ADDIS ABABA UNIVERSITY SCHOOL OF GRADUATE STUDIES

THE ROLE OF PARENTS OF CHILDREN WITH AUTISM IN THE EARLY INTERVENTION PROGRAMMES

BY

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ABSTRACT

Although we think that autism is not an illness and cannot be cured, a lot can be done to improve the life situation of children with autism and promote their learning and development. Parents have a critical role in the over all development of the children. This being the case, the major purpose of this study was generally to investigate the role of parents of autistic children in the early intervention programs (EIP).

A qualitative research approach using interview, observation, Focus Group Discussion and document analysis were employed to collect the empirical data for the study. Six parents of children with autism were included in the study. All of he respondents were found through J-CCARDD. So, the finding of the study is presented and analyzed accordingly: Back ground information about the mothers and their autistic children, areas of parental involvement in the EIP, needs of parents to involve in the EIP, and extent of parental involvement in the EIP.

The finding of the study revealed that almost all parents (except case four) have positive understanding about the causes and the intervention strategies of autism.

The extent of direct involvement of the parents in teaching their autistic children seem to vary according to the educational and the socioeconomic status of each case of the parents. In addition to this, all parents of children with autism are not using enough teaching and playing materials and are practicing the teaching process at home.

Parents require training and counseling on the consequence of autism and its treatment techniques so that they can know the role they can play to help their children to develop in to active members of their community.

Table of Contents

Page

CHAPTER ONE

CHAPTER TWO

CHAPTER THREE

CHAPTER FOUR

CHAPTER ONE

INTRODUCTION

1. Background of the Study

Childhood autism, the most characteristics of subgroup of the broader - Pervasive Developmental Disorders (PDD) category, is a severe form of psychopathology evidenced early in childhood and characterized by severe, pervasive behavioral deficits and bizarre behavioral patterns. It reflects impairment in diverse domains of functioning including social interaction, communication skills, cognitive function, comprehension and imaginative activity (Ollendick & Herson, 1998).

Although in the past there was a wide spread ignorance of autism, today there is a growing awareness of the particular needs and difficulties that a child with autism experiences. This is particularly true in the developed countries. Unfortunately the majority of the public in Ethiopia including many professionals, in the medical, educational and vocational fields are still unaware of how autism affects people and how to effectively work with individuals with autism. In addition most parents of autistic children lack information about the nature of and its symptoms further most of them are ashamed of their autistic children and do not feel at ease to talk about them openly. Hence thousands of children with autism in this community are confined to their homes without any formal education while their siblings attend schools. It is also observed that the parents of these children do not let these children meet and play with other children. Instead, they were hiding them at home without giving them any stimulation and motivation of learning and participating in home activities. Therefore, these children have no access to education and rehabilitation.

Autism has a major impact on the lives of the affected children and their families. The family of autistic child often experiences disappointment, social isolation, added stress, frustration and helplessness. The compound stress of the presence of an autistic child may affect the families well being and interfere with the child's development. Therefore, to prevent the incidence of these socio emotional barriers and to further the development of children with autism and the well being of their family members, early intervention for autistic children should be planned and implemented systematically. Further early intervention is highly recommended for children with autism as it fastens the development of them and reduces the impact.

Early intervention can result in parents developing improved attitudes about themselves and their child with autism and gain improved information and skills for teaching their child, and constructively utilize their time for leisure and employment. Besides, the child gains developmental and educational improvement and decrease dependence upon social institutions.

To make early intervention program more effective, it should include parents as a critical component in the intervention for young children with autism. But at present there are not enough local studies on the early intervention programs for autistic children and particularly on the role of parents in the early intervention programs. It seems that the importance of parents' role in the education and intervention programs, is not given much attention although it is very important for the development of all children and children with autism in particular. The responsibility is given to the concerned professionals.

In order to improve the quality of the life situation of children with autism, it is necessary to include their parents in the process of planning and implementing educational and other intervention programmes. Through parents' involvement in such process, intervention and education programmes have better possibilities to become successful. Besides, family involvement is an important factor for success of a program because parents can provide unique insight into creating an intervention plan and can provide additional hours of intervention. Including parents in the intervention can also help children achieve greater maintenance and generalization of skills and can help reduce parents stress level.

Parents are the ones who shoulder the responsibility of caring for their children. It becomes a burden when it comes to those parents of children with disability. An autistic child is indeed with many special needs and requires close attendance.

To sum up, parental role is especially of great importance in the process of assessment, programme planning and implement on educational and other intervention packages and as such in the process of improving the life situation of children with autism. Therefore, the present research mainly focuses on the role played by the parents of autistic children in the early intervention programmes.

1.1. Related Literature Review

1.1.1 The Nature of Autism

Howard and Orlensky (1988) explained that autism is a neurobe havioral disorder characterized by impairment of social relatedness, delayed and disordered communication and restricted responsiveness and bizarre behavior patterns occurring in young children.

Seigel (2003) indicated that autistic people often suffer from a bewildering array of problems sensory disturbances, food allergies, gastrointestinal problems, depressions, obsessive compulsiveness, sub clinical epilepsy, and attention deficit hyperactivity disorder. Children on the autistic spectrum, however, are "mind blind"; they appear to think that what is in their mind is identical to what is in every else's mind and that how they feel is how every one else feels.

Autism is a worldwide problem among all races, nationalities and social class. It affects only 4 or 5 of every 10,000 persons. However, recent research on J-CCARDD (2005) reported that with a ten fold spike in numbers over the past 20 years-one in every 166 children is now diagnosed with an Autism Spectrum Disorder (ASD). Approximately 80% of them are boys. Two children with autism in three remain severely impaired in to adulthood and are unable to lead independent lives (APA, 1994). Studies show that there are over 300,000 autistic children in the USA alone and more than 500,000 in the UK and the rest of Europe. In Africa, although actual count is not ready available it estimated that there are hundreds of thousands of children with autism.

Although autism has had a relatively brief history, it has nonetheless been marked by confusion, controversy, and change less than 50 years age, when Kanner first described it, autism was considered a rare type of childhood psychosis. Today, it represents the only specific severe or profound emotional disorder of childhood (McLaughlin and Wehmen, 1992).

1.1.1.1 The Clinical Picture of Autism

The American psychiatric Association (1994) listed the major diagnostic criteria for autism. These are:

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2)and (3).

1. Qualitative impairment in social interaction, as manifested by at least two of the following.
    a. Marked impairment in the use of multiple non-verbal behaviors such as eye to eye gaze, facial expressions, body postures, and gestures to regulate social interaction.
    b. Failer to develop peer relation ships appropriate to development levels.
    c. A lack of spontaneous seeking to share enjoyed, interests, or achievements with other people (e.g., by a lack of showing bringing, or pointing out objects of interest).
    d. Lack of social or emotional reciprocity
2. Qualitative impairments in communication as manifested by at least one of the following.

   a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures)
   b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
   c. Stereotyped and repetitive use of language or idiosyncratic language.
   d. lack of varied ,spontaneous make -believe play or social imitative play appropriate to developmental level.

3. Restrictive repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following.
   a.. Encompassing preoccupation with one or more stereotyped and restricted patterns of interests that is abnormal either in intensity or focus.
   b. Apparently inflexible adherence to specific, non functional routines or rituals..
   c. Stereotyped and repetitive motor mannerism (e.g., hand or finger flapping or twisting, or complex whole-body movement).
   d. Persistent preoccupation with parts of objects

B. Delayed or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

1. Social interaction,
2. Language as used in social communication or
3. Symbolic or imaginative play

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

- Besides, Eaves and Hooper (1988) and Eaves (1990) as cited in McLaughlin and wehmen (1992) found evidence to suggest five primary factors to diagnose autism. These are: affective and cognitive indifference, expressive affect, passive affect, anxiety/fear, and cognition.

I. Affective and cognitive indifference

This factor might reflect lower order behavior controlled by the brain stem and the cerebellum. Among the dimensions and behavior contributing to the affective and cognitive indifference factor were:

- *Autism-* avoids eye contact, blank expression: emotionless, prefers to be left alone, dislike for hugging.
- *Hand and body movements-* finger flicking, hand shaking, rocking, head banging, stares at hands close up.
- *Sensory stimulation-* spins jar lids and plates, plays with spinning tops, fascination for rushing air and "crinkly" sounds.
- *Bizarre compulsive-* behavior I -unusual interest in texture, inappropriate toy play, enjoys "dangling" objects, mouthing.

II. Expressive Affect

Among the dimensions and behavior contributing to the expressive affect factor were:

- Distorted affect- cries on "happy" occasions: cries without vocalizing hits, bites, or scratches others.

- Unwarranted whining, crying, and screaming when desires are unmet, smiles or laughs without reason, no response to pain.
- Hallucinations/ superstitions- sees or hears things not present, picks up objects with the backs of hands, makes peculiar sounds inside the mouth.
- Masturbation/howling
- Sensitivity to certain smells.

III. Passive Affect

Among the dimensions behavior contributing to the passive affect factor were:

- *Collecting/* hoarding- saves or hoards items of no value, carries a special objects with them.
- *Meticulosity*- Exaggerated interest in cleanliness has special locations for objects.
- *Bizarre compulsive behavior II*- walks on tiptoes, pins and whirls body: over-reacts to environmental changes: rarely stacks objects, usually lines them up.

IV. Anxiety/Fear

Few autistic subjects exhibited extreme fears or anxieties. Among the behaviors contributing to the anxiety/fear factor were:

- Believing harmless entities to be dangerous
- Excessive fear of loud noises
- Anxiety around water; and
- Fear in crosses

V. Cognition

Among the dimensions and behavior contributing to the cognition factor were:

- *Savant behavior-* extreme skill in one area, memorizes commercials and advertisements
- *Speech-* misuses pronouns, monotonal or "wooden" speech, echolalia switches from normal to monotonal or glottal speech, loud speech.
- *Skill development-* spontaneous use of skill lags behind elicited use of skill, uneven skill development, exhibits surprising skill at times.
- The factors of autism reflect the three major human attributes; the motor, emotional, and cognitive domains. Unlike many other disabilities, the condition is not characterized by slow development that mirrors the usual developmental sequence. Instead, the autistic individual displays a unique behavioral topography that may be fairly described as strange, distorted, even bizarre. No autistic person demonstrates the full range of the behavioral topography.

1.1.1.2 Etiology

Seigel (2003) explained that yet autism, a vexing brain disorder, remains largely a mystery. Researchers still don't know what causes it, nor do they know best to treat a condition. There is at present nearly universal agreements that autism is caused by some form of brain damage or abnormality in brain development. The evidence for this includes:

1. The high incidence of EEG (Electro encephalograms) abnormalities
2. The increased incidence of autism in certain diseases that are known to cause brain damage, such as untreated phenylketonuria (PKU) and congenital infections.
3. The high frequency of mental retardation in autism
4. The high incidence of prenatal infections; prematurely, birth trauma and so on. These observations suggest that autism may result from brain damage sustained in a number of ways, including genetic abnormalities and environmental influences, and that the damage may be anatomical, physiological, &/or biochemical (Batshaw and Perret, 1992). Neurochemical studies have implicated various neurotransmitter disturbances in autism, although none with consistency. Some researches have noted similar behaviors between children with autism and animals given opiates, suggesting that abnormalities in these levels may play a role in autism (Seigel,1996).

A genetic basis for autism has been suggested by studies that have identified subgroups of children with autism who have a known genetic cause of brain injury, such as fragile x syndrome (Hamilton, 2000). And News week (2005) reported that autism occurs at higher rates among identical twins than among fraternal twins and that the risk of autism is much higher in families with one child with autism than in the general population. Taken together, these studies indicate a genetic predisposition to autism (McLaughlin, and Wehmen, 1992).

1.1.1.3 Diagnostic Procedures of Autism

As Mclaughlin and Wehmen (1992) explored that to date, there are no medical tests like x-rays or blood tests that detect autism. And no two children with the disorder behave the same way. In addition, several conditions can cause symptoms that resemble those of autism. So parents and the child's pediatricians need to rule out other disorders, including hearing loss, speech problems, mental retardation, and neurological problems. But once these possibilities have been eliminated, a visit to a professional who specializes in autism is necessary.Such specialists include people with the professional titles of child psychiatrist, child psychologist, developmental pediatrician or pediatric neurologist.

Autism specialists use a variety of methods to identify the disorder. using a standardized rating scale, the specialist closely observes and evaluate the child's language and social behavior. A structured interview is also used to elicit information from parents about the child's behavior and early development. Reviewing family video, tapes, photos, and baby albums may help parents recall when each behavior first occurred and when the child reached certain developmental milestones, The specialists may also test for certain genetic and neurological problems.

After assessing observations and test results, the specialist make a diagnosis of autism only if there is clear evidence of

- Poor or limited social relationship

- Under developed communication skills
- Repetitive behaviors, interests and activities

People with autism generally have some impairment within each category, also require that these symptoms appear by age 3. However, according to Mclaughlin and Wehmen (1992), there are at least four reasons why the disorder is often misdiagnosed.

1. Autism shares a number of characters tics with other disorders; infant wing and Atwood (1987) offered reasons for confusing) Autism with 16 othei conditions. For instance, most autistic and all mentally retarded people exhibit low IQs, and both may manifest stereotypic body movement. The autistic person may appear to be hearing impaired and thus may be confused with that population. Speech and language disorders (including autism) are common among autistic individuals.
2. Because they usually demonstrate severe disorders in more than one domain, autistic children are often simply labeled multi handicapped.
3. The inability of the professional community to establish a stable classification system has undoubtedly caused confusion among practitioners with little or no personal experience with the autistic population.

1.1.2 Early Intervention

Dunst, Synder and Mankinen (1985) as cited in Tirusew (2000) indicated that the term early intervention has been broadly used to describe efforts designed to prevent or ameliorate developmental or behavioral problems resulting from environmental or biological influences or the combination of the two. In this context early intervention is considered as a set of actions that have the intent or effect of altering the course of a process either by coping coming between or interrupting its future activities or purpose.

The National Association for the Education of Young Children (1990) also explained that early intervention may be defined as the provision of educational, therapeutic, preventive, and family support services to young children with disabilities and their families. The underline premise of early intervention is that by providing these services as early as possible, we maximize the likelihood of later success for children and support families during a critical time in family growth and adaptation.

Early intervention may focus on the child alone or on the child and the family together. Early intervention programs may be center based hospital based, or a combination services range from identification. That is, hospital or school screening and referral services to diagnostic and direct intervention programs. Early intervention may begin at any time between birth and school age; however, there are many reasons for it to begin as early as possible. It has to be clear that before embarking on any intervention program, the processes of early identification and assessment or screening need to be in place (Tirusew, 2000).

In the process of early identification or detection parents particularly mothers can play a vital role. Right after birth there is a day-in-and-day-out close contact and a continues dialogue between the mother/care giver and the child which gives ample opportunities for detection. If detection of impairment or disability is not possible at home, the next ideal place for early detection will be the pre-school environment. In a pre-school situation the pre-school teacher or the caretaker has a lot of possibilities to observe the child's overall performance both in the indoor and out door activities. Therefore, both parents and teachers need to be informed about the importance of early detection and they need to be keen observers of their children's behavior.

After the identification of the problem a comprehensive assessment on the degree of disability as well as both the liabilities and assets need to be undertaken. The child should be referred for medical and psychological assessment.

Assessment should be followed by an intervention program usually focusing on influencing the child's development as well as improving the child's immediate environment which has a direct bearing on his/her over all growth and development. The consequence of working with the potential of the child with disability not only enables him/her to optimally mobilize the latent resources, which are the basis for leading a quality life in society, but also enhances self-confidence and motivation (Tirusew, 2000).

1.1.2.1 Prevention As Early Intervention

According to Odem, Hanson and Blackman (2003) early intervention can be viewed as prevention. The World Health organization (WHO) defined three levels of prevention: primary, secondary, and tertiary. Primary prevention includes measures to preclude disorders or circumstances that lead to disability. For example, administering the rubella (German measles) vaccine to prepubertal girls diminishes the risk of their contracting the disease as adults and causing serious damage to the fetal brain during pregnancy.

Once impairment has occurred, secondary prevention efforts are aimed at avoiding additional impairments that might arise. For example, hearing impairment, if unrecognized and untreated, can lead to permanent communication impairments, and hypertonia in children with cerebral palsy reduces joint range of motion without a number of secondary preventive treatment modalities- such as a physical therapy, Orthotic devices, or Orthopedic surgery- permanent joint contracturs are likely to develop, reducing the child's functional mobility.

Tertiary prevention is designed to minimize the impact of a particular disability. A worldwide trend toward integration into community life has markedly diminished the institutionalization of children with disabilities, supported families to care for those children at home. And led to their inclusion in general education schools and community activities.

1.1.2.2 Goals of Early Intervention

The goal of early intervention is to prevent or minimize the physical, cognitive and emotional, and resource limitations of young children with biological and environmental risk factors (Odom et al, 2003). Also suggest that early intervention is designed to accomplish a number of other goals.

1. Early intervention should support families in achieving their own goals and in securing the support they need for the successful adaptation to a child

with a disability.

2. Early intervention ought to help children become actively engaged in their environments, be independent, and exhibit a desire to master their environment.
3. Early intervention should promote children's development in key areas including cognition, communication, self-help, social-emotional, fine motor, and gross motor skills. In fact the basic goals of early intervention ought to be "to improve children's accession and use of important motor, social, affective, communication, and intellectual behaviors that, in turn, are integrated in to response repertoires that are generative functional, and adaptable".
4. Recognizing the pervasive social skills deficits exhibited by many children with disabilities, early intervention should build and support social competence, including peer social interaction skills.
5. Early intervention should provide and help prepare children for normal life experiences. This means that early intervention should be provided in typical environments with typical children.
6. Early intervention ought to prevent the emergence of future problems or disabilities. This goal is important both in terms of primary education of disabling conditions (e.g., through parent education and support programs, genetic counseling, community awareness, etc) as well as in terms of preventing secondary and tertiary effects for persons experiencing a primary disability.

1.1.2.3 Key Features of Early Intervention in Ethiopia

Teferra (1995) as quoted in Odom,Hanson, and Blackman (2003) indicated that in Ethiopia as in many other countries, one of the major difficulties encountered by people with disabilities is social. The vast majority of people with disabilities in Ethiopia do not have access to intervention, education, or health care; they live in poverty, constituting the poorest of the poor in the country.

Teferra (1995) also explained that in Ethiopia, both governmental and non-governmental services respond to the needs of people with disabilities. Among the millions of people with disabilities, however, only very few have access to special services. The types of services that operate in the country include special day schools, treatment centers, sheltered workshops, orthoses and prostheses production centers, homes for the children, and homes for "the aged"

Community-Based Rehabilitation centers (CBRs), operating through non-governmental organization (NGOs), have started door-to-door, home-based early intervention program. However, the vast majority of the people with disabilities in the country do not have access to such services. They either engage in begging and looking for alms or live out of public view. They constitute the poorest of Ethiopia's poor. Also, it is not uncommon to find in the urban centers the people without disabilities who generate their daily income by having individuals with disabilities to beg for alms. This can be referred to as "double dependency syndrome."

Even NGOs once gave little attention to the importance of early intervention for children with disabilities. The Ministry of Health does have various immunization programs for young children and offers primary health care for mothers to possibly prevent disabilities. Childhood "crippling diseases" such as poliomyelitis's have not yet been controlled although encouraging results were reported by Ministry of Health.

1.1.2.4 Early Intervention Programmes for Autistic Children

There is a wealth of research to support the notion that autistic children experience more gains when treatment is provided to them at an early age (Comer, 1998). The most important thing is to start treatment as early and intensively as possible. Some researchers indicate that the early years are crucial for developing language and social behavior in autistic children (Mortimer, 2001). There is no cure for autism, but effective education for young children with autism spectrum disorders is an achievable goal. However, it well required that sufficiently individualized and intensive instructional opportunities be delivered over time in a well-coordinated manner by both educators and family members.

Early intervention programmes usually comprise of a collection of professional from different disciplines collectively working towards common treatment goals for the autistic children and families involved.

The most widely used early intervention services for autistic children are behavioral intervention, speech-language therapy, physiotherapy, occupational therapy, sensory-integration therapy, pediatric and neurological examination and parent training.

I. Behavioral Therapy

Behavioral approaches have been applied to person with autism for more than thirty years. According to Hamilton (2000) Applied Behavioral Analysis (ABA) teaches complex tasks by breaking them down into bite-size pieces that can be learned more easily, with each piece building upon the previous one. Rewards, called "reinforces," are given for correct responses or behaviors while inappropriate responses are corrected, ignored, or redirected precise data on each learning trial is corrected, and adjustments in the educational program are made accordingly. ABA targets development in many areas of skills, including attending, initiation, language, social, self-help, and academic.
Attending skills include learning how to sit in a chair, decreasing tantrums, making eye contact, and listening.

Imitation skills are both physical and verbal. These skills eventually developed into complex imitations of actions, play, and language. Verbal imitation skills start out simply. If a child is nonverbal, the goal is to get him to imitate a sound. The therapist says, "say aah," and the child is supposed to say " aah." If the child is already verbal, he will start out with the more complex verbal imitation skills.

Language skills have two aspects, receptive and expressive. Because of the complexity of language. Lovaas says, "About 80 percent of intensive behavioral treatment with young children is focused on helping the children develop more meaningful language. The requirement of teaching language requires that the provider of treatment knows how to teach a variety of skills, from helping mute children acquire verbal imitation, to teaching abstract language such as pronouns, prepositions, and time concepts. Finally, the therapist /teacher has to teach the child how to talk & play with normal peers." ABA can also help children who don't develop verbal language to express themselves through augmentative communication.

Social skills, which come naturally to most children, need to be specifically taught to children with autism. These skills include such basics as playing with toys appropriately and transitioning between them, initiating interaction, sharing toys & experiences, and developing friendships.

Autistic children often have delayed self-care skills. They may present with a variety of motor, sensory, communication, and behavioral difficulties, which influence their ability to perform self-care tasks with ease and independence. There fore, as the development of self-care skills directly impact a child's self-confidence, and level of independence, both at home and at school. The treatment centers on dressing, eating, toileting, hygiene, as well as, provide therapeutic strategies for facilitating skill development. Applied Behavioral Analysis(ABA) targets each self-help task with small, attainable steps until the child can take care of his personal needs independently.

Academic skills begin with learning shapes, colors, letters, and numbers and then advance to reading, writing, spelling, and mathematics. Since many children with autism have scattered skills, some advanced and some lagging behind, a child as young as two or three may begin reading or spelling.

Beyond the skills that are taught to the child, Lovaas points out two fundamental goals of this therapy: "to make the child want to learn, and to make the child feel that he can learn."

II. Speech Language Therapy

As Comer (1998) indicates despite intensive behavioral treatment, half of a person with autism remains speechless. As a result many therapists also turn to non-vocal modes of communication, including sign language and simultaneous communication, a method combining sign language and speech. Other therapists advocate the use of augmentative communication systems such as communication boards or computers, that use pictures of a fork to represent "I am hungry," or point to a radio for " I want music." Mortimer (2001) suggested that speech therapist offer support and advises to carers such as parents, teachers and nursing staff to help them understand the nature of the problem and how they can help. Specialist advice is also available on articulator, phonological and fluency problems in young children.

III. Physiotherapy

It is conducted by physiotherapist to autistic children following assessment and therapeutic diagnosis, the physiotherapist will work closely with parents or carers to establish appropriate goals for the child. This individually planned programme of physiotherapy might cover careful positioning and movement, advice and support, special handling skills exercise regimes, walking practice, balance and co-ordination exercises, stretching of muscles, chest physic therapy and the function of Heart and lungs. And they concentrate on how to perform daily tastes and recreational activities, etc. (Mortimer, 2001).

IV. Occupational therapy

Occupational therapy is also rendered for autistic children. The therapist is committed to helping each individual maximize their potential to function fully and independently within their total environment. Mortimer (2001) also explained that the occupational therapists aim to develop the child's maximum level of independence thereby improving practical life skills, which hopefully promotes a better quality of life. They assess gross and fine motor skills, and dyspraxic difficulties, writing independence skills, visual perception and body awareness, and the need for specialized equipment for home and preschool. Children with autism often have delayed fine motor skills (i.e., finger dexterity, grasp hand preference, eye-hand coordination). As the development of fine motor skills impacts a child's cognitive and emotional well being, in addition to influencing their ability to play, and perform many self-care tasks, it is often a key area of intervention.

V. Sensory integration therapy

Some children with high-functioning autism are overly sensitive to and early overwhelmed by everyday sensations. Such as certain sounds, tastes, textures, or smells, or by being touched. Sensory integration (SI) is the name of the process by which incoming sensations are interpreted, connected, and organized, some thing that is necessary for a child to feel safe and comfortable and able to function effectively in the environment (0zonoff, Dawson and Mcpart land, 2002). This therapy helps to overcome problems experienced by many young children in absorbing and processing sensory information. Encouraging these abilities ultimately improves balance and steady movement. Therapies include stimulating touch sensations and pressures on different parts of the body. With the use of certain items, such s Styrofoam chips, water, or textured toys, this therapy will also motivate children to learn sequences of movement.

VI. Pediatric and Neurological Examination

As a doctor, the pediatrician offers pediatric and neurological examination, with investigations and work with parents to identify cause and diagnosis. Early diagnosis, counseling and support, perhaps even before referral to the multidisciplinary team, are sometimes provided. Pediatricians also have a role in providing or arranging genetic counseling when necessary, and in tapping in to in-patient facilities. Pediatricians also provide the service of monitoring medical condition and needs as the child grows older, and monitoring hearing and vision are an important part of this (Mortimer, 2001)

VII. Parent Training

Another critical feature of successful programs is training parents. Behavioral programs, for example may include parent training components to help parents learn and apply behavioral techniques at home, and some offer instruction manuals for parents and home visits by teachers and other professionals. Individual therapy and support groups to help parents address their own feelings and needs also becoming increasingly available. In addition, a number of parent associations and lobbies are providing emotional support and practical help (Comer, 1998).

1.1.3 Parental Involvement

In the first place we all believe that autistic children can be helped to help themselves to become more independent and to function a higher level. That the parents want the child to learn and to become more self-sufficient is obvious. Several studies in the field of disability indicate that the type of home environment, parent-child relationship and particularly the quality of interaction in the early years of life has a lasting effect on the overall development of the child. This accounts to the social, cognitive, emotional and psychological well being of the child.

Parents have not only to cope with autistic child they must also help their other children to understand and to adjust to this new dimension in the life of the family. As parents, the first priority is to love and support their autistic children to build within him/her a healthy center. The second is to teach functional skills.

1.1.3.1 Adaptation Process

Mitchell and Brown (1991) explained that adaptation in this context is a process which parents experience in adapting to their child's disability. The various reactions will now be described in the order in which they are typically experienced.

A. *Shock*- parents report feeling confusion, numbness, disorganization and helplessness. They often say that they were unable to take in much of what they were told at his time. This typically lasts from a few hours to a few days.

B. *Denial*- disbelief or denial of the reality of the situation often follows the shock reaction. As a temporary coping strategy this is quite healthy. However, prolonged denial can lead to parents shopping around for a more favorable diagnosis, which, if pursed, could retard the adaptation process.

C. *Anger*- Parent may blame themselves or hospital staff and experience anger which may be displaced on to their spouse, the child, or on to professionals involved. Underlying the anger may be feelings of quilt about producing an imperfect child.

D. *Sadness*- parents may feel depressed, despairing, or just very sad. This is often a reaction, which pervades the whole process to some extent.

E. *Detachment*- many parents experience a time when they feel empty or flat. They accept the reality of the disability but have lost some of the meaning of life.

F. *Reorganization*- this phase is characterized by realism and hope parents consider their cup is half-full rather than half empty.

A. *Adaptation*- when parents have come to terms with the situation they exhibit a mature emotional acceptance of the child with the disability.

Max (1985) as cited in Mitchell and Brown (1991) explained that in the adaptation process (phase) they are fully aware of the child's special needs and strive to provide for these. The parents may always experience some sadness that their child has a disability but they do not let this interfere with their efforts to make the best out of life. It is suggested that the various reactions which are evoked are not resolved but become an integral part of the parents' emotional life. This reworking of parental reactions can occur at various milestones in the handicapped child's development such as school entry, the onset of Puberty and leaving school.

1.1.3.2 Model for Parent Involvement

As Mitchel and Brown (1991) said a model for parent involvement with parents of children with disabilities has been adapted from the work of Kroth (1985) and Lombana (1983). The model takes into account both parents' needs (what they require from professionals) and parents' strengths (what they can contribute). The model describes 4 major strengths and four major needs of parents.

I. Parents' strengths

*A. **Information***- Seligmen (1979) as cited in Mitchell and Brown (1991) explained that all parents can contribute valuable information about their child with special needs and about the family. Information concerning the child's strengths and weaknesses, likes and dislikes, along with relevant medical details can be gathered by professionals at the initial meeting. As Siegel (1996) indicated, as parents, they watch their children day in and day out and they know them best. They may not know all the medical terminology and labels, but they know their condition. Only they are aware of their children's complete history. It's imperative that parents accurately document their children's ongoing medical treatments and reactions, recording anything that may affect treatment decisions. Does your child have bowel problems? Does he wake up during the night? Does he have headaches or stomach pains? Document it. How often does it occur? How severe is it? Keep track daily to see if changes occur as a result of different events, diets, or medication. Making full use of this information is essential if interventions are to be effective. But it does not do much good if it remains merely with parents. They need to accurately relay that information to the concerned professionals.

B. ***Support***- Most parents are willing and able to contribute more than just information. Most parents can support the efforts of professionals in facilitating the development of their child with special needs, by reinforcing treatment procedures and by participating in planning the child's program professionals therefore need to develop the skills of collaborating with parents in parent-professional partnership (Mittler and MC Conachie, 1983).

It is witnessed that parents have a great influence on their children's learning and adjustment. The importance of parent involvement becoming a highly significant components. In the light of this, after summary of past early intervention studies for children with autism, hat for infant and toddler programmes, in particular parents were either trained to be the primary service provider, or to provide additional programmes at home, often reinforcing, supplementing, and generalizing lesson activities. Over all, the instructional burden for children was placed clearly on parents. It is very difficult to teach autistic children due to their limited communication skills, social impairment, and problematic behaviors. Autistic children should be taught by their parents in the areas of: functional communication skills, improving social awareness and peer interaction skills, addressing cognitive deficits, teaching appropriate play skills, decreasing rigidity, encouraging independence, addressing sensory issue, teaching daily living skills

C. ***Resource***- Michael (1980) as cited in Mitchell and Brown (1991) indicated that some parents have the ability and time to act as voluntary aides assisting with the intervention programme, in the preparation of material or provision of resource from the community. Others may have special skills, which they can contribute such as in fundraising or helping prepare newsletters. Still others may have the time, skills and knowledge needed to provide support to other parents. Professionals should ensure that they make good use of this valuable resource.

D. ***Leadership***- a few parents able to provide training experience for professionals through writing about their own experiences or speaking to groups such as teachers or doctors. Others may contribute their skills through executive membership of professional or parent organizations.

II. Needs of Parents

A. ***Communication-*** all parents need to have good communication with each of the professionals who is dealing with their child with special needs. They need to feel able to contact the relevant professionals with any question or concern they may have. Also all parents need to have up to date information about the various services and facilities which can help them care for their handicapped child. This can be provided by leaflets and handbooks written especially for parents. However, professionals need to continually check that parents have received this information and are fully aware of all the services available to them.

B. ***Conferencing-*** most parents want to be kept informed about their children's progress and to be given suggestions as to what they can do to help. They typically regard professionals involved in early intervention as a major source of information and support, and therefore need to have good working relationships with them. Professionals can facilitate this by maintaining regular contact with parents by telephone, mail or home visits. In addition, parents should be actively involved in any case conferences concerning their child with special needs.

C. ***Education-*** Many parents want to receive guidance from professionals in order to help them cope with their children's behavior problems and facilitate their development. Such guidance, or parent training, can be organized individually as in the portage programme or in-groups as with behavioral group training. Group parent programmes can be designed to combine training with group counseling in order to provide a supportive environment in which parents can learn new skills and gain confidence through talking with other parents can learn new skills and gain confidence through talking with other parents. Likewise it has been acknowledged that professionals who provide such guidance individually should also combine it with the availability of counseling. Therefore, in addition to the expertise of their own profession, early intervention personnel should also have good basic counseling skills.

Family resources or parental perception and attitudes towards themselves, their disabled child and parent intervention programme(e.g. training about parenting skills)seem to be important factors for the effectiveness of early intervention .Without the willingness of parents toward EIP, professionals social support have nothing to contribute for the successful achievement of EIP. Thus, professionals should know the needs of parents or families of children with disabilities before starting their own different kinds of professional services. Parent education is, there fore, one of the needs of parents to participate in the programme of early intervention against their child's autistic syndrome. Parent education is a programme geared towards assisting/empowering them to enhance self-awareness, more effective methods of dealing with behavior problem and techniques of measures or action against it.

Education and /or training can be bring about better understanding between the parents and the child resulting in healthy communication, and successful life. One of the conditions that urge parents of children with disabilities to seek training is the very manners of the children . In spite of the general experience that children act out frequently, the condition of those with handicap particularly demands the acquision of systemic and exceptional training skill on the part of parents.

D. ***Counseling-*** Some parent may need counseling beyond that which can be provided as part of the intervention program. So, in addition to having basic counseling skills sufficient to deal with every day concerns, early intervention personnel must be able to refer parents on to professional counselors when the concerns raised would take them beyond their level of competence. Therefore, it is important that professionals be aware of the various individuals and organizations in their community which can provide such counseling.Heward and Orlansky(1988) explained that the great stress the handicap , owing to its own inherent condition ,exerts on the interpersonal harmony of the family members especially on the relation ship between the husband and the wife. The difficulties include, argument over who should blame for the child's disability, how it can be delay with the management of likely behavior problem and how much the resource (time, money, and energy) should be allocated for caring the child with the handicap. So that the rest of the family members would not feel neglected. To this end, support or counseling must be available for parents of children with disabilities.

1.1.3.3 Early Needs of Parents

A. Receiving the Diagnosis

Cunningham and Davis (1985) as cited in Mitchell and Brown (1991) explained that the vast majority of parents want to be told of the diagnosis by a professional who communicates with empathy, sensitivity, openness, and a positive yet realistic outlook. This person should be knowledgeable about the possible causes and likely consequences of the disability and of the services available. Parents want to be told as soon as possible after the diagnosis is made with both of them together and with the child present. They want to be told in a private place with no disturbances, and to have adequate time for information to be given questions asked, and further interview scheduled. When the diagnosis is given in this way, parents tend to adapt more quickly and establish a more positive relationship with each other, the child and professionals, the parent and professionals.

B. Obtaining Information

One of the very first requests of parents after receiving the diagnosis is for comprehensive, accurate and up-to-date information about their child's handicapping condition. Most parents also want suggestions as to how they can facilitate the child's development. Parents should also be told, as this time, about all the services and benefits. This information should be widely available in the form of both written materials and professional expertise (Mitchell and Brown, 1991).

C. *Receiving Support*

Soon after the diagnosis parents need to have supportive counseling available to them. They need someone to help them express and clarify their feelings and to help in understanding their reactions and those of others around them. In this way parents can be assisted to make a speedy and successful adaptation to the situation. If they do not receive such counseling parents may experience considerable anguish and take much longer to move through the adaptation process. However, parents will seldom directly ask for information on their child. Therefore, it is important for the person who supplies parents with this information to also have the skills necessary to carry out supportive counseling.

D. *Meeting Other Parents*

Surveys have shown that most parents want to meet others with similarly disabled children. Whereas, many parents wish to do this shortly after the diagnosis, when parents do meet they typically report great benefits both in terms of obtaining information and receiving support. Professionals can help to facilitate these contacts by making parents aware of the various support groups and others organizations such as parents-to-parents schemes 'operating in the area. According to Ozoneff et al. (2002) parents often find it useful to talk with other parents, who understand better than professionals what you are going through and who may have useful remedies for situations you find your family in. These support groups do indeed make it clear that you are not alone. Feeling of isolation at the time of diagnosis are almost universal among parents. Joining a support group will diminish those feeling considerably, as well as provide much constructive and practical assistance.

1.1.3.4 Parent-Professional Partnership

Parents can play a number of important roles in their relationship with their child's school organization members; care providers, political advocates and facilitators of professional decisions. A partnership in which both parents and professional share knowledge and skills in order to facilitate the child's development and meet the needs of other family members is the best basis for parent involvement (Hamilton, 2000).The parents' first task is to try to help the professionals to get to know them and the other members of their family as quickly as possible (Mitchell and Brown, 1991).

There should be a very close interaction and a continuous dialogue between parents and rehabilitation workers as well as other professionals working toward promoting the quality of life for the child with disability. Parents, due to their day-to-day contact with the child, have rich and enormous data about the over all development and progress of the child at different stages of development. In addition to the child's personality development, information collected from the parents of the child should be used as a basis for designing intervention program. This means parents should act as a major source of information for these professionals or practitioners intending to provide back up support for the child with special need. Their role should not be limited as passive information provider. They also need to be trained and involved in the process of intervention as well as in under taking the follow up and monitoring of the program. In a nutshell, parents of children with disability need to actively compliment the work of the professionals (Tirusew,1999).

Hardman, et al. (1986) indicated that unfortunately, in many cases both the parent and the professional may not possess, the communication skills necessary for positive interaction. Too many professionals talk down to parents in a patronizing, authoritarian manner. They some times think that the parents lack sufficient experiences or background to understand. These attitudes result in many professionals communicating poorly, or failing to communicate at all. Professionals must remember that parent have the right to question information or decisions made by professionals that are inconsistent with family value.

Parents need to both receive and send messages accurately, parents require information presented in a clear, concise manner. Parents often feel ambivalent when receiving information from professionals. They want the truth because they must have it to deal with their problems effectively. At the same time they do not want to hear the truth if it is too painful (Drew, Logan and Hard man, 1986). Fore instance, parents and professionals should work together to increase the level of parent participation in the Individualized Education Program (IEP) team. Parents should share the rights and responsibilities of decision-making in regard to their child's educational program. Seligman and Darling (1989) explained that like parents of children with other disorders, these parents need to serve as effective members of the IEP or Individual Family Service Plan (IFSP) team, helping to ensure that appropriate educational

1.1.3.5 Parent Training

Parents must be trained in behavioral techniques and encouraged to provide additional hours of instruction to the child. Parent training is important to help the family incorporate these techniques into the daily routines of the child and family and to ensure consistency in the intervention approach. It is recommended that training of parents in behavioral methods for in terracing with their child be extensive and ongoing and include regular consolation with qualified professionals.

It is important for schools to recognize that parents need both initial training and ongoing support for trouble shooting if they are to sustain their effort at home teaching (Harris, 1995). Simply providing a basic training course in teaching principles is often insufficient to ensure the long-term ability of many parents to solve new problems as they arise.

1.2. Statement of the Problem

The involvement of parents in implementing intervention strategies designed to help their autistic children has long been accepted as helpful and crucial. Guralinick and Bennet (1987) as cited in Mitchell and Brown (1991) suggested that parents have a key role in early intervention for their infants with special needs. There are several reasons for this;

First, without active involvement of parents the developmental progress made by children will typically be reduced. Second, unless the intervention has some impact on parents themselves, it is unlikely that the gains, which the children make, will be maintained in a long term. Finally, since the improvement of family functioning as a whole is a goal of early intervention, the needs of parents for support and guidance must be a major consideration.

The potential benefits of early intervention are increased skills and reduced stress for parents as well as children. Parents are then faced with a critical and life determining question; what should I do to help my child? The decision on which treatments to implement (and not to implement) will likely determine the child's prognosis. Therefore, the central aim of this study was to ascertain parental role in the early intervention program emerged from the following interrelated leading questions. These are:

1. In what ways are parents of autistic children involved in the early intervention programmes?
2. What kind of support parents need to effectively participate in the early intervention programmes?
3. To what extent does parental involvement contribute to the effectiveness of the early intervention program?

1.3 Objective of the Study

As to the knowledge of the researcher, in Ethiopia the role of parents of autistic children is not studied for with primary intention of addressing the problems parents and their autistic children face and finding solutions for a better psychosocial, cognitive and biological adjustment of autistic child. Therefore, the general objective of this study is to examine the level of parental enrolment in the early intervention program designed and implemented to help their autistic children. The study also has a major objective of assessing the over all contribution of the parents in the implementation of the intervention programme that is mainly hopes to better the life condition of their autistic child.

Specific Objective

1 To realize in what ways parents of autistic children are involved in the early intervention program

2 To identify the kind of support parents need to effectively participate in the early intervention programmes.

3 To know to what extent parental involvement contribute to the effectiveness of the early intervention program.

1.4 Significance of the Study

The life of children with autism cannot be improved to its maximum only by the efforts of therapists. The interaction of parents with their autistic children as well as the involvement and interaction of parents with concerned professionals are of paramount importance in intervening the maximum educating and therapeutic efficacy. Studying the role of parents with regard to early intervention program is important for strengthening the involvement of parents in planning and implementing educational programs for their children and to create awareness and empower the parents and ultimately the community as a whole. Besides, the study is expected to provide relevant information on the effectiveness of parental involvement in the early intervention of autistic children to teachers, community workers special educators and other professionals and therapists who work with children with autism. Further, it is expected to give insight to autism center (J-CCARDD) so that it can employ various means and options to encourage parents and professionals to come together to work more on problems of children with developmental delays in general and autism in particular. . Finally, the study serves as a stepping-stone for further studies on the area.

1.5 Operational Definition of Terms

1. **Parental role:** - it refers their actions or behavior with regard to the whole process of treatment of their autistic children.
2. **Parent:** - it stands for both father and mother or a person who has parental responsibility for the care and up-brining of a child with autism
3. **Early intervention:** - is the interception of unproductive or undesired behavior or condition as and changing or directing them in ways that are more advantageous (Siegel,2003).
4. **Autistic disorder:** - is an absorption in self or fantasy as a means of avoiding communication and escaping objective reality. In this pervasive developmental disorder, the child's word is one of profound aloneness (Davison and Neale, 1990).

1.6 Delimitation

The study used samples from only one organization (Joy Center for Children with Autism and Related Developmental Disorder) working at Addis Ababa. The study has been conducted mainly using six parents of autistic children. Parents were only used as source of information about parental involvement and excluded the members of the interdisciplinary team in the early intervention program as source of data.

CHAPTER TWO

2. Methodology

2.1 Research Design

The present study aims at examining the role of parents in the early intervention program for their children with autism. The research methodology has been carefully designed to elicit detailed and intensive reliable knowledge about the role of a small number of subjects (6 parents of children with autism) in the early intervention programme for their autistic children.

To meet the aim of the study, an indepth qualitative approach has been used so that reliable and detailed data could be collected. Gall et al. (1989) stated that one of the main characteristics of a qualitative research is its focus on the intensive study of specific instances that is cases of a phenomenon. So this seemed to be compatible to the present study as the intention of this study was to do an in-depth investigation on a limited number of parents.

The aim of this chapter is to present the research design, and tools of the study, the procedure used to collect the data, steps undertaken for the organization and analysis of the data.

2.2 Study Area

Joy Center for Children with Autism and Related Developmental Disorder (J-CCARDD) is a pioneer in Ethiopia in providing services to children with autism and autistic tendencies. In a rented house located at Addis Ababa, joy center was established in May, 2002, by a mother of an autistic child. Currently the center has 44 autistic children. In which 38 children receive school-based intervention, the rest (6) are receiving home-based intervention and 75 children are in the waiting list. Currently 60 parents of autistic children are working in the early intervention programmes. Among 60 parents the researcher decided to select 6 parents for this study. It has been decided to conduct the study at Addis Ababa because as it is the only place where a center for autistic children is in existence. Therefore, J-CCARDD had been selected as the study area along with the home of the participants as well.

2.3 Population and Sampling

The target population of this study was parents of autistic children. Therefore, the sources of data for this study were children with autism and their parents. However, the parents of children with autism would be the major informants of the study. The researcher reached to an agreement with the center (J-CCARDD) to get the details of those parents and their autistic children. Therefore, J-CCARDD was used as a means of identifying these children and their parents. As a result, from the total population of 60 parents, the researcher selected 6 parents believing that they can provide valuable information needed for the study. The subjects were identified by the researcher's own judgment by considering the criteria of being biological parents of the child or the main care givers of the child. Their willingness and availability too were taken in to account. Therefore, the method used to select the subjects can be described as purposive way of selecting samples. The children of these parents are now being served in the center and the parents are currently involving in the early intervention programmes that are being implemented by the center.

2.4. Tools of Data Collection.

2.4.1. Interview guide

The researcher developed the interview guide after reviewing relevant literature regarding parental involvement in the intervention for children with disabilities in general and autism in particular. The interview guide was prepared in Amharic. It has 68 open-ended items. And has four sections. The first and the second part contain items on the background information about the parent and the child respectively. The third part includes areas of parental involvement. Items related to parental support (parents' need) to participate in the early intervention programme were included in the fourth part. Finally, items on the extent of parental contributions for the effectiveness of early intervention programme were included-in the fifth part.

The items in the interview guide were aimed to answer in what ways parents of autistic children involve in the intervention programs and to answer what contribution do they have for the effectiveness of the early intervention programs. And what do parents need to effectively involve in the early intervention programme. Efforts were made to make the questions easy and understandable for the interviewees in order to promote positive interaction between the interviewer and the interviewees.

The draft items were given to an expert working in J-CCARDD. This expert made some thematic correction and then an appropriate modification was made on the instrument.

This Amharic preliminary version was given to an Amharic language expert for correction and clearness of the items .The expert then made all the necessary thematic and grammatical inspections and corrections. On incorporating all the modification, the final version of the interview guide was printed for final data collection. Then the Amharic version was translated into English by the researcher and was given to the academic advisor for further scrutiny and improvement. Then the necessary modification was made. And finally this final copy of the interview was prepared for a pilot study.

2.4.2 Observation Guide

As interview, observation guide was also developed by the researcher after reviewing related literature. Twelve items guiding the observation were included in this instrument .The interaction and communication between the parents and their autistic children, parents commitment and efforts to make the programme practical, fruitful and their other related activities could be observed using the guide. Besides the extent of parents and the center interaction in general and parents-professional partnership in particular could also be observed using the tool. So, ultimately the tools help the researcher to observe what the parents do to the best of their autistic children.

2.4.3 Focus Group Discussion Guide

To conduct focus group discussion with parents of autistic children, a focus group discussion guide was developed. To make the discussion more interesting and resourceful, eight guiding questions were prepared. Each of the items represents the main idea of the research questions. All the items in the F.G.D. guide were designed in the form of open-ended questions.

2.5 Procedures of Data Collection

Prior to designing the instruments, theoretical and imperical literature was reviewed. Instruments for data gathering were used to assess parent's role in improving the condition of their autistic children. Before, the main study, the tools of data collection were pre tested with pilot study. After the results of the pilot data, items were modified, corrected, rejected and rearranged. The researcher developed all the instruments. An attempt was made to produce items that are able to figure out the study in the area. The researcher used four ways of data collecting instruments. These are interview, observation, and focus group discussion and document analysis.

2.5.1 Interview

In this study semi structured interview was used as the main method of gathering information. The researcher used interview because it helps the researcher to make an in-depth investigation of the problem.

Advantage of interviewing is that the interviewer can explain more explicitly the investigation's purpose and just what information the researcher wants. Besides, it is believed to illicit or generates more information in desirable depth. It also allows for drawing data more exhaustively than perhaps other techniques can do. For example, Gall, et al. (1989) indicated that interview is often superior to other data gathering devices. One reason is that people are usually more willing to talk than to write. After the interviewer gains rapport as establishes a friendly secure relationship with the participant certain types of confidential information may be obtained than an individuals might be reluctant to put in writing.

Also Robson (1997) added that interviews carried out for research of enquiry purposes are a very commonly used approach, possibly in part because the interview appears to be a quite straightforward and non-problematic way of finding things out. Therefore, based on the above arguments semi-structured questions help to elicit more specific answers on the part of parents. Hence, it is found to be important instrument for gathering information about the problem of the study.

2.5.2 Observation

There are kinds of research question, which can best be answered by observing how people act or how the parent child relationships look like. This method of study is well supported by Selltize et al (1976) since observation helps one to describe how people behave by watching and recording what they do and say. Robsen (1997) also said that a natural and obvious technique is to watch what they do, to record this in some way and then to describe, analyze and interpret that we have observed. Moreover, observation was useful to fortify the information gathered through the interviews and in a way to compare what the parents told the researcher during these interviews and what they actually are doing at home in relation to their children. Therefore, observation found to be appropriate supplementary tool for the study of the problem because it is possible to examine the parents' role in the early intervention programme.

2.5.3. Focus Group Discussion

The focus group discussion is highly substantial and supplements the information gathered through interview, observation and document analysis. It was designed to collect information in connection to the general experience of intervention parents have had in relation to their autistic children. It was helpful to examine their common understanding about their involvement in the early intervention programmes. Besides; it gives a higher quality of information and more efficient use of time

2.5.4 Document Analysis

Information regarding the early intervention programmes specific to parental involvement to the program was gathered from various documents that are available in the center. For instance, documents of the center (J-CCARDD) was studied and analyzed to get relevant information about the research questions. Information collected using this method was recorded on a logbook.

With regard to the data collection process all the interview and focus group discussion items were translated and prepared in Amharic so that the researcher and the informants can communicate easily. Visiting the interviewees several times before the actual interviews help me and the informants to be come acquainted. In addition to this, during these visits, appointments for dates and times to interviews were made by the choices of the parents themselves. Each parent was interviewed separately and in private. The average interview time was one hour and thirty minutes. This was done for a minimum of six days based on the availability of the mother. It was challenging to make parents willing for interview.

During interviewing parents in their homes, informal observation was done observing the interaction between the parents and their children while the interview is going on. Moreover, observation is useful to compare what the parents tell the researcher during these interviews and what they actually are doing at home in relation to their children. During observation, the obtained data was kept in the logbook.

During FGDs, notes will be taken by the researcher. The FGD was held with parents of autistic children chaired by the researcher in which the participants took great interest to forward their opinions and views.

Here two major tasks were performed-the pilot study and main study. The researcher first contacted the office of Joy Center to get a permission to conduct the study. And with the help of a person from the office, the researcher introduced himself to the parent of autistic children. Then observation and visiting the homes of the children was made accompanied by one of the staff members.

After visiting the homes of identified parents, the pilot study was conducted using two randomly selected parents of children with autism to the relevance of the instrument. After going through the pilot study, the following adjustments were made:

-The more general questions used in the pilot study seemed to be difficult for parents to understand and the researcher have learnt to ask them in a very concrete way. Therefore, I decided to modify and simplify the interview guide.

_It was also necessary to modify some words in the interview guide according to the culture and religious background of the informants.

On the basis of all the above information and after considering these necessary adjustments in the instruments, the main study was conducted.

In the main study, data collection process was accomplished by the researcher in collaboration with one assistance. The assistance was given orientation how to proceed with the study. Besides, all participants were also informed about the objective and purpose of the study. And was asked for their willingness to be interviewed and to participate and giving information in the focus group discussion program.

2.6 Methods of Data Analysis

Through the designed instruments the data was gathered and analyzed and interpreted in line with the research question raised by this specific study. The data was analyzed qualitatively. It was carried out for the purpose of meeting the objectives of the study adequately. The findings concerning each case were independently presented in a description form then general discussion was made and finally, conclusion and recommendations were made based on the discussion.

CHAPTER THREE

3. Results and Discussion of the Findings

3.1 Results of the Finding

The purpose of this study was to identify and describe the role of parents of autistic children in the early intervention programmes (EIP). As indicated chapter two, the researcher has collected information from six mothers of autistic children. These mothers were selected with the collaboration of J-CCARDD .

This chapter encompasses the results and discussion of the case reports of the participants of the study .To make the report readers comfortable presentation and general discussion of the results were written separately. To respond the major research questions, a qualitative research design was applied. The findings of the study were presented and analyzed in relation to some major categories (for more detailed information of the data that was obtained through interview, observation, focus group discussion, and document analysis).

The interview presentation was made using first person pronoun with the intention of bringing the cases alive to the reader. To describe the research study clearly the report of the participants was presented under five main categories. These are:

_ Background information about the parents.

_ Background information about the children.

_ Areas of parental participation in the EIP

_ Needs of parents to participate in the EIP

_ Extent of parents' contribution in the EIP

3.1.1 Background Information about the Parents

For the purpose of conducting an in-depth qualitative study on their participation in the early intervention programmes, six parents of children with autism were identified and participated in this study. The following table is organized to give a general overview of the background information about the parents.

Table 1: Back ground Information about the parents

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6
Relation with the child	Mother	Mother	Mother	Mother	Mother	Mother
Age	43	35	30	40	42	27
Education	High school completed	High school completed	3rd grade	Illiterate	10th grade	High school completed
Occupation	House wife	Housewife	Housewife	petty trader	Housewife	Housewife
Religion	Orthodox	Orthodox	Muslim	Muslim	Orthodox	Orthodox
Marital Status	Widow	Married	Married	Widow	Married	Married
Language	Amharic	Amharic	Amharic	Amharic	Amharic	Amharic
No. of children in the family	2	2	2	3	4	2

All the participants were mothers of autistic children. As far as the age is concerned, it ranged from 27-43. With regard to education, three mothers have completed high school. One mother has studied up to grade 3, and the other one is grade 10. And case 4 is illiterate. Regarding occupation, five mothers are housewives and the remaining one is a petty trader. This helps to conclude that all the subjects can be categorized as a mother belonging to low-income classes. Religions affiliation shows that four mothers are Orthodox and two mothers are Muslim. Among the six mothers, four mothers are married, the remaining two were widowed. The family size or number of children ranges from two to four. Five parents have only one child with autism and they were not having any other children with any other disability. But, case five has two children with mental retardation in addition to her autistic child.

3.1.2 Mother one: R.T

About the child

My son is a twelve year old who is the second and the last child for his mother. He has a sister who is a diploma graduate. My child was diagnosed as autistic at the age of four by a physician. Before that I exerted the maximum effort to cure my child by taking him to holy water. Because, most of the symptoms he has shown were like that of insane individual. Therefore, most of the neighbors and significant others used to consider him insane and used to advise me to take him to traditional healers. But, the efforts had not helped the child at all. Finally, I took the child to health center where he had been diagnosed. After several years, later he joined Joy Center for Children with Autism and Related Developmental Disorder (J-CCARDD).

Before he joined J-CCARDD he used to avoid eye contact, he has vague expressive language, suddenly kicks or bites his sister, cries obstinately on happy occasions and screams when desires are unmet, smiles or laughs without reason and makes peculiar sounds like "an evil possessed person." Especially his fascination for pouring water from one container to another for several hours had made him unique. Still the child is showing many of the above mentioned behavioral problems.

Most of the time my child does not understand what people tell him. He repeats the words of others like a parrot. Now he learned to say some common words.

Regarding self-care, which he cannot dress or go to the bathroom completely unassisted. Therefore, he would always be vulnerable and need protection; he is going to live a full life span as a severely handicapped person. When I think of this I fear for his future. He is always the center of attention in his family. I already accepted the fact that the child and his problems could fill a battleship of parent duty and obligation. I have a strong believe that the child would improve in many ways as long as he keeps attending the training.

Areas of involvement in the EIP

With regard to autism I do not have clear understanding. But I know its symptoms specifically my child's. Before the establishment of the center, I never had awareness about autism. Rather I was thinking that it would be a mental illness. When my child was diagnosed at the age of four, it was really heart breaking. I just felt terrible hopelessness and frustration. Finally I accepted my child with his disability and tried to find a solution. Then I created a link with the center and started participating in many areas in the early intervention programs. For instance, I contact the center in the morning coffee ceremony and exchange information regarding the improvement of the child; I document every progress my child shows and keeps detailed records of the results and discuss with the center in the area. And I encourage my child to do some activities at his level and reward him when he performs well. Besides, I give him care and attention as long as I have plenty of time to train and teach my child at home.

As far as training is concerned I did not receive any training on autism and its intervention. But informally the center tells all of us how to handle the problem of our children in relation to nutrition, medication and education. But on my part, I could not address the entire needs of the child due to the death of my husband. Currently I have no job. I am highly anxious about the future fate of my child. After the death of my husband, the responsibility for the child fell solely upon me. The problem costs me a lot. The cost is staggering well out of the reach of me and of most parents with autistic children.

The other problem is that, it is difficult even impossible to get the therapists, because most of them are part timers. When they come they have only a brief stay in the center. Therefore, I could not communicate with them.

Almost all the intervention programmes need parental involvement. The center also believes that without parental involvement it is just like clapping with one hand. That is why the center invites us whenever there is a program to implement.

Regarding my visit, I sometimes visit my child while he is in treatment and I assist caregivers. The other thing is the most of the neighbors and communities are still unaware of about the problem and when I tell them about autism, most of them could not understand and accept me. They are resistant to accept. I am trying to tell them when the neighbors come to visit my home for tea and coffee ceremony and also in other places as well. Besides, I participate in the awareness raising programme when it is launched by the center (J-CCARDD)

Besides awareness giving, I am making an effort to strengthen the early intervention program by attending meeting, giving comments and suggestion on issues regarding the improvement of the life condition of the child.

All the parents of autistic children have the duty to meet at morning coffee on Sunday so that they can have the opportunity to share information about their common challenges. All parents of autistic children should strengthen their linkage with the center and within themselves so that they can have the power to be heard by governmental and non-governmental organizations. And every parents of autistic children should come and forward and give their children education and treatment.

Needs to participate in EIP

Joy Center for Children with Autism and Related Developmental Disorder (J-CCARDD) is willing to incorporate parents in the program. However, there are things that should be fulfilled such as, the availability of therapists and the empowerment of parents of autistic children. For example, I do not have communication with professionals at all. Because they are not available, but the center promised me that relevant professionals would visit my home soon, but not yet.

The center facilitates programs so as to encourage the parents to discuss and give novel ideas and solution to the problem. It also facilitates conditions where in parents come and assist the treatment process while their children are in treatment. However, many parents due to time and financial problems do not exert their optimum effort to involve in the intervention program. On my part even though I am willing to involve in the program, I have a lot of problem in relation to economy. My focus of attention is not only my son. There are also other problems that I am facing. Now I am living in a small rented house with my children and I pay 100 birr monthly for the center excluding transportation fee for my child. It is the smallest amount of money given to the center because the center already understood my problem. There are parents who can play more than 800 birr per month.

As far as information is concerned, I regularly exchange information with workers through communication logbook. The center regularly records the condition of the child and I record the situation too. And we discuss together about it.

In fact I did not receive any training, but we are informally given about the overview of the treatment process. In addition to this I have never received supportive counseling. Our only method of expressing our feelings and needs is just to talk with caregivers and with other parents with the same problem.

Question regarding parents constraints, there are different obstacles that hamper the intervention process. Fore example, financial problem, very limited knowledge about the intervention mechanism; poor relationship between parent and professionals, etc have negative impact to effectively participate in the EIP. I encountered all those problems. It is very difficult to have such a child with not having money. Therefore, I need help form any organizations that are working on children.

Extent of contribution in the EIP

I think and hope that the life condition of my child could be improved if an intensive care and support is available. I am very sure that the child's life could be improved if I actively involve in the intervention program. That is why; the child is getting improved due to my continues effort in collaboration with the center. Currently he is manifesting progress in language he can say a few words, and understands people.

Parents especially mothers can contribute in providing latest information so that it allows therapists to be current with the total picture of he child, making financial support, and attend meeting and conferences. Hence, a lot is expected on the part of parents than therapists. In fact, I do not believe that my involvement is effective and efficient. I do have a lot of problem that impedes my contribution. Still I have a great impact on the life of my child more than anybody else; I feel that I am already absorbed too much of this burden. I think every parent of autistic children are keen to treat their children in a positive way if they have knowledge about the scientific procedure of intervening autistic children. Therefore, parents should be empowered through training and current information about their children's weakness and strength, so that they can involve in a right way. What I want to say is we lack knowledge. We need support in training and since we are poor we need money to improve the situation of our children's life.

3.1.3 Mother two: M.K

About the child

My child is a five-year-old boy, who is the first child for me and has one younger sister. When he was around seven months, he was infected with meningitis. Right after that time, his behavior was totally changed. It was an abrupt phenomenon. All the family was highly disturbed, because he was totally strange. He does not talk rather screams with peculiar sounds, over reacts to environmental changes, he does not want to dress himself, he likes to run back and forth, does not sleep regularly. Finally J-CCARDD recognized that the child was suffering from a devastating developmental disorder: autism.

My son has no improvement so far regarding education and communication. He does not discriminate alphabets and has no writing skill and verbal language. He does not want to involve in home activity, so nobody orders him. He usually likes to play alone. He is extremely stubborn and will not give away his material unless he is asked politely. He usually likes to spend his time lonely and sometimes with me. Because I am the only closest person to him. Because of his odd behavior, he rarely plays with his age mates.

I have a great fear that he might injure himself when I was not around. Therefore, he needs close supervision. The child does not show significant improvement as it is expected in three years intensive training. Besides, I hope that the problem would be alleviated and positive outcome could be achieved if J-CCARDD and the parents work together for the benefit of the child.

Areas of involvement in the EIP

As far as autism is concerned I know a bit about the symptoms of autism. But it is very difficult to identify the causes. I think it is due to the meningitis attack that autism occurred to my child. Before his illness, he used to play and socialize properly. Most parents even professionals do not have a clear idea about the causes.

I am currently participating in various programs that are being rendered by Joy center for Autistic children. I, for instance, provide valuable information regarding the child's weakness and strength and all other relevant details too; I am implementing all the treatment procedures at home and attend conference at least monthly. As therapists are not available, I did not receive any training in the area. The only full time available workers are caregivers and the psychologist who are employees of the center.

The treatment I implement is nearly similar to behavior intervention: such as training self care, social skill, and adaptive skills through play and music and giving reward or reinforcement after the child performs well. In addition to this all the parents have to meet at morning coffee and discuss and share their common problems and how do they go about it. For example, different issues are raised such as nutrition, medication and recreational facilities for the child. Besides, I daily contact the workers so that I can get access to updated information about my child.

All the programs in the center necessarily need parental involvement. Nevertheless, there is no relationship between parents and professionals because almost all professionals are running for their business. These children are forgotten. And also parents sometimes forget the condition of their children. That is really irritating. Parental involvement is crucial factor for the effectiveness of the treatment. Because children spend most of their time at home than at the center

Regarding awareness raising activity, I tell my friends and neighbors about autism. As I understand almost all of them consider that as a punishment by God "Likift". In addition to this, the center launches awareness raising program. I participate in this program too.

In general what I want to add is that I do not know in-depth about the scientific procedures of the intervention mechanism. So I need formal training about the treatment by well-trained professionals.

The center argues that using reinforcement technique is the best way of treating these children. The center advises us to use this method. In relation to profile monitoring, the best way to check the day to day progress of my child is evaluating his profile. There is a problem on both sides of writing the day-to-day condition of the child.

Needs to Involve in the EIP

J-CCARDD is facilitating the environment so that parents and other concerned bodies can contribute a lot. The center needs support in many ways. Such as financial, professional and community support. The center lacks professionals. There is only one psychologist working as behavior therapist. But the others are trained caregivers. As I said before, I do not have any connection with professionals. There is no exchange of information with them except the psychologist. No professionals or caregivers visited my home so far; out reach service is not yet implemented.

In relation to training, I think the center is at its infancy stage, it does not have the capacity to train all parents of autistic children, because empowering parents require professionals. So I did not receive training related to the treatment.

The center designs group parent program so that we all the parents of autistic children especially mothers can share and discuss openly about our common challenges.

The other thing I want to raise is that I have never been helped by any organization. I pay monthly for the service for the treatment he gets from the center, even though I am a homemaker. The only source of income in my family is my husband.

The main constraints that adversely affect my contribution in the intervention program are lack of money to meet my child's needs and also lack of knowledge- what treatment he needs and how to treat him.

Extent of contribution in the EIP

As long as my child is 4 1/2 years old, I have great hope that he can get improved in all areas if all the treatments and facilities are available to the child. Now my child is showing improvement in communication and socialization.

As to me to improve the life condition of these autistic children, network should be formed between parents and various relevant professionals. I believe that more than any body I can play a pivotal role on the life of my child. Of course, my extent of involvement is entirely contingent on my income and level of education. And certainly the child began to manifest improvement as the result of my participation. Any time the only available person for the child is me.

3.1.4 Mother Three: W.T

About the child

My son is a twelve-year-old boy. He is the second and the last child for me with one older brother. I had already guessed that the child has got a problem, but I have no thought that it would be autism, because I had never heard about it before. The child was diagnosed autistic at three months of age when it developed to epileptic seizure. It was very difficult to me to understand what autism means. It took me a long time to grasp the concept. Physician told me that he could not be cured, but I can make a difference if I treat him properly.

I used to take him to holy water and other traditional healing places for a possible cure. Currently the child is taking medicine to his epileptic seizure. Besides, the child is getting better access for treatment in the center.

Regarding the child's education, I felt hopelessness and frustration, because no improvement is seen so far on his basic academic skills. He cannot read and write no arithmetic either.

I always encourage him to do some activities at home, but he does not want to follow instruction, he does only if he is interested. The child is still non-verbal, but at times he understands what he is told and body language too. Other times he behaves as if nobody were around him.

If I tried any thing that might help, the child does not stop manifesting undesirable behavior. He beats and scratches anybody who is around him, rocking back and forth, less responsive to playful interaction with others, likes to ride on my back, screams and cries agitatively.

When my son is home, he spends most of his time with me. And he plays home alone; does not want to play with children without disabilities and they do not want to play with him too. He has one brother and helps in taking care of himself.

Areas of Involvement in the EIP

With regard to autism, I was informed of the general overview of autism. Now I can even teach those who do not have any concept about it. But I do not know exactly why my child becomes this way. Before the establishment of J-CCARDD, I used to take him to traditional healers. As a mater of fact the child did not get any improvement. Then I finally turned to medical doctors. Then, I have got the direction where to go. Currently the child is receiving treatment in the center.

I somehow know how to handle the problem of my child when he is home. I train him about self-care, adaptive skills and speech training by using behavioral intervention. I·am trying to put into practice what the center advises me. It is me who daily take the child to the center and bring him back to home. Along the way I can exchange information with workers. Moreover, parents have a program called morning ceremony.

It is quite clear that parental involvement is critical for the improvement of their children's life. However, on my part I am not effectively participating in the program. I wish I could use my optimum potential. However, due to economical and other reasons, I could not totally participate in the program. Of course, most parents have the trend to diffuse responsibility to the center. This kind of action adversely affects the effectiveness of the intervention program.

Now a days, the best way of intervening autistic children is applying behavioral technique. I assess my child's needs and check the day-to-day improvement of the child. In relation to this, discuss personally with parents of autistic children and also in-groups when there is a meeting.

Now days, the best way of intervening autistic children is applying behavioral technique. I assess my child's needs and check the day-to-day improvement of the child. In relation to this, I have the trend to discuss personally with parents of autistic children and also in-groups when there is a meeting.

More than anybody parents of autistic children are expected to involve in the early intervention programs. They should organize together and give awareness and advocacy program so that other parents of autistic children can send their children to school, and get access to medication and other related services.

Needs to Involve in the EIP

I can say J-CCARDD is now providing conducive environment for those who want to actively participate in the intervention program. The door is open for all parents, but due to various reasons, most parents' involvement is restricted.

I regularly contact with the psychologist and other caregivers, but I have never seen other therapist such as physiotherapist, neurologist, speech therapist, etc. Therefore, I only get updated information from the psychologist. Besides, no therapist ever visited my home.

There is time when parents of autistic children come together and discuss about their problem through group parent program. This meeting is held with parents and caregivers not with relevant therapists. In this meeting different issues are raised regarding how to handle their children's problem and exchange experience.

With regard to financial support, I have never got any financial aid from any body. Things that surprised me is that attention is not given to invisible disabilities in general and autism in particular. Even, the center (J-CCARDD) needs professional and financial aid but not yet supported. It is the parents of autistic children who provide finances to run up the program. Therefore, it is very difficult to fulfill the needs of these children.

Regarding my involvement, the center gives me positive comments so that I could come and contact regularly when I am in need of help.

To add more we parents are facing various factors that inhibit us to fight this pervasive developmental problem. Such as lack of money (finance), the negative attitude of the community, lack of attention from governmental and non-governmental organizations, etc made us slow to participate in the early intervention program.

Extent of contribution in the EIP

Regarding the situation of my child, I hope that he can get improved if intensive training is available (accessible), but I felt sorry about his education, because no improvement is seen so far. But I believe that to make the dream realistic, my involvement is critical. Without my family and me nothing can be done. So my involvement in the program certainly has paramount importance for the overall progress of my child. Besides parental participation, siblings can play a pivotal role. I have two children and the older one is in 8th grade. He assists the child when he is in need of help.

Within my family, I am the main caretaker of my child. I do not know what to say about my level of participation. But I believe that I am trying my level best. My child is showing me a sign that one day all his problem would be alleviated. In addition to this as far as I know all parents of autistic children feel responsible to the problem of their children. They are participating in the program. But the extent of their participation may vary according to their economic and educational level.

3.1.5 Mother four: A.F

About the child

My daughter is a ten-year-old girl, who is the third child for me with two siblings. I used to take her to different health institutions for procuring remedies. But all the efforts did not make a change. Finally the child was diagnosed as, autistic at the age of four. I am now financially drained off due to the expenses for the child's care. Now I have lost everything I had and became a petty trader.

With regard to education, I just stopped thinking about my child's academic situation because no improvement is seen so far. Rather, the mother is concerned about the child's bizarre behavior. E.g., spoiling her cloths ignores all family members and cries all the time, resistance to change, beat anybody who is on her way. This usually creates conflicts between persons and me who complain to be harassed.

Until the child completed seven, His siblings and I had faced great challenges in handling the problem, but after the establishment of J-CCARDD, the child started to spend most of her time in the center with other autistic children and trained care givers.

The child does not involve in the home activities, she indulges herself with routine activity and spends most of her time with me. If I leaves home; I will lock the door and leaves the child inside. Because the child may cause some damage if left out side without an attendant.

Areas of participation in the EIP

As far as autism is concerned, I poorly understand the problem; I cannot read and write, I can only hear what the center told me. And I believe that the problem occurred due to "evil eye". Right after I gave birth, an old strange woman asked me, "how did you bear such a giant baby?" Then the child began to cry day and night and became deviant in many ways. Therefore, due to that strange woman, my child became in this way.

I am not fully involved in the early intervention programme, because I have to work to get money so as to fulfill my child's needs, I am the breadwinner of the family, and my husband died six years before. Any way I am trying my level best to implement at home what I am told and advised. I do not believe that I have sufficient idea/knowledge related to the treatment. What I am doing is giving love and attention, encouraging the child when she performs well. Besides I attend meeting when I am invited and receive and give information.

With regard to my contact with the center I go to the center at least once a week and contact the available therapist (psychologist) and discuss about the overall development of my child. Besides, it helps me how to apply some treatment techniques.

All the early intervention programs need parental contribution, but most parents' contribution is limited due to lack of awareness and economical problem.

Currently there are many people including neighbors and friends who are confused about my child's problem and ask me what the problem is. And I inform them what I know.

As far as my effort to strengthen the program is concerned, I previously said that on my part my contribution is at the level of receiving and giving information. All other programs are beyond my capacity. The other thing I want to add is I do not know which technique is best for my child I just follow my (unscientific) method of treatment.

Needs of Involvement in the EIP

As to me, the center (J-CCARDD) has already facilitated conducive atmosphere for those who want to involve in various areas. This conducive environment encourages parents to support the center financially and professionally, encourage parents to receive and give relevant information daily and encourage attending meeting. However, I cannot fully exhort my effort due to various factors. I did not mean that I do not have interest to involve. One of the problems the center faces is lack of relevant professionals who are dealing with children with autism. This implies that parents cannot maintain regular contact with professionals. As a result parents could not be kept informed about their children's progress and could not be given suggestion as to what level they can do to help. No professional and workers in the center visited my home. Rather, I am invited by the center to attend meeting.

With regard to training, I received no training and counseling in relation to early intervention procedures. Besides, I do not get any financial help for my child's medication, nutrition and education.

I believe that I am not playing a pivotal role to strengthen the program as it is expected on the part of parents. The main constraint I encounter is shortage of money; I could not buy necessary things for my child. All the problem of my child is beyond my control. Therefore, I need help.

Extent of Participation in the EIP

As far as my child's situation, I believe that one day God (Alah) will cure her. In fact no improvement is seen regarding academic skill. And little improvement is shown in communication and socialization skill in three years effort. Even if my participation is too limited, I am still important for my child more than any body else.

I believe that, family members (siblings) have a great role next to parent in supporting exceptional children. My other children do not have any contact with the center and do not receive any advice about the treatment. But they can understand and help the child when she is home by helping to take care of herself and playing with her.

As I previously said my relationship with the center is not matured. I am the member of the center like any other parent but did nothing to strengthen the center when I compare myself with other parents of autistic children. There are many parent's who contribute a lot. Some of them contribute more than 800 birr per month besides their other aids. Hence a lot of contribution is expected on my part.

When caregivers are not available the whole responsibility of dealing with the problem of my child falls on me. The child needs intensive and daily supervision. I cannot leave the child alone because she might be lost, damage herself, or screams.

Currently the center actively runs its program for ten months. At summer time the child is allowed to take a break for a couple of months. And the child stays all day with me. It really hard (challenging) for me when she is home.

3.1.6 Mother Five: F.H

About the Child

My son is an eight-year-old boy, who is the fourth and the last child for us. I have got two children with mental retardation in addition to my autistic child.

The child was not seen by specialists until he has passed his sixth (6th) birth day. We used to consider all his problems as the problems of any other "normal" children. However, he showed symptoms, such as misusing pronouns (utter unclear continues voice), screams when desires are unmet, smiles or laughs without reason, extremely restless, and difficulties in attentioning. But the problem was recognized when the child entered elementary school where he was restless and used to disturb the class.

After the child was diagnosed as autistic, I used to take him to different healing places in search of remedies. Finally I was told by J-CCARDD that the child couldn't be cured like those of her mentally retarded children. But he can show progress with day in and day out supervision and training.

Then the center admitted him for treatment. With regard to his education, now the child is eight years old but could not join any formal school. Two of my mentally retarded children are not attending school too. They just spend their time at Mekanisa Center for Mentally Retarded Children.

The only thing the child differ from his brothers is that he is very active and he can do whatever he wants like washing dishes, feeding himself, identify objects and brings them when ordered. But at times he looks ignorant. The child has no friends without disabilities; children in the neighborhood reject him. Because, the child cannot speak and play as they like. They consider him as a special creature. Currently the child plays with other autistic children and when he is home he prefers to be with his siblings.

The child needs intensive support besides what I am doing. I alone cannot address all his needs. Hence, to fight this problem parent-professionals partnership should be strengthened.

Areas of Participation in the EIP

Regarding the nature of autism, I am kept informed of the nature of autism. So, I know a bit about it. I think the cause of my children's problem is my taking of dozens of pills during my pregnancy for asthma.

Currently I am involving in two institutions in J-CCARDD and Mekanisa Center. Both institutions have their own intervention programs. So I allocate time to address my contribution, I have an experience how to handle the problem, because I spent many years of handling the problem of my mentally retarded children. I have been informed for many years how to manage the situation.

Among my contribution, I deliver up dated information to the center; I try to perform what I am informed. I follow their advice, I believe that my goal is to find the best care for my child and I strive to keep the relationship with the center. In addition to this, my first child comes over and helps me in treating these children. Also I buy playing material and supplies I prepare and provide those materials to my children.

I daily contacts with the center because it is me who take the child to the center and bring him back home. So along the line I exchange information with workers. However, except the psychologist, I have never contacted with other therapists. As the result, the information that I get from the center is limited.

Currently the best intervention mechanism is to apply reinforcement techniques because through this method the child and even the other two children have shown improvement.

When the child's problem is beyond my control, I seek help from the only available psychologist. In addition to this I contact other parents with autistic children at least once a week and at coffee morning program to get much constructive and practical assistance.

Finally what I want to suggest is parents of autistic children should create a link with professionals so that they can address their children's needs. And provide care and support to their children by accepting their children with their disability and treat them like that of their other children without disability.

Needs to Involve in the EIP

With regard to facilities, Joy Center should facilitate conditions. Such as: parents should get access to contact with relevant professionals with any question or concern they may have. All parents should be kept informed their children's progress and to be given suggestions as to what they can do to help. And also the center should facilitate medical services to the child through its professionals, Besides the center should facilitate interaction between parents parent between the center and professionals. This result, failerity to create communication with professionals at all. Now I could not receive and send information to professionals who are working toward promoting the quality of life for autistic children. Besides no professionals so far visited my home, because they are not available and I do not know how and where to communicate.

As far as I know J-CCCARDD is headed by one psychologist all mothers of autistic children have meeting once a month to share and discuss their common interests and they receive advise about the treatment. But I have never received training and counseling which can be provided as part of the intervention program. Furthermore, I do not get any financial or material aid from any body. I believe that if I get sufficient income, I would make the child improve much more by meeting the child's needs.

Extent of contribution in the EIP

As far as the life condition of my child is concerned, some of his behaviors are manageable. If he is trained intensively with the collaboration of parent and the center, the child would develop desirable behavior. I am really grateful to the child's caregivers and or the founder of the center for his improvement and for their provision of special support for my child.

I believe that whatever kind of service provided, without family involvement, intervention is not effective as expected. However, poverty is the main factor that hinders the parents' effort of bringing considerable change in the development of children with autism. Most of us live in a poor condition. Our poor standard of living seems played a large role in not fully involving in the intervention of their children with autism. What I want say is that I am not effectively and efficiently participating in the rehabilitation program.

Most parents of children with autism including me would not entertain the idea of educating our children when we are required to earning the daily bread of the family. Lack of participation of parents particularly of mothers in turn negatively affects the goal of the early intervention program.

3.1.7 Mother Six: H.F

About the child

My child is a six-year-old boy who is the first child for me with one younger sister. I used to take him to Tikur Anbesa Hopsital to get remedies. However, they could not identify what his problem was. Rather the hospital recommended me to take him to another hospital and I tried different hospitals and health institutions to get him diagnosed. But it was beyond their scope. Neighbors and my relatives used to advise me to take him to traditional healers. However, again the efforts had not helped the child at all. Finally the psychologists who are working in the Joy Center for Children with Autism and Related Developmental Disorder (J-CCARDD) recommended me to bring the child to the center. Because the psychologist understood that most of his symptoms are a clear picture of autism. Then he began to spend most of his time in the center.

With regard to education, I can say that in the future he may improve but currently he has got no change. He could not read and write. He has a host of behavioral problems. Such as, he is resistant to adult authority, has peculiar speech pattern, and avoids eye contact, rocking back and forth, and sometimes he screams without any reason.

I sometime let the child to do some activities at home. But he does not want instruction and order. Even if he cannot speak he can understand what I tell him. However, he behaves as if he were deaf. When the child is home, he wants to spend most of his time with me and with other children without disabilities.

The child needs effective early education and should get access for intensive instructional opportunities in a well-coordinated manner by both educators and parents. Besides, relevant therapists should support the child.

Areas of Participation in the EIP

As far as autism is concerned, when I first heard the term autism, I became confused because I had never heard it before. Then I began to build my awareness by asking the center and collecting information from written documents. Now I know better.

Regarding my child, I gave birth through surgical procedure. The child had low birth weight even we all thought that the child was still birth. But finally we recognized that my child was alive. I still don't know why the child had low birth weight or why the child became in this way.

With regard to my participation, I am really keen to create a strong relationship with the center and involve in the treatment program. Currently I am trying to make it practical. I for instance, watch my child day in and day out; I accurately document my child's ongoing treatment and reactions, recording any thing that may be useful for treatment decisions. Such as, does my child have bowel problem? Does he wakeup and cry during the night? Does he have any other physical pain? How often does it occur and how sever is it? Does he show any progress due to treatment? Then I exchange all these information with the center and I receive advice and instruction. The center advise me to provide the child with a better diet, give him love, let him be with people, let him have medical checkup regularly. As a matter of fact I cannot afford all these needs. I daily contact with care givers in the center, but professionals are not always available to help these children. In addition to this, as a part of involvement in the treatment program, I keep telling the neighbors and my friends about the problem, but as I said before many people look confused when they heard it

Regarding my husband, he is the breadwinner of the family. He is not home all-daylong all the responsibility of caring my child falls on me. As long as I am a housewife, I have time to spend with my child.

With regard to parent-to-parent relationship, the center organizes parent group program at the coffee morning ceremony on Sunday. This program is facilitated for parents so as to discuss about their autistic children.

Needs to Involve in the EIP

Question regarding facilities of J-CCARDD, I can say that there is a problem on the part of the center. Even though, the center is strengthening the intervention program as its maximum possible with the collaborative effort of parents. It is not equipped with available staff members. Hence, I cannot say that the center prepares conducive environment to participants. Parents have their own problems too. Most of them have great challenges to afford all their children's needs. They are in a low socio economic status. We do not have the opportunity to contact with therapists at all, because they are not there to help children. If that is so we could not exchange updated information.

I have been having the privilege of being invited by the center to attend meeting specially the parent-to-parent program. And we discuss about our problems. J-CCARDD did not offer any training related to early intervention. Besides, it did not offer supportive counseling. Currently, it focuses or centers on children, it is not in a position to empower parents by training and education. At its level the center needs capacity building. On my part, I am incapable of bearing the financial burden incurred by the child's needs for things like health service, food and clothing.

Extent of Participation in the EIP

I hope that with the collaborative effort of parent and professionals my child can show progress in the near future, because the child is in a good condition after getting training in the center. The main contribution of parent to run up the early intervention programs is receive and send information to the available professionals, working together with professionals, contributing money so as to strength the program, attending meeting and conferences and giving comment about the raised issue, creating awareness for the public regarding autism and, etc. Besides, parent siblings and other family members assist the center for caring educating some basic skill for autistic children. And I believe that parental involvement has paramount importance for the effectiveness of the program. Nothing can be done without them.

Finally, I can say that of course all parents are trying to enhance the overall personality development of their children, but their participation may vary to the extent that some parents of autistic children who sit back and observe passively without searching a remedy for their children.

3.1.8 Observation and FGD Results

In a one and half hours FGD, parents (mothers) were asked to explain the nature of autism. All the six mothers understood that it is not due to evil or bad sprit that made their children autistic. Rather it is due to some defects during prenatal period. As they explained there are a lot of parents who kept their autistic children at home for many years with out any medication due to their belief about the cause of autism. And there are also parents who consistently use holy water to cure their children. Within the respondents there is one mother (case two) still believes that holy water might cure her child. Currently all of them believe that systematic intervention programs are the best way of treating autistic children. As they said, they are delighted by the center's effort to handle the problem of their children. Because if reduces their day to day stress.

All the participants were informed that autism cannot be cured but autistic children can make a great change if they diagnosed and take intensive intervention as early as possible. All parents are now well aware of that Joy center is the only place where these children can get treatment. And they hope that their children problem would be minimized and could utilize their optimum emotional, social and intellectual functioning if they get intensive training with respect to various life skills.

Regarding the parents' areas of involvement in the EIP, they suggested that they are participating in the morning coffee ceremony, parent group program, serving as a co-therapist (teaching their children at home), financial contribution to run up the programs, giving and receiving information about the weakness and strength of their autistic children; attending meetings and conferences, awareness raising program and etc.

Every parent is responsible to attend in the morning coffee ceremony and know the current situation of his/her autistic child. It is held once a month on Sunday. All the attendants of the ceremony discuss about the child's feeding condition (all children with autism are not allowed to eat foods having high sugar and cream content) the skills they should be taught, and all about the ongoing treatment program.

Parent group, program is designed so as to bring all parents of autistic children together to discuss about their common challenges. The program makes them confident and accepts the problem and motivate them to give care and attention to their autistic children. Beyond parent-to-parent relationship, they create awareness about the nature of the problem to friends and significant others.

As the observation result revealed that all the respondents are teaching their autistic children about various skills at home. However, they are not as such they are expected to perform teaching their children. In spite of the low level of parental involvement in teaching their autistic children at home parents of these children have been identified as playing the greater role in teaching their children about the realities of the out side world than other members of the family.

As it is observed their techniques of treatment is almost similar. Besides, the degree of direct involvement of the parents in teaching their children varies according to the educational status and the socio economic level of the parents. A few of them can afford for medication, nutrition and provide playing materials for their autistic children. And most of them could not afford most of their child's needs.

For instance, half of the participants (mother 2,5,6) are helping their children by providing educational materials and reading children stories together with or for their children and by giving feedback to their children's good performance. But the other children can get educational and playing material only in the center.

As it is observed all the parents are not usually practicing playing with their autistic children as the best mechanism of teaching their autistic child. Some parents do not even allow their children with autism to play out with other children. So these parents are not giving much emphasis to by children books, play materials and to arrange play activities for their children as a means of teaching their children with autism at home.

As the result indicates parents of children with autism are not willing to send out and see their children while they are playing with other normal children. They have the tendency to over protect them. Because of fearing that the children might injure them selves or quarrel with other children with out disabilities. Even though parents allow their children to play with other children without disabilities with close supervision. Some of these children do not want to play with their normal counter parts. They want to be alone.

With regard to home teaching, most parents teach various skills to their children at home, such as attending, imitation, language, self help , academic and social skills . These skills are commonly taught in the center too.

Attending skill is the initial training given for these children. As the mothers are advised by the center, attending skill is a stepping-stone for all training and helps to develop their readiness to attend all the training with concentration. It helps them to be stable, tolerant and decreases tantrums. For example, as the researcher observed at the home of mother- two the mother first called her child over to his chair at the table by saying "come here' he did not respond at all. So she carried him over to his chair despite his tantrum. When she got him in the chair, she gave him a piece of cookie (a reinforcers) and told him how well he did with each command. She gave him two opportunities to accomplish the task on his own before she physically prompted him to do it.

Regarding imitation skill, the mother said" do what I did" she then took her child's hand and helped her child do the same thing the mother helped her child imitate her action. When the child did, even with help, he was rewarded.

Concerning language skill, as the research observed almost all autistic children could not speak. So the center and parents teach these children some common words or sentences .As the mother instructed, she places something (e.g. shoe) on the table and tell the child " touch shoe" she then took his hand, physically helped him touch the shoe, and reward him. So that over time the child can learn that objects have names.

And also the mothers train their children about self-help skills. This included dressing and undressing, toilet habits, and safety. They encourage their children to practice the daily life skills. For instance, the child is expected to dress by himself and wash his face right after the child wake up. If he cannot he is helped to do that and then rewarded. The other most commonly thought skill for these children is academic .It includes numbers and letter spelling, reading, writing, and basic arithmetic. Each child is encouraged to spell, read and write and know basic arithmetic skills.

As far as home activity is concerned, even though parents sometimes encourage their autistic children to participate in the home activities, in all the cases parents preferred not to ask their children. It is not due to lack of care and attention. Rather, these parents considered that the activities of these children are governed by the unconscious behavior. Therefore, they think that these children cannot properly perform. And parents prevent their own children from participating in any relevant home activities adapted to the children potentials and needs which makes the condition more worse.

All the cases do not neglect their autistic children. All of them do not feel shame to be seen with their "unique" children. That is why they took their children to the center in order to get access for treatment. As it is observed all the parents respect and feel excitement about their children's feelings and initiatives if it is in the appropriate manner. If it is not in a proper way these children are redirected or forced to reject the activity. Besides, all of them give more time to their autistic children because these children need care and attention. They do not bias to their non-disabled children.

Although the impact of having a child with disabilities is significant for both parents, mothers tend to report stronger reactions. The observation result revealed that most fathers tend to leave all the responsibility to the mothers and avoid providing the necessary care and attention. Mothers are generally faced with additional parenting burdens in multiple realms including maintaining the physical health of the child and assisting the child in achieving certain developmental goals that normally occur without much parent effort (walking, talking, self care and etc.)

Parents were asked whether they have constraints those adversely affect their participation in the EIP. They said that they encounter a number of problems such as their low socio-economic level, low educational level and unavailability of relevant professionals. They all are mothers and they always face shortage of money to cover the expense of the child's care. As they said autistic children are extremely moody they need different things at different times. So it is very difficult especially for poor parents to handle the problem of their autistic children. Their low educational level also negatively affects their contribution too.

3.2 Discussion

3.2.1 Areas of Parental Involvement

A parent is a child's first teacher, the person who is always there to give prompts, encouragement, praise, and corrective feedback. The parent is responsible for helping the autistic child learn literally hundreds of skills. In many respects no one ever knows as much about a child as a parent does. Children acquire many important skills as a natural result of the every day interactions between parent and child. Of course, there are many parents who have responded by systematically teaching their autistic children needed self-help and daily living skills.

It could be seen that mothers are currently working together with the center (J-CCARDD) and involving in many areas to improve the life quality of their autistic children.

3.2.1.1 Information Exchange

Even though parents may not know all the medical terminology and levels, they know their children better. They know their children's weakness and strength. And they want to contact and exchange information with therapists who have taken special training in dealing with developmental difficulties. The information parents possess is valuable in their children's treatment, but it does not do much good if it remains merely with them. They need to accurately relay that information to the doctors (Seigel, 1996). This implies that parents and professionals should work together and exchange valuable and accurate information about the day-to-day condition of the child.

Parents and professionals should collectively and make the best decisions for children affected by this disorder. Without open and honest communication between professionals and parents, many of the positive outcomes cannot be achieved. In the case of J-CCARDD most participants often needed to talk with the relevant therapists. However, there is only one psychologist working as a full timer. The rest therapists, such as; neurologist, physiotherapist, speech therapist, nutritionist, medical doctor, etc. are not available as the parents need them. So parents are complaining that professionals are unavailable, patronizing and non-cooperative or are not willing to get involved. The center (J-CCARDD) is telling the parents that all the professionals are part timers. When they come to the center, they only dealt with children and do not have time to contact and discuss with parents. Currently these parents are communicating with the trained caregivers and the psychologist who is working as a behavior therapist. Therefore, these parents lack accurate and current information about their children.

According to the finding all parents of autistic children were instructed to have a detailed record of the day-to-day situation of their children and expected to report to the center. The center also documents every progress of the children and then they discuss each other.

It seems that daily exchange of information is accessible between parent and the center. But the basic issue we have to consider is that with whom do parents to exchange information? Are they professionals or merely trained workers? if it with workers, How much the information received from them is accurate and relevant? If that is not the case, how do we expect the effectiveness of early intervention program without the involvement of relevant professionals and without reliable information?

As document analysis revealed that the researcher found out that Joy Center for Children with Autism and Related Developmental Disorder (J-CCARDD) has all relevant professionals such as physiotherapist, psychiatrist, speech pathologist, neurologist, nutritionist, medical doctor, developmental pediatricians, linguist, and special needs educator assist the center. The twenty devoted social workers and educators get short term regular training in the area and is the asset of the center. However, all the participants responded that with the exception of behavioral therapist, all are unavailable. Besides, during the data collection phase, the researcher could not come across any therapists except the psychologist. Therefore, it seems that parents have no communication with various therapists. And it results inaccessibility of collecting information and suggestions that can help professionals and providing information to parent. In general parents need clear guidelines on the answer about which therapies should their children have? For how many hours? For how long? Who can provide the best guidance? But, unfortunately for these parents of autistic children many areas still remain gray.

3.2.1.2. Parent Education

Regarding the issue of education, two important aspects should be considered. These are: parent training and supportive counseling. Parents of autistic children should be trained and should get supportive counseling so that they can educate their children in an appropriate manner and in a scientific way. As Mitchell and Brown (1991) indicated that many parents want to receive guidance, parent training and counseling in order to help them cope with their children's behavior problems and facilitate their development.

A. Parent Training

As Comer (1998) explained one of the main features of successful program is parent training. Seigel (2003) also indicated that including parents in training workshops for home based therapists and behavioral skills training classes and using parents as cotherapists and treatment "reinforcers" during non-treatment hours have, as a group, been shown to amplify the successfulness of any treatment regime.

The respondents reported that J-CCARDD is not in a position to give them intensive training due to its low capacity. But, the center designed and implemented a two-day workshop for parents, professionals, and for other concerned individuals. This workshop is held annually so as to build parents awareness with respect to the early intervention strategies. However, the center could not have the capacity to give the opportunity for all parents to attend the workshop. Besides, J-CCARDD organizes group parent program to strengthen parent-to-parent relationship. In this program, parents receive advice and instruction from the psychologist. It is also helpful to reach mother to meet another parent whose child has similar syndrome and exchange relevant experiences.

B. Supportive Counseling

With regard to counseling, it should be provided as part of the intervention program. And it should be conducted by well-trained counselors. Like parent training, counseling for parents can be conducted individually and in groups.

Counseling has a great importance for parents to accept the problem and make them to strive to get solutions. However, parents of autistic children responded that none of them got supportive counseling by professionals. These parents said that most parents may have significant anxiety or depression about their child's diagnosis or future, irrational guilt about having in some way contributed to the problem, anger and frustration about the availability of services, resentment about the effects of a difficult child on the family. So a skilled counselor can help them work through these feelings, learn to cope with needs of their child.

In accessibility of parent training and counseling cause many parents to hide their autistic children at home and denied access for education and medication and exposed for maltreatment. Supportive counseling enables parents to have a positive attitude or hope toward the educational achievement of their children, they are more likely eager to consider the home environment as the learning environment and equip the child's home with the teaching and play materials so as to create a simulative home environment for their autistic children. All the respondents argued that they need counseling so that they can easily adapt to the situation.

In a one and half hour FGD, parents responded that they needed counselors who listen to them and understand them in order to help them clarify their thoughts and feelings. They added that parents should then be helped to gain a clear understanding of the problem situation that they face or concern which they have. Because most parents feel acute pressure to find the best treatment for their child.

According to the finding all mothers want professional support who positively facilitate and promote constructive parent involvement which will in turn facilitate the effectiveness of early intervention program. J-CCARDD promised parents that professionals would be available for al parents so that they can express their feelings and thoughts. However, no expertise contact any parent so far.

3.2.1.3 Parents as a Co therapists

Parents are involved in many areas of the early intervention program. They are a natural and necessary resource for expanding treatment services to the child. They have proven to be much more than just reporters of behavioral change

They can tell what skills their children have already acquired. Parents can work with professionals to provide needed extra practices of skills at home even to teach their children new skills. Even though all children act out from time to time the range and severity of maladaptive behaviors of some autistic children demand more systematic and specialized treatment. Parents must learn to be behavior therapists in order to have a good relationship with their handicapped children.

Heward and Orlansky (1988) explained that educators do not all agree on the role parents should play when it comes to teaching handicapped children. Some professional gives a variety of reasons that parents should not tutor their children. Parents do not have the teaching skill required for effective tutoring; home tutoring is likely to end in frustration for both parent and child. The other perspective holds the notion that parents can effectively serve as teachers for their children at home. The opinions expressed by the majority of parents who have participated in home-tutoring programs indicate that they considered it positive experience for both parent and child.

The respondents of the present study do wish to tutor their children at home, they believe that they can and should be helped to do so. All mothers are trying their level best to apply intervention technique. In fact there is no as such diffident techniques in the center (J-CCARDD) that would be applied by parents. As the researcher understands from the interview and FGD result, the center is commonly informing parents to structured teaching (routines, schedules, individual work systems, visual structures and physical organization of materials) through Applied Behavioral Analysis technique (ABA).

According to Hamilton (2000) behavioral therapy teaches complex tasks by breaking them down in to bite -size pieces that can be learned more easily, with each piece building upon the previous one. Rewards, called "reinforcers" are given for correct responses or behaviors while inappropriate responses are corrected ignored, or redirected. A reinforcer can be any thing the child wants and likes food, drinks, hugs, and kisses tickles, a favorite toy. It has been used in a wide variety of disorders for any years with notable success.

The researcher could observe that at their homes no parents apply /follow/ the correct procedure of the treatment. For instance, they do not have the knowledge about the intensity of intervention such as number of hours per week, hours per day, numbers of interaction, or child responses per hour. Parents simply instruct their children when they are in need of help. For example in the mealtime the children are encouraged to eat food and if they perform well, they are stroked.

Seigel (2003) indicated that intensity of initial interventions that include 25 or more hours per week for the first two years of intervention have been repeatedly been supported. Besides, is seems that all the cases have difficulty in understanding how much teaching is done, i.e., a closely related aspect is how supportive, contingent, developmentally geared, motivating, individually responsive, and mindful of opportunities to promote independent learning the teaching is. To implement this technique successfully, parents need education and support by a well-trained professionals.

Document analysis reveals that J-CCARDD render a number of intervention strategies, such as medication, behavior therapy, vitamins and nutritional supplements, sensory integration techniques, auditory integration training, visual training, tactile therapy, aversive therapy, facilitated communication and music therapy. Some explanations concerning the above mentioned types of sensory of stimulation are given in the following manner.

- ***Auditory stimulation:*** provide records, radio, television, music, story telling. Speak directly to the child. Ask him/her questions that can be answered with a "yes" or "no". If he is non-verbal, observe his eyes for response.
- ***Visual stimulation:*** provide colorful play objects, pictures, etc.
- ***Tactile stimulation:*** provide a variety of play activities involving textures.

All aspect of care must be taken for a child to combat autism through EIP for the restoration and maintenance of the child's emotional, intellectual and social competencies. For example, exposing the child with all senses of stimulation (Auditory, visual, and tactile stimulation) to maintain the intellectual competency of the child with autism, is one aspect of good intervention by parents.

Most researchers argue that there is no best method of intervention for autism. Because some methods are seen as being very good for some children some of the time. Each of this method also has disadvantage for some children some of the time too. But it does not necessarily mean that every parents need to understand multiple approaches to teaching children with autism. Applied Behavioral Analysis (ABA) is commonly used for intervening children with developmental delay in general and autism in particular. Currently, J-CCARDD offers education/intervention-rehabilitation services such as behavioral modification-(Applied Behavior Analysis-Lovaas, TEACH), communication therapy-(picture exchange communication system, symbolic gesture, facilitated communication, speech and language therapy, verbal behavior, relationship development intervention), sensory intervention training (tactile therapy, auditory integration training, visual training), occupational and physical therapy-physiotherapy, physical exercise, circus, gross and fine motor skills, nuero feedback), social skill development training (group and community interaction therapy), self-help skills training- (toilet training, dressing and undressing, grooming, personal hygiene, and cooking), cognitive skills, biomedical treatments-(gluten free casein free diet, vitamins and nutrition supplements) and music, water, sand therapy and others.

The mothers reported that they teach their children on basic functional skills. To support this idea mother two said, “I do not marginalize or neglect my child. I love him, day and night my focus of attention is my child. Even I sometimes forget my husband and may other child. My husband understands me, he does not complain, I give love and attention to my child, I train him at home on self-care, socialization and academic skill. Because, I already accepted my child with his problem. I do not feel guilt or shame of having him."

According to Minett (1989), parents can play a role as a teacher of their child by:- looking at books together with the child, reading and listening to children's stories, providing their child to get a variety of books, encourage their child in play activities like discovery play (of texture, size, color of things), physical play (as in physical exercise) creative play (to express ideas/ feelings in the form of picture drawing and writing), imaginative play, like imitation role, manipulator play (use of hands, brick building or bricks play) which takes place when children play together to learn the feeling of cooperation to share and to be honest.

With regard to play, parents are expected to encourage play activities and to arrange play opportunities for their autistic children with in and out of home play situations. This is true by the fact that encouraging play opportunities are one of the means of teaching children with cognitive disability. However, as it is observed parents of children with autism are not willing to send out and see their children while they are playing with other normal children. The consequence of this is that these children donot get the chance of language or social interaction with other children so that these children would face a deteriorated process of social and language developmental skills in their later life.

It seems that all of the children are given attention in the family, however, except case five. In all cases, parents preferred to ask their other children to do something for them than a child with autism. Because these children are resistant to adult authority. They don't want to be instructed or ordered. Except in one family (case five) where the child was participating in some home activity.

All the respondents reported that parents of these children prevent their own children from participating in any relevant home activities adapted to the children's potentials and needs which makes the condition more worse. Besides, the very nature of the child's behavior (resistant to instruction) made parents not to allow their children to participate in the home activities.

To sum up, all mothers are a bit aware of autism. However, they need guidance, counseling and training how to work with professionals and how to treat their children at home. Most of them are applying behavior therapy or intervention to teach their children on self-help skills, social skills and academic skills.

3.2.1.4 Parent to Parent Relationship

According to the result, one mother said, "Now I have learned to talk more with other parents and find out what they are doing. Several of us have become close, so when one learns something new, she is quick to inform the rest. By doing this we help one another." This statement highlights that parents of autistic children want to discuss and share their experiences .As parents said the meeting help them to strive to get solution and to be confident as well. Mothers in J-CCARDD reported that morning coffee ceremony is designed for parents so that each mother of autistic children can communicate and discuss about their experience in relation to the life situation of their children like talking existing issues, count their blessing, appreciate their potential angels, crying together, confronting each other, and teaching each other. further, the psychologist and the founder of the center about what mothers must do to their children.

Ozonoff, Dawson and Mc Partlan (2002) said that parents often find it useful to talk with other parents, who understand better than professionals. These groups do indeed make it clear that each parent is not alone. Mitchell and Brown (1991) also explained that most parents want to meet others with similarly disabled children. Here we can understand that how significant parent-to-parent relationship is to run up the EIP effectively.

One mother said "I can daily contact mothers with the same problem and exchange our feeling and emotions. Because it is me who take the child to the center and bring him back home. So that it helps me a lot."

3.2.1.5 Awareness Raising and Advocacy

Parents of autistic children can play a great role educating public about autism. And they are largely responsible for making the public aware of their children's needs. The finding indicates that all respondents make their friends and neighbors aware of the condition. Besides, parents participate in a public awareness raising program. Since 2004, J-CCARDD dedicates one week every year with special focus on raising awareness about autism. Accordingly, in 2004, over 2000 people walked 10Km with wide media coverage. It also conducted a panel discussion entitled "autism and public awareness." However, it is not in a systematic and organized way. They tell others when they are asked. Grand parents, aunts, uncles; neighbors can all have an important effect on the handicapped child's development. Howard and Orlansky (1988) explained that parents of handicapped children know they cannot simply rely on appropriate interaction. Parents of handicapped child must try to be sure that, as much as possible, other people interact with their child in a way that facilitate the acquision and maintenance of adaptive behavior.

Therefore, every parent of autistic children should teach the public so that the public develop positive attitude towards these children and seek direction for positive outcome.

3.2.2 Extent of parental Involvement

The extent of parental involvement is highly determined by the facilities prepared by the center and the environment in which they live.

With regard to facilities, what opportunities or environments are prepared in order to encourage parents to participate in the early intervention programs (EIP). As it is said before, most parents as parents do not know the role they play. This is because most parents have not been asked (and in some instances have not been wanted) to participate in the child's treatment. And most parents have the problem of diffusing their responsibility to professionals and become uninvolved. That, therefore; made parental participation more often passive than active. It is not surprising that parents have a variety of feelings about how much their participation is really desired and how much they really can or should contribute.

The results indicated that all mothers believe that their contribution can make a great difference in the life quality of their children. However, they need clear guideline in the areas in which and to what extent they should participate. Professionals should guide these parents so as to increase their level of participation. Heward and Orlansky (1988) suggested that parents are at least being made aware of what special services their children are receiving. However, in relation to J-CCARDD, we can say that parents are not clearly aware of what they must do to their children. They still need much support so as to know their role in the EIP.

Generally, parents believe that their contribution has a great role to the improvement of their children. They also know that their level of contribution is not sufficient. Besides, they have a variety of feelings and emotions about to what level /extent / their participation is desired. For some parents financial aid and for some other parents exchanging information is their maximum contribution.

With regard to the environment in which parents live, the socio economic status of the parents is the critical element. Parents in a low economic level, cannot effectively support and treat their children. As it is obviously known, poverty is the main factor thet hinder the parents' effort of bringing considerable change in the development of children with autism.

According to the finding, all of them are housewives and one of them is a petty trader, so they are living in a poor condition. Their standard of living seems played a large role in not fully involving in the rehabilitation of their children with autism. No mother got financial aid from anybody. So most of the parents could not afford to the financial burden for their children's medication and nutrition. All of the participants indicated that their low economic level seriously affect their involvement in the treatment program. Therefore, it could be concluded that lack of participation of parents particularly of mothers in turn negatively affect the goals of the J-CCARDD programs.

CHAPTER FOUR

4. Conclusion and Recommendation

4.1 Conclusion

Early intervention is the strategy of avoiding or arresting the development of unproductive or undesirable behavior or condition and changing or directing them in ways that are more desirable. Now a days, a wide range of treatments are being given for autistic children. Such as: physiotherapy, occupational therapy, speech therapy, behavior therapy, music therapy, medication, etc.

Due to the invisibility of the disorder, attention has not been paid on to the problem for many years. This made parents to use alternative treatment like holy water and seeking help from traditional healers. Still the disorder is mysteries in its nature. All concerned professionals do not exactly know what causes it besides; recent studies show that there is no best treatment for autism due to the very nature of the problem. Although it was unknown for most parents, all the participants were found to have positive understanding on the causal factors and medication of autism. Because, parents of autistic children are being taught by the center (J-CCARDD) about the nature and the treatment mechanism of autism through the morning coffee ceremony which is held monthly.

Parents of autistic children can get the essential knowledge on the features of autism and its treatment mechanism through advice and instruction. It seems that parents training was not in place so far: rather informal instruction and advise is accessible individually and in groups.

Parents know their own children best, as well as the environment in which the child is growing up, parents will usually have a special bond with their children which will give them an understanding of their children that would be different from other people. Professionals may have certain specific strategies and methods to help children with autism. However, without co-operating with parents and without a mutual sharing experiences with them, the educational and development goals may not be achieved.

Even though, the degree of most parents' involvement varies according to their educational and socioeconomic status, they do care and teach their children with autism at home. Though most parents assist their children with autism to develop the cognitive and social skills of the children, it is traditional type for they are not using standardized teaching materials and practicing the teaching process at home in a planned and systematic manner.

Even though parents often need to talk with each therapists, it was found to be very difficult for parents to communicate regularly with professionals. So, this resulted in accessibility of accurate and current information. i.e. which therapies should their children have? For how many hours? For how long? Who can provide the treatment or training?

Of all the therapists needed to make early intervention work, parents are the most important. Given enough information, parents can help to prevent many risks and causes of the problem. Given the chance, parents can become active in determining their children's educational needs and goals. And given some guidance and training, parents can teach their autistic children at home and at the center.

The results of the study show that J-CCARDD is encouraging and advising parents to use Applied Behavioral Analysis (ABA)- learning through playing. Autistic children are trained with various skills by their parents such as communication skill, social skill, self-help skill, and academic skill. But, parents do not have the knowledge about the details of intervention, such as: number of hours per week, hours per day, number of interaction, or child responses per hour. So, no parents apply (follow) the correct procedure of the treatment.

It seems that all the parents are not some how aware of the systematic way of handling the situation of these children through stimulating them learn and participate in some relevant activities. If the child does not get the necessary stimulation within the family and is not participating in activities at home, it will be very difficult to manage the problem of the child in the future.

Therefore, the priority needs of these parents seem to be education, support and counseling while the primary focus of professionals should be raising awareness of parents and the entire community. Parents need to understand the nature of their children's condition. And they also need to know what to expect in terms of the children's development and what they can do to help these children. In addition, they need support in coping with the fact that their child has autism. Furthermore, they need information and support in raising their children so that they will be prepared and it will be easy for them to cope with the situation and to become involved in intervention and other programs. Therefore, professionals should of to them and see what the parents' needs are and teach them instead of waiting them to come to us.

4.2 Recommendation

In the light of the findings of the study, the researcher would like to make the following recommendation.

1. Create a supportive environment for parents of children with autism. This can be done through parents' association, professional support and family support
2. It is also important to conduct regular parents meetings so that parents will get the opportunity to meet other parents with the same situation which in turn would help them to feel that they are not the only parent with this situation and to become psychologically ready to help their children.
3. For the better provision of services for children with autism, there must be strong relationship between parents and professionals. And the first and major condition which should be taken in to consideration in planning intervention and education programs for children with autism, is making parents and other people to have positive attitudes towards these children so that they will be involved in the programs. Hence, appropriate parent training programmes are to be designed, developed and implemented so as to develop positive attitude towards autism as well as to ensure their participation in all the intervention programmes.
4 Parents of children with autism should be provided with counseling service to realistically understand the nature and causes of their children's disability

and it can be improved through learning up to the expected level of development.

5. Education and awareness raising for the parents and their children about "scientific" explanations on cause, prevention, and remedy of autism, to change the preset understanding of parents that is biased by their beliefs.
6. Parents of children with autism need societal and governmental or non-governmental organizations supports to minimize their own stress from being hopeless and the burden of caring or teaching their child so that they can cope up positively with the behavior problems, parenting, teaching and future care of their children and their behavioral problems.
7. Encourage their child's play activities with out restriction and punishment
8. Parents should organize the physical and temporal environment of the child, such as the provision of appropriate play materials and varied, balanced, and patterned sensory inputs that much with their child's cognitive, social, emotional and motor organizational levels that promotes the over all developments of the child.
9. Parents should create chances for their child to be cared by, to contact and interact frequently with few adults who are physically, verbally, and emotionally responsive and who can value and reinforce the child's achievement in education and language /communication in an accepted norms, emotions.
10. Parents should observe that their relationship with the center and involvement could bring about real changes.

11. J-CCARDD should encourage parents as much as possible to feel free to work with them on issues/ challenges of education of their children.
12. This organization (J-CCARDD) should recognize the significance of parent-professional association for the success of the mission it is advocating.

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Appendix- A

The Role of Parents of Autistic Children in the Early Intervention Programs

Interview Guide to be Used with Parents

I would like to talk about the role you are playing by involving the EIP. My objective is to come up with possible recommendations that would contribute to the efforts being done to day to improve the life qualities of children with autism and others. In this regard you play an important role. That's why I wanted to ask you some questions. Please answer the questions that I'm going to ask you by sharing your experiences. All the information obtained will be kept confidential. Thank you for your cooperation in this study

I. Background Information about Parents

1. Sex M____ F______

2. Age_________

3.Relation with the child father_____ mother_____ other_____

4. Educational level: Indicate mother's educational level

Primary_______ Secondary_______

College and above_______

5. Occupational status: Indicate mother's occupational status?

Employed______ Home maker_______

Business woman _______others _______

If employed indicate the kind of profession?

6. Religious back ground: Protestant_____ Catholic_____

Orthodox _____Muslim _____other

7. Language_______________

8. Marital status: Married______ Unmarried______

Divorced______ Separated________

9. Number of children___________

10. Do you have any other children with disability other than your autistic child? If yes what kind?___________________________

II. Background Information about the Autistic Child

1. Age
2. Sex M_____ F_____
3. Educational level __________________
4. Birth order __________________
5. At what age of the child did you know that your child was autistic?
6. How is the child's medical history? Have you ever taken the child to anywhere for cure?
7. What do you expect in relation to the child's education?
8. Do you let the child to do some activities at home? If yes what kind of activities?
9. Can the child understand what you tell him/her very well?
10. Besides your assistance, how much support does he/she require from other people?
11. Does the child have or show any behavioral disorder? If yes, describe?
12. Whom does the child spend most of his/her time with?

13. Where does the child usually play?
14. Does the child have a friend without disability? If yes, how long and often does the child spend his/her time with them? If no, why not?
15. Do the siblings include the child in games/ other play activities?

III. Areas of Parental Involvement in the Early Intervention Programs

1. What is your understanding about autism?
2. Why this child became in this way? What do you believe the causes of autism?
3. Do you participate in the early intervention program that is being implemented by Joy Center for autistic children? If yes, in what area? If not, why?
4. Do you practice at home what you have been trained /advised by the professionals who are involving with your child in the center? If yes, what practices do you perform? If not, why?
5. How often do you contact with the center to get relevant information?
6. Do you contact regularly with each professional to know the condition of your child? If yes, tell me the profession whom you contact? What do you mostly discuss?
7. Are there any programs that necessarily need parental involvement? If yes, what is the program?
8. Do you frequently visit the center while your child is in treatment? If yes, why do you visit? If no, why?
9. Do you make awareness raising activities for neighbors? If yes, where and how? If not, why?

10. Do you make any effort to strengthen the early intervention programs that are being rendered by the center? If yes, please specify.
11. What intervention measures do you think are effective to minimize the problem?
12. Do you monitor your child's profile to know the day to day improvement of the child?
13. Do you share responsibilities with your spouse to treat your child? If yes, please specify? If not, why?
14. Where do you get help when your child's problem grows beyond your control?
15. What kind of treatment do you mostly exercise to your child when you are at home?
16. Do you discuss about your child with other parents who have children with autism?
17. What have you been doing for the improvement of your child's life before the establishment of the center?
18. What would you suggest to be done in the future for these children on the part of the parents of autistic children?

IV. Needs of parents to participate in the early intervention programmes

1.Do you have supportive environment to participate in the early intervention programme? If yes, what are those facilities? If not, why?

2.do you have good communication with each of your proffesionals? If not, why?

3.do you get up to date information from the professionals about the condition of your child? If yes, what kind of information? If not why?

4.Do professionals frequently visit your home? If not why?

5.Have you been having the privilege of being invited by the center to attend conferences?

6.have you get any related training in the area?

7.Do you receive supportive counseling so that you can express your feelings and needs?

8.Does the center design group parent programme (for group counseling) so that you can share your problems to one another?

9.Do you get financial help for your child education and medication?

10.Do you get any comment or suggestion from the center regarding the role you play in the early intervention programme ? If yes, what are the comments? If not, why?

11.Have you been having the privilege of being invited by the center/professionals whenever you were indeed of help? If yes, tell me the experience that you had?

12.What are the main constraints that negatively affect your contribution in the early intervention programmes?

13.Could you tell me what kind of materials or things you need to effectively participate in the early intervention programmes?

V. Extent of Parents' Contribution in the Early Intervention Programs

1. Do you think that the situation of your child can be improved? If yes, how? If not, why?

2. Do you believe you can improve the life of your child by participating in the

early intervention programs? If yes, how? If not why?

3. What is the main contribution of parents in the early intervention programs?
4. What is the main contribution of family members in the treatment programs?
5. Do you think that early intervention is effective with the involvement of parents? If yes, how? If no, why?
6. Do you believe that parental involvement n the early intervention program is important? If yes why? If not why?
7. Do you believe your involvement in the early intervention program is effective and efficient if not why?
8. In which way do you consider your self? As a regular observer as a main caretaker or in any other role in the treatment of your child with autism??
9. How much support does the child require from you when professionals are not there?
10. Did the child show significant improvement as the result of your involvement in the early intervention program? If yes, please specify. If not why?
11. Is your participation seasonal or consistent? If your answer is seasonal in which season do you participate?
12. Are there parents of autistic children who do not participate in the early intervention program? If yes, why

Appendix - B

Observation Guide

I. Observation when the Child is at Home

1. Do parents treat the child in the same way as they are treating their other children?
2. Is the child given adequate attention by the parents and other members of the family?
3. Do parents implement the program prescribed by the center at home?
4. Does the child have the opportunity to participate in all the activities at home?
5. Is the child allowed to participate in discussions in the family?
6. Do parents respect the child's feelings, initiatives etc?
7. Do parents allow the child to play with other children?
8. What is the general behavior of the child?

II. Observation in the Center

1. What do they perform when they come to the center?
2. How do they interact with professionals in the center?
3 How often parents go to the center?

Appendix - C

3. Focus Group Discussion

1. How do you explain the condition of your child? What do you think about the condition?
2. Do you think autism can be cured? If yes, what kind of treatment is effective
3. Do you think that the effect of autism could be minimized and the individuals with autism could utilize their optimal functioning if they get early intervention services?
4. What are the involvements and contribution of parents of autistic children in the early intervention programs
5. What are the duties and responsibilities of parents of autistic children in helping their children?
6. What are the major problems of parents of autistic children face in implementing the program
7. What kind of support parents need to effectively participate in the early intervention programmes?
8. Suggest possible solutions to solve the problem of these children on the part of parents, people in the community, the government and other non-government organizations?

DECLARATION

I, the under designed candidate declare that this thesis is my original work, has not been submitted for a degree in any other university and that all sources of materials used for the thesis have been acknowledged duly.

Efrem Sahle

Candidates' Signature

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

10/6/2005

Dr. R. Sreesvalsa Kumar