EFFECTS OF CHILDREN’S DISABILITIES ON THEIR FAMILIES IN TANZANIA: THE CASE OF AUTISM SPECTRUM DISORDER

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A THESIS SUBMITTED IN FULFILLMENT OF THE REQUIREMENTS
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CERTIFICATION

The undersigned certifies that he has read and hereby recommends for acceptance by The Open University of Tanzania a thesis entitled: **“*Effects of Children’s Disabilities on their Families in Tanzania: The Case of Autism Spectrum Disorder*”**, in fulfillment of the requirements for the degree of Master of Arts in Sociology of the Open University of Tanzania.

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Prof. Mary Damas Kitula

(Supervisor)

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Date

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DECLARATION

I, **Machunde Hamisi Mauma,** declare that the work presented in this thesis is original. It has never been presented to any other University or Institution. Where other people's works have been used, references have been provided. It is in this regard that I declare this work as original mine. It is hereby presented in fulfilment of the requirement for the Degree of Master of Arts in Social Work (MSW) of the Open University of Tanzania

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Signature

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Date

DEDICATION

I dedicate this thesis to my beloved son, Nathan Machunde Mauma. You have inspired me to do this study. I hope one day you will read this thesis. God bless you always.

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I would like to acknowledge and wholeheartedly thank parents of children with autism spectrum disorder, special education teachers, social workers, nurses, and medical doctors who took part in this study for their time and valuable contributions. In addition, I thank all experts at the Muhimbili National Hospital who participated in this study, “Thank you very much for everything.”

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ABSTRACT

With a sample size of 21 participants—11 parents and 10 professionals—the study used an exploratory qualitative design. Using purposive and snowball sampling methods, the sample was chosen. Using Microsoft Excel for coding and topic tracking, interview transcripts were thematically analyzed using Braun and Clarke's six-step thematic analysis process. The majority of families with children with ASD reported having to shoulder the financial burden of raising their kids, according to the study. Some parents then had health issues as a result, including high blood pressure, stress, anxiety, depression, and antisocial behaviour. The majority of participants weren't happy with the kind of care their kids got at public hospitals. The participants discussed the difficulties and obstacles associated with raising children with autism, including inexperienced medical professionals, exorbitant therapy fees (music, occupational, speech, and language), financial strain, ignorance of harmful customs, stigmatization and discrimination, stress, anxiety, and depression, and marital/spouse conflicts. It is anticipated that the study's findings will provide the government—more especially, the Ministry of Health—and other relevant parties with scientific information about how to handle and treat ASD disabilities. The report specifically recommends that the government lessen the multiplying effects of the ASD problem by assisting families and individuals (socially and economically). To promote early diagnosis and intervention against ASD, the study also calls on the government and society to educate individuals about detrimental traditional practices and beliefs. Lastly, the government ought to work towards constructing new schools and renovating outdated ones with subpar settings and infrastructure for kids with autism and related developmental disabilities.

Keywords: *Children with autism, detrimental traditional practices, ASD*

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ADDM	Autism and Developmental Disabilities Monitoring Network
ASD	Autism Spectrum Disorder
CDC	Center for Disease Control and Prevention
CWDs	Children with Disabilities

CHAPTER ONE

INTRODUCTION

1.1 Background to the Problem

According to estimates from the World Bank and the World Health Organization, over a billion people worldwide—roughly 15% of the total population—live with a handicap. Of these, 110 million (2.2%) to 190 million (3.8%) adults struggle to function at a very high level (WHO, 2012). Furthermore, according to UNICEF (2013), 80% of children with disabilities (CWDs) under the age of five reside in developing nations, with the majority of them being in sub-Saharan Africa (UNESCO, 2010).

A child may experience issues with their vision, hearing, comprehension, mobility, communication, emotion regulation, social interactions, or mental health. The child may experience challenges with sitting, crawling, walking, holding or manipulating items, using the lavatory, speaking properly and understood, understanding simple directions, dressing or feeding themselves appropriately, and using words to communicate (Sammon & Burchell, 2018). While some kids only have one disability, others could have two or more disabilities. For example, a child with hearing loss may have difficulties in developing communication and language skills. The child's experience of disability is determined by different factors, ranging from personal, environmental, and other health conditions (WHO, 2012). Because each child is unique, disability can affect individual children differently, even among children with the same type of disability. Children can also be affected by more than one type of disability; for example, their movement and sight can be affected (Sammon & Burchell, 2018). Children with disabilities affect their family members and family well-being as well. The attention of the present study focused on autism spectrum disorder parse as one of the child's disabilities. A child with hearing loss, for instance, could struggle to acquire language and communication skills. Many factors, such as environmental, personal, and other health issues, influence how a child experiences disability (WHO, 2012). Due to their individuality, children with disabilities might have varying effects on them, even on children who have the same kind of condition. It is possible for children to experience multiple forms of disabilities, such as impairments to their sight and movement (Sammon & Burchell, 2018). Families with disabled children also have an effect on the well-being of their family members. The study's attention was drawn to autism spectrum disorder as one of the children's problems.

Autism spectrum disorder (ASD) is a neurological and developmental illness that manifests early in childhood and persists throughout an individual's life (National Library of Medicine, United States, 2016). It has an impact on how someone behaves, engages with people, communicates, and learns. Pervasive developmental disorders and what was formerly known as Asperger syndrome are included. Those with ASD may experience a wide range of symptoms, which is why it is known as a "spectrum" disorder. People with ASD, for instance, may find it difficult to communicate with you or may avoid looking you in the eye while you speak. They could also engage in repetitive behaviour and have limited interests. They might take a long-time organizing thing, or they might repeat the same phrase. Frequently, they could appear to be in their "own world." (National Library of Medicine, United States, 2016).

Children with ASD frequently avoid making eye contact with others and may not react when their names are called. Additionally, because they may miss social cues like tone of voice and facial expressions and don't pay attention to other people's faces for cues regarding appropriate behaviour, they have trouble deciphering what other people are thinking or feeling. They consequently relate poorly with others and lack empathy (Manji & Hogan, 2013). People with ASD can have exceptional learning, thinking, and problem-solving skills, or they can be extremely challenged. Because of this, some ASD sufferers require a great deal of assistance, while others require less.

A spectrum of developmental disorders known as autism spectrum disorder (ASD) can lead to severe difficulties with behaviour, social interaction, and communication (CDC, 2010). An estimated 160 people worldwide are believed to have ASD, which accounts for 7.6 million years of life adjusted for handicap. Since it is yet unknown how common ASD is in low- and middle-income areas like Africa, this burden is currently underestimated. For instance, among African children with developmental problems, a study including two North African nations found a high frequency of ASD at 11.5% and 33.6%. Although the representativeness of these research is debatable, other studies with children of African heritage have revealed a significant prevalence of ASD. Similar to this, research on ASD shows that African children with ASD have a high burden of nonverbal ASD cases (50–71%) and over 60% of concomitant intellectual disability. The need for additional study on public health responses in this region is highlighted by these and other unique characteristics of ASD in Africa, including possible viral etiology, delayed diagnosis, and inadequate management (Abubakar et al., 2016).

Epidemiological research over the last half-century suggests that ASD is becoming more commonplace worldwide. For example, since the first epidemiologic studies were carried out in the late 1960s and early 1970s, the prevalence of autism has increased twenty- to thirty-fold worldwide. Prevalence estimates from big surveys in the 2000s were between 1% and 2% of all children, although at that time estimates from European research were one in 2,500 children in the community (CDC, 2014).

The issue of ASD has been the subject of numerous investigations. Malhi and Singhi (2014) and Zwaigenbaum et al. (2009) discovered in their research that parents of children with ASD would be worried about their child's development at 18 months. Researchers who investigated home videotapes from the child's first birthday onward (Palomo et al., 2006; Werner & Dawson, 2005) found that it is feasible to see behaviour associated with ASD at this age in children who are later diagnosed with the disorder. Examining the younger siblings of children with ASD is an additional strategy. The first behavioral symptoms appear to emerge in the second year of life, and throughout this period, social skills and language abilities differ more between children with and without ASD. All 18- and 24-month-olds should have an ASD screening performed during routine medical visits, according to the American Academy of Pediatrics’ recommendation (Stenberg et al., 2014).

Arvidsson et al. (1997) examined all forty-one children, aged three to six, living in a town outside of Goteborg, Sweden, for autism. It was discovered that out of 10,000 children evaluated, 31 had an autism diagnosis, and 15 had a diagnosis despite meeting some but not all of the diagnostic criteria. According to Fombonne et al. (1997), 325,347 French children born between 1976 and 1985 were evaluated. According to their findings (Matson & Kozlowski, 2010), the prevalence rates of all-pervasive developmental disorders were 16.3 per 10,000 and autism was 5.37 per 10,000 children. The Autism and Developmental impairments Monitoring Network (ADDM) was founded in 2000 by the Centers for Disease Control and Prevention (CDC) to gather information for estimating the incidence of ASD and other developmental impairments in the US. The complexity of ASD, the paucity of biomarkers for diagnosis, and the constantly shifting diagnostic standards make tracking its prevalence particularly difficult. According to the CDC's most recent figures (2009), there are 90 cases for every 10,000 people. (CDC, 2014).

For instance, according to Mahapatra et al. (2019), 1.7 to 2 million youngsters in India suffer from ASD. According to Adak and Halder (2017), ASD cases range from 21.1 to 181 per 10,000 in Japan, 264 per 10,000 in South Korea, and 10.3 per 10,000 children in China. Even though there is a lot of discrepancy in these figures, the researchers did find that the numbers are indeed rising.

Better reporting expanded diagnostic criteria, enhanced awareness, and improved diagnostic instruments are all credited with the rise in ASD cases (WHO, 2017). As an example, the diagnosis of ASD now encompasses a number of symptoms that were formerly labelled as different disorders, such as Asperger syndrome, autism disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). The CDC (2017) has renamed these illnesses as autism spectrum disorders.

The most crucial realization is that family dynamics play a role in the occurrence of autistic behaviour. Consequently, the behavioral issues linked to autism provide a host of difficulties for families raising autistic children. According to Bashir et al. (2014), having an autistic child in the family can have a negative impact on several aspects of family life, including as marriages, sibling relationships and adjustment, family socialization techniques, and regular family routines. For instance, during the first few weeks or months, some children with autism do not sleep through most of the night. Consider a situation where a child diagnosed with autism spends the first twelve or more years of life not only sleeping through most of the night, but also exhibiting behaviour such as singing, yelling, repeating conversations, running around the house, and/or attempting to escape (Glass, 2001).

The government of the United Republic of Tanzania (URT) has made a number of attempts to address this issue in relation to the child's impairment. The government has created laws, regulations, and a number of initiatives to address the disabilities of children. These comprise the following: The First and Second National Strategies for Growth and Reduction of Poverty (NSGRP I & II-in Kiswahili, MKUKUTA I & II) policy; the Persons with Disabilities Act of 2010; the National Survey on Disability, 2008; the National Policy on Disability, 2004; and the National Disability Mainstreaming Strategy, 2010-2015 (EFA National Review Report, 2015; URT, 2010b).

Tanzania still has issues with the wellbeing of kids who have ASD, nevertheless. First, data on six categories of disability were gathered for the 2012 Population and Housing Census: self-care, albinism, sight, walking, hearing, memory, and other sorts of disability (NBS, 2016). That is, no particular information about autism was gathered throughout the exercise. Given that the national Census provides the basis for the distribution of finances, projects, and strategies, it can be inferred that the government of the United Republic of Tanzania places little emphasis on these categories of disabilities. Two to four cases of autism per 10,000 children were estimated to be prevalent in the early research on the condition conducted in Europe and the United States in the 1960s and 1970s. According to Boat & Wu (2015), Miodrag et al. (2012), and Stigler et al. (2013), this gave rise to the perception that autism was an uncommon childhood illness. However, autism is today a pressing public health issue in Tanzania that requires preparation.

In a similar vein, on April 18, 2019, Mr. Joseph Kakunda, the Deputy Minister of State in the President's Office (Local Government and Regional Administration), stated in parliament that there were 1,416 autistic pupils in the nation but only 157 teachers in 18 elementary schools. According to Mr. Kakunda, the small number of teachers was unable to provide instruction for so many kids with ASD. He saw that certain instructors at Patandi College in Arusha, who had received training to work with autistic children, had not yet been assigned to special needs schools. Subsequently, by December 2018, Mr. Kakunda ordered all municipalities in the nation to assign these teachers to special needs schools, which included those serving students with autism. Global health authorities' guidelines state that one teacher is currently needed for every autistic child, however Mr. Kakunda claimed that Tanzania does not adhere to this norm due to a teacher shortage. According to him, the government would work harder and spend more money to prepare instructors for special education classrooms (Tanzanian Parliament, 2018). Naturally, the 1,416 autistic kids listed above do not accurately reflect the total number of ASD-affected youngsters in the nation. This is due to the fact that a number of kids with ASD do not attend school. As a result, additional study is required to determine the total number of children in the nation that have ASD.

The fact that there is now so little information available about autistic children in Africa hides the severity of the issue (Bakare & Munir, 2011). A small number of previous research have estimated the prevalence of ASD in Africa. For example, a survey conducted in 2014 by Lagunju and colleagues at a pediatric neurological clinic enrolled 2320 patients. 54 of the 2320 patients underwent a thorough screening process and received an ASD diagnosis, translating to an estimated 2.3% prevalence. Furthermore, at a mean age of 22.1 months, the parents reported a development deviation, and at a mean age of 44.7 months, they were diagnosed. About 75.5% of people diagnosed with ASD also had concomitant neurological conditions. Eight of the 1169 children examined, aged 2 to 9 years, got a positive diagnosis of ASD in one community-based study conducted in Uganda's Kampala District, which is half rural and half urban. An unadjusted prevalence of 6.8/1000 for ASD was found by Kakooza-Mwesige et al. (2014). Nevertheless, convenience sampling was employed in most of this research, and the data primarily came from hospital and specialized units for kids with special needs.

There aren't many studies on ASD conducted in Tanzania (Harrison et al., 2016; Manji and Hogan, 2014). Remarkably, they ignored the impact of ASD on the corresponding families, which was the subject of this study, and instead concentrated on the prevalence, awareness, and attitude of ASD.

1.2 Statement of the Problem

Given that autism spectrum condition is linked to uncomfortable circumstances, anxiety, financial load, sadness, and stress for family members, it has an effect on the well-being of the family (Tansley, 2013). Autism is also linked to unfavorable stereotypes, which have a psychological effect on parents of children with autism. To lessen the severity of the issue and enhance people's lives, the government, families with children with ASD, non-governmental organizations, and private institutions have all made several efforts.

However, the success of the efforts is limited by the lack of research on autism spectrum condition in sub-Saharan Africa (Bakare et al., 2019). As a result, Tanzania has no government statistics on the incidence or effects of autism. Thus, not much is known about the initiatives and assistance provided to Tanzanian families whose children have ASD. The kind and efficacy of services provided to kids with ASD are also still up for debate. In other words, it's uncertain if the offered solutions achieve their objectives or need further examination.

Considering this, the purpose of this study was to investigate the effects of autism spectrum condition in Tanzania. It assessed the approaches used by educators, medical professionals, nurses, social workers, hospitals, and non-governmental organizations to address ASD. It answered issues like: Do ASD stakeholders have the resources needed to cope with ASD? Do they receive enough assistance to manage ASD? What strategies do parents of autistic children employ to manage the situation? And how can ASD affect the overall wellbeing of the family?

To improve the solution and lessen the severity of the issue, the study will inform interested parties about the measures used to lessen the consequences of autism. Consequently, this will enhance the well-being of the impacted kids, their families, and the community at large.

1.3 Main Objective

This study aimed to examine the effect of autism spectrum disorder on the family's well- being.

1.2.1 Specific Objectives

The specific objectives which guided the research were to:

i) Explore parents' experience encountered before their children were confirmed diagnosed with ASD

ii) Examine the perspectives of parents and professionals on the effects of autism spectrum disorder on the family family's well-being

iii) Evaluate the status of the government services and support for autism spectrum disorder.

1.2.2 Research Questions

The study was guided by the following research questions:

i) What is parents’ experience encountered before their children were confirmed diagnosed with ASD

ii) What are the perspectives of parents and professionals on the effects of autism spectrum disorder on the family family's well-being?

iii) What is the status of the government services and support for autism spectrum disorder?

1.4 Significance of the Study

The findings of the study could potentially assist the Tanzanian government, particularly the Ministry of Health (MoH), in modifying health policies that would enhance resources and services specifically related to autism spectrum disorder. The study emphasizes the necessity of modifying educational policies to better serve and accommodate students with autism spectrum disorders. The findings of this study may also contribute to changes in the ways that educators and healthcare professionals in special schools operate. The community is also made aware of this issue by the study. In other words, the data will give parents important information for early child assessments, allowing them to see any indicators of autism and take appropriate action as soon as possible.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

Some pertinent theories that are directly related to the study were included in the theoretical framework and literature review of this chapter. Furthermore, an analysis is conducted of the empirical literature review that is directly related to the ideas, elements, and circumstances linked to autism spectrum disease and its consequences for the welfare of the family.

2.2 Theoretical Literature Review

The two primary theories that drove the present study's assessment of the effects of autism spectrum disorders on family well-being were Ecological Systems Theory and Family Systems Theory.

2.2.1 Family Systems Theory

The Family Systems Theory was introduced by Dr. Murray Bowen (1954). It suggests that individuals cannot be understood in isolation from one another but as part of their family. The Family Systems Theory was one of the first comprehensive theories of family systems functioning. It is a theory of human behaviour that views the family as an emotional unit and uses systems thinking to describe the complex interactions in the unit. Members of the family are intensely connected emotionally. Family members have such a strong influence on one another's attitudes, sentiments, and behaviour that it frequently appears as though people share the same "emotional skin." Individuals respond to each other's wants, expectations, and distress as well as seek out and give each other's attention, approval, and support. Family members' interactions are interconnected because of their responsiveness and closeness. Predictably, as one person's functioning in the functioning of others changes, there will be reciprocal changes as well. Although the level of interconnectedness varies throughout families, it is always present to some extent (Brock & Sacks, 2008; Kerr, 2000; Wright & Leahey, 2005). Many times, people feel as though they are cut off from their family, although this is more of an emotion than a reality.

Emotional interdependence most likely developed to foster the cooperation and cohesion families need to provide for the needs of their members in terms of food, shelter, and safety. Problems might arise when these mechanisms that foster harmony and teamwork are heightened by strain. When members of the family experience worry, it can become contagious and worsen. Family members' emotional closeness becomes more taxing rather than consoling when anxiety rises. One or more members eventually experience feelings of overwhelm, isolation, or uncontrollability. These are the ones who go above and above to ease others' tensions. It is a two-way relationship. For instance, someone assumes excessive responsibility for other people's suffering because of their inflated expectations of him. The family member who is most accommodating absorbs anxiety the most, making them the most susceptible to issues like depression, drunkenness, extramarital affairs, or physical disease (Brock & Sacks, 2008; Kerr, 2000).

The family systems approach suggests that having a child with autism spectrum disorders (ASD) affects all nuclear and extended family members. In this view, the family systems theory states that the family's well-being can be measured through the effectiveness of the family in the following: performing tasks, socializing, social control, physical conservation, economy, self-esteem, and membership functions (Zimmerman, 2013).

The reason that an ASD in a child affects not just the child but the entire family system is explained by the Family Systems Theory. In particular, the child's impairment frequently causes disruptions to the system's stability, organization, and homeostasis and necessitates considerable adjustments from several members. For instance, family members frequently need to modify their goals and expectations for the child, take on new roles, consider their attitudes and values regarding ASD and disabilities, deal with their feelings and the stigma associated with these conditions both internally and externally, and acquire new knowledge about the condition and how to best care for the child (Wang, 2016).

ASD kids can be overly demanding. To care for their children, some parents must quit their jobs or work fewer hours due to communication issues or serious sleep issues. According to this theory, evidence clearly shows that parents of ASD children experienced much higher levels of parental distress, anxiety, and depression than parents of children who developed normally (Padden & James, 2017). Mothers of children with ASD are more likely than mothers of children without health constraints to work fewer hours per week and make significantly less money, according to one study (Cidav et al., 2012). Thus, one of the main factors this study looks at is parental stress.

Family systems theory has been criticized that most problems are best treated in a familial context, which leads to a kind of family-based reductionism (Merkel & Searight1992). It assumes that the context for resolution to the problem is the family, which by doing that the theory denies that the families themselves are organized and influenced by larger political, environmental, economic, social forces (Hare-Mustin, 1987; James & McIntyre, 1983; Koch-Hattem, 1987; Merkel & Searight1992;). Because it only focuses on the level of the family, it has been used as a supporting theory in this investigation. This explanation by itself is unable to account for all significant components of the study, since the difficulties associated with raising a kid with ASD extend beyond the family.

2.2.2 Ecological Systems Theory

The scientific study of the progressive, mutual accommodation that occurs throughout a person's life between an active, developing human being and the changing properties of the immediate settings in which they live is known as ecological systems theory. This process is influenced by the relationships between the settings as well as by the larger contexts in which the settings are embedded (Bronfenbrenner, 1989). Ecological Systems Theory by Bronfenbrenner served as the primary theoretical framework for discussing the study's findings.

According to some, Bronfenbrenner was a pioneer in the field of investigating the ecology of human development, having made significant contributions, and influencing the writing and research of other academics. Ecological techniques have been included into human development and psychology, as well as geography, sociology, anthropology, and economics (Barnes et al., 2006; Brendtro, 2006; Cole, 1979; Lerner, 2005; Moen, 1995; Pence, 1988).

Urie Bronfenbrenner's (1977) ecological systems theory can help understand the dynamics of families with an ASD child as well as the possible impact of the disorder on the family and overall well-being. The theory discusses how social support, families, and individuals are impacted by culture (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). According to the idea, each human and his surrounding systems have complicated, reciprocal impacts on one another, and every individual develops within a complex, nested collection of systems.

The four main elements of Bronfenbrenner's Ecological Systems Theory are time, context, people, and process (Wachs & Evans, 2010). The ecological setting is the most well-known and, arguably, the most crucial of the four when it comes to planning and conceiving child development research.

The term "context" describes the various settings that alter the proximal processes, including the physical, social, and economic contexts in which the kid is constantly interacting. For instance, a caregiver's ability to provide high-quality care and positively impact development increases with the number of children they care for (Krishnan, 2010). Four separate concentric systems make up the context, according to Bronfenbrenner: micro, meso, exo, and macro. Each of these systems has an impact on the child's development, either directly or indirectly. Later, the fifth system—chrono—was introduced to include the aspect of time and how it relates to the child's surroundings. This could entail modifications that are internal or external, like physiological shifts or life experiences like parent death (Krishnan, 2010).

Microsystem: The child's immediate environment, or the level nearest to them, is the microsystem. The settings where the proximal processes take place, such as the family, playmates, creche, school, and neighborhood, make up the microsystem. The child is most directly and early influenced by this layer. Since the child's family can affect the child's behaviour and vice versa, the relationships at this level can be bidirectional (Krishnan, 2010).

The microsystem is in the mesosystem, which is the second immediate stratum. It focuses on the relationships that exist between two or more systems, which are essentially distinct microsystems like the house, the playroom, and the school. For instance, events in the child's home can affect their experiences at school or on the playground, and interactions at home might be influenced by events at the school or playground. More precisely, the mesosystem functions when a parent and a teacher are both actively involved in their child's education.

Distal processes are also likely to be at play in the relationship between other bigger structures, such a church or community, since they assist families in giving children the essential support they require. For instance, the mesosystem's ability to function can be impacted by the counselling services that are accessible to the family during difficult times (Krishnan, 2010). Another instance is when a child with ASD's parents and teachers work together to support the child's language development or food self-eating.

The term "exosystem" describes one or more contexts in which the developing person is not an active participant but where events take place that either influence or are influenced by the developments in the developing person's setting (Bronfenbrenner, 1977). For instance, the quality of early experiences and social development can be impacted by social status, poverty, and parental employment. The workplace that parents provide is another illustration of the exosystem. That is to say, even while the child is not physically present in this setting, work-related elements such as stress levels, family leave rules, and pay schedules may have a big impact on the child's life.

The macrosystem encompasses any belief systems or ideologies that underlie consistencies at the subcultural or cultural level, as well as the shape and content of the lower-order system that exists or could exist (Bronfenbrenner, 1977). The larger system or broader societal influences, such as the recession, laws, policies, social norms, power structures within and between social groups, cultural norms, ideology, cultural values, customs, and conventions that impact social interaction and development, may be included in the macrosystem. For instance, how families adjust to their children's ASD may depend on cultural perceptions about disability and children. Cultural norms and ideas can also influence how a family views and makes use of social support. In Wang (2016).

The last level of the theory, the chronosystem, was left out of the study's analysis and debate. This study did not include cultural and societal changes over time that could impact the wellness of a kid and family (Bronfenbrenner, 1994). The investigation encompassed all of the previously described levels of the theory.

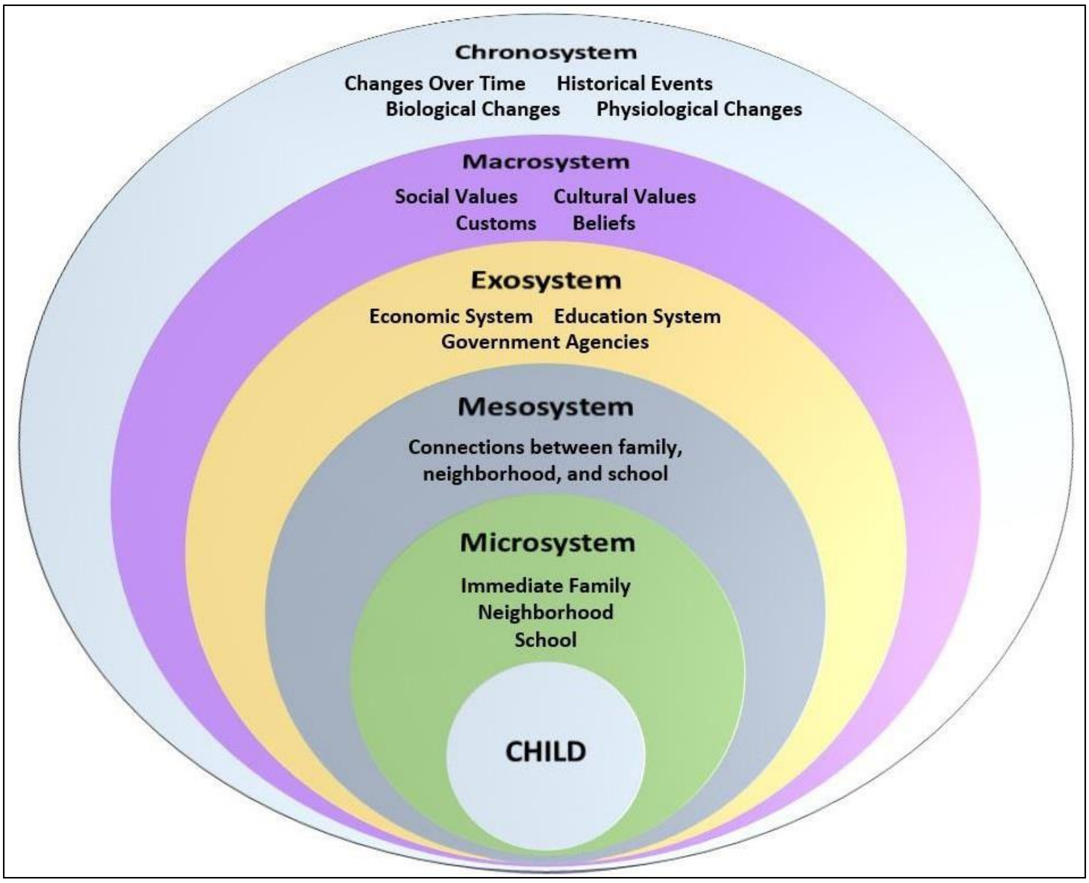

Figure 2.1: Bronfenbrenner's Systems Framework

Source: Adapted from Walker, T. L (2016)

2.3 The Importance of the Theories to the Study

Theories are crucial to research because they direct, give proper direction, and interpret the world around us. A researcher must have a clear understanding of the information that is important to gather before beginning an investigation or gathering data through focus groups or interviews. A clear lens is necessary for a researcher to use when looking. Costley (2006); Longo & Soto, 2016). Theories offer intricate and thorough explanations for intangible concepts, such as how social groupings operate, how societies operate, and the reasons behind particular behaviour among individuals. They are offering a structure to carry out their analysis. Reeves et al. (2008) and Mueller & Urbach (2017). The direction of data collection, analysis, and discussion in this study was provided by the Ecological Systems Theory by Bronfenbrenner and the Family Systems Theory by Murray Bowen. The primary theory, Ecological Systems Theory, helped to clarify the family dynamics influencing children with autism spectrum condition (Paat, 2013). A child with autism may be impacted directly or indirectly by the greater social structure in the family, school, and educational systems (Paat, 2013). These theories provided insight into the data during interpretation and analysis, and also assisted the researcher in crafting interview questions. Being conscious of the perspectives you are adopting when doing your own study is one of the cornerstones of qualitative exploratory research (Sutton & Austin, 2015). Without this understanding, it is simple to start interpreting other people's stories from your own perspective as opposed to the participants' (Sutton & Austin, 2015).

2.4 Empirical Literature Review

A review of the literature reveals that the following factors are more likely to have an effect on a family after a child is diagnosed with ASD: stigmatization, poor cultural practices, the role of support, family stress, marital stress, financial and emotional stress, and interference with work and earnings (Grey, 2002; Howell et al. 2015; Mandell, 2012; Tansley, 2013).

2.4.1 Delaying Seeking Care and Awareness of ASD

Crane et al. (2016) investigated the experiences of receiving an autism diagnosis by surveying more than a thousand parents in the UK. The purpose of this study was to examine more than a thousand parents whose children had been diagnosed with ASD within the previous 15 years. The purpose of this study was to: (i) give a summary of the process parents in the UK go through to get a formal diagnosis of ASD for their child; (ii) pinpoint important variables that affect parents' perceptions of the diagnostic process; and (iii) investigate the needs for post-diagnostic support. An online survey was completed by 1047 parents as part of the study. Research indicates that parents usually experience a 3.5-year wait between reaching out to a healthcare provider for the first time and getting a formal diagnosis of ASD for their child. According to the survey, the majority of participants were unaware of ASD. Additionally, some medical professionals were unable to promptly diagnose a child with an accurate diagnosis, which caused a delay in receiving the correct diagnosis.

In Gona et al. (2015)'s study, they investigated the causes and treatments of autism spectrum disorders (ASD) as regarded by parents and experts on the Kenyan coast. It was carried out in Mombasa and Kilifi, two culturally distinct counties on Kenya's coast. In this qualitative study, professionals and parents of children with an assumed diagnosis of ASD participated. There were 103 participants in the study, 60 from Mombasa County and 43 from Kilifi County. It has been stated that cultural views on witchcraft, curses, and evil spirits have a significant impact on parents' decisions to take their children to the doctor. Most people in these locations thought that disregarding cultural norms could have negative effects, possibly even becoming a curse that could cause autism spectrum disorder (ASD). Rather than using the contemporary healthcare system, some parents choose to treat their child's autism using traditional healers. The study concluded that parents should be encouraged to seek expert healthcare and that awareness of ASD is crucial.

Parental and marital stress: Loepp (2015) investigated how parents of autistic children grow in response to stress. The purpose of this study was to determine which factors—stress, coping mechanisms, perceived social support, age, and gender—are linked to faster growth and if moms and fathers raising autistic children differ or are similar in these areas. A total of 239 participants in the study accessed the online survey. For this survey, only respondents from the United States and Canada were gathered. Every parent in this survey expressed worry and stress about the difficulties their children with ASD will face in the future. My study examined the relationship between stress and the development of parents raising autistic children as well as stigmatizations and cultural perception.

Francis (2017) conducted a study titled ‘exploring autism, a case study on the impact of autism on three Jamaican families. Francis sought to find out the impact of autism on families emotionally, financially, and socially. The specific research questions that guided this study were: *What are the emotional factors that impact families with a child diagnosed with autism on families? What are the financial factors that impact families with a child diagnosed with autism? And what are the supportive systems offered by the state to support families who have autistic children? "Exploring autism, a case study on the impact of autism on three Jamaican families" was the* *title of a study done in 2017 by Francis. Francis investigated the psychological, financial, and social effects of autism on families. This study was specifically directed by the following research questions: What emotional factors affect families who have a kid diagnosed with autism? What financial considerations affect families who have an autistic child? And what assistance programs does the government provide for parents of children with autism?* Francis supported the study with intentional sampling and qualitative case study research. Francis also conducted interviews with three people on autism and how it affects families. According to Francis (2017), parents contested the diagnosis even though they recognized something was wrong with their kids since they did not anticipate this outcome. Parents also looked to other doctors for help in their search for answers. After the diagnosis, parents grieved nonstop and were overcome with terror; they also revealed sentiments of tension, denial, and abandonment. Furthermore, when the parents first discovered that their children had autism, they felt frustration (Francis, 2017). Notwithstanding their sadness with the diagnosis, parents generally tried to get their kids the assistance they needed to be as productive members of society as possible.

Parental coping mechanisms: Tadesse (2014) conducted research on the difficulties and coping strategies faced by families with an autistic kid. The Joy Centre for Children with Autism and Related Developmental Disorder in Ethiopia was the site of the study. Understanding the psychological, social, economic, and marital difficulties parents of children with ASD face was the primary goal of the study. Additionally, he looked at the coping strategies used by families with an autistic child. Tadesse employed a case study as part of a qualitative methodology. Six respondents in total—two fathers, one grandmother, and three mothers—were involved in the study. The respondents' ages range from 27 to 63.

Tadesse (2014) found that social isolation, discrimination, and embarrassment were common experiences for families with a child diagnosed with autism. The results show that respondents' financial stress and labor market engagement were significantly impacted by the condition. The respondents reported having to pay more for food, clothing, and transportation. Additional costs placed on families caring for a kid diagnosed with autism cause disruptions. For most families, it was also challenging to pay for the extra expenses while still offering a balanced diet (Tadesse, 2014). Nearly all the participants saw that their autism affected their ability to enter the workforce. A few of the families had given up their jobs, while some had only minimal involvement in the labor force. It also turned out that the majority of the families under study had no idea their child had autism until it was diagnosed. The study also discovered that there was little psychosocial help given following the diagnosis. Since most medical personnel were unaware of autism, the diagnosing process was also time-consuming and exhausting for them.

In Kilifi and Mombasa, Kenya, Gona et al. (2016) also carried out a study titled "Challenges and coping strategies of parents of children with autism on the Kenyan coast." The study looked at two research questions: What difficulties do parents of autistic children in coastal Kenya face? Which coping mechanisms do these parents employ? The research employed a phenomenological technique and a qualitative design. The respondents were divided into two groups: professionals who regularly interact with parents of autistic children and parents whose children have been diagnosed with autism. A total of sixty respondents came from rural counties and forty-three from urban counties. The study participants were chosen through a purposive–convenience selection process.

According to the study, raising an autistic child in this region of Kenya presents several common difficulties for parents. The main difficulties the parents faced were stigma, embarrassment, and isolation of the child and family. In these places, parents dealt with issues navigating public interactions, social isolation of their kids, and intolerance in the community (Gona et al., 2016). According to the study, this encouraged the parents to look into potential therapies.

Limited research on autism spectrum disorder in Tanzania: There hasn't been much study on autism spectrum disorder published in Tanzania. A small number of studies on autism concentrated on the condition's awareness, assessment, and knowledge gap. Studies on the impact of autism spectrum disorder on the wellbeing of the family are not available in this regard. Gaps in Tanzania's understanding, prevalence, and treatment of children with autism spectrum condition were noted by Manji and Hogan (2014). They made use of a variety of techniques, including as facility visits, key person interviews, and resource identification in order to provide better care for kids with ASD. Manji and Hogan discovered that Tanzania lacked adequate resources in terms of knowledge, infrastructure, and personnel for dealing with autistic children. Along with this, they reported on the dearth of human resources and the continuous development of carers' capacities among the schools assessed and the school administrators they spoke with. Similarly, they provided scant and dispersed data on autism-affected children in Tanzania. There were also reports of the public facility's inadequate care and education, and the private facilities' enormous financial load and reliance on donations.

The study "Development of a Brief Intervention to Improve Knowledge of Autism and Behavioral Strategies Among Parents in Tanzania" by Harrison et al. (2016) was conducted in Tanzania. The main goal of the project is to provide an intervention that educates parents about ASD and behavioral techniques that have been shown to work. Harrison and associates created a two-phase intervention to increase carer awareness and teach them some fundamental behavioral intervention techniques. 14 carers took part in an ASD knowledge intervention and a needs assessment session during the first phase. During the second phase, an intervention was conducted with 29 carers, with an emphasis on basic behavioral tactics. These included parenting skill training, basic abilities like copying and making eye contact, and self-help skills like feeding. Almost all participating carers regarded the intervention effective, and the initial evaluation showed that it was viable to execute despite a few problems (Abubakar et al., 2016).

2.5 Research Gap

The effects of autism spectrum condition on the family have been the subject of numerous studies carried out in industrialized nations. Few researches on the effect of autism on the family have been conducted in Africa, especially in Tanzania. As this literature review demonstrates, no thorough investigation of how autism spectrum condition affects a family's well-being has been done. According to research, the following factors are more likely to have an effect on a family after a child is diagnosed with autism spectrum disorder: stigmatization, poor cultural practices, the role of support, family stress, marital stress, financial and emotional stress, and interference with work and earnings (Grey, 2002; Howell et al. 2015; Mandell, 2012; Tansley, 2013). As a result, there is a knowledge gap that requires attention.

2.6 Definition of Concepts

The following are the key terms and concepts that were defined to enhance the readers' knowledge to understand this study better. The definitions provided here were used in the context of this study. The definitions of the following important terminology and ideas will help readers better understand this study. This study's context was applied to the definitions given here.

2.6.1 Autism

A type of autism spectrum disease that is usually identified before the age of three and is characterized by delayed or abnormal behaviour in at least one of the three domains: behaviour, interaction, or communication (Willis, 2006).

2.6.2 Autism Spectrum Disorder (ASD)

A general phrase for autism and four other disorders that impact socialization, communication, and environmental response (Willis, 2006). The broad range of abilities, symptoms, and degrees of impairment, or handicap, that children with ASD may exhibit is referred to as the "spectrum." Some kids may have minor symptoms, while others have significant disabilities.

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychological Association, 2013) states that limited, repetitive behaviour and difficulties with social communication and social interaction are the hallmarks of autism spectrum disorder (ASD).

Social communication and social interaction symptoms involve (American Psychological Association, 2013):

i) Deficits in social-emotional reciprocity range from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

ii) Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

iii) Difficulties in forming, sustaining, and comprehending connections, such as the inability to modify behaviour to fit different social circumstances, the inability to share creative play or make friends, or the lack of interest in peers.

Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (American Psychological Association, 2013):

i) stereotyped or repetitive motor movements, for example, hand flapping, use of objects (for example, spinning or lining up toys), and/or speech (using repetitive and/or unusual words or phrases).

ii) insistence on sameness and/or ritualized behavior patterns, for example, extreme distress at small changes, difficulties with transitions, and needing to follow the same schedule or sequence of completing activities.

iii) unusual or overly intense interests, for example, interest in an unusual object or topic, intense in a narrow area.

iv) hyper- or hypo-reactivity to sensory input, for example, negative reactions to certain textures or sounds; excessive smelling, peering at or touching objects.

2.6.3 Family

Family is described as "a set of persons related to each other by blood, marriage, or adoption who constitute a social system" in the Encyclopedic Dictionary of Sociology (Frank et al., 1986). According to Encyclopedia Britannica online (2018), a family is a group of people who are related by marriage, blood, or adoption; they live together in a single household; they interact and communicate with each other as members of different social roles, such as spouses, mothers and fathers, sons and daughters, or brothers and sisters; and they create and preserve a common culture.

Scholars from a wide range of fields, including sociology, economics, anthropology, political science, and law, have given their own unique definitions to the very broad idea of family. Some academics restrict their research to the nuclear family. Some academics define families only as consisting of single parents. Some academics adhere to the term found in the country's Law of Marriage Act. As a result, it is quite challenging to encompass all those facets of the family in a single term.

For the purposes of this study, the family consists of single parents, parents who are not related by blood, and carers such grandparents, living aunts, and uncles. However, the social and cultural background of Tanzania will not be examined in this study using the same gendered parent household.

2.6.4 Family Well-being

Using an emotional, intellectual, physical, spiritual, and social component to enhance one's capacity to live, work, and make a meaningful contribution to society is what it means to be well-being (Corbin & Lindsey, 1994). The aspects of parent well-being, carer well-being, child well-being, and healthy family interactions are all considered to be components of family well-being in this study. Consequently, the study has looked into the factors that affect each family member's well-being as well as the relationships they have in common, which might be many, interconnected, and reciprocal.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

The purpose of this study was to investigate how autism spectrum disorder has an effect on the welfare of the family. This chapter provides specifics about the research design, data collection techniques, ethical considerations, and study limits in order to accomplish the primary goal of the study.

3.2 Study Design

In this study, an exploratory qualitative design was used. According to Burns and Grove (2005) and Yin (1994), it is described as a study done to obtain new insights, to pose questions, to find new concepts, and to evaluate phenomena in a different way. When conducting in-depth interviews, flexibility is essential, and exploratory qualitative design provides it (Saunders et al., 2019). It aims to provide an explanation for "how" and "why" a specific social phenomenon functions in a given way within a given setting. It tries to assist us in comprehending the social environment in which we live and the reasons behind the status quo (Polkinghorne, 2005).

This study aims to explore professional and parental perspectives on how ASD affects the family. In order to comprehend this phenomenon, the researcher has chosen a design that draws on the perspectives of professionals and parents (Saunders et al., 2019). With this design, the researcher can investigate participant data in a field with limited research experience. It gives participants a chance to share their thoughts, viewpoints, and experiences, which advances the creation of new information in that field (Hunter et al., 2019; Reid-Searl & Happell, 2012).

3.3 Study Population

It is important to identify the study population beforehand and provide clear inclusion (eligibility) criteria. The population subset with the ailment or traits of interest for the study is known as the study population. The trial's study group of responders is chosen from the study population (Friedman et al., 2015). Consequently, all of the biological parents of children who received an autistic spectrum disorder diagnosis were included in the study's population. Social welfare officers/social workers, physicians, and nurses made up another category of respondents.

3.4 Study Area

The study was carried out at Muhimbili National Hospital (MNH), Sarm's Occupational Therapy and Rehabilitation Centre, and Sinza Maalum Primary School. These locations were selected based on the respondents' convenience and availability. The largest and only public hospital in the nation that identifies and treats kids with ASD is Muhimbili National Hospital. There isn't a single other public hospital in the nation with physicians that specialize in ASD except MNH. Although there are ASD-affected children all around the nation, they often visit Muhimbili National Hospital (MNH) and other private clinics. The study eliminated several private clinics and schools due to their lack of participation.

One private Clinic refused, and one Private School did not answer my letters despite several follow-ups. Sarm's Occupational Therapy and Rehabilitation Centre was accessible, well organized and the owner was willing to cooperate in the study.

3.5 Sample Size

The researcher collected data until he/she reached a point of saturation when no new information was coming through (Mocănașu, 2020; Vasileiou et al., 2018). A total of 21 participants were included in this study, whereby 11 parents and 10 professionals (four social workers, two medical doctors, two nurses and two special education teachers were interviewed where the point of saturation was reached when no new information was coming through, see Table 3.1.

Table 3.1: Participants' characteristics

SN	Gender	Age/ Yrs	Education	Occupation	Relationship with child	Location/ Area
1	Female	50	Masters	Teacher	Mother	Bunju, Dsm
2	Female	45	Secondary	Housewife	Mother	Mbagala, Dsm
3	Male	40	Primary	Baker	Father	Mwananyamala, Dsm
4	Female	43	Secondary	Business	Mother	Magomeni, Dsm
5	Female	38	Diploma	Business	Mother	Manzese, Dsm
6	Female	34	Degree	Housewife	Mother	Uyole, Mbeya
7	Female	37	Diploma	Teacher	Mother	Igumbilo, Iringa
8	Female	29	Secondary	Teacher	Mother	Mwenge, Dsm
9	Male	44	Degree	Driver	Father	Kilimani, Dsm
10	Female	46	Diploma	Accountant	Mother	Kimara, Dsm
11	Female	33	Secondary	Business	Mother	Tegeta, Dsm
12	Female	45	Degree	S/worker	Professional	MNH, Dsm
13	Male	42	Degree	S/worker	Professional	MNH, Dsm
14	Female	38	Degree	S/worker	Professional	Sinza, Dsm
15	Female	35	Degree	S/worker	Professional	Sinza, Dsm
16	Male	51	Degree	M/doctor	Professional	MNH, Dsm
17	Female	45	Degree	M/doctor	Professional	MNH, Dsm
18	Female	44	Degree	Nurse	Professional	MNH, Dsm
19	Female	37	Degree	Nurse	Professional	MNH, Dsm
20	Male	39	Degree	SE/teacher	Professional	Sinza, Dsm
21	Female	36	Degree	SE/teacher	Professional	Sinza, Dsm

When no more data could be obtained, the researcher continued to gather data until it reached a saturation threshold (Mocănașu, 2020; Vasileiou et al., 2018). There were twenty-one participants in all, including 11 parents and 10 professionals (two social workers, two doctors, two nurses, and two special education teachers) who were interviewed until the point of saturation was reached, or until no more information could be obtained (refer to Table 3.1).

3.6 Sampling Techniques

This study used snowball sampling and purposive sampling. The parents of the children with autism were selected by using snowball sampling. Snowball sampling is a non- probability sampling technique used by the researcher to identify potential subjects in studies where subjects are hard to locate (Explorable.com, 2009). This sampling method is used if the sample for the study is limited to a very small population subgroup and hard-to- reach. After observing the initial subject, the researcher asks for assistance from the subject to help identify people with similar traits of interest. The process goes on like a chain. This sampling technique was employed due to the limited number of families with children with autism, as well as the sensitive nature of the study.

Purposive sampling was used for specific reasons such as qualities the participants possess, knowledge, experience, availability, and willingness to participate in the study. It is the sampling method for the participants who can communicate experiences and opinions in an articulate, expressive, and reflective manner. This method was used to select Muhimbili National Hospital, Autism Centers/clinics and

Schools, teachers, social workers, and medical doctors.

The primary subjects of this research were the biological parents of children who had received an autistic spectrum disorder diagnosis at least four weeks prior to the study's commencement. In order to prevent possibly confusing effects, parents who have another family member diagnosed with a physical or developmental handicap were excluded from this study. To obtain a clear picture, firsthand knowledge, and thoughts about raising a kid with autism spectrum disorder (ASD) as well as daily reflections on the child's condition, only biological parents were chosen. This is a result of the biological parents' superior understanding of the child's condition. Moreover, the child presents daily problems to the biological parents, who are the primary carers. Their experiences may be comparable to those of biological parents, but they are not always the same, according to the researcher, who acknowledges the shifting dynamics of family life as more non-traditional carers take on the role of parent. The majority of research has been on the fathers and mothers of children diagnosed with autism spectrum disorder (ASD). Based on the facts at hand, the researcher decided to concentrate on biological parents (Joachim, 2011; Stein et al., 2011).

3.7 Methods of Data Collection

Semi-structured interviews provide rich details about parent experiences, reveal parent perspectives, and illustrate adaptations and reactions made throughout their child's growing up years. Based on information provided by medical doctors and nurses who work with children in the Speech and Occupational Therapy sections at

Muhimbili National Hospital, a semi-structured interview was used to gather data from teachers, social workers, nurses, and medical doctors who are the biological parents of children diagnosed with ASD. Semi-structured interviews are also important in understanding the specific challenges associated with raising a child with autism spectrum disorder, the effect on families' daily lives and the parental coping responses that manage stress productively. Parents were asked where they wanted the interview to take place. The equipment used during the interview was a voice recorder, pen, and notebook. The participants were asked to be recorded before starting an interview. All of them agreed to be interviewed and were recorded.

Patients from all across the nation visit Muhimbili National Hospital's clinic since it is the only public hospital in the nation with autism specialists. As a result, the patients that visited the MNH clinic provide a useful representation of the various instances across the nation. With the assistance of the autism specialists at MNH, Sinza Maalum Primary School, and Sarm's Occupational Therapy and Rehabilitation Centre, the researcher was able to gather the necessary data.

3.8 Methods for Data Analysis

Transcription and translation of the gathered interview data were steps in the data analysis process. In this study, data analysis was done using thematic analysis. Braun and Clarke's six-step theme analysis process were used to thematically analyze the interview transcripts: Acquaint yourself with the data, create preliminary codes, look for themes, evaluate themes, define and label themes, and produce an analysis of the themes found. With Microsoft Excel, data coding and theme tracking were carried out. The study included 21 participants in all, 11 of whom were parents of autistic children. Additionally, ten different specialists—four social workers, two medical doctors, two nurses, and two special education teachers participated in a face-to-face interview.

Thematic analysis tries to “understand how people feel, think and behave within a particular context relative to a specific research question” (Braun, V., & Clarke, V. 2006). It analyses classifications and presents themes that are associated with the information collected. It illustrates the data in detail and deals with interpretations of different themes (Alhojailan & Ibrahim, 2012; Boyatzis, 1998). It can help to ‘link the various concepts and opinions of the learners and compare these with the data that has been gathered in different situations at different times during the project. All possibilities for interpretation are possible’ (Alhojailan & Ibrahim, 2012). According to Braun and Clarke (2006), thematic analysis is the best choice when investigating an area that may be insufficiently researched like what has been done in the present study. Encouraging students to "link their various concepts and opinions with data that has been gathered in different situations at different times during the project" might be beneficial. There are infinite ways to interpret this. Ibrahim & Alhojailan, 2012). Braun and Clarke (2006) state that theme analysis is the most appropriate method for examining a topic that may have received less research than the current study has.

3.9 Ethical Issues

The Open University's office of the director of research and publications provided ethical approval. Furthermore, the Executive Director of MNH asked and was granted authorization to carry out the study. Key concerns that have been considered are risk factors, confidentiality, consent, and withdrawal. Every necessary step was done to reduce the hazards while gathering data. In this study, informed consent was also considered. Participants were informed of the interview's goal and the implications of taking part in the study as soon as they were identified. The study only included people who understood and consented to participate. The participants were given the researcher's word that the information they submitted would be kept private and, in the event that it was released, would not be associated with them. Additionally, it is guaranteed to the participants by providing them with adequate and pertinent information about the study, enabling them to make an informed decision regarding participation. ensuring that there isn't any direct or indirect coercion so that potential participants can freely and intelligently decide whether or not to participate.

In research, findings dissemination is crucial. The study's findings will be shared with each and every participant. Feedback on the study will be extended to participants and other relevant parties. Those who are unable to attend due to unforeseen circumstances will receive a brief explanation on the study's findings. The brief explanation will be delivered by phone, email, or letter.

3.10 Limitations

The use of qualitative research in this study only restricts the findings' applicability to a wider population. One further study weakness is that not every parent whose child was diagnosed with autism at the MNH came back for a follow-up appointment. Some parents just showed up for a few of clinic visits before leaving to assist their kids in another way. It was challenging to recruit these parents to take part in the study.

It was also challenging to persuade certain parents to talk about the difficulties and experiences they had when raising children with ASD. Some of them were embarrassed to discuss it or felt bad about having children in such a situation. Since there is a lack of appropriate data on children with autism spectrum condition, which restricts the use of quantitative research, it was challenging to create a sample frame.

CHAPTER FOUR

DATA ANALYSIS, PRESENTATION AND DISCUSSION OF THE FINDINGS

4.1 1ntroduction

This chapter examines the five themes that the study found: i). Parental experiences prior to and following an ASD diagnosis; ii). Parental experiences following an ASD diagnosis; iii). Government support and services for families and children with ASD; iv). The effect of ASD on family wellbeing; and v). Policy, legal, and regulatory framework changes. The study was carried out at Sarm's Occupational Therapy and Rehabilitation Centre, Sinza Maalum Primary School, and Muhimbili National Hospital (MNH). Parents of autistic children, MNH's autism specialists, Sinza Maalum Primary School, and Sarm's Occupational Therapy and Rehabilitation Centre were among the participants in this study. This chapter included an analysis of their data.

4.2 Parental Experience Before Their Child Diagnosed With ASD

Every participant in this research shared the experiences they had prior to receiving a formal diagnosis of ASD for their children. This theme's main goal is to talk about how parents' experiences affect their decision to get professional assistance. It also means determining whether their experience affected their children during this process and contributed to the delay. During the interview, two problems pertaining to the parents' experiences prior to their children receiving an ASD diagnosis were discovered.

4.2.1 Wrong and Incorrect Information

Nearly all of the participants stated that when parents were looking for treatments for their children's ailments, friends, relatives, and family members gave them inaccurate and misleading information. Before their child's diagnosis, the majority of the parents who were interviewed knew very little about autism. Prior to acquiring an autism diagnosis for their children, they claimed to have been given a lot of inaccurate information. They were perplexed by this information because they had no prior knowledge of autism. The only highly educated parent who could handle the information was the one who had attended a university course on autism. One dad from Mwananyamala, Dar es Salaam, shared during the interview the confusion he had when he first started looking for answers to the problems associated with autism. The man said:

> *First, we went to the region* (outside Dar es Salaam). *We went there and talked to our parents. They said the boy was not talking because some rituals had not been conducted. They said that the rituals were needed because the children were twins; that twins must undergo some traditions and customs. We decided to take our twins for such traditions and customs in our families. We went to our village first, then to my wife's village. We bought goats and many things related to our customs, with instructions from our grandparents.*

Another participant, a parent from Mbagala, Dar es Salaam, gave the following explanation of her early experiences with autism:

> *'"I had no prior knowledge of autism." Many claimed my son was growing up too slowly, while others argued it was typical. They asserted that children of other people likewise postponed speaking for five to six years. I was simply waiting, then. I was unaware of autism until I made the decision to visit the hospital, at which point I was informed of the issue.*

Prior to the diagnosis, almost all parents were unaware of anything regarding ASD.

Just one parent, a professional teacher with training and a college lecturer, claimed to have done some research on autism. She completed her education bachelor's and master's degrees, and at the time of the interview, she was working towards her doctorate in education. The first parent/participant from Bunju, Dar es Salaam, said:

> *My line of work is teaching. As a result, I can spot issues in kids straight away. I'm able to conclude that they have a problem. She had some issues, particularly with speaking, so I noted that before I went for a formal diagnostic.*

Before their children are diagnosed, parents frequently receive inaccurate information, according to all specialists surveyed. According to experts, this is because the parents of these children are among the majority of individuals in society who are unaware of autism. According to some experts, parents of autistic children put off getting their kids a correct diagnosis because they think witchcraft and spiritual forces exist. The medical doctor's comment below reveals that the parents were given inaccurate and misleading information.

Medical doctor/participant No. 16 stated:

> *Most parents who visit me explain that they put off visiting the hospital because friends, parents, or other family members advised them to see witch doctors or religious authorities. The majority of them would stay there for months or years before realizing they needed to visit a hospital for a diagnostic.*

4.2.2 Noting Differences in the Behavior of Their Children

The researcher posed the following question to parents of autistic children in regard to noticing behavioral anomalies in their kids:

> *"How did you know that something was different with your child?"* The following were the answers.

Parent/participant No. 1 from Bunju shared a story of her son as follows:

> *At the kindergarten he attended, I saw that the teachers were not making any necessary interventions. Since I work as a teacher, I was paying great attention. I knew what he ought to do at that point because I was a teacher. Though my son was the issue, I saw that teachers had been carrying out their assigned duties. Despite my lack of training in teaching kindergarten, I began tutoring my kid when I saw that he was having academic issues. I discovered that he had a condition that was not widely recognized. Furthermore, I would say that I prayed a great deal. I thought that my prayers had worked. After reading numerous books, I gained a diverse yet deep understanding of the issue.*

Parent/participant No. 2 from Mbagala reported the following:

> *When my son was two and a half, I enrolled him in a nursery school. However, he would cause such mayhem at school that a teacher would become concerned. He observed that compared to other students at the school, he was not as motivated to study.*

Parent/participant No. 3 from Mwananyamala stated:

> *He was not talking in the first place, and then he would continue to rotate and roll his eyes. He used to cry all day and all night. He was always crying for no apparent cause. I questioned him about why he was crying. Or if he was ill? He was unable to respond. What is the matter with you? Nothing at all! He would occasionally hit a cabinet; you see, he would destroy and consume cutlery. What is wrong with this child, I wondered then. He cries all night long; why? Why does he cry all the time and occasionally breaks and eats cutlery? It was then that I realized the boy was not like his twin sister. He would howl all night long, while his twin sister would sleep. He was often crying. He held his head when he sobbed. He shielded his ears and held his head.*

Parent/participant No. 4 from Magomeni stated:

> *My son couldn't pronounce a single word correctly when he was three years old. He also acted quite hostilely towards me and his father. He wouldn't stop being aggressive even if you defeated him. At three years old, he was unable to play like other children. The toilet was not his place to poop. He was unable to clothe himself. That is not typical behaviour for a three-year-old. It was then that I realized he was not like other youngsters.*

Prent/participant No. 5 from Manzese stated:

> *I have four children; three sisters are normal except for the last-born son. I have experience in raising four children. His sisters were talking when they reached two years old. They were playing and following instructions when they were two years old. The last born couldn't do it. He was aggressive toward his sisters. He liked to beat them without any reason. He played alone almost all the time. That's not normal.*

4.2.3 Parental Reaction After Noting Differences in The Behavior of Their Children

When a parent of a child with autism notices that their child's growth and development are being hampered, they respond differently. A further query posed to the attendees was, "How did you respond when you realized something wasn't right with your child?" Parents behaved differently when they realized something was off with their kids. In the course of the interview, one dad revealed that he had taken his child to a witch doctor because he thought the youngster was possessed by bad spirits or demons and had been charmed. Afterwards, he visited the hospital and returned to the witch doctors to get his child's illness treated.

Participant No. 3 from Mwananyamala, Kinondoni District, Dar es Salaam Region stated:

> *I travelled to Tanga, Tabora, Mwanza, and other locations in search of answers to my child's issues. I was informed by others that my son had fallen under a spell. I sought assistance from multiple witch doctors here in Dar es Salaam. In an attempt to solve my child's problem, I travelled to Mbagala, Temeke. I was eager to see my child's illness go better. They informed me that he was possessed. They told me that he had demons and demonic spirits and that I needed to acquire goats, sheep, and other items.*

Parent/participant No. 3 from Mwananyamala stated:

> *The government owned the hospital that we went to first. My child's*

> *diagnosis was their first action. Nothing was found by them. They saw nothing wrong. I asked them what was upsetting him so much at night. They assured me that it was commonplace. I took my child to a private hospital for a diagnosis so I could find out what was preventing him from speaking. It was explained to me that they had to cut something under the tongue known as ankyloglossia, or tongue knot. My aunt works in nursing. After she brought my kid to the hospital, they cut it. They advised me to remain for a month before going back to the hospital. No changes were visible after that. Everything was still as it was.*

Prent/participant No. 2 from Mbagala stated:

> *I went to see this paediatrician before I travelled to Muhimbili. Dr. Abbas in the fire zone. After seeing that physician at Fire, he advised me to see Dr. Karim Manji, a paediatrician, on Mindu Street in Upanga. He practices paediatrics. The physician suggested that I bring my child to Muhimbili Hospital for therapy. After that, he made plans for me to attend Almuntazir Primary School. I went to Muhimbili Hospital on that very day. All of it was done all at once. I first went to Muhimbili to complete the paperwork and make an appointment before continuing on to Almuntazir Primary School.*

Parent/participant No. 5 from Manzese described:

> *I enrolled my son in a nearby nursery school when he was three years old. Compared to the other children in his class, he was unique. He was unable to concentrate on the lesson while seated. He was unable to play with his classmates. I should take him to the hospital to see a paediatrician, suggested his teacher. Upon visiting three distinct hospitals, none of the paediatricians could determine whether my son was autistic. They all agreed that the youngster appeared normal and would eventually get better. Until his school's nursery teacher called to break the news to me, I was living in denial.*

Parent/participant No. 4 from Magomeni stated:

> *Prior to my child's autism diagnosis, I had little knowledge of the disorder. Some of my relatives advised us to ask religious authorities for assistance. I visited three separate sheikhs, but my boy was without hope. The doctors at three separate hospitals that I visited were unable to locate anything. It appears that medical professionals were ignorant of autism. They noted that children's stubbornness and delayed speech are common. My buddy then suggested that I bring my child to Muhimbili National Hospital.*

4.3 Parental Experience After Their Child Diagnosed With ASD

The purpose of this theme was to look at how a family with a child who has autism spectrum condition deals with that youngster. The participants were invited to provide their thoughts, insights, and experiences regarding the care they provided for children with autism. "How do you describe how you parent your child with ASD?" was a question posed to parents of ASD children during the interviews. Every parent who was questioned noted how different raising an autistic child is from raising a typical child.

"It is too tough to take care of autistic children because they have their own diet and they are not supposed to overeat food," said participant number two from Mbagala, Dar es Salaam. She contends that children with autism should eat a range of foods that are distinct from those eaten by regular individuals. She went on to state that his child was not permitted to drink milk or eat anything cooked with wheat or sugar. She claimed that her child's school had given her this guidance.

The second participant mentioned that her child's school receives visits from an Indian doctor. That doctor speaks with parents as well as children at the school when he travels to Tanzania. In addition to diet manuals, the parents receive instruction on how to raise their children. She acquired her knowledge of child care in this way. Additionally, Mwananyamala, Dar es Salaam participant No. 3 said:

> *They did not provide my wife with any training or instruction; rather, they told her to take care of her child and educate him on her own. She's not been trained before today. I'm not lying. She would inform me whether she was trained. I've also been there twice, picking him up from school and returning home.*

Parent/participant No. 3 stated:

> *My youngster dislikes playing with other children. He dislikes socialising with his classmates. He like to be alone himself. He enjoys watching television. His favourite music channels are. He wants no one to touch him when he is by himself. He waits for you to hold a stick or a belt before he eats; you set it aside so he can see it and begin.*

Parent/participant No. 1 from Bunju, Dar es Salaam, responded to the question by saying:

> *People take advantage of this incredibly arduous process to trick you. Some people might claim, for instance, that it is a demon. You will hear from others that you disrespected our customs. It's not necessary to involve your kids in rituals. I was advised by senior psychologists not to send a child to a place where they may feel discouraged to perform. Taking your youngster to places like this will instill in him the belief that you are possessed by a demon or that someone is bewitching you. A child will begin to realise that because of those around me, I have little control over my body. God needs to be prayed to. You know I handle these problems with God's aid; I have to ask him why he given you such children.*

Parent/participant No. 1 stated:

> *My son struggled to talk and use his voice. In order to help my child quit stammering and learn how to pronounce phrases correctly, I so sought the advice of a speech therapist. It appears to me that these kids have communication difficulties. There was a communication barrier for my son, but I was optimistic. It's not easy, as I have said. It was difficult. God grants me strength through my prayers.*

Some parents have little faith in anyone to look after their kids. In order to have more time to assist their children in growing and overcoming these obstacles, a few of them were forced to quit their jobs. The second parent/participant said:

> *I believe that only I am capable of raising my child. That is, I have no faith in anyone. That's how my heart feels. It's not a house girl here. I have no faith in anyone to take care of my autistic child. I think I should be in charge of it. Only I am capable of doing it. I am unable to participate in anything else and don't perform any other things. My kid is*

> *too mischievous. I have to know where he is and what he is doing for the next twenty-four hours. It is hard for someone else to take care of him, therefore I have to watch over him.*

Participant No. 3 chose to take his child to witch doctors in Tanga, Tabora, Shinyanga, and Rukwa in search of a remedy because he thought his child was impacted by some supernatural forces. The third parent/participant told his tale in the following way.

> *I first went to Tanga from Dar es Salaam. I visited a location in Tanga known as Malamba. They informed me that my son had been hurled some demons when I brought him there. They informed me that those demons needed to be exorcised. They demanded payment from me in the amount of 350,000 Tanzanian Shillings. They also gave me a prescription for a medication called mavusho, which I was to take in my bath water, and they instructed me to buy a few other things. My youngster used to bathe in water laced with prescription drugs. I took care of my son for seven days while I was in Tanga. They would give him a smoke and some medication bath. They would then take him to the river and offer prayers for him (somewa dua). My kid and the four Ustadhi and I walked to the river with falling water around 4:00 AM. My son was being doused with water by them. The cold was making him tremble like a bird. They claimed to be driving out demons. Then it stopped working.*

The researcher also inquired, "What assistance do you have in raising your child?" during the parent interviews. Every participant admitted that they didn't have a helper. It was done by them.

Participant No. 10 stated:

> *There isn't any help. Just my spouse and I are here. All I have to help me is a houseboy. All household tasks, including those of a child, are done by me. I left my work. These days, I spend most of my time taking care of my autistic child and the family. I personally drive him to school, though occasionally my spouse does as well. These children don't have access to a school bus. They have a bus for regular kids, not for kids with autism. These kids are said to be mischievous; it will cost a lot of money to have a school bus for them as they can fight and jump out of windows. Because*

> *of the length of the excursions back and forth, they have determined that each parent should arrange their own transportation.*

Parent/participant No. 9 stated:

> *My spouse is caring for our child from home. She was employed at the petrol station, but she was forced to leave to care for our child at home. Nobody is available to assist us. The unfortunate problem is that our parents have all already departed from us. Both my wife's and my parents are no longer with us. How were we going to leave the boy at home then? My wife and I have decided that I will work alone, and she should stay at home. My wife thus remains at home. She takes no action. I am the family's leader; I am everything.*

Parent/participant No. 3 stated:

> *I'm not going to lie; my son is six and a half years old, and I have never received a cent. I have nobody to help me. My neighbours have never given it to me. Nobody has ever offered me assistance. I'm fighting by myself. I have something occasionally, yet I don't always have anything. God be praised for that. I've never gotten assistance.*

Parent/participant No. 5 stated:

> *I have nobody to help me. I'm separated. My former spouse isn't entirely cooperative. He sends money occasionally and not at other times. I drop my autistic child off at school by myself and then head to the market to conduct business. The boy sometimes won't go to school, so I don't work. Either I take him to work or I stay home. It is difficult to handle alone. Alone with four kids is an extremely hard job.*

The goal of the study was to gather views, experiences, and opinions from various specialists regarding how they assisted parents in raising their autistic children. "How do you help parents to raise and take care of their autistic children?" the researcher posed to the experts. All experts agree that it is exceedingly challenging to raise a child with autism, particularly if you are doing it alone and don't have the resources.

Social worker/participant No. 13 stated:

> *When my children were autistic, I used to counsel parents not to hit them. The majority of them are unaware of the negative consequences of hitting their autistic kids. I explained to them that children occasionally cry or damage items at home in order to get what they need. Instead of hitting them, you need to figure out how to soothe them. Aim to comprehend their requirements by listening to them. Perhaps they're fatigued or hungry. It's not necessary to defeat them. I informed them that beatings don't work for autistic children and that meltdowns are typical with these kids.*

Social worker No. 12 stated:

> *As social workers, our role is to watch children's behaviours to assess if they have autism. Our contribution is a school identification programme for kids with these issues. The evaluation process in the assessment centres falls under our purview as well. Children with various special needs are evaluated at these centres. In those centres, we used to find children with autism. We attend schools for students with autism as well as schools for students with other special needs. I am required to make a minimum of one weekly visit to the assessment centre for children with exceptional needs. In addition, I have one weekly assignment to attend different schools.*

Social worker No. 12 said:

> *When I go to school, the assessment centre, or anyplace else where I interact with parents. Children from other parents are not permitted to visit the hospital. Some parents lack the means or capacity to take their kids to the hospital. Additionally, Muhimbili's service procedures and processes are difficult to navigate. They are therefore using me as a referral to the hospital in order to avoid having to deal with bureaucratic processes. I ensure that they are able to schedule appropriate appointments with physicians for necessary diagnoses and other services. I see to it that they have an exemption when their doctors prescribe drugs or medications. In order to avoid having to pay for services, I also make sure that they have a status of referred patients. Using a referral form, I identify these individuals and let Muhimbili know that they require diagnosis and treatment. I make sure to fill out the form with their history and enter all necessary data into the Muhimbili information system. They can therefore receive the services they are entitled to because they are recognised as children with special needs. If there are any issues, they get in touch with me.*

Medical doctor/participant No. 16 stated:

> *Most of parents that visit me are angry, anxious, and worn out. In society, some of them are stigmatised. I instruct them on how to raise a child with autism. As there isn't much information on autism in Tanzania, I also advise them to read online. Every autistic child is different. As a result, my advice varies depending on the situation that is brought up. Because they believe we are not doing enough to support their children, some parents wish to resign. I explain to them that autism requires time and complexity. It doesn't require going to the hospital for one or two days.*

Though their expertise in diverse fields meant that they all acknowledged that raising a child with autism was challenging and stressful, their responses varied. For instance, participant No. 21, a special education instructor, said:

> *I always tell parents to schedule time for reading and studying with their kids when I meet with them. Generally speaking, I suggest Swahili books with some illustrations. Children with autism can easily understand books that have illustrations. They relate to people and stuff more readily when they see pictures. However, I also counsel parents to never give up. When their kids first go to school, the majority of parents want to see them talk or read books. I advise them to exercise patience as it may take a little longer and that children with autism are not like other youngsters.*

4.4 Government Support and Services for Families and Children With ASD

This theme's data was centred on the state of government assistance programmes and services for people with autism spectrum disorders. Participants were invited to provide their thoughts, insights, and perceptions regarding the role played by the government in the autism epidemic. The researcher's primary inquiries were: *How does the government deal with the autism issue? What kind of assistance does the government provide you with? What steps should be taken to enhance the assistance and services provided to families and children with autism?*

Through interviews, the researcher also investigated the kinds of services that the government offers parents of autistic children. When asked this issue, the parents who participated gave varying answers; most of them said that the government did not provide any assistance.

For instance, parent/participant No. 7 said:

> *I am not going to lie; up until now, the government has not offered me any assistance. It's only been a few days since I received this school. But I am grateful to God that my son is now attending school and not staying at home. To be honest, I have spent a lot of money searching for a solution to my child's issue. If I had utilised that money for constructing, I could have even completed two houses. I am not going to lie; up until now, the government has not offered me any assistance. Since you always need money, I made the decision to process my son's health insurance. There has been no help from the government for me.*

Another participant from Mbagala stated:

> *I don't have any support. I do everything on my own. Not yet, not yet. There is no one to support me. I handle everything by myself. No, no, not quite yet. Perhaps I'm the only one who hasn't gotten assistance from the government yet. I am at a loss for words; perhaps I am the only one who has not received it. However, it was seen in the media. The government must first raise public awareness of autism. The hospital will inform you that it is not an illness if you visit them. I found out about autism through Googling. I am aware that it is treatable, but there are others who will tell you there is no treatment for the issue and those who will argue that it is not an illness. Ultimately, you're not sure what it is. Up to now, you do not understand.*

The participants were then questioned by the researcher about recommendations for government action aimed at enhancing services for parents and children with autism. The majority of them brought up funding as well as constructing and renovating schools and hospitals. The ninth participant/parent said:

> *If it took my child, the government would come to my aid. We impoverished people would benefit from that. My son would be sent to a boarding school and forced to stay there by them. All we would need to do would be to pay visits and on holidays. During the holidays, we would take him home from school. Given that these kids wander outdoors*

> *without permission and are found on the fourth street, we have a lot of issues because we rent our home. It poses a risk. They can murder them, or beat them.*

To make autistic children feel unique, a participant made an argument that the government should provide specific programmes for them. Says she,

> *We may state that the government is not involved. When it comes to learning, the government views children with special needs as having the same needs as people with physical disabilities, such as arm or leg impairments. But the head is really important. A condition in which a person's brain is affected is autism spectrum disorder.*

Even among health professionals, especially doctors, autism is not widely understood, according to a participant from Mbagala, Dar es Salaam. She emphasised that it is essential that the government increase public awareness of ASD. According to her, some medical professionals would just mislead the public and parents of autistic children since they were ignorant of ASD. When she visited hospitals, she claimed that some doctors diagnosed her with autism as a mental disorder, while others diagnosed it as a fever or malaria. Although several of these doctors seemed to be specialists, she said they had not seen any cases of autism.

When questioned about the government's involvement in providing health professionals who work with autistic children on a daily basis in a professional interview, one of the participants at MNH responded as follows:

> *Nothing has been released by the government. lack of knowledge on autism spectrum disorder. I've never heard of any such instruction. A handful have firsthand experience from their time in college or school. There haven't been any ASD workshops. Nothing at all! You need to study books and go over many tests in order to comprehend it; nothing more. There's no instruction. not dependent on acquiring experience. Nothing compares to that.*

A social worker at MNH stated:

> *Sure, I conduct evaluations at centres and schools. I visit that place once a week. The hospital gives me nothing at all, not even a farewell. All I do is volunteer because I see difficulties in individuals. I'm a nationalist. I offer my services. He he, he, he (laughing) They do not provide me with any resources or allowance. No, Nothing, no fair, no money to buy water, they don't pay me. Is there money allocated for these kinds of things? I have no idea! I'm not sure! When I ever inquired about funding or a budget for these kinds of evaluations at schools and centres, I was told that there wasn't any! No funds are available for it. They said that until things improve, I should keep doing it. Nothing has been found as of yet, though. When I go there, I keep a record of every expense. After all these years, I have no idea if I will get paid. With a laugh, ehehehehe Since a long time ago, I have been doing it.*

An MNH physician clarified the government's lack of assistance and the significance of increasing training expenditures.

> *Obviously, as career development includes training. Thus, training would be crucial, particularly in various environments. Medical personnel may have the chance to attend seminars. Most seminars take place overseas. As a result, staff members may be able to get support if they find a seminar on autism in Kenya or somewhere else. However, some centers—particularly those that work with kids who have autism—are also quite well-developed. Employees at these centres could be allowed to receive attachments for a period of two weeks or a month in order to teach them the A, B, and C of managing autistic children in all contexts, including management, education, and communication. They could be able to practise assisting the children and stay up to date on their understanding with such training.*

What steps should be taken to enhance services and support for children with autism and their families, the researcher posed? The participants' suggestions and opinions varied. The topics that came up most frequently were increasing awareness, enhancing education and career training, cutting health care expenses, developing policies for children with autism, and providing autism education to professionals and parents.

During a face-face-interview, social worker/participant No. 12 stated:

> *My experience is that standards in schools are not very high. One such illustration is the lack of training and authority for educators working with students on the autistic spectrum. When I visited certain schools, I observed instructors lamenting that the Ministry of Education was pressuring them to complete assignments pertaining to these kids that were outside the scope of their training and expertise. They were asked to participate in tasks that were beyond their capabilities during certain meetings that they had attended. They are incapable of such things. Additionally, their surroundings are appalling. The majority of schools lack the tools necessary to manage the students.*

She continued to argue,

> *The majority of schools actually lack the necessary supplies and have unfavourable conditions. One day, when we visited a certain school, we discovered that the students were studying in a store that housed broken or undesired desks. These are the kind of classrooms that kids with autism were using. I'm not sure what went wrong; when we tried to find out, neither the headmaster nor the head of the special needs department was there. They promised to provide us with information, but we haven't heard back from them as of yet. We warned them about the extreme dangers of placing such kids in such a classroom. We sat and spoke about the issue. We alerted them.*

Social worker/Participant No. 13 stated:

> *The government should investigate, in my opinion. In order to educate the public and promote autism awareness, the government must support social workers and other professionals in their job. The unique needs of children must be recognised by society. When I tell my professional coworkers here at Muhimbili National Hospital that I work with children who have unique needs and mental health issues, they usually just look at me. There are medical personnel at Muhimbili who are unaware of it. How therefore can someone who has never attended any school be able to comprehend the issue? They don't comprehend, even when I explain that I visit schools to speak with students and analyse them. I'm being asked if I'm a social worker. What am I doing at the schools, they want to know. This suggests that the stakeholders are not very aware of this. including the educated ones. And those Tanzanians who never attended school? When it comes to these special need's challenges, we are lagging behind. In this regard, we are still far, far behind.*

Medical doctor/participant No. 16 stated:

> *A plan that can result in the Ministry of Education and the Ministry of Health working together should, in my opinion, be the top priority. The professionals from these two ministries can collaborate and act together. These youngsters can receive services from both the Ministry of Health through rehabilitation and the Ministry of Education through special education. One possible area of cooperation between them would be societal awareness-raising. If only one of these ministries tries to spread awareness while the other stays out of it, it is challenging.*

Nurse/participant No. 19 stated:

> *In order to support children with autism, the government must actively work to increase the number of specialists who are needed, including occupational therapists and speech therapists. To encourage many to apply, the government could grant 100% study financing to candidates majoring in these fields. It is feasible to accomplish this in this field because it was done to general practitioners. Following their training, these experts ought to be sent to Tanzania's main public hospitals in order to support the wellbeing of autistic children. Schools that accept these exceptional kids should set up and follow protocols for follow-up. They are occasionally abused in schools and are unable to report it.*

4.5 ASD Affects Family Wellbeing

Every parent and expert who took part in this research agreed that ASD has an effect on family well-being. Participants stated that ASD has an effect on families' well-being in a variety of spheres. The following topics will be discussed in more detail below: how ASD affects the family's finances; how it affects marriages; and how it affects parents' relationships with friends and family. These difficulties were the main ones found during the interviews.

4.5.1 ASD Affect the Family Financially

Parents of autistic children experienced budgetary difficulties or financial loss. These monetary losses were brought on by the high expense of transportation, medical bills, private instruction, speech and occupational therapy, and specialty food purchases. Regarding spending from the budget and monetary loss, participant/parent 2 said the following.

> *"If you want to support your autistic child and watch him grow, you will need to spend a lot of money. Their schools are highly expensive, especially the equipment they utilise, so you will need to invest a lot of money. The five senses that children have should be included by their teachers in their instruction. If you want to teach kids about 'A,' they need to be able to see and touch it in person. Writing on the chalkboard is not sufficient. Additionally, a pupil ought to earn his own "A." It's a programme with high financial requirements.*

Parent/participant No. 6 stated:

> *He's spending half of our money. Hehe! Only a quarter is used by the other family members. The funds are used for transport and education. Three hundred thousand to three million dollars is the annual cost of schooling. His weekly food expenses come to twenty thousand. The cost of tuition has never gone down; it has always stayed the same. He has now attended the institution for four years. At the age of three, he began attending that school. My spouse covers the expenses. I don't work, thus he pays for everything on his own.*

Parent/participant No. 3 stated:

> *My life has been profoundly impacted. I've spent a lot of cash. In addition to visiting the Tanga Region, I also travelled to Mbeya and Iringa in search of medical supplies and care for my child. My inability to construct a home on my property has had an impact on me. Since I started seeking for my son's treatment, I have not moved an inch. I haven't carried out any of my plans. I travelled to Iringa, Mbeya, and Tabora in search of traditional healers and witchdoctors. This implies that you have to pay the witch doctors and travel. My son, they told me, had demons. They said that my son's inability to speak and his nighttime cries are caused by demons. They said it was not him when my son cries in the middle of the night. They claimed to have transformed him. They bring someone else. He isn't the one.*

Parent/participant No. 5 stated:

> *I am divorced, as previously mentioned, and my ex-husband is not entirely cooperative. His monthly contribution is a mere 300,000 Tshs.*

> *My four kids are mine. That is insufficient. I drop my kid off at school by myself. In order to get to school on time and go to the market to do business, I have to ride a motorbike, or boda boda. However, you should also take him to Muhimbili National Hospital once a week for occupational and speech treatment. I occasionally take him to Kijitonyama for private therapy. Every session, I pay 25,000 Tshs. To get from my house to the private rehabilitation facility, I have to ride a trike or a motorcycle. I refused to attend there three times a week as recommended by the private speech and occupational therapist, claiming I couldn't afford it. It costs a lot.*

Parent/participant No. 4 stated:

> *Every year, I was paying 4,000,000 Tshs. But the annual cost of games, transport and other expenses was more than 6,000,000 Tshs. At Mbezi Beach, I would also take him swimming lessons, which run 100,000 Tshs a session. I can't afford that right now. As a single parent, I'm having trouble with my business. It's a hard life. I'm going to drive him to the public school. That will come with very subpar services at a low cost.*

Professionals who participated in the discussion all agreed that raising a child with autism spectrum disorder is exceedingly costly. Depending on their areas of specialisation, they had varied experiences. For instance, social worker/participant No. 14 said:

> *Parents of children with autism frequently experience financial difficulties. Numerous parents visit my office seeking government grants, loans, or assistance. Some of them don't pay their educational expenses. It's said that autistic children attend prohibitively expensive private schools. Most of these parents are low-income and illiterate. Regretfully, I am unable to provide them with any money because I am a social worker. I advise them that enrolling their kids in public schools is the best course of action.*

Social worker No. 14 stated:

> *Based on my observations, issues related to money and marriage are frequently brought on by autism. Parents of children with autism frequently blame one another for their child's illness. Their disputes typically involve financial constraints. Fathers accuse mothers of misusing the money to provide for their children.*

The special education teacher/participant 20 stated:

> *I often suggest that parents enrol their kids in music therapy since it may help kids with ASD develop better comprehension and motor abilities. Additionally, advise them to bring their kids to the swimming class. In Dar es Salaam, swimming lessons and music therapy are costly. In actuality, the majority of the parents at my school struggle financially. Sometimes they lack the funds to cover the cost of transport, thus they are unable to afford to send their kids to school. You can see how challenging it is to raise these kids now.*

The medical doctor/participant 16 stated:

> *Autism costs the family a lot of money. A parent who has an autistic child has to make more financial contributions than a parent of a typical child. The payment for therapeutic sessions at the hospital and private facilities must be arranged by him or her. Over 100,000 Tshs are charged per session by several private centres. There are also non-medical and medical expenses. Pharmacy, home care, and outpatient treatment are all included in the medical costs. Special education, child care, and intervention services are included in non-medical costs. The wellbeing of the family is impacted by all of these. It can occasionally have an impact on marriages, with some ending in divorce.*

4.5.2 ASD Affect Marital Relationship

It was discovered that parents' approaches to coping with autism's difficulties varied. Some parents were not at fault; their relationships with their kids had grown incredibly close. But some parents damaged the relationship by blaming themselves for having an autistic child. Disagreements arose on treatment and education. For instance, a mother might insist on going to the hospital, but a father would prefer to see traditional healers. A parent would learn about therapy someplace, but their spouse would not go because of the high expense of the programme or the unpredictability of the course of treatment. Additionally, parents with autistic children did not receive adequate family time. Similarly, a lot of autistic kids had trouble sleeping, which left their parents tired. In order to assist or soothe the child, parents would go up in the middle of the night. Fathers were typically left alone by their moms, who would spend a lot of time with their kids. A few marriages and relationships were impacted by this, and some of them resulted in divorce or separation.

Parent/Participant No. 4 stated:

> *My ex-husband used to accuse me of being the reason our child wasn't well. He claimed that neither their family nor clan is the source of this illness. He claimed that the illness must have been passed down to our offspring by our family and clan. I was offended, so we got into a fight. In addition, he was not at all cooperative. I used to work alone on everything. He would go for work at the crack of dawn and return at late. If I asked him why he constantly arrived home late, he would beat me. He made threats to divorce me and get married to someone else. It was awful.*

Some individuals, despite the hardship of raising a child with autism, had a fantastic marriage. Parent/First Participant described:

> *Since he has supported me so much over the years, he is, in all honesty, a pretty wonderful man and a nice spouse. We agreed to take on the task. My spouse is incredibly polite and understanding. He agreed to it. We didn't blame one another because he adores his kids so much. We have always been there for one another. We have all agreed on things like education. Together, we strive to support our son. We sent our child to school in Kenya. In East and Central Africa, Kenya offers the best schools for children with autism. My spouse stated that his kids ought to attend the top school. He has made a lot of contributions to the kids and family.*

Professionals that interact with parents of autistic children occasionally chat to them about their marriages. They all concur that having an autistic child has increased marital difficulties for the majority of parents.

The nurse/participant 18 stated:

> *Based on my observations, the expenses surpass just the monetary strain. Marriage and autism interact. Wives report arguing with their spouses about their autistic kids. By blaming their women, I believe that the majority of husbands are the root of the arguments. Whenever wives brought their kids to the hospital, I used to question them about the whereabouts of their husbands or boyfriends. They get really emotional when you ask them about their partners. In front of the kids, the majority of them start crying. They claim that their spouses rejected the requirement. They said that their partners held them responsible for the state of their kids. They were mostly under stress.*

4.5.3 ASD Affect Parent's Relationship with Their Friends/Relatives

"Can you explain how having a child with autism affected your relationship with your friends?" the researcher also questioned. Every parent acknowledged that their child's autism had impacted their friendships and relationships with friends and family.

According to the analysis, parents of kids with ASD spend more time with their kids and don't get enough time with friends or family. Parent/participant No. 3 mentioned his friendships with his pals in the course of the interview.

> *Yes, the majority of my friends believe that I did it on purpose, which has severely damaged our connection. They claim that I have ruined my son. Witchcraft is believed by some Tanzanians. They think you can offer your son the chance to become wealthy. They say that in order for me to advance in my work, I sacrificed my son. I've overheard them conversing with others. Some people have told me that, but they have never said it directly to me. I recently learned that they discuss topics similar to that. Not just my pals, but my family members agree as well. There are moments when people are scared of me. I was silent when I heard it. I am unable to dispute with an ignorant individual. If I argue, I'll be viewed as ignorant, so I just stay silent. Say it, God! You alone own knowledge. That is my explanation to them. For this reason, I haven't gotten assistance from friends or family.*

Parent/participant No. 1 stated:

> *But things aren't going so well between me and my friends. We spend a lot more time with kids as a family than with other individuals, so I did it on purpose. I can't, for instance, spend a lot of time at send-off celebrations or wedding ceremonies. The child God has given me will suffer, but if I take care of these, I will be referred to as "mtu wa watu" (a man of the people). While others get together to organise wedding ceremonies on Sundays, I spend time with my child, work out, and prepare meals for my household. I'm meant to be at home with my child going over homework in the evening, while others are out drinking. You read to him and listen to him. I do not merely spend a lot of time outside; I have not made enemies.*

Parent/participant No. 11 stated:

> *I participate in social events like marriage ceremonies and kitchen parties to a certain extent. I don't go; most of the time, I just submit my contributions. These days, you can give a little money and request a justification. I use it often. I occasionally have the ability to financially support the event and attend the ceremony, but I am not permitted to serve on any committee that plans them. It's not that I despise them that I don't do it. On the other hand, even if I enjoy them, my child is more in need of my care than these; taking this stance has really helped.*

Parent/participant No. 7 stated:

> *To put it briefly, I have stopped having in-person conversations with my pals, but other than that, I am the same. Due to the child, the only way they communicate is via the phone; they do not visit. I am unable to visit someone while carrying the child. due to the surroundings and his mischievous behaviour there. My son ruins other people's belongings. That is how it is. I steer clear of that. Will the owner be understanding if I go out with him and he ruins anything there? I will have to pay them. He broke a dryer playing in a salon one day when I went with him. The dryer broke when he pushed it. The dryer's owner insisted that I pay. I informed the proprietor that my son was ill and had a problem, but she persisted in requiring payment. To fix it, I had to call a technician. The price came to almost fifteen thousand. That was fixed.*

Parent/participant No. 1 stated:

> *I can't attend weddings, sorry! (laughs) Typically, I don't go to parties when I send in my pledges. I beg your pardon, please. I explain to them that although I don't have a house girl to leave him with at night, I do*

> *have a child with a problem. That's all I tell them. These days, Whatsapp groups are created by party planners. Whatsapp groups are used for meetings, and it is there that the budget is visible. They don't mind if you don't attend these events as long as you donate some money. They do, however, take great offence if you fail to participate and show up. Therefore, I am keen on joining Whatsapp groups for social events and donating. You contribute your money, but you do not show up on the day of the event. Others do ask; others don't. Other people do not know that my child has a problem. Those who know are only my close friends.*

Nearly 50% of the parents think that members of their friends, family, and community have stigmatised and discriminated against them. A number of parents have expressed that they experienced social stigma when friends and family made disparaging remarks about them because of their child's actions in public. Parent/participant No. 7 recounted how she was stigmatised by her child's grandparents:

> *We received an invitation to my child's grandfather's birthday celebration approximately five months ago. On this day, my father-in-law celebrated turning 70. My son was screaming and running around when we were there. The majority of them were enraged by my son's actions. His actions infuriated them, and they ordered us to leave before the child ruined the occasion. I was miserable. I have not returned to their house since that day.*

4.6 Change of Policy, Legal and Regulatory Framework

Although there was no explicit question regarding the legal and policy framework during the interviews, the participants made suggestions about changes that Tanzania should make and put into effect. After learning that the majority of participants desired changes to the laws and policies already in place for special needs children, the researcher created this theme. The majority of participants said that the laws and regulations did not adequately assist and safeguard autistic children.

4.6.1 Change of Policies on Children with Special Needs

Nearly all of the participants recommended that the ministries of health and education alter their current policies in order to better assist children with autism. Participants said that children with physical disabilities are favoured by the existing health and education policies. Some participants stated that there is no commitment or mention of supporting and assisting parents of children with autism in the present health and education policy. The participant quotes that follow demonstrate the need for certain adjustments to the current policies.

Social worker/participant No. 12 stated:

> *They ought to go over the policy on education. Upon examining the special education system, one finds that after completing elementary school, children with autism do not pursue further education. They have no access to secondary education; what will become of them? No college or vocational programme will accept them. Here at the clinic, I have encountered such kids. It is possible to assist these kids in doing other things. Sure, they can't attend secondary school, but what about other options? They are able to. What is their destination? VETA claims they are unable to accommodate them if you take them there. Because they are really brilliant at certain things, I believe that special education should continue, and if a child is unable to go secondary school, they should attend special colleges. Their writing and certificate-giving skills are inadequate, but their design abilities are strong.*

4.6.2 Change of Legal and Regulatory Framework

The majority of participants recommended alterations to the existing legal and regulatory structure. A change in the legal framework was proposed by all professionals in the form of an autism act that would safeguard parents and children with autism. The experts thought that the autism act would mandate required ASD training for medical personnel, mandated child diagnosis, and mandatory training and information sharing. They claimed that a large number of medical school and other educational institution graduates do not now receive instruction on autism, which causes difficulties for them when they begin their careers. The attending physician (participant 16) said:

> *Children with autism should be able to receive therapy funded by national health insurance. For instance, certain medications, such concerta and ritalin, are highly costly. The fact that these medications are not covered by the national health insurance is causing many parents financial hardship. Some of these expensive services should be covered by the law for the parents. Parents should be required to take their kids to the hospital for diagnosis. Any parent whose child exhibits certain autistic signs needs to take their child very early.*

The social worker/participant 15 stated:

> *Health care workers and those in similar fields should be required to complete training and ongoing education. These experts will assist in the early identification of autistic youngsters and the improvement of decision-making. As these professionals routinely interact and deal with a variety of children, including those who have autism spectrum disorder, there are currently some medical professionals and educators who know nothing about autism.*

CHAPTER FIVE

SUMMARY OF FINDINGS AND DISCUSSIONS

5.1 Introduction

The effect of autism spectrum disorders on family well-being was investigated in this study. The study aimed to investigate three key areas: the experiences parents had prior to receiving a formal diagnosis of autism spectrum disorder; the current state of government services and support for this condition; and the opinions of professionals and parents regarding the effect of autism spectrum disorder on the well-being of the family. Twenty-one interviews with parents, teachers, social workers, and health experts were used in the study to gather data. In accordance with earlier research and theoretical frameworks covered in the literature review, this chapter summarises and examines. Following the discussion of each objective, the researcher's thoughts on the findings and conclusions were presented.

The study employed Bronfenbrenner's Ecological Systems Theory to investigate the impact of autism spectrum disorders on the overall welfare of the family. Because it considers internal and external elements that affect family well-being outside of family structures, this theory provided a valuable framework. It also considers the social and cultural context of the children as well as the interactions between parents and children.

The results demonstrated that the majority of parents whose children had autism were unaware of the disorder before it affected them. The results showed that the majority of parents were unaware of the issue beforehand. This result is in line with a study by Anwar et al. (2018) that discovered parents don't know enough about autism and aren't aware of it. Parents don't know about diagnosis and treatment options in addition to indications and symptoms. In the interview, the majority of parents stated that prior to their children's diagnosis, they did not receive information about autism from their acquaintances. It was also noted that prior to learning about the issue through their children, parents knew very little or nothing about it. This result is consistent with a study by Zuckerman et al. (2014) regarding the understanding of autism in the Latino community and its connection to early diagnosis, which discovered that no one was aware of developmental disabilities services, early intervention, or other specialised community resources available to kids with developmental delays.

The results demonstrated that neither the medical community nor the media provided parents of autistic children with much information on the disease. According to Bakare et al. (2009), Bakare et al. (2008), and Franz et al. (2017), inadequate knowledge and awareness regarding childhood autism in Sub-Saharan Africa, particularly among educators, social workers, and health workers, may jeopardise early detection and interventions. In a similar vein, Al-Sharbati et al. (2013) found that Omani teachers have little awareness of children with ASD. According to Al-Sharbati et al. (2013), most educators who took part in the survey believed that abuse or neglect suffered by the kid in their early years causes autism. This suggests that the teachers in Oman thought autism could be caused by unhealthy parent-child connections. Similarly, Zhang et al. (2018) discovered that child healthcare providers in Chongqing, China's grassroots health care system lacked information about childhood ASD. The results of this study contradicted the expectation that parents of children with ASD would receive assistance from the mass media. Prior to their children's diagnosis, the majority of the parents in this survey had not seen anything about ASD in the media. Research on how ASD is covered on radio and television in Sub-Saharan Africa is scarce. Studies on ASD that are easily obtainable and available in industrialised nations like the United States and Great Britain (Ressa, 2021; Jang et al., 2019; Kang, 2013) indicate that ASD is widely covered on radio and television. This suggests that in order to increase public awareness and understanding of autism spectrum condition, local television and radio programmes should be highlighted.

There is no official handbook or set of guidelines on autism in Tanzania to assist parents in raising autistic children. A standard handbook has been created by certain industrialised nations, such as Denmark, England, and Scotland, to assist parents in raising children with autism spectrum condition. The results of the current study indicate that social media and local medical practitioners are the main sources of information for parents on child care. Parents usually consult a nurse or doctor when they bring their kids to the hospital so they may learn a little bit about how to handle tantrums, meltdowns, sleeping, eating and using the loo.

The current study's findings demonstrated that most parents have learned how to care for their autistic children from social media. According to Abel et al. (2019), social media has permeated many people's daily life. As such, it presents a potentially formidable means for service providers to educate the public about autism. Furthermore, according to Thackeray et al. (2013), parents of ASD children are using social media to research health-related topics. Rhoades et al. (2007) discovered, however, that while the majority of parents in their research stated using social media to learn more about ASD, the vast amount of conflicting information available online confuses the parents. Many parents are unable to obtain the necessary and high-quality information regarding ASD from the internet in the absence of suitable guidance and directives.

The results of this study demonstrated that most parents had not watched local television programming to learn how to care for their autistic children. In contrast, the majority of the African American respondents in the prior study by Campbell et al. (2019) stated that they first learned about autism from radio and television shows. A few earlier studies (Holton, 2013; Maich, 2014; Prochnow, 2014) have critiqued how people with ASDs are portrayed in films and television. They maintained that a number of films, television shows, and television programmes have unnecessarily biassed viewers and inaccurately portrayed people with ASD. Television is nevertheless a vital source of information about ASB for parents, kids, the government, and society at large, despite these detractors. Politicians, health policymakers, the public, and parents of autistic children can all benefit from the public's education provided by television news, series, and shows that address autism spectrum disorders (ASD) (Kang, 2013).

According to the findings, the majority of the population lacks knowledge about

ASD, which can result in inaccurate information about the condition and unfavourable reactions to it, like taking children to witchdoctors or religious leaders or having them participate in rituals that don't always address the issue. Similar results were observed by earlier study. For instance, Newton et al. (2015) described witchcraft, evil spirits, and a curse in their investigation on the alleged causes of ASD on the Kenyan coast. Participants in this study linked cultural beliefs about witchcraft, evil spirits, and curses to autism spectrum disorders in children. This finding is consistent with research (Cohen, 2012; Nyarambi et al., 2011; Shilubane & Mazibuko, 2020) where data showed that ASD was connected by parents and the community with witchcraft and supernatural abilities.

This result is consistent with the findings of (Mansell & Morris, 2004; Rhoades et al., 2007), which found that inaccurate, unsuitable, and misleading information on ASD may cause a delay in diagnosis. This research highlights the significance of giving educators, medical professionals, and social workers correct information regarding ASD. All people should have access to information in order to lessen the difficulties associated with ASD. The results suggest that more parents should be informed about ASD during clinic visits, that kindergarten instructors should receive training on ASD and how to manage it, and that parents should receive counselling. Similarly, as most physicians seemed to be ignorant of the illness they were supposed to diagnose and counsel patients on, the curriculum for medical schools should emphasise the material on ASD. Inaccurate information from important sources, such as physicians, friends, and family, causes parents to receive bad advice, which makes managing children with these disorders much more difficult.

Additionally, the study discovered that parents of autistic children receive minimal assistance from their moms, fathers, and other family members in raising these children. The majority of parents raised their children without assistance from parents or other family members. This is comparable to a study conducted in 2009 by Altiere & von Kluge, who discovered that a large number of the couples in their research reported feeling unsupported by friends and relatives. After learning that their child had autism, the spouses also mentioned having serious difficulties with relatives who live far away. Others claimed that because their extended family did not comprehend autism, they were unable to provide support. According to Galpin et al.'s (2018) study, parents' difficulties in providing complex needs care for their kids frequently extended beyond the children's individual autism symptoms. They included the requirements of kids for self-care, language, nutrition, and sleep. The majority of parents are burdened by this since caring for children with autism is highly costly and demands additional labour. Enlightening the community about ASD and the need for mutual support in treating it would help to minimise the low level of support from the family.

Tanzanian government assistance and services for autism suffer greatly from a general state of disrepair. The majority of participants expressed dissatisfaction with the calibre of care their kids will receive in public hospitals. This result is in line with earlier research conducted in Africa (Abubakar et al., 2016; Dillenburger et al., 2016; Kamau, 2017; Orfson-Offei, 2021) that shown the inadequate care that public hospitals provided for autistic children.

The results of this study demonstrated that health professionals' capacity to assist parents of children with ASD was limited due to a lack of training. Due to a lack of training, participants thought that most medical staff members knew very little about ASD. According to Dillenburger et al. (2016), the majority of professionals had attended either few or no training sessions, indicating a serious shortage of proper training for them.

Every parent expressed the strain of high medical costs as a result of the lack of government assistance. Parents complained that their income was lost as a result of working fewer hours, that some health procedures were not covered by insurance, and that private hospitals charged high prices for these services. Wang et al. (2013) discovered a similar deficiency in government funding for autistic youngsters. Nonetheless, the results of this study differ from those of studies conducted in Europe (Education, 2000; Pejovic-Milovancevic et al., 2018; Van Kessel et al., 2019a; Van Kessel et al., 2019b)), which stated that parents of autistic children were given special government assistance for their child, primarily in the form of financial support. By aiding parents of autistic children, their government allowed them to unwind. The current investigation revealed the exorbitant costs associated with special education teachers, schooling, occupational treatment, music therapy, and speech and language therapy. The parents were severely limited by these expenses. The government should fully support families and individuals with ASD and make sure they have a decent quality of life, according to the study's conclusions.

The results imply that the majority of participants felt that children with autism did not receive a high-quality education in public schools. The availability of better autism-specialist teachers, class size, classroom atmosphere, school social workers and psychologists, and improved and appropriate teaching aids for children with autism are some fundamental factors to consider when offering quality education. According to earlier research by Mujkanovic et al. (2017), the majority of parents and teachers said there weren't enough educational resources for kids with ASD. The results of this survey showed that several public-school primary school teachers were dissatisfied with the Ministry of Education's demands for high performance, citing a lack of skills, knowledge, and resources as the main causes of their complaints. Consequently, educators expressed dissatisfaction over their professional workload and insufficient knowledge and abilities to assist kids with autism (Majoko, 2018). This conclusion suggests that Tanzanian government and health policies are needed to enhance special education teachers' and health professionals' training, as well as to provide more resources for screening and intervention (Wannenburg & Van Niekerk, 2018). Furthermore, every participant thought that insufficient funding was being provided by the government to support children with autism. This is in line with the findings of earlier research that was carried out in Tanzania, Ghana, Zambia, and Nigeria (Adeyanju, 2012; Alexander, 2014; Bird et al., 2011; Busiku & Matafwali, 2022).

The results of this investigation indicated that healthcare and the educational environment receive less funding. According to studies (Azad et al., 2018; Güleç-Aslan, 2020; Lushin et al., 2020; Thomasson, 2018), the majority of respondents felt that public school classrooms were overcrowded and therefore not suitable for children with autism. Some autistic children were reportedly studying in places like workshops.

According to most research participants, the government was only doing a mediocre job of raising public awareness of the issue, which was making the condition's impacts worse. Prior studies examined the detrimental impacts on society of a lack of knowledge on ASD (Dillenburger et al., 2013; Jamidin et al., 2019; Shrestha & Santangelo, 2014). On the other hand, earlier research conducted in Europe (Della Fina & Cera, 2015; Winter, 2017) demonstrated the significant influence that governments play in raising public awareness. According to Nicolle (2022), the United Kingdom's House of Lords enacted an amendment to the Health and Care Bill in March 2022, making autism and learning disabilities required for nurses and other healthcare workers in England. They believed that the UK government had not done enough to address and raise awareness of autism and learning difficulties, despite having invested large sums of money in these areas.

The majority of survey participants indicated that paying for autism care is expensive and that their health insurance does not cover these expenses. Likewise, Mbamba & Ndemole (2021) discovered that the majority of parents involved in their research faced financial limitations when it came to raising their kids. In their study, the parents said that therapies and clinical care for their ASD children were costly and not covered by health insurance plans. Brown et al. (2006), Francis (2017), Horlin et al. (2014), Memari et al. (2015), Ntre et al. (2018), Ou et al. (2015), Parish et al. (2015), Tadesse (2014), Thomas et al. (2016), and other studies have all found that parents of these children have experienced a significant financial burden as a result of trying to meet their needs, which include special foods, music and occupational therapy, medical bills, and education.

Similarly, studies conducted by (Eseigbe et al., 2015; Marsack-Topolewski & Weisz, 2020; Roddy & O'Neill, 2019) discovered that most parents brought their autistic children to public hospitals, most likely due to financial constraints. They contended that parents were grumbling about having to pay for their autistic children's private therapeutic sessions and evaluations out of pocket. The results contradict the findings of Al Jabery et al. (2014), who discovered that parents in Jordan mostly voiced complaints over the financial burden associated with obtaining medical and health care, as well as the cost of treatments (primarily provided by private clinics). The ecological systems theory states that the welfare of the family is impacted by current laws and policies (Bronfenbrenner 1986, 1989). For instance, the family faces financial hardship as a result of the absence of laws and regulations protecting vulnerable children.

According to the current study, some parents gave up their careers to care for their kids full-time. This is in line with earlier research (DePape & Lindsay, 2015; Lee et al., 2008; Lin et al., 2008; Myers et al., 2009; Ouyang et al., 2009; Ozdemir & Koç, 2022) which discovered that parents were forced to change careers, quit their jobs, or reduce working hours due to issues with their children or an inability to find childcare. Some of the moms in this study had to quit their jobs in order to have adequate time to care for their autistic children. To support his children and his unemployed wife, a husband had to put in a lot of labour. Income loss occurs when a parent quits or leaves their employment. Parents of children with ASD may find their financial burden increased, either directly or indirectly, by a loss of income (Vohra et al., 2014).

The ecological systems theory states that the degree of agreement between the child and the surrounding ecological systems determines the well-being of the child with ASD (Bronfenbrenner 1986, 1989). Additionally, it is thought that the child at the centre of the circle is also impacted by the interactions between the child with ASD and other members of the system, including family, the economy, schools, and healthcare facilities. The child's and family's wellbeing will probably suffer if the system isn't operating at its best.

The results of the current study are distinct from those of previous research conducted in three developed European nations (Denmark, Sweden, and Finland) (Johannessen et al., 2017; Zakirova, 2019). Good health policies and regulations that safeguard children with autism and other disabilities were reported by the research. Furthermore, the majority of participants in their research did not believe that families with autistic children had to bear a financial burden from their children. The government provided funding to parents and autistic children in order to lessen the financial strain that the condition may have caused (Clevnert & Johansson, 2007).

According to the current study, the majority of parents experienced stigmatisation when others held them in low regard because of their child's improper behaviour in public. According to the study's findings (Gona et al., 2016; Grey, 1993), people with autism have experienced stigmatisation and discrimination from friends and family as a result of misconceptions, ignorance, and prejudice. Baffoe (2013) claims that people with disabilities frequently get disrespectful treatment. According to the results of this study, prejudice and contempt can result in aggressive behaviour, bullying, societal marginalisation, scorn, and a reduction in one's sense of value (Baffoe, 2013). People with autism experience oppression as a result of this kind of discrimination in all facets of life, including housing, employment, education, meaningful relationships, and the standard of living that is available to all people.

According to Veroni (2019), parents of children with ASD found life to be considerably more challenging due to stigma. Parents sought to hide their child's illness, were afraid they would be treated differently, or were just embarrassed or ashamed of their child's condition. According to studies (Broady et al., 2015; Grey, 2002; Wong et al., 2016), when children misbehave in public, moms are frequently held accountable for their actions and are perceived as being irresponsible and inept. Furthermore, according to Oti-Boadi et al. (2020), having a child with ASD has a detrimental effect on the mother's psychological well-being, her relationships with other family members and society, and the family's general functioning.

According to some parents in the current study, caring for their autistic children wears them out. Additionally, parents in this study reported feeling worn out from caring for their children and having their relationships damaged as a result of breaking regular household routines. Mayes & Calhoun's (2009) study, which included a retrospective examination of clinical data on 477 autistic children already in the public domain, demonstrated that the degree of anxiety and mood symptoms parents expressed was correlated with their inability to get enough sleep. Given that children with ASDs frequently experience sleep issues, parents of these children are more vulnerable to sleep disturbance and poor-quality sleep (Bangerter et al., 2020; Giallo et al., 2013). According to research by Seymour et al. (2012), moms of children with ASD may find it more difficult to manage their children's challenges and that their own weariness may even increase the stress levels of the mothers. Mothers may also experience exhaustion because of the increased need for monitoring and help with daily chores for their children. The current study's analysis supported earlier research (Al-Farsi et al., 2016; Falk et al., 2014), which discovered that some parents' health issues, including high blood pressure, stress, anxiety, depression, and antisocial behaviour, were brought on by the stress of caring for children with ASD.

Most of study participants reported that after receiving an ASD diagnosis for their kids, their stress levels went up. In in-person interviews, one mother said that she had considered suicide due to her overwhelming financial obligations and her role as a single parent raising four children—one of whom has autism—all by herself. According to Kousha et al. (2016), parents of children with severe chronic illnesses like ASD are most likely to experience stress due to their concerns about their children's behaviour, learning difficulties, and peer bullying. Additionally, parents' discomfort levels and the well-being of their families might be significantly impacted by their children's explosive behaviours, eating issues, sleep patterns, routines, and sensory impairments (Kousha et al., 2016; Smith & Grzywacz, 2014).

A small percentage of the parents in this study reported having depression, yet the frequency is still relatively high when compared to the overall population. That implies that parents of children with ASD still struggle with depression. This result is consistent with the earlier research by Machando Junior et al. (2016), which discovered that the prevalence of anxiety symptoms was 33.7%, the prevalence of depression symptoms was 26.7%, and the prevalence of both symptoms combined was 18.9% among the parents of children with ASD. Compared to parents of typical children, parents of autistic children experience higher levels of stress, a worse quality marriage, melancholy, anxiety, and greater hostility (Magana & Smith, 2006).

The results of this study indicated that the majority of parents were anxious and worried about the future of their kids. This result is consistent with other research (Sedgewick et al., 2018; Watson et al., 2013), which found that the majority of parents consider their children's futures. These are some of the often-asked questions by parents of kids with ASD. How do their kids manage to live independently? What kind of assistance do they still require as they become older? Who will be their steadfast ally? Will they always be understood and supported by the community and society? Who's going to be their lover? Can they become self-sufficient financially? When they grow up, who will hire them? What happens if I become sick or get old? Who's going to help my kid? According to the presented data from the current investigation, each of these increased stresses.

The results of this study demonstrated that the parents of autistic children had difficult relationships with other family members and spouses. This was probably because of unproven myths and a lack of knowledge about the nature of ASD. According to the analysis of the current study, some divorced parents claimed that their autistic children were the primary cause of their split. Previous research on the relationship between ASD and marital status is conjectural. Some studies (Hartley et al., 2010; Shumaker, 2013) indicate that parents of children with ASD have a higher chance of divorcing, but other research indicates that having an ASD diagnosis strengthens ties, fosters love, and increases caring for the children. Naseef & Freedman (2012) state that marriage research indicates families choose to remain together more frequently than what the autism community and the media had previously thought. In general, the current study found very few divorces and separations that had anything to do with the autistic child. The majority of spouses believed that their wives were to blame for their child's illness. In addition, unmarried couples have reported disagreements and miscommunications as a result of their child's ASD. According to ecological system theory, a kid with autism and their parents' relationship might be impacted by a dysfunction in one micro-system, such as marital disputes between parents. (Magnusson & Allen, 1983; Bronfenbrenner, 1977, 1979).

According to the results of this study, the majority of participants said that raising their autistic children required a lot of time and effort. According to the report, the majority of parents made the decision to forgo going to social gatherings because they were short on time and needed the money to take care of their kids. This is in line with a 2013 study by Hoogsteen & Woodgate that discovered parents of autistic children put a lot of time and effort on raising their kids, leaving little time for the parents, spouses, family, or themselves. Bagatell (2015) also discovered that because they did not need to deal with professionals instructing them how to care for their children, parents with ASD avoided taking their child to the market, church, friend's house, birthday parties, theme parks, and family activities. This can occasionally lead to marital problems, relationship breaks down, a decline in family trust, and a sense of alienation from friends and family. It is necessary for parents of autistic children to engage in social contacts and events. Parents ought to make time for their kids to attend social events and parties despite all of life's obstacles. It is appropriate for their families and their children's health and wellbeing.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

The effect of autism spectrum disorders on family well-being was investigated in this study. The study looked at what parents went through before their kids were officially diagnosed with autism spectrum disorder, how the government supports and provides services for those with this condition, how families with children who have this condition manage their child, and the opinions of professionals and parents regarding the effect of autism spectrum disorder on a family's overall well-being. Parents of children diagnosed with autism spectrum disorder, special education teachers, social workers, nurses, and physicians who treat these children comprised the study population. Sarm's Occupational Therapy and Rehabilitation Centre, Sinza Maalum Primary School, and Muhimbili National Hospital (MNH) served as the study areas.

This study's design, findings, and analysis may not apply to other contexts, but it does provide parents with a fair amount of information about the experiences, obstacles, and knowledge that come with raising children with autism spectrum disorder. These include inexperienced medical professionals, the high cost of therapy (music, occupational, speech, and language), financial strain, ignorance, damaging customs, stigma and discrimination, stress, anxiety, and depression, and marital/spouse disputes. The majority of parents whose children have autism and their families are adversely impacted by their children's condition.

The conclusion from the analyzed data from all the specific objectives is hereunder detailed.

The conclusion drawn from the data analysis of each of the individual objectives is explained in full below. The primary goal of this study is to investigate the experiences parents had prior to receiving a formal diagnosis of ASD for their children. In general, there was virtually little knowledge on ASD. According to this study, parents were not aware of the diagnosis or available treatments for ADS and were unable to identify its symptoms. Prior studies have also demonstrated that parents, professionals, and the majority of the public lack awareness of and sufficient knowledge about ASD (Igwe et al., 2010; Igwe et al., 2012; Bakare et al. 2008; Bakare et al., 2009). Furthermore, the majority of participants stated that prior to their children's diagnosis, they did not get information on autism from their acquaintances. This is also indicative of the general public's knowledge, comprehension, and awareness of ASD.

The majority of parents spend time and money searching for solutions that are impractical for their children's problems, which has an effect on both the parents and the children due to their lack of understanding about ASD. Some parents chose to treat their children with witch doctors and religious leaders rather than hospitals because they connected cultural beliefs about bad spirits, witchcraft, and curses with autism spectrum disorder (ASD). More parents must be made aware of ASD so they can send their children to the hospital as soon as possible.

The study's second objective looked at professional and parent perceptions on how autism spectrum disease affects a family's overall well-being. In this study, parent work, marital/friend relationships, and the financial/economic burden of ASD on the family were the key effects on the family's well-being. According to the study, the majority of parents were heavily in debt as a result of trying to meet the requirements of their autistic children. For the parents who took part in this study, the financial consequences of ASD, both direct and indirect, are too high. For instance, having a child with the highest severe level of ASD was linked to increased caring and financial costs, according to a study by Lavelle et al. (2014). Their study provided comprehensive estimates of the total economic burden of childhood ASD and concluded that having a child with autism costs more than three times compared to normal children. It is also reported that the parents of children with ASD earn less than those of children with normal children because of their time caring for them. Their study indicated that having a child with autism costs more than three times as much as having a child without autism, and it gave detailed estimates of the overall economic burden of childhood ASD. Additionally, because they must spend more time caring for their children, parents of ASD children are reportedly paid less than parents of normal children.

The results of this study demonstrated that married couples were likely to experience marital stress, and some of them experienced marital problems as a result of having ASD children. There are moments in their lives when they misunderstand and blame one another for their children's condition. A few married couples divorced because they were unable to handle the stress of raising an autistic child. According to Chan and Leung's (2020) research, parents who have an ASD child may find themselves in a very demanding circumstance where their marriage's dynamics and quality may suffer. Parents' marital bond may be weakened by issues associated with raising a kid with autism spectrum disorder, they contended. Professionals who work with families raising children with ASD, including counsellors, therapists, psychologists, doctors, school administrators, special education teachers, and social workers, should be united in their approach to educating parents and assisting them in accessing formal and informal respite care services (Harper et al., 2013). Parents of children with ASD will have less marital stress as a result of this.

The third goal of this research assessed the state of government assistance programmes and services for people with autism spectrum disorders. The results demonstrated Tanzania's government's inadequate support and services for people with autism. The majority of participants expressed dissatisfaction with the calibre of care that their kids will receive in public schools and hospitals. According to the analysis, the majority of participants stated that autistic children did not receive a high-quality education in public schools. The study also showed that teachers and public health experts were not trained on ASD and were therefore unable to work with autistic pupils. Special consideration, care, and instruction are required for students with autism. Certain children with autism attend schools, but their teachers may not have received the necessary training because autism education is not mandated in Tanzania. Enforcing required autism training for educators can contribute to the mitigation of this issue.

According to the report, the majority of parents struggle to pay for their children's medical expenses as there is little help from the government. The cost of raising an autistic child is high. Treatments for autism spectrum disorders (ASD) may include occupational therapy, music therapy, animal therapy, specialised foods, and special diets; nevertheless, the majority of the parents in the survey reported that these therapies were too expensive. This suggests that the state must step in and provide these parents with financial assistance.

6.2 Recommendations

I suggest the following to different stakeholders based on the analysis in Chapter 4, the findings summary in Chapter 5, and the discussions in Chapter 5:

6.2.1 To the Government

In Tanzania, students with ASD are currently not allowed to pursue higher education after finishing secondary school. It is therefore recommended that the government construct new training facilities. In order for the current colleges and vocational training facilities to be able to accept and instruct students with autism spectrum disorder, they should also be strengthened and improved.

The results demonstrate how some detrimental customs and attitudes impact both parents and kids with ASD. Because of this, the government and society at large must inform the public about dangerous customs and beliefs that cause delays in ASD diagnosis and treatment.

The majority of parents of children with ASD are insecure financially, according to the data. As a result, it is recommended that the government provide complete social and economic support to families and individuals, as well as guarantee a high standard of living for those with ASD.

It was noted that overcrowding in public school classrooms made them uncomfortable for kids with autism. For this reason, the government must construct new schools and renovate the outdated ones with inadequate facilities and surroundings for kids with autism and other developmental disorders.

According to reports, parents and kids with ASD are impacted by stigmatization and discrimination. In order to raise awareness of ASD and assist in ending or reducing stigmatization of children with ASD and their parents, the government is recommended to collaborate closely with non-governmental organizations and community-based groups.

The findings indicated that there is no national policy to support parents and kids with ASD. To better assist the kids and their parents, the government is encouraged to develop a national strategy for people with autism spectrum disorder that includes early diagnosis, funding for existing ASD human resources, inclusive education, awareness, and community empowerment. Therefore, it is recommended that the government create an Autism Act. The legislation will address the required diagnosis of children, the required training of health professionals in ASD, and the required dissemination of information and knowledge on ASD.

The results indicated that there aren't many specialised radio and television shows that deal with ASD-related concerns. In order to educate the public and parents of autistic children, the government, through the ministry of information, communication, and information technology, should collaborate closely with national and commercial radio and television stations to produce special shows and television programmes.

6.2.2 To the Health Ministry and Ministry of Education

The results demonstrated that social workers and special education teachers are dissatisfied with the challenging environment—including the rewards and allowances—of working with children who have ASD. To encourage social workers and special education instructors who deal closely with children with ASD in hospital and school settings, it is necessary to implement unique allowances and incentives.

The results showed that there was no database available that provided information on the prevalence and actual number of autistic children across the nation. As a result, the Ministry of Health ought to involve all relevant parties in a nationwide survey on ASD. A database on ASD in the nation will be created with the aid of the nationwide survey.

The results demonstrated a problem with early ASD detection throughout the nation. As a result, the Health Ministry needs to make sure that ASD is diagnosed correctly, treated promptly, and supported by research.

The results of this study demonstrated that health professionals' capacity to assist parents of such children was hampered by their lack of training. Thus, in order to provide new professionals with specialised training, the Health Ministry should employ seasoned medical staff who have expertise working with children who have ASD.

The findings demonstrated that special education instructors in both public and private institutions lacked sufficient training. Therefore, it is recommended that the Ministry of Education give current special education teachers additional training because their knowledge and abilities to work with autistic students are limited.

The analysis showed that there is a national shortage of special education teachers. The current special education instructors are complaining about their excessive workloads; thus, the Ministry of Education is being asked to hire more of them.

Because they primarily engage with children at the village and ward levels, the Ministries of Education and Health must make sure that its health workers receive training regarding ASD.

The results indicated the lack of a nationwide standard technique for ASD diagnosis and evaluation. As a result, the Ministry of Health has to develop a national standard tool that uses local content to diagnose and evaluate ASD.

6.2.3 Non-Governmental Organizations (NGOs) and Community-Based Organizations (CBOs)

The results indicated that parents of children with ASD were burdened financially.

The majority of parents mentioned how difficult it is to pay out-of-pocket, and how it has become a burden. As a result, non-governmental and community-based organisations (CBOs) ought to assist low-income parents of autistic children in covering the costs of private therapeutic interventions and evaluations for their kids.

The results demonstrated that most Tanzanians were unaware of or lacked knowledge of ASD. As a result, non-governmental organisations (NGOs) and the Ministry of Health should work together to design intervention activities that raise awareness about ASD in the public domain.

It was discovered that some parents of ASD children experience health issues as a result of the disorder running in their family. As a result, non-governmental and community-based organisations ought to assist the parents by offering psychological services and counselling to lessen health issues like high blood pressure, stress, anxiety, and depression, as well as antisocial behaviour linked to their involvement with and care for an autistic child.

6.2.4 To Parents

The results demonstrated that some parents of ASD children withdraw from society because of fear of prejudice and stigma. It is not expected of parents to live alone. They have to make sure that, in spite of the difficulties and problems they encounter, they keep up family customs and routines. Attending events like games, parties, the mosque, and churches will help them deal with the difficulties they are facing.

Instead than waiting for specialists to take care of everything for them and their kids, parents are recommended to educate themselves and their family on ASD. It is suggested that they read up on autism spectrum disorder in books and publications. They can also view television shows, films, and documentaries regarding autism. These will serve to educate both them and their kin or families.

Parents are also encouraged to ask for assistance and support from anyone they think can be of assistance to them. They ought to refrain from experiencing stress and not seek assistance. Someone is always willing to assist them, somewhere.

To share and exchange ideas and experiences with other parents, parents should physically join a parent group or use social media platforms such as Facebook, Instagram, YouTube, WhatsApp, and Facebook. Some organisations ask various ASD experts to assist them in resolving difficult and perplexing inquiries.

They ought to schedule time for their other kids as well. It is suggested that parents instruct and assist other typical kids. More time spent with an autistic child will have a detrimental effect on other kids.

Instead of choosing dangerous customs, parents are encouraged to instill in their children a desire to seek medical attention and to visit accredited facilities.

Unfortunately, some parents hide their children and put off diagnosis and care out of fear of discrimination and stigma. As soon as a parent discovers that their child is experiencing developmental difficulties, they should cease hiding them.

6.2.5 Community, Relatives and Friends

The results demonstrated that some family members exacerbate the issues by stigmatising, discriminating against, and isolating parents of children with ASD rather than supporting them in resolving the situation. Family members should therefore assist rather than cause issues. Friends are also encouraged to love and assist parents of children with ASD.

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APPENDICES

Appendix I: Interview Guide Tool for Parents of Children with Autism Spectrum Disorder

Demographic questions (age, gender, family size, birth order etc.)

1. How much did you know about ASD before your child was diagnosed?

   Probes:

   - where or not they knew about ASD before
   - specific info that was known e.g. about its nature, challenges, services
   - medium of such info e.g., media, friends and family
2. How did you know that something was different with your child?

   Probes:

   - Things observed about the child (in behavior, socialization etc)
   - External remarks maybe (e.g., from family, friends, the teacher, the doctor)
   - Perhaps the treatment from other children, people around
3. What did you do after realizing that something was different with your child?

   Probes:

   - parent's first reaction (emotionally, socially)
   - Intervention initiatives opted (traditional medicine, visiting parents, the hospital etc)
   - How was the whole treatment process like? (Any challenges, lots of support)
4. How does the government address the issue of autism?
5. What kinds of support do you receive from the government?

   Probes:

   - Mention those services
   - When and where do you get them?
6. To what extent are you satisfied or dissatisfied with those services Probes:
   - How do you evaluate them? Are they excellent? Poor?
   - How much do you pay for the services? Or free?
7. What should be done to improve them?
8. How do you describe the way you parent your child with ASD?

Probes:

- knowledge of parenting a child with ASD (what they actually know & how to handle)
- specific behaviors elicited by a child with ASD (who they actually parent)
- approaches to nurturing/ catering for a child with ASD (what they actually do when the child is in need)-you know, the roles of a parent like educating, disciplining, etc

9. Autism affects everyone differently. The three primary characteristics of autism are communication and social deficits and repetitive behaviors. Tell me specifically how these three symptoms have affected your child.
   - Which ones have been the most challenging and why?
   - Describe the changes in these symptoms over the years, if any.
10. What assistance do you have in raising your child?

    Probes:
   - Any other support e.g., caregivers, relatives (grandparents, aunt, sibling etc) especially if parents have to work,
   - how knowledgeable are they to care for a child with ASD?
   - Any specialized care? E.g., special clinic, school, and the specific services offered there
11. The effects experienced in your family from raising a child with ASD.

Probes:

- How did you feel at the first time you noted your child has autism?
- What steps did you take to address this problem for the first time
- Can you explain how it changed your routine work?
- Can you explain how it changed your budget expenditure?
- Can you explain how it changed your relationship with your spouse?
- Can you explain how having a child with autism affected your relationship with your friends?
- Can you explain how it changed the attention you always gave to your other children if any?

12. How does everyone in your family cope with your child?

Appendix II: Interview Guide Tool for Social Workers

1. Demographic questions (age, gender, family size, birth order etc.)
    - Years as a social work practitioner
    - Years practicing in healthcare
    - Employment Status (full time/part time)
2. How much do you know about ASD?
3. What is the role of the government in training as a profession?
4. Tell me about the role of social workers in screening young children for ASD.
5. Tell me about the role of social workers in raising awareness of ASD/ Probes.
    - What about the government? Any help?
6. Tell me about the role of social workers to engage in research and practice of ASD. *Probes.*
    - What about the government? Any help?
7. Do you believe providing support to parents with a child with ASD is a part of your role as a hospital social worker? Yes or no, Explain.
   Probes.
    - What kinds of support? Explain.
8. What is the most common support(s) you provide to a parent(s) of a child who has ASD?
9. How does the government help service and support of autism spectrum disorder?
   Probes
    - Funding?
    - Subsidizes?
10. What should be done to improve services and support for autistic children and their families?

Appendix III: Interview Guide Tool for Special Education Teachers

1. Demographic questions (age, gender, family size, birth order etc.)
    - Years as a social work practitioner
    - Years practicing in healthcare
    - Employment Status (full time/part time)
2. How much do you know about ASD?
3. What is the role of the government in training as a profession?
4. Tell me about the role of special education teachers in screening young children for ASD.
5. Tell me about the role of special education teachers in raising awareness of ASD. *Probes.*
    - What about the government? Any help?
6. Tell me about the role of special education teachers to engage in research and practice of ASD.

    Probes.
    - What about the government? Any help?
7. Do you believe providing support to parents with a child with ASD is a part of your role as a special education teacher? Yes or no, Explain.

    Probes.
    - What kinds of support? Explain.
8. What is the most common support(s) you provide to a parent(s) of a child who has ASD?
9. How does the government help service and support of autism spectrum disorder?

    Probes
    - Funding?
    - Subsidizes?
10. What should be done to improve services and support for autistic children and their families?

Appendix IV: Interview Guide Tool for Nurses and Doctors

1. Demographic questions (age, gender, family size, birth order etc.)
   - Years as a nurse/medical doctor practitioner
   - Years practicing in healthcare
   - Employment Status (full time/part time)
2. What is the role of the government in training as a profession?
3. What about the training as a professional – how helpful has it been in helping you recognize a child with autism

   Probes.
   - basic training and in-service/continuing education courses.
4. Do you think it is important for nurses/medical doctors to have knowledge and awareness regarding autism? If yes, why?
5. How do you help parents to raise and take care of their autistic children?
6. What should be done to improve services and support for autistic children and their families

Appendix V: Study Information Sheet and Consent Form

Good morning/afternoon. I am Machunde Hamisi Mauma, a Master student at the Open University of Tanzania. I am gathering information about ‘Effects of Child Disability on the family’s well-being in Tanzania. The Case Study of Autism Spectrum Disorder’. I would be grateful if you would be willing to assist by responding to questions related to this research. You will be interviewed alone, and it takes about 40 minutes.

Purpose of the Study

The aim of this study is to examine the effect of autism spectrum disorder on the family’s well-being. Your involvement in this study will help the researcher to get the required data to answer the proposed research objectives. The Research Ethics Committee of the Open University of Tanzania has approved the study protocol. This research is being conducted in Muhimbili National hospitals and some Autism Therapy Centers in Dar es Salaam.

Procedures

The researcher will interview you about your overall experience of living and taking care of an autistic child. You will be asked about your experience encountered before their children were confirmed diagnosed with autism spectrum disorder. You will also be asked about your experience and challenges of taking care of an autistic child. All information that is collected about you during the course of the study will be kept strictly confidential. In no circumstances will your name, address or telephone number be disclosed. The audio recordings will be stored coded, i.e., without any personal identities, only your centre name and date of birth. The information that you will give us might also be inspected by the Research Ethics Committee of the Open University of Tanzania or other persons appointed by the committee. Their involvement will be to make sure that your right and dignity is being protected by this research study. Your taking part in this study will benefit you and others directly and indirectly.

Right to Refuse or Withdraw

Your participation in this study is voluntary. If at any time you do not want to answer an interview question, you may skip that question. Your decision to take part or not to take part in the interview or your decision not to answer any question will be respected. The researcher will only interview you after you have agreed to participate and have signed this consent form. You are free to ask questions before agreeing to participate.

We will require your approval by writing your name (optional) signing in the space provided below:

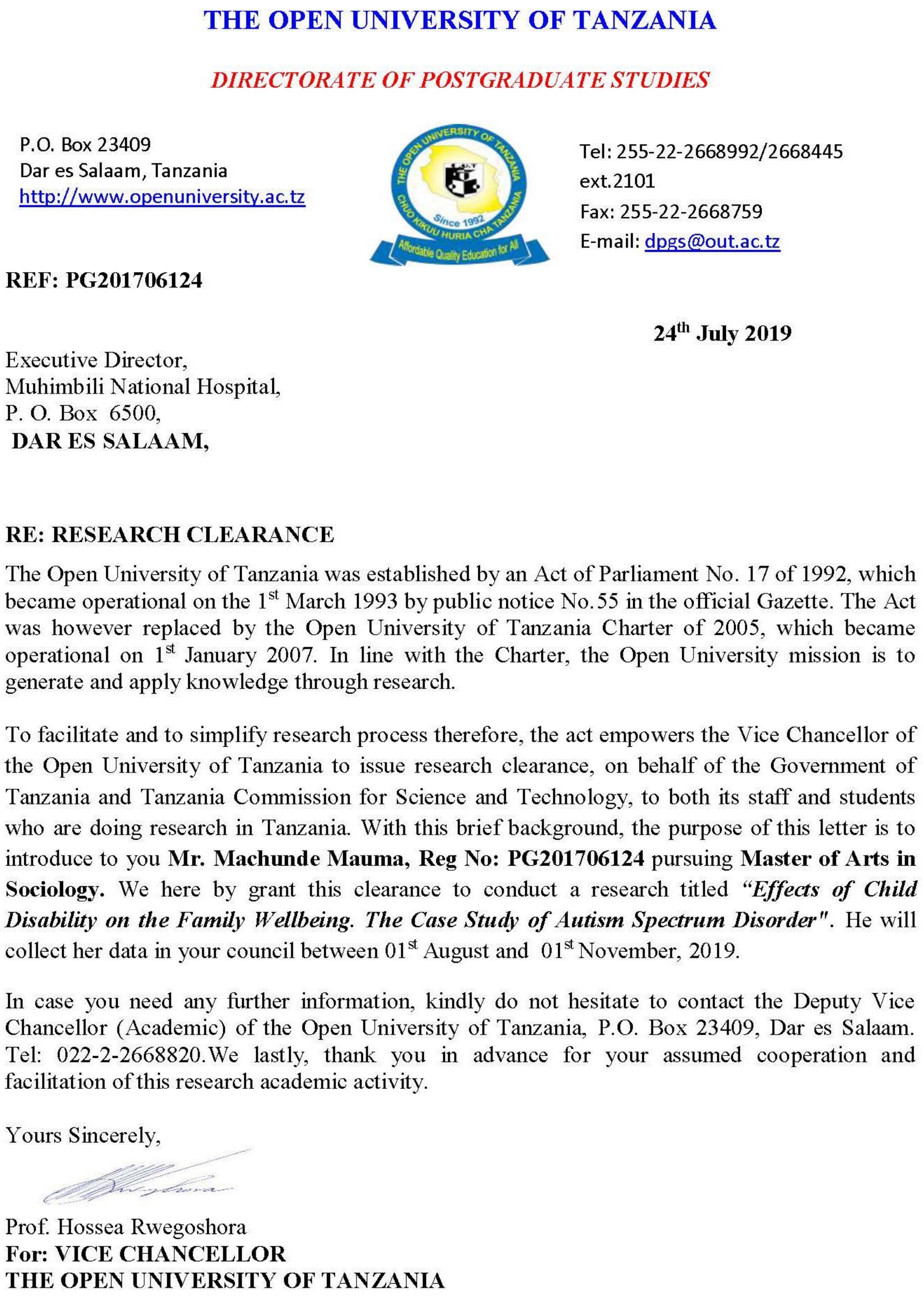
I ……………………………………… certify that the consent form has been read out to me and any questions I had, have been answered. I give my consent and agree to participate in this study about the effects of child disability on 'Effects of Child Disability on the family's well-being in Tanzania. The Case Study of Autism Spectrum Disorder'.

Signature of Participant: ………………………

Signature of interviewer: ………………………

Date: …………………………

Appendix VI: Research Clearance Letter



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REF: PG201706124

24th July 2019

Executive Director,
Muhimbili National Hospital,
P. O. Box 6500,
DAR ES SALAAM,

RE: RESEARCH CLEARANCE

The Open University of Tanzania was established by an Act of Parliament No. 17 of 1992, which became operational on the 1st March 1993 by public notice No.55 in the official Gazette. The Act was however replaced by the Open University of Tanzania Charter of 2005, which became operational on 1st January 2007. In line with the Charter, the Open University mission is to generate and apply knowledge through research.

To facilitate and to simplify research process therefore, the act empowers the Vice Chancellor of the Open University of Tanzania to issue research clearance, on behalf of the Government of Tanzania and Tanzania Commission for Science and Technology, to both its staff and students who are doing research in Tanzania. With this brief background, the purpose of this letter is to introduce to you **Mr. Machunde Mauma, Reg No: PG201706124** pursuing **Master of Arts in Sociology.** We here by grant this clearance to conduct a research titled ***"Effects of Child Disability on the Family Wellbeing. The Case Study of Autism Spectrum Disorder"***. He will collect her data in your council between 01st August and 01st November, 2019.

In case you need any further information, kindly do not hesitate to contact the Deputy Vice Chancellor (Academic) of the Open University of Tanzania, P.O. Box 23409, Dar es Salaam. Tel: 022-2-2668820.We lastly, thank you in advance for your assumed cooperation and facilitation of this research academic activity.

Yours Sincerely,

Prof. Hossea Rwegoshora
For: VICE CHANCELLOR
THE OPEN UNIVERSITY OF TANZANIA