



College of Education and Behavioral Studies

Department of Special Needs Education

**The Role of Parents of Children with Developmental Disability
for the Effectiveness of Center-Based Rehabilitation Services: The
Case of Addis Guzo Centre**

By: Fikiru Bedasa

July, 2023

Addis Ababa, Ethiopia

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**A Thesis Submitted to Addis Ababa University's College of
Education and Behavioral Studies, Department of Special Needs
Education in partial fulfillment of the requirements for the degree
of Master of Arts in Special Needs Education**

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DECLARATION

I, the undersigned, hereby declare that the following thesis entitled “The role of parents of children with developmental disability for the effectiveness of center-based rehabilitation services: the case of Addis Guzo Centre” is my original work, has not already received the degree award from another university, and that all sources of information utilized in the preparation of this thesis have been properly recognized.

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This affirmation is for the thesis named “The role of parents of children developmental disability for the effectiveness of center-based rehabilitation services: the case of Addis Guzo Centre” is Fikiru Bedasa's unique creation, completed under my personal supervision.

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ACKNOWLEDGMENTS

Without the help of the omnipotent God, this couldn't be possible. I start my gratitude by thanking Dr. Abebe Yehulawork, my adviser, for his expert, knowledgeable, & helpful support on my paper. Since his enlightening remarks and recommendations made my work on the thesis feasible, I am happy in expressing my gratitude again.

The Addis Guzo Center, from which the participants were chosen and contacted, has my sincere gratitude. Additionally, I want to incorporate my sincere appreciation to respondents of the study for sharing their personal experiences. I owe my gratitude for the success of my research to my family, especially my beloved wife, Meseret Mogos, who has always supported me in every aspect concerning my thesis.

Also my appreciation and thanks go to my instructors in Addis Ababa University and friends for their unwavering help, inspiration, and moral support. Finally, my gratitude goes to co-workers for their inspiration throughout designing my manuscript.

ABSTRACT

Rehabilitation services for children with developmental disability determine the interventions chosen by a multidisciplinary team with involvement of parents. Most of the needs for rehabilitation go unfulfilled in countries with low and moderate incomes, and more than half of those who need rehabilitation treatments do not receive them in Ethiopia. The purpose of the study was to examine the role of parents of children with developmental for the effectiveness of center-based rehabilitation services. Qualitative approach was applied a phenomenological design to conduct the study. The study was conducted at Addis Guzo Center wich wich is located in Addis Ababa, Lideta Su-city. Observation, interviews and document analysis were used to collect data. Fourteen parents of children with developmental disability were purposively selected as the study participants. The data was analyzed by categorizing the data into four thematic areas. The study findings showed that parents were not initially aware of their responsibilities and roles in providing rehabilitation services; however, the professional support and awareness-raising services that the professionals of the center provided for them encouraged their active involvement. Additionally, the study findings identified that rehabilitation services play critical roles in supporting children with developmental disability, and the involvements of parents in the process of rehabilitating children with developmental disability contributes to holistic progress of a child including improvements in their day to day activities, social inclusion, and advocate their fundamental rights. Rehabilitation centers should involve parents in providing rehabilitation services for children with developmental disabilities to assure expected outcomes.

Keywords: *Institution-based rehabilitation, Inter-Professional Collaboration, developmental disability, Rehabilitation, intervention, Parental role*

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ACRONYMS AND ABBREVIATIONS

CBR: Community Based Rehabilitation

CDG: Cross-Disability Group

CP: Cerebral Palsy

CRPD: Convention on the rights of people with disabilities

GO: governmental organization

IBR: Institution-based rehabilitation

ILO: International labour organization

IPC: Inter-Professional Collaboration

MoH: Ministry of health

NGO: Non-governmental organization

OT: Occupational Therapy

PHC: People's Heroes Center

PT: Physical Therapy

PWD: Person with Disability

SLT: Speech-Language Therapy

UN: united Nations

UNESCO: united Nations educational, scientific and cultural organization

WHO: World health organization

CHAPER ONE

INTRODUCTION

1.1. Background of the Study

Disability is the interplay among people with impairments, attitudes restrictions on their ability to participate fully and effectively in society on an equal footing (Unite Nations, 2006). Due to the limited access to services available to them and the numerous challenges they encounter daily, people with disabilities confront hurdles to receiving support, health care, rehabilitation, education, employment, and other services. Multiple disabilities in a child's cognitive, physical, and functional abilities may hinder the child's mobility, behavior, mood, or sensory functions (World Health Organization, 2011).

Children with developmental disabilities typically require intensive intervention. Extensive and on-going intervention should be given to them in the form of center-based, home-based rehabilitation model, or a combination of the two. Parents are a vital component of these service providers. This means parents and a team of professionals like physiotherapists work together to plan treatment and provide support, services, accommodations, modifications, and therapy that fit the individual child's needs with multiple impairments. Hence, it is believed that a multi-disciplinary team that includes the parents of the child with disabilities, physiotherapists, and other medical specialists in the area should cooperate and work together to plan and provide therapy services (Hyatt, 2004); Since rehabilitation is assumed as a collection of treatments intended to enhance functioning and lessen impairment in individuals with disabilities as they engage with their surroundings. A child can participate in important life roles and be as independent as possible in their everyday activities, as well as in their schooling, leisure activities, and entertainment. Rehabilitation is person-centered, which means their goals and preferences determine the interventions and approaches chosen for each individual. Different settings can deliver it, encompassing both inpatient and outpatient hospital settings as well as community settings like a person's home (WHO, 2010).

Professionals who specialize in rehabilitation include psychologists, occupational therapists, speech-language pathologists, prosthetists, orthotists, and nurses. Parental support strategies include family members who play a prominent role in supporting and guiding their disabled child (Aldersey, 2020). Multidisciplinary team in early rehabilitation techniques include physical exercise. Physical therapy (PT), which works on skills like walking, sitting, and maintaining balance; occupational therapy (OT), which helps the child develop fine motor skills like dressing, feeding, writing, and other daily living tasks; and speech-language therapy (SLT), for issues with speech and articulation, are some of the services that a child might receive for rehabilitation (Kosse et al., 2013 & WHO, 2010).

Parental role is the broad range of tasks or commitments parents make to encourage their child's acquisition of socially and developmentally appropriate abilities (Sandler et al., 2011). The list of responsibilities ascribed to parents during the intervention is the role of parents in rehabilitation services (Sugden et al., 2019). Parents of children with developmental disabilities may expand their occupational parenting role to include a range of tasks that are typical parenting responsibilities to fulfill a child's developmental requirements (Safe et al., 2012). These obligations include providing complex care for developmental needs or being involved in their child's therapeutic procedures (Albright et al., 2016).

Relationships between parents and professionals encourage parents to be involved in the intervention (Kemp & Turnbull, 2014). A promising way to facilitate task shifting from professionals to parents and help balance the power imbalance is through the parent-professional connection. Parents emphasize that when experts place an early emphasis on developing a relationship with clients, parental involvement is encouraged and supported (King et al., 2019). Parents are members making decision in rehabilitation. They collaborate with experts by giving input in an equal partnership (Burrell & Borrego, 2012). Parents and professionals, therefore, share equal responsibility to implement rehabilitation.

The interpersonal relationships that tie the intervention process between the parent, child, and professionals are where parental roles in rehabilitation are produced and developed (Carroll & Sixsmith, 2016). Through iterative exchanges with professionals, parents construct and develop expectations for their own and the professional's responsibilities and knowledge to carry out those roles (Davies et al., 2019). Parents who comprehend the aims and expectations of the professional are inspired to participate during sessions and extend the intervention to the house, assumes more responsibility both in and outside of sessions.

Positive interactions between parents and professionals encourages commitment to developing goals jointly and further validates the role of parent in the rehabilitation (King et al., 2019). As a result, there are various benefits to increased family participation for improved behavior in children, including family acceptance of children, advantages for parents, and advantages for the community. To modify behavior in children, parents must first adjust their perceptions. Although the environment certainly affects the forebears of children, it also provides them with the resources they need to succeed (Paromita, 2017).

During the first diagnosis of child disabilities, denial, rage, and guilt are possible early parental responses and takes time to build the family's trust and active involvement in the child's medical treatment, but it's crucial to encourage this involvement (Alsem et al., 2017). So, working to lessen the impact of disability and improving the status of health of the Ethiopian children with developmental disabilities through the provision and regulation of a comprehensive package of preventive, curative, and rehabilitation services should be the area of focus. In addition, considering the dominant facts related to the typical condition of children with developmental disabilities and their need for physical, psychosocial, and other rehabilitation services by multidisciplinary professionals and parents stated above, investigating the roles of parents children with developmental disability for effective center-based rehabilitation services is the purpose of this study.

1.2. Statement of the Problem

As per the report issued by WHO (2014), of the 93 million children with impairments, it is projected that 90% of children below the age of 15 live with moderate and severe types of impairments. Hence, about 1 billion people living with disabilities globally, including children can benefit from rehabilitation. The predicted need for rehabilitation services is increasing as the health and demographics of the world population change. Most of this need for rehabilitative services goes unfulfilled. In low- and middle-income nations, more than half of those who need rehabilitation treatments do not receive them (WHO, 2021). As a result, both nationally and internationally, rehabilitation has become a high-demand service for parents and children with disabilities. In order to characterize parents' involvement in the rehabilitation treatment process and determine what roles parents have for improving the child problems, the study should look at how and to what extent parents participate in all phases of the rehabilitation process (Esposito & Setoh, 2021).

People's entrenched negative attitudes toward disability and lack of proper understanding of the rehabilitation services required for PWDs remained a persistent challenge in Ethiopia. In addition, poor planning and management of rehabilitation services and a lack of multi-disciplinary team coordination lead to poor services for disabled people. All individuals with impairments who need to be rehabilitated should receive rehabilitation services, should involve parents. Children who have developmental disabilities may need considerable additional support that fits their situation. Increased parental involvement in goal-setting stressed benefits that services would better mesh with the actual needs of the family and be more responsive to their limits, strengths and daily challenges children face. Providing more opportunities in clarifying the goal and essential components of therapy to parents helps increase parents' involvement in treatment and make more responsive to their children's needs (Siebes et al., 2007).

Children with disabilities can access comprehensive and additional support services at the center level if parents and multidisciplinary professionals collaborate. Parental involvement ensures a smooth transition of services and allows parents to contribute meaningfully to rehabilitation service planning (Almalki, 2021). This approach aids in removing obstacles that prevent Ethiopia's underprivileged disabled children from receiving rehabilitative care. Presently, there are limited numbers of rehabilitation centers in Ethiopia, mainly focusing on operating physical disabilities (National Rehabilitation and Assistive Technology Services Management Guidelines for Ethiopia, 2020). Since many children seek rehabilitation services, the number of available centers does not reach children with developmental disability, which is a big challenge in Ethiopia. In addition, the limited number of institution-based services for those children and the lack of strategic directions, such as policies to guide such services, are challenges in the context of Ethiopia. These include a lack of standards for governance, leadership, and poor human resource management issues with rehabilitation services in the country.

According to the National Rehabilitation and Assistive Technology Services Management Guidelines for Ethiopia adopted by the Ministry of Health in 2020, the medical rehabilitation center should employ an appropriate and sufficient number of professionals based on the volume of services and workload that include physiotherapists, occupational therapists, prosthetists, orthotists, social workers, psychologists, mid-level professionals for vision and audiology services, community-based rehabilitation workers, assistant technicians, and technicians whose license and registration are current (MoH, 2020). In addition to the above, the National Physical Rehabilitation Guideline in the Health System of Ethiopia, adopted by the Ministry of Health in 2019, stated that the hospital's physiotherapy department needs to be staffed by the right mix and quantity of professionals depending on the volume of services and workload (Federal Ministry of Health, 2019).

Even though the participation of parents has a frontline role in rehabilitation, the above guidelines ignore the parents' participation in rehabilitation services. However, maximizing the parents' participation in rehabilitation services, decision-making, and choosing preferred rehabilitation services requires attention. Individual child outcomes have differed, which may be due to disparities in the intervention services delivery system. The researchers including Byrne & Cunningham (2021); Esposito & Setoh (2021); Roberts et al. (2011); Almalki (2021); Siebes et al. (2007); Alsem et al. (2017); Burrell & Borrego (2012); and Smith and Samuels (2021) employed several methods to assess the effectiveness of therapy and track the development of rehabilitation services needed for its effectiveness. Changes in test results and skill mastery are two examples of these indicators. The investigated intervention programs focus on age, intellectual and adaptive functioning, severity, and treatment intensity in children (Fava & Strauss, 2014). The question of whether the intervention has a significant influence on the parent's involvement in the child's pace of change, however, has not been well researched.

Several Numbers of children undergo therapy for rehabilitation in various settings. According to Roberts et al. (2011), children who received care at a center emphasizing child playgroups and concurrent parent support and training programs fared better. The outcomes for children when clinicians consistently provide treatment in a rehabilitation center with parental involvement are currently the subject of relatively little study. There are a lot of challenges to delivering rehabilitation services (WHO, 2010). In Ethiopia, causes of ongoing unmet rehabilitation needs include several issues, such as the absence of robust national strategies and programs for rehabilitation; long wait periods and a lack of rehabilitation services; a lack of resources, such as equipment, such as tools, consumables and assistive technology; also, information and research needs on the inefficient and underutilized referral paths to rehabilitation for children with developmental disabilities.

More study is required to fully comprehend how parental engagement might contribute to successful rehabilitation service outcomes; however, researchers have examined how center-based rehabilitation functions as a component of care that fosters improved outcomes. This study examined parent participation in rehabilitation services to understand how parents engaged with and supported center-based rehabilitation programs. This was gained through analyses of parents' experiences and descriptions of the advantages of receiving treatment in a center setting, focusing on the identified leading questions presented hereunder:

1. What kinds of rehabilitation services are made available in the study center for children with developmental disability to maintain the intended outcomes to be achieved as a result of such services?
2. How do parents perceive their participation while delivering rehabilitation services in the study center?
3. Why should adaptive skills and basic knowledge of rehabilitation services needed for children with developmental disability be transferred to parents?
4. How do parents play a role in rehabilitating their children with developmental disability to discharge their respective responsibilities?

1.3. The Objective of the Study

The overall objective of the study is designed to investigate the role of parents of children with developmental disability for the effectiveness of center-based rehabilitation services made available in for children with developmental disability as a role model intervention in Addis Guzo Rehabilitation Center in Addis Ababa.

1.4. The Significance of the Study

This inquiry is assumed depicting the importance of parents' involvement in providing rehabilitation services that could help to take appropriate action to solve the issues in the future rehabilitation service delivery system. The study would also reveal opportunities for

rehabilitation centers to align parents' participation to benefit and improving children with developmental disability's lives. Furthermore, the study could serve as a source of information for future study. The theoretical significance of this study is to address the knowledge gap identified in the most recent two Ministry of Health adopted guidelines.

1.5. The Scope of the Study

Examining how the involvement of parents of children with developmental disabilities at the Addis Guzo Rehabilitation Center impacts the efficacy of center-based rehabilitation treatments is the goal of this study. Not all facets of the life of parents of disabled children are included in this study when providing successful center-based rehabilitation programs. Therefore, the study mainly focused on the perception, roles, participation, achievement, responsibility, communication, adaptive skills, and basic knowledge of parents when delivering center-based rehabilitation services.

1.6. Conceptual Definition of Key Terms

Rehabilitation: Group of interventions intended to improve the functioning and reduce disability in children or adults by addressing underlying conditions (such as pain) and improving everyday functioning, a person can overcome obstacles with thinking, seeing, hearing, talking, eating, or moving about and become as independent as feasible in daily duties and participate in meaningful activities.

Institution-based Rehabilitation: A primarily individual focused, medically oriented, and institutional in which persons with disabilities receive rehabilitation services like specialized physiotherapy, occupational therapy, and other rehabilitative treatments designed and controlled by professionals.

Physiotherapy: a kind of therapy that emphasizes the science of movement by addressing the underlying physical problems, and helps patients regain, maintain, and enhance their physical strength, function, mobility, and general well-being.

Physiotherapist: A trained person who works with patients to develop customized programs helps to restore their functional ability and movement as much as possible.

Developmental Disability: a wide range of chronic illnesses that influence many aspects of a child's life and development, including language, mobility, learning, self-help, and independent living. These conditions can be physical or mental impairments that are present at an early age and last throughout a person's lifetime. When a kid does not go through the usual developmental phases, it might be first assumed.

Multiple impairments: Simultaneous occurrence of two or more disabling conditions or a number of cognitive, bodily, and functional impairments that affect individual life functions.

Occupational therapy: a method of treating people who are physically, mentally, or emotionally ill or handicapped by engaging them in activities like games, weaving, and other activities.

Speech Language Therapy: A program designed for preventing, screening, identifying, assessing, diagnosing, referring, offering assistance, and counseling those who have or are at risk of speech and language difficulties.

Assistive Technology: a tool, piece of technology, piece of software, or product system that helps people with disabilities increase, maintain, or enhance their functional capacities to enhance their learning, working, and daily living.

CHAPTER TWO

REVIEW OF RELATED LITERATURE

2.1. Conceptualization of Rehabilitation from Disability Perspective: Its

Definition and Key Objectives

Rehabilitation from a disability perspective refers to restoring or improving the physical, mental, and social functioning of individuals with disabilities. It involves approaches that address atypical needs and promoting disabled people's independence, involvement, and inclusion in society presents a number of problems (Lakeland Health, 2017). The rehabilitation from a disability perspective recognizes that rehabilitation must address not only the physical impairments but also the environmental and social impediments that prevent people with impairments from fully participating in society (Boothroyd, 2007).

Additionally, rehabilitation from the perspective of a disability is person-centered care, which places the disabled person at the center of the procedure. It includes a team of the disabled person, their family, and a group of healthcare experts, such as doctors, therapists, and social workers. Therapies, such as physical, occupational, speech, and psychiatric counseling, are frequently used during rehabilitation. It also includes technological assistance and assistive gadgets like wheelchairs, prosthetic limbs, and communication tools (Wade, 2020).

Rehabilitation is the process of helping someone reaches their maximum degree of independence, functionality, and quality of life (Danquah-Amoah & Charan, 2017). It accomplishes the individual aim by focusing on the individual's impairment, developmental difficulty, or health concern rather than just their diagnosis. It comprises working together with the individual and others who are important to them in order to assist them in realizing their full potential, developing their independence, and taking charge of their own lives (Wade, 2020).

Through rehabilitation, a comprehensive and integrated program of medical, physical, psychological, and occupational treatments, a person with a disability can be enabled to achieve a personally fulfilling, socially meaningful, and functionally productive existence (ILO, 2008). As the result, rehabilitation services often encompass linked medical, social, educational, and vocational services. According to WHO (2017), the goal of rehabilitation for individuals with disabilities is to assist individuals in achieving and maintaining their ideal levels of sensory, cognitive, psychological, social, and physical functioning. Rehabilitation provides the resources required for people with impairments to gain independence and self-determination.

The goal of rehabilitation is to improve the quality of life of children or people with impairments by fostering their inherent talents in their natural surroundings (Daba, 2015). As Wade (2009) stated, the primary objective of rehabilitation is to change behavior. Setting goals with patients is a crucial step in the rehabilitation process of other healthcare settings. Restoration of the patient's physical, sensory, and mental capacities is the goal of rehabilitation. By enhancing their innate abilities in their natural contexts, rehabilitation improves the standard of living for children or those with impairments (WHO, 2010).

Rehabilitation aims to restore quality of life by removing, minimizing, or getting around these impairments and restrictions. Combining perceptual training to increase speech perception and communication, sensory management to improve auditory function, teaching in the use of technology, regulation of the listening environment, counseling to improve participation, and dealing emotionally and practically with lingering restrictions achieved this goal (Boothroyd, 2007). Rehabilitation can cure impairments, or patients can learn to live with deficiencies that medical treatment cannot cure in an effective rehabilitation program (Walker, 2013).

2.2. Rehabilitation Services for Children with Disabilities

Services in rehabilitation for disabled children should take into account the requirements of both the children and their families. These typically consist of organized, recurring, easily available rehabilitation evaluations and interventions, cooperation and support from the family, technological aid, and communication between teammates (Majnemer et al., 2014). The 2006-established UN-CRPD (United Nations Convention on the Rights of People with Disabilities) and the 2014- 2021 Global Disability Action Plan (GDAP), both globally represent a progressive introduction and execution of enhancing health-related rehabilitation (Gutenbrunner et al., 2020).

Rehabilitation services can treat a wide range of injuries and illnesses like musculoskeletal, neurological, brain, spinal cord, multiple trauma injuries, hereditary problems, degenerative diseases, and other conditions are among the common conditions treated (Cieza et al., 2020). Rehabilitation can be preventative, restorative, supportive, or used as a palliative measure for different diseases and impairments. Each program is customized to fulfill the needs of the patient and may involve one or more therapy services (WHO, 2011).

2.2.1. Medical Rehabilitation Services

Children with impairments can gain from medical professional support services, starting with a diagnosis. In medical rehabilitation, diagnosis is the process of determining an illness or challenge based on its symptoms and indicators (Kahsay, 2010). For various persons, the reason for a disability, the type of impairment, and the appropriate therapies vary. Medical professionals such as pediatricians, psychiatrists, ophthalmologists, and neurologists are involved in medical rehabilitation (Bingham & Beatty, 2003). The rates of accessibility to these health services among individuals with disabilities are correlated with the rates of accessibility to assistive technology and medical rehabilitation services.

Medical monitoring is essential to protect children with disabilities from additional health hazards since they struggle to resist sickness. People with disabilities may need access to costly specialty equipment, expert knowledge, or medications during medical rehabilitation (Kahsay, 2010). Numerous nations frequently depend on international humanitarian aid, specifically different kinds of emergency medical personnel. The WHO and other health organizations stress the importance of beginning medical rehabilitation as soon as possible and continuing treatment for a long time in the community (Rathore et al., 2012).

Medical care is often comprehensive and continues with the goal of identifying and treating abnormalities. By identifying and minimizing developmental disabilities and increasing functional independence through remediation and adaptive methods, rehabilitation services can be helpful immediately and over time. Hospitals' intensive care units should involve occupational and physical therapists as part of their consultation function. The assessment of neurologic health, including auditory responsiveness and neuromotor performance, would be the goal of interventions at this time (Majnemer et al., 2008).

2.2.2. Educational Rehabilitation Services

By giving them the same opportunities to engage in educational programs as other citizens, educational rehabilitation equips people with disabilities with the information they need to become independent (Kahsay et al., 2010). Access to free public education should be guaranteed to all citizens, including those with disabilities, and laws should be in place to promote and protect these rights (Mpofu et al., 2017). The start of school is a crucial turning point in a person's development since it may provide more challenges for those with developmental disabilities. According to Majnemer et al. (2008), these impairments may affect peer interactions, leisure activity participation, and academic achievement.

A sophisticated educational intervention is to address the various learning requirements of children with impairments. These include support services like direct services, which are

given by working directly with children with disabilities to improve, remediate, enrich, or speed up programs. Accordingly Kahsay (2010) confirmed, educational therapy might consist of screening and testing, counseling, occupational therapy, adapted physical education, and school health services.

2.2.3. Socio-Emotional Rehabilitation Services

Socio-emotional rehabilitation is the process of helping individuals recover from emotional and social difficulties caused by mental illness, trauma, or other life challenges. It involves a range of interventions and therapies that aim to improve an individual's emotional and social functioning, including social skills instruction, group therapy, and cognitive-behavioral therapy. The goal of socio-emotional rehabilitation is to encourage individuals maintain the skills and strategies for managing their emotions, build healthy relationships, and participate fully in their communities. This type of rehabilitation is often used with other forms of treatment, such as medication and psychotherapy, to offer a thorough method of mental health treatment (Ghanouni et al., 2017).

Social and emotional healing aims to help disabled people integrate as fully as possible into society, allowing them to meet their regular social obligations and the additional demands imposed by their impairment (Kahsay, 2010). Socio-emotional rehabilitation services for those with impairments aim for functional competence. This skill refers to a person's ability to function in different social contexts to meet requirements and their freedom to participate in society as fully as possible (Gamielien, 2015).

Family members, peers, the neighborhood, and all other people important to these target children should be included in the socioemotional rehabilitation of children with disabilities, so they make a difference in the rehabilitation area. The social environment is more inhibiting for persons with disabilities than their physical impairment. These have an impact on a person's ability to operate and adjust, and they show how difficult and demanding the social

environment is for those who have impairments. Consequently, the rehabilitation strategy is shifting to the rehabilitation of the community from disability (Ayalew et al., 2020).

Individuals with serious mental diseases, such as schizophrenia or bipolar disorder, who may struggle with social isolation and emotional regulation, may benefit most from socio-emotional rehabilitation. Working with a group of professionals in mental health, including social workers, psychologists, psychiatrists, and occupational therapists, is a necessary part of the socio-emotional rehabilitation process. Development of coping mechanisms, social and communication abilities, augmentation of self-esteem and confidence, and instruction in stress and anxiety management are some aspects of socio-emotional rehabilitation. According to Giusti et al. (2018), socio-emotional rehabilitation is a component of mental health treatment that can assist people in overcoming emotional and social challenges and leading satisfying lives.

2.2.4. Vocational Rehabilitation Services

According to ILO (2006), vocational rehabilitation is part of an ongoing and well-coordinated rehabilitation process that involves giving persons with disabilities access to vocational counseling, training, and placement. Its goal is to make it easier for someone who is at a disadvantage to integrate into society and assist them in finding and keeping a suitable job. Services for vocational rehabilitation include case management, vocational planning, and vocational evaluation and assessment to determine goals and additional vocational training (Bosco et al., 2015). Vocational rehabilitation helps identify suitable employment for people with impairments and prepares them for the workforce (Tebeje, 2004). The ability to work contributes significantly to one's health; advances physical and psychological well-being; and contributes to personal identity. Finding effective vocational interventions is crucial to boosting employment and job retention (Chiu et al., 2013).

2.3. Forms of rehabilitation Services for Children with Disabilities

Rehabilitation programs are crucial to helping disabled children reach their full potential and enjoy satisfying lives. These programs enhance the social, cognitive, and physical capacities of people with impairments. Depending on the kind and extent of the condition, many types of rehabilitation treatments are available for kids with disabilities. This review examines forms of rehabilitation services offered to children with impairments (Kumar et al., 2012).

2.3.1. Institution Based Rehabilitation

The way that rehabilitation services are organized varies from institution to institution and is mostly determined by the availability of resources. Today, the majority of institutions solely provide hospital-based services. Adopted in many nations, institutionalized based rehabilitation provides assistance to persons with disabilities largely through institutions and centers, which might only cover a small and negligible part of PWDs. In this approach, people with disabilities move to institutions where opportunities are available help children with disability for interacting with the community (Dambi & Jelsma, 2014).

According to Wegayehu (2004), IBR programs have obvious drawbacks since they are center-based rather than need-based and because these center-based institutes employ expensive, imported technology. Rehabilitation provided in institutions lacks flexibility since it must meet predetermined program objectives rather than the requirements of the client. Institutions, on the other hand, transport disabled children, teenagers, or adults to a location with ready access to facilities, staff, and knowledge. As a result, institutions have provided a lot of services for persons with impairments (Kumar et al., 2019).

2.3.2. Community Based Rehabilitation

A technique utilized in general community development for the recovery, opportunity of equality, and social inclusion of all individuals with disabilities is community-based rehabilitation. People with disabilities, their families, communities, and organizations work

together to implement CBR with the help of applicable GO and NGO health, education, employment, social, and other services (WHO, 2010). CBR is an approach to community development that incorporates it without assigning it a specific goal (Kahsay, 2017). The fundamental tenet seemed to be that individuals with disabilities can participate in the community and gain from societal growth (Finkenflugel, 2004).

According to Jacob (2015), there are several obstacles that people with impairments must overcome to fully and equally participate in society. PWDs are excluded from the workforce, health services, educational opportunities, and other parts of society, which can lead to poverty (World Health Organization, 2011). Additionally, they receive insufficient recovery services. A CBR plan within general community development is needed to reach these problems and promote social inclusion, opportunity equality, and rehabilitation of all PWDs.

It is a comprehensive plan for promoting neighborhood development, mainstreaming impairments, and completing an inclusive society for all people. Additionally, it mentions that PWDs, their families, and communities must work together to provide the necessary health, schooling, vocational support, and social services (World Health Organization, 2005).

Adopting and putting into reality this ideal CBR method still presents several difficulties. Hence, WHO revised the guidelines and provided updated recommendations based on some experience with CBR (WHO, 2010). This CBR matrix assesses the political tactics for improving the situation (empowerment) and the subject areas of social, health, and education circumstances. CBR guidelines seek to draw connections between the various categories and demonstrate the path toward inclusive development.

Only a small number of Ethiopia's among the millions of persons with disabilities benefit from rehabilitative programs (Wegayehu, 2004). Promoters of CBR engage in direct interaction with PWDs through cross-disability groups (CDGs). These organizations' goals

are to support income-generating enterprises, skill-training seminars in their communities, and the education of their children (Geiger, 2012).

Despite the present acceptance of CBR as a method for enhancing the lives of PWDs, it is hard to determine to what degree CBR is an effective strategy due to the absence of thorough research-based data on access, practice, and problems at both the global and national levels. Additionally, the formulation and implementation of efficient rehabilitation policies and programs are hampered by a lack of thorough research-based data on access, practice, and problems at both the global and national levels (World Health Organization, 2011). The majority of Ethiopia's rehabilitation services, according to Wegayehu (2004), are located in metropolitan regions. Less than 1% of the nation's PWDs' overall rehabilitation needs might be met by rehabilitation services (Yeshimebet, 2014).

2.3.3. Home Based Rehabilitation

Home-based rehabilitation is a type of rehabilitation provided to patients in their own homes. This type of rehabilitation is becoming increasingly popular as it offers several benefits over traditional rehabilitation methods (López-Liria, 2015). The importance of home-based rehabilitation is to allow patients to receive care in their own homes. This rehabilitation can be particularly beneficial for patients with mobility issues who cannot travel to a rehabilitation center. Home-based rehabilitation can also be more convenient for patients with busy schedules or who live in remote areas (Yang, 2015). Home-based therapy can also be more affordable than conventional rehabilitation techniques, which is another advantage. Additionally, home-based therapy saves patients the time and money it would otherwise take to go to rehabilitation services, lowering all treatment cost (Grindle et al., 2009). To fit the demands of each patient, therapists might modify their treatment regimens (Shin et al., 2009). Patients benefit from this kind of therapy, which has the potential to improve results and increase patient satisfaction. A young person's quality of life is mostly influenced by their

interactions with family and friends. Building and sustaining social networks and proximity depends on communication. Numerous people with developmental disabilities, such as those who have cerebral palsy, intellectual disabilities, or autism spectrum disorders, may also have a variety of communication impairments and limited social interaction and need home-based therapy (Raghavendra et al., 2011).

2.4. Integrated Approach of Rehabilitation

An integrated approach to rehabilitation is a procedure in which patients, families, and professionals collaborate to attain optimal physical, social, psychological, and functional functioning in the face of a potentially incapacitating condition (Curtin et al., 2003). For rehabilitation to be effective, many different professions must work together. In addition, to make decisions and produce a sustainable result, patients, families, physicians, nurses, therapists, social workers, case managers, psychologists, nutritionists, physiatrists, chaplains, payers, lawyers, and employers engage in a rehabilitation process (Behm & Gray, 2012). Collaboration often requires working with each team member with the knowledge that they are all working toward the same objective. The literature distinguishes between several team-based methods, typically concentrating on two teams known as "multidisciplinary" and "interdisciplinary." A team that involves multidisciplinary team is discipline-oriented, involves simultaneous work by all experts, and has defined roles, tasks, and hierarchies of authority (White, 2013).

Interest in interdisciplinary collaboration has exploded due to the increasing Complexity of patient care and attempts to control rising healthcare expenses, improve patient compliance, boost patient happiness, cut expenditures, lower mortality, shorten stays, and boost work satisfaction among team members (Rubinfeld & Scheffer, 2010). Interdisciplinary teams of professionals routinely work together to discuss, decide on, and implement therapy goals for clients. The interdisciplinary team concept fosters better teamwork and collaboration,

although there isn't enough data to support this claim. Teams that significantly use an interdisciplinary approach outperform teams that follow a multidisciplinary approach for team process and effectiveness (Körner, 2010).

Understanding of how one field interacts with other disciplines is another idea that appears frequently for the effectiveness of rehabilitation services. A fundamental professional collaboration must be formed for a professional to be understood by others, as a lack of understanding among them can annoy and devalue each other's contributions. Team members need to clearly and openly understand each other's duties since miscommunication about roles leads to conflicts within the team and reduces the effectiveness of rehabilitation services (White, 2013). Setting objectives with the patient, their family, and other experts is the first step in the rehabilitation process. These objectives aid in establishing a treatment strategy intended to enhance the patient's physical, perceptual, and communicative abilities while fostering the development of abilities to make up for any long-term disabilities (Stanton & Garfield, 2011).

White (2013) identified barriers to effective teams, which are also barriers to teamwork. Lack of understanding of how teams evolve the responsibilities and purviews of other professions' team members, and preconceived notions about other professionals limit opportunities to contribute to an effective team.

On the other hand, White (2013) found that successful rehabilitation teams have improved planning, effective center services, services dedicated to the needs of patient care, a lack of services duplication and fragmentation, and more satisfying roles for rehabilitation goals. Mauk (2007) stated that successful teams must trust, respect, communicate, coordinate, share responsibility, and have a commitment to other team members. This kind of interdisciplinary team determines the rehabilitation services' effectiveness.

Additionally, parents should be part of the rehabilitation team. Inter-disciplinary collaboration in the environment of the child plays a role in preventing of language-speech difficulties, and many intervention programs work with parents to help them achieve optimal communication difficulties for their child (Matijević et al., 2011). Serving children and families with complex needs and numerous risks is thought to be most successful when inter-professional collaboration (IPC) is used. A lack of interprofessional cooperation may worsen service delivery, increase effort duplication, and compromise safety. Therefore, effective inter-professional relationships are a crucial component of care models (Saia et al., 2020).

2.5. The Role and Responsibility of Parents in Promoting Rehabilitation Services for Children with Disabilities

The scope of stress must include several facets of family life, such as the need for constant care, emotional anguish, interpersonal challenges, financial issues, and negative societal repercussions. Stress is brought on by financial hardships to pay for the required services, additional financial burdens to raise a child with a disability, fatigue from caregiving responsibilities, and loss of leisure time (Byrne & Cunningham, 2021). Without the permission and involvement of the people using them, rehabilitation programs should no longer be mandated. Nowadays, rehabilitation is a process whereby people with impairments or their supporters choose the services they require to increase their involvement. People with impairments must be given pertinent information by professionals who provide rehabilitation services to make wise choices about what is best for them (Gire et al., 2019).

Parents of children with impairments confront a number of challenges as a result of raising their children. Parents' lives are significantly impacted by the problems, especially those of single mothers. For instance, moms who are raising children with a disability in Turkey are required to resign from their occupations. Therefore, the moms become discouraged. Another significant problem for mothers is accepting their children who have impairments (Yilmaz et

al., 2013). Another study by Beresford et al. (2007) found that mothers of disabled children run the risk of social isolation because raising a child with a disability requires a lot of parental time. As parents spend more time with their children, the community divides them and their circle of friends and relatives is smaller (Ntinda & Hlanze, 2015).

For moms, it can be challenging to maintain a network of friends and other connections with other families and people (Barrow, 2017). Particularly in developing countries like Ethiopia, mothers of children with impairments experience increased stress, social exclusion, stigmatization, a lower quality of life, and poorer mental health (Thwala et al., 2018). Because they are the primary carers, moms of children with disabilities experience despair and worry. They spend a lot of time with their disabled children and are overwhelmed by daily caregiving responsibilities (Sapkota et al., 2017).

Children with impairments and their guardians are more likely to be separated, stigmatized, and isolated as a result of negative traditional beliefs about disability (Aldersey, 2012). Research conducted in Kenya found that because of negative views and a lack of assistance, families with disabled children felt excluded from society (Gona et al., 2016). Raising a child with disability exposes a mother to financial constraints, restricted personal time, absence of familial support, and lack of commitment to the community. Emotional, social, financial, and material challenges confront parents of disabled children (Tigere & Makhubele, 2019).

In addition, all societal members must lend a hand to parents of disabled children. This kind of cooperation enables parents and kids to work together to help the child, and when they do so, parents and kids may have better lives in the community (Thwala et al., 2018). Finally, due to the unavailability of support networks accessible to moms, parents of children with impairments are fighting their own battles in parenting (Tigere & Makhubele, 2019).

To manage their lives with a kid who has a disability, parents themselves need knowledge, assistance, and skills (King et al., 2006a). According to Brehaut et al. (2011), there is rising

acceptance of the idea that healthcare treatments for children with impairments should include parental health. Positive caregiving settings may be created by parents who have access to sufficient resources, support, and who are in good physical and mental health (King & Chiarello, 2014). According to Kruijsen-Terpstra et al. (2014), family involvement in service delivery is better for positive outcomes for children. In order to maintain learnt skills and promote generalization to different life contexts, parents should help their children apply their knowledge in practical settings. Additionally, parents are crucial in encouraging their kids to practice the behaviors and skills they learned during rehabilitation and in encouraging the daily engagement needed to do so. The everyday routine of the family is reintegrated after successful treatments (McConnell et al., 2022).

According to Darrah et al. (2010), it is now customary for parents to actively participate in the service delivery process for child developmental services, disability services, and health services. Occupational therapy, physiotherapy, social work, and speech pathology services mentioned it as the preferable strategy for professional practice (Novak et al., 2009; Jansen et al., 2003; Neander & Skott, 2008; and Crais et al., 2006).

Collaboration the recommended message in rehabilitation that involves setting goals with parents, treating them as equal partners in the therapeutic process, and promoting parental engagement, self-assurance, and control over key choices pertaining to their child's developmental needs are all ways to work with parents. Collaborative goal setting is a crucial part of the procedure because it creates the conditions for honest communication with parents and lays out a strategy for subsequent action. Parents are more apt to take part in a therapy program when they actively partake in goal planning (Forsingdal et al., 2014).

Additionally, it has been shown that parents and therapists play distinct roles in the collaborative goal-setting process, with parents serving as facilitators for their children and therapists acting as educators who provide psychological support (Dunst & Dempsey, 2007).

To engage the parent-therapist relationship, in which parent engagement helps the child's developmental results, collaborative goal setting is essential. This additional knowledge may subsequently be applied to fortify collaborations and enhance therapeutic delivery (Forsingdal et al., 2014).

The importance of involving family members in the assessment, planning, implementation, and evaluation of assistive technology services and devices is emphasized in rehabilitation models and practices. When carried out correctly, these procedures lead to the delivery of aids and services that support the child's overall development and have a beneficial effect on the family and the professionals involved (Wilcox et al., 2006). Parent-professional interactions can have an impact on the specific intervention responsibilities that South African parents of children with developmental impairments take on (Smith and Samuels, 2021). The outcomes of intervention programs benefit from parent involvement (Almalki et al., 2021). According to Kaniamattam and Oxley (2021), it's crucial for Indian rehabilitation professionals to be aware of parents' requirements and expectations in order to work with families to achieve rehabilitation objectives that encourage social involvement.

The collection of duties or obligations assigned to parents in rehabilitative therapies is known as the parental role (Sugden et al., 2019). Parents of children with developmental delays, impairments, or chronic health issues may expand their parenting occupational role and reorganize their regular parenting obligations in order to satisfy their child's developmental requirements. These obligations could include providing for the complex care, medical, and developmental requirements of their kid (Lutz et al., 2012) or taking part in their child's therapeutic therapies (Albright et al., 2016).

Interventions in child and family rehabilitation are fundamentally centered on parental roles. In order to create and maximize chances that are in line with the child's ability and satisfy family requirements, parents must have an active part in their child's intervention (Sukkar et

al., 2017). A supportive and caring atmosphere that encourages parents to engage in the intervention is fostered by good parent-professional connections, which are characterized by a strong working rapport, trust, and fruitful exchanges (Reeder & Morris, 2018).

The interpersonal interactions between the parent, child, and professional that are so essential to the intervention process are where parental responsibilities in the intervention are established and developed (Carroll & Sixsmith, 2016). Parents build and acquire expectations for their own and the professional's responsibilities and knowledge to perform those roles specifically through iterative conversations with professionals (Brown et al., 2019).

Parents' awareness of how their involvement in the intervention benefits their child's development confirms the parental role in it. Growing parental competence (i.e., better knowledge and skills) encourages parents to take on more active in-session responsibilities and apply the techniques they learn to their everyday lives by taking on more active out-of-session roles (King et al., 2019). Parents who are aware of their responsibilities are prepared to participate sooner in the intervention and are willing to put up the effort to remain involved throughout the intervention (Davies et al., 2017). According to Smith & Samuels (2021), parental roles in early intervention in multidisciplinary team are highly important in a most clinic- or center-based rehabilitation.

On the other hand, the potential contribution of parents to CBR development is enormous, and their efforts could make a significant difference. This contribution includes overcoming ignorance, promoting sustainability, promoting the validity and relevance of rehabilitation activities, promoting education, and raising gender awareness (WHO, 2010).

2.6. Disability-Focused Rehabilitation Centers with Special Focus on Addis Guzo Center

Locations that include clinics, hospitals, skilled nursing facilities, sports medicine offices, and some health maintenance facilities or groups provide rehabilitation services. Its objective is to

enable community integration, productivity, and living for a sizable and diverse group of people who might otherwise face functional and societal limitations in reaching their maximum potential (Kahsay, 2010). Accessible and thorough rehabilitation services can demonstrate development gains in children who get therapy that serves the kid with a disability's natural setting. They are capable of being steady, autonomous, and capable of being productive. If rehabilitation treatments were offered, they would be more successful at a younger age rather than later in life (Walelign, 2018).

In addition to the government, civil society, which includes the private sector and the general public, must be involved if the status of children with disabilities is to be improved. Various governmental and non-governmental groups have been striving to improve the plight of PWDs in Ethiopia in regard to this. In particular, non-governmental organizations (NGOs) collaborate crucially with the government to construct early intervention programs that build the groundwork for delivering support services to children, their care providers, and others in the area (Tola & Negassa, 2023).

Plan International and Save the Children were two of the groups heavily active in early intervention initiatives in Ethiopia (Tefera, 2018). However, the majority of initiatives in underdeveloped nations like Ethiopia lack coordination and inadequately include the local population in rehabilitation efforts. Due to the exclusion of disabled children from society's systems of education, healthcare, work, and other facets, poverty may result or be made worse. Hence, evidence supporting the efficacy and effectiveness of CBR initiatives is required (Tola & Negassa, 2023). According to studies conducted in Ethiopia, rehabilitation facilities have not reached large numbers of the country's disabled children. In addition to the above, Their access to services is still few and mostly restricted to urban areas, with the majority of facilities found in Addis Abeba, the country's capital, at the Paulos specialty hospital, as well as in a number of regional cities including Mekele, Hawassa, Arba Minch,

Dire Dawa, and Jimma. As a result, these facilities are unable to give services to disabled children who reside distant from the service providers (Tola & Negassa, 2023). Ethiopian early intervention programs have not yet been thoroughly studied in terms of their effectiveness, advantages, and potential, particularly in the community (Tefera, 2018).

Hence, Living conditions are particularly challenging for those with impairments in Ethiopia. Medical-therapeutic treatments are expensive for them. There is a severe shortage of supplies and equipment, particularly wheelchairs. Because of this, it is uncommon for persons affected in Ethiopia to lead an independent, satisfying life, and rehabilitation programs struggle with issues like restricted treatment alternatives, increased distractions, a lack of privacy, and a lack of safety (Abebe et al., 2020).

Poverty, malnutrition, and limited access to vital services like education and health are consequences of disability in Ethiopia. Negative attitudes and ignorance regarding disabilities and impairments can harm mental health and wellbeing and result in societal isolation in several areas of life. The likelihood that a child with a disability will receive medical care and go to school is lower since there is limited rehabilitation service. As a result, this severely affects their quality of life, and they become more vulnerable to poverty (Abebe et al., 2020).

The beginning of CBR programs in 1993/4 saw the first iteration of rehabilitation program activities. There hasn't been much research on disability rehabilitation in Ethiopia, even though the People's Heroes Center (PHC) was one of the rehabilitation facilities that provided veterans with disabilities at this time (Wegayehu, 2004). Then, at facilities supported by Cheshire Homes, individuals with disabilities started receiving CBR therapies in Ethiopia as part of institutional-based rehabilitation. Founded in 1962, Cheshire Ethiopia is a non-governmental organization that provides childcare, hydrotherapy, physiotherapy, and training in skill development to children and teenagers with impairments to encourage the society's development that includes individuals with disabilities (Wegayehu, 2004).

Currently, there are rehabilitation centers, most of which are physical rehabilitation centers, operating in Ethiopia (National Rehabilitation and Assistive Technology Services Management Guidelines for Ethiopia, 2020). Addis Guzo Center is a Swiss non-profit organization established in 2010 in Bern, Switzerland, by Bernhard Wissler (an occupational therapist) and his wife, Christine Oberli (a teacher). In 2012, Addis Guzo Center achieved status as a non-governmental organization in Ethiopia and has operated a center for people with disabilities in Addis Ababa. After coming to Ethiopia and recognizing its potential, the organization is providing mobility aids to people with disabilities and facilitating their social and economic integration through consulting, providing technical aids, and providing therapy for disabled children and adults in Addis Ababa.

Addis Guzo Center is working on a program with four main service areas. The target groups of the organization's engagement are individuals directly affected by disabilities, including their parents and people in the environment. It offers different services to people with disabilities that include providing mobility aids, offering several rehabilitation services and psychosocial treatment, assisting with daily activities, and encouraging participation in sports and dance. They strive to uphold human dignity, empower clients to help themselves and others, and foster independence. The center promotes the active and self-directed participation of individuals with disabilities in social activities with the goal of improving their quality of life.

2.7. International and National Legal and Policy Frameworks That Support Children with Disabilities' Rights to Access Rehabilitation Services

Strengthening the rights of individuals with disabilities to participate fully in economic, social, cultural, religious, and political life as well as to have exceptional health and well-being is the goal of rehabilitation. Equal rights to public services and the capacity to participate in social and economic activities are available to people with impairments. The United Nations Standard Rules on the Equalization of Opportunities for Persons with

Disabilities addressed these rights and used them as a guideline for all CBR initiatives (World Health Organization, 2010).

To strengthen the UN Standard Rules more, the UN General Assembly established the Convention on the Rights and Dignity of Persons with Disabilities protects and promotes their rights and dignity. An optimal foundation for implementing the convention's requirements used a CBR strategy. CBR was considered a program to increase the accessibility of rehabilitation treatments for individuals with impairments (WHO, 2010). The foundation of rehabilitation is respect for human dignity, which is a legal duty for every community that upholds human dignity as its guiding principle. First and foremost, a criminal justice system that respects human dignity is necessary for a positive right to rehabilitation. According to Meijer (2017), respect for human dignity is a crucial basis for rehabilitation services under a state's penal code.

The CRPD, which was adopted by the UN General Assembly on December 13, 2006 and the Ethiopian government signed in 2010, seeks to outline a code of conduct and explain the rights of those with disabilities. In contrast to other races in the country, disability was recognized in the treaty as an identity deserving of protection under the law. Hence, it is significant victory for disabled individuals in Ethiopia and will revolutionize disability rights (Hendriks, 2007).

Several rules and regulations relating to disabilities have been established and used during the past few years. The state is required to ensure that individuals with disabilities are treated with respect and given equal access to opportunities, according to the General Law for the Integration of Persons with Disabilities (2005). The law also ensures that individuals with disabilities should participate in all facets of society. Today, there is widespread agreement that rehabilitation is a better option for those with disabilities and their families and

immediately enhances both their quality of life and the social and economic growth of all those around them (Skempes et al., 2015).

The United Nations Convention on the Rights of Persons with Disabilities, Article 25 stated, which has been expressly confirmed by 158 nations, having the best possible health without facing prejudice due to impairment is a human right (UN, 2006, P. 18). Article 26 requires taking "effective and appropriate measures, including peer support, to enable people with impairments to achieve and maintain maximum independence, total physical, mental, social, and professional ability, and full incorporation and participation in all areas of life." Governments must "organize, reinforce, and expand complete habilitation and treatment," the article claims (UN, 2006, p. 19).

Concrete steps to increase access to medical rehabilitation for people with disabilities are insufficient, and significant problems persist in low-, medium-, and high-resource nations despite this general global commitment, which is articulated in both the CRPD and the World Report on Disability. One of the reasons for this issue is the absence of monitoring systems to evaluate progress in enhancing access to rehabilitation and the lack of evidence-based policy advice. This shortcoming is brought on by the recognized gap in certain concerns pertaining to the implementation of human rights (UN, 2006).

Academic literature from the disciplines of global health and rehabilitation, in addition to legal sources, provided evidence of the connections between human rights and rehabilitation practice and organization. Prior to examining health-related rehabilitation in further detail within the specific framework of human rights legislation, it is necessary to provide some explanations regarding some of the accepted definitions and the conceptual approach (Chibaya et al., 2021).

CHAPTER THREE

RESEARCH METHODS

3.1. Research Design

The study was conducted using a qualitative research approach and a phenomenological design. The qualitative research approach helps to study situations as they occur naturally through detailed explanations that give a more thorough grasp of the participants' context (Maxwell, 2012). Questions those begin with what, how, and why are answered in the qualitative research approach (Green & Thorogood, 2014) In addition, this approach examines the issue under the study by focusing on participants' daily lives. Emphasis is placed on understanding and explaining the participants' situation from their perspective (Draper, 2004).

The participants' lived experiences were phenomena explained by themselves (Creswell, 2014). Accordingly, the researcher selected a phenomenological research design believing that phenomenological design was a relevant design describing the roles parents of children with developmental disabilities for this study's purpose. Creswell (2007) further explained the issue under discussion, saying that phenomenological research is a matter of direct experience rather than being assimilated, which requires the explanation of some abstract concept. On the other hand, phenomenology is a systematic subject approach used to describe lived experiences and the living conditions of individuals. It helps the researcher explain practical situations. Donalek (2004) asserted that phenomenological studies investigate lived experiences, which are human experiences as described by individuals.

3.2. Research Site

The Addis Guzo Center served as the study's site, where the specialized rehabilitation service needed for children with developmental disability is operational. The study center is situated in Addis Ababa City Administration, Lideta Sub-City, Woreda 05. The researcher chose the

Addis Guzo Center because it is the premier non-governmental organization offering comprehensive, high-quality, and pertinent care and support services for children with developmental disability using domestic and foreign professionals with the necessary training and experience.

The researcher selected this center because it also delivers free services to people with developmental disability and serves more than 3,000 beneficiaries annually. Because it offers different rehabilitation services for children and adults, the researcher selected the center. In addition, since it has successful experience delivering rehabilitation services, the researcher chose the center.

3.3. The Study Participants

Specifying study participants describes the sampling method and sample size for qualitative research by assuring findings will contribute rich data (Korstjens & Moser, 2017). Participants in this research were those who had experiences of raising and caring for youngsters with developmental disabilities and obtaining an understanding of their motives and behaviors on the roles of parents in rehabilitation. Phenomenological research participants should have lived experience and pass through the issue to be studied (Delve & Limpaecher, 2022c). Therefore, the standards identified to select target populations were based on being: biological parents/caregivers of children with developmental disability receiving rehabilitation from the center and parents who were ready to take part in the study and open up to share their experience.

3.3.1. Sampling Techniques

When the researcher selects participants who fulfill the requirements of sample selection, it is known as purposeful sampling. Purposive sampling, according to Kreuger and Neuman (2006, p. 34), is preferable for more in-depth analysis and comprehension of individual situations. So, purposive technique of sampling was used because it helps to seek out people who understand the situation and are willing to express their inner feelings and lived

experiences about their roles in providing rehabilitation services for their children with developmental disabilities. Hence, the researcher of this study selected the study participants based on their methodological considerations, the professional judgment of the researcher, and the cooperation of the professional staff and management of the center, focusing on how participants would be the most informative to get relevant answers to the research questions.

3.3.2. *Sample Size*

It takes skill to ensure that a sampling technique is suitable for qualitative research by selecting an appropriate sample size. The sample size is ultimately a question of judgment and expertise to determine the standard of the data to be collected in qualitative research (Hammersley, 2015). Sample sizes should be sufficient to develop knowledge and understanding of the phenomena under study, depending on several methodological and practical considerations (Emmel, 2015). In qualitative research, sample sizes are frequently small to support the in-depth analysis of this type of investigation. Additionally, a small sample size provides detailed information relevant to the phenomenon under study (Vasileiou, 2018). The samples used in phenomenological research must be small (Bartholomew, 2021).

Hence, the researcher for this study purposively selected 14 children with a developmental disability's parents. Since the numbers of phenomenological research sample should be small size 14 parents were selected by the decision of the researcher assuming they were enough to collect relevant data. In addition, the number of selected sample size was relevant for the researcher to collect detailed data regarding the parents' role for effective institution-based rehabilitation services. Criteria for selecting the samples were, selecting parents who understood the topic and could provide accurate and relevant information on rehabilitation services in the selected center. Therefore, the researcher chose parents based on the active participation they made in the service provision of the center, their understanding of the topic,

and their ability to explain the intervention made available for their respective children with developmental disability.

3.4. Data Collection Instruments

The goal of data collecting was to gather reliable facts that would be used in analysis to provide responses to the study questions that were convincing and credible (Canals, 2017). Since researcher was assumed to investigate a phenomenon or event by describing and interpreting participants' experiences in depth about situations under study and to understand specific cases, observation, interview, and document analysis were used as tools for data collection. Getting data that is relevant and convincing requires using multifaceted data collection tools. Consequently, three techniques for gathering data were used in the course of the data collection process.

3.4.1. Interview

To further identify the issue under study, the researcher prepared an interview guide containing relevant questions to maintain the consistency of the interview. For phenomenological research, an interview is a suitable data-gathering method (Gill et al., 2008). According to Marshall and Rossman (2010), phenomenology interviews enable the researcher to completely address the phenomenon by giving the informants a place to communicate their experiences in-depth and as accurately as possible.

The primary goal of the phenomenological interview is to describe the meanings of events, which necessitates a substantial amount of time to explore the phenomenon under study and demands that the researcher have outstanding interviewing skills (Turner, 2010). Hence, to gather comprehensive and accurate data, the researcher conducted semi-structured interviews with the participants in order to have a better knowledge of what is expected of parents in rehabilitation programs. Twenty eight semi-structured interview questions were developed in English and later translated to Amharic based on the leading questions. These semi-structured interview questions prepared in line with and covered all leading questions. Before the

interview, rapport was established with the participants, and consent was obtained. Subsequently, an agreement was reached to commence the interview sessions. On average, individual interview sessions that covered all contents of the four research questions lasted approximately an hour, with all interview sessions being recorded on a digital recorder.

3.4.2. Observation

According to Musante & DeWalt (2010), "the goal for the design of research using participant observation is to develop a holistic understanding of the phenomena under study that is as objective and accurate as possible." Therefore, being the right observer in the course of observation to record the evidence as it happened, the researcher conducted observation by developing checklists for direct observation. The observation checklists were prepared in line with and covered all leading questions. The researcher observed different service delivery sessions in the center to identify parents' service delivery roles and contributions.

Observation is a systematic process wherein the researcher focuses on several activities to illustrate how those activities differ from one another (Nespor, 2012 and Denzin, 2008). Hence, the researcher conducted observation by paying attention to the activities of the physiotherapists and parents to identify events that show a direct contribution of parents to the effectiveness of rehabilitation at the center level. During this observation, the researcher identified the interaction between parents and therapists that benefited the provision of rehabilitation by giving attention to the efforts and participation of parents as need fulfillment actors and activities of parents for children with developmental disability.

3.4.3. Document Analysis

In qualitative research, the strategy of document analysis entails analyzing both digital and analog records in order to evaluate, comprehend, and expand upon the data they contain. In order to explore the same phenomena more thoroughly, document analysis is frequently employed in conjunction with other qualitative research techniques (Bowen, 2009). Therefore, the researcher analyzed documents to give voice and meaning to the research on

this topic. The researcher analyzed clients' records and the background of rehabilitation services provided for clients. While analyzing documents, the researcher incorporated coding content into themes. The document analysis were prepared in line with and covered the third and fourth leading questions. With the aid of document analysis, the researcher was able to assess the achievement and improvement in children with developmental disabilities and assigned activities and responsibilities for parents in each rehabilitation service for the child.

3.5. Data Collection Procedures

The qualitative study employs several philosophical assumptions, strategies, data collection methods, analyses, and interpretations. These processes involve emerging questions and procedures (Creswell, 2007). The researcher gathered data from the participants in the center, and then inductively did an analysis from specifics to broad themes and interpreted the meaning of the findings. Hence, before data collection, the researcher asked for approval to conduct the research.

After approval, the researcher prepared conversation and a meeting about the study with the stakeholders of the center and participants to inform them about what the researcher would be doing. This was used as a transition for involvement and gathering relevant and accurate data. At the end of the discussion, the consent forms were given to participants to sign if they agreed to participate. Then all logistic issues, such as finalizing data collection instruments, providing orientation for respondents, and deciding specific schedules or dates, times, and venues to meet with the respondents, were designed.

If the interview is not conducted in the respondents' native language, it may lead to undercoverage. Language can affect how respondents create responses by influencing their cultural and cognitive perspectives (Andreenkova, 2018). Hence, to collect relevant and original data, the researcher prepared data collection tools in English but translated the interview questions into Amharic. Based on the research questions, the interview questions and observation checklists were set before gathering data, but there were revisions based on

the respondents' situations. Essential and contributing points for the document analysis were also prepared as a checklist before the document analysis.

The researcher collected data after ensuring validity by using the comments of advisor and by asking other experts and professional colleagues to check and assess the accuracy of the content area and reliability by using different data collection tools for triangulation purposes and enhancing detailed field notes by using recording devices and appropriately transcribing the document analysis.

3.6. Data Analysis Approach

The analysis of this study took place by categorizing the collected data into thematic areas. The researcher describes and lists each of the relevant quotes of the study topic to give them equal value to the respondents' expressions and proceeds to determine the phenomenon's key component (Creswell, 2013). The researcher analyzed the data qualitatively by focusing on the explanation of lived experience of the study participants regarding the phenomena under the study. The researcher systematically searched and arranged the interview checklists, observation notes, or other non-textual materials by accumulating them to understand the phenomenon within the study scope. As the qualitative data analysis involve coding or categorizing the data into themes, the research made sense by reducing the volume of raw information in large amounts of data and identifying significant patterns. Then the researcher drew meaning from the data and built a logical chain of evidence.

Creswell (2007) stated that using participants' own words illustrates themes that enable the reader to evaluate the interpretations' applicability and preserve the participant's lived experience. So, the results were stated using direct participant wording, field notes, and documents, separating the main points into segments and units and summarizing them into much smaller categories under four themes using descriptive and narrative text. Then, the researcher conducted the discussion by integrating the findings by addressing own words of participants with the review of related literature, the researcher's knowledge, skills,

experiences, and evidence-based judgment using descriptive explanations. Then, the researcher regulated the data interpretation by interpreting the findings inductively and synthesizing information.

Stories have a high role in conveying the lived experience of informants about the phenomena to be studied. The immediacy of the person, the working history to find the solution for the problems, and fitting pieces of evidence together to deal with their case is clearly explained only in a case story (Green & Thorogoo, 2014, p. 5–25). Therefore, from the interview conducted with 14 parents, two mothers were chosen to create a case story that reflected their experiences as parents of children with developmental disabilities eligible for the organization's services. Then, the researcher stated the conclusion and recommendation separately based on the interpretation of the result and professional judgment. Finally, the researcher wrote the report of the study.

3.7. Research Ethics

The rights of study subjects are at danger when ethical problems are not addressed. Prior to and throughout phenomenological research, the researchers should take ethical issues into account (Walker, 2007). As a result, the foundations of this research's collection of pertinent and acceptable data were secrecy and privacy. The confidentiality of the data was guaranteed by the researcher. Then, respondents were given the assurance that information obtained via data-collecting tools was exclusively utilized for academic reasons. Data and papers were kept safe and secure throughout the study process; they weren't given to outside parties. The research inputs and outputs were replaced and archived. Additionally, the respondents' data were only gathered after their assent, and the study was carried out with the organization's approval. On the other hand, the researcher properly recognized all of the documents and resources that were utilized.

CHAPTER FOUR

FINDINGS OF THE STUDY

This study looked at the role that parents have in raising children with developmental disability to determine the effectiveness of center-based rehabilitation services available in the Addis Guzo Rehabilitation Center. As a result, the primary study findings from the semi-structured interviews with the parents to find out their personal experiences are presented in this chapter that was combined with researcher's observation and document analysis. The researcher presented study findings in two sections: the demography of the participants with their profiles and the explanation of the practices, beliefs, thoughts, experiences, and feelings of the participants, categorized in four thematic areas, as well as two case stories.

4.1. The Demographic Characteristics of the Study Participants

The demographics of the study's participants are shown in this section, from whom the researcher generated data through interviews, observations, and document analysis. They were fourteen in number. The following table contains the profiles of the interviewed study participants. The profiles of all study participants are represented by Case 1 through Case 14.

Table 1: Profile of the Study Participants

No	Cases	Status of Parental	Marital Situation	Age	Academic Background	Occupation of Parents	Age of the Child	Diagnostic Age of the Child	Sex of the Child	Number of Siblings		
										M	F	T
1	Case 1	Biological Mother	Married	30	Grade 10	Has no job	3	8 months	M	0	1	1
2	Case 2	Biological Mother	Married	37	12+1	Has no job	3 ^{1/2}	5 days	F	1	1	2
3	Case 3	Biological Father	Married	46	Grade 8	Has no job	5 ^{1/2}	1 year	M	0	1	1
4	Case 4	Biological Mother	Married	30	MA	Teacher	5	2 ^{1/2} years	F	0	0	0
5	Case 5	Biological Mother	Married	30	Grade 10	Has no job	2	6 months	M	0	0	0
6	Case 6	Biological Mother	Divorced	28	Grade 8	Has no job	5	3 days	M	0	1	1

7	Case 7	Biological Mother	Divorced	30	Grade 4	Tapers & candles Seller	5	6 months	F	0	0	0
8	Case 8	Biological Mother	Married	39	Grade 8	Merchant	2	5 days	M	2	1	3
9	Case 9	Biological Mother	Married	28	Diploma	Has no job	6	7 months	M	2	0	2
10	Case 10	Biological Mother	Unmarried	31	Grade 8	Janitress	5	3 months	M	0	0	0
11	Case 11	Biological Father	Married	45	Grade 8	Fruit seller	5	6 months	M	1	0	1
12	Case 12	Biological Mother	Married	40	Degree	works in Government office	3 ^{1/2}	6 months	M	2	0	2
13	Case 13	Biological Mother	Married	40	Illiterate	Has no job	4 ^{1/2}	1 year	F	4	5	9
14	Case 14	Biological Mother	Married	24	Grade 8	Has no job	5	2 years & 10 months	M	0	0	0

4.2. Perception of Parents towards Their Participation while Delivering Support Services in the Study Center

All participant parents were asked whether they were aware of their responsibility when assisting their children with developmental disability to reach the specialized services at the study center. In their response, six respondent mothers explained they heard about Addis Guzo Center from Cure Hospital health professionals. The other four respondents stated that they heard from Yekatit 12 Hospital health professionals about the institution-based rehabilitation service of the center underway targeting children with developmental disability. In addition, three participants said that they received information about the center from their friends, where the services of physiotherapy and the supply of wheelchairs for needy children with mobility difficulties are obtainable. The other participant of the study said that she received information about Addis Guzo from Addis Ketema Sub-city. Based on the information they got about the center, the participant parents took their children to the Addis Guzo Center in search of rehabilitation services and aid for their children.

The respondents unanimously explained that they stayed in the Addis Guzo Rehabilitation Center for five months receiving rehabilitation services for their children with provision of monthly follow up and evaluation per three months after discharge. The center welcomed them with good manners and dignity from the beginning of the rehabilitation services and throughout their presence in the center. All participants evaluated the atmosphere of hospitality in the center as highly interesting, and they blamed the government's hospitals when comparing them with the Addis Guzo Center. The participants of the study unanimously acknowledged that they were not aware of their responsibility and role in providing rehabilitation services for their children with developmental disability, alongside with the specialized services that needed to be provided by professionals. They further confirmed that it was due to the awareness-building service of the center that they were able

to understand about their respective responsibilities and involvement in the process of the rehabilitation of those children. The Case 3 interviewee in the study stated about the services and journey of his success in facilitating his child with developmental disability to access the therapy services of the center as follows:

I noticed that my child had developmental disability while he was one year old, which was different from the developmental milestones of his sisters. After talking about the problem of my child with my wife, we took him to the hospital to get the right support for his issues from the medical staff, but the diagnosis result for my child was difficult to pinpoint. We also took him to different diagnosis centers, but they found no difficulty in my child. Because the impurities of my child were unknown, they gave us no direction for facilities he needs. The severity had increased because my son received no assistance until he was three years old. We ultimately brought him to Black Lion Hospital to identify his condition. Finally, the Black Lion Hospital diagnosed him as having CP. Since they told me they could not cure my child's developmental disability, I returned home and prepared myself for his death. But I once confided in my friend that I had fallen into problems that had happened to my child. After discussing my child's issues with him, my friend informed me about a center called Addis Guzo that provides wheelchairs for such a child. I brought my child to the center, and the staff recommended starting physiotherapy treatments. I stayed here in Addis Guzo Center for five months, receiving and providing therapy services for my child with physiotherapists.

The direct expressions of the twelve study participants showed that they had received practical skill training in providing therapy, feeding, and taking care of their child from professional support at the center. Regarding drawbacks existing in the center, eleven respondents did state that there was no existing drawbacks in the center that blurred the

contribution of the rehabilitation service of the center. On the contrary, the remaining three respondents stated that the center is not at an appropriate location and is not well known by people who need such services for their children. According to these three respondents, even those who have known the center, it is difficult for them to come to the center for rehabilitation services as the place is not conducive to transportation. The three respondents stated that the government should facilitate an appropriate environment to redress those problems and help them open another branch.

Five respondent mothers said that they received services for only five months and were discharged by the end of five months rehabilitation services provision, and they recommended that it is better if there is a time extension for rehabilitation services, and it is good if the center supplies standing and waking frames as they do wheelchairs. In addition, one respondent expressed that it would be better for the center if they hired a speech therapist. The study respondents were similar in believing that the parents' participation is significant as well as supportive for effective rehabilitation services provided by the center. They all said their participation made the benefits of the therapy services multi-fold because they gave home services following the same procedure they got from the center. So, all respondents stated that their perceptions were positive, their participation was active, and that these benefited the child, parents, and center directly and indirectly to maintain the expected outcomes. One respondent mother, who was assigned Case 9, reported her perception when she was participating in the provision of rehabilitation services for her child as follows:

When I identified that my child had disabilities, I was shocked that I was the only person to cover almost all activities expected of my son with disabilities. I even stopped my job because I had to help him at home. In addition, I knew that our community understood disabilities as the manifestation of abnormality and the parents' wrongdoing. My relatives advised me to take my child to a traditional wegesha and get remedies for

him. Since people with such opinions were annoying, I took my child there, and the only good thing I got out of it was that I met the woman who told me about Addis Guzo Center. Then I discussed this with my husband and took him to the Addis Guzo Center. I received practical exercises in providing therapy, feeding, and caring for my child as professional support from the center. The professional support from the center allowed me to treat my son at home and in the center, which helped him bring about the change observed in him. My child can now eat, drink, sit alone, and stand up with support. My child showed better improvement, even though the problems I encountered were discouraging. So, it will be good if the center gives us a time extension. In addition, I will be happy to have a standing and walking frame, as they provide a wheelchair. The last thing I want to say is that parents should cooperate, be strong, be active participants in rehabilitation services, take their children to health centers early, and pay attention to their children to accomplish the expected outcome of the intervention.

The observation was conducted to identify the perception by observing their happiness, readiness, willingness and acceptance of recommendation from professionals; and level of participation of parents in facilitating access to specialized services available in the study center for their children with developmental disability. The data gathered through observations demonstrated and elaborated that the study participants' perceptions were favourable for rehabilitation service provision and that they were actively participating in therapy service delivery. In addition, these observations indicated that female participants were more active than male participants in the therapy service delivery sessions. Therefore, the data was triangulated by observation of the study participants.

4.3. The Importance of Knowledge and Adaptive Skills Transfer to Parents for the Effective Provision of Rehabilitation Services to Children with Developmental Disability

Each participant's parents were asked questions regarding the importance of knowledge and adaptive skills transfer to them for providing effective intervention to their children with a developmental disabilities. All participant parents stated that parents confront significant obstacles while caring for children with developmental disabilities who have complex requirements, and they often need coping mechanisms for the unique issues they encounter. As a result, parents may engage in the activity of providing cooperative, comprehensive, and child-centered care by evaluating and fostering all facets of their growth.

All respondents believed that raising a child with impairment has an influence on child's life and harmed theirs. In addition to the above, eight study participants stopped their occupations; three participants left their residences to facilitate services for their child; and one respondent started begging since she had nothing to feed her child because of the developmental disability in her child. Additionally, nine respondents experienced social segregation, and two mothers divorced after having children with disabilities. In their responses, six participants reported that while they struggled to improve problems in their children, they experienced at least one problem with anxiety, depression, or other unresolved health issues, and their children were repellent from school. Case 2 explained her experience regarding the situation of her child and her lived experience as follows:

I was born in Dire Dawa City. I got married and gave birth to three children there. My first two children had no disabilities, but my third child was born with disabilities. The doctors diagnosed her with disabilities at birth. She had spina bifida and had surgery when she was six months old. Hence, she had the communication disorder and physical movement limitations expected from her age. Since I knew I was responsible for my

child's care and health, I tried to provide home-based therapy services in Dire Dawa, but my child did not show progress until she was two years old. Since my child has integrated and played with her peers, I was always crying when I saw children playing together in the playground. The other painful challenge was that I stopped working, which led my family to face limited financial capacity to afford food and other needed goods. I also faced health problems like high blood pressure. Facing such problems made me discuss the issue with my husband to find professional support. However, it was disappointing to see the non-availability of rehabilitation professionals and a center that could resolve the developmental disability in my child in Dire Dawa. Then I decided to move to Addis Ababa to find appropriate rehabilitation services for my child. Then, I started to live in Addis Ababa and found Cure Hospital to provide services for my child. On his advice, one doctor from Cure Hospital told me that I had to take my child to Addis Guzo. Following his advice, I took her to Addis Guzo Center, where she received therapy services two days per week for about five months. As a result of the rehabilitation services provided by Addis Guzo with my full participation, my child started to speak and walk with minimal support.

The first measure that six respondents took to overcome these challenges was taking the child to religious institutions to get holy water for healing, whereas eight respondents took the child to hospitals to overcome these challenges. All respondents expressed that they faced different challenges and contributed more than what was expected of them to see the progress of their children and become as normal as possible. However, only two respondent mothers supported their child by providing home-based physiotherapy before the enrolment in Addis Guzo, but the result was not as positive as they expected. Case 8 of this study explained her experience regarding the above issue as follows:

My child became disabled as a result of problems that occurred at birth. This made me hate government hospitals and I don't go there and other hospitals for diagnosis and medical support. When my child was born, the doctors and nurses hadn't paid attention to the child. After the third day, I observed an abnormal situation in my child and talked to doctors about what I had observed. They did not want to tell me about my child's problems after the diagnosis on the fifth day of birth. The first measure I took was taking him to the church to get holy water for healing, but there was no improvement seen in my child.

According to all respondents, speaking and walking are the life skills that are most important for a child's future success in life and work. In addition, four parents anticipated that their children would attend school with others of a similar age. The respondents unanimously supported and trained their children to walk and play, fed the child properly, kept hygiene, reacted or treated behavior, cared for the child, and asked or sought ways to cope with the child's problems to improve their adaptive skills, help them develop their problem-solving abilities, and attain the knowledge that is appropriate for their age based on the practical training they gained from the center and their experience.

The study participants unanimously explained that they had never undergone official training in the adaptive skills necessary for providing care and rehabilitation services in a center, at home, or in community. But the Addis Guzo Center allowed them to observe the therapists during therapy, actively participate in giving rehabilitation services, cooperate with others during service delivery, and accept the advice and recommendation of professionals. The center also helped them be able, willing, and prepared to take on more active roles. Case 5 described the following scenario regarding her child's everyday living and her responsibilities, as follows:

The doctor from Pawulos Hospital told me I was pregnant with male and female twins when I went there for a prenatal visit. I had not given birth at term since one of the twins had a respiration problem. I lost my female twin, and the male twin stayed in the incubator for one week. Even though the doctors did not inform me of his problems early, I observed that he had a disability six months after birth. He did not crawl or move his legs and hands. In addition, he had communication difficulties. Hence, I took him to Pawulos Hospital, and they referred him to Abet Hospital. He received medical treatment at the Abet Hospital for a year. One of the beneficiaries of Addis Guzo told me about the Addis Guzo Center when I was there with my child. Then, I took my child to Addis Guzo Center. At the beginning of the therapy, the professionals told me that I was responsible for my child's life skills, which he must achieve because of the therapy services. I want my child to walk and say "Mama" to me. To see improvement in my child, I actively participated in therapy and gave him therapy services at home.

According to the opinion raised by three participant mothers, the center is engaged to transfer therapeutic skills and support to parents with an objective to enabling them to be paraprofessionals in providing rehabilitation services at home for their respective children with developmental disabilities. Hence, these informants further reported that they were actively engaged in supporting and treating their children at home and discharged their responsibilities stated above.

The study respondents unanimously highlighted that they are in charge of raising their adaptive skills and knowledge development to support their children. They all explained that they do not want their children to depend on others; they want them to learn and participate in all activities expected of them. They all stated that they dreamed of the best for the future lives and careers of their children. In addition, five respondent mothers said that they want their child to be a doctor for children, and to accomplish this expectation, they are doing all

that is expected of them. Case 11 of the study, the father presented his aspirations about his child's life after having a developmental disability in the following scenario:

My child is not yet proficient in reading and writing letters even though he has begun attending preschool. However, it is heartening to see how much progress he has made in learning to read and write letters. My first concern was that he must be literate in reading and writing and develop functional daily living skills, mainly interpersonal and social interaction abilities. I hope that my child will be able to stand and walk to school like his peers. That is why I am currently caring for him and searching for opportunities that benefit him. As it is known, I will no longer be with him in the future for all of his needs. Something that I am afraid of is that my child will be left alone without assistance. Hence, I am assisting him in seeing him as independent of others. I wish my child should stand, walk, learn, and be capable of leading an independent life and exercise that ability with confidence and the spirit of self-reliance. I want him to be a specialist doctor for children with disability.

The researcher conducted observations and document analysis to investigate the importance of knowledge and adaptive skills transfer to parents in providing effective treatments for children with developmental disability. The data gathered through observations showed that they all supported and trained their child to walk, communicate, react or treat the behavior, and asked questions at the time of problems. Parents were also providing physiotherapy services with the physiotherapists and assisted them properly. They could operate assistive materials and fix them for their children. In addition, the analysis of the documents identified each daily activity planned for parents.

4.4. Types of Rehabilitation Services Made Available in the Study Center for Children with Developmental Disability

All participant parents were asked to explain the types of rehabilitation services made available in the study center. The respondents unanimously explained ranges of rehabilitation services that were available in the study center. As they stated, the study center incorporated physical rehabilitation, speech, emotional, behavioral, and adaptive skills therapy; served as an assistive aid provider; provided referrals for medical services as needed, practical child problem-based skill training; and served hygiene materials, food for children, and a transport allowance. One respondent expressed that one of the physiotherapists came to her residence to see her life situation and assisted her in providing home therapy services. After the visit of the physiotherapist, the center also supported her with food supplies for about three months. By the end of the rehabilitation services, eight of the parents expected their child to be able to control their head, sit, stand, walk, and speak independently, and they all saw improvement in minimum of one of these areas. In addition, six parents expected their children to attend school with their peers.

According to all respondents' explanations, their child had mobility difficulties, and five participants said their child could not crawl, but there was an improvement after rehabilitation therapy. In addition, ten participant mothers said that their child had communication difficulties, and six parents said their child had made improvements and started to communicate following the therapy services. On the other hand, four participant mothers stated that their child produced no sound before therapy, and they all began to babble and produce simple words because of rehabilitation therapy. Among these parents, Case 6 firmly discussed the situation of her son as follows:

I had no any complications during pregnancy of my child. My child also didn't have any prenatal history regarding his current problems. But, he was diagnosed as a child

with disability at Yekatit 12 Hospital on the third day of his birth. He had an abnormal body part with limited body movements and communication difficulties. Hence, I treated him at Yekatit 12 Hospital as an outpatient for about four years. Suddenly, one of my child's doctors advised me to take him to Addis Guzo Rehabilitation Center. I took him to the Addis Guzo, where my child began to receive physiotherapy, assistive materials, adaptive skills therapy, hygiene materials, and practical child problem-based training and a transportation allowance.

All participants explained that the therapists provided rehabilitation services for their children in the center; of these respondents, ten stated that the center made them think there would be a good change in their children; enabled them to be satisfied with the service; and equipped them with the knowledge, abilities, and assurance required to actively participate in rehabilitation services in the center and at home. Seven participants explained that providing services with respect and love for the child makes them active participants in the rehabilitation services. All participants stated that the services in the study center strengthened their ability to provide services at home. Case 1 of the study explained the rehabilitation services provided for her child by the center as follows:

I face no challenges that make me sad concerning the provision of services for my son with developmental disability at the Addis Guzo Center. Before coming to Addis Guzo, my feelings and emotions were affected, as I always thought of my child's future. Many people were trying to help me overcome the issue of my child. My neighbors helped and supported me as I cared for my son, who has developmental disabilities. They also took the lead in integrating my son with their typically developing children so that they could see him play in peace and closeness with his peers. I attested to the fact that this circumstance allowed me to become hopeful for the future career of my child and started to search for solutions on how to facilitate his life. As I started to provide

rehabilitation services in Addis Guzo, my child began to receive therapy services from the therapists. The services they provided encouraged me to believe that my child could improve. I can declare that the support and facilities from the center enabled me to participate in the rehabilitation services, to feel satisfied with the service, and equipped me with the understanding, skills, and self-assurance required for me to actively take part in organizing and providing rehabilitation services at home. I argued that I was a partner in rehabilitation services when all service providers treated my child with respect and affection. I agreed that the center's services helped me become capable of providing services at home, during center-based rehabilitation and after the end of the program. I saw satisfactory improvement in my child's problems because of rehabilitation services and my active participation.

In addition, the conducted observations and document analysis identified the types of rehabilitation services made available in the study center for children with developmental disability. The center incorporated physical rehabilitation, speech, emotional, behavioral, and adaptive skills therapy; served as an assistive aid provider; and provided referrals for medical services as needed, practical child problem-based training for the parents, hygiene materials, food for the children, and a transport allowance.

4.5. The Role, Contribution and Duties of Parents in Rehabilitating Their Children with Developmental Disability

The other prepared questions for the participant parents' interview intended to investigate their role, contributions, and duties in providing treatment for their children with developmental disabilities in the study center as well as in their respective homes. In responses to the questions indicating the roles, contributions, and duties, all parents said that even their children with developmental disability are at the stage of child age and started rehabilitation as early as possible to maintain improvement; they are deeply concerned about

the implications of these disabilities for their children's future lives. Therefore, they were all eager to carry out their assigned responsibilities to see improvement in their child.

All participants clearly stated the types of responsibilities that the center assigned to them to provide therapy services for their child with developmental disability. These responsibilities include assisting the therapists, providing adaptive skills in rehabilitation services, equally participating in rehabilitation services for the child, managing the behavior of the child during therapy services, knowing their responsibilities and acting to discharge them, meeting the needs of the child, positively interacting with other professionals, supporting and training the child to sit, crawl, roll, stand, walk, communicate, and play, and feeding the child properly, and keeping the child's hygiene following non formal practical training they gained from professionals.

The participant parents unanimously did believe that the improvement of the capacity of parents being equipped with those specialized services and skills enables them to discharge their responsibilities and protect/treat their children with developmental disability. All participants stated that they were assigned to provide rehabilitation services for their child at home. Hence, they all provided therapy services at home and will continue until their child achieves the expected outcome. One of the study participants' mothers, Case 12, explained her roles in rehabilitating her child with developmental disability, as presented below:

I believe that parents' strengths in rehabilitating children with disabilities are preferable to achieve the expected outcome. I tried different opportunities to get appropriate service providers for my child before joining the Addis Guzo Center. When I began to follow rehabilitation services at Addis Guzo, I discussed the whole issue of my child with them. Then, they assigned me responsibilities by providing practical professional support and appropriate counseling at the beginning of the day. I provided physiotherapy services equally with physiotherapists in the center. Based on what we

had done with physiotherapists in the center, I provided therapy services at home. I discharged the responsibilities assigned to me by assisting the therapists, providing adaptive skills in rehabilitation services, participating in the rehabilitation services for my child, managing the behavior of the child during therapy services, meeting the needs of my child, providing child care, positively interacting with other professionals, supporting and training my child to walk, communicate, and play, feeding the child properly, and keeping hygiene. In addition, I provided practical training for my husband and my children, as it can be difficult for me to discharge the above activities alone. We all cooperated to help my daughter improve her daily living skills and the activities expected of her. The participation of my family and I highly supported the activities of the center.

Finally, the observations of parents' roles, contributions, and duties in providing rehabilitation services for their children with developmental disability at the study center confirmed the data collected through interviews with study participants. Hence, the data collected through observations demonstrated and elaborated on the data that study participants described as their lived experiences.

Generally, as part of findings of this study, "Two Case Stories" were used to illustrate the thematic areas and give more detailed information about the parents of children with developmental disabilities' experiences compared to roles they provided in center-based rehabilitation services. The researcher selected two of the participant's parents to prepare "Case Stories," and the following are the details of their stories:

A. Case Story I

Case 10 was born in 1984 in Addis Ababa, around Cherkos. Her father was a storekeeper, and her mother was a housewife. When she was nine years old, she began to learn. Since her age was ten years, she was forced to be engaged in daily labour work to assist her parents who

had no financial capacity to adequately afford the cost of their household. Despite being a clever student, she went through six rounds of repetition in school. She became pregnant when she was in the ninth grade. After completing grade nine, she gave up school because the school community rejected her and embarrassed her family.

She then vacated her home and began living with her lover in a house they had rented for approximately four months. Her parents were aware of all her problems and took her back home after four months of looking for her. When she was pregnant, her boyfriend told her that she had to give birth to a beautiful girl to remind his deceased sister of him. Unfortunately, she gave birth to a male baby with disabilities in 2010 at the age of 26. After that, her lover started to drift away from her. She lost her father three months after giving birth, who used to support her and her family by doing additional daily labor jobs on days when he wasn't busy with storekeeping. As a result, she had a lot of troubles raising her child. She stated that when her child was six months old, she observed and found that her child had developmental disability that he could produce no sound, had behavioral problems, and limited body movement. She began to pay attention and realized her son couldn't even crawl. She also noticed her child's legs were unusually bent inward. She informed her partner what she had seen in her child. However, what she heard from him was tragic. He adamantly asserted that the child was not his and that he had no business with her. In addition, he warned her not to call her child by his name as a father. So, she gave him the name of her father as his father.

Although it was tough to accept such treachery, Case 10 indicated that she was wilful that her child would be capable and decided to care for him. Then she began to talk about the issue of her child to all the people she met on her ways. As a result, one of her neighbors told her to take her child to Cure Hospital, so she took him there to seek appropriate treatment based on

a more thorough and deeper diagnosis. After the diagnosis, the findings revealed that her son had a cleft lip and palate and an abnormal position of the legs.

Her feelings were sad due to the difficulties her child was experiencing, the passing of her father, and the information she heard from her lover. When she realized how negatively the developmental disability was affecting her son's life and career, she was highly depressed. Her inability to pinpoint the exact cause and course of action for her son's developmental disability also disturbed her. She needed to accept the situation, look for expert assistance from the hospital to find a solution, make plans for the future, and learn how to care for her son. She encouraged herself to be resilient, told herself to be strong, and believed she could resolve the problems.

As she became committed to searching for ways to facilitate treatment services for her son, she gave her consent for Cure Hospital doctors to perform two surgeries (legs surgeries and lip and palate surgeries) on her child. The surgeries were successful and enabled her to continue her persistent endeavor to enhance the overall capacity of her son and advocate for services for children with developmental disability. She explained that it is difficult for her to work and earn money.

Case 10 became dependent on her mother and her younger brother. She had nothing to buy diapers and soap for cleaning and washing the baby and clothes. In addition, her emotions and interactions with others were affected because our local community members believed in that disability is punishment for parents' wrongdoing. She stated that a few of her neighbors said, she had a child with developmental disabilities because her parents condemned her for becoming pregnant before being married. These few neighbors began to ignore her, even though most of her neighbors supported her.

When her son turned four years old, she started looking for a center that provided physiotherapy and speech therapy for him. However, getting a center with specialized

services for her child was not an easy task for her. She lacked the financial means to pay for the therapy services of her child at a private clinic, so she found the Cheshire Rehabilitation Center and took her son there to get physiotherapy services. She became happy as she found appropriate services for her child, but they only provide therapy services once per month. She thought this could not bring about the outcome she planned to see in her child. Then she began to search for other physiotherapy services for her child.

Finally, she found the Addis Guzo Center, which provides specialized services for children with developmental disability. Her child received therapy services for five months at the Addis Guzo Center. She also provided therapy services for her child at home. As a result of their guidance, support, therapy services, and other rehabilitation services that Addis Guzo Center provided with her full participation, her child started to speak and move with minimal support. She gained confidence as a result of her child's developmental improves and began to work as a janitor around her residence. Generally, her experience with the Addis Guzo Center has been life-changing for her and her child. She was happy about the Addis Guzo Center's dedication to helping children with developmental disability.

B. Case Story II

Case 7 was born in Menz, Mehal Meda, of the Amhara region. She was 30 years old. As she explained, she used to live in stability with her siblings as a rural child. Her parents allowed their children to learn even though they were illiterate farmers. Regarding her academic career, she stopped learning after completed the fourth grade. At the age of fourteen years, her father forced her to get married with a man she didn't know before. This made her to be despondent and lost ambition and the will to pursue her dreams of having a fulfilling future and being competent in all aspects of her life. She knew lots of teenagers in her neighborhood living an ambiguous life as they got married at their teenage age. She thought that she had to leave her parents and live alone. She succeeded in doing so and moved to Addis Ababa.

According to her expression, she worked as a maid for eight years while residing in Addis Ababa, Gedam Sefer. She stated that she suddenly fell in love with her husband and married at 23 years old. Since he was construction worker, her husband had a sufficient income. As a result, they changed their residence and rented the house from Bole Arabsa. She also started construction work there as a new job with her husband. After they lived there for one year, she became pregnant. She reported that even though she was happy because they were ready to have a child, due to her poor infertility status, her medical diagnosis showed that she needed to work with a medical assistant. She gave birth in 2010 E.C. after receiving nine months of extensive medical treatment.

Case 7 reported that her child had a cheerful face and appeared to be robust and handsome during infancy. Six months after birth, she understood that her child produced no sounds and maintained no physical movements expected in her babyhood. Her bones were not strong enough to provide gross and fine motor movements. She was alarmed and concerned when she learned of the unanticipated developmental disability with her child.

She said that because her husband knew her child's developmental disability, he dumped case 7 and found another wife. He once choked and kidnapped her child to kill her, but she yelled and forced him into jail. A bad thing she heard about her husband was that he also had a blind child from his second wife. He also left her, and she doesn't know his address. Since the only person who cares for her child is her, she first took her to Katila Mariam for a rite and had priests pray for her child. In addition, they also put holy water on her every morning for one year. But she saw no improvement in her daughter. Since life was difficult, she went back to her family in Menz. She stayed there for six months, taking her child to different holy water places, but she saw no change in her child's development. After six months, her family members began to hate her as their interaction with the community began to decrease from

time to time. Some of the community members also began to deny her greeting. Only one of her sisters supported her in providing care for her child.

As she said, Case 7 returned to Addis Ababa to continue looking for assistance to make her child's future life independent. She returned to Katila Mariam and began residing in a plastic-made home. To address the problems in her child, she took her child to a Protestant church and a mosque. She said she decided to switch her religion if they could improve her child's disabilities. Even though the craftsman did nothing to her daughter, she paid him 19,000 ETB deducted from her savings account and 20,000 ETB that her sister had deposited. During this time, what always makes her restless is the death of her sister, who was the only person beside her at the time of her problems. Seeing her difficulties, people around Katila Mariam collected 17,000 ETB and made her take her child to a known traditional witch. She took her there and gave him 17,000 ETB, but she saw no improvement. Some people advised her to beg since her child showed no developmental progress expected for her age. But she was not discouraged about the changes she expected to see in her child. She contracted heart and kidney disease as she spent so much time caring for her child without rest.

Finally, Case 7 took her daughter to Cure Hospital, where one of the health professionals advised her to take her child to Addis Guzo Rehabilitation Center. She discovered the Addis Guzo Center, which provides specialized services for children with developmental disability. It was her ambition, and she felt happy and took her child to the Addis Guzo Center. Following therapy services from the Addis Guzo Center and her full participation, her child began to show modest improvement. As a result, she developed confidence and started to sell tapers and candles around Katila Mariam Church. Even though she is living beside the church in a plastic-made home, she is happy since her objectives for her daughter are on the right track to being accomplished and for the fact that her child is alive.

CHAPTER FIVE

DISCUSSION

The leading research questions based on the study's overall goal that addressed the study's main thematic areas were: the perception of parents about their participation in rehabilitation service delivery, the process and importance of transferring adaptive skills and fundamental knowledge to parents, types of rehabilitation services made available in the study center for children with developmental disability and the expected outcomes, and roles of parents in rehabilitating children with developmental disability and benefits that occurred from their contribution.

5.1. The Perception of Parents towards Their Participation while Delivering Support Services in the Study Center

As confirmed by the study, all participant parents were not aware of the presence of institution-based rehabilitation services including Addis Guzo Center and their respective responsibility in rehabilitation services for children with developmental disabilities. Hence the center provided full information about the center, available rehabilitation services at this institution, and their participation and responsibilities. These study's findings have been supported by studies done by many academics. For instance, growing parental competence via knowledge and skills promotes parents to take on more active responsibilities at home, according to King et al. (2019); Siebes et al. (2007) and Davies et al. (2017) also suggested that giving parents greater opportunity to attend therapy sessions and clarifying essential components of therapy to parents helps increase parents' involvement in intervention and perceive these services as more responsive to their children's needs.

The study findings disclosed that what the Addis Guzo Center is doing on human rights and dignity is encouraging, especially for parents and provide holistic rehabilitation services for individuals in need. As noted by Meijer (2017), the core of rehabilitation is respect for human

dignity, a crucial basis for rehabilitation service, and necessary for positive and right rehabilitation services.

In addition, the study's findings showed that even though Addis Guzo Center's rehabilitation services seem holistic; the location of the center is not as such accessible and they didn't have speech therapists in their service even though most children with developmental disability have communication disorders and need services from speech therapists. Opposing the above issue, findings by White (2013) and Stanton & Garfield (2011) stated that a multidisciplinary team that involves simultaneous work by all experts and has defined roles, tasks, and hierarchies of authority and goals helps to develop a therapy strategy that would enhance the patient's mobility, perception, and communication.

As indicated by the study findings, parents' participation made the benefits of the rehabilitation services multi-fold as they provided home services following the procedure they got from the center, had positive perception concerning their participation and were active rehabilitation service providers in the center. This discovery is consistent with the information gathered by other local researchers. For illustration, to modify behavior in children, parents must first adjust their perceptions and make thoughtful plans to give their children the care and attention they require (Paromita, 2017).

The findings of the study depicted that the Addis Guzo Center enabled parents to be satisfied with the service, actively participated in rehabilitation service delivery, equipped them with the necessary information, skills, and confidence, and strengthened their ability to provide services at home. Supporting the above finding, Alsem et al. (2017) pointed out that gaining the family's trust and active involvement in the child's treatment is crucial; their participation in rehabilitation encourages parents to play active roles in the intervention.

5.2. The Importance of Transferring Adaptive Skills and Fundamental Knowledge of Rehabilitation Services for Children Developmental Disability to Parents

The study findings set out that the center was engaged in transferring therapeutic skills and support to parents to enable them to be paraprofessionals in providing rehabilitation services for their respective children with developmental disabilities at home. Supporting this finding, King et al. (2019) and Wilcox et al. (2006) disclosed that, there is a potential technique to assist the work shifting of parents from experts and help balance the power imbalance is through the parent-professional connection, which promotes the overall child's improvements and positively impacts the professionals and parents involved.

As findings of this study confirmed, nurturing children with developmental disability is challenging for parents that include experiencing problem like anxiety, depression, or other unresolved health issues, and their children were repellent from school. Hence, overcoming these could be the activity of parents. Byrne & Cunningham (2021) and Abebe et al. (2020) noted that rearing a child with a disability affects daily care obligations, emotional discomfort, interpersonal challenges, financial difficulties, and negative societal repercussions fatigue, and loss of leisure time due to caretaking responsibilities are only a few components of family life. In addition, parents struggle with issues like restricted treatment alternatives, increased distractions, a lack of privacy and safety, and being vulnerable to poverty and illness.

Other studies by Beresford et al. (2007), Ntinda & Hlanze (2015), Yilmaz et al. (2013), Thwala et al. (2018), Tigere & Makhubele (2019), & Sapkota et al. (2017) highlighted that mothers with disabled children endure pressure, loneliness in the community, stigmatization, face sadness and anxiety, particularly in nations with low economic status, and parents of children with disabilities face emotional, social, economic, and material difficulties.

The study findings demonstrated that parents are responsible for their children's adaptive skills and knowledge development since they do not want their children to be dependent on others and participate in all activities making them maintain the best future lives and careers. This result is consistent with research by Kruijsen-Terpstra et al. (2014) and Kahsay (2010), which showed that family involvement in service provision is better for good child outcomes and parents help the child apply learned skills in real-world environments, as well as sustain and foster these skills in other life contexts, and allowing them to meet their regular social obligations and the additional demands imposed by their impairment.

5.3. The Types of Rehabilitation Services Made Available in the Study Center for Children with Developmental Disabilities and the Expected Outcomes

As the study findings further delineated, the range of rehabilitation services that children with disability received from the center, include physiotherapy, speech therapy, emotional and behavioral therapy, assistive materials, adaptive skills therapy, practical child problem-based training to provide services for the child, hygiene materials, food for children, and a transport allowance. Concerning this finding, ILO (2008) and Wade (2020) indicated that people with disabilities should attain a life that is individually fulfilling, socially significant, and functionally productive life through rehabilitation, a comprehensive program that combines medical, physical, psychological, and occupational therapies; thus, rehabilitation services often encompass linked medical, social, educational, and vocational services including psychiatric counseling, and aids technological assistance and assistive gadgets like wheelchairs, prosthetic limbs, and communication tools. In addition, WHO (2017) stated that the goal of rehabilitation for individuals with disabilities is to assist individuals in achieving and maintaining their ideal levels of sensory, cognitive, psychological, social, and physical functioning. The study findings have proved that parents' expectation for their children were pertaining to advancements in mobility, communication, education, and quality of life that

include able to control their heads, sit, stand, walk, speak, and attend school with peers. The studies by Wade (2009) and Daba (2015) pointed out that each treatment service is customized to meet patients' needs and may involve one or more therapy services enhancing their natural abilities in their natural environment to raise the standard of living for children who have impairments. In addition, a treatment plan that aims to enhance the patient's physical, perceptual, and communicative capacities while gaining skills is shaped by creating goals with the patient, their family, and other experts (Stanton & Garfield, 2011).

5.4. The Role of Parents in Rehabilitating Their Children with Developmental Disability and Benefit Occurred from Their Contribution

The study findings confirmed that parents of children with developmental disabilities played significant roles to executing assigned responsibilities that help them to bring needed improvement to their child. They were concerned about the implications of developmental disability for their children's future lives. These aspirations of parents are similar to multiple works of literature, including the study by Mauk (2007) and McConnell et al. (2022). Their findings confirmed that the contribution of parents to rehabilitation services is enormous; their efforts could make a significant difference; their commitment determine the effectiveness of rehabilitation services; they play a crucial part in encouraging the children's everyday involvement necessary for practice in rehabilitation and in inspiring them to do so. Aldersey's (2020) study also reported that parental support strategies include family members who play prominent roles while supporting, guiding their children with disabilities and aiding the implementation of rehabilitation services.

As the finding of this study disclosed, in order to address their children's developmental requirements, parents of children with developmental disabilities broadened their parenting duties by working on tasks typical to their parenting obligations. Parents were assigned and discharged responsibilities which include assisting therapists, providing adaptive skills in

rehabilitation services, equally participating in rehabilitation services for the child, managing the behavior of the child during therapy services, knowing their responsibilities and acting to discharge them, meeting the needs of the child, providing child care, positively interacting with other professionals, and supporting and training the child to maintain expected outcomes. This finding of this study has been proved by Lutz et al. (2012), Dunst & Dempsey (2007), and Sugden et al. (2019), who described that clear roles for parents and therapists in collaborative goal setting have been identified. These roles include therapists as educators providing psychosocial support and parents as facilitators of their children. Responsibilities may be related to meet children's extensive care, medical, and developmental requirements. This study's findings confirmed that improved capacity in parents which equipped with those specialized services and skills enables them to discharge their responsibilities and treat their children with developmental disability. Hence, parents comprehend the expectations of the professionals are inspired to participate during sessions, extend the intervention at home, and assume more responsibility both in and outside of sessions. This finding of the study is accordant with the study findings of several authorities in the field. For instance, it was noted by Sukkar et al. (2017), Carroll & Sixsmith (2016), & King et al. (2006a) that parents need knowledge, assistance, and skills to manage the lives of their disabled children as well as to create and maximize opportunities that fit their needs as a family and the children's abilities. Another study by Davies et al. (2019) elaborated that through iterative exchanges with professionals; parents construct and establish goals for their jobs, as well as expectations for their own and the professional's duties and competence.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1. Conclusion

Children with developmental disability require specialized care and attention to reach their full potential. The study's aim was to examine how parents of children with developmental disabilities contribute to the effectiveness of center-based rehabilitation treatments offered at Addis Guzo Center. The study was organized to be undertaken in four major areas of focus so that key findings were presented accordingly. These central themes of the study are:

- The parents' perception of their involvement in delivering rehabilitation services;
- The purpose of transferring adaptive skills and basic knowledge from professionals to parents in rehabilitation services;
- The types of rehabilitation services offered at the study center and their expected outcomes; and
- The roles and contributions of parents in provision of the rehabilitation services for children with developmental disability.

The study disclosed that parents of children with developmental disability effectively discharged the responsibilities assigned to them, as their perception of their involvement in rehabilitation service delivery became positive after the provision of professional support and awareness-raising services from Addis Guzo Center. This non-governmental organization provided holistic rehabilitation services that could be aligned with the bio-psychosocial model of rehabilitation, placing children with disabilities at the center and surrounded by medical, psychological, and social components, with the involvement of parents. The center provides these rehabilitation services with respect for human dignity, which is crucial for effective rehabilitation services.

The findings of this study depicted that parental understanding of their children's requirements, provision of appropriate care and rehabilitation services, and enhancement of children's independence and quality of life as paraprofessionals have all been made possible

by the development of essential knowledge and therapeutic skills from the professionals and parents. The study center offers a variety of therapeutic treatments, such as physical therapy, speech therapy and counselling services. A collaborative approach involving parents and other professionals ensures that care for children with developmental disabilities is sufficient and thorough, and reach their full potential in terms of motor, communication, cognitive, and social skills, as well as becoming more independent in community life. As a result, both the center and parents expect to see improvements of children with developmental disability.

Finally, the study's findings identified that center-based rehabilitation services play critical roles in supporting children with a developmental disability, where active involvement of parents plays a critical role in supporting the child's progress outside of therapy sessions, leading to improved outcomes, and advocating for their needs. Ensuring parents' involvement grant that children with developmental disability receive appropriate services in the community and make the center-based rehabilitation services more effective.

6.2. Recommendation

The following recommendations are suggested to be used as valuable inputs for concerned and responsible stakeholders for the improvement of parents' roles in facilitating center-based rehabilitation services needed for children with developmental disabilities based on the study's findings.

- Rehabilitation centers those are providing rehabilitation services for children with developmental disabilities should involve their parents or caregivers to assure achievable outcomes for children with developmental disability. As specialized care and attention are necessary for children with developmental disabilities to reach their full potential, their parents should search for and advocate for the provision of rehabilitation services for them as early as possible.

- Based on the experience that Addis Guzo Center has gained in providing holistic rehabilitation services and the Ministry of Health has gained in other health-related public services, they should develop national guidelines concerning the optimal profile of rehabilitation service delivery for children with developmental disabilities paying attention to parental involvement.
- Together with local health offices, regional health bureaus and the Federal Ministry of Health, Addis Guzo Center is required to establish rehabilitation units in selected health centers and hospitals that provide holistic rehabilitation services and equipped with specialized professionals and devices for the diagnosis and early intervention of children with developmental disability.
- A nationwide plan should be developed and implemented by the Addis Guzo Center and Federal Ministry of Health to establish a link between governmental and non-governmental health institutions and rehabilitation centers where children with developmental disability receive rehabilitation services to enhance their progress and community participation, taking the involvement and contribution of parents into account.
- Addis Guzo Center in cooperation with the Universities' community service units and the Federal Ministry of Health, should facilitate and support the community in establishing new rehabilitation centers where children with developmental disability and their parents can receive holistic rehabilitation services and experience providing care for their children with disabilities.
- Addis Guzo center should invite health professionals and university professors to conduct comprehensive studies on the overall situation of children with developmental disability. These studies should aim to integrate higher education institutions' community services with children with developmental disabilities since the findings of these studies can be used as a reference and input for policy dialogue.

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APPENDIX 1

**Addis Ababa University
College of Education and Behavioral studies
Department of Special Needs Education**

Date _____

Consent Letter

My name is Fikiru Bedasa. I'm a graduate student studying special needs and inclusive education at Addis Ababa University. This study is conducted to complete the prerequisites for a master's degree in special needs and inclusive education. The purpose of this interview guide is to gather information from parents of children who have developmental disability

The objective of this study is to investigate the role of parents of children with developmental disability in determining the effectiveness of centre-based rehabilitation services made available at Addis Guzo Rehabilitation Centre for children with developmental disability. As a result, your response contributes significantly to meet the central theme of the study. I am pleased to confirm you that the information collected from your interview will be used only for the purpose of the study and it will be kept confidential. Hence, I kindly request your cooperation for the provision of clear and genuine response to the questions presented below, and the researcher appreciates your collaborative engagement.

The researcher would like to let you know that you are under no obligation to continue sharing any kind of information and can suspend your involvement at any time during the interview process. I would also like to let you know that the interview may last an hour, and I may record your interview on digital recorder only based on your consent, and once the final document of the study is accepted, the recorded information will be deleted.

Lastly, but not least, I would like to express my utmost respect and thank you for your willingness to participate in the interview.

I. Interview Guide for Parents/Guardians of Children with Developmental Disability

1. Profile of the interviewee

Parental Status

- Biological mother

- Biological father
- Guardian
- Sex Male Female

Marital Status

- Single
- Married
- Divorcee
- Age _____
- Academic qualification _____
- Occupation _____
- Child sex _____
- Child age _____
- Child diagnostic age _____
- Number of siblings _____
 Male _____ Female _____

2. Interview Questions related to the role of parents for the effectiveness of center-based rehabilitation services

2.1. Assess how parents perceive their participation while delivering support services in the study center rehabilitation services

- 2.1.1. How did you find the rehabilitation service of the study center in reference to the condition of your child?
- 2.1.2. When and how your child joined Addis Guzo to access rehabilitation service of the center?

- 2.1.3. How do you evaluate the atmosphere of the hospitality of the center that you have observed in the first day of the admission of your child to the center?
- 2.1.4. Have you been informed about the need of your participation and how you have been participating in the process of the delivery of the rehabilitation services made available for your child?
- 2.1.5. How did you feel when you were told that your participation is mandatory?
- 2.1.6. Do you believe that the participation of parents/guardians of children with developmental disability is significant and supportive for the effectiveness of the rehabilitation service of the center? If yes, how?
- 2.1.7. What kinds of professional support did you receive from the center to be active participant in providing rehabilitation services for your child?
- 2.1.8. How did you perceive your participation in rehabilitation services for your child?
- 2.1.9. How did you advocate for your child to start receiving rehabilitation services undertaken targeting your child?
- 2.1.10. What kind of rehabilitation service that your children have been receiving?
- 2.1.11. In your opinion what kind of challenges exist in the center that blurred the contribution of the rehabilitation service of the center, and what should be done on the way forward to redress those problems.

2.2. Assess the fact that how and why adaptive skills and fundamental knowledge of rehabilitation services for children with developmental disability should be transferred to parents

- 2.2.1. Do you believe that the impairment of your child may impact his or her life and have an adverse effect on yours? If yes, what kinds of measures are you taking to overcome the challenges you and your children encountered?
- 2.2.2. How did you support your child prior to the enrolment of your child in Addis Guzo that enabled him/her to access the rehabilitation service of the center?
- 2.2.3. What types of daily living skills do you suggests or recommends your child to achieve for the success of his/her life career?
- 2.2.4. How do you support your child to improve his or her adaptive skills and expected knowledge for his or her age?
- 2.2.5. Have you received training support on adaptive skills needed to be applied for your child at home and within a community at large from center? If yes, Please mention them and explain briefly!

2.2.6. Do you think that you are responsible for your child's adaptive skills and knowledge development? If yes, why?

2.2.7. What is your realistic dream regarding the future life career of your child?

2.3. Assess the types of rehabilitation services made available in the study center for children with developmental disability and the expected outcomes of the rehabilitation services intended to be achieved.

2.3.1. What types of rehabilitation services does the center provide for your child?

2.3.2. What did you hope to accomplish by the end of the rehabilitation service underway for your child?

2.3.3. Do you believe that the expected outcomes are being achieved as a result of rehabilitation services? If yes, what changes did you observe on your child?

2.3.4. What types of rehabilitation services made available in the center do you prefer to be offered for your child?

2.3.5. How do the therapists provide rehabilitation services for your child?

2.3.6. How did the center provide you with the feeling that you have been equipped with the necessary information, skills, and confidence to assume your roles?

2.4. Investigate the issues how parents play a role in rehabilitating their children with developmental disability and to what extent the study center benefited from the contribution of parents by enabling them to discharge their respective responsibilities

2.4.1. What types of responsibility did the center assign to you to provide services for your child with developmental disability?

2.4.2. How do you act and treat your child with developmental disability in order to discharge your responsibility?

2.4.3. Do you think that you have been contributing to the change observed on your child as a result of center-based rehabilitation services? If yes, please explain briefly how you have been contributing to bring about progress and improvements own your child.

2.4.4. Do you provide rehabilitation services for your children at home? If yes, please describe briefly how you are donating.

APPENDIX 2

Date-----

Interview Agreement

I am Mr. Fikru Bedasa, a graduate student at the Special Needs and Inclusive Education Department of Addis Ababa University, and I am currently working on my thesis at the Addis Guzo Center. Therefore, in order to collect important information for the thesis, I have chosen to interview Mr. /Mrs._____. I agree to keep the information collected during the interview confidential and use it only for the intended purpose. I confirm my agreement with my signature.

I, Mr. /Ms. _____, participate in the services given to my child at Addis Guzo Rehabilitation Center. Having the above stated points in mind I also agree to participate in the interview with my consent. I also confirm my agreement with my signature.

Agreement Acceptor

Agreement Giver

Name_____

Name_____

Signature _____

Signature _____

Date_____

Date_____

APPENDIX 3

I. Observation Checklist

1. Observed child parent number (code) _____
2. Date of observation _____
3. Place of observation _____ (inside the center attending a rehabilitation service)

No.	Activities	Status of the Activity		Remark (Brief Description of the Activity)
		Yes	No	
1.	Observations to assessing how parents perceive their participation while delivering support services in the study center rehabilitation services			
1.1.	Actively participate in giving rehabilitation services			
1.2.	Cooperate with others during service delivery			
1.3.	Happy while serving services with other professionals			
1.4.	Accept recommendation of professionals			
1.5.	Provide rehabilitation service with dignity			
1.6.	ready, willing, and able to play more active roles			
2.	Observations related to assessing how and why adaptive skills and fundamental knowledge of rehabilitation services for children with developmental disability should be transferred to parents should be transferred to parents			
2.1.	Support and train child to walk and play			
2.2.	Feed child properly			
2.3.	Keep child's hygiene			
2.4.	React to child's behavior properly			
2.5.	Give care for child			
2.6.	Ask or seek how to cop up with child's problems			

3.	Observations related to assessing kinds of rehabilitation services that are made available in the study center for children with developmental disability and the expected outcomes intended to be achieved as a result of rehabilitation services			
3.1.	Provide physical rehabilitation			
3.2.	Provide speech therapy			
3.2.	Provide emotional and behavioral therapy			
3.4.	Serve assistive aid			
3.5.	Give adaptive skill therapy			
3.6.	Provide medical services			
4.	Observations related to investigating how parents play a role in rehabilitating their children with developmental disability and to what extent the study center benefited from the contribution of parents by enabling them to discharge their respective responsibilities			
4.1.	Assist the therapists			
4.2.	Provide adaptive skill rehabilitation service			
4.3.	Equally participate in rehabilitation service for child			
4.4.	Manage child's behavior during therapy services			
4.5.	Know responsibility and act to discharge given responsibility			
4.6.	Meet child needs			
4.7.	Provide child care			
4.8.	Has Positive interaction with other professionals			

APPENDIX 4

II. Checklist for the targeted child portfolio Document Analysis

1. Analyzed client document (code) _____
2. Date of analysis _____
3. Document Type _____
4. Date of the document _____
5. Responsible person _____

6. For what purpose was the document written?

7. What are the main issues listed in the document of the child?

8. What processes should be followed when the client come to the center for service?

9. How is the child assessed?

10. What are the child problems and what are recorded achievements?

APPENDIX 5

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የትምህርት እና የባህሪ ጥናት ኮሌጅ
የልዩ ፍላጎት ትምህርት ክፍል

ቀን _____

መግቢያ

ፍቅር በዳሳ እባላለሁ። በአዲስ አበባ ዩኒቨርሲቲ ልዩ ፍላጎት እና አካቶ ትምህርት ክፍል የድህረ ምረቃ ተማሪ ነኝ። ይህ ጥናት የሚከናወነው በልዩ ፍላጎት እና አካቶ ትምህርት ውስጥ ለማስተርስ ዲግሪ የመጀመሪያ ደረጃ ቅድመ ሁኔታን ለማጠናቀቅ የመመረቂያ ማሟያ ነው። የዚህ ቃለ-መጠይቅ ዓላማ የእድገት ጉድለት/ችግር ካለባቸው ልጆች ወላጆች መረጃን መሰብሰብ ነው።

የዚህ ጥናት ዓላማ በአዲስ ጉዞ የተሳተፈ ማእከል ውስጥ የሚገኙትን የተሳተፈ አገልግሎቶች ውጤታማነትን ለመወሰን የእድገት ጉድለት/ችግር ያለባቸው ልጆች ወላጆች ሚና መመርመር ነው። ስለሆነም ምላሽዎ የጥናቱን ማዕከላዊ ጭብጥ ለማሟላት ከፍተኛ አስተዋጽኦ ያበረክታል። ከቃለ-መጠይቁ የሚሰበሰበው መረጃ ለጥናቱ ዓላማ ብቻ እንደሚውል እና ሚስጥራዊ ሆኖ እንደሚቆይ ለረጋግጥሎት እወዳለሁ። ስለሆነም ከዚህ በታች ለተዘረዘሩት ጥያቄዎች ግልፅ እና እውነተኛ ምላሽ ለመስጠት ትብብርዎን በትህትና እጠይቃለሁ።

ማንኛውንም ዓይነት መረጃ ማካፈልዎን ለመቀጠል ምንም ዓይነት ግዴታ እንደሌለብዎት እና በቃለ መጠይቁ ሂደት ውስጥ በማንኛውም ጊዜ ተሳትፎዎን መቋረጥ እንደሚችሉ እና ቃለ-መጠይቁ ለአንድ ሰዓት ሊቆይ እንደሚችል ላሳውቅዎት እፈልጋለሁ። በመሆኑም ቃለ መጠይቁን በዲጂታል መቅረጫ መመዝገብ እንድችል የእርስዎ ፈቃድ ያስፈልገኛል። በመሆኑም የጥናቱ የመጨረሻ ሰነድ ተቀባይነት ካገኘ በኋላ የተመዘገበው መረጃ ይሰረዛል።

በመጨረሻም፣ ለሰተፍዎ እና ለቃለ መጠይቁ ፍቃድዎን ስለሰጡኝ እና ለጥናቱ ስኬት ለሚኖረው አስተዋጽኦ ከፍተኛ በመሆኑ በቅድሚያ ከሌብ የመነጨ ምስጋናዬን እና አክብሮቴን እገልጻለሁ።

የእድገት ጉድለት/ችግር ላለባቸው ልጆች ወላጆች/ የልጆች ጠባቂዎች ቃለ-መጠይቅ መመሪያ

1. የቃለ መጠይቁ ተሳታፊ ግለሰብ ሁኔታ/ማንነት መረጃ

የወላጅነት አይነት

- ወላጅ እናት
- ወላጅ አባት
- አሳዳጊ
- ፆታ ወንድ

የጋብቻ ሁኔታ

- ያላገባ
- ያገባ
- የፈታ/ታች
- ዕድሜ _____
- የትምህርት ዝግጅት _____
- የሥራ ሁኔታ _____
- የልጅዎ ፆታ _____
- የልጅዎ ዕድሜ _____
- ለልጅዎ የምርመራ የተደረገበት ዕድሜ _____
- የልጆች እህት ወይም ወንድም ብዛት _____
- ወንድ _____ ሴት _____

2. የተቋም-ተኮር የተሓድሶ አገልግሎቶች ውጤታማነት ከወላጆች ሚና ጋር የተዛመዱ ቃለ-መጠይቆች

2.1. በጥናቱ ማእከል ውስጥ ወላጆች የተሓድሶ አገልግሎቶችን በሚያቀርቡበት ጊዜ ተሳትፏቸውን እንዴት እንደሚገነዘቡ የምገመግሙ

- 2.1.1. ከልጅዎ ሁኔታ ጋር በተያያዘ የተሓድሶ አገልግሎት የሚሰጥ ማእከልን እንዴት አገኙ?
- 2.1.2. ልጅዎ ተቋም-ተኮር የተሓድሶ አገልግሎትን ለማግኘት ከአዲስ ጉዞ ጋር መቼ እና እንዴት ተገናኙ?
- 2.1.3. ልጅዎ ወደ ተቋሙ ሲገባ ለመጀመሪያ ጊዜ የተመለከቱትን የተቋሙ መስተንግዶ ሁኔታ እንዴት ይገመግማሉ?

- 2.1.4. ለልጅዎ በሚደረግ የተሓድሶ አገልግሎቶች ማቅረቢያ ሂደት ውስጥ መሳተፍ ለምን እንደሚያስፈልግ እና እንዴት እንደሚሰተፋ ያውቃሉ?፤ ማብራሪያስ ተደርጎሎታል?
- 2.1.5. ተሳትፎዎ ግዴታ ነው ተብሎ ሲነገርዎ ምን ተሰማዎ?
- 2.1.6. ተደራራቢ የእድገት ውስንነት ያለባቸው የልጆች ወላጆች/ጠባቂዎች ተሳትፎ ለማግኘት የተሓድሶ አገልግሎት ውጤታማነት ወሳኝ እና ደጋፊ ነው ብለው ያምናሉን? አዎ ከሆነ ፣ እንዴት?
- 2.1.7. ለልጅዎ የተሓድሶ አገልግሎቶችን ለመስጠት ንቁ ተሳታፊ ለመሆን ከማዕከሉ ምን ዓይነት የባለሙያ ድጋፍ አግኝተዋል?
- 2.1.8. ለልጅዎ የተሓድሶ አገልግሎቶች አቅርቦት ውስጥ ተሳትፎዎን እንዴት ተመለከቱ?
- 2.1.9. ልጅዎ በችግሩ ላይ ያተኮረ የተሓድሶ አገልግሎቶችን እንዲጀምር እንዴት ተከራክረዋል?
- 2.1.10. ልጆችዎ ከተቋሙ ምን ዓይነት የተሓድሶ አገልግሎቶችን አግኝተዋል?
- 2.1.11. በማዕከሉ ውስጥ የተሓድሶ አገልግሎትን አስተዋፅኦ የሚያደባባዙ ምን ዓይነት ተግዳሮቶች አሉ? ለወደፊት እነዚህን ተግዳሮቶች ለማስተካከል ምን መደረግ አለበት ብለው ያምናሉ?

2.2. የእድገት ጉድለት/ችግር ላለባቸው ልጆች የተሓድሶ አገልግሎቶችን ለመስጠት መሰረታዊ ክህሎት እና ዕውቀት ወደ ወላጆች እንዴት እና ለምን እንደተላለፉ የምገመግሙ

- 2.2.1. የልጅዎ ጉዳት ህይወቱን ወይም ህይወቷን ሊጎዳ እና በእርስዎ ላይ መጥፎ ተጽዕኖ ሊያሳድር ይችላል ብለው ያምናሉን? አዎ ከሆነ እርስዎ እና ልጆችዎ ያጋጠሟቸውን ተግዳሮቶች ለማሸነፍ ምን ዓይነት እርምጃዎችን እየወሰዱ ነው?
- 2.2.2. የተቋሙ የተሓድሶ አገልግሎት እንዲያገኝ ያስቻለውን አዲስ ጉዞ ውስጥ ልጅዎ ከመመዝገቡ በፊት ልጅዎን እንዴት ይደግፉ ነበር?
- 2.2.3. የልጅዎ የወደፊት የስራ ህይወት የተሳካ እንዲሆን ምን ዓይነት የዕለት ተዕለት ችሎታዎች እንዲያዳብር ይጠቁማሉ ወይም ይመክራሉ?
- 2.2.4. ልጅዎ በዕድሜው/ዋ የሚጠበቅበትን/ባትን እና መሰረታዊ ችሎታዎችን እንዲያዳብር/እንዲታዳብር ምን ዓይነት ድጋፎችን አድርገዋል?
- 2.2.5. በቤትዎ እና በአጠቃላይ በአንድ ማህበረሰብ ውስጥ ተሓድሶን ለመተግበር የሚያስፈልጉ ችሎታዎች ላይ ከማዕከሉ የስልጠና ድጋፍ አግኝተዋል? አዎ ከሆነ እባክዎን ይጥቀሱ እና በአጭሩ ያብራሩ!

2.2.6. ለልጅዎ መሰረታዊ ችሎታዎች እና የእውቀት እድገት ለውጥ ሃላፊነት ያለዎት ይመስልዎታል? አዎ ከሆነ ለምን?

2.2.7. የልጃችሁ የወደፊት የሥራ ሕይወትን በተመለከተ ተጨባጭ ህልምዎ ምንድነው?

2.3. የዕድገት ጉድለት/ችግር ያለባቸው ሕፃናትን ለማገገም የታቀዱ በጥናቱ ማዕከል ውስጥ የሚገኙትን የተሓድሶ አገልግሎቶች ዓይነቶችን እና የሚጠበቁ ውጤቶች መሳካታቸውን ለመመርመር

2.3.1. ማዕከሉ ለልጅዎ ምን ዓይነት የተሓድሶ አገልግሎቶችን ይሰጣል?

2.3.2. ለልጅዎ በተሓድሶ አገልግሎት ማብቂያ ላይ ምን እንዲከናወን ተስፋ አደረጉ?

2.3.3. በተሓድሶ አገልግሎቶች ምክንያት የሚጠበቁ ውጤቶች እየተከናወኑ ናቸው ብለው ያምናሉን? አዎ ከሆነ በልጅዎ ላይ ምን ምን ለውጦች ተመለከቱ?

2.3.4. በመዕከሉ ከሚሰጡ የተሓድሶ አገልግሎቶች የትኛው ዓይነት አገልግሎት ለልጅዎ እንዲሰጥ ይመርጣሉ?

2.3.5. ቴራፒስቶች ለልጅዎ የተሓድሶ አገልግሎቶችን እንዴት ይሰጣሉ?

2.3.6. ማዕከሉ ሚናዎን ለመውሰድ አስፈላጊው መረጃ፣ ችሎታዎች እና በራስ የመተማመን ስሜት እንዲሰማዎት ወይም እንዲኖሮት እንዴት አስቻሎት?

2.4. ወላጆች የልጆቻቸውን የዕድገት ጉድለት/ችግርን በማደስ ረገድ እንዴት ሚና እንደሚጫወቱ እና የጥናት ማዕከሉ የራሱን ኃላፊነቶች ለመወጣት ከወላጆች ተሳትፎ ምን ያህል ጥቅም እንዳገኘ ለማወቅ የሚረዱ

2.4.1. የዕድገት ጉድለት/ችግር ላለበት/ባት ልጅዎ አገልግሎት ለመስጠት ማዕከሉ ምን ዓይነት ኃላፊነት ወይም ድርሻ ሰጠዎ?

2.4.2. የዕድገት ጉድለት/ችግር ላለበት/ባት ልጅዎ የተሓድሶ አገልግሎት ለመስጠት የተሰጠዎትን ሃላፊነትዎን እንዴት ይወጣሉ? ልጆትን እንዴት ያስታምማሉ?

2.4.3. በተቋሙ ላይ በሚሰጡት የተሓድሶ አገልግሎቶች ምክንያት በልጅዎ ላይ ለታየው ለውጥ አስተዋፆ ያደረጉ ይመስልዎታል? አዎ ከሆነ እባክዎን በልጅዎ ላይ የታየውን የለውጥ ህይወትን እና ማሻሻያዎችን ለማምጣት እንዴት አስተዋፆ እንዳበረከቱ በአጭሩ ያብራሩ!

2.4.4. በቤት ውስጥ ለልጆችዎ የተሓድሶ አገልግሎቶችን ይሰጣሉ? አዎ ከሆነ እባክዎን እንዴት እንደሚሰጡ በአጭሩ ይግለጹ!

APPENDIX 6

ቀን _____

የቃለ-መጠየቅ የዉል ስምምነት

እኔ አቶ ፍቅሩ በዳሳ በአዲስ አበባ ዩኒቨርሲቲ ልዩ ፍላጎት እና አካቶ ትምህርት ክፍል የድህረ ምረቃ ተማሪ ስሆን አዲስ ጉዞ የተሓድሶ ማዕከል ዉስጥ የመመረቂያ ፅሁፌን እየሰራሁ እገኛለሁ። በመሆኑም ለመመረቂያ ፅሁፍ ጠቃሚ መረጃዎችን ለመሰብሰብ በአዲስ ጉዞ ለልጆቻቸው የተሓድሶ አገልግሎት ከሚያገኙ ወላጆች መካከል አቶ/ወ/ሮ _____ ለቃለ-መጠየቅ መርጨለሁ። በቃለ-መጠየቁ የተሰበሰበውን መረጃ በምስጥር ለመያዝ እና ለታለመለት አላማ ብቻ ለማዋል ተስማምቻለሁ። መስማማቴንም በፍርሚያዬ አረጋግጣለሁ።

እኔም አቶ/ወ/ሮ _____ አዲስ ጉዞ የተሓድሶ ማዕከል ዉስጥ ለልጄ የሚሰጠው አገልግሎት ላይ ተሳታፊ በመሆኔ ከላይ የተጠቀሰውን ተስማምቼ ቃለ-መጠየቁ ላይ በፍቃዴ ተሳታፊ መሆኔን በፍርሚያዬ አረጋግጣለሁ።

ውል ተቀባይ

ሥም _____

ፍርማ _____

ቀን _____

ውል ሰጪ

ሥም _____

ፍርማ _____

ቀን _____