also for the advancement of knowledge building in the area of caring of a child with multiple disabilities.

Except the time you spend with me, I do not see any risk that you will under go by participating in this study. Although your input would be greatly appreciated, your participation in this study is absolutely voluntary. You may withdraw from this study at any point in time when you believe to do so. Your decision will be respected. Finally if you are agree to be part of this research under the provided conditions, confirm by signing this form.

**Pseudonym** _________________________Date___________________________

Signature_______________________

## Annex II

## In-depth Interview Guides

Good morning/ Good afternoon again sir/Madam? The information I want from you are categorized under six sub titles. As you confirm to be part of the study, Can we start by telling me about your background information like?

### I. Background information

- Age…….
- Sex……..Educational status……..
- Marital status………….
- Religion…………………..
- Family size… Male----------Female-----------
- Employment Status……….
- Gender of the disabled child you are caring for: Male-------Female----------
- Age of the disabled child/children: ----------------
- Your relationship with the disabled child………
- Tell me with whom do you live with………………..
- Duration (in years) of your involvement in care giving…………

- How did you first come to this organization or how did you know about the services available in this organization for children with multiple disabilities?

## II. Knowledge about disability, needs of children with disabilities, care giving process, and experiences

- Tell me about your child's disability? Causes of disability of the child: congenital or after birth? Please explain.
- Have you ever had any knowledge about multiple disabilities? Or is there anyone in the family who has that knowledge?
- How did you first know about the child's disability? (This question is asked only if the type of disability is not easily observable)
- How did you learn about caring for child/children with multiple disabilities?
- Tell me the reason for being the primary caregiver of the disabled child in relation to other family members.
- Please explain to me: your routine caregiving experience from morning to the evening in a chronological order?
- Would you explain for me about the general reflection about the care giving process?
- Tell me the participation of other family members in the caregiving process?
- Explain your feeling about being the primary caregiver of the disabled child in relation to the role played by other family members?

### III. How care givers manage care giving responsibilities?

- What does care giving to children with multiple disabilities include? (Please ask questions emphasizing on the caregivers knowledge about the nature of the child’s disability, such as complications related to the physical, mental, psychological/emotional, social or relational..health of the child…
- What does caregiving to children with multiple disabilities include? Please focus on the caregivers’ skills pertaining to communication with the child, empathy and the ability to understand the feeling of the child, identifying the strength of the child,
- How do you mobilize internal family resources and external resources for the care of the child? (Here focus on the mechanisms of resource mobilization)
- What help do you get from home environment, school environment and from community, neighborhood, peers, associations GOS and NGOS?
- What do you think is your care giving for your child with multiple disabilities looks like?
    - Make the child with disability get basic needs?
    - Getting other source of supports for a child with multiple disabilities?
    - In a way to improve the safety of a child with multiple disabilities
    - In a way of communication and to teach and help how to become independent

## IV. Feeling about caregiving experience of a child/children with multiple disabilities

- How do you describe your personal feelings for having a disabled child in the family and as primary caregiver to the child?
- What is the meaning of caring for child/children with multiple disabilities to you?
- What meaning do you give to your personal life experience of having a child with multiple disabilities and caring for the child?
- What is your feeling about caring for child/children with multiple disabilities in the family?
- Please describe the family’s belief system about having a child with multiple disabilities. How is this belief system reflected in the interaction among family members, and in collaborating or otherwise for providing appropriate care for the disabled child?
- What is your feeling when you are with the child with multiple disabilities in public?
- Please describe your worry about the child with multiple disabilities.
- Please describe your worry about the family at large.
- What are your hopes about the future of the child and the family

## V. challenges and coping mechanisms of the caregiver/the family

- What are the challenges of having a child with multiple disabilities in the family?
    - Challenges related to the child

  - Challenge related to the caregiver such as its impact on the daily life (marital relation, relation with other family members, resource depletion, participation in religious and other social networks, on your physical and psychological health….
  - Challenges related to the family (economic, internal family relations, interaction with neighbors and other external environment…)
  - Challenges related to societal belief system, culture, tradition…..
  - What are the major negative psychological effects the family experienced in relation to being with a child with multiple disabilities (like fear, depression, frustration etc,)?

- Please describe the positive aspects of caring for children with disability in your family. (Care givers level of intimacy, caregivers derive greater satisfaction and how sibling's commitment……)
- What are the coping mechanisms that the caregiver individually and the family as a group developed in the course of caring for the child/children with multiple disabilities?

## VI. Family members' recommendation in improving the care and support for a child with multiple disabilities

- What do you think is the most effective way to care giving?
- What do you think care givers need to seek and do for the betterment of service provision?
- What do you expect from father, siblings, grandparents, neighborhood peers, society, community, professionals, etc?
- What do you think the local government, organizations and the society at large do to help families of children with multiple disabilities?
- What additional points do you have?

## Annex III

### Guide for Focus Group Discussion with care givers of a child with multiple disabilities

**Introduction**: Hello, I am Woynishet Kerebih, a post graduate student at Addis Ababa University, School Social Work. I am here to have open discussion as a group with families who are responsible for caring a child with multiple disabilities on How do family members feel about and give meaning to their experience of caring for a child with disability?, How do they handle the responsibility of care giving for a child with multiple disabilities?, How do the care giving experiences for a child with disability affect family member's life? And how do families explain their experiences of caring for children /child with multiple disabilities?

All comments, both positive and negative, are welcome. I would like to assure you that confidentiality for your comments will be respected and will be used only for research purpose. Are you willing to participate in the discussion? I greatly appreciate you, taking time to speak with me.

If yes, proceed. If no, thank and stop here.

Signature of interviewer certifying that respondents has given informed consent__________________________

1. Introduction of each member to the group
2. What do you know about the situation of your child with multiple disabilities?
3. What do you think are the possible causes of your child's disability?

4. Would you discuss with me about the general reflection about the care giving process?

5. Would you tell me about the support services you accessed in relation to the challenges faced by you and your entire family?

6. How does care giving affect your daily lives socially, psychologically, health wise and economically?

7. In your view, what would be adequate support for you as a family care giver caring a child with multiple disabilities?

8. What are the common challenges of caring for children with multiple disabilities?

9. What are the shared experiences in terms of coping with challenges of caring children with multiple disabilities?

10. What should be improved for providing better care for CwDs?

11. What types of supports are most important for such types of families?

12. What should be the role of government, development organizations, and the community in helping children with multiple disabilities?

13. Anything you want to add before we conclude?

Thanks for giving your time for this important discussion!

## Annex IV

## Observation Guide/Protocol

**Pseudo name: ____________________**

**Date: ___________________________**

**Time: ___________________________**

**Place: ___________________________**

| **Observation in relation to care giving experience by family members caring a child with multiple disabilities** | **Reflection** |
|---|---|
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# Annex V

## Interview guide with Government Experts or Officials

**Introduction**: Hello, I am Woynishet Kerebih, a post graduate student at Addis Ababa University, School Social Work. I am here to have an interview with you. The purpose of the interview is to assess policy and programmatic issues concerning a child with disability and their families, social protection policy and its implementation in relation to a child with disability, available supports and implementation institutions, government’s commitment for its implementation and the challenges and successes so far.

All comments, both positive and negative, are welcome. Are you willing to participate in the interview? I greatly appreciate you, taking time to speak with me and participating in this research.

Signature of interviewer verifying those respondents has given informed consent__________________________

1- Would you explain for me about policy and programmatic issues concerning child/children with disability and their family members who are involved in caring?
2- Would you tell me about what social protection policy says about a child/ children with disability and their family care givers?

3- Would you tell me about how resource is mobilized, how to enhance ownership and active participation of those families and how to involve different stakeholders while dealing with those families?

4- Would you tell me about the available policies and strategies concerning children with disability and their family care givers?

5- Would you explain briefly about institutional structures to implement policies concerning children with disabilities and their family care givers Which organization is responsible for family affairs, what institutional structure exists, which institution is responsible for children with disabilities, what institutional structure exists to help them…….

6- Tell me about to what extent policies and programmes of children with disabilities and their family care givers are implemented so far?

7- Would you please tell me government's commitment in the area human resource and financial resource allocations in the implementation process?

8- Would you please tell me about the type of support the government is offering to the implementing organizations in relation to children with multiple disabilities and their family care givers?

9- Tell me about Monitoring and evaluation mechanisms of policies and programs dealing with problems of children with multiple disabilities and their family care givers?

10- Would you please tell me about policy and programmatic gaps and challenges in addressing the problems of families with multiple disabled children?

11- Would you please explain about the roles of different stakeholders and who should do what for helping families of children with multiple disabilities?

12- Would you please tell me about your recommendation for social work education and in research areas in relation to families of children with multiple disabilities?

13- As a government body, tell me about the recommendation for future improvement of the support being organized for families and children with multiple disabilities at macro, mezzo, and micro levels?

14- Anything you want to add before we conclude our interview?

Thank you

## Annex VI

## የቃለ መጠይቅ የስምምነት ቅፅ

ውድ የጥናቱ ተሳታፊ እንደምን አደሩ/ እንደምን ዋሉ?

ወይንእሸት ቀረብህ እባላለሁ፡፡ በአዲስ አበባ ዩኒቨርሲቲ በሶሻል ወርክ ትምህርት ክፍል የድህረ ምረቃ ተማሪ ነኝ፡፡ የተደራራቢ የአካል ጉዳተኛ ልጆችን እንክብካቤ በሚሰጡ የቤተሰብ አባላት ዙሪያ ያላቸውን ልምድ በማጥናት ላይ እገኛለሁ፡፡ የጥናቱ ዋና አላማ ተደራራቢ የአካል ጉዳተኛ ተንከባካቢዎች ምን እንደሚሰማቸውና ለሚሰጡት እንክብካቤ ምን አይነት ትርጉም እንደሚሰጡት፣ ሀላፊነታቸውን እንዴት እንደሚወጡት፣ እንክብካቤ መስጠታቸው በቤተሰቡ ህይወት ላይ ያለውን አዎንታዊም ሆነ አሉታዊ ተፅዕኖና አጠቃላይ ያላቸውን የእንክብካቤ ታሪክ እንዴት እንደሚገልፁት ለመረዳት፣ ለመፈተሽና ጥልቅ የሆነ ትንተና ለመስጠት ነው፡፡

ለጥናቱ በስኬት መጠናቀቅ የተደራራቢ የአካል ጉዳት ያላቸውን ልጆች በመንከባከብ ላይ የሚገኙ የቤተሰብ አባላትን ትብብር ማግኘት ወሳኝ በመሆኑ በጥናቱ ላይ ለመሳተፍ ፈቃደኝነትዎን እጠይቃለሁ፡፡ በጥናቱ በመሳተፍዎ በጥናቱ ለማወቅ የተፈለጉትን ነገሮች በጥልቀት ለማወቅ ይረዳኛል፡፡

በዚህ ጥናት ውስጥ ለመሳተፍ የሚያስፈልገው ሁኔታና ጊዜ ለእርስዎ በሚመች ሁኔታ የሚመቻች ሲሆን የምጠቀመው ጥልቅ ቃመጠይቅ ነው፡፡ በቃለ መጠይቁ ወቅት ግልጽ ያልሆነልዎት ጥያቄ ቢኖር ጥናት አድራጊው ያብራራሉ፡፡ በጥናቱ ሂደትም ሆነ ከዚያ በኋላ ማንነትዎ በምንም ሁኔታ ግልፅ እንደማይደረግ ለአረጋግጥልዎት እወዳለሁ፡፡ በዚህም ሁኔታ የሚሰጡት መረጃ በጥናቱ ትንተናና የፅሁፍ ዘገባ

በሚቀርብበት ወቅት ትክክለኛ ባልሆነ ስም ወይም መለያ በሚሆን ምልክት ይሆናል፡፡ ይህ የሚደረገው የእርስዎን ማንነትና የሰጡትን መረጃ ሚስጥራዊነት ለመጠበቅ ነው፡፡

ያደረግነውን ቃለመጠይቅ ለመረዳትም ሆነ ለመቅረፅ ቴፕ የምጠቀም ሲሆን ቅጅውም በጥንቃቄ ተቆልፎበት ይቀመጥና ማንም እንዳያገኘው ይደረጋል፡፡ የሰጡኝን መረጃ የምጠቀመው በሶሻል ወርክ ለሁለተኛ ዲግሪ የማሚያ ጥናት ለማድረግ ብቻ መሆኑን አረጋግጥልዎታለሁ፡፡ ጥናቱ ከተጠናቀቀና በሶሻል ወርክ ትምህርት ቤት ከተረጋገጠ በኋላ በቴፕ የተቀረፁ፣ የተገለበጡና የፅሁፍ ማስታወሻዎች በሙሉ ይደመሰሳሉ፡፡ በዚህ ጥናት በመሳተፍዎት ጥናቶቼን እንዳሳካ ብቻ ሳይሆን ተደራራበ የአካል ጉዳት ያላቸውን ልጆች በመንከባከብ ዙሪያ ያለዉን ግንዛቤና እውቀት እንዲጨምር ያደርጋል፡፡

ከእኔ ጋር ለቃለመጠየቅ ከሚያሳልፉት ጊዜ ውጭ በጥናቱ በመሳተፍዎ የሚያጋጥምዎት ምንም አይነት ሥጋት የለም፡፡ ምንም እንኳን ለጥናቴ የሚሰጡኝ መረጃ ጠቃሚና የሚበረታታ ቢሆንም ተሳታፊነትዎ ሙሉ በሙሉ በእርስዎ ፈቃደኝነት ላይ የተመሰረተ ነው፡፡

በቃለመጠየቁ ወቅት ቃለመጠየቁን መቀጠል አልፈልግም ወይም ማቋረጥ እፈልጋለሁ ብለው ካመኑ ማቋረጥ ይችላሉ፡፡ ውሳኔዎት የተከበረ ነው፡፡ በመጨረሻመ ይህንን ቅፅ በመፈረም ከላይ በተጠቀሱት ሁኔታዎች ላይ ተስማምተው ለመሳተፍ ፈቃደኛ መሆንዎን ማረጋገጥ እወዳለሁ፡፡

የጥናቱ ተሳታፊ መለያ ________________

ፊርማ ___________________

ቀን ______________

## Annex VII

### የቃለ መጠይቅ መመሪያ

ውድ የጥናቱ ተሳታፊ እንደምን አደሩ/እንደምን ዋሉ? በቅድሚያ በዚህ ጥናት ስለተሳተፉ አመሰግናለሁ፡፡ ማግኘት የምፈልጋቸው መረጃዎች በስድስት ክፍሎች ተከፋፍለዋል፡፡ ስለሆነም የጥናቱ ተሳታፊ ለመሆን በወሰኑት መሰረት በቅድሚያ ስለእርስዎ አጠቃላይ መረጃ በመጠየቅ እጀምራለሁ፡፡

I. አጠቃላይ የጥናቱ ተሳታፊዎች መረጃ

- እድሜ ______
- ፆታ ________የትምህርት ደረጃ _________
- የጋብቻ ሁኔታ ___________
- ሀይማኖት _________
- የቤተሰብ ብዛት ____ወንድ ______ሴት ________
- የስራ ሁኔታ _____________
- የአካል ጉዳተኛዋ/ጉዳተኛው ፆታ ሴት ______ ወንድ ______
- የአካል ጉዳተኛዋ/ጉዳተኛው እድሜ ___________
- ከአካል ጉዳተኛዋ/ጉዳተኛው ጋር ያለዎት ግንኙነት ________________
- ከማን ጋር ይኖራሉ________
- የአካል ጉዳተኛውን/ጉዳተኛውን በመንከባከብ ምን ያህል አመት ቆዩ
- የበጐ ስራ ወንድሞች የምክክርና ማህበራዊ አገልግሎት መስጫ ማዕከል ለተደራራቢ የአካል ጉዳተኛ ህፃናት አገልግሎት እንደሚሰጥ እንዴት ሊሰሙና ሊመጡ ቻሉ?

## II. ስለአካል ጉዳተኝነት ያለ እውቀት፣ ስለአካል ጉዳተኛ ልጆች ፍላጐት፣ እንክብካቤ የመስጠት ሂደትና ልምድ

- ስለ ልጅዎት የአካል ጉዳት፣ ስለመነሻ ምክንያቱ ሲወለድ ወይስ ከተወለደ በኋላ በስፋት ሊያብራሩልኝ ይችላሉ?
- በእርሶም ሆነ በቤተሰብዎት ስለተደራራቢ የአካል ጉዳተኝነት መረጃ ወይም እውቀት ነበረ?
- ስለልጅዎት የአካል ጉዳተኝነት ለመጀመሪያ ጊዜ እንዴት ሊያውቁ ቻሉ? (የአካል ጉዳቱ በቀላሉ ለማየት ለመለየት የሚቻል ከሆነ ጥያቄው ይታለፋል)
- ተደራራቢ የአካል ጉዳተኛ ልጅን እንክብካቤ መስጠት እንዴት ሊያውቁና ሊማሩ ቻሉ?
- እርስዎ ከሌላው ቤተሰብ በተለየ ሁኔታ ለአካል ጉዳተኛ ልጅ ቀዳሚ ተንከባካቢ የሆኑበትን ምክንያት ቢገልፁልኝ፡፡
- የቀን በቀን እንክብካቤዎትን ከጧት ጀምሮ እስከምሽት ያለውን ሂደት በቅደም ተከተልና በጥልቀት ቢያስረዱኝ፡፡
- በአጠቃላይ ለተደራራቢ የአካል ጉዳተኛ ልጅ የሚሰጡትን እንክብካቤና ሂደት ያለዎትን ምልከታ ቢገልፁልኝ?
- ከእርስዎ ሌላ ሌላው የቤተሰብ አባላት ለአካል ጉዳተኛው/ዋ ልጅ ለመንከባከብ የሚያደርጉትን አስተዋፅኦ ቢገልፁልኝ?
- ሌሎች የቤተሰብ አባላት ያላቸውን ሀላፊነትና እርስዎ ለአካል ጉዳተኛዋ/ው ልጅ ቀዳሚ ተንከባካቢ መሆንዎትን አመዛዝነው ያለውን ስሜት ቢገልፁልኝ?

### III. የአካል ጉዳተኛው/ዋ ልጅ ተንከባካቢዎች እንዴት ሀላፊነታቸውን ይወጣሉ፡፡

- የተደራራቢ የአካል ጉዳተኛ ልጆች እንክብካቤ ምን ምን ነገሮችን ያጠቃልላል? (መጠየቅ ያለበት ተንከባካቢዎች ስለልጆቻቸው የአካል ጉዳት አይነት ያላቸውን እውቀት እንዲሁም በአካል ጉዳተኛው/ዋ ላይ ያመጣውን የአካል፣ የአዕምሮ፣ የሥነልቦና፣ የማህበራዊና የጤና ተፅዕኖ…)
- የተደራራቢ የአካል ጉዳተኛ ልጆች እንክብካቤ ምን ምን ነገሮች ያጠቃልላል? (ትኩረት- ተንከባካቢዎች ከልጆች ጋር ያላቸውን የተግባቦት አቅም፣ ነገሮችን በልጆቹ ቦታ ሆኖ የማየትና የአካል ጉዳተኛዋን/ውን የሥሜት ሁኔታ የመረዳት ብቃት እንዲሁም የአካል ጉዳተኛውን/ዋን ጥንካሬ የመረዳት ሁኔታ…)
- በቤት ውስጥም ሆነ ከቤት ውጭ ያሉ የአካል ጉዳተኛውን/ዋን ለመንከባከብ የሚረዱ ሀብቶችን ወይም ግብዓቶችን የማየት፣ የመለየትና የመጠቀም ሁኔታ ቢገልፁልኝ?
- የአካል ጉዳተኛውን/ዋን በመንከባከብ ዙሪያ በቤት ውስጥ፣ በትምህርት ቤት፣ ከጎረቤት፣ ከጓደኞች፣ ከማህበራት፣ መንግስታዊ ከሆኑ ድርጅቶችና መንግስታዊ ካልሆኑ ድርጅቶች ያገኙትን ድጋፍ ቢያብራሩልኝ?
- እርስዎ ለአካል ጉዳተኛው/ዋ የሚሰጡት እንክብካቤ ምን ይመስላል?
    - መሠረታዊ ፍላጎት ማሟላት?
    - ሌሎች ድጋፎችና ለአካል ጉዳተኛው/ዋ ያገኛሉ?
    - የሚሰጡት እንክብካቤ ደህንነቱን/ደህንነቷን በመጠበቅ ዙሪያ ነው?

- በተግባቦትና እራሱን/ሷን በሚችሉበት ሁኔታ ነው?

IV. ለተደራራቢ አካል ጉዳተኛው/ዋ በሚሰጡት እንክብካቤ ስለሚሰማዎት ስሜት

- እርስዎ በቀዳሚነት የተደራራቢ የአካል ጉዳተኛ ልጅዎን በመንከባከብዎትና የአካል ጉዳተኛ ልጅ በቤትዎ በመኖሩ በግል የሚሰማዎትን ስሜት ቢገልፁልኝ?
- የተደራራቢ የአካል ጉዳተኛ ልጅ መንከባከብዎት የሚሰጥዎት ትርጉም ምንድን ነው?
- የተደራራቢ የአካል ጉዳተኛ ልጅዎን መንከባከብዎ ለግል ህይወትዎ የሚሰጡት ትርጉም ምንድን ነው?
- የተደራራቢ የአካል ጉዳተኛ ልጅዎን በመንከባከብዎት ምን ይሰማዎታል?
- በቤትዎ ውስጥ ተደራራቢ አካል ጉዳተኛ ልጅ ከመኖሩ ጋር ተያይዞ ያለው የቤተሰቡ እምነት ምንድን ነው? ያለው እምነት በቤተሰቡ ውስጥ ባለው ተግባቦት እንዴት ይገለፃል፡፡ እንዲሁም ትክክለኛ እንክብካቤ ከመስጠት አኳያ ያለውን ግንኙነት ቢገልፁልኝ?
- ከተደራራቢ የአካል ጉዳተኛ ልጅዎት ጋር በህዝብ ፊት በሚሆኑበት ጊዜ የሚሰማዎትን ስሜት ቢገልፁልኝ?
- ከተደራራቢ የአካል ጉዳተኛ ልጅዎት ጋር በተያያዘ ያለዎትን ጭንቀት ቢገልፁልኝ?
- ከተደራራቢ የአካል ጉዳተኛ ልጅዎት ጋር በተያያዘ በአጠቃላይ በቤተሰቡ ያለውን ጭንቀት ቢገልፁልኝ?

- ለወደፊት ለአካል ጉዳተኛው ልጅ እንዲሁም ለቤተሰቡ ያለዎትን ተስፋ ቢገልፁልኝ?

V. የተደራራቢ የአካል ጉዳተኛ ልጅ ቤተሰቦች ያለባቸው ተግዳሮቶችና የመቋቋሚያ መንገዶች

- ተደራራቢ የአካል ጉዳተኛ ልጅ በቤት ውስጥ መኖሩ ያሉት ተግዳሮቶች ምን ምን ናቸው?
  - ከአካል ጉዳተኛው/ዋ ጋር ተያይዞ
  - ከተንከባካቢ ጋር ተያይዞ ለምሳሌ የቀን ውሎ (ከትዳር ጋር በተያያዘ፣ ከሌሎች የቤተሰብ አባላት ጋር ያለ ግንኙነት፣ የቤተሰቡን አቅም በማሟጠጥ ዙሪያ፣ በእምነት፣ በማህበራዊ ግንኙነት እንዲሁም በአካል በሥነልቦናና በጤና ያለውን ውጤት…)
  - ከቤተሰብ ጋር ያለውን ግንኙነት (በኢኮኖሚ፣ በቤት ውስጥ ያለን ግንኙነት ከጐረቤትና ከቤት ውጭ ካለዎት ተግባቦት ጋር በተያያዘ)
  - ተግዳሮት በህብረተሰቡ ካለው እምነት ጋር፣ ከባህል እንዲሁም በህብረተሰቡ ውስጥ ካሉት ልምዶች ጋር በተያያዘ…
  - ተደራራቢ የአካል ጉዳተኛ ልጅን ከመንከባከብ ጋር በተያያዘ ያሉት አሉታዊ የሥነልቦና ውጤቶች ምን ምን ናቸው? (ለምሳሌ ፍርሃት፣ ድብታ፣ ተስፋ መቁረጥ…)
- ተደራራቢ የአካል ጉዳተኛ ልጅን ከመንከባከብ ጋር በተያያዘ ያሉትን አወንታዊ ውጤቶች ቢገልፁልኝ? (ከልጅዎት ጋር ያለዎት ቅርርብ፣

በመንከባከብዎ ያለዎት እርካታ እንዲሁም የእህት የወንድሞች ለአካል ጉዳተኛው ያለቸው ቁርጠኝነት…)

- ተደራራቢ የአካል ጉዳተኛ ልጅን ከመንከባከብ ጋር ተያይዞ ያሉትን ችግሮች እርስዎ እንደ ቀዳሚ ተንከባካቢ እንዲሁም መላው ቤተሰብ ያዳበራቸው የመቋቋሚያ መንገዶችን ቢገልፁልኝ?

VI. እርሶዎ እንዲሁም መላው ቤተሰብ የተደራራቢ የአካል ጉዳተኛ ልጆችን በመንከባከብና ድጋፍ በማድረግ ዙሪያ የሚኖርዎት አስተያየት

- ተደራራቢ የአካል ጉዳተኛ ልጅን ለመንከባከብ የተሳካ መንገድ ምን ይመስልዎታል?
- የአካል ጉዳተኛውን/ዋን እንክብካቤ የተሻለ ለማድረግ ተንከባካቢዎች ምን ይፈልጋሉ?
- እርስዎ በእንክብካቤ ዙሪያ ከአባት፣ ከወንድም/እህት፣ ከአያቶች፣ ከጐረቤት ከህብረተሰቡ እንዲሁም ከተማሩ ሰዎች ምን ይጠብቃሉ?
- ለተደራራቢ የአካል ጉዳተኛ ልጅ ያለውን እንክብካቤ የተሻለ ለማድረግ መንግስት፣ ህብረተሰብና ድርጅቶች ምን ማድረግ አለባቸው?
- ተጨማሪ ሀሳብ ካለዎት ይግለፁልኝ?

## Annex VIII

# ለተደራራቢ የአካል ጉዳተኛ ልጅ ተንከባካቢዎች ጋር ለሚደረግ ውይይት የመነሻ ሀሳቦች

**መግቢያ፡-** እንደምን ዋላችሁ/እንደምን አደራችሁ? ወይንሸት ቀረብህ እባላለሁ በአዲስ አበባ ዩኒቨርሲቲ በሶሻል ወርክ ትምህርት ክፍል የድህረ ምረቃ ተማሪ ነኝ፡፡ እዚህ የተገኘሁት ተደራራቢ የአካል ጉዳተኛ ልጆችን መንከባከብ ሥለሚፈጥረው ሥሜትና የሚሰጠው ትርጉም፣ የመንከባከብ ሃላፊነትን ለመወጣት የተንከባካቢዎች ሀላፊነት ምን እንደሆነ፣ ለተደራራቢ የአካል ጉደተኛ ልጅ የሚሰጥ እንክብካቤ በአጠቃላይ በቤተሰብ ላይ ያመጣውን ተፅዕኖና አጠቃላይ የተደራራቢ የአካል ጉዳተኛ ልጆችን ለመንከባከብ ተንከባካቢ የቤተሰብ አባላት ያላቸውን ልምድ ይዳስሳል፡፡

ሁሉም ሀሳቦች አሉታዊም ሆነ አወንታዊ የተከበሩ ናቸው፡፡ ሁሉም የምንወያይባቸው ሀሳቦች ሚስጥሪዊነታቸው የተጠበቀ መሆኑን እየገለፅሁ አላማውም ለድህረ ምረቃ ማሟያ ጥናት ለማድረግ ብቻ ነው፡፡ ውይይቱን ለማድረግ ፈቃደኞች ናችሁ? ከእኔ ጋር ጊዜ ወስዳችሁ ለመወያየት ስለፈቀዳችሁ ከልቤ አመሰግናለሁ፡፡

እዎ ከሆነ ይቀጥላል አይቻልም ከሆነ ያቆማል

ተሳታፊዎች ውይይቱን ለማድረግ ለመስማማታቸው

የአወያዩ ፊርማ __________ቀን ____________

1. ሁሉም ተሳታፊ እርስ በርስ ይተዋወቃል

2. የልጆቻችሁን ተደራራቢ የአካል ጉዳት ሁኔታ እንዴት አወቃችሁ?
3. ለልጆቻችሁ የአካል ጉዳት መነሻ ይሆናሉ ብላችሁ የምታስቧቸውን ብንወያይ
4. በአጠቃላይ ለተደራራቢ የአካል ጉዳተኛ ልጆቻችሁ የምትሰጡትን የመንከባከብ ሂደት መወያየት እንችላለን?
5. እንክብካቤ ከማድረግ ጋር ተያይዞ በእናንተም ሆነ በቤተሰቦቻችሁ ላይ በገጠማችሁ ችግር ላይ ምን አይነት ድጋፎችን ፈልገዋል?
6. የልጆቻችሁ ተንከባካቢ በመሆንዎት የእናንተ ህይወት በማህበራዊ፣ በሥነልቦናዊ፣ በጤናና በኢኮኖሚ ዙሪያ ያጋጠሞትን ተፅዕኖ ብንወያይ?
7. እናንተ ተደራራቢ የአካል ጉዳተኛ ልጆቻችሁን ለመንከባከብ በእናንተ ሀሳብ በቂ የሆነ ድጋፍ የሚሉትን ቢገልፁልኝ?
8. ተደራራቢ የአካል ጉዳተኛ ልጅን በመንከባከብ ምክንያት የሚያጋጥሙ የተለመዱ ችግሮችን ቢገልፁልን?
9. ሁላችሁም ተደራራቢ የአካል ጉዳተኛ ልጆችን ከመንከባከብ ጋር በተያያዘ በጋራ የምትጋሯቸው ችግሮች ካሉ?
10. እንክብካቤን የተሻለ ለማድረግ ምን ቢደረግ ይሻላል?
11. ለተደራራቢ የአካል ጉዳተኛ ቤተሰቦች ምን አይነት ድጋፎች አስፈላጊ ናቸው?
12. ተደራራቢ የአካል ጉዳተኛ ልጆችን ለመንከባከብ የመንግስት፣ የልማት ድርጅቶችና በአጠቃላይ የህብረተሰቡ ሀላፊነት ምን መሆን አለበት?
13. ከመጨረሳችን በፊት የምትጨምሩት ነገር ካለ

ለውይይቱ ጊዜ ስለሰጣችሁኝ አመሰግናለሁ፡፡

## Annex IX

# ለመንግስት አካላትና ከአካል ጉዳተኝነት ጋር የተያያዘ ሥራ ለሚሰሩ የቢሮ ሀላፊዎች የተዘጋጀ የቃለመጠይቅ መመሪያ

**መግቢያ፡-** እንደምን አደሩ?/ እንደምን ዋሉ? ወይንእሸት ቀረብህ እባላለሁ በአዲስ አበባ ዩኒቨርሲቲ በሶሻል ወርክ ትምህርት ክፍል የድህረ ምረቃ ተማሪ ነኝ፡፡ ከእርስዎ ጋር ቃለ መጠይቅ ለማድረግ ተገኝቻለሁ፡፡ የቃመጠይቁ ዋና አላማ በአካል ጉዳተኛ ልጆችና ቤተሰቦቻቸው ዙሪያ ስላሉ ፓሊሲዎችና ፕሮግራሞች ዙሪያ፣ ከአካል ጉዳተኛ ልጆች ጋር በተያያዘ በብሔራዊ የማህበራዊ ጥበቃ ፖሊሲና አተገባበሮቹ ዙሪያ፣ ለአካል ጉዳተኛ ልጆችና ቤተሰቦቻቸው ድጋፍ ስለሚሰጡ ተቋማትና ድጋፎች ዙሪያ፣ ፖሊሲዎችን ለመተግበር የመንግስት ቁርጠኝነት፣ እስከአሁን ስለተሰሩ ሥራዎችና ስለተግዳሮቶች ውይይት ለማድረግ ነው፡፡

ሁሉም ሀሳቦች አሉታዊም ሆነ አዎንታዊ ተቀባይነት አላቸው፡፡ ቃመጠይቁን ለመስጠት ፈቃደኛ ነዎት? ጊዜ ስለሰጡኝና በጥናቱ ተሳታፊ ስለሆኑ ከልብ አመሠግናለሁ፡፡

ቃለመጠይቁን የሚያደርገው ሰው ፊርማ ቃለመጠይቅ ሰጭው ፈቃደኝነቱን ለመስጠቱ ፊርማ _______________ ቀን _____________

1. አካል ጉዳተኛ ልጆችን በሚንከባከቡ ቤተሰቦች ዙሪያ ያሉትን ፓሊሲዎችና ፕሮግራሞች ሊገልፁልኝ ይችላሉ?
2. ብሄራዊ የማህበራዊ ጥበቃ ፖሊሲ በአካል ጉዳተኛ ልጆችና በቤተሰቦቻቸው ዙሪያ ያለውን ነገር ሊገልፁልኝ ይችላሉ፡፡

3. የአካል ጉዳተኛ ልጆችና ቤተሰቦቻቸው ያሉባቸውን ችግሮች ለመፍታት እንዴት ሀብት እንደሚሰባሰብ፣ የባለቤትነት ስሜት ለመጨመር እንዲሁም ንቁ ተሳትፎ ቤተሰቦች እንዲያደርጉና ባለድርሻ አካላት እንዲሳተፉ የተደረገውን ነገር ቢገልፁልኝ?
4. በአካል ጉዳተኛ ልጆችና ቤተሰቦቻቸው ዙሪያ ያሉትን የፖሊሲ አቅጣጫዎች ሊገልፁልኝ ይችላሉ?
5. በአካል ጉዳተኛ ልጆችና ቤተሰቦቻቸው ዙሪያ ያሉትን ፖሊሲዎች ለመተግበር ስለተዋቀሩ ተቋማት ሊገልፁልኝ ይችላሉ? ይህን ግልጋሎት ለመስጠት ሀላፊነት ያለባቸው ተቋማት እነማን ናቸው? በቤተሰብ ዙሪያ ላይ ያሉ ችግሮችን ለመፍታት ሀላፊነት ያለባቸው ተቋማት የትኞቹ ናቸው? በተለይ የአካል ጉዳተኛ ልጆችንና እንክብካቤ በሚሰጡ ቤተሰቦቻቸው ዙሪያ ድጋፍ ለማድረግ…
6. እስከ አሁን ድረስ የካል ጉዳተኛ ልጆችንና ቤተሰቦቻቸውን የሚመለከቱ ፖሊሲዎችና ፕሮግራሞች በምን ደረጃ ተተግብረዋል?
7. በአካል ጉዳተኛ ልጆችና ቤተቦቻቸው ዙሪያ ለሚሰሩ ስራዎች የሰው ሃይል፣ የገንዘብ ምደባና ፍሰትን በማስተባበር የመንግስት ቁርጠኝነት እስከምን ድረስ ነው?
8. በአካል ጉዳተኛ ልጆችና እንክብካቤ በሚሰጡ ቤተሰቦቻቸው ዙሪያ አገልግሎት ለሚሰጡ ተቋማት መንግስት ምን እገዛና ድጋፍ ያደርጋል?
9. ለአካል ጉዳተኛና እንክብካቤ በሚሰጡ ቤተሰቦቻቸው ዙሪያ ያሉትን ፖሊሲዎችና ፕሮግራሞች የግምገማና የክትትል ሂደቱን ቢገልፁልኝ?

10. ተደራራቢ የአካል ጉዳተኛ ልጆችን እንክብካቤ በሚሰጡ ቤተሰቦች ችግሮችን በመፍታት ዙሪያ ያሉትን የፓሊሲና የፕሮግራም ክፍተቶች ሊነግሩኝ ይችላሉ?
11. የተለያዩ ባለድርሻ አካላት የአካል ጉዳተኛ ቤተሰቦችን ችግሮች ለመፍታት የሚኖራቸውን ሀላፊነት ቢገልፁልኝ?
12. ለሶሻል ወርክ ትምህርትና በአካል ጉዳተኛና ቤተሰቦቻቸው ላይ በሚጠኑ ጥናቶች ዙሪያ የሚሰጡት አስተያየትና ምክር ምንድን ነው?
13. እንደ መንግስት አካል በአካል ጉዳተኛ ልጆችና ቤተሰቦቻቸው ዙሪያ የሚሰጠውን ድጋፍ የተሻለ ለማድረግ በአነስተኛ፣ በመካከለኛና በከፍተኛ ሁኔታ ምን ቢደረግ የተሻለ ይሆናል?
14. ቃመጠይቁን ከመጨረሻችን በፊት የሚጨምሩት ነገር ካለ?

**አመሰግናለሁ፡፡**