Lived Experiences of Mothers of Children with Multiple Disability: in the case of Brothers of Good Works in Addis Ababa

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Declaration

I, undersigned, declare that this Master's Thesis is my original work and all the sources are acknowledged properly.

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Advisor's Approval

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

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Examining Committee Approval

This is to certify that the thesis prepared by Hiwot Kebede, entitled: Lived experiences of mothers of children with multiple disability in the case of Brothers of Good Works in partial fulfillment of the requirement for the degree of Masters of Arts (Social Work) complies with the regulation of the University and meets the accepted standards with respect to originality and quality**.**

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Acronyms

ACPF - African Children Policy Forum

ASP - Autism Spectrum Disorder

BGW- Brothers of Good Work

CBR - Community Based Rehabilitation

CSA- Central Statistics Agency

CWD - Children with Disability

CWMD - Children with Multiple Disability

EBS - Ethiopia Broadcasting Service

GO - Governmental Organizations

HIV - Human Immuno deficiency Virus

IDEA - Individuals with Disabilities Education Act

IDI - In depth Interview

JICA - Japan International Cooperation Agency

KII - Key Informant Interview

MD - Multiple Disability

MOLSA - Ministry of Labor and Social Affairs

NGO - Non- Governmental Organization

PWD - Person with Disability

UNICEF - United Nations Children Fund

WHO - World Health Organization

Abstract

The purpose of this study is to describe what the lived experience of mothers of children with multiple disability look like. The study is conducted using qualitative study, that follows phenomenological design and cross-sectional research with descriptive nature. A total number of 12 participants from Brother of Good Works; 10 mothers of child with multiple disability and 2 field workers have participated in the study. Purposive sampling was used with predefined inclusion criteria. The data collection tools were observation, In-depth and Key informant interview. The data gathered from the tools is thematically analyzed and presented. The findings of the study indicate having a child with multiple disability affects the life of the mothers in burdening responsibility, psychologically, socially, economically, and in their marital life and there is a need to provide support for the mothers themselves in addition to the child with multiple disability. The study also has social work implications for research, education, practice, and policy points of view.

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Chapter One: Introduction

1.1 Background of the Study

Under the Disability Discrimination Act (1995, p. 2), disability is defined as…"a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities". In the case of International Classification of Functioning, Disability and health (ICF), functioning was divided into three levels: the first considered body function and body structures, the second was concerned with activities, and the third looked into participation (World Health Organization, 2007). Hence, disability is defined considering all the above classifications of functioning.

Disability types are put in different types of categorizations in different literatures. According to IDEA (National Dissemination Center for Children with Disabilities [NDCCD], 2012), autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, orthopedic impairment, other health impairments(chronic or acute health problems), specific learning disability, speech or language impairment, traumatic brain injury, visual impairment and also multiple disability are considered as types of disability.

Whereas "Multiple disability is defined as an individual having two types or more than two types of disabilities which required more attention and support in education programming. It is also called double disabilities or complex disability in various occasions" (Chen, 2004, p. 62).

There hasn't been a comprehensive global study to estimate the number of people with disability in the world. Based on available data from the 2004 World Health Survey, the study done by WHO (World Health Organization, 2011) estimated the average prevalence of disability for adults 18 years and older of the world to be 15.6%, which was ranging from 11.8% for higher income countries and 18% for lower income countries. This figure considered adults who have significant functioning difficulties in their everyday lives, which indicates there are hundreds of millions of adults with disability in the world. The high occurrence of disability in low economic countries is a good evidence to show the strong relationship of disability with poverty. It is believed that poor living condition is one reason to the occurrence and high prevalence of disability. Poor nutrition, lack of health and sanitation facilities and exposure to various forms of accident are some examples. In the contrary the existence of disability is a problem so that individuals face many obstacles while fighting against poverty. Among peoples with disabilities the existence is higher on women and children(African Decade of Persons with Disabilities[ADPD], 2010).

When we come to Ethiopia, according to the Central Statistics Authority (2007), the number of PWD was 864,218 out of the total population of 73,750,9320. The African Child Policy Forum (2011) also estimate the prevalence of disability in Ethiopia to be 1.09%.

Disability can be caused due to various reasons. Human-made reasons, prenatal causes, during natal and postnatal periods, alcohol and drug addiction, communicable diseases, harmful traditional practices which are exasperated by low economic situations like malnutrition, lack of environmental hygiene are among them (ADPD, 2010).

According to Japan International Cooperation Agency (2002, p. 10), "disability factors in Ethiopia are considered to be pre and post-natal disabling factors. These are infectious diseases, complications at time of delivery, under-nutrition, malnutrition, harmful cultural practices, lack of proper child care and management, civil war, periodic drought and famine". However, there are governmental and NGO working towards giving intervention for the PWD. MOLSA is entitled to the obligation of working to enhance the rights of PWD in a country level. And for the purpose of implementation, Bureau for Labour and Social Affairs are established regionally

(Sida, 2014). The study also states that the Ministry of health and Ministry of education have responsibilities in the implementation of mainstreaming approach and provision of health service to PWD.

Furthermore, 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 are established in a federation level to work with PWD. And civil societies such as 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)are among the active intervening organizations (International Labour Organization and Irish Aid, 2013).

Parents utilized different support system available in their social environments. These are mainly their other children, extended family members, cloth relatives, in-laws, friends, and neighbors. Besides, parents also use formal and informal institutions such as hospitals, religious organizations, police and Idirs (Merhawit, 2017).

When we come to mothers of a disabled child, they have high responsibility in their day-to-day activity. They are entitled in making big decisions which limit their individual interest so as to fulfill the interest of their child with disability (Rudolph, Rosanowski, Eysholdt, & Kummer, 2003).Another study on mothers of children with intellectual disability also shows how they experience high level of stress because they stay longer time with their children alone than other members of the family (Sapkota, Pandey, Deo, & Shrivastava, 2017).

These studies and our own day-to-day experience with our own family makes us believe how the impact of having a child with multiple disability is high on mothers' than the fathers' or siblings'. Rudolph et al (2003) made a research on the extra care giving role of mothers of speech impaired children. It describes that because they have the biggest care giving role they are burdened physically. As a result, they are pushed to the verge of dropping their job and giving up their dreams so as to give the necessary care for the disabled child. In addition to the physical difficulty, they are also affected by depression in a significant level.

Another study by Sapkota et al (2017) stated that mothers of children with intellectual disability are affected by depression and anxiety because they are mostly the primary caregivers loaded with day-to-day care giving practices and spend longtime with their children with disability. Beside this, the researcher has raised the importance of mental health screening of caregivers by mental health providers at earliest possible time before it reaches the stage of major psychiatric problem.

Mothers in Turkey mostly sacrifice their job when they marry which makes them far apart from friends, when she have a disabled child her case worsens. She will be forced to stay at home beside her child much or all of her time. This gets the mothers into depression. Moreover, the coming life of her child whether the society and environment understands and accepts him/her is big headache of the mother. The depression and anxiety level gets more affected when the children with a cerebral palsy have speech impairment which is considered as multiple disability (Yilmaz, Erkin, & Nalbant, 2013).

The researcher's rationale to do this research is the interest on the area of multiple disability due to two reasons. The researcher's personal experience as a sibling of an autistic daughter is one reason. I am an eye witness on what it means to have a child with a disability in a family. And especially what it means to mothers, where I have seen all the difficulties my mother is experiencing. My mother was the one shouldering almost all the responsibilities with little family support and no social support available. So, when I think of all mothers of children with multiple disability, I feel their pain, understand their suffering and know their fear. And I always wanted to boldly show what their day-to-day life with a CWMD looks like and what they have gone through and this opportunity has become a never miss it opportunity.

My second reason is a recent incidence where I saw a Sunday afternoon television program on EBS show called 'Wilo'. It was a program which presented what the daily activity of a multiple disabled child family looks like. It was a very heart touching video where the difficult and tiresome parental obligations were shown. However, it was clearly evident, as to my understanding, that the condition the mother is in is by far burdensome than the father.

Majority of researches conducted are about different kinds of disability and little is studied specifically on multiple disability. And of the existing few studies on multiple disability high emphasis is given on the CWMD, their families or care givers in general. However, my study focuses merely on mothers of CWMD. It describes what the experiences of mothers of CWMD looks like and how it is affected due to having a CWMD. And it tries to give emphasis on the attention and support that has to be given for mothers specifically, as it is being given for the CWMD.

1.2 Statement of the Problem

Studies have been conducted on mothers of children with disabilities. Yilmaz et al (2013) has made a quantitative study on mothers of children with cerebral palsy and the finding show that the levels of depression and anxiety on them appeared to be much more than mothers of healthy children. This study has pointed out that compared to other family member’s mothers are traditionally expected to take care of children with disability and as a result are burdened with responsibilities where their personal life is obliged to stuck and are forced to stay at home to do all the care all day long.

In case of mentally disabled children, study by Al-Kuwari (2007) revealed that their mothers are highly affected by psychiatric morbidity and stress compared to mothers of normal children. Moreover, it has been found out that fathers of mentally disabled children did not exhibit a psychological problem as mothers do due to the unequal burden towards staying with the child for longer time and care giving.

Another study on the psychological morbidity level of parents of children with mental retardation concluded that mothers are more affected psychologically than fathers (Chandorkar & Chakraborty, 2000). The study also found out that generalized anxiety disorder and hypochondnacal disorder are among the commonly diagnosed psychological illnesses.

One of the few qualitative researchers on the experience of mothers of CWD, Barbosa, Chaud, & Gomes (2008), discussed about the pain mothers undergo. The study shows mother's difficult life experience commences from the time they knew they have lost the chance of becoming a mother for an ideal child. It also points out the feelings of helplessness and hopelessness mothers' face due to the non-acceptance of the society to a different child and lack of support system.

Study by Al-Kuwari (2007) noted that the situation of the child does not enable him/her to do daily activities independently and the mother will be forced to stay with the child for longer time. In case of children with multiple disability, maternal support is highly required which imposes a burden on the mother than the other family members. This is true because multiple disability hampers the ability or activity of the CWMD more than a child with single disability.

As a result, the support expected from the mother to the child highly increases. More attention and more support should be given to the CWMD, which is mostly the task of the mother.

A research by Aynalem (2014) on the challenges and coping mechanisms of families living with a child diagnosed with Autism confirmed that they face psychological, social, and economic challenges. Merhawit (2017) conducted a research on the experience and coping mechanism of parents of children with autism. This study concluded by pointing the experience of parents in regard to financial burden, high occurrence of conflict, social stigma and discrimination. Woynishet (2017) also made a study on the family members care giving experience towards their children with disability and the challenges they encounter.

The gap in literatures regarding the experience of mothers of CWMD in giving care for the disabled child, family and community coupled with the existing gender inequality, my personal experience and the program I saw on EBS television show are the reasons to conduct this research. The main aim of this research is to contribute as a knowledge base and more importantly to uncover what kind of life experience mothers of children with multiple disability have and to understand what their living experiences are.

1.3 Research Questions

- What are the responsibilities of mothers for their children with multiple disability?
- How does having a child with multiple disability affect the mother psychologically ?
- How does having a child with multiple disability affect the mothers' social life?
- What are the economic challenges of mothers of children with multiple disability?
- What is the marital condition of mothers of children with multiple disability?
- What are the available support systems for mothers of children with multiple disability?

1.4 Objective of the Study

1.4.1 General Objective

The general objective of this study is to describe the experiences of mothers of children with multiple disability in the case of Brothers of Good Works.

1.4.2 Specific objectives

- To describe the responsibilities of mothers for their children with multiple disability.
- To examine the psychological experiences of mothers of children with multiple disability.
- To examine the social experiences of mothers of children with multiple disability
- To identify the economic challenges of mothers of CWMD.
- To understand the marital condition of mothers of CWMD.
- To identify the available support systems for mothers of CWMD.

1.5 Significance of the Study

This research is primarily believed to describe and give knowledge what the lives of mothers of children with multiple disabilities is like. By doing so it will enable readers of this research to know about their lived experiences. Hence, the society will get awareness and start giving attention to the problems of mothers as equal as it is done to children with multiple disability, which is relatively better. This research is also supposed to give insight to researchers and concerned organizations to further study on this area where different support systems and intervention strategies will be advised in order to minimize these mothers’ life challenges.

1.6 Limitation of the Study

The study involved only ten mothers whose children with multiple disability are enrolled at BGW and most are below the age 8. It would have been better if there was involvement of children above this year in order to get in to account what the responsibilities of mothers looks like in different angle of care giving. In addition, the participant mothers are with low economic condition and less education background. However, life experiences of mothers of CWMD who are in a better economic condition and educational background may add new information. Another limitation the study faces is only mothers who are living only in Addis Ababa were included in the study. This was due to time and resource limitation which made it impossible to include mothers out of Addis Ababa to participate in the study. This has influenced the quality of the study finding, as the experience of mothers living out of Addis Ababa may be different.

1.7 Operational Definition of Terms

Disability is any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a person of the same age, culture and education.

Economic is the financial constraints the mothers face to overcome their daily life and the need of the CWMD.

Life Experience is the day to day experience mothers get while interacting with their family, friends, neighbors and the community.

Marital the marriage relationship the mothers have.

Multiple disability is a disability where more than one type of impairment is found at a time on a person.

Primary Caregiver- A person who have a direct responsibility to raise, care and support the child.

Psychological means the mental wellness; feeling of stress, worry, unhappiness, and loneliness.

Responsibility amounts to what is expected of the mother to fulfill the day to day need of the family as a whole and the CWMD.

Social is the social interaction, acceptance of the society and relationship between the mother and the society around her; friends, neighbors, extended family members, community etc

Support System means the support mother's get from their family, extended family, neighbors, community, GO and NGO in every way that helps to improve her selves and families living condition.

Chapter Two: Literature Review

This chapter consists of reviewed literatures about understanding disability, defining multiple disability, experience of mothers of children with disability special emphasis given to psychological wellbeing, family and marital relationships, economic impact, social impact, work load related to care giving and physiological impact.

2.1. Definition of Disability

Definition of disability is found using different dimensions on different studies. Grönvik (2007,p.12) defined disability as "nothing a person has by itself, rather it is an interaction that appears in some situations but not in others". While Mont (2007, p.2) defined it as "a physical, mental, or psychological condition that limits a person's activities."

In another literature, disability is defined in comparison with impairment. It states that "disability represents the larger and more complex interaction between an individual with impairment and the structures and processes of society. Whereas, impairment refers to the difficulties in everyday functioning"(Australian Association of Social Workers, 2016, p.4).

Individuals with multiple disabilities can present sensory deficit, motor disorders, syndromes, autism, associated with developmental delays, challenging behaviors, learning difficulties (Hathazi, 2014). Multiple disability is defined as an individual having two types or more than two types of disabilities which require more attention and support in education programming (Chen, 2004). In addition to these definitions, different scholars define disability using different perspectives. This different models of disability will be discussed below under the title intervention models.

2.2. Causes of Disability

According to The African Child Policy Forum (ACPF,2011), of the children who participate on the study, causes for their disability is found to be illness (38%),being born disabled (35%), accident (10%), violence (1%), hereditary cause (1%), other causes like God's curse and punishment for sin (2%) and unknown reasons (14%). However, the study note that lack of documentation during birth of a child makes it difficult to get correct information and work on prevention.

According to Yetnebersh (as cited in Sedeto & Dar, 2019, p. 3) disability in Ethiopia is caused by "manmade disaster, prenatal causes, during natal and post natal periods, alcohol and drug addiction, communicable diseases, harmful traditional practices and aggravated by poverty such as malnutrition and lack of environmental hygiene."

The 2007 population and housing census considered the following to be causes of disability. These are vehicle accident, other accidents- which are caused by failing, electric shock, ... etc., polio, leprosy, post-natal diseases, intra- uterine and during delivery, war and unknown cases. However from the lists leprosy, epilepsy and mental problem except mental retardation were not considered during the census counting (Central Statistics Authority, 2007).

2.3. Types of Disability

Studies categorize disability in different ways, as they differ in giving meaning to disability. " Sensory, physical, mental, and intellectual impairments are considered as types of disability" (Sedeto & Dar, 2019, p. 3). Under IDEA, Individuals with Disabilities Education Act, which is American legislation enacted for serving the issue of education of disabled students, there are thirteen types of disability stated. They are autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disability, orthopedic impairment, other health impairment, special learning disability, speech or language impairment, traumatic brain injury and visual impairment (NDCCWD, 2012).

2.4. Definition of Multiple Disability

According to Chen (2004), multiple disabilities involves a person who has two or more types of disabilities that can be simple or complex in their effect on the individual. These disabilities need special focus in the educational environment.

When there are multiple types of disability, the impairments are simultaneous, the combination of which causes such severe educational needs that they cannot be addressed with a single form of special education programs (NDCCWD, 2012).

2.5. Experience of Mothers of Children with Multiple Disability

2.5.1. Psychological Wellbeing

Barbosa et al (2008), had described the situation as:

> The birth of a disabled child had destroyed the dream of the ideal infant and, with it, the woman's expectation to be a mother was completely lost. The non-satisfaction of her desire to have an infant as she had idealized is perceived by her as a hollow area in her being, and a feeling of not having become a mother emerges. (p. 49).

Moreover, negative feelings of guilt are experienced. The mothers' blame themselves for giving birth to a child with disability. She also blames herself for having a rejection feeling towards her child until she accepts the reality (Barbosa et al, 2008). "Majority of mothers of children with mental retardation who were part of a study were blamed by their in-laws for giving birth to such child" (Rani, 2016, p. 65). "These mothers often had to deal with shock, confusion, and anxiety related to a delay in diagnosis and/or inconsistency in medical diagnostic opinions." (Nelson, 2002, p. 522)."This, in turn, leads to experiencing feelings of disbelief and hopelessness" (Barbosa et al, 2008, p. 49).

Glasscock, McKeever & Larson (as cited in Nelson, 2002, p. 524) discussed how mothers give meaning to their mothering experiences differently. Some found care giving rewarding while others found it less rewarding due to absence of reciprocal communication from their child with disability. However, they claim that though they get nothing in return from their children, they get something special pleasurable from them.

2.5.2 Family and Marital Relationship

"Intra family relationships were significantly affected by the presence of a disabled child." (Nelson, 2002, p. 524). "Each delayed developmental milestone has the potential for additional stress, depression, chronic sorrow and an effect on marital intimacy" (Fisman, Wolf, & Noh, 1989, p. 524). As a result, "mothers make difficult decisions such as changing location of living and separating from extended families so as to get a support for the child" (Heer, Rose, Larkin, & Singhal, 2015, p. 224)

A study made by the (DOBE&UNICEF, 2015, p. 29) on mothers of CWD found out that having a child with disability aggravates the problem which used to exist between parents.

Friedrich and Friedrich (as cited in Ravindranadan & Raju, 2007, p. 138) study the satisfaction difference between parents of mentally handicapped and non-handicapped children and reached to conclusion that parents of mentally retarded children are less happy in their marriages than the parents of normal children.

2.5.3 Economic Impact

The impact of having a child with special needs children is highly noticed on the mother's employment (Nelson, 2002). "The mother will be forced to leave her job so as to fulfill the extra care that is demanded by her disabled child" (Barbosa et al, 2008, p. 51). Hence, this results on reduced income in the family which will have a direct impact on the economic situation of the family.

2.5.4 Social Impact

Societal judgment towards the child with disability and the mother herself is also boldly noticed. While they take their child outside and people points on the child due to the different behavior they show and became mocked by other children, the mothers' felt guilty for it (Rani, 2016)

Due to this many mothers have recognized "the lack of acceptance of the community towards their child" (Nelson, 2002, p. 525). "When the mother recognizes these, it strengthens her feeling of shame of her child's disability and reaches to conclusion not to show off her child in public so that she can protect her child from judgment" (Barbosa et al, 2008, p. 49).

Due to social judgment and/or other reasons isolation from the society is experienced by mothers. MacDonald, McKeever, & Woody- Wood (as cited in Nelson, 2002, p. 525) stated that "Sometimes, isolation was related to the necessity to adhere to a strict medical regime, difficulty traveling with cumbersome equipment, or instability of the child’s condition". "Their social life is often affected without much recreation and leisure for many positive opportunities and activities to score for their credit" (Rani, 2016, p. 65).

2.5.5 Work Load Related to Care Giving

"The burden on mothers related to care giving is a major issue. It is the lives of them which is highly affected because they are the primary care takers of children. And the likelihood of getting assistance from other members of the family is less likely" (Nelson, 2002, p. 525).

"Daily care for children with disabilities is different from that of normal children due to the special care that needs to be provided. Some or all of immobilized children's activities of daily living are dependent on someone else." (Ergun, & Ertem, 2012, p. 779).

2.5.6 Physiological Impact

A quantitative study made on mothers of speech impaired children found out that the prevalence of depression is significantly higher compared to a control group. On the same study, the researcher has even recommended the significance of screening mothers of speech impaired children for emotional disorders (Rudolph et al, 2003).

Another study by Spakota et al (2017) has also stated the high level of anxiety and depression on mothers of children having intellectual disability. Additionally, the necessity of early mental health support before the problem reaches to a level of grave psychiatric disorder and burn out is also raised.

Chapter Three: Research Methods

This chapter demonstrates the method of research used in this study. It explains the research design, study area, study participant, sampling technique, data collection tools, data collection procedure, methods of data analysis and ethical consideration.

3.1 Research Design

In order to assess the experience of mothers of children with multiple disability a descriptive, cross-sectional, qualitative research is used. Qualitative research method is employed because it helps to get a detailed understanding of the issue direct engagement and discussion with participants is important (Creswell, 2007). It is cross-sectional since the research is conducted at one point in time (Chris & Diane, 2004).

"Qualitative research is a means for exploring and understanding the meaning individuals or groups ascribe to a social or human problem" (Creswell, 2014, p.246). "Qualitative researchers are not interested in causal laws but in people’s belief, experience and meaning systems from the perspective of the people" (Brink, 1993, p. 35).

This research used qualitative methods to describe in detail the lives of mothers of CWMD by investigating the psychosocial effect of having a child with MD, its economic challenges, its effect on mother's marital life and the supports given to mothers from the family internally and externally from the community or responsible organs so that they will overcome different difficulties. For this purpose, among the varieties of qualitative designs phenomenology is selected. Moustakas (as cited by Creswell, 2007, p. 58) stated that "phenomenology will be the appropriate method to contain descriptions of "what" they experienced and "how" they experienced it.

This study is phenomenological study because of its nature of being a qualitative research design which emphasize on the subjective response of the mothers about their experience of a phenomenon. Lester (1999), quoting Husserl stated that pure phenomenological research seeks essentially to describe rather than explain, and to start from a perspective free from hypotheses or preconceptions. Taking this into account the research plans to be descriptive rather than explanatory and also free from assumptions. The research question to be answered by this particular method is, “*What is the lived experience of mothers of children with multiple disability?*”*.* *"* A phenomenology provides a deep understanding of a phenomenon as experienced by several individuals" (Creswell, 2014, p. 83). Thus this study is a phenomenological study describing the lived experience of being a mother of CWMD.

3.2. Study Area

The study was conducted at a local NGO called Brothers of Good Works project Ethiopia. Brothers of Good Works project Ethiopia is counseling and social services center which came to operation on 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. Currently, the Center is providing its services using its four big departments; Education, Social and Economic Empowerment, Community Based Rehabilitation (CBR) and Youth empowerment program.

The CBR program works on children with disabilities and their families emphasizing on rehabilitation and social and psychological integration. This research focus was on mothers who were responsible for caring a child with multiple disabilities. Since the CBR department works closely with families of children with disabilities, it is a good opportunity to locate the mothers of children with multiple disabilities. For this reason, the researcher has chosen this area to conduct the research.

3.3. Study Participant

The mothers of children with multiple disability and counselors and/or social workers at Brothers of Good Works during the study time were participants of this research.

3.3.1 Criteria for Selection

Inclusion criteria were;

- A mother/guardian of children with multiple disability. The multiple disability of the child is proven according to BGW's diagnosis on multiple disability.
- Primary caregivers or guardians of a CWMD.
- Who are the beneficiaries of BGW CBR project
- Worker at BGW CBR project.
- Who give free consent to participate in the research

Exclusion criteria were;

- Mother of a child who is with single disability
- Mother of a CWMD but who is not primary caregiver

3.4. Sampling Technique

For determining the appropriate targets, a non-probability sampling technique was used. Of the different types, purposeful sampling is the best fit. In addition, the researcher knows what to look for and all the participants must have experienced the same phenomenon which is having a child with multiple disability in this case (Creswell, 2007). The qualitative research usually relies on small numbers with the aim of studying in-depth (Miles &Huberman,1984).

Total of twelve respondents were selected using purposive sampling. Out of which ten of them are mothers of CWMD who participated on the in-depth interview and two are key informants selected from CBR workers.

The researcher has set an inclusion and exclusion criterion to select participants. The criterions are mothers of children who according to BGW diagnosis have multiple disability, who are the main care givers for the children, who are the beneficiaries of BGW CBR project and those who gave free consent to participate in the research. However, to get different kind of story lines from the participants' differences in age at the time they gave birth for the child with MD, educational background, available support system, living neighborhood, economic level were considered.

3.5. Data Collection Tools

In this research primary data was used. It was found from the observation, in-depth interview and KII (Key informant interview).

3.5.1. Observation

Observation was undertaken according to the observation guide that is prepared to collect data. The type of observation the researcher used was a complete observer. The researcher prepared the guide from the available literature and own personal experience in a way it helps to assure that each item was in line with the stated research objective.

"If something happens to you, if you personally see it or experience it, you accept it as true. Personal experience or seeing is believing has strong impact and useful source of knowledge" (Kreuger & Newman, 2006). This indicates that critical observation is essential data collection method for having firsthand information about the issue. It also helps the researcher to gather relevant data with an intention to cross check the congruence of the data obtained from the interviews.

The researcher made an observation on the mothers repetitively on different places. One of the it was the physiotherapy program. Where all the mothers brought their CWMD three times a week to a room where equipments for this purpose were available and a trained physiotherapist gave the children different exercises. Again I made observation at the homes of these mothers as a visit program and during a coffee ceremony program held at their houses.

3.5.2. In-Depth Interview

In-depth interview provides an opportunity for detailed investigation of each person's personal perspective (Ritchie, Lewis, Nicholls, & Ormston, 2013). A Semi-structured interview is chosen. Thus a researcher is able to re-structure the questions, or probe for more information based on interesting idea raised by the participants on the interview session. Often multiple interviews are conducted with each of the research participants. "A total of 10 participants will be used" (Creswell, 2007, p. 131). However, the number is decided tentatively in which it will be decided considering the issue of data saturation while collecting data (Yin, 2003). By data saturation the researcher is meaning that failure to get additional idea or reaching a point where redundant information is obtained.

3.5.3. KII (Key Informant Interview)

For the purpose of this paper the researcher conducted an interview with key informants. The key informants are selected from BGW organization. Those who have close work relation with the mothers of CWMD were chosen. The need to conduct KII is for triangulation purpose. Since using alternative data source is necessary to check the trustworthiness of data collected, the researcher used KII to fill gaps that may appear from the data collected by the other type of data collection tools. Then data were recorded, transcribed in the language of the respondent and translated into English.

3.6. Data Collection Process

After obtaining the approval of research topic, preparing research proposal was the starting point of this study. After doing this, instrument development and data collection procedures were done step by step. There was instrument development procedure, instrument translation procedure and data collection procedure consecutively.

In the instrument development process, the target groups were identified then the data collection document was formulated so as they are able to understand. The criteria to include participants was also set in the instrument development process. Then the instrument translation process mainly dealt with preparing the English interview guide and translating it into Amharic for the purpose of creating smooth communication with the participants . The detailed procedures of the instrument development and translation process is described below.

Instrument Development Process

Beforehand, who the target groups are and the issues to be emphasized on were sorted out. The study participants were found by the help of Brother of Good Works office workers especially the Community Based Rehabilitation department officers. Through them eligible participants for the purpose of this research were selected. 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. The inclusion criteria to select the participants are being 18 years old and above, who have a child with multiple disabilities, who are the main care givers for the children, who are the beneficiaries of Brothers of Good Works Center Community Based Rehabilitation project and those who gave informed consent to participate in the research.

These helped to get a firsthand data information from the lived experiences of mothers of MDC. The interview guide was prepared based on the research questions that were set in the research proposal stage of the paper. At most care was made by the researcher to avoid redundancy and questions that are unrelated to the research area.

Instrument Translation Process

The interview guide was prepared by the researcher in English language. However it was translated into the language of the participants, which is Amharic. The media of the interview was held in Amharic and the data collected from the participants was again translated back to English to make it part of these research paper.

Data Collection process

Initially the participants were informed of their involvement and were requested for their consent for the interview to be recorded solely for the research purpose. The researcher was the one collecting the data in audio format, which was then transcribed into text. In case of in-depth interview, the place of conducting the interview was decided according to the interest of the participants. Some were interviewed at the venue they were conducting physiotherapy for their CWMD while others at their housed. The identity as well as information got by the researcher while working on this research is and will strongly be kept confidential. The participants were informed that their identities will be anonymous. Study code was assigned for the participants while transcribing data by the researcher. So, anonymity of information was strongly maintained in the whole process. The obtained data were translated directly from Amharic to English by the researcher.

3.7. Technique of Data Analysis

The data collected was analyzed by adopting qualitative content analysis (Strauss & Corbin, 2008). In qualitative research, data analysis begins at the same time the data is collected (Kreuger et al, 2006). It also requires prior management of the raw data in order to categorize systematically (Maxwell, 2005). The data that was collected through multiple interviews were transcribed and aggregated for analysis by their thematic area. Therefore, the data that was collected from interview through audio was first transcribed in English language. When transcription of all interviews was finalized, data that have the same idea were given same code. This helps to sort out the data according to their respective themes and makes it easier and clear to analyze the issues with the existing related literatures. The observational notes were also reviewed.

During the transcription, maximum effort was made to maintain the original meaning of the intended information and different names were given for the participants to maintain their confidentiality. The transcription was done by the interviewer. Interviewer self-transcription gives the opportunity to fill unclear passages and insert clarifications (Padgett, 2016). After the transcription is finalized it was translated to English language to make it suitable for the analysis of this research paper. Then by reducing the data through collecting it on themes, coding and condensing the codes, finally data will be analyzed in a discussion form (Creswell, 2007). Based on the guiding questions, conceptual framework, and reviewed literatures defining codes with same categories were made and sub-categories were also created to refine the coding.

The researcher have come up with six themes for these research purpose. They are what are causes of disability, what are the responsibilities of mother of CWMD, the mothers' psychological experience, social experience, economic challenges, and marital challenges. Sub categories were found under some of the main categories. Under psychological experience of mothers subcategories like knowing their child condition, behavioral difficulty of the CWMD, denial, economic dependency and quitting of job, people perception toward them, worry and suicide attempt are discussed. Under economic challenges subthemes like quitting of Jobs, Need of the CWMD, housing Problem, and medical expenses.

3.8. Quality Assurance

The study used alternative data sources so as to fill any gap that may happen and to check the trustworthiness of the data. The researcher used data triangulation method to verify the quality of data collected. That means the data found from the in-depth interview with the mothers of the CWMD was checked against the key informant interview held with BGW field expert workers. Observation, home visit of the participants, was also the another data source where the researcher used for data triangulation.

3.9. Ethical Consideration

The ethical measures in this study include consent, confidentiality, anonymity, privacy, and the right to withdraw from the study. Primarily, the researcher got support letter from the Social Work Department of Addis Ababa University and submitted to the office of BGW where appointment was held for their response. Then on the appointment date the organization gave the researcher a permission to conduct the study and area of work for decided upon discussion, the CBR project.

Before going direct to the interview process, the researcher took two weeks as an introduction stage to be familiar with the mothers by attending the physiotherapy program and coffee ceremony sessions.

The interview session began with thorough explanation of research purpose to the selected study participant in order to obtain their consent prior to their participation in the study. To assure ethical consideration of informed consent, each participant signed on informed consent letter indicating that they have read the letter and agreed to participate in the study. The issue of confidentiality was insured by not using their names in any written material or discussions concerning the research and storing interview materials in safe place free from disclosure. The researcher also ensured to keep audio records in safe place and promises to destroy after defense of the thesis.

Chapter Four - Finding

4.1. Demographic Characteristics of Participants

The participants of this study are mothers of MDC who are the beneficiaries of BGW and field workers of BGW. The IDI was held with 10 mothers and 2 professionals were participated in KII. The participants were selected based on a predetermined inclusion criterion.

The below table explains the details of each of the participants who participate in IDI;

No	Pseudo Name	Age	Age of CWMD	Marital Status	CWMD Siblings	Types of MD
1	Participant 1	32	3	Married	1	Intellectual and physical disability, lack of speech
2	Participant 2	27	3 1/2	Single	-	Intellectual disability, cerebral palsy, epilepsy, lack of speech
3	Participant 3	25	4	Divorced	-	Intellectual disability, lack of speech and cerebral palsy
4	Participant 4	28	1 1/2	Married	1	Intellectual and physical disability, cerebral palsy, lack of speech
5	Participant 5	28	8	Married	1	Intellectual disability, lack of speech and cerebral palsy
6	Participant 6	34	2	Married	1	Hydrosophalic and Spinabifida
7	Participant 7	30	6	Divorced	-	Intellectual disability, epilepsy and cerebral palsy
8	Participant 8	48	8	Married	2	Intellectual disability, epilepsy and cerebral palsy
9	Participant 9	40	4	Married	1	Intellectual and Physical disability, lack of speech
10	Participant 10	40	17	Widowed	4	Physical disability, epilepsy

The interviewees, KII-1 and KII-2, are both women who work in the organization as Field Worker and Assistant Program Coordinator with 15 and 14 years of service respectively.

4.2. Responsibilities of mothers of CWMD for the family

The responsibilities of mothers goes from inside home responsibility to outside home, from the CWMD to other members of the family. Almost all mothers shoulders the main responsibility to take care of the CWMD. Activities such as bathing, cooking, feeding, washing clothes and sanitary clothes, changing diapers, giving physiotherapy are among the usual.

Besides this, mothers who has additional member than the CWMD are also entitled with the activities of cooking for the whole family, washing clothes of the whole family, and doing all the home works. Few mothers who are working to get income for the family have the responsibility to finish all the household works and do the outside work too. However almost half of the mothers are house maids who have stopped working when they give birth to their CWMD. Because such kind of children needs all day and night attention and care unlike other children.

Participant 4 said *My prior day to day activity is about my child. I feed him, give him bath, wash his clothes in addition to my other household works. Then I will take him to a nearby church and I spent the rest of the day there.*

Participant 10 *also said that because they, the mother and CWMD, spent many time together when they were at holy water places for long time he is attached to her that he only prefers being feed by her. So she can never be far from him.*

As most of the mothers are single mothers with no family support they are the only one present for the child. These mothers do the household works, cares for the child and then go out and work on income generating activities that BGW has provided to them. However they carry their child on their back and take them with them since they have no one to look or babysit their child.

According to participant number 2, she earn their livelihood by selling coffee and tea inside *tej bet*. Her daily activity is washing her child, feeding her, going to church and then after preparing the tea and coffee she will go out to work by caring her child and the needed materials for her business. But she confessed that caring her child on her back the whole day and working at the same time makes her very tired. And there are times she is unable to go out for work.

Some are lucky enough to get support from their families. This reduces the responsibilities the mothers are shouldering by themselves. Participant number 1 and number 4 has their sisters living with them. They support them in babysitting the child as well as in household activities when they get spare time from their school and work.

Participant number 8, mother of three children, discussed comparing the burden of raising a CWMD and normal children. She described the difficulty of raising her CWMD that he always needs her presence and is always dependent.

KII 2 also mentioned that *Most mothers left their jobs when they give birth to CWMD. As a result their social interaction and economic condition decreases. They are burdened with the inside home works and outside responsibilities. They are the one who take care for the CWMD and other children in addition to the father or other relative leaving with them. They cook food, feed them, cloth them, take them to schools, wash clothes and give care to the CWMD all day long. Most behavior of such children is difficult, moody, less appetite; hence mothers struggle with all this problems. There is no proper school that accepts her child, no proper medication facility and transportation that fits their condition.*

4.3 Psychological and Social experiences of Mothers of CWMD

4.3.1 Psychological experiences

From the interviews conducted and observation made by the researcher I have witnessed the mothers are in deep and grave psychological problems. But they do not consider it as main problem for them. They usually tend to discuss about their children disability and their economic problems when asked about the effect of having a CWMD in their life. The impact on their own livelihood was unnoticed to the mothers. But as we made a longer discussion and deeper connections I was able to understand the emotional damages they are encountering. Most of the interviews were interrupted with the crying and sobbing of the mothers.

The researcher has made personal observation on the mothers while interviewing them. And made her personal reflection from the way they were talking where most of them were in tears. They are sad for their child condition and their own. They have a feeling of loneliness.

The mothers have more or less common psychological experience. They are mostly depressed, stressed, unhappy, have anger inside, cry a lot and hopeless. These psychological problems seems to have relation with their health condition. They said that they have gastric disease, high blood pressure and forgetfulness among their known health conditions.

Reasons for the psychological distress are shared by most of the participants during the interview, and are summarized as follows.

Knowing their Child condition

One is the incident of giving birth to or having a child who is not normal. Participant number 4 remembered how damaging it was to hear doctors telling her that the child in her womb has a problem in his spinal cord and his brain contains a fluid which highly affects his health. Then she gave birth to her child when he was 8 month and 10 days preterm because I chose to deal with his condition holding him in my arms than in my womb. She added that it hurts to deliver this kind of child after caring in your womb for months expecting to hold a healthy normal child.

In the case of participant number 1, she said that *as he was normal and healthy when he was born, when I knew he was sick I felt very sad. I suffered a lot because it was unexpected situation for me.* Similarly participant number 5 also said that the feeling she encountered at the time she knew about her child was very difficult that she was thinking of killing herself.

Behavioral difficulty of the CWMD

The second reason is the difficult behavior of the CWMD. Participant number 1 said that her son used to cry all day and night until he was one year and ten months old and was very frustrating and tiresome to handle. She even said that she had wished for his death. Also now there are days where he cries a lot which become difficult for her to handle. In the same case participant number 9 also told me that her daughter have a difficult behavior of becoming aggressive and cry when she chat or laugh with other peoples around her. She just want her to keep quiet and carry her.

Denial

Being unable to accept the fact is also the other reason that affects them psychologically. Participant number 10 discussed that how is difficult to accept that her child cannot play and talk as he used to do. She said that t was better if he had this disability since he was born. He was a strong and active child. Seeing him sitting in one spot the whole day, not talking, not communicating and not asking for the things he want breaks my heart.

Dependency and quitting of job

The other psychologically degrading factor for the participants is that they are obliged to stay at home since the nature of CWMD needs a caregiver to be with them all the time. Though they are happy and satisfied of caring a good care for the child that there is no one like them for the child, in another side they are made economically dependent on another person.

Participant number 3 mentioned that *the difficult part that make me feel bad is sitting (staying) at home with my child when I have the potential to work and earn money for my family livelihood. That affects my emotion.* Another participant, participant number 6, said that because she is not able to work around freely and most people does not want me to take my child with me to their place my work options are limited. And she added *I live in a poor condition unlike my friends and neighbors, I don't even have cloth; I am wearing the clothes I bought back in the days. I have inferiority feeling.*

People perception toward them

People perception about the disability of the child is the other challenge they face. One of the participant, participant number 5 describes it as follows. *Beside the condition of my child what people say about us is difficult for me to manage. I hear people saying that this happened because of evil spirit I follow. But I don't know what they are talking about. I am an Orthodox Christian and I worship my one and only GOD.*

Participant number 3 also shares these challenge. She said that her ex-husband says that I was the reason for my child disability. He claims my engagement in bad spiritual conditions have resulted on this. But all this is not true.

In the same way participant number 1 describes that *peoples around me and my neighbors say that God gave me a sick child due to due to my wrong doings. And because I have no faith in God. But there is nothing different I did to deserve this and a child is not chosen by us rather it is the gift of God. And we have no choice than accepting it.* KII 2 also stated about the existence of high stigma and discrimination both on the child and the mother within the community. She added that *the society relates such kind of disability with evil spirit and forbid entering to that house, this has both psychological and social effect on the mothers.*

Hence from the in depth interview, key informant interview and observation, I have found out that all the above reasons resulted in difficult psychological condition of the participants. However, none of them gets psychological support for their problems and they even do not give attention for their problem rather to their child's.

Worry

The other pressing issue I noticed is the worries the mother's have for their child future life. They said as long as they are alive and fit they fight for the betterment of their child livelihood. But they deeply worry about their CWMD fate if something bad happens to them. Since they are the only family and care giver the child have, mothers said that these idea worries them a lot. A mother of a CWMD whose husband is paralyzed due to stroke said that *when I think of them I worry for what will happen to them if something happens to me.* Participant number 8, who is a mother of 3 and whose husband is high blood pressure patient also said that *I worry who will look after him if something happen to me.* Another participant number 7, who was living in streets before getting support from BGW, has a worry that she may go back to street life one day when she finish the money she saved from her small business activity.

Suicide attempt

As a result of the multi-dimensional stresses and depressions they have due to the overloaded responsibilities they have for their family and the countless problems they are facing most mothers hated their life and thinks life has ended to them. They felt hopeless. These has forced some to attempt suicide. Participant number 4 said that she have tried to kill herself when doctors first told her the child's condition while she was 7 months pregnant. She describes it by saying *when I heard what the doctors said I felt like my life has ended then I tried to kill myself but I failed and the child was born anyway. And it is unbelievable to see my current condition despite what I have gone through.*

Participant number 5 who has not known about her child multiple disabilities until he was 2 years old also said that she had tried to kill herself when she was told her child's condition. Participant number 7, who claims to have a stress problem since she lost her whole families due to the 1977 drought back home, admitted that her stress and depression became worse and worse that she thinks of killing herself various times.

4.3.2 Social challenge

The findings of this study also identified social impact of having a CWMD on the participants. The main identified social impact is decline in social activity. Responses from the participants indicated 7 participants from 10 have agreed that they encounter social problems because of having a CWMD. Three of them said they have still good social interaction.

Participant number 1 explained that *before the birth of my child with disability I used to participate socially and I had ample time to be with people close to me but now my social interaction has become restricted. It is difficult to put my child alone at home and also to take him with me by carrying him at my back. If I even take him by carrying him he will not put me comfortable and I can't play freely like my friends do. Also it will not be comfortable to change his dipper and do other things he need me to do at peoples home or in public places. So I prefer staying at home with him.*

Participant number 3 describes her reason to the decline on her social relation by saying *nobody was beside me while I was in many problems. No one cared about the condition I was in. So, I decided not to get close with anyone. I don't interact with neighbors and I am known to be quiet person in the neighborhood. Since my child has difficulty of using toilet, the odor that may* *come from her diaper makes me uncomfortable and lose confidence when socializing with people. Many times people have said bad things against me. So I usually stay home and I have reduced my interaction with people*, was what participant number 6 said when she describes her social experience. She also mentioned it is difficult to her to visit her father who lives outside Addis Abeba and is recently paralyzed due to sickness because she cannot travel with her CWMD in a public bus due to the above problems.

In addition to the above reason financial problem was the other reason for their decline in social interaction. Participant number 5 said *though it is difficult to participate socially with relatives and neighbors due to lack of free time and financial problem, I didn't stop from participating. Social relationship is a must. By borrowing money from neighbors or so, I participate in every social engagements like my friends. I have edir, mahiber and participate in birthday celebrations. I go wherever I should go by caring my child on my back. I do all these because I value social life and I am being paid in return by my supportive neighbors. They are always beside me in every bad and good moments.* In the opposite participant number 7 said that she have no interaction with her neighbors because of the gap she have financially. Because of these differences she cannot cope up with their living style.

KII 1 said that *transportation with the CWMD is also a challenge mothers face whenever they need to go to clinics, hospitals, schools or other social places. Because their child is different, noisy and is not able to use toilet the mothers won't be comfortable to take their child outside their home.*

The researcher has made an observation at most of the participants home together with the BGW field workers. By then had witnessed when one mother had no one to invite to a coffee ceremony program at her home. In addition to these scenario, the researcher was able to notice most of mothers were seating at their home with their CWMD in closed doors. Only those mothers living with their families are seen to be more open and free to their surroundings.

4.4. Economic Problems

The finding of the research shows that economic problem became major problem to the participants than the psychological and social challenges they are facing. The researcher came up with these finding by going through the mothers response when asked what kind of support they need for themselves and the betterment of their child's condition. Most of the mothers need was for economic support. Their quitting of jobs, being unable to work because they have a dependent child, the un-ending needs of CWMD for diaper and the fact that they are living in rental houses are considered as some of the reasons for their economic problems.

Quitting of Jobs

Let alone having a CWMD, currently raising a normal child has become difficult. And many mothers are quitting their jobs so as to give care for their new born babies. The case of having a CWMD is a very difficult condition for the mothers. Because these children need a continuous care and support from the family, and from the family members it’s mothers responsibility in our countries current situation. The research finding shows that half of the mothers have quit their job as a result of giving birth to a CWMD. And the rest are fighting for small daily works so as to survive and thanks to BGW they have started small scale businesses by the start-up capital they were given after taking a basic business skill training. Among the types of businesses selling injera and selling potato and other vegetables in Gulet are some of the participants business work.

Participant number 10 said that she was a government employee before her child accident happened. When the accident happened she decided to take her child to different holy water places to get healing, so she was forced to quit her job. After a stay for more than 3 years they come back to their home. And now she says *as I was the one supporting my family financially before now I have become dependent on others*. Participant number 4 also mentioned that she used to work in a hotel before the birth of the child. But now she have quit her job and her son is her number one priority to give care. In the same condition, participant number 1, 3 and 6 have stopped the better work they were working in for sake of taking care their child. But now since they can't afford to live without job as a single mom and no support from their husband, they have started small works though it is not sufficient for their livelihood.

Need of the CWMD

Except two of the participants eight of them have a daily expense for diaper to the child. They say that the expense for the diaper is their main financial burden. Participant number 1 said *BGW supports me with a monthly diaper which is 30 pieces, I use it only for 15 days and for the rest of the days I buy from my pocket.*

Participant number 4 also describes her economic challenges as follows. *Even though the government policy says medication is free for 'cheklahisanat', while we were at Zewditu hospital we were buying many medications including gloves every day. It's by the support of our family and relatives we were able t o survive. And now diaper has become our major cost. In fact BGW gives us support of diaper monthly but it's not enough so I try to do homemade diaper with cloth.*

Milk is also the other expense of the participants. Since the children have balanced diet deficiency during pregnancy and they need special attention on their intake most of them uses milk. BGW support them a one pack of milk powder every month. But many of the children has no appetite for other foods and they mainly depend on milk. So mothers are obliged to buy in addition to the support they get. These puts financial burden on the mothers.

Housing Problem

More than half of the participants live in rental houses. Though the houses are very small and not comfortable to live they pay from 400 birr to 1,000 birr for it. According to their income paying such amount of money means giving away more than half of their income. Besides these the participants say that peoples are unwilling to lease their house for us because of their children condition.

Participant number 5 said that *my husband pension payment and the money I get by washing peoples cloth is not enough to feed four family members, pay rent and fulfill the needs of my CWMD and my patient husband. Rent payment is getting costly from time to time. Now it has reached to the level that I can't afford that I have told my lessee that I am unable to pay more than this and my only option is to start living at church gate.* Furthermore, the KII 1added the difficulty mothers to get a house to rent because of their CWMD. Many people perceive that these children disturbs the compound, are noisy and also have bad spirit.

Medical Expenses

All participants have gone through difficult and lengthy medical examinations at the early time they knew about their child condition. And some has still ongoing medication follow ups. Although many of them conducted their medical follow ups in governmental health centers and hospitals, they have incurred expenses for medicines and medical utensils. Participant number 1 and 2 said that they followed their child's first medication at Paulos hospital. The first stayed for a month while the latter stayed for 9 days. They even got referred to Girum hospital and Amanuel hospital respectively. Through these they spent much amount of money for the examination costs.

In the case of participant number 3, her child's medical examination was at Zewditu hospital. She said that despite my long stay at the hospital I was not able to get help. So I took him to private hospital where they operated him and inserted a tube that connects the fluid part in his brain to his urinary tract so that it will be discharged as a urine. I paid 58,000 birr. I spent the money I saved while I worked at Saudi Arabia for 4 years.

Participant number 6 described that *first when they found my child's medical condition they put her in warming room for 15 days. This was at Petros hospital. Then she was referred to Zewditu hospital. There I suffered due to lack of bed for some time then we got one and continued the examination. When she become 3 months old she made spinal surgery. Then after 8 month from the first surgery she made a brain surgery to insert a tube that helps to discharge the fluid secretion in the brain with her urine and prevents her brain from growing bigger*. She also said that *I owe people money which I have used for my child medication expenses including city scan costs and it is not still paid. I stress on how I am going to pay my debts as it has even become difficult to fulfill my basic needs.*

However after the participants has joined BGW, they are entitled to support in the children medical expenses including their transportation costs. The key informant told me that after the mothers took their child to hospitals and clinics and paid the expenses, BGW will reimburse 90% of the total expense for them. The payment will be made when they come with receipts. But still few have problem of getting money on their hand to be able to take their child to hospitals even though they will be paid back by BGW.

4.5. Marital Conditions

When we come to their marital conditions, from the 10 participants 6 are married; 3 divorced and 1 widowed.

The two divorces of the participants happened while they were pregnant. The reason was the occurrence of the pregnancy. The other participants cause for the divorce is the CWMD. She said that *he used to blame me for I have born a child with disability. He say this thing happened because of you and your bad spiritual practices. But this is not true. I didn't follow any spiritual practice than my God. Rather I heard after sometime that he himself used to go to different spiritual places.* Hence these mothers have become their families bread winner as well as career for their child at the same time. Having no one to support them the burden they have is countless.

Even for the six married participants, life has not been easy and their marriage life has not become free from obstacles after giving birth to the CWMD. There is disagreements and disputes between the couples. The stressful, depressing and unhappy occasions has resulted in big gap between them. While explaining about her marital condition she said that *my marriage is getting tougher and tougher. The problems we had have aggravated after I give birth to my CWMD. There is big gap between me and my husband. Now I have reached to a level that I hate my marriage and have no hope on it. We always argue. He abuses me in addition to the pain I am experiencing related to my child. I am suffering a lot due to my child.*

Participant number 4 also discussed how her marital relationship was affected. *On the first days he used to get angry on the child saying he put me in great burden. He may also think it is only my problem to overcome. We used to argue on issues and we were unable to understand each other most of the time. It is because we both feel sad about what happened to our child. Because my husband has good soul and my strength that time has passed and now he is supportive to me. When he get home from work he holds him, give him bath, change diapers and feed him.*

Participant number 1 also affirmed that there are changes on her marital relations after the birth of the CWMD. *My relation with my husband has of course changed as having a child with multiple disability has its effect on us individually. We are not as we were before. We argue on ideas related to our baby. And there are many times we feel low and sad which affects our family life. But he is supportive in cases related to covering family expenses.*

Three of the participants are married ones. But their husbands are staying at home due to illnesses. The husband of participant number 5 is paralyzed due to stroke and is always in bed. She said that he used to be very supportive to his family. He used to work at Yekatit 12 hospital as health assistant and was very supportive to her in the house too. But the unexpected happened. When she explains what the reason for the stroke can be *he used to get disturbed, sad and depressed because of our child's condition. I used to advise him not to be stressed. I even made his Godfather to talk to him about it. But finally he become patient of high bold pressure and as a result a stroke made him paralyze and stay in bed.*

KII 1 also added that marital problem is among the main problems that these mothers are facing. She said that *husbands mostly think it is because of the wife they have a CWD, as a result they disappear letting the mother alone with the CWD. Those living together even don’t consider their wife as a person. They don’t respect or support them. They don’t think they have responsibility to their children. Family thinking that all responsibilities are entitled to the mother is a problem. Still there are few fathers who participate in care giving of the child, bringing the child to physiotherapy but it is not significant number.*

4.6. Family and Other Supports

The study has tried to understand the supports participants get from different directions. Support from husband, other children, participant's family, spouses family, neighbors, community, public services and government bodies are considered during the interview.

Support from husband

The study shows that from the participants included in this study, four of the participants get support from their husbands. However the level of support varies from only financial support to support in holding and giving care for the CWMD.

Participant number 1 and 9 stated that their husbands spend their time outside to earn the family's livelihood. They are supportive to the family financially. But since they come home late and exhausted they do not support me in child caring or other house hold activities. In the contrary participant number 4 and 8 said that their husbands supports them in child caring and babysitting. When my husband come home from work he supports me on activities like holding him, give him bath, change his diapers and feed him was the word of participant number 4. Participant number 8 also said he supports me in holding the child, if I have some place to go he will babysit him.

Other participants do not get husband support. Some are single mothers. And the rest, due to the fathers incapability to support due to illness and unwillingness to do so, mothers are the only parent burdened with responsibility of fulfilling the families need in terms of financial and daily basis needs.

Support from other children

From the 7 participants who have children other than the CWMD, those who have old enough children to give support are only four of them. Participant number 5 said that due to my economic problem my first born child who is 8th grade student works washing cars in his spare time and supports me by covering his own expenses. In the same way participant number 10, a mother of five, said that her elder children support her and her CWMD financially and my younger daughter support me in giving care to him, washing his cloth, cleaning him and changing his diaper. The rest do not get any support from their children. One of the participants raised her disappointment by saying s*ince I am responsible for my husband and three children I will be occupied with house hold activities I get no time to spent with my child, to play with him, taking him outside to be refreshed. So, if his brothers were supportive and spend time with him he would have improved his skills like walking and talking.*

Family support

Two of the participants live a complete segregated life from their families. They get no support from any of their family members and they shoulder all the responsibilities as a single mother. Participant number 2 said that her families live in a countryside and get no support from them. In the same token, participant no7, who lost all her family by death, is the only one responsible to care for her child.

Whereas participant number 3 and 8 said that the only support they get from their family is regarding a place to live in. Participant 3 lives with her aunt while participant 8 is given a house to live in her husband's family compound. Whereas participant number 1 and 4 get support of their two sisters who are living with them. They said that when they get free time from their work and school they support them in giving care to the child, washing his clothes and do household activities. These helps the participants to get time to rest and be able to socialize.

Medical support

Except one participant the rest knew about the disability of the child before and after delivery. All have stayed for lengthy of time at hospitals hoping to get cure or be able to know what exactly the problem of their child is. Many have suffered by going from one hospital to another through referrals. But almost all have ended up being disappointed not by the lack of positive results of the children but by the hopeless words from medical persons. When they shared me their experience most of them are unhappy by the medical supports they get. Participant number 3, mother of a 4 years old CWMD, said that she raised a boy that doctors has said will die within a shorter period.

Beside this, majority of the participants were not clearly advised on what the problem of their child is during the times they stayed in the hospital. In addition to this they were not clear what to expect from their child in the future. They were simply left confused and wondering by themselves what they should do for their child.

Participant number 2 told me about her stay in a hospital likewise

When I knew I was pregnant I made a pregnancy checkup. By then she was 6 months old. I was checked using ultrasound and the health professionals told me that it was fine and normal pregnancy. I delivered at a health center near to my living area. They said the child lacked air at time of delivery and they referred me to Paulos hospital. There they put her in warming room for 9 days. During all those days I was alone and no one looks after me nor my child. My families live in country side and they had no knowledge about my delivery. During my stay I was not notified about my child's condition. I was afraid to ask so I was simply following the checkups and examinations they ordered me to do. Because I was alone I had no courage to ask. I started guessing she have some kind of disability when I was sent to Amanuel hospital for some *examination. Then when my child was about one years old, I asked one nurse what the problem of my child is. Then he gave me simple answer saying she is sick because she had shortage of oxygen and fluid had come through her nose at the time of delivery. But I knew that she is not just sick but she cannot talk and move afterwards from other persons whom I knew at the hospital.*

Participant number 7 also said that *he didn't cry as normal kids do at time of delivery. They said he was suffocated. His weight was only 1 Kg. Then I was referred to Yekatit Hospital from the health center I delivered. While I was at the hospital I didn't asked them and they haven't told me the condition of my child. After 16 days I was discharged from the hospital.*

Support given by Brothers of Good Works

For the purpose of these research two key informant interviewees were selected who work at BGW and are in direct relation with the CBR (Community Based Rehabilitation) program. This program is selected from all the programs BGW was involved due to its proximity and close work with the mothers of CWMD.

From the two key informants one of them is the assistant program coordinator and the other one a field worker. Both have worked for longer time on the program; 14 and 15 years respectively. Hence they are considered to have a detailed information on this study's focusing area. They described the support given in relation to the CBR program as follows.

KII 1 said that, *the CBR program centers on giving support to children with disability while they are living within the community. It works toward empowering both the disabled child and their parents. Our concern is on the livelihood of the CWD which mainly emphasizes on health, psychological well being, economic situation, education, medical expenses, pampers &*

milk support, and physiotherapy. A feeding program for children will be given once a week at selected health centers. Counseling service and trainings are also given to mothers.

KII 2 also discussed about the support of BGW as follows:-

The prior work of this program is directed towards creating awareness about disability. What it means, how it is caused, how we can prevent it, how we can support those with disability, and etc will be addressed due to different trainings. Various counseling service will be given by field workers and CBR program coordinators to the parents of the child with disability. When additional support is needed they will be referred to the professional counselors of BGW. Most parents think it is only their problem and mostly stay at home closed door. Even when they have interest to take their child outside, the society may influence them otherwise. To alleviate this we do a home to home coffee ceremony at the houses of the CWMD where neighbors will be invited to drink coffee together with health extension workers. We work on creating awareness about disability. In schools there is child to child program which helps to create awareness and knowledge about what disability means and how we can give support to those with disability. This helps to create awareness among the school community; teachers, students and parents.

Mothers of the CWMD get support towards engaging in income generating activities. Mothers of CWD who are fit and not above 50 years of age, will be given Basic Business Skill Training(BBST).When they graduate, BGW grants them the needed materials to start up the type of business the mothers choose to do. Furthermore, other kind of trainings that help in taking care of the child will be given like physiotherapy, toileting and trainings on how to use catheter.

Result of the services given by BGW

Data found from both key informants and in depth interview indicates improvement of the child's health and disability from time to time. This brings happiness and hope in the mothers. And mothers also become psychologically strong as they start going out from home, interact with people and the like.

According to KII 1, *Our support helps the parents get acceptance and inclusion by the community by correcting the negative and bad perception most people holds against them. We see most mothers psychological condition become improved in a short period of time. Mothers who used to be angry, sad and talk impatiently with us in the first days get changed after some time and become calm and hopeful in their life. In case of the children too, great improvement is witnessed. Especially when the mothers are stronger and responsible major skill changes happen in short time such as being able to sit, stand, walk, use toilet. This gives us satisfaction on our work.*

The first participant gave her testimony that her life is changed with the 5 month stay in BGW. She said that *when I started the program of BGW, I saw different cases which are worse than my child condition. This made me strong and enable me accept my child's condition. My life also has changed from a depressed one to a better life where I am able to start a small work to support my family economically*. Participant number 5 also shares this idea. She said that *I manage myself when I get disturbed by thinking that other peoples are in a worse situation. I told myself to be thankful for what I have and accept my life. Especially after I join BGW I got stronger & accepted my life because I saw different kinds of disabilities which are worse.*

As to the 2nd KII participant *visible changes are seen on the children. Those who were not able to sit, walk, swallow etc have improved and become able to do so. Mothers get high awareness about disability and knowledge on what they should do for their CWMD and where to go for any support they need. They become able to understand that having a child with disability is not their fault, it is not a problem they only have rather there are many children with different* *kinds of disabilities out in the community, and it is not a taboo to have such a child. When they see more worse situations than theirs they become strong and hopeful for their child's improvement. They become very happy when they see their child go to school like others do. I have no enough words to describe the change I see on the mothers. They think we come to help them from above(heaven). Many parents who were not open and close to the community have changed when they see the improvements of the child thinking they are no less and different from others.*

Participant number 2 and 3 mentioned how BGW's physiotherapy service helped their child to get physical improvement. Participant number 3 described the positive results she got on her child by comparing BGW's support with another support giving organization she was participating. She said *I used to get support of physiotherapy from one organization found around salite miheret area. It was not as effective as BGW for my son. And its location was too far that I spent 30 birr each day for transportation. So I stopped taking my child there because I am happy by the improvements I saw on my child after I joined BGW.* Participant number 4 also added how BGW's support of diaper, medical cost and transportation cost has supported her economically.

Need for Additional Support

Most of the participants have a need for economic support. They said that the basic problem they are facing is economic problem. The children need for diaper and milk in addition to the mothers poor living condition and expensive house rent is the reason for their need for economic support. Four of the participants added need for professional support to their children. Participant number 4 and 5 raised their need for government attention to work for the betterment of such kind of children life. They said the government should establish schools and daycares that are specially designed for these children .

The key informants pointed that BGW's support by itself can not address the problems mothers face. The company's mission is a specified one, whereas the problems faced by the mothers is multi-dimensional.

KII 1 said that *support on establishment of government schools suitable for CWD in sufficient number and granting of kebele houses would minimize the major problems that affect the life of mothers.* KII 2 added on this by saying *support from concerned organs to give place and support on construction of centers where CWMD spend the day helps the children to get education and training as to their ability. Moreover enough amount of professionals to special needs education is also necessary. These will have dual effect both for the child and the mothers. Children will be able to educate, learn, socialize and become a productive citizen for the future. Whereas parents will get a relief from the occupying and tiresome time they spend with the children, they get rest, time of their own. These help them improve their psychosocial condition. They will be able to think they and their child matter for the community. They will get time to socialize with the community as their friends do. It also helps them be able to work and generate income.*

Chapter Five - Discussion

This chapter of the paper presents the discussion of the research findings. This study is designed to describe the lived experience of mothers of children with multiple disability(CWMD) in the case of Brothers of Good Works. It is a cross-sectional study that employed qualitative techniques to understand the life experience of the mothers of CWMD by exploring their experience, perspectives and histories from their point of view. The effect of having a child with multiple disability in the life of mothers is discussed in accordance with different researches carried out by different academicians.

The findings to be discussed are causes of multiple disability, the responsibilities of mothers of CWMD, the psychological, social, economic and marital experience of mothers of CWMD.

5.1 Causes of Multiple disability

The study participants indicated that they do not know for sure what caused the disability of their children. Some have said they have done the necessary medical follow ups during their pregnancy where they were told was normal and healthy. However the disability occurred. They said that they were not told the clear reason for it during their medical examinations in hospitals. So there is no a clearly known reason for their causes. However, Central Statistics Authority (2007) has listed vehicle accident, other accidents- which are caused by failing, electric shock, ... etc., polio, leprosy, post-natal diseases, intra- uterine and during delivery, war as causes for disability.

5.2 Responsibilities of mother of CWMD

It is found out that almost all the participants shoulder all the responsibilities related to their CWMD and other family members if there are any. Mothers are responsible for taking care the family needs. Most of the participants do household activities like cooking, cleaning, washing clothes, taking children to schools in addition to their work outside the house. Moreover, the children with MD needs the continuous care of their mother to do all the activities like bathing, feeding, toileting etc. Similarly a research by (Inan, Kucuk, & Civelek, 2018) showed the difficult caring experience of mothers related to their children behavioral problems and lack of basic skills such as toileting. This finding resonates with Nelson (2002) where it is shown how the life of mothers, primary care givers of children with disability, is highly affected and the assistance they get from other family members is significantly less.

5.3 Psychological Experience

The finding of this study shows that all the participants have experienced negative psychological impact related to having a CWMD. These are caused due various reasons among which un expectation of giving birth to a child with disability, difficulty of the children behavior, absence of support, and burden of responsibilities are some of them. As a result they experience stress, depression, hopelessness, anger, and lack of confidence. Three of the participants, participant number 4, 5, and 7, have even reached to the stage of attempting suicide.

This finding is in line with other researches for example with Spakota et al (2017) which shows the high level of depression and anxiety on mothers of children with intellectual disability and added the importance of early mental treatment to prevent them from high degree psychiatric disorders. Similarly, Rudolph et al (2003) in a quantitative study found out that prevalence of depression on mothers of speech impaired children is significantly higher than the control group.

5.4 Social Experience of Mothers

Similar to the study of Rani (2016), this study found out that the mothers are affected by societal judgment towards the CWMD and the mother herself decreased their social interaction. The difficult behavior of the child and lack of toileting skill coupled with the societies stigma and discrimination are among the main reason that affected mothers social participation. The other reason the participants claimed affecting the mothers social life is lack of support in babysitting the CWMD. Since transportation is not easy for CWMD to take child with them and they are unable to go out putting the child alone at home. They are forced always to stay with their child at home.

5.5 Economic Challenges Faced by Mothers of CWMD

This research found out that the economic challenges faced by the participants is major one. Though our countries majority of people are living in a low economic level, these participants are living in a worst situation. And these economic problem is considered as one of the cause for the psychological, social, and marital challenges of the participants. Participants dependency on other peoples hand financially has a psychological effect. Though the mothers are fit to work and have interest to do so, the condition of their child will not allow them to be out for work. The differences between participants and their friends in their living condition brings felling of inferiority, which makes them hate their life. Financial problem also affect their participation in their social life. Because they will be unable to contribute for social occasions that needs monetary contributions like *Edir, Ekub and birthdays.* Moreover, the effect of economic problem goes beyond this to the marriage of the participants. Among the other reasons that instigate for the separation of participants with their spouses and the unhealthy or unhappy relation of couples, economic problem can be considered as one of it.

Mothers decision to quit their job so as to give the necessary support for the child has impacted half of the participants economic status. The impact of having a child with special need in the mothers employment is also showed in a study by Nelson (2002). Adding to this, the fact that mothers of CWD will be forced to quit their job so as to fulfill the extra care of the child is found out on another study (Barbosa et al, 2008).

5.6 Marital Challenges of Mothers of CWMD

A study by Friedrich and Friedrich (as cited in Ravindranadan &Raju, 2007) showed that parents of mentally retarded children are found to be less happy in their marriages than parents of normal children. The results of this study also shows how the marital affair has become challenged after the coming of the CWMD to the family. There were many disagreements and misunderstandings between the married couples.

Another study also supports this study finding which showed the problem which used to exist between couples gets aggravated because of having a child with disability. Majority of the husband's of the participant's blame the mothers for the disability of the children. It is considered as the fault and the problem of only the mothers.(DOBE&UNICEF, 2015)

However the researcher have not found a literature that supports the finding of this study that says fathers mostly either leave or divorce the mothers for the reason the mother gave birth to a CWMD or withdraw themselves from any responsibility toward raising the child with disability.

Chapter Six- Conclusion and Social Work Implications

6.1 Conclusion

The study was conducted to describe the lived experience of mothers who have a child with multiple disability. It had the objective of identifying their responsibilities, psychosocial experiences, economic challenges, marital condition and the available support systems they enjoy. The study was based on the experience of mothers of CWMD who were all above the age of 18, and had been the beneficiaries of BGW at the time of the interview.

These mothers daily activities are burdened with multi-faceted responsibilities. Such as household duties, caring for their child with multiple disability who is very dependent on them and needs continuous follow up, and outside responsibilities like working to support the family economically.

Depression, stress, hopelessness, unhappiness are noticed on the mothers psychologically. It is caused due to the problems they face due to denial, the child's difficult behavior, negative perception of people toward them, and the worry they have for their CWMD's future life. These also had an impact on their health conditions in which some of them had a serious gastric disease, high blood pressure and become forgetful of things.

Their social interaction has also declined after having a child with multiple disability. Being unable to go out leaving their child alone in the house coupled with the difficulty to carry the child with them whenever they had to go out to socialize have forced them to stay home. Most have loose connection with their families and neighbors.

Almost all mothers are living in economically lower condition. There are many factors that contribute to this challenge. The extra need of the child for diaper, medication, transportation to hospitals and schools is one factor. Hence, the fact that most mothers quit their job so as to give care to the child is the other factor. Expensive housing rent is also their other challenge.

Regarding their marital condition of there are divorced mothers who are their families only breadwinner and caregiver at the same time. These brought high burden and stress on the mothers. The others are married however their marriage is full of quarrels and unhappiness. From the married mothers half of them has a husband with health problems and are dependent on the mothers economically and care.

The research has tried to see the existing support mothers get from husbands, other children(if any), extended family support, and medical support. From the findings some husbands give economic support however only few render support for the mothers regarding child care giving. The support of other children is almost none except one of the participants get financial support for the expenses of the CWMD. In case of support from extended family, two of the participants get shelter support and other two participants live with their sisters who support them in sharing household works and child caring.

Mothers are not satisfied by the medical support they are given. They were not given full information about their child health condition by the time they were first at hospitals. So, the mothers were left confused with their children problems. There were also mothers who were told by medical practitioners that their child has no hope of living which the mothers claim it as irresponsible approach which does not take their feeling in consideration. Due to this incidence, most mothers claim they have lost trust on medical peoples.

6.2 Social Work Implications

6.2.1. Implication for Research

The findings of the study imply that more has to be explored on the subject matter. As the researcher reviewed several reading materials, she has witnessed that researchers tried to study the different kinds of disabilities and their effect on the family of disabled family as a whole. However, a lot has to be done on specific thematic areas as the current study at hand attempted which is about the lived experience of mothers of a child with multiple disability. Therefore, the findings can be used as a spring board for other researchers who are interested to explore more.

Additionally, the cause for the occurrence of multiple disability needs more research. Because knowing the exact reasons helps to work toward avoiding it by creating awareness and educating mothers.

6.2.2. Implication for Social Work Education

As a profession, one of the roles of social worker is being educator. Social worker can play a pivotal role as an educator at individual, organization and community level. As the findings of the study indicate there is a need to intervene through education.

One of the gaps noticed while doing this research is mothers’ lack of awareness about their child's disability. Most of them have not been clearly told by medical professionals about their child's disability; its permanent effect on the child and what the mothers should do to improve the child's condition. These lack of information put the mothers on a blind spot and hopelessness. Hence, the medical support given to the CWMD and the information given to mother should be improved. Mothers who are primary care givers should be helped to get full information about the condition in the language they understand. This is the spot where social workers play an educator role in collaboration with other health professionals.

The families of CWMD are not willing to disclose that they have a child with multiple disabilities. This will aggravate the situation and kills the little opportunity that the child have. It is only when they reveal the truth and seeks support from the limited available services that their child can have a better future. In this regard, a social worker can start to educate mothers and all family members, on the CWMD condition and on how to provide care. Educating the mother in providing care will equip her to systematically and fruitfully address the needs of the CWMD. Having family members support the mother will elevate some of the burden the mother faces.

Furthermore, the social worker can potentially educate the community around the CWMD and the mother. The community in this case primarily include neighbors, staff in health facilities, schools, etc. The major challenge mothers of CWMD face is stigma and discrimination. Creating such awareness in the community would at least reduce the level of discrimination, which could lead to involvement of the community members in helping the mother of CWMD.

6.2.3. Implication for Policy

As the findings of the study indicated, there is a need to intervene at policy level. Social workers must advocate for the betterment of existing government policies and initiation of new policy pertaining to the CWMD and families, especially the mothers. Policies must be designed with clear goal to bring about meaningful impact in the society. Such policies must have GO and NGO collaboration in mind to bring about shared responsibility for all stakeholders working in the health, social, education, economic, housing, etc sectors.

Shortage of availability of school for the CWMD in the community is evident. Hence, construction of special needs school in communities with enough number and skilled professionals are necessary. Having the opportunity to make the CWMD join a full day school will enable the mothers to get time to engage in income generating activities until the child comes back from school. It also helps the mothers to get free time and participate in social activities with neighbors and extended families etc, which in turn improves the quality of life to the mothers.

The other challenge the mothers are facing is being unable to cover expensive house rent. The expensiveness of renting of house coupled with the difficult behavior of the CWMD which makes property owners unhappy to lease their house for such families makes the problem very worse. Hence it will be very helpful if these mothers can be entitled to get Kebele houses from the government. The government must design policies that give priority in housing families with CWMD.

6.2.4. Implication for Social Work Practice

The finding of the study implies that there is no or little support provided for the mothers of the CWMD. Although there is a limited support available for the CWMD, there is no enough or far from enough support given to the mothers, making what the mothers are going through not well recognized. Therefore, psychological support is one of the primary areas where the mothers are in need of. A professional counseling support should be available to the mothers of CWMD starting from the time the mothers knew about their child's condition. These help them to be able to accept the condition, accept their life, move forward and have a smooth interaction within their family and the society. These helps to tackle the psychological problems the mothers are facing. It also helps to prevent the mothers from being exposed to stress related health problems.

Moreover, social workers are important in linking the mothers with resources. The findings of the study indicate that the mothers are challenged with a serious economic problem. To curb their economic problem, which will in turn be a solution for the multiple problems they are facing, a social worker can provide for supports by networking them for income generating activities with organizations working on capacity building.

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Annexes

Annex -I- Observation Checklist

The researcher will put reflections and/or descriptions on the areas of observation.

Observation areas	**Reflection /Description**
The house setting of the mother of CWMD	
The economic living condition of the mother of CWMD	
The daily activities of mothers regarding giving care (feeding, cleaning, clothing etc) to the CWMD.	
Psychological condition of the mother of the CWMD(anxiety, stress, anger, sadness, worries etc.)	
Social interaction of the mother of the CWMD	

Annex II- In-depth Interview Guide

Dear esteemed participant, the following questionnaire is developed for conducting a study in partial fulfillment of MA degree in social work at Addis Ababa University, school of social work. The study focuses on describing the lived experiences of mothers of children with multiple disabilities. In this regard to undertake the study successfully and give meaning to what the experiences of mothers of children with multiple disability is like, your participation has a valuable contribution. So, I invite you to participate in the study by attending an in-depth interview session and answering the following open ended questions.

1. Personal information:

- Pseudo name or Code:
- Age:
- Sex:
- Marital status:
- Educational status:
- Employment status:
- Monthly income:
- Where does the family live?

2. Family information

- How many children do you have?
- Which child has a problem of multiple disability?

  Probing questions - How was the pregnancy in relation to other children, if any?

- How was the medical issue at time of birth?

- How did you feel about it?

- What are the roles of each family members?
- Whose main responsibility is care giving to your child with multiple disability?
- What does the family think about having a child with multiple disability?

3. Mother's responsibility

- Can you please tell me more about your day-to-day activities?
- What are your responsibilities towards giving care for your child with multiple disability?
- What does it mean to give care for a child with multiple disability?
- Which behavior or actions of your child are very difficult in handling?
- Who else from the family helps you in caring the child with multiple disability?

4. Marital aspect

- Are you married?

  If "no", can you please tell me your marital status?

  If "yes", for how long did you live in marriage/relationship?
- How was your marital relationship before the diagnosis of your child with multiple disability?
- Did your marriage life get affected by having a child with multiple disability?

  If "yes", in what aspects was it affected?

  If "no", what did you do to overcome the challenging conditions you faced due to the difficult behaviors of the CWMD?

- Does your husband share responsibilities of the family and the CWMD?

  If **''yes''**, how?

  If **''no''**, why?

5. Psychological condition of mothers of CWMD

- What was your feeling when you first knew about the multiple disability condition of your child? how did you react?
- What did you feel when you think of your CWMD?
- How you manage when you face the above feelings?
- What kind of treatments did you get from health centers and/or psychosocial support providers?
- What worries you a lot? Why?
- Whom do you talk to informally when you have bad feeling?
- Where do you go when you need formal psychological support?

6. Social condition of mothers of CWMD

- How was your participation in your social life before having a CWMD?
- How does the condition of your child affect your social relationship? With your neighbors, extended family, community, religious affairs?
- What does the society in your community think about your child?
- What kind of attitude does they have towards you and your family?

7. Economic condition of mothers of CWMD

- How was the family making a living before the diagnosis of the CWMD?

- What is the income of the family currently?
- Do having a CWMD affect your economic situation? How?
- What major economic challenges did the family face after the diagnosis of the child?
- Which costs of living increased as a result of having a child with MD in your family? Medical costs, cleaning materials, transportation costs, house rent?
- How are you managing these economic challenges?
- Can you please tell me about the financial support you might get from NGO's, GO's or any organizations?

8. Support system

- What kind of support do you get from your husband?
- What kind of support do you get from your other children, if you have?
- How does your extended family support you? Your own family? your spouse's family?
- What support do you get from your neighbors? The community? The government? Public services?
- Do you think each support you are getting is enough?
- What kind of support do you think is important to address your child problem?
- What kind of support do you think is important to address your problem?

Annex -III - Key Informant Interview

1. How long have you been working at BGW?
2. How often do you meet the mothers of CWMD?
3. What kind of support do you give to the mothers as an officer of BGW?
4. What are the major problems faced by the mothers of the CWMD as to your understanding? (psychologically, socially, economically, and in their marriage life)
5. What do you think should be done to support them on the above problems?
6. What are the challenges you faced while you give professional support for both the children and mothers?
7. What kind of professional support do you get for the trauma you experience due to the support you give?

Annex -IV - Consent Paper

My name is Hiwot Kebede. I am Masters Student of Addis Ababa University School of Social Work. I am conducting research on the title "Lived experiences of mothers of children with multiple disability". Participation in the process is based on your written informed consent. You can skip any question, or withdraw from the entire process. Your honest answer to these questions will help the researcher to better understand and describe the lived experiences of mothers of children with multiple disability. Information you shared for this study purpose will not be shared to anyone who can harm the participant. It is used only for research purpose being imbedded in research ethics. If you agree to be participant in this study, signing on this consent paper helps the research. Singing on this paper means you understand the purpose of the research as it was stated on the consent paper.

Thank you for your cooperation and honest response!

Name of participant_______________	Name of the Researcher: Hiwot Kebede
Signature ______________________	Signature ___________________________
Date: _________________________	Date __________________________