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THE IMPACT OF RAISING CHILDREN WITH DOWN SYNDROME ON FAMILIES IN ADDIS ABABA

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Declaration

The researcher hereby declares that the thesis on the title “The Impact of Raising Children with Down Syndrome on Families in Addis Ababa’’ is my original work and that all source of materials used for thesis have been properly acknowledged.

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

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Abstract

The study aims to explore the impact of having a child with Down syndrome on the families that are registered at Deborah Foundation. Deborah foundation is one of the few non-governmental organizations which supports families with intellectual disabilities and majorly focusing on Down Syndrome. The study utilizes qualitative research design study approach. The data is collected from the families registered at Deborah Foundation using semi structured interviews with families with Down syndrome. The criteria for selection is based on, if they have a child with Down syndrome from 4 to 10 years of age, are able to communicate in Amharic or English, and if they are willing to participate. Data is collected using an in-depth interview, key informants and FGD. There were 14 participants in the in-depth interview, 5 key informant and 1 FGD with 5 participants. The data analysis used a thematic approach to identify categories. There are 7 major themes identified in this research: Initial reaction, Coping mechanism, Emotional and Psychological impact, Social impact, Economic impact, Impact of family interaction, and Basic services. The findings of the study indicate that respondents reported a significant impact on overall family functioning when raising a child with Down syndrome. The study highlights the socio-economic effects, with both social and economic aspects of the family being influenced, as well as the psychological impact. More importantly, it underscores the impact on family interactions, revealing the dynamics of the family as a unit. The implication of this study is to guide the development of support systems that strengthen the family unit as a whole for families with children born with Down syndrome in Ethiopia.

Key Words: Family, Down Syndrome, Impact, Child.

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CHAPTER ONE

Introduction

1.1. Background of the study

Down syndrome is a genetic disorder that is caused by the presence of an extra copy of chromosome 21, which leads to intellectual and developmental delay of the child (National Down syndrome society, 2021).

It is estimated that 1 in 700 births worldwide are affected by Down syndrome. It is the most common genetic disorder worldwide and the common genetic cause of intellectual disabilities. Medically children with Down syndrome face other associated medical conditions such as, heart defects, vision problems, hearing loss, infections, hypothyroidism, blood disorders, hypotonia (poor muscle tone) and other related conditions (World Health Organization, 2021). Even though people with Down syndrome are characterized by their sociability, they still encounter social problems due to the lack of understanding from their environment.

A family is considered to be the smallest social unit, and as a social unit of the system it interacts with and is influenced by other systems. A family is a complex system where various factors interact and change over time. To understand and manage this dynamic system, researchers have used multiple approaches to identify the most important factors that affect the stability and well-being of a family (Cunningham, 1996), Among the different types of families the research focuses on the nuclear type of family.

Families of children with Down syndrome face unique challenges; they are often concerned about psychological, economic, and social challenges they might face (Maroulis & Valaes,1982). Psychologically, the unexpected nature of having a child with Down syndrome

can bring about psychosocial stress and anxiety. Socially, families may face stigma and lack of acceptance in society, especially in areas with limited awareness about Down syndrome. These may include difficulties in finding inclusive educational opportunities, accessing appropriate healthcare, and navigating social interactions. Economically, the high cost of treating children with Down syndrome can be a significant burden on families. The related comorbid conditions such as heart defects, thyroid problems, hearing and vision problems, and others can add to the financial strain. While these are some of the presumed effects, it is important to recognize that there are other subgroups of challenges that families of children with Down syndrome may face.

The purpose of this study is thus to explore the impact of having a child with Down syndrome in the family in Ethiopia. Individual members of the family are influenced by the condition such as, mothers, fathers, and siblings. It is important to understand the overall impact on the family unit. This research provides valuable insights on the impact of children born with down syndrome on families as a unit in the context of our country.

1.2. Statement of the problem

Raising a child by its own can be overwhelming due to the responsibilities and obligations that follow it. Let alone the work it takes to raise a child with a normal development, when a child is born with Down syndrome there are extra steps that are expected from the family when compared to raising a child with a normal development. This is because the children's future can be determined on how much they are supported and nourished by their environment. Among the factors, family plays a big role in a child's development. There have been studies that are based on intellectual disability, including Down syndrome. Some of the local as well as international studies explored ideas, such as the challenges faced by parents, the experience of siblings, prevalence, coping strategies, and psychosocial impacts are some of them.

Maulik, Pallab, Mascarenhas, Mathers, Dua, & Saxena, (2011), conducted a meta-analysis of population-based studies on the Prevalence of intellectual disability. The review was done across 52 studies which were published from 1980 to 2009. The results showed that the prevalence of intellectual disability across the world is around 1%, as it was stated the prevalence was two times more in low- and middle-income countries compared to high income countries and the highest number is seen in children and adolescent age groups. In addition to the data presented it has also been identified that intellectual disability affects the individual, his/her immediate family, and the community.

In 2016, a study was conducted on 57 participants who were South African urban caregivers raising a child with Down syndrome. The purpose of the study was to examine the gap in knowledge and emotional responses among caregivers with children born with Down syndrome. The findings revealed that a significant proportion of parents, 50.8%, had limited knowledge about Down syndrome. Additionally, 37.9% of the sample reported experiencing mixed emotions while raising a child with Down syndrome. The community provided the least support resources to caregivers, accounting for only 7.4% of the available support (Barr et al.,2017). Similarly,the data found from Tsakani, Marie, Chris, & Nompumelelo, (2021), explored the experiences of parents of adolescents with intellectual disability in Giyani, South Africa. The descriptive data shows that parents experienced lack of support from family members and the society, in addition to that they experienced a lack of emotional support and caring service. The study suggested a collaborative approach from relevant stakeholders can bring a positive impact for the parents of adolescents with intellectual disability.

In 2017 a study was done on Ecuadorian families with Down syndrome children in order to determine the societal influence on the family. Findings demonstrated that the arrival of a

child with a disability not only increases the workload for a family but can also disrupt the dynamics and relationships among family members. In addition to that in 2013, a meta-analysis study determined that there are emotional, physical, and socioeconomic burdens that are experienced by family caregivers of children with Down syndrome. The emotional burden may include feelings of stress, anxiety, and depression. The physical burden may involve increased fatigue and health issues due to the demands of caregiving. Socioeconomic burdens may arise from financial strain and limitations on employment opportunities (Mohammed Nawi et al., 2013)

Orsmond, & Seltzer, (2007) examined Siblings Down syndrome and the effects on adult lives. The result showed a comparison based on the closeness, siblings of the children with Autism have less emotional closeness and are more pessimistic about the future of their brother or sister's than the siblings of individuals with Down syndrome. Naledi, & Anwynne, (2022), also conducted a study on the experiences of siblings to children with autism spectrum disorder in South Africa, it highlights the impact of being raised with a sibling diagnosed with Autism. The data analysis indicates experiences of unfair treatment, premature development, feelings of being highly burdened with responsibilities and high efforts for acceptance in their environment due to their sibling's diagnosis.

In the Ethiopian context, Tilahun, Hanlon, Fekadu, Tekola, Baheretibeb, & Hoekstra, (2016) conducted a study on the stigma experiences, explanatory models, unmet needs, preferred interventions and coping mechanisms of caregivers of children with developmental disorders in Ethiopia. The study showed that caregivers experienced a high level of stigma. A higher number of stigma was observed among those who had sought help from traditional institutions, and those caregivers who had a supernatural explanation about their child's diagnosis.

Zeleke, Hughes & Chitiyo, (2018), studied the path to an autism spectrum disorders diagnosis in Ethiopia based on parents' perspective. It explored the characteristics of children with Autism based on the parent's experience. As the result shows they described some characters from their personal characteristics such as, hand flapping, unusual attachments to objects and poor social interactions.

Tekola, Kinfe, Girma, Hanlon, & Hoekstra, (2023), researched the experiences of parents raising children with developmental disabilities in Ethiopia. The finding of this study illustrated the different challenges faced by parents raising a child with developmental delays such as, the lack of understanding from others, and scarcity of service based on where they live whether it's urban or rural. Among those parent's single mothers are faced with greater challenges including lack of social support, poverty and stigma. The study also suggests future research and intervention to create awareness and understanding because much work has not been observed in our country.

Therefore, undertaking research on the impact of raising a child with Down syndrome on families in Ethiopia is valuable, considering the limited studies available regarding the impact on families in our country. This brings new insights in supporting the systems available, and the specific cultural and societal factors that may influence the experiences of families.

1.3. Significance of the study

This study determines the impact of raising children with Down syndrome on families in Addis Ababa among children who are registered at Deborah Foundation. This study fills the knowledge gap in the understanding of the limited research on how the whole family as unit is impacted by having a child with Down syndrome.

- It sheds light on the challenges faced by families with Down syndrome children.
- The study's findings can be instrumental in advocating for program and services that address the specific needs of families raising children with Down syndrome, leading to improved support systems.
- Highlights areas where additional resources or support services are needed.
- Contributes to the existing body of literature on Down syndrome and family dynamics. As stated above there is a gap of information and research related to Down syndrome in Ethiopia, due to this reason this study is helpful in filling out the gap.
- Empowers families by validating their experiences and providing a platform for their voices to be heard.
- Understanding the specific challenges faced by families raising children with Down syndrome in Addis Ababa allows social workers to work towards the interventions that address the unique needs of these families.

1.4. Objective

1.4.1. General Objective

To study the impact of having a child with Down syndrome on the family, among families that are registered at Deborah Foundation.

1.4.2. Specific objective

1. To identify the impacts on the life of families with Down syndrome children who are registered at Deborah foundation.
2. To explore the social impact on families with Down syndrome
3. To find out the challenges of the families with Down syndrome and their coping strategies in raising a child with Down syndrome.

4. Based on the research finds, to provide some suggestions to improve the challenges of raising a child with Down syndrome at a family level.

1.5. Operational definition

Child: is a young human being who is in the early stage of development between infancy and adolescence. For this research purpose a child is with an age range of 4 to 10.

Chromosome: it is a thread-like structure made up of DNA (deoxyribonucleic acid) molecules and proteins.

Down Syndrome: also known as Trisomy 21, is a genetic condition caused by the presence of an extra copy of chromosome 21.

Family: "Family is a group of two or more people who are related by birth, marriage, or adoption and who live together and share economic resources, emotional support, and responsibilities for decision-making" (APA Dictionary of Psychology, 2023). In this context it refers to nuclear or extended family units residing in Addis Ababa and actively involved in the upbringing of a child diagnosed with Down syndrome. This includes parents, siblings, and other caregivers directly contributing to the child's well-being and development.

Impact: the term is described as having a strong effect on someone or something.

Raising Children with Down Syndrome: refers to the process of providing care, support, and education to individuals with Down syndrome, a genetic disorder caused by the presence of an extra copy of chromosome 21. It involves addressing the unique physical, cognitive, and social-emotional needs of children with Down syndrome to promote their overall development and well-being (National Down Syndrome Society, 2022).

Trisomy 21: is a genetic condition characterized by the presence of an extra copy of chromosome 21 in each cell of an individual's body.

1.6. Delimitation and Limitation of the study

The predominant limitation of this study was conducting the research solely within the Deborah Foundation, a non-profit organization in Addis Ababa, and limiting the data collection to families registered there. This limitation affects the generalizability of the findings to the entire population of families raising children with Down syndrome in Addis Ababa. This study is also limited in availability of data specifically focused on Down syndrome and the impacts on families in Ethiopia.

CHAPTER TWO

Literature Review

2.1. General overview on Down syndrome

Down syndrome is a congenital anomaly which is present from conception of a child and has an impact on the health and wellbeing of the children and their families. Down syndrome (DS) is a genetic disorder in which an individual has three copies of the 21st chromosome instead of two (Irvine et al., 2015). In 1866, a credit was given to the physician John Langdon Down for the initial articulation of Down syndrome (Langdon & Down, 1966). Even though Down syndrome is the most common genetic cause of learning disabilities in children associated with developmental delays, the exact causal factor is still unknown. It occurs in all races and economic groups without any restrictions. It happens randomly during the reproductive cells formation or very early in the development phase leading to Down syndrome. There is no clear evidence that shows relatedness to any behavioral or environmental factors of the parents to have a child with Down syndrome (National Institute of Child Health, 2007).

According to a study published in the New England Journal of Medicine (2020), there are physical characteristics of children born with Down syndrome that are different from other children, some of the feature include epicanthal folds around the eyes, a broad and flat nasal bridge, a round flat face, eyes that slant upwards, small ears, a short neck, and a downward-turned mouth. Associated medical conditions are also common that affect their health, development, and function such as cardiac complications, hearing disorders, pulmonary problems, autoimmune disorders, hematologic disorders, musculoskeletal problems and neurodevelopmental disorders can be mentioned. In addition, the National society of Down

syndrome (2021), suggested another important aspect to consider is the cognitive development of children with Down syndrome. This can have a different impact on the individual such as their ability to communicate, learn, emotional status and social engagement. Furthermore based on the study made by Perkins (2017), Down syndrome is marked by a range of manifestations in children. These encompass learning challenges, difficulties in speech and language development. Due to medical advances over recent decades many of the medical conditions associated with Down syndrome can be treated with medication, surgery, or other interventions (Diamandopoulos & Green, 2018).

Based on the research by Deakin et al. (2018), it is indicated that children with Down syndrome demonstrate early insight into their condition and the associated social attitudes. Children and young people with Down syndrome are easily recognized due to their physical features, which makes them more susceptible to stigmatization. The negative attitudes towards individuals with Down syndrome result in uncomfortable situations and unsatisfactory interactions with those around them. According to a study conducted in Iran by Hemmati et al. in 2010, the origin and sources of stigma towards individuals with Down syndrome can vary. These sources may include healthcare professionals, interpersonal relationships with neighbors, families, friends, as well as media influence. The findings from Mathabane's study in 2016 highlight the negative impact of cultural perceptions on maternal acceptance and adjustment in the context of Down syndrome. In many black ethnic cultures, congenital abnormalities such as Down syndrome, are commonly viewed as a curse or related with witchcraft. These cultural beliefs have an effect on mothers, impeding their ability to accept and emotionally process the experience of giving birth to a child with DS.

2.2. Historical development on Down syndrome

In the 15th and 16th century scientists found paintings that demonstrated the existence of Down syndrome. Approximately 2500 years ago there were also sculptors and potteries that showed Down syndrome features. Even though Down syndrome was present thousands of years before, John Langdon was the first physician to describe the clinical description in 1866. He provided a comprehensive description of the phenotype of the children born with Down syndrome due to the common features that were noticed different from other children with mental retardation. John Langdon referred to them as "Mongoloids" because he stated that they looked like Mongolians in their physical appearance. Later in 1866, it was named as Down syndrome in honor of John Langdon down, because he was the first to recognize and describe the features (Kazemi, M., Salehi, M., & Kheirollahi, M., 2016).

The cause for Down syndrome was not known until 1959, until researchers found the presence of an extra copy of chromosome. The revolution started when Joe Hin Tjio and Albert Levan did an experiment on determining the normal human chromosome was 46, then after 3 years of the experiment Jerome Lejeune and Patricia Jacobs identified an extra chromosome in children with Down syndrome (Mégarbané et al., 2009). According to Luder, J., & Musoke, L. K., (1955) it was assumed that there are no black children born with Down syndrome. The first black African child was discovered in 1955 by Luder and Musoke. Until then it was commented that mongolism occurs in all ethnic groups except Africans. It took until 1982 to decline the myth of the rarity of Down syndrome among black people.

2.3. Prevalence and incidence of Down syndrome

Down syndrome is the most prevalent genetic disease worldwide and the common genetic cause of intellectual disabilities appearing in about 1 to 10 per 1000 live births. Down syndrome is the most prevalent genetic causing intellectual disability (WHO, 2020). Weijerman, Van Furth, Noordegraaf, Van Wouwe, Broers, & Gemke, (2008) determined the prevalence of Down syndrome, which was 16 per 10,000 live births in the United States. In total 86% of the children born with Down syndrome are admitted to the hospital right after birth, due to different associated health complications. Similarly a cross-sectional study conducted in the United Kingdom in 2014 examined the prevalence of Down syndrome within the general population. The findings indicated that among females, the prevalence was approximately 5.9 cases per 10,000 individuals. For males, the prevalence was slightly higher, at around 6.8 cases per 10,000 individuals (Alexander et al., 2016).

According to Oloyede, 2011 in developing countries the data describing the prevalence of children with Down syndrome is inaccurate. The prevalence of Down syndrome was considered to be rare, even to the extent where there was a postulation that Down syndrome is derived genetically from non-African sources and was believed it was rare and non-existent among Africans. The reason for the speculation was due to the accuracy of most studies concerned with prevalence and incidence in Africa. There are several reasons for acquiring accurate data in developing countries, among those one is that Down syndrome is not reported because of the traditional beliefs in the community which associates the reason to traditional beliefs which is due to witchcraft and a curse which come due to the misdeed of parents. The inaccuracy of the data in turn has consequences such as creating an assumption that the data presented is real so the government doesn’t have to work towards awareness and an inclusive environment.

Poaty, Moyen, Nirma, and Mavoungou (2018) completed a retrospective study in Preliminary Working among Congolese Children with Down syndrome on the Prevalence and Pattern of Associated Anomalies. The associated anomalies present in Down syndrome children was also detected; congenital cardiac defect in 40.3%, respiratory tract infection in 32%, digestive problems in 8%, cerebral problems 14.5%, Prematurity 2%, others comprising 3%. Christianson, (1996) explains the prevalence and incidence of Down syndrome appears to be lower in African countries, due to lack of clinical awareness of the problem among medical staff in African neonates. This leads to a high infant mortality of affected children and a limited awareness of the condition in the community, leading to a lower data of the prevalence.

In the Ethiopian context, according toAbaba.A, (2013) There is an estimation of 7 million people living with some kind of disability, which represents about 10% of the total population. The types termed as disability are majorly stated as the blind, the deaf and physically disabled, this is due to the assumption that disability is often addressed exclusively as a medical concern but it's not only medical rather affects the social inequity, poverty, and lack of human rights. According to Weldeab (2007), the term disability is most widely used to refer to the visible physical difficulties while intellectual deficits are not included. Although in the Ethiopian Proclamation No. 101 of 1994 it clearly defines "disabled person" as any condition which is manmade or has a natural cause, and any person who is unable to hear, speak, see or is suffering from intellectual disability or from injuries that limit him. Taye, M., Afework, M., Fantaye, W., Diro, E., & Worku, A. (2019), conducted a descriptive cross-sectional study on children 0–17 years of age in Addis Ababa and the Amhara Region to determine the prevalence of congenital anomalies. Among the 16 identified congenital anomalies, Down syndrome was about 6.8%.

Families are like variables which continuously interact with each other and gradually change with time. In the case of a family with Down syndrome child, the mother, father, sibling and the child with Down syndrome interact within and as a whole with the outer system. We cannot conclude that if there is a child with Down syndrome in the family, it is certainly going to bring a negative output. It depends on the families' perception and the environment's attitude towards the condition (Cunningham, 1996). On the other hand, Skotko et al., (2011), study showed despite the negative impact families with Down syndrome children can experience positive outcomes and resilience. The families might develop a strong bond and increased understanding towards one another. In addition to that siblings of children with Down syndrome might also develop compassion and social skills as well. The study conducted by Barakat and Mohamed (2019) demonstrated that nearly half of the parents experienced high levels of stress, indicating the unique challenges they face in caring for a child with Down syndrome. Furthermore, two-thirds of the parents exhibited low levels of psychological well-being, suggesting potential impacts on their emotional and mental states. Additionally, more than half of the parents demonstrated low levels of coping strategies, indicating difficulties in effectively managing the stress associated with raising a child with Down syndrome.

In the Ethiopian context, Weldeab, & Opdal, (2007) suggest that Ethiopia as a developing country has its own difficulties regarding having a child with intellectual disability such as Down syndrome. The condition affects both individuals with Down syndrome and the family raising them. The family raising a child with Down syndrome goes through emotional, social, and economic challenges. Similarly the study that was made to identify the perception and experience of stigma among parents of children with developmental disabilities in our country. It sheds light on the different dimensions of stigma experienced by parents of children with

developmental disorders in Ethiopia. These include public stigma, characterized by negative stereotypes from external individuals, social exclusion due to their child's condition, and affiliate stigma, where parents isolate themselves from social life due to a fear of stigmatization and challenges in managing their child in social situations. It is common that children with disabilities have been hidden at home, being restricted from school and other social gatherings. The perception of parents about their own child, perceived family support and the amount of knowledge they have can be considered as a contributing factor for the negative outcomes (Tekola et al., 2020).

Another study conducted by Tekola et.al. (2016) showed a new perspective, which is that the lack of awareness about developmental disorders among health care providers in Ethiopia can be considered to have an impact on the families raising a child with Down syndrome. It showed that the health care providers are not equipped in order to give the necessary support to families. In addition to this, due to the lack of knowledge among health care providers, families experience stigma and discrimination from the health care providers themselves. Similarly, According to Gebre (2016), several stressors are associated with raising children with autism, which is one type of intellectual disability. A significant factor contributing to these stressors is the lack of understanding about autism by the parents, and the lack of understanding about autism on a societal level. This lack of understanding causes challenges and hinders support creating additional stressors in various aspects of raising a child with autism.

2.4. Impacts influencing families with Down syndrome

The health issues of a person born with intellectual disability such as Down syndrome has medical, psychological, economic and social issues from infancy through adulthood. According

to research studies the health and functioning of any family is influenced by the characteristics of each family. Especially in developing countries it may cause different difficulties. From the social aspect it might be a cause of discrimination and stigma from the society on each of the family members. Regarding the economic issue of the family it might be a reason for an extra financial cost, especially as a developing country the lack of free health services might be one reason to mention (Owoade Philip Adeleke, James Abua Ewa, James Eburikuri Olayi and Samuel Orim Orim, 2020). Families with children Study conducted by Emerson and Hatton (2007), also showed that there is a high risk of experiencing poor health outcomes in the case of children with intellectual disability. Different reasons can be listed such as, predisposition, environment, genetics, and barriers of getting further health care access. A 2021 study by Said Mohammed et al. found that families with children born with Down syndrome exhibit lower levels of psychological well-being compared to families without children with Down syndrome. These families may experience increased stress, anxiety, and depression due to the additional care and support needed for the child.

According to Povee et al. (2012), functioning of a family indicates the relationship within a family. Relationship between parents, between the parent and the child with Down syndrome, between the parents and the siblings of the child with Down syndrome. Family functioning is not only the relationship within the family, rather it includes the daily activities families engage in. There are both positive and negative impacts on the family when a child is born with Down syndrome. The negative impact can be listed as, the whole family tends to revolve around the child with down syndrome due to this there is less attention given to the sibling and also might be a cause for not having a spontaneous lifestyle for the family. The other points were raised as social isolation of family members, strained marriage of parents due to lack of time as a couple,

the financial strains due to medical costs, the stress that arise by thinking about the fate of the child with down syndrome for the future. On the other hand the positive impact was most parents replied having a child with Down syndrome shapes the values they have and brought a positive environment to the family, teaching them to be more compassionate and empathetic. In addition to the impact on family functioning, the presence of a child with Down syndrome in the family can also have an effect on the mental health of family members.

According to the study by Skotko, Levine, and Goldstein (2011), due to the stress associated with caring for a child with special needs, mothers are likely at increased risk of experiencing depression and anxiety compared to other mothers with typically developing children. Similarly, Saloviita, Itälinna, and Leinonen (2003) explained the parental stress of fathers and mothers caring for a child with intellectual disability using the double ABCX model. The ABCX model was explained as; (A) stands for the stressors and strains, (B) stands for the family resources for meeting the demands, (C) stands for the meaning the family assigns to a situation, (X) stands for the family crisis and adaptation for post crisis. Among the components affecting the family functioning, based on the ABCX model; the "C" component stood out as the predictor of parental stress, which is the negative definition of the child's situation, meaning considering it as a catastrophe.

According to Bourke et al., (2008) it has been identified that parents of children with developmental disabilities experience a higher level of stress, mental problems and family problems compared with parents of healthy children. Mothers with Down syndrome children experience poor mental health and stress. The stress level of mothers is mostly associated with the behavior of their children. The higher the dependency rate of the child the higher the stress level of the mothers. The study conducted by Kózka & Przybyła-Basista, (2018) assumed that

psychological well-being to be a significant factor in the process of maintaining their mental health. According to their findings, perceived social support from family members and friends was an important determinant of parents' psychological well-being.

Durmaz, Cankaya, Durmaz, Vahabi, Gunduz, Cogulu, & Ozkinay, (2011) conducted an Interview with parents of children with Down syndrome in order to determine their perceptions and feelings. It showed the effects of having a Down syndrome child, the characteristics of the family and the causal factors. The results showed different facts; first, Down syndrome is observed mostly in low socioeconomic families and financial problems are also common. Second, most of the time mothers feel guilty, accusing themselves of finding a justification for the condition. Third, mothers are observed to be more responsible compared to their parents. Fourth, there is a high rate of unemployment among mothers when compared to fathers this might be due to two reasons; the traditional assumptions stating mothers should be the ones who look after their children, while fathers are responsible to meet the total income of the family and the other reason is the attachment of mothers with their child is stronger by spending more time. The fifth point is that mothers show a high level of stress and poor health when compared to fathers. Based on the study that was made determining family needs of mothers of children with Down Syndrome by Toker, M.et al., in 2008, mothers of children with Down syndrome have specific expectations as caregivers. They desire better education, increased support from specialists for their child's development, social activities, information and right understanding on explaining Down syndrome to others, and financial aid for their child's education.

According to Owoade Philip Adeleke, James Abua Ewa, James Eburikuri Olayi and Samuel Orim Orim, (2020), Intellectual disability has a significant impact on family. Among the result findings, having a child with intellectual disability has an effect on the siblings in the

family. The term resource dilution states that any given family possesses its own resources, so if there is only one child in the family, that child receives all the resources without having to share it. In larger families, the resources must be disintegrated so that each child gets some amount of resources. When a child is born with intellectual disability in a larger family there are disadvantages that are observed from the sibling's point of view. Parents have less time to spend with their siblings, decreased number of family activities, lower financial resources, increased caregiving responsibilities placed on siblings, and lower peer acceptance of siblings in the society. All the points stated affect the sibling's education, emotional status, health relationship with parents and social acceptances.

Weldeab, Chernet Tekle & Opdal, Liv Randi, (2007), completed qualitative study in raising a child with intellectual disability in Ethiopia. The data shows that most parents associate the condition of their child as a curse or punishment from God. This assumption leads them to a wrong perception where everything is beyond their control. Socio cultural impacts are highly influential in the lives of the families of intellectual disability. It's very common that children with disabilities have been hidden at home by their caregivers, kept away from social gatherings, schools and intervention programs due to the fear of the society's perception. It shows there is much work to do regarding families with intellectual disability such as empowerment and working towards inclusivity.

2.5. Theoretical framework

For the purpose of this study, the family systems theory is suitable among various theories. It is particularly relevant because it focuses on the family as a unit or a complex social system where members interact and influence each other's behavior. Family systems theory regards the family as the central environment emphasizes that where individuals develop and

strengthen their characteristic traits and behavioral patterns. According to this theory, symptoms exhibited by individuals are perceived as part of a series of interactions within the family unit (Johnson & Ray, 2016).

2.5.1. Family systems theory

Family systems theory was developed by several key contributors in the field of psychology and family therapy. While it is difficult to attribute the theory to a single developer, Murray Bowen is often recognized as one of the primary founders of family systems theory. The origins of Bowen Family Systems Theory (BFST) can be traced back to the 1950s. During the period from the 1950s to the 1970s, there was a notable shift in the field of clinical psychology, moving away from an exclusive focus on individual psychology towards a more relational and systemic perspective. Bowen played a prominent role in leading this paradigm shift, alongside other influential clinicians and scholars (Calatrava et al., 2022).

Bowen's theory encompasses a set of eight interconnected states that outline the persistent and enduring emotional tension found within family relationships. Family system theory concepts highlight the interconnectedness of family members, emphasizing that the family as a whole is more significant than its individual parts. These concepts recognize that any change or impact on one family member reverberates and affects all other members, ultimately influencing the overall balance and stability of the family system (Haefner, 2014). The central idea of Bowen's theory revolves around the concepts of the eight major ideas. These terms describe an individual's capacity to establish a distinct sense of self separate from their family of origin, both in terms of personal identity and intellectual perspectives (Bowen, 1978). Bowen's theory comprises eight key concepts, which are described as follows:

2.5.1.1. Differentiation of self

The first concept is the self-determination which states that the family is most influential in developing a sense of self. The term Differentiation is the individual's capacity to effectively integrate opposing and fundamental drives related to thinking and feeling. It involves finding a balance between these contrasting aspects within oneself. The poorly differentiated self requires approval from others, and in the reverse a well-differentiated self can handle conflict and criticism separate from the family (Bowen, 1978). Psychological fusion, observed in both individuals and the family as a whole, is a reflection of the level of differentiation. In familial fusion, there is a demand for individuals to sacrifice or modify their authentic sense of self in order to maintain a sense of togetherness within the family (LPC, 2011).

Bowen frequently discussed his extensive application of the concept of differentiation of self in his personal life.Through his personal journey of self-transformation and his dedication to developing, applying, and embodying the theory, Bowen refined the concept of differentiation of self (Titelman, 2014). The concept of self-differentiation highlights the capacity to separate innate emotional responses from thoughtful and deliberate decision-making. As the process of differentiation progresses, it leads to the establishment of a fundamental self that remains relatively stable. Both natural self-determination and intentional differentiation depend on the individual's ability, or lack of ability to distinguish their instinctual emotional reactivity from purposeful actions (LPC, 2011).

At the nuclear family level, differentiation in Bowen's theory pertains to the different ways in which family members demonstrate their emotional connectedness and individuality. Bowen referred to this as the nuclear family emotional system, which encompasses the patterns

exhibited by family members as they navigate their emotional unity while managing the interplay between the forces of togetherness and anxiety (Titelman, 2014).

2.5.1.2. Triangles

The second concept is the Triangles, a relationship involving a third individual that has the ability to stabilize a two-person system that is experiencing anxiety. When tension arises between two people, bringing in a third person can relieve anxiety (Bowen, 1978). Triangling becomes problematic when the involvement of a third party distracts the members of a dyad from resolving their relationship issues. Similarly stated by Titelman (2012), interlocking triangles have the ability to transfer anxiety away from the original anxious pair towards the most vulnerable individual within the emotional system, however the discomfort within the system does not disappear because the anxiety stemming from the original pair has not been resolved; it has merely been masked.

According to LPC (2011), triangles are a fundamental aspect of human interaction and can be observed in various contexts such as family systems, work environments, and societal systems. It is emphasized that triangles exist within families and are entrenched in emotional patterns that persist across generations. As new family members enter the system, they assume the functional positions in triangles previously occupied by their ancestors. The triangle concept in Bowen's theory is applicable to understanding the relationships among all members of a family, both within the nuclear and the extended family, throughout their lives. Titelman (2012) highlights that while the triangular processes within families are constantly changing; there are also recurring patterns over time where individuals often develop fixed positions in relation to one another.

2.5.1.3. Nuclear family emotional system

The Nuclear family emotional system is the predominant family structure in the United States during the 1950s, and was characterized by two adults and one or more children. This form of family organization represents an emotional system that encompasses a two-person relationship between the adults, along with the addition of a third person to create an emotional triangle. The emotional triangle serves as the essential unit within the emotional system (Alzoubi, 2018).This concept pertains to the emotional dynamics within a particular generation and the symptomatic patterns that arise due to the excessive fusion of individuals' emotional patterns, which reflects their limited level of differentiation. Four basic patterns of emotional functioning in a single generation are marital conflict, dysfunction in one spouse, impairment in one or more children, and emotional distance (Bowen, 1978). It encourages to carefully study the history of present generation patterns and reconstruct past generation patterns of emotional functioning, because these patterns will predict the same patterns for future generations (Titelman, 2014).

The lack of differentiation of self, which refers to the inability to distinguish between thoughts and feelings, within the nuclear family (consisting of the father, mother, and children) gives rise to four distinct patterns or mechanisms of emotional functioning. These patterns include emotional distance, dysfunction within one spouse, conflicts within the marital relationship, and impairment of one or more children (Bowen, 1978).

Emotional Distance: The expression of distance within a relationship involves both external and internal moves. External moves refer to actions taken to physically or emotionally distance oneself from the other person. On the other hand, internal moves involve efforts made to maintain emotional separation or a sense of distance between individuals (LPC, 2011, p.45).

According to Bowen (1978, p.203), Based on the relationship patterns established by each spouse in their respective families of origin, these patterns are likely to persist within the nuclear family and may lead to conflicts within the marital relationship.

Dysfunction within one spouse:In this type of marriage, one spouse takes on a submissive role while the other assumes a dominant role in an adaptive manner. Both spouses may believe they are adjusting to each other, but the one who adapts more extensively loses their sense of self, becoming dependent on the other for their thoughts and actions (Bowen, 1978, p.204).As highlighted in LPC (2011, p.45), one spouse in a relationship tends to over-function, taking on excessive responsibilities, while the other spouse adapts by under-functioning. This pattern continues until the adaptive spouse becomes vulnerable to physical or emotional dysfunction.

Conflicts within the marital relationship: In conflictual marriages, a fundamental pattern emerges where neither spouse is willing to compromise on major issues. These marriages are characterized by a high level of intensity, with both partners investing a significant amount of energy into the relationship . In this situation, neither spouse is willing to yield or adjust to accommodate the other's wishes or needs (Bowen, 1978, p.204). In the majority of marital conflicts, there is no clear adaptive-dominant spouse, but rather both spouses direct their energy towards each other. Additionally, within this dynamic, children are likely to become involved or drawn into the conflict as a way to reduce emotional intensity (Alzoubi, 2018).

Impairment of one or more children: This is the scenario in which anxiety and sensitivities accumulated over generations are projected onto one or more children by their parents.In this situation, parents project their inability of differentiation onto one or more of their children (Bowen, 1978, p.204).

2.5.1.4. The Family projection process

According to Bowen (1978), parents pass their emotional problems to their children, and children inherit strengths and problems from parents. The fundamental pattern in this scenario consists of a mother whose emotional system is more centered around the children rather than her husband, and a father who is sensitive to his wife's anxiety and actively supports her emotional involvement with the children. Primarily address the process of projection specifically pertaining to the parent-child relationship. The child who displays the strongest emotional attachment to a parent is the most susceptible to the projection process. This pattern is frequently observed in situations where the child is an only child, the oldest sibling, the only child of a particular gender among siblings, or a child with physical or mental disabilities.

Family projection is present in every family to varying degrees and serves as a mechanism for managing anxiety. Parental anxiety manifests in various ways, but the most common manifestation is seen through an excessive focus on a child, being overly attentive and doing tasks for the child that they can handle independently and reacting excessively to the child rather than responding in a realistic manner. In all instances, the anxiety originates from either the mother or father, and the child actively participates in reciprocating and perpetuating the cycle of anxiety.

2.5.1.5. The Emotional cut-off

Emotional cutoff refers to the emotional distance that individuals establish to manage the discomfort associated with their emotional attachment to their parents. Intense emotional fusion between parents and children can give rise to chronic anxiety, leading individuals to disregard the significance of their parental family. The function of this fusion is to ensure that individuals

remain closely attached to the nucleus of the nuclear family, usually their parents. Emotional cutoff takes on different forms, such as extreme emotional distance, internal detachment, or geographical separation (Titelman, 2014). Family members who are unable to effectively address their unresolved emotional issues with parents or other family members, completely disconnect themselves physically or rarely return home (Bowen, 1978).

As explained by Titelman (2014), emotional cutoff can be categorized into two types: primary and secondary emotional cutoff. The primary emotional cutoff pertains to the mother-father-child triangle, focusing on the relationship between the child and one or both parents. On the other hand, the secondary emotional cutoff occurs within the second triangle, involving the individual, their siblings, and other extended family members. The primary emotional cutoff primarily concerns the child's connection to their parents, while the secondary emotional cutoff relates to the individual's interactions with their siblings and other family members.

2.5.1.6. The Multi-generational transmission process

In this context, Bowen's theory hypothesizes that the level of functioning within a nuclear family is influenced by the stability or functioning of previous generations. Over the course of multiple generations, there is a gradual differentiation between parents and children, which takes place through both conscious teaching and unconscious influence on the children's development. Children acquire patterns of emotional processing that are similar to those of their parents, with slight variations (Bowen, 1978). It explains how the capacity to form positive and close connections with others can be transmitted across generations within the family structure. The term "multigenerational" is referred to as the strategies that center around three or more generations. According to multigenerational theorists, individuals carry unresolved emotional reactions from their parents, which makes them susceptible to repeating the same patterns in

subsequent relationships. Addressing these unresolved issues is crucial for fostering personal development within the context of their multigenerational family system (Skowron et al., 2015).

In 2019, Keller and Noone conducted a study to investigate whether the functioning level of a multigenerational family would be transferred to a nuclear family unit at a similar level. The researchers tested the hypothesis and found that the results supported the idea of multigenerational transmission. The study revealed that the level of symptomatology or functioning in different generations, particularly in the nuclear family of origin, was associated with the functioning level in the developing nuclear family. The research further indicated that the association between multigenerational and developing nuclear family functioning was stronger when the analysis focused exclusively on members of the nuclear family of origin (Keller & Noone, 2019).

2.5.1.7. The Sibling position

Bowen did not originate the concept of sibling position; instead, he borrowed it from Toman in 1969, because he believed that this concept would address a gap in his theory. Sibling position refers to the idea that the personality profile of each sibling position provides insight into the expected characteristics and functioning of siblings. It outlines the characteristics of the oldest, middle, and youngest siblings, as well as the dynamics between these positions and their parents and siblings who hold reciprocal positions. The level of differentiation among family members influences how rigidly these positions are manifested (Bowen, 1978).

According to Morgan& Christopher (2022), data from participants was analyzed to investigate the connection between sibling positions and leadership qualities. In the study, the Bowenian theory that described leadership traits was used. The findings revealed that first-born

individuals displayed greater leadership characteristics on both inventories compared to individuals who were born later in the birth order, but not compared to only children. Additionally, it was observed that first-borns tended to have higher leadership scores when they had younger siblings who were close in age, while younger siblings had higher leadership scores when they did not have older siblings who were close in age.

2.5.1.8. Societal regression

In Bowen's view, societal conditions reflect the anxiety and stress present in familial contexts. As families experience prolonged and intensified anxiety, they revert to a lower level of functioning. Likewise, when a society faces persistent stressors, such as population expansion, depletion of natural resources, and environmental pollution, it also demonstrates a comparable backward effect on the family (Bowen, 1978).

Summary

In summary, the reviewed literature highlights the general overview of Down syndrome, historical development of down syndrome, prevalence and incidence of down syndrome, factors influencing families with Down syndrome, as well as the theoretical framework. While some studies explore the impact of Down syndrome on families with Down syndrome, significant gaps remain, particularly in the context of developing countries like Ethiopia. These gaps include a lack of culturally relevant research, and limited studies focusing on the family unit as a whole.

To address these gaps, the next chapter presents the research methodology, explaining the approach and the methods used to investigate these issues within the Ethiopian context.

CHAPTER THREE

Research Methodology

This study explores the impact of Down syndrome on families with Down syndrome children registered at Deborah foundation. The methodology section includes the research design, study subjects, eligibility criteria, sample size, sampling methods, method of data collection, data quality assurance, and the data analysis.

3.1. Research design

This study uses a qualitative research design, which has a descriptive purpose. It is a qualitative institutional based cross sectional descriptive study. Qualitative research is appropriate for this study because it allows us to understand the experiences, perspectives and attitudes of a group of people (Colorafi & Evans, 2016). Qualitative data is mostly used to give meaning out of the data that we have.

The study is conducted in Addis Ababa, the capital city of Ethiopia, which comprises 10 sub cities. Addis Ababa city encompasses a few non-governmental organizations that work on intellectual disability. Deborah Foundation is one of the few non-governmental organizations found at Addis Ababa located around southeast of the city near Denbel Tower. The foundation's core activities include education, health, and policy advocacy, aiming to create an inclusive environment for children with intellectual disabilities.

It offers educational programs, physical and behavioral therapies, family information sessions, and medical screenings for children born with Down syndrome. Additionally, the organization engages in awareness-raising initiatives and provides free medical screenings for

families facing financial difficulties at certain intervals. The main headquarters is in Bole, with the secondary location currently under construction in Legetafo that includes school and therapy center. During the time of the interview1, 786 families were registered to receive services from the foundation. The organization registers families to receive various services. The registration process requires a medical certificate from a hospital confirming that the child has an intellectual disability, a photograph, and completion of a questionnaire to gather comprehensive information. There is no fee for registration. Although it is challenging to meet the needs of such many families who are registered, having the current resources available to the NGO, the organization continues to work toward expanding its capacity. There is a team of qualified professionals, including both medical and educational experts who are giving services. These professionals include psychologists, medical doctors, psychiatrists, physiotherapists, and others, working together to provide comprehensive care and support.

3.2. Research area and study setting

The study is conducted in Addis Ababa, the capital city of Ethiopia, which comprises 11 sub cities. Addis Ababa city encompasses a few non-governmental organizations that work on intellectual disability. Deborah Foundation is one of the few non-governmental organizations found at Addis Ababa located around southeast of the city near Denbel Tower. The foundation's core activities include education, health, and policy advocacy, aiming to create an inclusive environment for children with intellectual disabilities.

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3.3. Eligibility criteria

3.3.1. Inclusion criteria

The participants are families with down syndrome children who are receiving services from Deborah Foundation. Among the families the research focuses on early school age children from a range of 4- 10 years of age. This age is chosen because it represents the early school-age period, a critical developmental stage for children with Down syndrome. During this time, children are transitioning into formal education and require significant support for their social, cognitive, and academic development. This stage also places unique demands on families, particularly primary caregivers such as mothers, fathers, and siblings, who play a central role in supporting the child's growth. The study includes mothers, fathers and siblings who are primary caregivers of the children.

3.3.2 Exclusion criteria

There are several families with children born with different kinds of intellectual disabilities, including Down syndrome. Families who have a child with a disability other than Down syndrome are excluded from the study. The second exclusion point is families with children out of the range of 4-10 years of age. The third exclusion criterion is any families with Down syndrome children that are not registered at Deborah foundation.

3.4. Sample size

The sample size for this study was determined using data saturation. The data saturation occurred when similar information starts to be observed from the data collected. In the In-depth interview 14 participants were involved. For this study, a total of 14 participants were involved in the in-depth interviews, providing individual insights on their experiences. The in-depth interview was conducted privately; for each individual to share their true experience. Additionally, 5 participants took part in 1 focus group discussion (FGD), discussing shared experiences. The focus group discussion took about 40 minutes. Furthermore, 5 key informants were interviewed to provide professional perspectives. This sample size was considered sufficient as saturation was achieved, ensuring comprehensive and diverse data to address the research objectives.

The data saturation is a state where new findings consistently repeat the previous ones. Saturation is reached when new analytical insights are not seen anymore. This is the point where no new insights would be obtained (Yin, 2003).

3.5. Sampling method

Nonprobability sampling is used in qualitative research for different range of sampling strategies. It has an aim of producing a sample which represents the statistics. The sample units are chosen purposively, because it can provide detailed information. Nonprobability sampling is suitable for in depth and small scaled studies. Purposive sampling is one of the non-probability samplings, where the sample frame provides information that is required (Yin, 2003). The purposive sampling also known as the Judgmental sampling; the researcher includes participants in the sample because it is assumed that they justify the inclusion. The purposive sampling is preferred for explanatory research design (Taherdoost, 2016).

Deborah foundation is selected purposely because the organization is working mainly on children born with Down syndrome. Moreover, the nonprofit organization focuses on providing different services such as education, health, and policy. It also thrives to create a better environment for children born with Down syndrome as well as their families. Due to this reason, to get an information about the impact of down syndrome on families Deborah foundation is a convenient place. The participants are selected through purposive sampling, which ensures that the sample includes families with a range of experiences and perspectives with an age range of 4-10 years. The sampling method in this study is achieved by identifying the participants based on the inclusion and exclusion criteria.

3.6. Method of data collection

The data is collected through semi- structured interviews with participants, based on the objectives of the study. The semi structured interview combines balanced structured and unstructured interview. The primary data source is an interactive interview with the participants. In-depth interview is conducted with the person acquiring the emic knowledge

The interview is conducted by Amharic. To grasp all the information the interview was recorded with the participants consent. The interview is guided by a set of open-ended questions where it allows participants to share their experience and their own world view. The place where the interview took place is a private and comfortable setting to ensure the participant's comfort to share the true experience they had. Key informant interviews were also conducted to get an overview of the service given at Deborah foundation and the professional point of view regarding the families.

Focus group discussion is also conducted to understand the common grounds and the different points that are forwarded. The discussion was among the families with Down syndrome children with an age range of 4-10 years, it was guided to reach a point of an agreement or a disagreement.

3.7. Data quality assurance

Triangulation is used in this study to check the quality. This is where we check data coming from one data source to another data source. Here we compare and contrast the data that comes from one source to another.

3.8. Data analysis technique

The data collected from interviews is transcribed and translated into English. Data is analyzed by thematic analysis; themes related to the impact of having a child with Down syndrome on families are identified. Based on the data from the interviews and FGD, the data was analyzed and main themes were identified.

1. Data Collection

The data was collected through semi-structured interviews and focus group discussions (FGDs) with families who have children with Down syndrome, including mothers, fathers, and siblings.

2. Recording

All interviews were audio-recorded with participants' consent to ensure accurate capture of responses.

3. Transcription

The recorded audio was transcribed verbatim by a professional transcriber to ensure accuracy. All spoken words, including pauses, laughter, and non-verbal cues, were noted to preserve the context of the conversation."

4.Translation

Interviews were conducted in Amharic language, the transcriptions were translated into English to facilitate analysis, ensuring the accuracy of the meaning was maintained throughout the process.

5.Verification of Transcriptions

Once transcribed and translated, the transcripts were cross-checked to ensure accuracy and consistency with the original recordings.

6.Analysis

The final transcriptions were organized in a word format, coded for confidentiality, and prepared for thematic analysis by identifying sections relevant to the study’s research questions. Then Data analysis was done, based on the analysis 7 themes were identified.

3.9. Ethical Consideration

Ethical clearance from Deborah Foundation and permission from school of social work and a written consent of participants was obtained before the data collection. Regarding the participants consent assures their willingness. The consent form contains all the information they need to know about the purpose of the study, the use of the study, the rights they have regarding the research and so on. The second part of the document contains the part where they should sign, to assure their willingness to participate in the research. Respondents are assured about the confidentiality of the respondents. Participants are not mentioned on the data collection forms, rather numeric codes are used to identify the questioner.

CHAPTER FOUR

Findings

4.1 Introduction

This chapter of the research paper presents the results and analysis obtained from the study that examines the impact of raising a child with Down syndrome on families in Addis Ababa. Specifically, the study focuses on families registered at the Deborah Foundation, with children in the age range of 4 to 10 years. The primary objective of this research is to explore and understand the effects experienced by families who have a child with Down syndrome.

Within this chapter, a comprehensive understanding of the collected data is provided through various research methods, including in-depth interviews, observations, and input from key informants. These methods were employed to gather diverse perspectives from the families, enabling a thorough exploration of their experiences and challenges. The key findings are highlighted and their implications within the context of the research problem are discussed. The chapter sheds light on the research questions and objectives that guide the study. These findings serve as the foundation for drawing conclusions, making recommendations, and contributing to the existing knowledge on the impact of Down syndrome on families in Addis Ababa. Additionally, this chapter aims to encourage further discussions and serve as a basis for future research endeavors in this field.

4.1.1 In Depth Interview

The in-depth interviews served as a means to gather rich and detailed information about the impacts of down syndrome on their families based on their individual perspectives. There were 14 participants who represented a diverse range of backgrounds, ensuring a comprehensive exploration of the research area. Their participation was voluntary, and all participants provided informed consent prior to the interviews. Participant codes were also used to protect the privacy and confidentiality of the individuals involved. Through open-ended questions and attentive listening, a comprehensive understanding of their perspectives was obtained. The insights gained from these interviews contribute significantly to the findings and analysis presented in this research.

Socio demographic information (Personal data of the participant)

Participant	Relationship with the child	Age	Sex	Religion	Marital status	Educational Level	Monthly Income	Number of children in the house	General number of people in the Household
P1	Mother	45-54	F	Christian Orthodox	Divorced	Secondary school	Low Income	2	3
P2	Mother	35-44	F	Christian Protestant	Married	Secondary School	Low Income	2	4
P3	Mother	55 and above	F	Christian Orthodox	Married	Secondary School	Low Income	3	5
P4	Mother	45-55	F	Christian	Married	Primary School	Very Low	3	5

				Protestant			Income		
P5	Mother	45-55	F	Christian Orthodox	Divorced	Primary School	Very Low Income	4	5
P6	Mother	25-34	F	Christian Orthodox	Divorced	Secondary School	Very Low Income	1	2
P7	Sister	18-24	F	Christian Orthodox	Single	Secondary School	Middle Income	6	8
P8	Mother	18-24	F	Christian Orthodox	Divorced	Secondary School	Very Low Income	1	2
P9	Mother	25-34	F	Christian Orthodox	Married	Secondary School	Very Low Income	2	3
P10	Sister	25-34	F	Christin Orthodox	Single	Diploma	Low Income	4	6
P11	Mother	25-34	F	Muslim	Divorced	Primary School	Very Low Income	1	3
P12	Mother	45-54	F	Christian Orthodox	Married	Bachelor's Degree	Middle Income	2	3
P13	Father	45-54	M	Christian Orthodox	Married	Secondary School	Middle Income	2	4
P14	Mother	45-54	F	Christian Orthodox	Married	Bachelor’s Degree	Low Income	2	4

Information related to the child

Participant	Age of the child with down syndrome	Sex of the child with down syndrome	The birth order rank of the child with down syndrome
P1	8	Female	Middle Child
P2	9	Male	First Child
P3	10	Male	Last Child
P4	5	Female	First Child
P5	10	Female	Last Child
P6	7	Female	First Child
P7	7	Male	Middle Child
P8	4	Female	First Child (only child)
P9	4	Male	First Child
P10	10	Female	Last Child
P11	8	Male	First Child (only child)
P12	7	Male	Last Child
P13	9	Male	Last Child
P14	7	Female	Last Child

4.1.2 Key Informant

There were 5 key informant participants in this study, they played a crucial role in providing insights and specialized knowledge related to the topic. They were selected based on their experience working at Deborah foundation, having connections with families with down syndrome and the children themselves, their participation in this research was considered

valuable. The inclusion of key informants aimed to enhance the understanding of the topic by incorporating perspectives from professionals, who possess specialized knowledge in the field.

Participants	Sex	Educational Background	Occupation	Experience
K1	M	Medicine	Doctor	4 years
K2	F	Medicine	Doctor	3 years
K3	F	Educational Psychology	Education, Special needs Expert	3 years
K4	F	Phycology	Special needs Teacher	5 years
K5	M	Physiotherapy	Physiotherapist	2 years

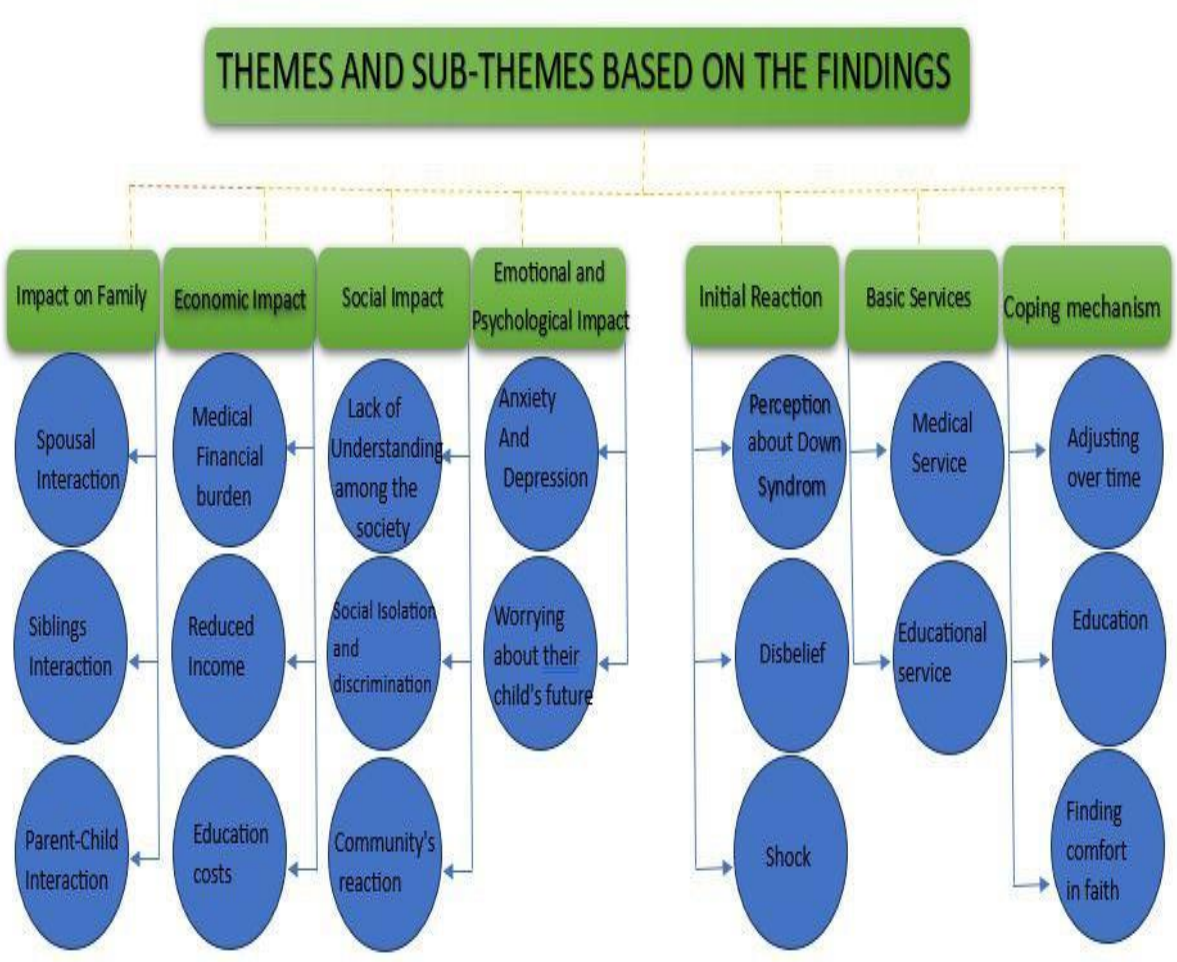
4.1.3 Focus Group Discussion

There was 1 focus group consisting of 5 participants, the focus group was held in a classroom separately to help create an environment of openness. The families were families who registered at Deborah foundation, to get services provided by the organization.

Participant	Relationship with the child	Age	Sex	Marital status	Educational Level	Monthly Income	Number of children in the house
P1	Mother	45-54	F	Divorced	Secondary school	Low Income	2
P2	Mother	35-44	F	Married	Secondary School	Low Income	3
P3	Mother	55 and above	F	Divorced	Secondary School	Low Income	1
P4	Father	45-54	M	Married	Degree	Low Income	2
P5	Mother	35-44	F	Married	Primary	Low Inc	1

4.2 Themes Identified by the research about Impact of Down syndrome

1. Initial Reaction
2. Coping mechanism
3. Emotional and Psychological Impact
4. Social Impact
5. Economic Impact
6. Impact on Family Interaction
7. Basic Services



4.2.1 Initial Reaction

4.2.1.1 Perception about Down Syndrome

Based on the finding, it seems that a lot of families are not very knowledgeable about Down syndrome when their child is first born with the condition. Many parents appear to be unaware or lack significant understanding about Down syndrome initially, when their child is delivered.

For instance, here are some of the participants who mentioned they were unaware of Down syndrome. “When I was first told that my daughter was born with Down syndrome, I had no idea what it was. So, when they told me that Down syndrome is a mental retardation, I was very sad, shocked, and cried a lot” (IDI, P1). “I didn't know what it was when I first heard about it” (IDI, P2).“At first I couldn't see anything except for crying and it was very difficult because I didn't know what Down syndrome was.” (IDI, P9)

When parents lack knowledge and understanding about a particular topic, especially when they are responsible for the well-being of their child, it can lead to a state of confusion. This confusion arises from their limited understanding and may cause them to perceive things incorrectly. In the context of raising a child with Down Syndrome, this lack of knowledge can be particularly challenging.

Here is a mother who didn't have the right understanding about down syndrome, thinking that the fate of her child with down syndrome was death, and it was the result of her own fault. “They said it might be down syndrome, but they didn't confirm it, and I didn't know what it was

for a long time, so I thought she would have died after birth. At first, I thought it was my fault so I blamed myself" (IDI, P14).

In addition to this, the results show that not only is the perception of the families wrong but also there is a lack of full understanding and explanation expected from the health professionals. Down syndrome is a condition that can be identified at birth or even before birth, but the lack of examination and knowledge of some of the health professionals is identifiable.

Participant 1 is a mother who was explaining about how they didn't get any kind of information regarding their child's condition from health professionals until she was 1 years old. Participant 6 is also another mother who encountered a similar condition, she was not given any kind of information until her child turned 2 years old. "When she was born we didn't get any kind of information related to her condition; we did not know she was born with down syndrome. When she was one year old, we took her to Black Lion Hospital because she was sick with tonsils. They told us about her condition that time, and later she was referred to Menelik Hospital. But since she was a baby, she often stuck out her tongue, so I had questions about that, but I didn't have any information" (IDI, P1). "No one told me about her condition when she was born, I didn't know anything until she was 2 years old because I had no information about her condition…" (IDI, P6)

Similarly participant 8 was also stating that due to the lack of proper examination and knowledge among the health professionals, even though she used to follow up there was no clear information given from the nurse. "They didn't tell me about her condition when she was born, even after that we went to the hospital several times because she used to get sick frequently. There was a nurse who prescribed her medications but still she didn't tell us she was born with

down syndrome. Later on when her condition was not getting any better we took her to another hospital, where they told us about her condition." (IDI, P8)

Another Mother explained that the information she got from the health professionals was vague and when they explained the condition using their own medical language which made things more complicated, due to this reason she started to explore and understand things on her own. "I was not given any advice at the health center level at first, they passed it easily. What I decided to do by myself after I knew about her condition was to do things on my own, for instance makes him move, talk, etc. In terms of treatment, I didn't get anything at the health center; it was by the help of God and by my own initiatives. At the hospital, they usually talk about my child's condition using their own medical language which I cannot understand. I try to understand what they are talking about by usually grasping one or two words and I translate it using my own understanding" (IDI, P3)

4.2.1.2 Disbelief

The data indicated that the news of the child being born with Down Syndrome left families feeling disoriented and unsure of what to think or do. They even question whether the diagnosis is accurate, wondering if there has been some kind of mistake. This sense of disbelief is amplified by the fact that many families don't have much prior knowledge or understanding about Down Syndrome.

One mother expressed how she felt when she heard about the condition for the first time and stated the disbelief she was in, "I didn't know what it was when I first heard about it. When they explained it to me, I couldn't believe it, and I couldn't accept it. When they first told me, I was

very hurt. I cried a lot at that time, and after that I went to many places thinking he would be cured." (IDI, P2)

The other reason for the disbelief might be families having a certain vision or dream in their mind about what their child will be like. But then suddenly, they are faced with a reality that is completely different from what they imagined, this also leads them to a state of disbelief. Below is a mother who could not believe the situation, "It was so hard to believe!!! I didn't know about her condition until she was 2 years old, but since she was diagnosed, I couldn't accept it and on top of that as a single mother it was hard to deal with her condition." (IDI, P6)

Similarly, here is a father with a child with down syndrome, he precisely stated his family's disbelief when they heard about the condition of their child being born with Down syndrome. We encountered disbelief and shock. (IDI, P13)

4.2.1.3 Shock

One of the initial reactions that have been mentioned by the families who were interviewed was shock. It is mostly caused by something which is unexpected. I have observed from most of the conversations with families with down syndrome children, before a baby is born families probably have a very clear idea in their minds about what their child would be like. But now when the child they expected and the child they had becomes different, most of them get shocked. When families find out their newborn baby has Down Syndrome, it can be a total shock to them because for most of them this news is completely unexpected and overwhelming. Here is a mother who states that she was shocked when she heard that her daughter was born with down syndrome and didn't know what to think next. "I was in shock when I heard the news, I didn't even know what to think." (IDI, P8)

Another mother who heard the news from the health professionals also recalled that she was in a deep shock. “The doctors told me that he is going to start walking slower than other children and will have a delay in his development, so we were responsible to give him the proper care and support. They also explained to me that it happens naturally, but I was very shocked, worried and upset” (IDI, P11). “There were no clear indications about the feelings of the other family members, but it was clear that everyone was heartbroken and worried about the situation. But it is not as bad as we first thought. When we first heard about his condition, I didn't think he would be able to walk or do anything on his own, so due to this my husband and I used to find information more about the case and try to find different solutions. My husband by his own also tries different things to make things better.” (IDI, P12)

Similarly, here is a father who expressed the family’s initial reaction including his own. At that moment, the news felt so abrupt and unimaginable that the families were unable to formulate a coherent response or plan of action. We can understand that the families seem to have been overwhelmed by the news they heard which led them to shock. “The whole family was in shock; the mother also had a similar reaction” (IDI, P13)

One sibling that was interviewed in an in-depth interview said this: “At first, we were shocked, but then we received it with grace.” (IDI, P10)

Different families have stated that their initial reaction was shock, including the sister that has been mentioned above. One thing she added was the family received it with grace; it is an expected reaction to be shocked after hearing the news but then the question leads to “then what's next?

4.2.2 Coping mechanism

The coping mechanisms observed within families who have children born with Down syndrome are both diverse and unique, reflecting their individual experiences and circumstances.

4.2.2.1 Adjusting over time and self-convincing

There are families that avoid the challenges they are facing. Rather than addressing and confronting their concerns regarding their child's condition, some families choose to disregard them. One of the key Informants perceives reluctance and unwillingness to engage with the challenges associated with down syndrome. “More often than not, they would resort to avoidance. Most families that I have encountered actively choose to disregard patent concerns. I feel like they usually demonstrate a sense of hopeless abandonment towards the issue and avoid dealing with it all together” (key informant1)

On the contrary, as a parent acknowledges that the process is hard, which is a fact but can accept it in a healthy manner by adapting and adjusting to the condition it shows their capacity to embrace and adapt to the unique challenges they face. “It's hard. Thank God, I got used to it over time.” (IDI, P9)

In addition to this, here is a parent who demonstrates an emotional and practical coping mechanism towards the challenge she is facing, embracing that having no one to support her raising her child. It is observed that the challenge led her to solely focus on her work to raise her child creating a space where other worries fade away. “Going through this will make you stronger without even wanting it. Thinking that you have only yourself makes you more independent and stronger. And then, focusing only on my work, makes me forget about

everything else. When I started to think that working to raise my children is the main thing, I didn't have time to remember other worries." (IDI, P1)

One person is different from the other, meaning there are people who cope faster than others and there are some who delay accepting the challenge they are facing. Here is a mother who faced difficulty to accept their child's condition for a longer period, due to this reason they even had health consequences. Because of the stress of her child being born with down syndrome, she had been having struggles to accept the situation, through this process she developed diabetes. It is hard to let go or cope with a stressor one faces," It took me a very long time to accept and live with my child's condition. I've only recently been letting it go. I used to worry a lot; I used to get upset because of this I became a diabetic. After I got sick, when the health experts advised me that I shouldn't get upset or else my health would worsen, I had to accept it and let it go." (IDI, P2)

Similarly, another mother also faced health consequences, in the process of accepting her child's condition; "After the birth of this child, I got very worried and angry, and due to this I couldn't sleep at night for a long period of time. Because of this, I have taken medicines prescribed by doctors for my anxiety issue." (IDI, P4)

One of the participants in the in-depth interview also demonstrated a coping mechanism which centers around self-resilience. She convinced herself that she can overcome the challenge by herself even without her husband's help. By adapting this mindset, she exhibited resilience and self-empowerment. "I often face challenges by convincing myself I can do things on my own. I know I can overcome it on my own even if no one helps me. I get out of my stress by listening to other music. I believe that disorder is not only a result of nature caused before a

person is born, but I believe that a person can also be born normal and can develop some kind of disorder, and in all cases, it is necessary to accept that and live with it ” (IDI, P14)

4.2.2.2 Education

According to the key informant, families facing the challenges of raising a child with Down syndrome employ a range of coping mechanisms. Additionally, families cope by educating themselves about Down syndrome, empowering themselves with knowledge and understanding to better support their child. “Families employ various coping mechanisms to navigate these challenges, including seeking social support from other families in similar situations, educating themselves about Down syndrome, and accessing professional support services such as therapy and early intervention programs. They also draw strength from celebrating their child's achievements and focusing on their unique strengths and abilities” (Key Informant 3)

Here are two parents (one is a mother and the other is father) who perceived that their child's condition was caused because of their sins but later they coped with the challenges due to the accurate information they got from health professionals. “First, it is the good advice I get from health professionals. I used to think that it was caused by my sins or because of some kind of default of mine, but then when the health professionals explained to me that it was caused naturally and that it gets better if it was monitored properly, hearing this strengthened me” (IDI, P11). The other participant who is a father of a child with down syndrome also added: “At first, we thought that our child’s condition was caused by our sin against God, but when we learned the teachings, we began to understand more about the situation. It was three years ago. Then,

after we realized that the situation was not caused by anything, we started to do the right thing and convinced ourselves well" (IDI, P13)

In addition, non-governmental organizations working on developmental delays are one of the information sources where accurate information is given for the families with children born with down syndrome. Several families interviewed mentioned that in the journey of raising their child, accurate information given from these kinds of organizations had helped them cope up. One mother stated that upon receiving information from these sources, she was able to convince herself with the right information. By connecting with these organizations, she was able to gain knowledge, validation, and a sense of reassurance, enabling her to navigate the difficulties associated with raising a child with Down syndrome more effectively. "In addition to that, some non-governmental organizations working on intellectual disability would give us advice and training about the families who are in need and, they would provide a platform where families with this kind of children could discuss their problems. I used to get very angry and upset just because of what I saw at home, but then when I hear information from these kinds of sources, I convinced myself with the right information (IDI, P11). Similarly, another participant in the key informant interview stated.: "I remember the time where an organization called Fikir Ethiopia gave us training on intellectual disability for a month and we got a lot of information during that training, for example, what kind of support a child need when he is born with Down syndrome, what Down syndrome was, whether it was a human error or a sin against God. They explained to us well that it is not wrath from God, or it was not caused by any form of sin, and due to this training, our perception about down syndrome was changed" (IDI, P13).

As the finding shows, not only families strive to get reliable information from external sources but also gather information and guidance from online searches. One of the participants in

the in-depth interview, who is a sibling of the child born with down syndrome reported that searching online was one of the coping mechanisms to educate themselves, “Our brother always suggested we search online, in order to know about the condition, especially in the beginning and it helped” (IDI, P10).

4.2.2.3 Finding comfort in faith

Majority of the families expressed their reliance on the faith they have on God as a coping mechanism to manage the associated impact of raising a child with down syndrome. Most of them share that they find comfort in the faith they have. For instance, one of the participants in the in-depth interview mentioned that she has been convinced by God himself and no other about her child's condition; “It's been a long time, and I couldn't accept it. It was only recently that God himself has been convincing me in his own time” (IDI, P9)

Most families emphasized that relying on God was their primary and fundamental way of coping with the challenges they faced. They described how entrusting their worries, fears, and uncertainties to a God brought them a sense of relief. By placing their faith in God, they found comfort in knowing that they were not alone in their struggles and that there was a greater plan at work. This faith in God provided them with a source of strength, hope, and guidance. They mentioned that trusting him is better and casting all the worries on him brought them to find inner peace amidst the stress and uncertainties of raising a child with Down syndrome.

One mother stated that trusting in God has helped her face her problems; “Now that I have cast my heart on God, I have been able to face the problem” (IDI, P2). Similarly, two of the participants in the in-depth interview said that there are no other ways to cope up with this situation, the fundamental and the only way is trusting in God. I have not used any other coping

mechanisms; it is better to trust in God. (IDI, P4).” by focusing on my religion and relying on God” (IDI, P1).

In addition to relying on their faith, families also engage in various religious practices to cope with the challenges they face when raising a child with Down syndrome. Such practice mentioned is the use of prayer and holy water.

Based on the findings, prayer becomes a source of emotional support, enabling families to find inner peace, and a renewed sense of hope as they navigate the complexities of caring for their child. The act of prayer not only strengthens their bond with their faith but also provides a space for surrendering their burdens. “We coped up through persuasion and prayer. Our mother especially is a very prayerful person. I think her faith and strength in prayer made us stronger” (IDI, P10),” Through prayer I find peace (IDI, P6).”

In addition to this, engaging in religious practices like using holy water allows some families to intertwine their religious beliefs with their coping strategies, “At the time I was very desperate. I tried taking her to different traditional medicine places, hoping that she would be cured. I also took her to holy water (Tsebel) places frequently” (IDI, P1)

4.2.3 Emotional and Psychological Impact

Having a child with Down Syndrome brings a multitude of emotional and psychological impacts, as described by the accounts of different families. The weight of these impacts is evident in the emotional struggles they have faced. Families have shared their experiences of anxiety, anger, and stress which have had profound effects on their overall wellbeing in this study.

4.2.3.1 Anxiety and Depression

Here is a mother of a child born with Down syndrome in the in-depth interview, which had a strong emotional and psychological impact. As she described her situation, she used to feel anxious and often got angry and stressed, which even led her to developing diabetes. “It has emotional and psychological pressures. I used to have anxiety, I used to get angry and stressed a lot, and because of that I became diabetic. I also was very sad and cried a lot due to my child's condition” (IDI, P2)

Similarly, there was another mother who participated in the interview, who was profoundly affected in her mental health and overall quality of life due to the challenges of having a child with down syndrome in her family. She experienced heightened worries and anger, which has resulted in the development of insomnia. “After the birth of this child, I got very worried and angry, due to this reason I developed insomnia. Because of this, I have taken medicines prescribed by doctors for my anxiety issue; I have a disease caused by anxiety.” (IDI,P4)

One of the participants said that she is afraid of giving birth afterwards, highlighting the profound emotional and psychological impact, “Being a single mother and her being my first child, it made me feel very vulnerable. I was very anxious, depressed, and just generally hurt. After that time, I am afraid to give birth to another child” (IDI, P6).

Here is a mother who was sharing one of the incidents she encountered in her journey of raising her child who is born with down syndrome, she says that she was deeply hurt by the protest in the school where her child has enrolled “He had a lot of slanderous actions, especially

when they were protesting my son's withdrawal from school. It was very hard for me, and I was hurt.” (IDI, P3)

The other participant also stated that struggling to understand the needs and emotions of the child and the lack of clarity can lead to anxiety and depression. “It’s not the same as raising a normal child. You don't understand what they say, they don't clearly state what they want and feel so this makes you feel anxious and depressed” (IDI, P11)

Similarly, one of the participants is a father of the child with down syndrome, he describes the emotional and psychological impact it had. He experienced a deep sense of emotional pain upon witnessing his child's challenges, leading to feelings of sadness and heartache. “As a father, it hurts your feelings seeing him. Especially in the previous times when I came home from work, it was hard for me to see him. As a father who carries the responsibility, I felt like I had to create a solution and that used to stress me up” (IDI, P13)

4.2.3.2 Worrying about their child's future

The responses from the participants highlight the emotional and psychological impact of raising a child with Down syndrome, emphasizing the ongoing struggles, fears, and uncertainties that parents navigate as they strive to provide the best possible care and support for their child. Here is a mother who persistently worries about the future of her child, expressing feelings of incompleteness and anxiety about what lies ahead. The uncertainty surrounding the child's development, and the challenges associated with their condition contribute to significant emotional distress for parents. “In the end, you don't feel that you are complete, and you worry about the future. I used to cry and worry a lot before, since the time they told me it was mental retardation, it was hard because I didn't know what the future held” (IDI, P12)

Moreover, the fear of not being able to provide continuous care and support for their child in the long term adds to the emotional burden. Families are concerned about their child's independence and well-being once they are no longer present or able to provide direct care. “I worry so much, and I still struggle with it. I wonder what her future will be, this worries me a lot. If I am there, there is no problem for me, but I worry about her fate if I am not around” (IDI, P14)

4.2.4 Social Impact

Families with children born with Down syndrome experience diverse impacts, including social challenges. In this study, many participating families highlighted various social impacts, such as a lack of understanding within society, social isolation, discrimination, and negative community reactions.

4.2.4.1 Lack of Understanding among the society

Lack of understanding among society regarding individuals with Down syndrome remains a significant issue, often leading to misconceptions and barriers. This lack of awareness and knowledge about the condition hinders meaningful inclusion and support for those affected. Due to the lack of understanding, here is a participant who has stated that the social impact on their family is significant. When they go out with their child who has Down syndrome, they often receive comments from different people, with most using the word "ምጥም " to convey sympathy worsens the parent's feelings. As a result, the parent has chosen to limit their participation in social life and primarily spends time alone with their child. This experience highlights the lack of understanding surrounding Down syndrome, leading to a sense of isolation and restricted social interactions for this family. “When I go out with her, there are comments

that come from different people wherever I go; most people think that she is sick, and they feel pity for me. Most people use the word "ምጥም " to express their pettiness, and that makes me feel even more bad so I don't participate much in social life, I'm always with her alone" (IDI, P1).

Another participant also stated that it is challenging for them to go out of the house with their child who has Down syndrome and visit other people's homes. The reason behind this difficulty lies in the perception of others, as people often believe that the child's actions are intentional. "First, it is difficult to leave the house with a child like this and go to someone's house. Because people perceive that my child's doing is intentional, and for instance when he does some kind of fault people don't understand. But the truth is he doesn't have the ability to identify what's right and wrong. People generally don't understand your problem. So now, wherever I go, i prefer going alone" (IPI, P4)

One of the participants also stated that society has limited knowledge about Down syndrome, leading to negative attitudes and exclusionary behavior. This social rejection and isolation experienced by the child and their family highlight the lack of understanding and acceptance within the community. "Society has little knowledge about Down syndrome, for instance people in our neighborhood don't want him to play with their children, parents get angry when their children play with him, and the children despise him" (IPI, P7)

Similarly, the following mother who was interviewed emphasized the need for education and understanding within society regarding down syndrome, because people have different negative views towards down syndrome. "There are people who have different views. Especially at this time, there are people who ask why he doesn't talk or walk" (IPI, P9)

In addition to this, another participant also shared their personal experience with the previous school their child attended, highlighting the prevailing misconceptions and stigma about Down syndrome within society. “In the previous school she was in, there were parents who didn't want to teach their children with children like mine, because they thought that her condition would be transmitted. Society's view still needs some work, we are far behind and still have a lot to do” (IDI, P14).

4.2.4.2 Social Isolation and discrimination

As expressed by a participant, stigma extends not only to the children with Down syndrome but also to their families, “There is stigma, not only for the children but including the family, and this makes you feel inferior; you need to be strong in everything. Not to mention the others, the attitude of some of the medical professionals themselves is distorted. I remember one time; I went to the hospital with my son. At this time, a doctor saw my son and told the other colleagues that he was not going to treat him before he even examined him; that time I was very shocked. I replied to him saying even if my child has intellectual disability, you shouldn't forget that he is a human being” (IDI, P3)

According to one participant's account, when their child goes out to play with neighbors, she faces rejection and even experiences physical aggression at times. Highlighting the social exclusion and mistreatment that the child with Down syndrome encounters, “When she goes out to play with our neighbors, they push her away, and even beat her sometimes. The children in our neighborhood don't want to play with her, so I also don't have much connection with our neighbors” (IDI, P1)

Similarly, two other participants added on this, “ Now I don't take her out of the house because the children in our neighborhood don't want to play with her, due to this reason they isolate her; they don't usually think that she can also play like a kid among them” (IDI,P5)

The other participant, highlighting the challenge faced when their child interacts with other children, showing the response from the other children which is avoidance and discrimination. “When he meets children, he often holds them, hugs them out of love, kisses them, and they run away from him, and discriminate against him” (IDI,P11)

Here is a participant who states that their son has been given nicknames based on his health condition by their neighbors. “My son gets along with other relatives at home, but in the neighborhood, he is given a name because It is difficult for him to socialize” (IDI,P3)

One of the participants also recalls inappropriate jokes being made at their child's expense, accompanied by physical aggression. “For example, there are things that happen at school, such as bullying and isolation. For example, I remember there was a time where he was going to school by the school bus and the children going with him snatched his water bottle and spilled his water. There are also times they make inappropriate jokes on him and hit him as well. We got this information from his sister because she goes with him to school. If she hadn’t told us we wouldn’t have known because he doesn’t speak much and these kinds of things hurt” (IDI, P12)

In addition to this, as part of the community religious leaders play a major role as a social figure. Here is one of the experiences of the participant in this study: she encountered a discriminatory behavior from religious leaders due to her child's condition. As a result, the participant developed a strong aversion to attending church and, currently, neither her nor her

daughter participate in religious services. “Even the attitudes of religious leaders are not correct. I remember after she was born, when we went to the church to baptize her, the religious leaders there were discriminative because of my child's condition, so afterwards I hated going to church. And currently my daughter and I don’t go to church anymore. It made me reach the point where my prayer alone with God is enough” (IDI, P14)

4.2.4.3 Community's reaction

Participants of this study also highlighted the community's reaction as a significant social impact. Their narratives revealed instances of discrimination, stigmatization, and exclusion experienced by their family. These negative responses further marginalized the children and their families, creating barriers for social integration and acceptance.

The sense of pity directed towards families with children born with down syndrome is a common response based on the findings. People feeling sorry might seem like a good deed, but this sympathy often leads to reluctance in approaching or engaging with them, resulting in a sense of isolation and exclusion. Moreover, the misconception held by the community that parents must have done something wrong or committed a sin to deserve a child with Down syndrome further exacerbates the emotional distress.

Here is a mother who clearly states the above statement. “Most people feel sorry for you. Some people are even reluctant to approach you. There are also others who think you did something to deserve a child like her. They think that you made some kind of sin or fault, and all this hurts a lot” (IDI, P1)

The insights provided by the participant below suggests that the social consequences extend to limited participation in social gatherings and events, as expressed by some participants. They feel cut off from people, with their family and neighbors avoiding physical contact. This isolation and the hurtful comments from others discourage participation in social gatherings altogether. “Most of the time I don't go to social gatherings, so I'm cut off from people. My family and neighbors don't want me to touch them. In the past, before he was born, they used to call me to go to Edir, but now they don't call me. On top of that, what people say about you will hurt you, so I prefer not going to any social gatherings” (IDI, P2)

Based on the input from another participant, the community’s wrong perception of their child as sick or abnormal adds to the discomfort, especially when their child's natural expressions of affection, such as hugging or kissing, are met with negative reactions. “I also feel bad when people see her as a sick abnormal child when we go out in public, and in addition to the circumstance when she sees people she likes to go and hug them or kiss them, so when that happens peoples, reaction makes me feel bad” (IDI, P5)

The negative attitude and lack of acceptance from neighbors and society are common concerns among participants, and it is seen that these negative attitudes influence the participants' social lives, impacting their relationships, interactions, and overall well-being. One of the participants stated that; “Regarding my social life, I always take him wherever I go; for instance funerals and birthdays. But the thing is as you go out in public, sometimes people see you as trash and you see them avoiding you, and some people don't even consider him as a human being and when you think about the situation as a mother it hurts your feelings” (IDI, P11)

Similarly, another mother stated; “The attitude of our neighbors and others is not good. I don't like them seeing her as a patient” (IDI, P10)

Here is a participant who connected the community’s reaction to the facial characteristics of the children: “The other children might encounter different challenges regarding societal attitudes but in our case, I guess it’s his facial appearance which doesn’t expose us to those kinds of situations. He is loved and cared for in the society where we live” (IDI, P13)

4.2.5 Economic Impact

Findings show that families struggle with economic challenges related to their child’s condition. Here are two responses from our key informants: “They face economic challenges which I believe are most prevalent” (key informant 1). “Financial burden caused by medical costs, specialized support, and the need for one or both parents to stay at home to care for their child” (key informant 2).

4.2.5.1 Medical Financial burden

One of the key informants working at Deborah Foundation also highlighted the financial burden of families with down syndrome related to the health conditions of their children: “Families raising children with Down syndrome face significant challenges, including limited access to specialized healthcare and therapies due to financial constraints, financial strain from the additional costs of care” (key informant 3)

One of the participants in the in-depth interview clearly stated that due to their child's health condition, they needed to follow up frequently and this was hard because of the high cost of medical treatments “ There is a lot of pressure regarding the economy, for example we may

have to go to the hospital every week for different treatments, which is difficult in terms of cost" (IDI, P1)

Similarly, another participant also mentioned the need of increased frequency and high medical cost, "The cost is heavy; He gets sick frequently" (IDI, P3)

The associated medical conditions of Down Syndrome are very prominent, besides the developmental delay. Different health conditions were mentioned by the participants, here is parent whose child's associated medical condition was intestinal disease and insomnia: " It has an economic impact because now he not only has limited mental development, but also has other related diseases, such as intestinal disease, he has to stop breathing at night when he sleeps, and then we used to be unable to walk. All of these have medical expenses. He was also in need of diapers, and it was 15 birr per piece, and this was unimaginable in our life. Many other examinations were required, such as MRI, which required five thousand birrs at once. I could not bear all this" (IDI, P4)

Here is another family, where their child's associated medical condition was pneumonia; "In the past, he was attacked by pneumonia and this had medical expenses" (IDI, P9)

But not only this, due to the high cost of medical treatments required for the associated medical conditions, findings show that this also leads to debts. "It has really affected us. For example, I paid 90,000 Birr for the intestine narrowing condition surgery when she was born which is in debt. I haven't paid off that debt yet. When you cover one, there is another gap that awaits" (IDI, P14)

The findings also show that families' health were also affected indirectly in some cases, for instance here is a mother who stated that she developed illness related to the stress of her child's health: “First, it's hard to get a job having a child like my own, I can't even leave him for some time, so I can't work and if you don't work it's hard to live. In addition, I have an illness related to my son's condition, the cost of which is itself a heavy financial burden. Not only mine but also my son has associated health problems, and my expenses for him are a heavy burden as well” (IDI, P2).

4.2.5.2 Reduced Income

Families involved in this study shared that they experience a decrease in income following the birth of a child with Down syndrome: “Currently I have stopped working because I had to be with him, and there is no one who can help me. I have no fixed income; some people help me out of pity. I can't go out and work, because there is no one who can help me take care of him, and this has a huge economic impact” (IDI, P11)

Similarly, another mother stated that she stopped working due to the responsibilities of her child; “it really has an impact, I used to work before I had her, but then I stopped working and my income stopped because she needs time and care” (IDI, P6)

In the previous household the costs which were covered by the combination of both husband and wife, now the economic burden mostly falls on the husband, this creates a stressful environment for the family. “One of my concerns is in the aspect of nutrition. In my perception I believe that I am not providing my child with the necessary nutritional supplements because of our low economic status. The other one is I have the ability to work but I can't work because I

have to be with my child, so all the economic burden falls on my husband which is also hard" (IDI, P9)

Most of the time fathers are considered to be responsible to cover the costs that are required by the family, on the contrary here is a family where the husband-and-wife work in shifts to sustain their family. This scenario highlights equal responsibility sharing. Most of the time based on our findings mothers are the ones who are considered to be the primary caregivers of the child born with down syndrome, creating an environment where fathers run away from responsibilities of taking care of the child: "Yes it affects your economic status, for instance since he was born my wife and I work in shifts which is if I work, she is at home taking care of him, and if she works, I am at home with him. When he was born at first my wife stopped working for about five years and then now for a while I stopped working and she goes to work. Now I'm the one who takes care of him at home"(IDI, P13).

4.2.5.3 Education costs

It is stated by one of the key informants that most families deprive their children the right of education as a result of the high costs of education: "families are more often than not depriving their children with ID as well as other children born into their household the basic rights of education as well as fulfillment of other life needs as well" (KI, P1).

Families who participated in the in-depth interview also shared their experience regarding the economic impact of educational costs; "Another thing is that in terms of education, it is difficult to educate children like them from an economic point of view" (IDI, P1)

Similarly, here is a mother who shared her experience regarding her child's school. She said that families with children like her are charged extra money for teaching their children. The increased amount of educational cost has a significant impact on families with down syndrome economic status: “It has economic effects, for example, in addition to the fees we pay for school, they charge us an additional five thousand birr compared to other children for a special need assistant” (IDI,P12).

4.2.6 Impact on Family Interaction

This category comprises three subthemes: spousal relationship, sibling relationship, and parent-child relationship. It primarily explores how the child's condition influences the closeness and cohesion within the nuclear family. It also reflects the level of acceptance and the dynamics of relationships among family members.

This research can be explained by the family systems theory, which states that the relationships among family members emphasize the family as a unit rather than its individual components. This theory acknowledges that any influence on one member has an effect on the entire family, impacting all other members and ultimately affecting the overall equilibrium and stability of the family system (Haefner, 2014).

4.2.6.1 Spousal Interaction

Regarding the spousal interaction of the parents with a child with down syndrome, the responses show that it is evident that the presence of a child with Down syndrome can have varied impacts on marital relationships. Some families experience strains leading to separation or divorce, as seen in the cases where husbands have left due to the child's condition. This separation can result in single-parent households or living arrangements where support comes

from other family members. My Husband left me because of our daughter's health condition, this has hurt us as a family. Now I live in a rented house with only my daughter. (IDI, P6)

Here is also another mother who highlights that her husband left her because of their child's health condition. I am raising my child alone; my husband is not with me and this has its own impact. Currently I live with my sister, and she helps me a bit. (IDI, P11)

Based on the findings, most participants' marital status describes the impact of having a child with down syndrome. Most husbands clearly show a lack of awareness about down syndrome, so they leave their wives to be a single mom: It has affected my relationship with my husband, and we are now separated.(IDI,P1)

Being a single parent has a major impact on family. Here we can see that raising a child with down syndrome can have emotional strains between spousal interactions, leading to changes in family dynamics and families living arrangements: "Now I live alone with my daughter, my husband left me because of her health condition" (IDI,P8)

Additionally, societal and familial beliefs about the causes of Down syndrome can exacerbate conflicts within marriages. In the below scenario it is seen that blame is placed on the mother for the child's condition. My husband thinks that God gave us our son, but my husband's family thinks that it is a sin for a son to be born with Down Syndrome. Especially when there is a conflict between me and my Husband, they always point out to me saying "your sin is the reason for the child to be born like this" because they believe that the deeds of the mother reflect on the child" (IDI, P9)

According to one of the participants' responses, the heightened stress levels caused by their child's health condition makes the spousal interaction more prone to disagreements and disputes. “You are exposed to conflicts in the family without thinking. Some conflicts are caused by all the stress, so you are exposed without thinking. And when you are in a stressful situation you are easily exposed to conflicts with other family members, most of the time the fights we have with my husband is due to this situation” (IDI, P12)

Here is a participant who shared her experience. The mother here is carrying all the burden of her child reflecting the imbalance of shared responsibilities creating a dysfunction. “Most of the time the burden rests on the mother, fathers run from responsibility of taking care of a child. All the pressure is on the mother, even if they help, they don't go for more than a day. And besides that, I always don’t want to nag him saying “Help me”, so what I do is take all the responsibilities of the house and do it on my own” (IDI, P14)

Despite these challenges, some families can maintain peaceful and supportive relationships, highlighting the diverse ways in which the presence of a child with Down syndrome can influence spousal dynamics. “We have a peaceful life with my husband and my other son. We live together and support each other” (IDI, P2)

Here is also another example which highlights, having a child with down syndrome does not amplify unhappy marriage or spousal interactions within a family. “The relationship with my wife is also peaceful” (IDI, P13)

Spousal interaction within families is significantly influenced by family systems theory, which shows that family members are interconnected and the dynamics between them shape the overall family life. The family systems theory emphasizes the importance of viewing the family

as a holistic unit rather than an individual. Here the interactions between spouses are not isolated events, rather they are part of a larger system where each partner's behavior affects the other and the family.

4.2.6.2 Siblings Interaction

A child with Down syndrome has a role in the family, just like any other member interacting as a whole: “He has two sisters at home and nephews; they all take care of him and he helps us in the house and he has his share of work” (IDI, P3)

They are also seen actively involved in caring for their sibling with Down syndrome, contributing to household tasks and seeking out resources and services that benefit their sibling. This active involvement not only reflects a sense of responsibility but also showcases the strong bonds and cooperation among siblings in providing care and support. “My 4 children and I live together. The interaction I have with them is good. They feel very responsible. They want to do so much for their sister, they are the ones who even found this foundation that can help her get some services she needs” (IDI, P5)

Additionally, the responses show that most siblings feel responsible, here is one of the participants who is a sister, she mentioned that she is always seeking a better opportunity and access for her sister paying the cost that is required. “Yes, our families are now scattered. My father and the other children are living there. Me, my mother and my sister (down syndrome child) have made our living in Addis Ababa so that she can have a better chance. Being scattered has its own effects as a family” (IDI, P10)

Similarly from the responses of parents, most of the time parents grow their children by sharing their responsibilities to the siblings of their child with down syndrome: “The older sister feels more responsible than us,” (IDI, P13)

4.2.6.3 Parent-Child Interaction

From the responses provided regarding parent-child interactions, the concept that emerges is the complex dynamics and impacts of having a child with Down syndrome on the relationships within the family unit. These interactions highlight a range of experiences, from increased attention and care directed towards the child with Down syndrome to shifts in relationships and perceptions among family members. “We don't have much interaction with my older son, I'm with her most of the time, we're not that close with him, most of my attention and time is on her, but he takes care of his sister” (IDI, P1)

In addition to that, the strain in parent-child interaction can have various causes. Here is a mother who shared her experience about her relationship with her other child. Showing the impact of societal perceptions and external influences on her relationship with her child. Negative attitudes or comments from peers and society can significantly impact the dynamics within the family, leading to misunderstandings, hurtful words, and strained relationships. “But our relationship with my first child has become strained. He used to take care of his sister very much, he used to play with her, he used to bring her home from daycare, but after a while he told me that he will never bring her home anymore, and he never brought her after that. The reason for him to change like that was that his friends saw him and said what kind of nature his sister had. Since then, his behavior has changed, he goes out in the morning and comes in at night to avoid meeting us, and when he comes in, he doesn't turn around and talk to us. Then when I

asked him what happened, he told me that “she is the child you brought because of your sins”. His words hurt me deeply, because if my own son doesn't understand me, no one will. Now I came to understand that he wants to stay away from her so as not to carry her burden in the future. Because he thinks that she will be a burden. Above all, it would be better if he kept quiet than saying those words. And if your son who is your own flesh can’t understand you, no one can help you” (IDI, P14).

However, there are instances where the presence of a child with Down syndrome serves as a unifying factor within the family, fostering love and togetherness among family members. This suggests that the child with Down syndrome can play a central role in strengthening familial bonds and creating a sense of unity.” It has no negative effect on interaction within the family. Everyone loves him; because of him we gather as a family” (IDI, P7)

4.2.7 Basic service

This theme focuses on addressing the basic needs of families with Down syndrome. The participants involved in this research are individuals who have registered with the Deborah Foundation to access the services offered by this non-profit organization. As it was clearly stated by the key informants there are basic services offered by the nonprofit organization. “We provide healthcare programs, inclusive education opportunities, awareness creation and capacity building platforms for children registered with our foundation. We also provide family support programs to families of children with intellectual disability” (KI, P1)

Additionally, one of the employees working as a psychologist in the foundation, also stated that their organization is working towards a holistic service. “Our organization, dedicated to supporting families and children with Down syndrome, provides a comprehensive array of

services. These include various training sessions covering a diverse range of topics, such as early intervention programs and educational support. Moreover, we facilitate employment opportunities for children with Down syndrome and their families, alongside offering counseling, occasional financial assistance, and regular health check-ups in collaboration with partner hospitals. The primary objective of these services is to foster the holistic development and well-being of the child while also extending support and resources to their families" (KI, P1)

4.2.7.1 Medical Follow up Services

Based on the data, it seems that most children born with Down syndrome also have other associated health problems. Due to this, it is clear that these children require ongoing medical follow-up and treatment. For instance, here is a mother who participated in the focus group: "I often have a big problem with medical centers because when I go to the doctor's office, they don't show me the right gesture. Some of the services we receive are not expected from medical professionals" (FGD, P3)

One of the key informants also stated that, most families struggle with financial burdens of medical care for their children. "Families often express concerns about the developmental delays their children experience, such as speech and language delays, learning difficulties, and motor skill challenges. They also struggle with the social stigma associated with Down syndrome and feel overwhelmed by the financial burdens of therapy and medical care" (KI, P2)

There are various comorbid conditions that are commonly associated with Down syndrome. Many families have mentioned the specific health issues their child with Down syndrome is experiencing. Here is what one the participants, who is a sister to the child born with down syndrome in the family says: "In the beginning, she had a thyroid problem related to

her condition, so it was said that she needed surgery, then she started proper follow up" (IDI, P10)

Some of the families also mentioned that the child born with down syndrome has a chance to be admitted to the hospital more frequently compared to other children, and this is due to the health conditions that are associated with Down syndrome. When this happens, families stated that they require more intensive medical care. A mother who was interviewed in the in-depth interview stated: "He was first admitted to the ICU the first time I took him to the hospital, later as he grew up and I started to follow up at the hospital because he had other comorbidities such as thyroid and apnea" (IDI, P12)

4.2.7.2. Education Service

Finding educational services for children with Down syndrome is challenging. Beyond the high costs, ensuring that the right services are available for each child is a significant concern. Participants noted that developmental delays vary among children, highlighting the need for individualized treatment. Unfortunately, in many areas of our country, children with developmental delays are often treated as if they all have the same needs, which is not accurate. Here is mother who participated in the focus group discussion stating her concerns about the educational services: "I get confused about what to do sometimes when I think about his education. Many school children with general intellectual disability are just kept in one room. I don't even think they provide them the right way of teaching. For instance, the previous school he was in, there are children who have worse condition than him, and as he was spending days with them he started to get worse and he imitates the action they do. So, I had no choice, but take him out of that school, it's better that he stays at home" (FGD, P4)

Additionally, many schools have practices that lead to the rejection of these children, preventing them from being accepted into the school: “When I go to the school itself and ask, they do not accept it, they give many reasons and this is also difficult” (FGD, P4)

Another parent shared their struggle in finding an appropriate school for their child, highlighting the broader problem within educational services, where a lack of proper training and understanding can lead to harmful practices instead of supportive interventions. “I had a hard time finding a school, and after finding one the teachers didn't follow him up properly at first. That was difficult. When he used to go to school, the teachers instead of understanding his behavior they hit him” (FGD, P2)

CHAPTER FIVE

Discussion

This chapter presents the major findings of the study in relation to the research questions and discusses the results considering reviewed literature and Family systems theoretical framework. The main purpose of this study was to explore the Impact of Raising Children with Down Syndrome on Families in Addis Ababa. In this section, the seven themes were explained relating to other literatures based on the findings of the study.

Initial Reaction

When families are first faced with a child being born with Down syndrome, there are likely a lot of different thoughts and feelings that come up. There were mother who stated that if they had done more or done things differently during pregnancy, their child would have been born healthier. This indicates that they are experiencing self-blame, all this comes from the wrong perception of Down syndrome. This is similarly stated in the results of another research, stating the lack of understanding causes challenges and hinders support creating additional stressors in various aspects of raising a child with intellectual disability (Gebre, 2016).

The findings show that most families lack the knowledge of what Down syndrome is in the first encounter. It's common for families initially lacking a comprehensive knowledge about Down syndrome upon the first encounter. This lack of knowledge is due to the limited exposure or education prior to the diagnosis of their child. Research done in South Africa in 2016, based on the participants' answers 50.8% showed they had a limited knowledge about down syndrome by the first encounter with their child (Barr et al., 2016).

Many families encountering Down syndrome may not have any prior knowledge or understanding about it. Without this background information, they might develop the wrong perceptions about the cause and consequences of Down syndrome. This finding aligns with another study made; stating mothers of children with down syndrome have specific expectations as caregivers to have the right understanding of what Down syndrome is. (Toker, M.et al., 2008). The unfamiliarity with Down syndrome can also present practical challenges. Families may not know where to turn for information, resources, and support. They may feel isolated and alone in their journey, as they navigate this new and unknown territory.

Through the journey of having a child with Down syndrome, health professionals play a crucial role in the initial phase, based on the findings some of the mothers stated that, at the initial phase the information they got from the health professionals was vague. Likewise, a study conducted in Iran, shows similar findings about the origins and sources of stigma directed at individuals with Down syndrome; among these sources' healthcare professionals are also involved (Hemmati et al., 2010). Down syndrome is still unrecognized in Saharan Africa due to the lack of clinical awareness among healthcare professionals. Being one of the reasons for high infant mortality rate and limited community awareness (Christianson, 1996). Regarding health caregivers, we should be careful not to generalize in a negative way. A study conducted in the United Arab Emirates revealed that medical health science students who are to be the future health care providers demonstrated a positive level of knowledge and attitude towards Down syndrome; 74.0% having a positive knowledge and 67.2% having a positive attitude towards down syndrome (Rabbani et al., 2023). Even Though the above finding illustrates the developed country data, there are also some participants in this study who clearly stated that being consulted by health caregivers has brought a huge difference in their understanding and

acceptance of their child's condition. But it is often noted that families face significant limitations in being informed about their child's condition at birth. As a result, Down syndrome is frequently identified later, usually when associated medical issues require them to visit a hospital. This delay in diagnosis is a common concern voiced by many families.

Healthcare professionals play a crucial role, particularly in providing information for the care of children with Down syndrome and facilitating access to healthcare services. The importance of their personal qualities was highlighted, including their kindness, attentiveness, strong communication skills, dedication to ensuring proper care for the child, and their ability to understand the needs of the mothers as well (Duarte et al., 2022). The personal qualities that are reflected by the health professionals can play a crucial role for families having a child with down syndrome.

Among the first reactions of family’s disbelief is mentioned to be one of it. Some parents were unfamiliar with the condition altogether, while others experienced denial becoming aware of it. The denial is mainly due to the shock of being in a situation they have never thought of, and largely due to the lack of prior awareness. This study made in line with the other findings show that even though most parents have gone through some kind of negative feeling towards their child being born with Down Syndrome, the initial reaction among most parents was refusal to accept their child's disability. It is also seen that families still had hope that one day their child would be free from Down syndrome (Albert, 2018). Similarly in another research, some parents hoped that the clinical diagnosis they heard was untrue, and hoped taking repetitive tests would change the outcome of the result; always hoping to hear their child doesn't have Down syndrome (Clark et al., 2020).

Parents who received the diagnosis of Down syndrome, whether prenatally or postnatally, vividly remember the moment, recounting it as deeply affecting and describing it as emotionally distressing. They described the experience as a state of shock. During those early moments, most of them spent hours looking for information and support to navigate their new reality (Clark et al., 2020). In line with the previous research, shock and anger were significant reactions reported by many parents upon receiving a Down syndrome diagnosis. While most parents experienced shock as their initial responses regardless of whether they received the diagnosis before or after birth some parents reported more positive sentiments, considering their child a gift and blessing (Nelson, 2013).

Coping mechanism

In the initial period following a diagnosis of Down syndrome, many parents focus on seeking assistance and support as a primary coping mechanism. This often includes searching for information about Down syndrome, as well as resources related to it. Initially, parents look for information to help them understand the condition and may later seek guidance on topics such as child stimulation and inclusion in society (Braga et al., 2021). Likewise, these results reinforce the findings of another study, which indicates that families sought out necessary information on effectively raising their children and addressing their special needs as one of their coping strategies. The gradual seeking of information and education regarding their child's condition is regarded as a coping mechanism for families (Gashmard et al., 2020). Many families actively see and gather insights from a variety of sources such as groups, educational materials and professional guidance. This approach helps them understand their child's needs and also empower them to make the right decision as they raise their child.

Not only do the insights they receive from professionals play a crucial role, but participating in discussion groups also helps alleviate their stress. Engaging with others who share similar experiences allows them to openly discuss their child's condition, providing emotional relief and fostering a sense of understanding. Similarly, it was highlighted that support from parent associations, which provide a platform for individuals with similar experiences, is a very valuable method. Engaging with these groups fosters a sense of belonging and security among families enhancing their ability to care for their children. This shared experience allows them to exchange insights, resources, and emotional support, empowering them to navigate challenges more effectively (Duarte et al., 2022).

In the findings, families also expressed their reliance on the faith they have on God as a coping mechanism to manage the associated impact of raising a child with down syndrome. These findings align with another research, believing in the divine providence was mentioned as one of the coping mechanisms. Families' deep spiritual belief and prayer reduce and eliminate the feeling of anxiety and stress through the process of raising their child (Gashmard et al., 2020). In line with this, another research states that families convey a deep belief in God and his authority to shape the direction of their lives. This faith not only offers them comfort but also trust in the divine plan (Duarte et al., 2022).

Emotional and Psychological

Families have shared their experiences of anxiety, anger, and stress which have had profound effects on their overall wellbeing in this study. In accordance with this research, another study finding also show that families with children born with down syndrome experience lower levels of psychological wellbeing compared to families with normal development (Said Mohammed et al., 2021).

The findings indicate a connection between anxiety and depression, with most responses coming from mothers. This suggests that mothers are more likely to experience anxiety and depression related to their child's condition. In accordance with this study, due to the stress that comes with caring for a child with special needs, mothers are more likely to experience an increased risk of anxiety and depression (Skotko et al., 2011). The findings from another research reveals that mothers of children with Down syndrome often experience heightened mental health challenges, particularly when their children face ongoing associated medical problems which are common in children born with Down syndrome. Those mothers whose children have experienced multiple episodes of illness report feeling more stressed and mentally strained compared to those with only one illness episode. In Addition, mothers of children exhibiting more serious behavioral and emotional challenges tend to report significantly poorer mental health (Bourke et al., 2008).

Social Impact

In this study, many participating families highlighted various social impacts, such as a lack of understanding within society, social isolation, discrimination, and negative community reactions. In line with these findings, Deakin et al. (2018) stated that children with Down syndrome exhibit distinct physical characteristics that are immediately noticeable, which makes them different. Due to these physical features, they are more susceptible to stigma. The physical characteristics described in another study highlight features of children born with Down syndrome that differentiate them from others. Some of these features include epicanthal folds around the eyes, a broad and flat nasal bridge, a round flat face, upward-slanting eyes, small ears, a short neck, and a downward-turned mouth (Bull et al., 2022).

From the responses provided, it is evident that families with children born with Down syndrome encounter various societal misunderstandings about the condition. As a result, they often face negative reactions from others. In line with this finding, In our country the socio-cultural impacts are clearly seen in the lives of families of intellectual disability. Due to this reason, most are kept away from social gatherings and hidden at home (Weldeab, Chernet Tekle & Opdal, Liv Randi, 2007).

As expressed by one of the participants, stigma extends not only to the children with Down syndrome but also to their families. Similarly, a qualitative study in Ethiopia explored the perceptions and experiences of stigma among parents of children with developmental disorders, including Down syndrome. The results show that parents encountered different types of stigma from society as well as their own families. And this stigma arises from the lack of understanding (Tekola et al., 2020). Another study revealed that caregivers faced significant levels of stigma. This stigma was more prevalent among those who sought assistance from traditional institutions and among caregivers who attributed their child's diagnosis to supernatural causes (Tilahun et al., 2016).

The negative response from the community also further marginalizes the children and their families, creating barriers for social integration and acceptance. For instance a study by Barr (2017) , shows that the community offered minimal support resources to caregivers, representing just 7.4% of the total available assistance. The negative attitude towards families with down syndrome could be related to the cultural beliefs of our society. Moreover this relationship can be understood through the study of Oloyede (2011), where it is clearly seen that the traditional beliefs stating the disabilities are caused by the curses and perceived as the misdeeds of the parents. Such belief leads to significant stigma and blame by the community.

Economic Impact

Children born with Down syndrome often have additional medical conditions, which puts a financial burden on the families raising them. The findings show that these medical costs have a significant impact on families, highlighting the financial challenges they face. Similar findings show that the lack of free health services are one of the reasons to create an extra financial cost on families (Adeleke et al., 2020).

The findings also show that families' health were also affected indirectly in some cases, for instance there was a mother who stated that she developed illness related to the stress of her child's health. Similar findings in Nigeria show that Intellectual disability which includes down syndrome affects the economic situation of families. Families often experience increased financial burdens due to the need for specialized medical care, therapies, and educational services which are necessary for the child. This can lead to significant expenses. In addition, caregivers may have to limit their work hours or even leave their jobs to provide the necessary support, resulting in lost income and reduced financial stability (Adeleke et al., 2020).

Unemployment is identified as a significant issue among these families, particularly affecting mothers who are often viewed as the primary caregivers after having a child. As a result, many mothers choose to leave their jobs due to this increased responsibility. In a comparable study, raising a child with Down syndrome or other intellectual disabilities often necessitates sacrifices from family members, which can result in feelings of lost hopes and altered visions for the future (King et al., 2006). First the traditional belief that mothers should primarily take on the responsibility of caring for their children and second, the assumption of mothers often developing a stronger attachment to their child becomes the primary reasons for

mothers' unemployment or job ceasing after having a child with Down syndrome (Durmaz et al., 2010). The results show that many mothers had the opportunity to work, but due to the increased burden they feel to take care of their child they stop working. Getting unemployed by itself has its own consequences, such as not being able to cover costs such as medical and other costs required to be fulfilled. The decision to become unemployed carries its own consequences. This situation can be related to the concept of poorly differentiated self or familial fusion. Familial fusion states that there is a demand for an individual in the family to sacrifice to maintain the togetherness of the family (LPC, 2011). Due to this reason, as the mother sacrifices her employment, it leads to becoming overly reliant on the caregiving role, merging her identity to her child. This can cause a difficulty for the mother to maintain her own identity outside of being a caregiver, leading to stress and anxiety.

Impact on Family Interaction

The impact on family's interaction is explained based on spousal relationship, sibling relationship, and parent-child relationship. It primarily explores how the child's condition influences the closeness and cohesion within the nuclear family. It also reflects the level of acceptance and the dynamics of relationships among family members. Similarly, according to Povee et al. (2012), the general term for family functioning showed the relationship between parent, child with down syndrome and siblings. This research can be explained by the family systems theory, which states that the relationships among family members emphasize the family as a unit rather than its individual components. This theory acknowledges that any influence on one member has an effect on the entire family, impacting all other members and ultimately affecting the overall equilibrium and stability of the family system (Haefner, 2014).

Regarding the spousal interaction of the parents with a child with down syndrome, the responses show that it is evident that the presence of a child with Down syndrome can have varied impacts on marital relationships. Some families experience strains leading to separation or divorce, as seen in the cases where husbands have left due to the child's condition. This separation can result in single-parent households or living arrangements where support comes from other family members.

Based on the findings, several mothers reported that their husbands left them due to the stress and challenges associated with their child's health condition. This phenomenon can be understood through the concept of emotional cutoff from Bowen Family Systems Theory. *Emotional cutoff* occurs when family members are unable to confront and resolve their emotional issues with one another, leading them to distance themselves physically or emotionally from the family unit. In this context, husbands chose to leave rather than engage in difficult conversations or confront their feelings about their child's health, resulting in a complete disconnection from the family. Bowen (1978), states that individuals who experience emotional cutoff often avoid returning home or maintaining relationships with family members, further exacerbating feelings of isolation and abandonment for those left behind. This dynamic highlights the impact of unresolved emotional conflicts can have on family relationships, particularly in the face of challenging circumstances.

As one of the participant mentioned, extended families also have a role to play in the stability of the family dynamics. This can be explained by the concept of triangle, triangle is one of the concepts in family theory, which states that bringing a third person can relieve the tension, when there is a dispute among two people. But triangle also has its negative side, this is when the third party involvement distracts the two other parties to resolve their problem (Bowen, 1978). In

this context the triangle involves the mother, her husband, and his family. So, when a conflict arises between the spouse, his family enters as a third party, not helping them focus on the solution but rather exacerbating the conflict. The husband's family contribution to the system not only impacts their relationship in a negative way but has also led to blame and isolation affecting the family's emotional stability. The triangle concept in Bowen's theory helps us understand the relationships between all family members, including both immediate and extended family, throughout their lives (LPC, 2011)

Another concept raised by the participants is the imbalance of responsibilities between spouses. This scenario is explained by the concept of *dysfunction of one spouse*. As noted in LPC (2011, p. 45), within a relationship, it is common for one partner to take on an excessive number of responsibilities, becoming the "over-functioner." The other spouse on the other hand adopts a role of "under-functioning," relying on the over-functioner to handle most tasks. Based on the findings, mothers tend to be the over functioners. This Imbalance of responsibilities among spouses can lead to increased tension within the relationship (LPC, 2011). Spousal Interaction is built by sharing responsibilities and sharing any challenges together. Walking in contrast to this leads to conflict and other emotional pressures on the spouse. The strain that is caused by the imbalance can lead to physical or emotional exhaustion on the person taking more responsibilities, ultimately affecting the family dynamics.

According to family systems theory the siblings position describes the personality traits of siblings associated with each sibling role which manifests in the form of behavior and interaction (Toman, 1969). as the results show most of the children born with down syndrome are the last child in the family, or the only child. This can be due to fear of having another baby with down syndrome.

Regarding sibling interactions, a general concept emerges highlighting the significant role that siblings play in the lives of individuals with Down syndrome and the impact on family dynamics. Siblings are often seen as sources of support, care, and responsibility within the family unit. Parallel to this result, it is seen that parents have less time to spend with siblings having normal development, decreased number of family activities, lower financial resources for the siblings, increased caregiving responsibilities placed on siblings, and lower peer acceptance of siblings in the society. Due to the factors stated, sibling's education, emotional status, health relationship with parents and social acceptances are impacted (Adeleke et al., 2020).

Based on the findings it is sought to be that Down syndrome children's siblings feel more responsible, than other siblings with normal development. This is because of the pressure from parents, as the siblings grow up, they are raised being told that it is their responsibility to care for their siblings. This can be explained by the *familial fusion concept* of family system theory, which is the demand for an individual to sacrifice in order to maintain togetherness (LPC, 2011). Self-differentiation is a very crucial concept in a nuclear family system. Being self-differentiated would help them be independent and make decisions without being influenced by others' needs. In contrast to this, a meta analysis by Hodapp (2007), states that even though it is traditionally perceived that siblings experience higher levels of negative outcomes compared to siblings to typically developing children, the review indicates a positive outcome, such as greater empathy and appreciation for others.

From the responses provided regarding parent-child interactions, the concept that emerges is the complex dynamics and impacts of having a child with Down syndrome on the relationships within the family unit. These interactions highlight a range of experiences, from

increased attention and care directed towards the child with Down syndrome to shifts in relationships and perceptions among family members.

Parents often express a significant focus on the child with Down syndrome, which can sometimes lead to feelings of neglect or strained relationships with other siblings. This shift in attention can result in changes in the relationships between parents and their other children, causing strains and negative feelings. The parent- child interaction can be explained by the family projection. The family projection explains the condition of a parent whose emotional system is more centered around the children rather than on each other, and unconsciously projecting emotional problems onto their children (Bowen, 1978). The strained relationship between a parent and a child leads to being emotionally distanced, affecting their connection. Being too occupied with the child with down syndrome deprives time and care for the other child leading to an imbalance and disruption of the family dynamics.

In addition, It shows that family members can become emotionally disconnected from one another, often as a response to anxiety or some kind of pressure. Based on the finding, in the parent-child interaction, *emotional distancing* can be seen as a way of coping with the anxiety. It seems that this can be explained by the term emotional distance which is incorporated in the nuclear family emotional system of Bowen's theory. The emotional distance can be referred to both internal and external moves. External moves involve actions taken to create physical or emotional distance from another person (LPC, 2011).

Basic Services

As it was stated, children and families with Down syndrome require different basic services to support the living condition of the children. In line with previous findings, it is highlighted that

most families make efforts to access and utilize community services aimed at enhancing their children's abilities. Families seek services like speech therapy, occupational therapy, and other services that play a crucial role in helping the children develop practical and communication skills. To support their children in managing their developmental delay, and to enhance their overall quality of life, it is clear that the participants actively seek assistance from different services (Gashmard et al., 2020).

Children born with down syndrome are at higher risk of health issues because of the genetic factors associated. There is an increased rate of morbidity due to different co morbid health conditions such as congenital heart defects, respiratory problems, gastrointestinal issues, and other infections. They also experience developmental and cognitive delays which might cause further complications in their health (Fitzgerald et al., 2013). The medical and therapeutic services that families require, or access is based on their child's specific need, the availability of the services, the family knowledge about the service options, and type of insurance coverage (Marshall et al., 2014). In Ethiopia, individuals with intellectual disability have the right to health care. Even Though it is the state's responsibility to provide necessary rehabilitation and support services for persons with disabilities; the term disability also includes intellectual disabilities. However, the implementation still remains a challenge, with much of the specialized care and rehabilitation services for people with intellectual disabilities being provided by non-governmental organizations (Rights of Persons with Disabilities in Ethiopia, 2014).

Finding educational services for children with Down syndrome is also challenging. Beyond the high costs, ensuring that the right services are available for each child is a significant concern. Participants noted that developmental delays vary among children, highlighting the need for individualized treatment. Unfortunately, in many areas of our country, children with

developmental delays are often treated as if they all have the same needs, which is not accurate. Cognitive delays among children born with down syndrome require a certain amount of attention and treatment. Corresponding to this finding, it has been suggested that among other medical conditions that are related with Down syndrome, congenital delay is also one important aspect to consider, because this has an impact on their learning, communicating, emotional status, and social engagement capacity (National Society of Down syndrome, 2021). In Ethiopia, children with disabilities face challenges in accessing education. Only 3% of children with disabilities including children with intellectual disability attend schools. And out of these children many drop out of school early, due to the lack of support and accommodations in school. In addition, there are no clear facts stating children attending schools are fully participating in the educational process receiving special education support (Rights of Persons with Disabilities in Ethiopia, 2014). There are challenges in ensuring the educational system for individuals with intellectual disability, providing support services such as accessible learning environments, trained teachers, and learning resources (Inclusion of People with Disabilities in Ethiopia, 2013).

CHAPTER SIX

Conclusion and Social Work Implication

6.1 Conclusion

The research shows that having a child with Down syndrome not only affects one individual in the family, but has an impact on the entire family. The families in this study reported social isolation, financial burden, and psychological problems which all lead to destabilization of the family as a primary unit of caregivers. It is clearly seen that the emotional strains experienced by caregivers resulting in problems of spousal relationship, financial burden, and overall family functioning. The study shows that having a child with Down syndrome impacts family interaction both in a positive and negative ways. the shift towards child care can lead to marital strain. In addition, the study highlights that siblings may feel burdened with additional responsibility, which can lead to emotional distancing. On the other hand, findings show that families with children born with Down syndrome experience closer bonds as a family, and increased empathy as they support each other. Overall, the family dynamics is influenced by the coping mechanism of each family. The coping mechanism of different family units is different from one another, and how well the family copes with the challenges will influence the family dynamics.

Socially, families face isolation and discrimination from the community as a lack of societal understanding about Down syndrome. Most parents reported that they had limited participation in social interactions. Additionally, the burden of taking responsibility of the child with down syndrome falls on mothers, which affects the family dynamics leading to different negative outcomes.

Economically, families bear significant financial responsibility due to medical follow ups, special education, therapies and other expenses. It is common for children born with Down syndrome to have related health issues with their developmental delay. Some caregivers have also stated that they were in depth for the sake of their child's medical costs, indicating that families' overall financial capacity is affected. In addition, the socio economic background of the participants indicates a lower economic status. The findings show that access to special education services is limited due to the financial capacity of the families, especially for those from lower socioeconomic backgrounds.

Families frequently struggle to afford specialized care for the associated health conditions. Educational services also remain limited, with only a few institutions offering programs fit to the needs of children with Down syndrome. As a result, many families face challenges in securing proper support for their children's development. The findings show the need for government and non-governmental organizations to improve service, in order to ensure that children with Down syndrome receive the necessary medical attention and inclusive education, which are very important for their overall growth and well-being.

6.2 Implication

Based on the findings, the implications suggest interventions must focus on the family unit as a whole. This includes providing emotional, social, and economic support to all family members; not just individuals in the family.

6.2.1. Implication for Policy program and Service Provision

Currently many families struggle getting access to appropriate medical care, and educational opportunities. The Government and local authorities should prioritize programs that

provide affordable and appropriate medical services, subsidized special education, and family support services. Families having access to these services would eventually help the family's overall wellbeing, decreasing the financial burdens.

Children with Down syndrome often face challenges in educational settings due to a lack of specialized services and inclusive education. The study implies a need for reform in the educational sector to support children with Down syndrome through the development of specialized education and trained educators. Inclusive education policies should be enforced to ensure that children with Down syndrome are not isolated and that they receive the educational support they need among others. Children born with down syndrome have the right to learn just like any other children. Inclusive education is suggested as the most effective way for the children's development. As the findings indicate, it is common for children born with down syndrome to be set in a separate room in the schools they might attend. This method increases the rate of isolation and discrimination. In addition, it is not considered to help the children in their cognitive development.

6.2.2 Implication for social work practice

The study shows the vital role of social work in supporting families raising children with Down syndrome. Social workers can work in different sectors to help families with down syndrome children. One of the roles they can play is facilitation. The approach can include assisting families to access various services, including health care, education, and community support groups. They can help families link to the right resources. Creating support groups, social workers can help families develop coping mechanisms.

In addition, this research implies social workers should work towards developing special training curriculum that focus on advocating the rights and needs of families with disabilities including children with Down syndrome within the educational and health care setting. The training curriculum could help how social workers can help when they encounter families with disabled children. In light of the objectives of social work education, professional social workers should help families to understand their rights to have access to services available. Unfortunately, there are very limited services in the country.

Working towards advocating inclusive education for children born with down syndrome is one of the key roles social workers may play. It is significant that the community lacks the right understanding about Down syndrome, due to this reason most social isolations and discriminations are seen. Facilitating social interactions can create opportunities to engage in an inclusive environment. Community based education reduces stigma and promotes social inclusion for children with Down syndrome.

Social workers using Bowens family system theory, they can enhance the functioning of families as a unit. By using the different strategies suggested by Bowen they can help families navigate challenges by creating a more supportive environment for the overall wellbeing of the family.

6.2.3 Implication for Research

The study shows that there is limited number of studies regarding Down syndrome and the impact of on families. Most research done are generalized, which is on intellectual disability. more research and should be done in order to bring awareness as well as changes in our country's policies.

The study highlights a significant gap in the availability and quality of educational services for children with Down syndrome in Ethiopia, pointing to the need for more focused education research in this area. Researchers should explore best practices for inclusive education, investigating how to create curricula and teaching methods that accommodate the unique learning needs of children with Down syndrome. This research could focus on the development of specialized teacher training programs and identifying effective strategies for integrating children with Down syndrome into mainstream classrooms. Furthermore, education research should examine the long-term outcomes of children with Down syndrome in the current education system, identifying barriers to their academic success and proposing solutions to improve access to quality education. By generating data specific to the local context, education research can provide the foundation for more effective educational policies and interventions.

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ANNEX I

English Version of Information Sheet and consent

Information Sheet

I am a master's degree student in the School of Social Work at Addis Ababa University. I am undertaking research on " the impact of Raising children with Down syndrome on families in Addis Ababa''. For this purpose, I have prepared this questionnaire to collect data pertaining to this issue. Hence, I want your full consent. If you are willing, there is no string attached to it. Before getting your consent of participation, you need to know all necessary information related to the study. Thus, the following information will be detailed about the study and your participation:

Title of the Research: The Impact of Raising Children born with Down syndrome on Families in Addis Ababa.

Name of the Organization: Deborah Foundation

Objective of the study: To study the impact of having a child with Down syndrome in the family, among families that are registered at Deborah foundation.

Participants: Those families with Down syndrome children who are receiving services from Deborah foundation, from the age of 4-10. The study includes mothers, fathers and siblings who are primary caregivers of the children. .

Procedure: data is collected through in-depth interviews and FGD.

Confidentiality: All information you give will be kept confidential and cannot be accessible to any third party. Your name will not be registered, rather it's written in numeric code.

Risks: The information retrieved will only be used for the study purpose and has no harm

On participants. During the interview you will not be forced to respond to the information you do not know.

Benefits: The study has an indirect benefit for the participant to bring out the impact on families due to having a child with Down syndrome in the family. The recommendation based on the finding will also help stakeholders and policy makers.

Consent:

Dear respondents:

This questionnaire is only for research purposes. I assure you that confidentiality and anonymity will be fully maintained. To strengthen this you are not expected to write anything such as name, ID, and address that may lead to your identification. Your participation is purely voluntary, and you can withdraw at any time after you get involved in the study without compromising your right. However, I hope that you will participate in this study since your responses are quite important. If you are willing to take part in the study, you are kindly requested to respond to all questions honestly!

Now do you agree to participate in the study? Yes _____ No _____.

Thank you very much for your cooperation!

Date _____ month_____ year_____

Amharic version of information sheet and consent

የመረጃ ገፅ

በአዲስ አበባ ዩኒቨርሲቲ የማህበራዊ ሳይንስ ኮሌጅ የሶሻል ወርክ ድህረ ምረቃ ትምህርት ፕሮግራም ተማሪ ነኝ። በመሆኑም አሁን ላይ እየሰራሁ ላለሁት ጥናት እንደተሳታፊ ሆነው ይመረጣሉ እናም የተሳትፎ ፍቃድ ከመስጠቶ በፊት ከጥናቱ ጋር የተያያዙ አስፈላጊ መረጃዎች ማወቅ ያስፈልግዎታል። ስለዚህም የሚከተለው መረጃ ስለ ጥናቱ እና ስለ እርስዎ ተሳትፎ በዝርዝር ይብራራሎታል፡

የጥናቱ ርዕስ፡ በአዲስ አበባ ከተማ አንድ ቤተሰብ ውስጥ አንድ ልጅ ከዳውንሲንድሮም ጋር ሲወለድ ምን አይነት ትፅዕኖ ሊያመጣ ይችላል።

የድርጅቱ ስም፡ ዲቦራ ፋውንዴሽን

የጥናቱ ዓላማ፡ በዲቦራ ፋውንዴሽን ከተመዘገቡ ቤተሰቦች መካከል ዳውን ሲንድሮም ጋር የተወለደ ልጅ በቤተሰብ ውስጥ ያለውን ተጽእኖ ለማጥናት ነው።

የሚካተቱት ተሳታፊዎች፡ ከዳውንሲንድሮም ጋር የተወለዱ ልጆች ሆነው ከዲቦራ ፋውንዴሽን አገልግሎት የሚያገኙ ቤተሰቦች መካከል ዕድሜ ከ 4-10 ናቸው። ጥናቱ የልጆቹ የመጀመሪያ ደረጃ ተንከባካቢ የሆኑ ማለትም እናቶች፣ አባቶች፣ ወንድሞች እና እህቶችን ብቻ ያካተተ ነው።

ሂደት፡ መረጃ የሚሰበሰበው በመጠይቅ እና ቡድን ውይይት ነው።

ምስጢራዊነቱ፡ ሁሉም ሰው የሚሰጠው መረጃ በሚስጥር የተጠበቀ እና ለማንኛውም ሶስተኛ ወገን የሚደርስ አይሆንም። ስም በቁጥር ኮድ ነው የሚጻፈው።

ስጋቶች፡ የተገኘው መረጃ ለጥናት ዓላማ ብቻ የሚውል እንጂ በተሳታፊዎች ላይ ምንም ጉዳት የለውም። በቃለ መጠይቁ ወቅት ለማያውቁት ጥያቄ ምላሽ ለመስጠት አይገደዱም።

ጥቅሙ፡ የጥናቱ ተሳታፊ የሆነው ቤተሰብ ከዳውንሲንድሮም ጋር አንድ ልጅ በመውለዱ ምክንያት የሚገጥሙትን ተግዳሮቶች በመጠናቱ ቀጥተኛ ያልሆኑ ጥቅሞች አሉት። በግኝቱ ላይ የተመሰረተ ምክረ ሃሳብ እንዲኖር እና ባለድርሻ አካላት እና ፖሊሲ አውጪዎች በማመቻቸት ላይ እንዲሰሩም ይረዳል።

የስምምነት ፈቃድ፡-

ውድ ምላሽ ሰጪዎች፡-

ይህ ቃለ መጠይቅ የሚውለው ለጥናቱ ዓላማ ብቻ ይሆናል። ምስጢራዊነቱን ሙሉ በሙሉ እንደሚጠበቅ በዚህ ፅሁፍ አረጋግጣለሁ። ይህንን ለማጠናከር እንደ ስም፣ መታወቂያ እና አድራሻ ማለትም ወደ መታወቂያዎ የሚወስድ ማንኛውንም ነገር እንዲጽፉ አይጠበቅብዎትም። የእርስዎ ተሳትፎ በፈቃደኝነት ላይ ብቻ የተመሰረተ ነው፣ በተጨማሪም በማንኛውም ጊዜ በጥናቱ ውስጥ ከተሳተፉ በኋላ የመመውጣት መብቶ የተጠበቀ ነው። ሆኖም፣ የእርስዎ ምላሾች በጣም አስፈላጊ ስለሆኑ በዚህ ጥናት ላይ እንደሚሳተፉ ተስፋ አደርጋለሁ። በጥናቱ ላይ ለመሳተፍ ፈቃደኛ ከሆንክ/ሽ ሁሉንም ጥያቄዎች በሐቀኝነት እንዲመልሱ በአክብሮት እንጠይቃለን፡-

አሁን በጥናቱ ለመሳተፍ ተስማምተሃል? አዎ _____ አይ _____.

ስለ ትብብርዎ በጣም እናመሰግናለን!

ቀን _____ ወር__ አመት_____

Appendix II

English Version of the In-depth interview and FGD

Part I - Socio demographic information (personal data of the participant)

Personal data of the participant

1.1. Age: ----------

1.2 Sex

1.Male

2.Female

1.3Address (Subcity in Addis Ababa):

1.Akaki Kaliti 2.Nifas Silk Lafto 3.Kolife Keranio 4.Gulele 5.Lideta 6.Kirkose 7.Arada 8.Adis Ketema 9.Yeka 10.Bole 11.Lemi Kura

1.4 Relationship with the child :

1. Mother
2. Father
3. Sibling
4. Close relative

1.5. Religion .....

1.6. Marital Status:

1. Not Married
2. Married
3. Spouse passed away
4. Divorced

1.7 If divorced, what was the reason?

1. Economical Struggle
2. Due to your child with down syndrome
3. Other personal issue

1.8 Highest educational level:

1. Not Formal Education
2. Elementary School Complete
3. High School Complete
4. College Diploma
5. First Degree
6. Master's Degree
7. PhD

1.9 What is the major source of income? (Occupation)

1. No Income
2. On Social Welfare(aid)
3. Government employee
4. Private employee
5. Self employed
6. Other .....

1.1. Monthly income (In Eth.Birr)

1. <2,250(very Low income)
2. 2,250-8,900(Low income)
3. 8,900-39,700(Moderate income)
4. >39,700(High income)

1.11 Number of children:----------

2.Part II-Information Related to the child

2.1 Age:

1. 18-24
2. 25-34

3. 35-44

4. 45-54

5. 55 and above

2.2 Sex:

1. Male

2. Female

2.3 Your child with Down syndrome, in the birth order rank:

1. First child

2. Middle child

3. Last child

Part II - Impact of children with Down syndrome

3.1 What were your first reactions when the child's condition was disclosed to you ?

3.2 Who first told you?

3.3 Where was the place?

3.4 What have you done after you were told about his/her condition?

3.5 How were the reactions of the rest of your family members about your child/s condition?

3.6 How long did you and your family members take to adjust to the child's condition?

3.7 What were the challenges you faced in the beginning and now?

3.8 What coping strategies have you and your family adopted to navigate the challenges associated with raising a child with Down syndrome?

3.9 What are the emotional and psychological impacts of having a child born with Down syndrome in the family?

3.10 How do you perceive the social attitudes, stigma and discrimination toward a child with Down syndrome and of their parents?

3.12 How does caring for a child with Down syndrome affect your economic status such as employment, financial stability and access to necessary resource and services?

3.13 How did it affect your family's interaction and relationship with in the families? Has it altered the family's relationship because of your child's condition?

3.14 What barriers do you encounter in accessing necessary service for a child with Down syndrome?

Thank you!

Amharic Version of the In-depth interview and FGD

ክፍል I- የተጠያቂው ማህበረሰባዊ እና ግለሳባዊ ሁኔታ

የተሳታፊው የግል መረጃ

1.1. ዕድሜ:

1. 18-24
2. 25-34
3. 35-44
4. 45-54
5. 55 እና ከዚያ በላይ

1.2. ፆታ:

1. ወንድ
2. ሴት

1.3. አድራሻ (ክ/ከተማ):

1.አቃቂ ቃሊቲ 2.ንፋስ ስልክ ላፍቶ 3.ኮልፌ ቀራኒዎ 4.ጉለሌ 5.ልደታ 6.ቂርቆስ 7.አራዳ 8.አዲስ ከተማ 9.የካ 10.ቦሌ 11.ለሚኩራ

1.4. ከልጁ ጋር ያለው ግንኙነት:

1. እናት
2. አባት
3. እህት/ወንድም
4. የቅርብ ዘመድ

1.5. ሀይማኖት: _____

1.6. የጋብቻ ሁኔታ

1. ያላገባ
2. ያገባ
3. የተፋታ/የተለያየ
4. ባል(ሚስት) የሞተባት/ችበት

1.7. ከተለያየየ መለያየት ምክንያት ምን ነበር?

1. የኢኮኖሚ ውጥረት
2. በልጁ የጤና ሁኔታ ምክንያት
3. ሌሎች (የቤተሰብ ውጥረት)

1.8. የአጠናቀቁት ከፍተኛው የመደባኛት/ት ደረጃ ውስንትነው?

1. መደበኛ ት/ት የለውም

2. የመጀመሪያ ደረጃ ት/ት

3. ሁለተኛ ደረጃ ት/ት

4. ተቋማዊ ዲፕሎማ

5. የባችለር ድግሪ

6. ማስተርስ

7. ኤም.ዲ/ፒ.ኤች.ዲ

1.9. ለቤተሰቡ ዋናው የገቢ ምንጭ ምንድን ነው?

1. ምንም ገቢ የለም

2. በማህበራዊ ደህንነት (እርዳታ)

3. የመንገስት ሰራተኛ

4. የግል ሰራተኛ

5. በራስ ተቀጣሪ

6. ሌላ

1.10. እራስዎን በኢኮኖሚ እንዴት ያስባሉ?(ወርሃዊ ገቢ በበር)

1. በጣም ዝቅተኛ ገቢ(<2,250 ብር)

2. ዝቅተኛ ገቢ(2,250-8,900 ብር)

3. መካከለኛ ገቢ (8,900-39,700 ብር)

4. ከፍተኛ ገቢ (>39,700 ብር)

1.11. ቤት ውስጥ የልጆች ብዛት: ——————————

<u>ክፍል II - ጥያቄ/ ከልጁ ጋስ የተዛመደ መረጃ</u>

2.1 እድሜ

1. 1

2. 5

3. 6

4. 7

5. 8

6. 9

7. 10

2.2 ፆታ

1. ወንድ

2. ሴት

2.3 ከዳውንሲንድሮም ጋር የተወለደው ልጅዎ፣ በውልደት ቅደም ተከተል ደረጃ:

1. የመጀመሪያ ልጅ

2. መካከለኛ ልጅ

3. የመጨረሻ ልጅ

<u>3.ክፍል ሶስት -ጥያቄ</u>

3.1 መጀመሪያ ስለ ልጆት ሁኔታ በምን አይነት መንገድ አወቁ ? የነገረዎትስ ማን ነው?

3.2 የህፃኑ ሁኔታ ሲገለፅ ልዎ የመጀመሪያ መላሽዎ ምን ነበር?

3.3 ቦታዎ የት ነበር ?

3.4 ስለልጆት ሁኔታ ከሰማችሁ በኋላምን አደረጋችሁ ?

3.5 የቀሩት የቤተሰብ አባላት ስለ ልጅዎ ሁኔታ የሰጡት ምላሽ ምን ነበር?

3.6 እርስዎ እና የቤተስበዎ አባላት የልጁን ሁኔታዎ ለመልመድ /ለመቀበል ምን ያህል ጊዜ ወስደዋል?

3.7 ከዚህ ጋር በተያያዘ በመጀመሪያ እና አሁን ያጋጠመዎት ፈተናዎች ምንምን ነበሩ?

3.8 እርስ እና የቤተስበዎ ከዳዎንሲንድሮም ጋርየ ተወለደውን ልጆትን ከማሳደግ ጋር ተያይዘው የሚመጡትን ተግዳሮቶች ለመቋቋም ምን አይነት ስልቶችን ተጠቅማችኋል ?

3.9 በቤተሰብ ውስጥ ከዳውንሲንድሮም ጋር የተወለደን ልጁ ማሳደግ ምን አይነት ስሜታዊና ስነልቦናዊ ተፅእኖዎች ይኖሩታል?

3.10 በቤተሰብ ውስጥ ከዳውንሲንድሮም ጋር የተወለደን ልጅ ማሳደግ በማህበራዊ ህይዎት ላይ ምን አይነት ተፅኖዎች ይኖሩታል?

3.11 ማህበረሰቡ ከዳውንሲንድሮም ጋር የተወለዱ ልጆች እና ወላጆቻቸው ላይ ሊኖረው የሚችለውን አመለካከት፣ መገለልና መድልዎ እንዴት ይገነዘባሉ? ከእርሶስ አንፃር የገጠመዎት ነገር ይኖራል?

3.12 ከዳውንሲንድሮም ጋር የተወለደን ልጅ መንከባከብ ኢኮኖሚያዊ ሁኔታዎችዎ ላይ ምን አይነት ተፅእኖ ያሳድራል?

3.13 ከዚሁ ጋር ተያይዞ ቤተሰብ መካከል ባለግንኙነት እና መስተጋብር ላይ ያለው ተፅእኖ ምን ይመስላል ?

3.14 ከዳዎንሲንድሮም ጋር የተወለደ ልጅ ለእርሱ አስፈላጊ የሆኑ አገልግሎቶችን ለማግኘት ምን መሰናክሎች ሊያጋጥሙት ይችላሉ ?

አመሰግናለሁ

Appendix III

English Version of Key Informant Interview Guide

1. Part I– Socio demographic information

1.1 Age:

1. 18-24

2. 25-34

3. 35-44

4. 45-54

5. 55 and above

1.2 Sex:

1. Male

2. Female

1.3 Occupation/position: _____

1.4 What is your work experience/ How long did you work in your position: _____

2. Part II –About the impact of Down syndrome

2.1 What are some of the common complaints you observe from families with Down syndrome children?

2.2 Based on your experience what mechanisms do they use to cope with the problems they face?

2.3 What are the most prevalent challenges faced by families with Down syndrome?

2.4 What are the criterias to accept such children to your organization?

2.5 How often do parents come to find help from your organization?

2.6 Describe the kind of service your organization provides for families and children with down syndrome?

2.7 What are the challenges you face when delivering services to families with Down syndrome children?

2.8 What kind of external support do you seek to improve your organization services if possible?

2.9 In your opinion, what should be done to improve the life of families with Down syndrome in Addis Ababa?

2.10 Is there anything you want to tell me about the children, the service you provide, the family of the children, and the impact it has on the families.