ADDIS ABABA UNIVERSITY
COLLEGE OF EDUCATION AND BEHAVIORAL STUDIES
DEPARTMENT OF SPECIAL NEEDS EDUCATION

PSYCHOSOCIAL IMPACTS OF AUTISM ON FAMILIES AND THEIR PERCEPTIONS ON THE SUPPORTS PROVIDED AT JOY CENTER NIA FOUNDATION FOR AUTISTIC CHILDREN IN ADDIS ABABA

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TABLE OF CONTENTS

CHAPTER ONE

CHAPTER TWO

CHAPTER THREE

CHAPTER FOUR

CHAPTER FIVE

CHAPTER SIX

ABBREVIATIONS

ABA	Applied Behavioral Analysis
FGD	Focus Group Discussion
IEP	Individualized Education Program
MA	Master of Arts
MOE	Ministry of Education
NGOs	Non Governmental Organizations
PBS	Positive Behavioral Support
UK	United Kingdom
USA	United States of America

ABSTRACT

The purpose of this study was to assess the psychosocial impacts of autism and the support systems to families of children with autism and their perception of the supports provided. To do this, a narrative research design was used for the study and qualitative approach was employed. Data were gathered from Joy Center Nia Foundation for Autistic children in Addis Ababa, Ethiopia. First, the researcher availed himself to employ observervation session. Then, using interviews, focus group discussion and observation; three teachers, including one head of teachers, five parents have participated in the study to obtain the necessary data. Findings of the study revealed that these parents were getting the support they needed even though there were a number of support systems yet to be accomplished. Experience and educational level of families appeared to have significant relationship with the provision of the support system and its application. Besides, psychological problems such as depression, exculsion, anxiety, fear, etc had also been their major problems. Caregivers are also found to get subsistence amount of money which can otherwise affect the support system. Following the findings and conclusions drawn, it is recommended that the government and other pertinent bodies should work in collaboration with the management of the center in areas where families can benefit a lot and ameliorate their current problems. It is also recommended that the center should do its very best to make the center a conducive research place for all who come to carry out their studies.

CHAPTER ONE

INTRODUCTION

1.1. Background of the Study

Autism is a neuro-developmental disorder first described by the American psychiatrist Leo Kanner (1943). Children with this disorder are extremely unresponsive to others, uncommunicative, repetitive, and rigid. Their symptoms appear early in life, typically before 3 years of age. A decade ago, autism seemed to affect around one out of every 2,000 children. However, in recent years there has been a steady increase in the number of children diagnosed with autism; it now appears that at least one in 600 and perhaps as many as one in 200 children display the disorder (Fombonne, 2003; Wing & Potter, 2002). Around 80 percent of all cases of autism occur in boys. As many as 90 percent of children with this disorder remain severely disabled into adulthood.

Autism has a major impact on the lives of the affected children and their families. The family of a child with autism often experiences disappointment, social isolation, added stress, frustration and helplessness. These compound stress and the presence of a child with autism may affect the families' wellbeing 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 children with autism should be planned and implemented systematically.

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. A child with autism is indeed with many special needs and requires close attendance.

Parents of children with disability are particularly vulnerable to stress. High levels of distress have been found in up to 70% of mothers and 40% of fathers of children with autism (Sloper & Turner, 1993). Parental distress and family functioning impact children in numerous ways, affecting their cognitive, behavioral and social development. Although there are many other developmental disorders, which also present parents with ongoing grief, autism is unique in several ways. First, this disorder has no clear biological marker, unlike many other developmental disabilities such as mental retardation. Without a definitive test, the diagnosis of and prognosis for autism is fraught with uncertainty. This ambiguity makes it extremely difficult for parents to accept the child's condition. Second, because it is characterized by problems of social interaction, such as forming attachments and showing affection, parents of children with autism are often denied some of the fundamental rewards of parenthood (Hartley et al., 2010). As a result, autism has been considered as one of the most complex and intractable developmental disorders with which families may have to cope. In fact, research has shown that autism can create greater parental anxiety and tension than parents of non-disabled children; than parents of children with other physical or learning disabilities; or parents with children with other developmental disabilities (Hastings &Johnson, 2001).

There is considerable and consistent evidence that mothers experience greater impact than fathers. Gray (1983) found that the most striking difference between mothers and fathers was the differing personal impact of their child's autism. Although most fathers noted the severe difficulties that their child's autism presented for their families, they usually claimed that their child's condition did not have a significant effect on them personally. For fathers, the most serious effect of their child's autism was the stress experienced by their wives. The relatively less severe impact of the child's autism on most of the fathers appeared to be at least partially due to the gender roles connected to work and child rearing (Gray, 1983). In this regard, added that fathers may have seen helping their child to reach financial independence, as being consistent with their role. It was noted that the fathers felt that their sacrifice was in having to work harder to support the extra demands on the family, as a result of the child's disability.

Burke and Cigno (1996) concur with these gender differences in the perceptions of and participation in parenting. Fathers were found less involved with physical care and domestic tasks, but can, and do provide a high level of support. Also, the fathers experienced considerable stress due to continual disturbed sleep and the need to take time off work, to support their partner in managing the child's behaviour. Anon (1998) indicates that siblings of children with autism are also at risk of bearing the psychological and emotional brunt of growing up alongside a child with behavioral difficulties. Many siblings have felt that their parents perceived their needs as being secondary, with more time and attention given to the child with autism. Whilst they may have a deep love for their sibling, they may also harbor feelings of resentment at the amount of time their parents are spending with the child with autism, and feel that they are being treated unfairly. Feelings of anger, embarrassment and guilt are also normal, as is feeling very protective of their sibling. It has been reported that the siblings of children with autism have high levels of loneliness and problems with peers. Kaminsky and Dewey (2002) found loneliness to be related to a lack of social support from friends. Social support from classmates is also significantly correlated with academic problems. Siblings of children with autism are significantly more likely to experience depression than the general population. Along with psychological problems, exhaustion may affect siblings who may be responsible for domestic tasks and physical care. Problems can also be there when the increased parental expectations are not accompanied by increased parental time or attention.

Attempts are now made to involve the parents in the intervention programmes being designed for the child. In India, the demand for service providers far exceeds the supply of available professionals, and the cost attached to accessing these services can be high. The professionals can therefore train parents in setting up their own individualized treatment programmes for their child. An expert may provide an initial short-term, hands-on training to the parents and then monitors student and trainee progress with a follow-up when as necessary. Parents are increasingly being taught the implementation of the programme through modelling and rehearsal; and the parents practise the programme with the expert's feedback (Cottrill et al., 2003). Anderson and Romanczyk (1999) say this method has been reported to be successful in training parents to teach a number of skills to their children, including play skills and communication. Symon (2001) says involving the parents at this level, by providing more information and making them an integrated part of the child's education programme not only enhances the child's skills but is also instrumental in reinforcing belief in their own competencies.

Families seeking to be an integral part of service-delivery process face many difficulties. Given the fact that autism is a spectrum disorder, it follows that a child with autism benefits from the presence of a variety of special educators (e.g., sensory therapist, occupational therapist, speech therapist, etc.) (Cottrill et al., 2003). Sloper (1999) found a key worker or a link person is assigned, whom the parent approaches for advice about any problem related to the child. The key worker in turn, maintains regular contact as needed with the family, and has responsibility to work together with professionals from a range of services, and coordinating support for the family. Particularly important aspects of the service are the key worker's knowledge of and ability to access information and services from a range of agencies. Glendinning (1986) added some of the positive effects in families with key workers include higher parental morale, receipt of more practical help, greater satisfaction with respite facilities, and less isolation. The greatest value of the service was seen as having someone to talk to who parents could turn to for help whenever they needed.

Coping with stressful situations that are beyond one's control is one of the greatest challenges of life. With no scope of reducing or eliminating the sources of stress, such situations require strategies where one changes the self to fit the situation. Wallander and Varni (1998) found understanding the ways of family coping is very important, as these are central to cognitive models of stress and coping often applied to families of children with disabilities. Beresford (1994) found that coping resources and strategies used by the families have a more decisive effect on the stress experienced by them, than the child specific variable (e.g., age, sex and severity of problem); and socio-demographic variables (e.g., social class, income and domicile). Randall and Parker (1999) suggest that, often there are two general ways of coping that the families use. Firstly, they make the child with autism the center of the family's attention and efforts and secondly, subjugate natural and spontaneous emotional expression, in order to show greater patience and understanding towards the child with autism. Though these strategies may be helpful in the short term, they prove detrimental to the mental health of the parents in the long run.

Gallagher, Beckman and Cross (1983) identified the following as important coping strategies that influence the stress felt by the families: expectations, attributions, parent's view of the causation of the handicap, nature and quality of daily interactions with the child, parent's notions about their child's efficacy as 'changing agents' in facilitating child's development, attitudes and social support. Beresford (1994) reinforced other mediating factors that have been identified, include family beliefs and perceptions, religious and moral beliefs, overall philosophies and ideologies held by the families, family lifestyles and extent of harmony in the family. The way in which a family functions, is influenced by the parent's perception of their child's difficulties. Dunn (1984) studied children's close relationships and suggested that a family's response to of stress influenced the siblings' perception of the situation. If parents react positively to their child with special need, then the sibling relationship tends to be more positive. If the parents took an optimistic and caring view, then the sibling was more likely to do the same. Thus the parent's ability to accept their child's difficulties influence the ways in which a family functions. Holroyd and Lazarus (1982) found cognitive mediation plays a significant role in such stressful situations and can be conceptualized in terms of two interacting processes: appraisal and coping. Appraisal may determine whether a situation/encounter is personally stressful or not, thus altering one's cognitive appraisal can reduce stress. The impact of events still perceived as stressful can be minimized through effective coping skills.

Supports focused on parents' coping skills have reported positive results. Terry and Haynes (1998) depicted these supports use ideas from stress and coping theories to inform parent training in problem solving and decision-making, communication skills, skills in accessing and utilizing social networks, and coping strategies such as positive self-statements, self-praise and relaxation.

Some successful strategies include gaining perspective, finding meaning in an event, acceptance, positive reinterpretation, and humor. According to Kirkham (1993) training has often been carried out in groups rather than individual programme. Intervention group mothers showed a great deal of improvements in communication skills, coping skills, satisfaction with family support and intimate support. Howlin and Yates (1990) said sibling support groups have been found to benefit siblings of a child with autism in offering support, but ideally follow-up sessions should be organised. In their article Gupta and Singhal (2004) report studies recognising families that have been successful in developing positive perceptions regarding raising a child with disability. It has been reported that families with a child with disability can and in fact do have positive perceptions which leads to a better quality of life for the family, and scope for maximizing the child's potential. In line with this, Folkman and Moskowitz (2000) found positive perceptions play a central role in the coping process and assist us in dealing with the traumatic and stressful events. Not only do they benefit the parents and the siblings in coping with the child, the disability, and the difficulties associated with it; but it also helps the family unit as a whole.

Family’s strength for handling and raising their children with autism should be given a considerable acknowledgement. According to this, Mesibov, Shea and Schopler (2005) identified the key fundamental values that families of children with autism should be acknowledged with. These are respect for the family’s knowledge of their child, the family’s individuality, the love that family members have for their children with autism, the resilience that family’s show under great pressure, the contributions families make, and the family’s needs for accurate knowledge and effective support.

1.2. Statement of the Problem

Apart from the type and severity of the specific stressors caused by having a child with autism, coping with the general stress of a developmental disorder requires significant, long term adaptation within the family, and these changes affect both the individual family members and the family unit as a whole. For a significant number of individuals, the entire burden of providing emotional, social and economic support falls on the family members, especially the parents. There is a greater burden on caretakers and a higher probability of disruptive routines within the family of a child with autism, than in the families of children with other disorders (Randall & Parker, 1999).

Studies indicate that the associated stress effects of having a child with autism, impact on most aspects of families’ lives, including: housekeeping, finances, emotional and mental health of parents, marital relationships, physical health of family members, limiting the response to the needs of other children within the family, poor sibling relationships, relationships with extended family, friends and neighbours, the opportunities for the personal development of each family member and time spent in family recreation and leisure activities (Sander & Morgan, 1997).

Parent-professional collaboration approach, views the child and the family in the broader environmental context. Parents may look to professionals such as physicians, therapists, and others, who have the expertise in working with the children with disabilities to determine what they feel, are the best services for their children. However, since each child is a member of a broader family system, it is important to consider the socio-cultural context when assessing the needs of individuals and their families and in developing effective intervention programmes. Thus, the support providers must consider the individual needs of each family, in order to provide effective support for families of children with disabilities.

Many variables influence families' experience of having a child with disability and it is important to consider the individual needs of each family, when determining what support is required. Cultural values, financial needs, available resources, severity of the disability, level of social support, family structure, and geographic location are all variables to consider in designing and implementing effective intervention programmes. All or any of these variables can enhance or limit the effectiveness of a programme and highlight the need for individualisation. For example, a low-income, single parent family would have different needs, sources of stress and/or available resources than an affluent, both parent families. Thus the level and type of support should fit the needs of the individual family. Ecological approaches can be used to provide a framework for considering a child as a member of a larger contextual system.

The research aim to answer the following questions:

1. What are the psychosocial impacts experienced by families of children with autism at Joy Center-Nia Foundation for Autistic Children?

2. What are the psychosocial supports given by professionals to families of children with autism at Joy Center-Nia Foundation for Autistic Children?
3. How far the supports provided were effective as perceived by families in solving the problems in relation to handling the child with autism?

1.3. Objectives of the Study

1.3.1General objectives

The general objective of the study is to investigate the major psychosocial impacts of autism on families and their perceptions on the supports provided at Joy Center-Nia Foundation for Autistic Children.

1.3.2 Specific objectives

The specific objectives of the study include:

- Assessing factors related to having a child with autism that impacts families of children with autism.
- To evaluate professional support provided to families of children with autism.
- To clearly identify the psychosocial support needs of families of children with autism.
- Find out the nature of psychosocial and other challenges of families of children with autism.
- Find out if families of children with autism experience social isolation, stigma, and poor social relationship.
- Identify if families of children with autism have psychological problems such as lack of self confidence, fear, anxiety, and frustration.
- Assessing the effectiveness of the support system to families of children with autism as perceived by families.

1.4. Significance of the Study

- This study is primarily believed to equip practical solutions for families of children with autism who are socially and geographically deprived by identifying their psychosocial challenges and highlighting major aspects of supports.
- It may also provide information for policy makers as well as school owners to think about extra support needed for these families.

- Since these families are those who have special needs, it may give insight for teachers about the psychosocial challenges, the support system and the perception of the support system of these people, for taking the necessary steps in their support process to improve the psychosocial wellbeing of families of children with autism.
- Finally, it may inspire other researchers and NGO’s who are interested to undertake further study and work in the area.

1.5. Delimitation of the study

The current study is aimed at understanding the major psychosocial impacts of autism on families and their perceptions on the supports provided at Joy Center-Nia Foundation for Autistic Children. The study was delimited to families of children with autism who are regularly coming to the center in matters related to their children and themselves. Families who were not actively participating in the education of their children with autism were difficult to find and were not included in the inquiry.

1.6. OPERATIONAL DEFINITIONS

Autism: a mental condition, present from early childhood, characterized by great difficulty in communicating and forming relationships with other people and in using language and abstract concepts.

Impact: to have a strong and bad effect on something or someone.

Intervention: is a combination of program element or strategies designed to produce behavior changes or improve health status among individuals or an entire population

Neuron: relating to nerves or nervous system.

Perception: the ability to see, hear or become aware of something through senses.

Psychological: of, affecting, or arising in the mind; related to the mental and emotional state of a person.

Psychosocial: of or relating to the interrelation of social factors and individual thought and behavior.

Therapeutic: the branch of medicine concerned with the treatment of disease and the action of remedial agents.

CHAPTER TWO

REVIEW OF RELATED LITERATURE

2.1. Overall perspective of Autism

Howard and Orlensky (1988) explained that autism is a neurobehavioral 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 people with autism often suffer from a bewildering array of problems such as sensory disturbances, food allergies, gastrointestinal problems, depressions, 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 everyone else’s mind and that how they feel is how everyone else feels.

Autism is a worldwide problem among all races, nationalities and social class. It affects only 4 or 5 every 10,000 persons. However, recent research by Mesibov, Shea and Schopler (2005) reported that with a tenfold spine in numbers over the past 20 years-one in every 166 children is now diagnosed with autism. Approximately 80% of them are boys. Two children with autism in three remain severely impaired into adulthood and are unable to lead independent lives **Kallegrew** (1994). Studies show that there are over 300,000 children with autism in the USA alone and more than 500,000 in the UK and the rest of Europe. In Africa, although actual count is not readily available, it is estimated that there are hundreds of thousands of children with autism.

Gallagher, Beckman and Cross (1983) identified that from the moment families begin to suspect that their child isn't developing in a neuro-typical way, families of children with autism begin to face challenges that set them apart from other family groups. This disorder can be emotionally devastating for parents, especially just before and after the child is diagnosed. Additionally, there's the stress of navigating complicated therapy schedules, following through on treatment at home, juggling family commitments with job responsibilities, and many other issues. While these difficulties may feel insurmountable, most families learn to cope and adjust with time.

In these regard, Ferguson (2001) and Olkin (1999) contributed their part by saying, there is an increasing understanding among disability scholars that disability is a social construct, which is defined variably across cultures. Culture has implications for how families define and experience disability, how families experience their interactions with the formal service system, and how parental child rearing values develop. While many examples of cultural differences around disability could be given, it will give a few that highlight issues that practitioners need to consider.

Ferguson (2001) and Olkin (1999) again forwarded that culture influences the way families define disability. Two examples, the first one coming from one of the author's clinical experience, illustrate how families from India and China might define a specific condition very differently than a clinician native to the United States. For example, a clinician from an early intervention program, targeting children from birth to age 3 with developmental delays or disabilities, was referred to a family who recently emigrated from India. The presenting problem was that the child was not walking, or even crawling very well. During the assessment, the worker noticed that the child had extra digits on both hands and feet. When asked when they planned to schedule surgery to remove the extra digits, the mother indicated that no surgery would be scheduled as several of their extended family members had extra digits (fingers) and were not hampered or hindered by being polydactyl. The clinician identified being polydactyl as a disability based on her culture, while the family identified the condition as a family trait based on their culture.

In line with this, McCabe (2007) mentioned that a study conducted in China also illustrates how culture can influence how a problem is defined. Families may experience different levels of social stigma related to disability depending on their cultural context. For instance, "There are many people in China who continue to think that any child who develops in a non-typical fashion is a shazi--an idiot”. Weiss (2002) found that children and their families experienced discrimination, limited educational opportunities, and limited support.

2.1.1. Parents as therapists

Due to the nature of the disability, it is wise to involve parents as therapists in their children's intervention programmes. With regard to this, Symon (2001) added that training parents as therapists increases the amount of support for children who require intensive, individualised intervention. He further added, it also provides a cost-effective model of service delivery and contributes to the children's rate of progress.

Moes (1995) has demonstrated that parents can be effective implementers of behavioral, Social and communication programmes with their children with autism. (Koegel et al., 1996) pointed out the effects of including parents as direct service providers in their children's intervention process as a means of increasing the quantity and availability of intervention and as a means of providing support not only to the individual but also the family.

Moes (1995) again forwarded on parent education which includes training the parents in specific procedures to work directly with their children, to teach them specific skills, reduce problem behaviours, pivotal response training, and improve non-verbal communication skills. Besides, Anderson & Romanezyk (1999) also wrote on the importance of parent education which also includes verbal communication skills, increase appropriate play skills and also includes teaching parents to advocate for their children and to provide information and support to other parents.

Parent education can be beneficial not only for the children but also for the parents. Parents can learn techniques to work with their children with autism, to help them overcome their socially avoidant behaviors (Koegel et al., 1996). Randall and Parker (1999) reported that Parents with children with autism have reported having lower parenting competence, suggesting that they may feel uncertain about whether they are good parents. Usually, they doubt their competence because their child does not respond as expected. There appears to be increased self-blame as a coping strategy, greater caretaker burden, family burden and more disrupted planning, thus thwarting their chances of developing any support systems.

Specific groups of parents have been identified as being less likely than others to benefit from a parent education programme alone, due to various factors. Single parents, low-income families, and parents experiencing depression, divorce or with poor social support, may be less likely than others, to benefit from such programmes without additional support (Singer et al., 2001).

To give extended strength to the aforementioned concept, Brofenbrenner (1986) explained parents may look to professionals such as physicians, therapists, and others, who have the expertise in working with the children with disabilities to determine what they feel, are the best services for their children. However, since each child is a member of a broader family system, it is important to consider the socio-cultural context when assessing the needs of individuals and their families and in developing effective intervention programmes. Thus, the support providers must consider the individual needs of each family, in order to provide effective support for families of children with disabilities.

2.1.2. Families Coping strategies to stress

According to Tarakeshwar & Pargament (2001) the effectiveness of coping depends on the positive coping strategies used by the parents, the resources available within the family, and the availability of social support from the spouse, family and informal networks. Fathers of children with autism report more frequent use of wish-fulfilling fantasy, and information seeking as coping strategies (Rodrigue et al., 1992). Acquiring social support and reframing the experience to see some positives are most frequently used coping strategies (Luther et al., 2005). Hardiness and social support are predictors of successful adaptation (Weiss, 2002). There is no direct relationship between social support and isolation suggesting that some of the parents feel isolated despite receiving social support (Dunn et al., 2001). The Internet allows stressed parents of children with autism to forge ties among themselves and extricate themselves from their isolation (Fleischmann, 2005). Poorer adaptation was predicted by other family stresses, unwarranted maternal self-blame for the handicap, and maternal definition of the handicap as a family catastrophe (Bristol, 1987). Research indicates that it is important to discourage parents from using escape and avoidance as a coping style. Encouragement of more appropriate coping methods and receipt of social support is seen as beneficial in buffering the stress and reducing negative outcomes (Dunn et al., 2001).

Further, Tarakeshwar & Pargament (2001) elaborated by saying, involving parents of children with autism indicate a positive evaluation of direct services to their child, (e.g.,"…believing that my child's program has my family's best interest in mind.") was the most helpful resource in coping with the challenges of autism.

2.1.3. Friend's and family's help to relieve stress

Michele (2012) added relatives and friends who can help support and relieve stress on families using these helpful strategies like reaching out to parents. That is, to be willing to sometimes just listen, to offer to baby-sit so that parents can get out and have fun or time to themselves or with siblings, to make phone calls for parents who may be looking for services-especially if both parents work and can't take time during the day, to remember to accept the decision the parents come to -even if the friends did all the legwork and phone calls, to run errands for the parents who may be juggling several therapy sessions, appointments, meetings, etc; and to spend separate time with siblings of a child with autism; many times they feel left out or not as important, to go with parents to IEP meetings, doctor's appointments, etc; to encourage family to stay involved with the areas of their lives that are important to them that is church/temple, old friends… Some parents may feel guilty for continuing their lives when they see other parents only focusing on the autism, to offer to go out to dinner with the family to help out; many parents simply stop going out to eat because it is too overwhelming.

2.1.4. Therapists help to relieve stress

Again, Michele (2012) added couples need to be encouraged to acknowledge and face the emotions of the grief cycle (i.e., denial, grief, depression, anger) and the loss of the child they were expecting, and to work through these emotions. Misdirected anger is often released at school personnel in Individualized Educational Program (IEP) meetings or taken out on service providers, thus alienating the very people who are there to help them. Encouraging couples to regularly schedule time together without the children is important. However, this suggestion is useless unless the therapist can support them in devising a practical plan for finding the respite help they need. The lack of qualified babysitters can be a very real obstacle to finding time together or continuing therapy. Working on good communication skills and looking at how they can support each other is important. The couple needs to realize and accept that their partner may react differently to having a child with autism and a different viewpoint when it comes to how much effort and money to put into treatment, as well as what kinds of treatments to pursue.

Encouraging fathers to take a more active role with agreed upon treatments, generalizing some of the skills the child has learned through his ABA (Applied Behavioral Analysis) program, helping with structure, limit setting and discipline can be very helpful. For this to occur, father needs more information and training. Perhaps coming up with some father-oriented informational materials could be useful. In the same way, providing available and willing grandparents with information and a little training that can enable them to step in and give the parents a few hours of respite can be beneficial to all involved. Explaining to them why their grandchild acts the way they do (i.e., sensitivity to sound and light, not being able to make sense of the world, lack of communication skills) is helpful. Suggestions they offered to do specific tasks, such as teaching the child to catch and return a ball or play a simple game, or teach a simple learning skill which needs much repetition and positive reinforcement, can be helpful. In this way they could understand both the effort needed and the excitement to be acquired in teaching their grandchild an interactive skill. Grandparents will feel empowered knowing they are making a positive difference in the family’s life, the parents will feel supported and more relaxed.

To the non-autistic sibling, knowing that they can ask questions and discuss their feelings about their sibling and autism is important. By helping parents understand the needs that siblings have is helpful, as sometimes these get lost in the shuffle. The non-autistic siblings need some quality time alone with their parents on a regular basis. Parents need to be aware of the sibling's feelings in order to develop strategies of support to help him/her adapt. Providing the siblings with information about autism (such as why their sibling acts the way he does) in a positive manner at their age level is necessary, and there are many children's books available now that can be very helpful. Joining a support group for other siblings of special needs children can be extremely helpful so they do not feel they are the only ones going through this. The siblings need to be reminded often that they have just as much of their parents' love as their autistic sibling, even if parents may need to give more time and attention to their brother or sister with autism. It is important that the non-autistic sibling have a private autism-free zone to call their own, and a secure place to keep their precious objects. They also need to see that the sibling with autism is given consequences if he wrecks their things, and that he is expected to improve his behaviors over time.

2.1.5. Other Strategies to Cope with Stress

Senel (2010) added when it comes to reducing stress, be creative. You may want to consider one or more of the following approaches: Prayer, exercise, deep breathing / relaxation exercises, writing in a journal, keeping a daily schedule of things to accomplish, advocacy, and Individual, marital or family counseling

If you or a family member is exhibiting signs of stress, you need to take action. Even if it takes the last bit of energy you have left, getting assistance can only make things get better.

2.2. Family support systems

As Brofenbrenner (1986) identified many variables influence families' experience of having a child with disability, and it is important to consider the individual needs of each family, when determining what support is required. Cultural values, financial needs, available resources, severity of the disability, level of social support, family structure, and geographic location are all variables to consider in designing and implementing effective family support. All or any of these variables can enhance or limit the effectiveness of the support and highlight the need for individualisation. For example, a low-income, single parent family would have different needs, sources of stress and/or available resources than an affluent, both parent families. Thus the level and type of support should fit the needs of the individual family. Becker-Cottrilland Mc Farland(2003) further elaborated, using formal and informal supports, services to be tailored to the needs of the family. A team of individuals, including the family, relatives, neighbours, and appropriate agency personnel, assist in the development of a plan directed at providing the supports, necessary to meet the needs of the family and the child.

2.2.1 Behavioral Support

Becker- Cottrill and McFarland (2003) added to address challenging behaviors and improve lifestyle outcomes that serve to increase the overall quality of individual's life, positive behavioural support (PBS) has been found to be successful. According to them, three professional activities that could improve services to children with severe behaviour problems were suggested:(a) developing and implementing family-centered, home based positive behavioral support services, (b) expanding the analysis and intervention to focus on family routines, (c) teaching professionals to build collaborative partnerships.

PBS employs procedures derived from the behaviour analytic literature, is grounded in person centered values, and focuses on making meaningful changes to enhance a person's quality of life (Horner et al., 1990).Additionally they stated that, behavioural interventions employed, are non-aversive and are driven by functional assessments of behaviours. Functional assessments of behaviour involve employing methods to determine the motivating variables that maintain a specific challenging behaviour. Once the functional assessments are complete, hypothesis statements regarding the function of the challenging behaviour(s) are formed. These hypothesis statements then provide the foundation by which to select ecological, antecedent, and/or consequence strategies to address the challenging behavior.

Dunlap and Fox (1999) pointed out that, also inherent in a philosophy of PBS, is an emphasis on building new adaptive behavioural repertoires that address a broad range of skills that will generalise across a wide variety of people, settings, and situations. Thus, the quality of a person's life is more directly considered. Since the process is ongoing, programmes are monitored closely to ensure that they are meeting the needs of the family and child. Typically, applied to individuals with severe developmental disabilities and/or challenging behavior.

2.2.2 Adaptation Support

Bernheimer, Gallimore and Weisner (1990) mentioned one ecological approach which is the Eco-cultural theory that provides a foundation for designing programmes for families with children who have disabilities. This theory emphasizes the contextual variables, including child characteristics, family values, and culture that should be considered when assessing a family's needs and developing a support plan for that family. This theory considers a family's value systems, niche, accommodation, and perception in determining the type of treatment or support that would be most beneficial for a family.

On this point, (Bernheimer et al., 1993) added the family niche involves the ways that the family's material environment (e.g. income, housing) changes over time, and accommodation refers to how a family reacts or adapts (e.g. adopting a new parenting style) to the forces in its members' lives. The aforementioned approach considers the family members to be active participants in an active process of change. It describes the interaction among the environment, the family, and the family values. Perceptions and values are also considered as agents in the interactive process. For instance, families may perceive the severity of their child's disability differently. While one may perceive to be the most salient hurdle to overcome, another family may not consider it as the most challenging obstacle. To determine the family's value system, ecological theory looks at how families construct their daily routines Kallegrew (1994). Besides, Eco cultural theory suggests that family values are embedded in daily routines and that family maintain their routines, in order to adapt to the continuously changing environment. Daily routines include ordinary events that occur regularly and that family members do together, such as preparing meals, cleaning up, waking up and getting dressed. During these routines, parents interact with their children and therefore, provide their children with predictable events and natural learning opportunities. Through daily routines, children learn how they are expected to behave, and they learn the values embedded in their family system. Symon (2001) explains that a

family placing high value on meal preparation and dining, might expect a child to assist in meal preparation and sitting together for meals. Whereas, another family may perceive meal times as a function of survival rather than a time of social exchange and may allow the child to eat while watching television. In general routines are based on family values, cultures and subcultures. They are means of organizing the family system into meaningful events. Families rearing a child, who has a disability, accommodate in certain ways by organising the environment around them into daily routines. It is important that the family accommodations made in regard to their child's disability be sustainable. If the cost of accommodating to a valued routine exceeds the benefit, the accommodation will not be sustained. The process of raising a child with autism, presents unique challenges to families. Getting a diagnosis of autism and accepting a lifelong responsibility of bringing up a child with autism is a traumatic experience for the parents. Raising a child with autism is an all-encompassing task that is often exhausting and isolating. As the families learn about the limitations of
Pediatricians, autism specialists, school systems and state intervention, many of them begin to perceive the social system as unjust and unfair, for the first time in their lives. As a result, parents quickly discover that if they do not advocate for their child with autism, that child will not receive suitable education or treatment. It is important to note how families deal with issues of grief, loss, marriage strain, stigma and shame. Several of these aspects are relevant to the issue of providing psychosocial support to the families of children with autism.

The development of these approaches is a response to the call for a shift from provider based or expert driven services to a collaborative approach with a formal focus on family context and quality of life concerns.

2.2.3 Financial and respite support

Caregivers of children with disabilities benefit from concrete services such as stipend (payment) programs and respite care. In two studies of a cash subsidy program, Herman (1991; 1994) found that parents rated the cash subsidy as helpful, as improving their overall family life and ability to care for their child with a disability, and that they were able to get more respite care and professional services due to the subsidy. Similarly, Meyers and Marcenko (1989) found that cash subsidies reduced family financial stress and led to fewer families anticipating out of home placement. Chan and Sigafoos (2001) found that respite care reduced short term stress for mothers and had a particularly positive effect on mothers of younger children in their review of the respite care literature. Herman and Marcenko (1997) found that the respite care had an indirect effect on maternal depression mediated by adequacy of time and adequacy of babysitting resources. When mothers received respite care, they felt they had more time and more adequate babysitting resources. These more positive perceptions in turn led to a decrease in maternal depression. Since mothers bear the brunt of the economic impact of having a child with a disability, it is not surprising that stipend and respite care programs would be particularly beneficial to mothers. Although concrete services are beneficial to families, they are often under-funded and difficult for families to access. Clinicians can assist families by advocating that they get adequate services.

2.2.4 Therapeutic and educational support.

The work that has been completed on educational strategies for children with autism indicates that interventions can have a positive outcome in terms of teaching children with autism new skills and coping strategies (Schroeder et al., 1996). Existing data suggests that stress and depression associated with autism are amenable to psycho-educational intervention (Hastings &Johnson, 2001). Anger management programs based on helping children with autism to recognize triggers, exert control over their physical arousal, and develop strategies through such avenues as role play have been shown through impressionistic reports to be effective (Kellner & Tutin,1995). Improved verbal and physical sharing has been demonstrated (Sawyer et al., 2005). There is some evidence of improvements in the child's sociability, emotional control and attention span during treatment (Gray, 2002). Training courses have been shown to have a beneficial effect on both parent's and children's communication skills (Mc Conachie et al., 2005). It is recorded that the best teaching arises from an empathetic understanding and a willingness to be flexible, the worst, from rigidity and an expectation that it is the child who must change (Jordan, 2005).

In addition to the above point, (Pakenham et al., 2005) added that parents are an important part of treatment for a child with autism and have been frequently trained and referred to as *co-therapists*. Importantly, the research indicates that special education teachers received the highest support rating in terms of parental perception of support for coping (Newsome, 2000). Several studies have reported decreased parental stress as a result of early intervention with children (Hastings &Johnson, 2001). Indeed, research indicates that beliefs about the efficacy of the educational/therapeutic interventions were associated with lower reported stress (Hastings &Johnson, 2001). As intervention in autism are often intensive, time-consuming, and financially draining, it has been argued there is an ethical imperative to ensure that such programs are assessed through independent research (Hastings & Johnson ,2001). However, the available evidence indicates that few providers have a clear understanding of evidence-based practice, and all providers report concerns about adequate training (Stahmer et al., 2005). Effective evaluation and documentation of efficacy for educational and therapeutic interventions for children with autism through research is seen as essential to ensure a high standard practice (Simpson, 2005).

2.3. Impact of autism on Family

According to a report from families of children with autism, a greater number of stressors would encircle them. Hastings and Johnson (2001), Sivberg (2002) and Tarakeshwar and Pargament (2001) explained that parental depression and anxiety, difficulties in daily management of the child, financial worries, and concerns over adequate educational and professional resources are their primary concerns than those with children with other disabilities

In relation to the above point, a child diagnosed with autism represents a constant source of stress on the family unit, as not only are the caregivers affected, but also siblings and relationships among family members (Higgins et al., 2005). The child with autism typically requires vast amounts of parental time and energy (Tarakeshwar & Pargament, 2001). Mothers of children with autism have been found to experience greater stress and difficulties in adjustment compared with mothers of children with other physical and intellectual difficulties (Pakenham et al., 2005). Besides, as it is further asserted by Holmes and Carr (1991) that the brunt of caring falls upon the mothers with fathers helping mainly with supervision rather than physical care or domestic tasks. Siblings also appear not to be involved. Fathers of children with autism report more financial impact and disruption of family activities (Rodrigue, Morgan & Geffken,1992).

The child’s state is the primary factor behind anxiety and stress among parents with autism. Fleischmann (2005) threw crucial points that among the most difficult problems that parents mention are, poor language skills; inappropriate and embarrassing public behavior; disruption and destruction in the home; violence and aggression; inappropriate sexual expression and obsessions with eating and toileting. Higher levels of autism symptomatology are associated with higher reported parental stress (Hastings & Johnson, 2001). The more severe the child’s symptom, the greater is the degree of parental stress (Dunn, Burbine, Bowers &Tantleff-Dunn, 2001). The extremely antisocial, disruptive behaviours associated with autism, such as self-injurious behaviours, tantrum and obsessive/compulsive behaviours, may preclude a normal family life (Higgins et al., 2005). Less favourable outcomes are documented in cases of families with aggressive or violent children (Gray, 2002). The parents in these families have higher levels of stress and have few resources in terms of treatment or residential placement to deal with their situation (Gray, 2002). Mothers appear to be the most severely affected member of the family (Dunn et al., 2001; Moes, Koegel, Schreibman & Loos, 1992).

Fleischmann (2005) reported that among members of families with a family member with autism have found a rise in depression, stress and anxiety. Caregivers of a child with autism often experience helplessness; feelings of inadequacy and failure; anger; shock; guilt; frustration; resentment (Higgins et al., 2005). Longitudinal data suggests that families do not experience a single stressor; rather they experience a pile-up of demands (Pakenham et al., 2005). These studies show that social support is very important in combating depression and stress (Fleischmann, 2005).

2.3.1 Emotional Impact

Seigel (2003) indicated that autism is an emotional related disability that begins before diagnosis and continues throughout life. Mothers of children on the autism frequently rated their mental health status as "poor" or "fair." They had a much higher stress level than the general population (Mc Conachie et al., 2005)

In addition to the higher stress level, many parents of children with autism experience the following emotions: Feelings of being overwhelmed, relief at having a name for the challenges their child faces, anger at their spouse, the doctors, or themselves, resentment of the child and guilt for that resentment, despair at the incurable nature of the disorder, guilt that something they did may have caused their child's challenges, frustration that the parenting experience they have is not what they envisioned, feelings of social isolation, embarrassment at child's behavior in public.

2.3.2. Physical Impact

Seigel (2003) also indicated that autism also has an indirect impact on the physical health of family members. Anxiety, depression, and exhaustion all take a toll on the physical health of families with children on the autism spectrum. Stress can lead to lowered immunity, and sleep deprivation may result in difficulty concentrating, memory impairment, and other health complications.

2.3.3. Financial Impact

Glendinning (1986) added the financial impact on families of children with autism is enormous. Most private health insurance plans do not cover all expenses related to therapy and treatment for children with autism, and the co-pays for office visits and medications often results in huge financial debt. In addition to therapy and medical expenses, there are added financial burdens like specialized educational toys, equipment like weighted blankets and vests, and much more.

Having a child with autism resulted in an average of a 14% loss in total family income. It is often extremely difficult for both parents to continue working full-time, which means a reduction in household income to go along with the increased expenses. Since many parents need a full-time job in order to provide health insurance, loss of full-time employment can have a dramatic and negative impact on the family's finances (Mc Conachie et al., 2005)

2.3.4.Impact on Marriages

Hastings and Johnson (2001), Sivberg (2002) and Tarakeshwar and Pargament (2001) explained that one of the biggest ways that autism impacts families is by placing additional stress on the parents' marriage. Newsome (2000) suggested that parents of children with autism were

9.7% more likely to get divorced than their peers. There are several ways that autism stresses the marriage: often parents accept the child's diagnosis in different ways and at different rates, leading to conflict, inconsistent schedules and numerous commitments make it difficult for parents to spend time together, it can be challenging to find child care for children with autism, which also makes it hard for parents to go out as a couplet, financial stresses can cause additional conflict between parents.

2.3.5. Impact on Siblings

Hastings & Johnson (2001), Sivberg (2002) and Tarakeshwar & Pargament(2001) explained that autism also affects neuro-typical siblings. These children face many of the same pressures as the rest of the family, and they may not have the full support of parents who are overwhelmed with the needs of their child with autism. Sibling rivalry can become more intense in a family with a mixture of typically developing siblings and children with autism. If the child with autism's need for extra time and attention becomes a permanent issue, as often happens with autism, siblings can feel left out, and resentment can build. However, many families are able to sort out these challenges as long as they can control other stress factors.

Bristol (1987) found that the biggest predictor of sibling emotional adjustment was the presence or absence of other risk factors like low socio-economic status. If these factors were controlled, the experience of being a sibling to a child with autism actually enhanced the emotional and psychosocial health of the sibling.

2.4. Family’s perception of the provision of support

Minnes (1988) and Sencar (2007) illustrated that one of the most important factors in efforts of families for coping with stress and attunement due to having a child with developmental disabilities is the internal and external resources of crisis overcome of the family. These resources include family members’ personal resources, family role structure and features related to family that contributes to organization and close society of family such as relatives, neighbors, friends, professionals and the other institutions in society’s social support.

According to Gallagher, Beckman and Cross (1983) social support explanation, which enables individuals are loved, are valued, are cared, reducing negative results of a crisis, a change in his/her life and getting easy to adaptation of critical life event and protection of psychological health, can be defined as an emotional, physical, informative, instrumental and monetary helps provided by people around individual. Family social support means various support types. These are, in family home environment, towards the child and the family, which have developmental disabilities and includes: (a)money management, (b) services, provided via professionals, (c) supports from other individuals and units, (d) foods and products, (e) combinations of services (Turnbull, summers, Lee & Kyzar, 2007). As to the beliefs of Wang and Brown (2009) social support provided to families includes supports that are needed by families in home environment and functional canalization of whole family and family member to have a better position in society. Family social support mediates policies and practices, that toward to family and family member with developmental disability, to be more effective.

Social support patterns for families with a child are divided into two as formal and informal. Formal social support systems are perceived as to be given by professionals and informal support systems are perceived as family members, friends and being a member of social groups that are integrated into family's daily life. Formal support resources can be family therapist, family education professionals etc. Informal support can be provided by family members; friends, neighbors, family support groups (Dunst et al., 1986). Informal support is more efficient than formal support for protection from negative effects of stress (Boyd, 2002).

Researchers reported that although relatives, friends and neighbors are willing to provide emotional support to the family with a developmental disability, level of support towards the practice is low (Brown et al., 2003).

According to Brown and Isaacs (2009) as social support level of families with a developmental disability having child increases, it is seen that parents behave more positive towards child, interact with child more positive while playing game and behavior development of child with disability is more.

Children have less physical limitation, behavioral problem and more social acknowledgment and power of personality trait if their parents have more supportive social network (Dunst et al., 1986). It was observed that mothers of children with autism have less depression and worry if they get more social support (Gray & Holden, 1992). Limited social support causes withdrawal from stress reducing social activities, which is a negative effect (Boyd, 2002).

CHAPTER THREE

METHOD

This chapter briefly outlines the research design, study setting, population and participants, tools utilized as well as the process followed to conduct the study. The method employed to analyze the data and the ethical considerations regarding the study are also described in this chapter.

3.1. Design of the Study

The main purpose of this study was to investigate psychosocial impacts of autism on families and their perceptions on the supports provided at Joy Center Nia Foundation for Autistic children in Addis Ababa and assess the existing psychosocial support put forwarded for these families. In order to achieve this objective, narrative research design was employed with the assumption of getting the inner most feelings and emotions of participants in the natural setting. Hence, qualitative research approach was found to be appropriate for this particular study with the intention to understand the existing psychosocial support of these families.

3.2.Research setting and source of data

Joy center – Nia foundation for autistic children is found at 'Kirkos' subcity in Addis Ababa. Relatively, it is located opposite to Vatican Embassy.

For this particular study, Joy center-Nia foundation for autistic children was taken as a research site purposely for couples of reasons. Firstly, in this center, there are integrated services provided both for the children with autism and their families. Next, the school (center) is known for its recurring participation in different societal affairs. Therefore, conducting this study in this setting to understand psychosocial impacts of autism on families and their perceptions on the supports provided is both logical and worthwhile for suggesting timely interventions that could address their problem and further lessen the psychosocial tension.

Furthermore, to attain this objective, primary source of data was utilized for the study to be comprehensive as well as informative. Accordingly, the major sources of data for this study were:

a. Parents of children with autism who have experience and information and are assumed to give ample information. Therefore, five parents of children with autism, four mothers and one father were the major sources of data for the study.

b. Primary school teachers: these were four female teachers who have been teaching at Joy center-Nia foundation for Autistic children for long period of time and believed to have more information, rich experience of teaching these children and considerable interaction with familiess of children with autism. Hence, they are expected to provide information on the families psychological, social and economical situations of these parents.

c. Head of teachers: the head of the school was another source of data included in the interview and FGD for the study. Accordingly, she was asked and provided information concerning the existed support system and intervention practice in the school for families of children with autism.

Initially the researcher had planned to select the participants on his own but the center's administration has been against the idea and provided the participants by themselves for unknown reason. And this, by large, has created a hindrance to get the required information as deeply as possible. Again, it has been tried to incorporate more family members. However, the researcher could manage to get only from five parents due to the unwillingness of the rest of families. With this regard, the researcher was given the participants deliberately considering their experience in the center hence, they may give better information. Moreover, teachers, and head of teachers were included in the study.

For this study, five parents of children with autism –four mothers and one father, four experienced teachers including the most experienced head of teachers were active participants of the study. This enables the researcher to observe any disparity that might exist on the psychosocial impacts of autism on families and their perceptions on the supports provided since they are from different section of the society.

As far as the selection of respondents was concerned, the selection criteria were, willingness to participate in the study, years of experience in the center, having enough time and ability to express ideas clearly. In the case of selecting teachers and the head of teachers, purposive sampling was employed by the researcher to collect relevant information from them. At this point it should be made clear that, the selected participants have extensive knowledge in the area.

3.4. Instruments

As it is intended to understand the psychosocial support for families of children with autism and assess the support system, semi-structured interview was the chief data collecting instrument developed and used as this tool is important in qualitative research to collect an in-depth and detailed data from participants.

In addition, Focused Group Discussion (FGD) was held with four teachers, and one head of teachers as a complementary instrument for triangulating and enriching the data obtained through observation and semi-structured interview. Furthermore, observation guide was another way of collecting data followed by interview and focused group discussion (FGD). Hence, the following tools were prepared and used.

3.4.1.The Semi-Structured Interview

As far as the preparation of the semi-structured interview guide for families of children with autism was concerned, questions that could elicit relevant information were prepared by the researcher from the available literature and own personal experience. Once the semi-structured interview guide was prepared, it was commented and reshaped by the advisor, and peers (M.A students) so as to assure that each item was in line with the stated research objective.

After the researcher had revised and shaped the interview guide in line with the objective of the study, it was made ready to be used in the field work. The next task-translating the semi-structured interview was carried out by language expert together with the researcher. The translated interview guide was later retranslated back by other language expert to see the translated versions’ congruence with the original English semi structured interview guide.

Since Amharic was a vernacular language for the researcher, it had made the interview process smooth and without any communication barrier. In addition, the participants were friendly as the interviewer used their mother tongue language. And detailed clarifications were given on matters that needed brief explanation.

In the case of teachers and head of teachers the interview was also carried out using the language they understood as it was frequently used by teachers in their school environment. This in turn helped the researcher to establish rapport and intimate contact with participants.

3.4.2. Focused group Discussion (FGD)

As far as the preparation of the focus group discussion guide for families of children with autism was concerned, questions that could elicit relevant information were prepared by the researcher from the available literature and own personal experience. Once the focus group discussion guide was prepared, it was commented and shaped by the advisor, and peers (M.A students) so as to assure that each item was in line with the stated research objective.

It was an intensive and hot discussion made with four teachers, including head of teachers and five parents of children with autism in order to get detailed information in depth and breadth. This was with the intention to triangulate and enrich the data obtained from families of children with autism through interview and observation.

3.4.3. Observation

Regarding the preparation of the observation guide for families of children with autism was concerned, questions that could elicit relevant information were prepared by the researcher from the available literature and own personal experience. Once the observation guide was prepared, it was commented and reshaped by the advisor, and peers (M.A students) so as to assure that each item was in line with the stated research objective.

This was another data collecting tool used by the researcher to gather relevant data with an intention to cross check the congruence of the data obtained from families of children with autism through interview and focus group discussion. Accordingly, observation guide was prepared and used to collect data about the psychosocial impacts of autism on families and their perceptions on the supports provided in the school (center).

3.5. Procedures

The researcher's plan in this regard was to avail himself first in the center to employ a participant-observer method using interview, focus group discussion, and observation.

3.5.1. Interview

This was a form of an informational and in-depth conversation made with five parents of children with autism, four teachers and one head of teachers. At the time of the interview, the researcher asked to tape record and they agreed while having the interview hence the researcher had recorded while conducting the interview. Each parent participant was interviewed for an average of 2 hours. Therefore, a total of 10 hours was allotted for this purpose. In the case of interviewing teachers, each teacher was interviewed for about an hour.

Regarding the way the interview was held, after getting the willingness of the interviewees, the center arranged time for the researcher to interview the teachers at their free time and with the parents, when they came to take their children home because that was the only possible time available.

3.5.2. Focus Group Discussion

The researcher requested the center to carry out a focus group discussion with the willingness of the selected four teachers including head of teachers and five parents of children with autism. Then the researcher got their agreement to hold it on the day of coffee ceremony which is held once a month for longer hours. On the ceremonial day, the researcher asked to tape record and they agreed while having the discussion hence the researcher had recorded while conducting the FGD. In the course of the discussion, the researcher sat, with his recorder and FGD guide, with the parents and the teachers respectively and asked questions that would elicit hot discussions

3.5.3. Observation

The way to carry out observation was anecdotal. That is, the researcher was constantly available in the center early both in the morning and afternoon to observe the kind of service to be given in the center to parents. Moreover, the researcher was frequently present in classes in class time to see the type of lesson given to the children with autism which could help parents when the children are at home. In line with this, photographs were taken to record the information while observation was taken place.

3.6. Method of Data Analysis

The data collected from participants was thematically grouped, coded, transcribed, organized and analyzed qualitatively in a narrative form. In doing so, the thoughts, feelings, emotions and beliefs of participants were emphasized. Hence, attempt was made to put the direct speech of participants. The researcher had paid special attention to the actual words that participants uttered frequently.

The obtained written data was translated directly from Amharic (mother tongue) to English by the researcher with consultation to language expert. Finally, discussion of major findings was made by categorizing findings in to the following major themes.

These were: Psychosocial challenges and consequences, nature of school support system and perception of the support system by families.

3.7. Ethical Considerations

In the preparation and administration of questions ethical consideration was taken in to account. In doing so participants' privacy was not invaded, their consent was sought, and they were made clear about the purpose of the study as well as guaranteed confidentiality of their responses. Initially, they were let to know to be tape recorded and they agreed while interviewing participants hence; they had been recorded while conducting the interviews.

In addition, they were given complete freedom to stop their participation on the research at any time if they want. Fictitious names were also used while presenting the findings of the study in order to keep privacy of the participants.

3.8. Credibility, Transferability, Conformability and Authenticity

According to Mertens and McLaughlin (1995) there are criteria for judging the equality of qualitative research which are parallel to the positivist, quantitative research. Hence, to enhance the quality of this study, the researcher had used the following criteria.

Credibility

In qualitative research, the credibility test asks if there is a correspondence between the way the respondents actually perceive social constructs and the way the researcher portrays their view points. To enhance the credibility of this study, therefore, he summarized what has been said by the participants and asked if the records were reflecting their view points accurately at the end of each interview session as a method of *member checking.* In addition, triangulation was made to check the consistency of data obtained from parent participants, teachers and head of teachers.

Transferability

Transferability in qualitative research is identified as the quantitative parallel to external validity and refers to the degree to which one can generalize the results to other situations (Guba & Lincolon; 1989 cited in Mertens & McLaughlin 1995). Since families of children with autism experience the psychosocial challenges where the societal superstitious thinking is practical, other families of children with autism including the involved ones are also in the participation.

Conformability

Guba and Lincoln (1989) cited in Metrens and McLaughlin (1995) identified conformability as the qualitative parallel to objectivity in quantitative paradigm and refers to the condition where the data and their interpretations are not figments of the researcher's imagination. In order to secure the conformability of this study, the feelings and emotions of participants were taken and quoted directly. Furthermore, to minimize the subjective bias of researcher's judgment, peers were invited to review the transcribed interview notes to determine whether the conclusions inferred were supported by the data.

Authenticity

Authenticity refers to the presentation of a balanced view and belief of all participants. It answers the question: Has the researcher been fair in presenting views? In this study, the researcher had paid due attention to give fair presentation of all participants.

CHAPTER FOUR

FINDINGS

At this stage, the researcher had successfully collected the data from the field, through semi structured interview, focused group discussion and observation which was relatively the most rigorous stage of the study. Hence, this chapter is exclusively dedicated to present major findings of each case independently. Accordingly, the background information of participants including the age, sex, grade level, socioeconomic status, family back ground which were believed to have their own contribution on the psychosocial impacts of autism on families and their perceptions on the supports provided were presented.

The psychosocial experiences of parents of children with autism such as their feeling, self-confidence, fear, worries, aspirations and other related psychological conditions of each case were also presented in detail.

Concerning their age, the age of parents ranged from 35-60 years. As to their educational background, two cases were found to be uneducated and socio-economically disadvantaged where as the other cases were found to be educated. Two of the cases were diploma holders in the field of laboratory technician and in teaching; the other one is engaged in her own business after taking some business courses.

The social experiences of families which mainly revolve around the social life of participants, particularly, the social isolation, exclusion, social support, friendship formation and related social experiences of participants and the perception of the support system existed for these families at school (center) and outside of the center were presented.

Case one

Asnakech was a thirty eight years old single mother who lived in Addis Ababa around Mekanisa. She had a fifteen years old daughter with autism. Previously she used to live around Kotebe with her husband and daughter. After her husband died, she continued to raise her only child by herself. And life was not easy for her to raise a child with autism alone.

Asnakech expressed those difficult nine years like this:

> *"Right after I gave birth, unfortunately my husband died unexpectedly and life was very difficult for me because I had no income. Then I started baking 'injera' brewing tela' by going from house to house to support myself and my child although my employers are unhappy about my having a child with autism. What is worse, my child became unable to speak, communicate and do nothing at all. What is more, she started to shout continuously that the neighbors were complaining a lot and this put me under a lot of pressure and stress together with my big financial problem. And the worst thing was that she hurt herself so badly that I did not know what to do. Then I took her to different holy waters, sorcerers and other places to find solution. But none of them helped me one way or another. Consequently, just because I had to work to support us I detained her out of frustration at home by chaining her hands and legs because no kid wanted to be or play with her for their parents told them so. When I tied her constantly, my child became sick especially the bruises on her hand (wrist) and legs put her in great agony. Then people started nagging me to give her over to adoption. The truth is no body was willing to accept a sick child."*

Even when Asnakech took her child with autism out to do something, she always experienced uncomfortable expressions from the people like sympathy and pity and their sympathetic looks as if I was wronged or cursed. About this issue she had to say;

> *"Whenever I am with my daughter on the streets walking, people stare at us as if we were aliens from another planet. This hurt my morale a lot and made me feel inferior and unworthy."*

Asnakech continued her life in such miserable way for nine solid years up until one day somebody told her that her child is with autism. The truth is she didn't know anything about autism. Then, that same person informed her that there was a place he knew that could help children with autism and gave her the address. She directly went there after some days. Asnakech had to say about it like this:

> *"When I heard about the center, I went there directly after some days. When I got there, I stood by the gate for quite some time for fear that they would reject me. But at last, I gathered my courage and went inside. There someone asked me what I wanted*

> *and told him my problem. He, then, directed me to the owner. Finally, I explained the reason for my being there in detail and she told me to come back with my daughter the next day and took my address."*

After that moment Asnakech didn't want to go back to that place thinking that it would be naïve to take her child to such kind of exotic place.

Days gone by and there was no sign of Asnakech's return to the center. Then, the owner of the center personally went to her place to look for her after discovering the address Asnakech left in the center.

Finally, the owner could manage to get Asnakech and brought her daughter to the center. The people in the center helped her get a house to rent around the center. Furthermore, the center again helped Asnakech get a job – baking 'injera' outside the center and involved her in the small scale business called 'Baltina' which has been owned and run by the center itself. Now Asnakech has got jobs because of the support of the center. She admitted this by saying: -

> *"Because of my child, I could get my own income to support us and has become known for I am witnessing about what God has done to us where ever I go. Now she is my life."*

In addition to these, the center has also been giving her monthly training on how to feed, dress, eat, and make her child sleep soundly at night. What is more, even to and from school she used to carry her child on her back and now this problem has become history for the child did these by herself. And this gave relief to the mother.

To this end, Asnakech wanted to get additional help from other pertinent bodies especially medical help for her child as it was very expensive.

Case two

Alemu was fifty five years old father who lived in Addis Ababa around Kaliti. He has had three children one of them was with autism. As far as his education background was concerned, he has had diploma and served as a teacher for twenty five years. It has been believed by many that it was mothers who have suffered mostly in handling children with autism but when it comes to Alemu the reverse was true. That is, Alemu has always been the one to take care of the boy.

Alemu's child with autism was Twelve years old. And up until this year, the boy as well as his family members could get no support from any one in particular. In this regard, Alemu had to say the following:

> *"When I looked at the boy, I was beginning to feel sorry that I didn't do anything worth telling. From then on, I started asking people on what I should do to help him and most of them told me to take him to holly waters. On the other hand, I started to read more about the disability. In fact, I found much more information on the overall perspective of the disability even if I know nothing on how to practically apply it. Accidentally, while I was waiting for transportation with my child to go somewhere, a stranger asked me where my child was learning. But when I told him the tragic truth that my child had never been to any school, he, then, was highly surprised and thought I was joking. Eventually, he informed me that there are some two places he knew and gave me their addresses. Then, I directly went to both places and discovered some things about how they have been working. Then I chose the place called Joy center for Autistic children for some convincing reasons. These are: firstly, the center's relative location (proximity). Secondly, the plausibility of the support system. And thirdly, the hospitality of all the workers. I eventually went there and explained my problem and they accepted my boy after sometime."*

It has been six months now since his boy started to get support. Besides accepting the child, the school (center) was also willing to support him (the parent) with school fee, but he was not willing because he could afford by himself.

Alemu was very satisfied for he was getting support. He even said,"

> *"Before my child came here, he was very naughty, sleepless, eats a little, disobedient, undisciplined. But now all these are partially solved due to the training we (the servant and me) get from the center once a month and the feedback we get from the communication book the school prepares to communicate with us. On this book, the teachers brief us the points we should apply to help my child. The points are ranged*

> *from the kind of food I should serve to my child to the different kinds of skills I should teach him like games, toileting, cooking, dressing, and shopping"*

On the other hand, among the many challenges he faced the family member especially his wife and children were not willing to help him by not also taking the training given in the center. The disobedience of the children might have come due to the reaction their mother show to me in front of them.

Alemu has many challenges in raising his child with autism. Primarily, his family members especially his wife and children were not cooperative particularly in taking the training given in the center and did not support him in taking the boy to and from school. Second, and most importantly, he had this huge transportation problem. This is because; he came from a very distant place. Third, since he used public transportation the drivers along with their assistants were always complaining transporting the child for he produced uncomfortable sounds which in turn created uneasiness for passengers. In this regard, Alemu explained bitterly like this:

> *".... When I am about to put him in the car, the assistants push us away and show their unwillingness to transport such kind of child since he disturbs and creates uneasiness to the passengers ....the bottom line is these service givers should be educated and instructed on how to handle people with any kind of disability."*

He further protested that the center couldn't provide adequate transportation service for those who come from far areas. Their primary reason was shortage of cars but in his opinion, the problem can be tackled if the center took the initiation in communicating with NGOs and other governmental organizations for their help.

Even if he perceived that the service given in the center was inadequate, he never complained. Because there was no any other option available nearby. In general, Alemu was somewhat happy with the service given in the center primarily because he got relief and could manage to do other routines; secondly, his child has also become responsive because of the support from the center. In this regard, he has recommended some important points to be executed like;

> *"The government should take the initiative to open up other schools for children with autism at some main parts of the city, other stake holders should also involve in helping strengthen the existing centers and prepare them to be fully fledged institutions that provide different kinds of sport activities, the center ought to hire psychiatrists, psychologists, nurses for these children by any means necessary as there are shortages of trained work force particularly for these children, the center should also make possible incentive packages for teachers and assistants to maximize their performance and to stay in the profession, parents/families should be assisted to the maximum both from the center and the pertinent governmental bodies with the things they are challenged with such as provision of transportation, hiring psychiatrists, and availing some necessary utensils."*

Case three

Feven was a forty year old woman who lived in Addis Ababa with her family. She was married and had three children. One of the children, the youngest who was nine years old was with autism and the other two were not. As far as her family background was concerned, her husband was a business man and had good income. Nevertheless, he had little concern about the sick child except for providing him financially and deliberately acted as if the child did not belong to him and this has always stressed the mother out. Unlike their father, my other two children without autism helped me in any way necessary whenever I asked of them regarding their brother with autism even though they were teenagers. Concerning the child, at first she discovered some stereotype abnormal behaviors and took him to a family doctor. The doctor there told her that the child was with autism and immediately she reacted as if she was struck with thunder. With regard to this situation, Feven reported in her own words like this:

> *"When he told me that my child was with autism, I was very shocked and couldn't accept the fact for a long time…then after calmed myself up, I again went back to my doctor and asked him what I should do and advised me to consult the pertinent professionals and get help."*

Consequently, she imparted the issue to her husband in case he helped her but suggested to take the child to her mother. Being desperate, she gave her child with autism over to her mother to watch him over by budgeting large amount of money but that did not even work out because the grandmother complained of his nasty behavior and the scold of the people around and eventually gave him back to her.

After that, she started taking care of him by herself by quitting her job. With regard to this situation, Feven reported in her own words like this:

> *"After my own mother told me that she had had enough of my child, I decided never to give him away from me no matter how but it was in vein because through time I began to experience loneliness ,depression, and stress especially when my other two children were away to school and finally I got sick. Then, the doctor to whom I told my story about was unhappy about neglecting his last time advice and exclaimed me to take some immediate solutions such as finding the right place to teach my child important life lessons and hire a maid although they didn't stay long due to his hyperactive behavior."*

The next step she did was to look for a center/school to get support for both of them. She replied that;

> *"In fact, it was not an easy job to look for a center and got acceptance. Fortunately, when I confided in my child's situation to some friends, they directed me to this center. Then, I went there and requested them to take in my child. Nevertheless, they told me that I had to wait on the waiting list until they called me when they got vacant place."*

At the end, they accepted her child and started to teach him basic life skills like talking, toileting, writing, playing; cooking, shopping and the like even though the change was very slow. The fact was many of her problems with regard to her child were being solved despite her child's being resistant to change. She said."

> *"It is very interesting that I am beginning to experience happiness just because primarily I get a place to teach my child. Second, the monthly formal training and the feedback about his daily activities from the communication book together with a series of tips such as the kind of food I should feed him and the like are helping me a lot in shaping my child when he is at home with the family. However, when it comes to writing, he is still not able to write properly because he is defensive to change. What is more, before he was admitted to the center, he was very nasty in the car when*

> *I took him to some recreational centers but now he is becoming peaceful. This change is achieved because of the unconditional support he gets from the center and I am grateful to this. "*

What is more, her very happiness nowadays was that she could do whatever she liked because of the incalculable support she got from the center. She further reported that as a parent she wished her child to have his own teacher. That is to say, one teacher for one child even though it would be too costly.

At last, she recommended in her own words by saying;

> *"Unlike me there might be parents who can't afford for any of the costly expenses to raise a child with autism. So any pertinent body ought to help them. "*

All in all, she has found the service provided in the center to be satisfactory. Nonetheless, the support from the society was embarrassing when you had a sick child not to mention her husband's misunderstanding of autism and it was hoped that he would change his mind for good when he understood it well.

Case four

Worke was a fifty year old married woman who lived in a small house rented from "kebele" with her husband and three children out of which the youngest was nine years old and had a severe autism. With regard to Worke and her husband's educational background, both of them were uneducated and their life was in poverty. Previously, Worke used to have job in a factory as a janitor though she stopped it because of her son. Coming to her husband, he worked in a dairy ranch in the area of milking cows. Nevertheless, what he earned was very little to feed the family. Due to this, the two daughters were engaged in different income generating businesses to support the family.

At first, Worke didn't know anything about autism up until she heard about it from other persons secretly talking about her own son. Some of them even asked her whether it could affect their children while playing with him. Then, she started searching for some information about the kind of problem it was although it was very difficult to get because almost nobody was willing to communicate with her for she had a child with autism. However difficult it was, at last, she managed to know the kind of disability it was and told to her family though in vein then she started to look for its solution if there was one.

Worke lived in a village where many household lived and this affected her a lot because of the complaints she received due to her child’s recurrent scream and aggressive behavior. About her past miserable life, she didn’t want to talk or remember anything about those nine challenging years she had been through because of her child with autism. Her problems were bi-dimensional i.e. the problem she was facing were not only from the community but also at her own home before she came to the center. Speaking of the center, she came to know about it when two friends of her husband came home and spoke about the child’s disability and advised her to go to “kebele” to get cooperation paper. She, then, immediately went there and got the paper. After some days, she went to the center and got acceptance.

With regard to this she has to say: -

> *“Thanks to the center it has been three years since my son joined the center and more or less things are now conducive. Even though my other two children and my husband are unwilling to listen whenever I start to discuss anything about the child’s condition”*

According to Worke, she was psychologically unbalanced for she was highly discriminated both outside and inside her home and this led her to different kinds of emotional problems. Currently, Worke has got some supports from the center like how to boost her confidence. To mention, her child got education and got food for free. Besides, he got good care and love. Even though her child has been in the center for quite some time, he couldn’t bring the required changes like eating by himself, toileting and talking. It is profoundly affecting her because she didn’t have ample time. With regard to this she has to say: -

> *“I couldn’t perform the given training from the center practically because I am the only person who cares for the child and does the house chores since my other two children are out all day to win their bread.”*

Whenever Worke raised the issue of taking training to her husband, he says, “It doesn’t concern me.” He thought that she was responsible for the child’s being with autism by saying that nobody was like this both from his father and mother side. And she was that close to accepting the blame until she was given the right education from the center. About this, she had to say:

> *"In fact, it would be unfair to trouble my husband and my other two children to go to the center to take training because all of them were busy to support the family. So, this was the very reason for the child not to bring the change my son deserved because I am the only one who take training from the center. Since I am illiterate, I am usually unable to execute what I have been taught properly."*

With regard to transportation, since she lived far from the school i.e. around 'saris'., she had to take public transportation to take and bring the child from school four times a day with a meager amount of money she got from her husband. She endured this burden because her child was benefiting free education and food from the center. Needless to say that 'Higer' bus drivers and the assistant, especially in the morning, are always resistant in letting in the child in the car due to his (the child's) hyperactive behavior and this was found to be a huge problem according to her.

Worke further complained that she asked the center to involve her in women's 'Baltina' which was headed by the center but has not yet found any response unknowingly. In line with this, Worke has admitted that even if she was given the chance to work in women's 'Baltina', she herself knew the fact that she couldn't do it properly because her entire time was spent by taking her child to and from school.

At last, she admitted receiving satisfactory services and for that she was highly grateful to the whole personnel in the center for their support for persons like them.

In the meantime, she bitterly wished to get her husband's and the other two children's attention towards the child and minimize her stress for she was getting older. What is more, she wanted people like her neighbors to be informed about the nature of autism. Because once, some years back some of her neighbors were totally unwilling to have anything to do with her and family with regard to even exchanging goods.

Case five

Mulualem was a forty year old married woman who used to live in Gambella due to her husband's nature of work but now moved to Addis Ababa with her husband and daughter. Her daughter was a fifteen year old girl with autism. The girl has not been educated or supported for quite some time for there were not centers to support students like her in Gambella.

As far as Mulualem's educational background was concerned, she worked as a Laboratory technician though was not working with it for the sake of taking care of her only child. Her being educated helped her to dig massive information from the internet about her child's disability and was able to find a center to send her daughter right after they came to Addis Ababa. Therefore, it could be understood from the above statement that her husband was the only active person on duty in supporting the family and cover the costly expenses of their child with autism though unhappy about it. She wanted to have another child but he remained deliberately negative about it and told her that he would think about it some other time yet nothing has happened. She used to remind him that they were under oath in the eyes of God to help each other for good and for worse but still nothing worthwhile came out of him. So, she always insisted on God to revive their former happiness.

Mulualem complained that even her parents- father and mother, together with the society, were highly superstitious towards her child's condition. Especially her parents blamed her husband by claiming that their race was pure and nothing like this kind of disability has ever happened in their life. With regard to this, she had to say;

> *"The first seven years, i.e. before my child was admitted to the center, were the times that I hated my being human because I had almost no body to support me including my husband who is blaming me and my parents who are blaming him. In the middle, I was stuck and was profoundly discriminated for I have a child with autism."*

Having passed those seven years at home with her child with autism, she started to look for a center to get support since she was equipped with the information from the internet. Then, she asked other people the location of the centers that gave support for such children. Then, she went to Joy center for autistic children after visiting center after center, and found the aforementioned center convenient for her in some aspects like transportation.

She was then easily accepted after some months because at the time of the discussion between the management and Mulualem, the management discovered her knowledge of the disability and reached to a consensus that she would be an advantage both for herself and the center for she could benefit other parents after getting additional training from the center.

In the center, at first the girl got some communication therapy, and could manage to utter some words and phrases that enabled the mother to know her child's wants. In this regard she said;

> *"To my surprise my child has not only started to say some basic words but starts to listen some commands as well which is a miracle for me to see what seemed to be impossible not only for me but also for some who knows her before and I am grateful."*

Again with the help of the center, her child has got different kinds of shoes from Cheshire foundation with which she can walk properly for long. That is, the child has had walking problem as well as it is customary for some children with autism.

Surprisingly, she further said in her own words:

> *"It is amazing for me to see the owner's, the teachers', and the assistants' smiling faces whenever I am there at any time. And these lift my hopes up profoundly and make me think that I am accepted and not alone."*

She, again, added if any parent practically executed what was forwarded from the center as training, it would give a lifelong benefit to handling the child with autism in different dimensions and even the person can be of a great use for others.

Mulualem again was satisfied with the center's service and for getting something to count on and got relief in everything. These days, she was successful in teaching her girl toileting, cooking and some games which were great problems previously.

When she was asked if she had anything to say about the center, she amazingly pointed her finger at some disobedient parents (as a matter of fact, their reasons might be otherwise) who could not accept their child’s disability and fail to practically perform the trainings given from the center. She further said:

> *“When I discuss with other parents in matters related to our children’s disability when we meet while taking our children home they usually tell me that they are highly occupied in doing house chorus. And that it would consume much of their time and unable to practically execute the trainings given to them from the center.”*

She anxiously concluded by suggesting that particularly pertinent government bodies must take the initiative to open up other centers for children with autism because when they got older it would be inevitable for the children to leave the center and no longer be cherished as there was no ample space to keep them when the time comes. This is simply because other children on the waiting list must be admitted to the center to get support. So, ultimately, the expelled children’ fate would likely be at stake for there has not been other centers prepared to accept older children with autism. In addition to this, she suggested that the center should make available transportation services as much as possible by creating linkages with respective bodies especially for mornings when barely transportation services are available.

Interview results obtained from teachers and head of teachers

An interview was made with three teachers and one head of teachers mainly focused on the kinds of professional support systems, challenges of the support system, and plausibility of the support system as perceived by the families. Accordingly, the following major findings were obtained:

1. **Professional support systems**

It was reported by the teachers that families were active in supporting and making their children less hyperactive. This change has been achieved due to the effective implementation of the trainings by the family members given from the center. However, time constraint was a major problem for families to carry out their training on their children effectively ; this has happened due to the various responsibilities they shoulder starting from fetching their children to taking care of everything at home. In the mean time, the trainings for families were on how to cook and feed their children recommended food stuffs, drinks; socialize in the community, how to train their children to cook and dress their clothes, and most crucially on how to boost their confidence in time of difficult situations. Apart from the families, the children were also given trainings like walking properly in the street, preparing simple meals, toileting, playing, singing, and speaking. In fact, all the trainings consumed much of the teachers time as most children were defensive to changes.

Finding depicted especially single mothers are organized in women's 'Baltina' and earned their livelihood by participating in the preparation and selling of various kinds of spices

Parents were always exclaimed to change at least: the colors of toilets and toileting materials (popo), recreational centers, roads, shoes, playing materials, the peoples around and these would minimize the routine nature of their life and they can become cooperative and happy. If they did these, they could certainly get the changes they wanted in due time.

2. Challenges of the support system

The finding added, there were some families who did not follow the school's instruction on the communication book. That is to say, when they were told not to feed their children carbohydrate foods and drinks (beverages, chocolates, candies, bread, etc.) they seemed to be reluctant and gave them. And these food stuffs could make the children more hyperactive than they were before. And the problem bounced back to them. When the children got toothache, parents took them to hospitals. And every time they took them, parents were requested not to give the children carbohydrate contented stuffs before they went there. This was because the anesthesia did not work properly on these children if they consumed what they shouldn't have.

Apart from the above themes, the professionals in general suggested that it would be better if there were many ample schools for these children, if parents especially single parents and poor parents were given free transportation services, if the society did not stigmatize the children and the families since autism was not pandemic, if they were given homes because nobody wanted to rent them for their children created weird sounds.

According to the parent participants' understanding, in order to intensify teachers' devotion to the profession, and to make them adore the children more than they did, incentive packages should be designed for what they do in the center has always been highly challenging.

3. Plausibility of the support system as Perceived by the families

Parents were witnessing their satisfaction with the centers service for getting something to count on and getting relief in everything. These days, they were successful in teaching their children basic skills such as toileting, writing, shopping, dressing and playing which were great problems previously. In addition to this, because of the communication therapy, the children have now been able to manage to utter some words that have enabled families to know the children's wants. Additionally it is found out that the trainings families get from the center are helping them a lot in shaping their children when they were at home with the rest of the family. Besides, the center made it possible for a child to get uniquely designed shoes as she couldn't wear the familiar shoes as other children. Despite the fact that, families' perception towards the support system was good, they have had a number of complaints particularly transportation problem which has been a headache for them.

Major findings obtained through FGD

As it is mentioned earlier in the methodology section, focus group discussion (FGD) was another tool used in this study to generate some data particularly on the psychosocial supports provided, psychosocial impacts and the perception of the support system by families of children with autism. Accordingly, the following major findings were obtained.

Accordingly, the focus group discussion was conducted with three teachers and one head of teachers and five parents of children with autism. In the course of the discussion, they had revealed the following major points. The discussion was held at the time when the school prepared the monthly coffee ceremony for the sake of creating discussion among families of children with autism and the teachers working there to share their views on various subjects. Besides, on this occasion, families would have the opportunity to get lots of important information on how to deal with their children successfully in the form of training.

As it was observed from of Focus Group Discussion, teachers were seen instructing the family members as deeply as they could possibly provide information on every topic they were asked. However, the most amazing thing was that there were family members who explained other families' questions effectively which should have been answered by the teachers. This encounter clearly showed that most family members have been applying the teachings obtained from the center practically. In line with this, most questions aroused from families were on their children's inability to bring about the intended change as quickly as they intended to. For this, they blamed some of their own family members for not taking part in the improvement of the children's overall situations.

As to the existing support system given for these parents to ameliorate their multifaceted problems, a satisfactory support is being provided with regard to feeding, toileting, taking care of their children. Besides, parents were also given teachings on how to boost their confidence for it is very crucial psychosocial support.

In the course of the discussion, some family members were heard complaining on financial issues. Some of them strongly insisted on getting financial support where ever the source. The complaints came because of the costly expenses in matters of their children with autism. One mother complained of the maids' payment. That is to say, whenever she told them that she had a child with disability, they asked more money than they should have normally been paid without even asking her the kind of disability. This was because they thought that there would be inevitable burdens awaited for them no matter what. And this was confirmed by other family members as well.

About financial issues one case said;

> *"What I earn is not sufficient for raising a child with autism because the expense for raising a child with autism is very costly in every way and this leads me to live a hand to mouth life."*

Hence, in order to maximize the psychosocial support for parents of children with autism, it was suggested that, parents should be benefited with free school fees, free recreational moments and health care supports should be provided for these children including transportation service. These in turn would benefit the parents otherwise. Moreover, teachers strongly recommended families to exert their maximum potential in taking the trainings and apply them properly if they wanted to see changes they aspired. Speaking of this, teachers strongly blamed familiar family members who regularly nourish carbohydrate oriented foods to their children which could potentially make them more hyperactive. But teachers were defended by families by saying that they were unable to feed their children the recommended foods for they had no enough money to afford for those kinds of foods. Another case was also heard forwarding his successful experience in the discussion. According to his experience, he regularly sent his child with autism to toilet with his sister without autism then through time he learnt from her to use toileting properly and quitted peeing on his trousers and this change was acquired from the trainings he received from the center. To sum up, the psychosocial challenges of parents, however, were mainly from the ungrounded superstitious thinking of the people around. Due to this, most of them were subjected to marginalization. Whereas, their financial problems were rooted at home since their counterparts were unwilling to assist them. What is more, from the atmosphere of the discussion, it was found out that most of the problems became persistent because of the failure of the families to perform the given trainings from the center for many convincing reasons.

Findings obtained through observation

Observation guide was another way of collecting data particularly on the psychosocial supports provided, psychosocial impacts and the perception of the support system by families of children with autism. Accordingly, the following major findings were obtained.

Early in the morning, families were observed bringing their children to the center. And the teachers' heartfelt hospitality while receiving the children in the morning was amazingly encouraging to families. And this was confirmed while they were asked by the researcher.

In the compound early in the morning these children were given practical lesson on how to celebrate flag ceremonies and to sing the national anthem of Ethiopia together with different kinds of songs to break their stereotypic behavior. Hence, primarily, this was believed to bring the children into a state of calmness. Secondly, these calm behavior children develop through this Practice would benefit families profoundly when they take their children out on the streets and on transportations.

During school time, the children were taught basic life skills like preparing simple foods (by wearing apron by themselves), eating properly, toileting on their own, wearing their clothes, playing different kinds of games and the like in different materially equipped classes. Besides, the children were given some sport activities like foot and basket balling, bicycling, and playing on a swing and on merry go-round. When they show hyperactive behavior, they were taken to a special class where they could be cooled down. All these in return would benefit families a lot in managing their children at home.

Recurring compound observation revealed that two of the cases were having transportation problem when they took their children home and had to ask for a lift. Moreover, many families were seen sitting outside of the compound at7.30 local time until 9.30 to take their children home. This depicted that they had transportation problem and this was the reason for them to come early.

Parents were observed treated by the care givers cordially when they enter the compound in the morning and afternoon. Furthermore, most of the families were repeatedly observed asking questions about their children’s stay at the center in each day and took the feed backs they got positively and in the mean time, they were given various game materials about which they took training for.

So, all in all, as it was observed by the researcher the given service was satisfactory given the country’s current situation.

CHAPTER FIVE

Discussion

In this section, major findings of the study are discussed based on the themes including: psychosocial challenges for families, nature of the support system and perception of the support system by families

5.1. Psychosocial impacts for families

5.1.1. Social problems

As it is discovered, centuries old hazardous traditional beliefs of discriminating and looking down of families of children with any disability is still vivid hence, the psychosocial well-being of families of children with autism is profoundly jeopardized. The fact that, families of children with autism are the central targets of social stigma and discrimination, their social relationship with other societal groups is found to be very slim. This in turn makes them have a feeling of isolation and loneliness. In addition to this, the superstitious thinking of the society is so hard that they don’t even want to share things with these families.

The society shows pity and sympathy when ever these families are out on streets with their children with autism. But these feedbacks would not help the families rather can destroy their confidence. For this and other reasons, families have to be integrated into the society unconditionally by educating the people at large. If this endeavor is performed in time, families are to be with the society whom they talk and confide in their problems. The fact is, these families (especially mothers) are profoundly affected socially both from the society and their own family members. Speaking of family members, fathers’ negligence in taking care of these children is negligible when it is compared with mothers overload. Therefore, from all family members, especially fathers ought to be active participants in matters related to their children with autism since they are the primary stake holders in matters related to these children.

5.1.2. Psychological problems

These problems are exactly the case of some cases in the study, thus, their state of depression leading to feeling of inferiority and self-hat redness should not be surprising. The fact that, parents of children with autism are secluded and underrated by their own families and the society often made them hide themselves. This happened because especially the media are not doing their very best in educating the people through different programs. Accordingly, apart from their impaired social life and consequences of continuous rejection and exclusion, families of children with autism often face psychological problems which make their condition more cumbersome and unbearable. According to Balogun (1995) psychological depression involves mood swing, anger, anxiety, distress and withdrawal. This sometimes affects people who suffer from a devastating damage or loss of a valuable possession.

Self-esteem is the degree of self-evaluation an individual places on him or herself to any given time. It is often learned more accurately from others and the value we think others attach to us (Balougun, 1995). An individual who reports a low level of confidence, enthusiasm and evaluation of him/her is said to have a low or poor self-esteem. In line with this idea, the reactions that are forwarded to families of children with autism by the people around makes them perceive themselves as worthless or useless.

Since the center is established to reach children with autism and their parents, it has every responsibility to train them in home level as deeply as possible to bring about tangible changes on all the family members. Consequently, this endeavor helps those family members who cannot come at the center to take training. Therefore, the task burdened family members can be relieved psychosocially and/or financially.

In fact, some of the participants are socio economically disadvantaged hence; no one wants to meet their physical needs required for supporting their children. It is clear that, the curtained economic condition families has which leads them to be engaged in different rigorous income generating activities can be solved so long as the stakeholders devout the money, they get from donation in the name of the these people, in its appropriate place. For families who take care of the children at home, apart from their running from place to place to win their daily bread, it is not fair to excessively engage them in different household chores such as preparing food, washing clothes, bringing children to and from school and by far they are also responsible for training their children with autism basic life skills acquired from the center. This in turn creates a big hindrance allowing them little or no time for themselves and societal activities.

5.1.3. Financial problems

The economic capacity of these families is very low because of their subsistence way of life hence, unable to afford to buy different materials for their children with autism. Supporting this, Traverse (2000) stated that poor families cannot afford the cost of education for their children. Therefore, urge their under age children to engage in hard labors, trade or deal with other income generating activities. Due to the burden the siblings have, they are unable to come to the center to take trainings that are important to both their sibling with autism and themselves. Mothers are also forced to travel long distance with their children with autism to school to save the little amount of money they get from their husbands. And this in turn creates extra burden for the mothers since they are the ones to take care of the house chores back at home. In line with this, because of money problem, these families are urged to use public transportations to take their children with autism to and from school. Therefore, it is the center that should design other income generating packages other than the ones available in the center lately.

5.1.4. Transportation problems

Another major hindrance for these families is found to be the remoteness of the center. It is clear that, travelling long distance daily to fetch a child with autism to and from the center is a cumbersome routine. Transportation problem is something that these families are suffering due to the place where the center is situated let alone the laborious ups and downs they should undergo to get transportation. For these reason, parents of children with autism are forced to neglect the house chores that expect them at home because of the distant location of the center. Concerning this, Tadesse and Adane (1993) indicated that, school zoning has a direct relationship with high dropout rate (in my) case failure to participate in societal activities and execute house chores. Accordingly, the center itself must either prepare services for the troubled or find a way from the government or any concerned individuals by any means necessary.

5.2. Nature of the Support System

As we can see from the interviewees report, the positive relationship between the center and the families is appreciable. As far as special care and systems in the school (center) is concerned, parents of children with autism are found to be benefiting a lot from the center's support systems such as provision of life skills, job opportunities, and modified shoes etc. Concurrently, the finding of this study clearly showed that all of the participants were provided with all the types of support the center has to offer. The support system can be strengthened when there are competitive centers nearby because competition has the power for any service to be given effectively. Besides, the availability of centers would optimally boost the family's self confidence to a greater level for they will have options to relay on.

According to the finding, only one student who has walking problem was provided with specially made shoes from Cheshire Foundation Ethiopia. The thing is, there are many seen in the centers that need such shoes. Therefore, in order to help others to get this kind of shoes, it is very easy for the center to create connection not only with Cheshire Foundation but also with other domestic shoe factories to manufacture it domestically to alleviate their problems and the families' who walk with the children where ever they go.

According to the finding, families are provided help only when they come to the center to collect their children or on the monthly coffee ceremony training day. But this is found to be minimal. That is, in order to really reach them to the level expected, professionals ought to go to their homes and give the supports they need on the ground.

As was revealed from the finding, the way the supports provided from the center are only through communication books and the monthly trainings. Nevertheless, recorded audio and video CDs, invited professionals, and teachers from other same centers can be of great uses in providing additional feedbacks on how to further reach these families and their children. Subsequently, the center is the only stakeholder in creating conducive provision of support by designing different solution oriented strategies starting from finding ample space to accepting more children and relieving families on pending list.

As it was seen at the observation session, to teach the children walking manners on the street, they are seen lined up and walk in circle quietly before flag ceremony starts and this should also be applied by taking them out side of the compound. This in turn can help families a lot while taking their children out on streets.

5.3. Perception of the support system by families

According to Dewdney (1993) children are more likely to attend their education in school and the objectives of the school are facilitated when the participation of parents in the school program is active. In this study, parent – school interaction was found to be very high. Due to the inaccessibility of the school (center), families of the children are always welcomed to participate on matters pertaining to the education and support given to their children and themselves.

In fact, the families' acceptance of the support systems comes from some convincing reasons. These are: firstly, it is the only center available around because of this they do not have the exposure to compare the services with other centers. Secondly, most families are less supported from the center. Due to this, whether they like it or not they remain appreciating it. Conversely, families disclosed that the caregivers do not get at least a balanced payment and from this they are doubtful that they are getting the utmost support from the center. What is more, families' perception of the support provision with regard to transportation is negative because it is only limited to those who could afford the fee when it should actually be given for the poor as well.

Needless to say, the helps families get from the center seem to be fully acknowledged by families. This is because other kinds of support systems are not available such as: providing professional psychological support, medical help, financial help and the like. In the mean time, families are obliged to wait on longer queues in hospitals looking for medication. Frankly speaking, such problems could have been solved provided that the center creates the link between the families and the respective hospitals. Given their children's' hyperactive behavior. Therefore, unless they are helped professionally in the center, the change needed would not come only through the communication book and the monthly training.

The fact that families of children with autism are welcomed and given the opportunity to interact with the school (center) creates good link between them and helps the children and their families get proper follow up and support.

CHAPTER SIX

Summary, Conclusions and recommendations

6.1. Summary

The major objective of this study was to explore the psychosocial impacts, the supports given and the perception of the support system by families of children with autism at Joy center Nia foundation for Autistic children.

The information gathered through interview, FGD and observation were discussed qualitatively. Hence, based on the review of literature and presentation of data the following findings were made.

Regarding personal information of the respondents, the finding showed that the number of male respondents was smaller than the number of female respondents. So this implies that the entire burden is almost laid on women at large than men.

In order to achieve the above objectives, the researcher had employed a qualitative research approach namely, a narrative method. The study was carried out at Joy Center – Nia foundation for autistic children around Vatican Embassy Addis Ababa. For this, five parents of children with autism (four female and one male) four teachers (care givers) and one head of teachers were selected from the targeted center for interview and focus group discussion questions by the center itself. Qualitative data was obtained via semi-structured interview, observation and FGD. To this effect, the following summaries were obtained:

As it was found, the psychosocial experiences of these families which mainly revolve around the social lives particularly the social isolation, exclusion, social support, friendship formation and related social experiences of participants were major impacts. According to some, they are now psychologically unbalanced for they are highly discriminated within the family and by neighbors who are somehow unwilling to have anything to do with them with regard to exchanging goods. And this leads them to different kinds of emotional problems.

Previously, when children came to the center, they were very naughty, sleepless, ate a little, disobedient, undisciplined. But now some of these are being solved due to the training they get from the center and the feedback they get from the communication book that the school prepares to communicate with them.

Among the many challenges the center face, some family members do not perceive and/or are not willing to take the training given by the center willingly. Due to this, parents admit that even when they are given the chance to work in women ‘Baltina’, they themselves know the fact that they can’t do it properly because their entire time is spent by fetching their child to and from school and even couldn’t perform the given trainings from the center practically because they are the only persons at home who care for the children with autism and do the house chores.

With regard to the service, some are found to be very happy primarily because they get relief and could manage to do other routines. Second, their children are also becoming responsive and this helps them a lot in shaping their children when they are at home with the rest of the family because of the support they get from the center. Again with the help of the center, some children have got different kinds of shoes from Cheshire foundation with which they can walk properly for long.

It is discovered that, the warm hospitality the owner, the teachers and the assistants towards the families whenever they go there has been found to lift their hopes up profoundly and makes them think that they are not alone.

Although families are given trainings on how to help themselves and their children, some failed to practically perform them because of the multi faceted burdens awaiting them at home. On the other hand, those parents that executed the trainings well could manage their as well as the children’s life as smoothly as possible..

Families are trained on how to cook food for the children, socialize in the community, and lift their hopes in time of despair. With regard to the intensity of exposure to challenges, mothers are found to be the primary victims. Result shows that, after getting psychological support from the center, families are now able to work properly and get mental satisfaction. Especially single mothers are organized in women’s ‘Baltina’ and could earn their livelihood there.

In contrast, the finding added that, there are some families who do not follow the schools instruction on the communication book. That is to say, when they are told not to feed the children with autism carbohydrate food and drink, (beverages chocolates, candies, bread, etc.)

they seem to be reluctant and give them. Consequently, these food stuffs would make the children more hyperactive than they are before then the problem would bounce back to them.

According to the finding, there were also potential parents who wanted to see sudden changes which were actually impossible due to the nature of the disability.

6.2 Conclusions

As the central goal of any school or center is to provide learning through effective teaching learning process, school stakeholders are expected to provide effective services for the attainment of the school goals. On the basis of the preceding findings, the following conclusions are drawn on each basic question.

1. There is a widely hold agreement that centuries of hazardous traditional practice of rejecting, discriminating and looking down of parents of children with autism. Due to their children's disability, the aforementioned truth is still vivid and the fact that these parents are discriminated and underrated by the society as well as their own family members. These have seriously threatened and further destroyed the psychological well-being of these parents hence, lack of self-confidence, frustration, fear, feeling to inferiority, mistrust and depression are found to be everyday experiences of these families. Apart from the psychological crises these families have, they experience social stigma, discrimination and poor social support from the society at large. The fact that, they are indirectly not allowed to participating in societal group activities and are found to be the central targets of social stigma, exclusion and poor social support leaving them lonely, without friend and hope. This in turn makes their life bitter and sorrowful which sometimes leads to the feeling of wishing death of their children with autism.

2. In addition to the above psychosocial problems, , many other challenges are hovering around them that make their life at risk. Among others that curtains economic condition to support their family including the costly expense of their child with autism. In addition to this, location of the school (center) is also out of the challenges these families face. So, it can be concluded that these families are deserted profoundly.

3. The research depicts that there are a number of children with autism on the waiting list to get support so the center has to do its very best to solve this problem.

4. The research also indicates that most teachers are unhappy for the management is not trying hard to please them, as their task is highly frustrating and tiresome, regarding preparing incentive packages. In conclusion, unless the management shows its optimism for teachers questions, quality education will be at stake.

5. It is identified from families that there are barriers to properly apply the trainings they take from the center. Therefore, it can be summed up that the center's training strategy needs to be improved a lot.

6. Contrary to the above point, the trainings given to these families are encouraging particularly on things that should be applied at home which are highly educative and informative with regard to helping families of children with autism in giving packages on how to benefit themselves and their children. And from these, these families are found to be beneficial both economically & psychologically. Therefore, it can be deduced that they have managed to acquire their lives back. Due to these, parents find the provision of support system from the center to be highly relieving with regard to alleviating their psychosocial pains and sufferings.

7. The support systems families get in the center are considered positively even though there are several things yet to be accomplished. In the mean time, another finding shows that there are potential parents who want to see sudden changes which are actually impossible.

Despite the fact that most respondents agree with the presence of timely and satisfactory support systems, it is discovered that there are space, transportation, provision of food, and money problems observed in prevalence. In line with this, teachers report their discontent towards the ignorance and reluctance of the center in giving them fringe benefits when they do extra tasks and this is found to bring about lateness to the required change on the children and the families..

6.3 Recommendations

The current study came to an understanding that families of children with autism were surrounded with many alarming circumstances. Therefore, unless some immediate and feasible measures are taken, the miseries and bitter sentiments of these families remain unsolved and further trigger them to serious psychosocial disturbances. Hence, based on the findings the following recommendations which are mainly from the voices of their own were forwarded.

1. The center together with other pertinent bodies should create means of income by participating families in marketable small micro-enterprises with credit provision to ameliorate their financial problem. This may put an end to their dependency.
2. Continuous education and awareness raising programs geared towards combating discriminatory attitudes should be given to teachers, family members as well as the community through conferences and public meetings including ‘Idirs.’
3. In order for families to get the support they deserve, the center ought to give continuous rewards and encouragements for all caregivers who cherish love and care for families of children with autism and take them as role models for the school community.
4. The school has to create a strong network with families and the community through Parent Teacher Meeting and continuous discussions should be made to mitigate psychosocial challenges of these families.
5. Concerned bodies in collaboration with the government, Education Bureau, NGOs’ and other stake holders must take the initiative to open up other centers for children with autism primarily because the families’ perception of the current support system can be rational balanced if there are optional centers. Second, when the children get older, they have nowhere to go for there are no other centers nearby.
6. Kirkos ’ sub city education office and the school management should provide seminars, workshops or formulating policies on the improvement of families of children with autism and the society’s relationship.
7. It was suggested that it would be better if there are many ample schools for them, if parents especially single parents would be assisted, if poor parents would be given free transportation services, if the society wouldn’t stigmatize them since autism is not pandemic, if they are given homes because nobody wants to rent them for their children create weird sounds. Moreover, this was suggested to minimize the routine nature of their lives and they can become cooperative and happy.
8. Finally, the school management has to create conducive environment for research works and strong professional relationships with and among school communities through continued efforts.

REFERENCES

Aluri U, Karanth P. (2002). Rehabilitation facilities available for children with autism/PDD in Bangalore city – A survey. *Asia Pacific Disability Rehabilitation Journal*; 13: 115-124.

Anderson SR, Romanczyk RG (1999**)**. Early intervention for children with autism: Continuum based behavioral models**.** *Journal of the Association for Persons with Severe Handicaps*; 24: 162

Anon (1998). All in the family autistic spectrum disorders and sibling relationships**.** Communication; 13-17.

Becker-Cottrill B, McFarland J, Anderson V (2003). A model of positive behavioral support for individuals with autism and their families: The family focus process**.** *Focus on Autism and Other Developmental Disabilities;* 18: 110-121.

Beresford B (1995). *Expert opinion: A survey of parents caring for a severely disabled child***.** Bristol: Policy Press,.

Beresford B (1994). Resources and strategies: How parents cope with the care of a disabled child**.** *Journal of Child Psychology and Psychiatry*; 35: 171-209.

Bernheimer LP, Gallimore R, Weisner TS (1990*)*. Ecological theory as a context for the individual family service plan**.** *Journal of Early Intervention* 14: 219-233.

Bhan S, Mehta D, Chhaproo Y (1998). Stress experienced and the coping methods used by the mothers of children with cerebral palsy**.** Praachi *Journal of Psycho-Cultural Dimensions*; 14: 15-19.

Boyd, R.L. (2002). Three decades of quality of life. *Focus on Autism & Other Developmental Disabilities, 15(2),* 116-128.

Brofenbrenner U (1986*). Ecology of the family as a context for human development: Research Perspectives***.** *Developmental Psychology*; 22: 723-742.

Burke P, Cigno K (1996*). Support for families: Helping children with learning disabilities***.** Aldershot: Avebury,

Dalal AK, Pandey N (1999). Cultural beliefs and family care of the children with disability**.** *Psychology and Developing Societies*; 11: 55-75.

Daley TC, Sigman MD (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians**.** *Journal of Autism and Developmental Disorders;* 32: 13-23.

Dunn J (1984). *Sisters and Brothers***,** London: Fontana Books,.

Fine MJ, Gardner A (1994). Collaborative consultation with families of children with special needs: Why bother? *Journal of Educational and Psychological Consultations*; 5: 283-308.

Folkman S, Moskowitz JT. (2000) Positive Affect and the Other Side of Coping**.** *American Psychologist;* 55: 647-654.

Fombonne, L., (2003) Wing, J.,Wing, D., & Potter, S. (2002). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 40*(2), 167-178.

Gallagher JJ, Beckman P, Cross AH (1983). Families of handicapped children: Sources of stress and its amelioration. Exceptional Children; 50: 10-19.

Gallimore R, Weisner TS, Bernheimer LP, Guthrie D, Nihira K. (1993***)*** Family responses to young children with developmental delays: Accommodation activity in ecological and cultural context**.** *American Journal on Mental Retardation*; 98: 185-206. Asia Pacific Disability Rehabilitation Journal 83 Vol. 16 No. 2 2005 J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

Gray DE. (2003) Gender and coping: The parents of children with high functioning autism**.** Social Science and Medicine; 56: 631-642.

Glendinning C. (1986) A single door: Social work with families of disabled children**.** London: Allen and Unwin,

Gupta A, Singhal N. (2005) Positive perceptions in parents of children with disabilities**.** *Asia Pacific Disability Rehabilitation Journal* 2004; 15: 22 – 35 *Asia Pacific Disability Rehabilitation Journal* 82 Vol. 16 No. 2 J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd

Gray DE. (1993) Perceptions of stigma: The parents of autistic children**.** Sociology of Health and Illness; 15: 102-120.

Hartley., Hong, J., Seltzer, M., Greenberg, J., Almeida, D., & Bishop, S. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 40*(2), 167-178.

Hastings RP, Johnson E. (2001) Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism**.** *Journal of Autism and Developmental Disorders*; 31: 327-336.

Hauser-Cram P, Howell A. (2003) Disabilities and development**.** In: Lerner RM, Easterbrooks MA, Mistry J, eds. Handbook of psychology: Vol. 6. Developmental psychology. New Jersey: Wiley,: 513-533. *Asia Pacific Disability Rehabilitation Journal* 81 Vol. 16 No. 2 2005 J.C. No. 123. D:\Jayaprakash\A P D R J\APDRJ_Vol.16-2.pmd-173. Sloper P. Models of service support for parents of disabled children. What do we know?

Holroyd KA, Lazarus RS. (1982) Stress, coping and somatic adaptation**.** In: Goldberg L, Breznitz S, eds. Handbook of stress: Theoretical and clinical aspects. New York: The Free Press,: 21-35.

Howlin P, Yates P. (1990) A group for the siblings of children with autism**.** Communication 1990; 24: 11-16.

Sheridan SM, Kratochwill TR, Elliot SN. Behavioral consultation with parents and teachers: Applications with socially withdrawn children**.** School Psychology Review; 19: 33-52.

Horner RL, Dunlap G, Koegel RL, et al.(1990) Towards a technology of "no aversive" behavioral support**.** *The Journal of the Association for Persons with Severe Handicaps*; 15: 125-132. 50. Dunlap G, Fox L**.** A demonstration of behavioral support for young children with autism. *Journal of Positive Behavior Interventions* 1999; 1: 77-87.

Johnson C. (2000) What do families need*? Journal of Positive Behavior Intervention*; 2: 115-117.

Kaminsky L, Dewey D. (2002*)* Psychosocial adjustment in siblings of children with autism**.** *Journal of Child Psychology and Psychiatry and Allied Disciplines*; 43: 225-232.

Kohler FW. (1999) Examining the services received by young children with autism and their families: A survey of parent responses. Focus on Autism and Other Developmental Disabilities; 14: 150-158.

Koegel RL, Koegel LK, Carter CM. (1999) Pivotal teaching interactions for children with autism**.** School Psychology Review; 28: 576-594.

Kirkham M. (1993) Two-year follow-up of skills training with mothers of children with disabilities**.** *American Journal of Mental Retardation*; 97: 500-520.

Koegel LK, Koegel RL, Kellegrew D, Mullen K. (1996) Parent education for prevention and reduction of severe problem behaviors. Baltimore: Brookes,: 81-98.

Leo Kanner. A. (1943). Assessing Need for Social Support in Parents of Children with Autism and Down Syndrome. *Journal of Autism & Developmental Disorders*, 36(7), 921-933.

Lucyshyn E, Blumberg R, Kayser AT. (2000) Improving the quality of support to families of children with severe behavior problems in the first decade of the new millennium. *Journal of Positive Behavior Interventions*; 2: 113-115.

McGee GG, Jacobs HA, Regnier MC. (1993) Preparation for families for incidental teaching and advocacy for their children with autism. OSERS, News in Print; Winter: 9-13.

Moes D. (1995) Parent education and parenting stress. In: Koegel RL, Koegel LK, eds. Teaching children with autism: Strategies for initiating positive interactions and improving learning opportunities. Baltimore: Brookes,: 79-94.

Peeters T. (2000) The role of training in developing services for persons with autism and their families. *International Journal of Mental Health*; 29: 44-59.

Randall PE, Parker J. (1999) Supporting the families of children with autism. Chichester: John Wiley,.

Robbins FR, Dunlap G, Plienis AJ (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention*; 15: 173-184. Sloper P, Turner S. (1993) Risk and resistance factors in the adaptation of children with s evere physical disability. *Journal of Child Psychology and Psychiatry*; 34: 167-188.

Sander JL, Morgan SB. (1997) Family stress and Adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. Child and Family Behavior Therapy; 19:1532.

Seifer R, Sameroff AJ, Baldwin CP, Baldwin AL.(1992) Child and family factors that ameliorate risk between 4 and 13 years of age. *Journal of American Academy of child and Adolescent Psychiatry*; 31: 893-903.

Symon JB. (2001) Parent education for autism: Issues in providing services at a distance. *Journal of Positive Behavior Interventions*; 3: 160-174. Singer GHS, Goldberg S, Peckham-Hardin K, Barry L, Santarelli G. (2001) Toward a new synthesis of family support: Practices for families of people with challenging behavior.

Sloper P, Turner S. (1992) Service needs of families of children with severe physical disability.

Child: Care, Health and Development; 18: 259-282.

Terry DJ, Haynes GJ. (1998) Adjustment to a low-control situation: Reexamining the role of coping resources. *Journal of Personality and Social Psychology*; 74: 1078-1092.

Tunali B, Power T. (2002) Coping by redefinition: Cognitive appraisals in mothers of children with autism and children without autism. *Journal of Autism and Developmental Disorders;* 32: 25-34.

Turnbull A, Blue-Banning M, Turbiville V, Park J. (1999*)* From parent education to partnership education: A call for a transformed focus. Topics in Early Childhood Special Education; 19: 164-172.

Vygotsky LS. In: Rieber RW, Carton AS, eds. (1993) The collected works of Vygotsky LS: Vol. 2. The fundamentals of defectology. New York: Plenum,. (Original work published in 1924-1931) What do we need to know*?* Child: Care, Health and Development 1999; 25: 85-99.

Wallander JL, Varni JW. (1998) Effects of pediatric chronic physical disorders on children and family adjustment*. Journal of Child Psychology and Psychiatry;* 39: 29-46.

Appendix I

ADDIS ABABA UNIVERSITY
SCHOOL OF GRADUATE STUDIES
COLLEGE OF EDUCATION AND BEHAVIORAL STUDIES
DEPARTMENT OF SPECIAL NEEDS EDUCATION

Interview guide for families of children with Autism

Dear participants, the following interview questions are designed to collect data for MA thesis study on the Psychological impacts, the supports provided and the perception of the support system by families of children with autism.Therefore,1 would like to thank you in advance for your kind cooperation.

Please read the instruction and each item in the questionnaire carefully before you give your response. If you want to change any of your response, make sure that you have cancelled the unwanted ones.

PART I: INTERVIEW HOLD WITH FAMILIES OF CHILDREN WITH AUTISM

A. Back Ground Information

1. Name__________________________
2. Age :- 20 – 25
   25 – 30 ☐
   30 – 35 ☐
   35 – 40 ☐
   40 and above _____________
3. Sex _________

4. Level of educational attainment

BA/BSc
MA/MSc ☐
Above ☐

Other______________________

5. Qualification

Major ___________________
Minor ___________________
Other ____________________

6. Year/s of work experience (service)

0 – 5 years ☐
5 – 7 years ☐
7 – 10 years ☐
10 years and above ☐

7. Position _____________________

1. Can you tell me about your child's disability and type?

2. Would you please elaborate the problems you face due to your child's disability with regard to communication, upbringing and schooling?

3. What challenges do you encounter in the center or from the people around?

4. What should be done to improve the services provided to parents of children with autism?

5. Is there any support from the center given to you?

5.1. If you say yes for the above question, what type?

5.2. If you say no, what was their reaction/reason for refusal?

6. What action did you take to solve the problem?

7. Do you think that children with autism benefit more when they are in the center?

7.1. If you say yes for the above question, can you mention some of the advantages?

7.2. If you say no, what are the disadvantages?

8. Do you think you are getting adequate support from the center?

8.1. If yes, what types?

8.2. If no, indicate the types of support you should have received in the center.

9. How do you see the support system given to you from the center?

Part II: Interview with Care Givers

A. Background information

a. Name _____________

b. Sex M ☐ F ☐

c. Age

Below 20 ☐

21 – 30 ☐

31 – 40 ☐

41 – 50 ☐

Above 50 ☐

d. Level of education

Diploma ☐

B. A /B. Sc/ ☐

M. A /M. Sc/ ☐

Others Specify ___________________

e. Area of specialization ______________

f. Experience _____________________

1. As it is known there are different types of Autistic spectrum disorders, can you tell me the prevalent type in this center out of the spectrums?
2. What challenges do you face when providing the services?
3. How do you evaluate the interaction between children with autism and their families?
4. If families of children with autism get support from the professionals, what type?
5. Do you believe giving support to families of children with autism benefits them?
   3.1. If you say for the above question, how?
   3.2. If no, what are the disadvantages?
6. How do you see the interaction of families of children with autism with professionals?
7. Do you think families get the supports they deserve from the center?
   7.1. If you say yes for the above question, explain them?
   7.2. If no, why?
8. What challenges/barriers do families of children with autism encounter in the center as well as from the society?
9. What supports do families of children with autism need?
10. What should be done to overcome the challenges and improve the provision of support to families of children with autism?

Appendix II

Guide for in- depth Interview

1. Can you tell me about the type of your child's disability?
2. How do you perceive the support you get from the center?
3. Did you get any support from people around you?
4. What was your experience with the psychosocial support given in the center?
5. What challenges did you face so far due to having a child with autism?
6. What did you tell yourself about your child's problem?
7. How was your life affected by having a child with autism?
8. What measures did you take to tackle the problem
9. Did you experience any negative situation due to having a child with autism?
10. What must be done to minimize the challenges you face?
11. Do you have anything to add?

ADDIS ABABA UNIVERSITY

DEPARTMENT OF SPECIAL NEEDS EDUCATION

Part I: General for Focus- group discussion guide for families of children with autism

Dear participants, the following focus group discussion questions are designed to collect data for MA thesis study on the Psychological impacts, the supports provided and the perception of the support system by families of children with autism.Therefore,1 would like to thank you in advance for your kind cooperation.

1. Does the center provide you services in relation to your problem?
2. What services does the center provide you to help you in day to day tasks?
3. What do you feel about the services provided?
4. Are these services adequate?
5. Are these services provided in a timely manner?
6. How does the center respond to your needs for accommodation?
7. What accommodations are provided for material?
8. Are these accommodations adequately provided?
9. What suggestions would you have to offer that would improve your life with a child with ASD?
10. Do you have any other comments? (Other questions I should ask?) a child with ASD?

Part II: Focus- group Discussion Guide for care givers

1. Do you think you are challenged when you give support to families of children with autism?
    1.1 If you say yes, how?
    1.2 If you say no, how do you handle them?
2. What challenges do you face when providing the services to families of children with autism
3. Do you think these families encounter challenges in home and from the society?
4. What should be done to overcome the challenges and improve the provision of support to families of children with autism?
5. How do you evaluate the interaction between families of children with autism and professionals in the center?
6. What type of support do families of children with autism get from the center?
7. Do you believe giving support to families would change their life positively?
8. What support do families of children with autism need?
9. Do you think these families are quite satisfied with the provision of support from the center?

Appendix III

General observation guide

To cross ascertain the data found from interview and FGD, this observation guide has to be designed to assess and collect live data from Joy Center-Nia Foundation for Autistic Children on the Psychological impacts, the supports provided and the perception of the support system by families of children with autism.

1. How are families of children with autism treated when they come to the center?
2. What are the lessons the children learn to improve their responsiveness?
3. How are the children treated and taught at class time?
4. What is the way that the families and the caregivers communicate in matters pertaining to the children and the families themselves?
5. How does the center train their families taught life skills from the center?
6. What is families' perception of the support system forwarded from the center?

ADDIS ABABA UNIVERSITY
DEPARTMENT OF SPECIAL NEEDS EDUCATION

Appendix I

ክፍል አንድ መግቢያ

ወድ የጥናቱ ተሳታፊዎች

እኔ የአዲስ አበባ ዩኒቨርስቲ ትምህርት ክፍል እና የባህሪ ጥናት ውስጥ የልዩ ፍላጎት የድህረ ምረቃ ተመራቂ ተማሪ ስሆን በአሁ ስዓት የመመረቂያ ጸሁፌን በማዘጋጀት ላይ እገኛለሁ፡፡ የጥናቴ እርዕስም "ኦቲዝም የሚያስከትለው ማህበራዊ ቀውስ በቤተሰብ አባል ላይ እና ለቤተሰብ የሚሰጠው ድጋፍ እና የድጋፍ አተያያቸው በጆይ ማእከል ኒያ ፋውንዴሽን ለኦቲዝም ተጠቂ ሕፃናት በሚል ነው፡፡ እርሶም በዚህ ጥናት እንዲሳተፉ ተመርጠዋል፡፡ እርሶ የሚሰጡት ትክክለኛው መረጃ ለጥናቱ ውጤታማነት አስፈላጊ መሆኑን በመገንዘብ ጥያቄዎቹን በጥንቃቄ አንዲመልሱ እጠይቃለሁ፡፡

ተሳተፎ በእርሶ መልካም ፍቃድ ላይ የተመሠረተ ነው፡፡ በመጨረሻም የሚሰጡት መረጃ ሚስጥራዊነቱ የተጠበቀ እና ለዚህ ጥናት አላማ ብቻ እንደሚውል አረጋግጣለሁ፡፡ የማንኛውም መልስ ሰጪ ማንነት በማንኛውም መልኩ የማይታተምና የማይሰራጭ ይሆናል፡፡ ሁሉም መረጃዎች ለትምህርታዊ አላማ ብቻ ይውላሉ፡፡ ጊዜውን ሰጥተው ስለሚያደርጉልን ትብብር በቅድሚያ አመሰግናለሁ፡፡

ዳንኤል ኃ/ሚካኤል

ክፍል ሁለት

ከቤተሰብ አባል ጋር የሚደረግ ቃለ መጠየቅ

ሀ. ግለ መረጃ

1. ስም ----------------------
2. እድሜ 20- 25 ☐

   25-30 ☐

   30-35 ☐

   35-40 ☐

   40- እና ከዛ በለይ -----------------

3. ጾታ -----------------

4. የትምህርት ደረጃ

የመጀመሪያ ዲግሪ ☐

ሁለተኛ ዲግሪ ☐

ከዛ በላይ --------------------

ሌሎች -----------------

5. የትምህርቱ ዓይነት

አብይ ---------------

ንፁስ ----------------

ሌሎች ---------------

6. የሥራ ልምድ

0-5 ዓመት ☐ 7-10 ዓመት ☐

5-7 ዓመት ☐ 10 ዓመት እና ከዛ በላይ ☐

7. የሥራ ድርሻ ------------------

<u>ክፍል ሶስት</u>

1. ስለልጆዎት የአካል ጉዳት እና ዓይነቱን ቢነግሩኝ?
2. በልጅ ምክንያት የደረሰቦትን ችግር ቢነግሩኝ? ያአስተዳደግ፣ በመግባባትና ትምህርትን በተመለከተ?
3. በተቋሙ ወይም በሕብረተሰቡ ምን አይነት ችግር ገጠሞት?
4. እገዛው በተቋሙ እንዲጎለብት ምን መደረግ አለበት ይላሉ?
5. ከተቋሙ የተሰጥዎት እርዳታ አለ?

ካለ ምን አይነት ?

ከሌለ ምን ነበር ምክነያቱ?

6. ችግሩን ለመፍታት ምን የመፍተሔ እርምጃ ወሰዱ?
7. ተማሪዎቹ በተቋሙ ቢማሩ ይጠቀማሉ ብለው ያስባሉ?

አዎ ካሉ ምን አይነት ጠቀሜታዎች አሉት?

አይ ካሉ ችግሮቹ ምንድናቸው?

8. ከተቋሙ የተሟላ ድጋፍ እያገኘሁ ነው ብለው ያስባሉ?

አዎ ካሉ ምን ምን አይነት ድጋፍ?

አይ ካሉ ምን አይነት ድጋፍ ማግኘት ነበረቦት?

9. እየተሰጡ ያሉትን ድጋፎች እንዴት ታያችኋላችሁ?

Appendix II

ክፍል አራት

ቃለ መጠይቅ ከድጋፍ ሰጭዎች ጋር

ሀ. ግለ መረጃ

1. ስም ----------------------------

2. ፆታ ሴት ☐ ወንድ ☐

3. እድሜ -----------------

ከ20 በታች ☐ 31-40 ☐ ከ50 በላይ ☐

21-30 ☐ 41-50 ☐

4. የትምህርት ደረጃ

ዲፕሎማ ☐ ማስተርስ ☐

ዲግሪ ☐ ሌሎች -------------------

5. የሰለጠኑበት የትምህርት አይነት ----------------------

6. ልምድ -----------------------

ቃለ መጠይቅ ጥያቄዎች

1. በተቋሙ ውስጥ በብዛት የሚታየውን የኦቲዝም አይነት ልትነግሩን ትችላላችሁ?
2. አገልግሎት ስትሰጡ ምን ምን ችግር ገጠማችሁ?
3. አገልግሎቱ ለቤተሰብ የሚጠቅመው ነገር አለ?

አዎ ካሉ እንዴት?

አይ ካሉ ለምን?

4. የቤተሠብ አባል ከተቋሙ ጋር ያለው ግንኙነት እንዴት ነው?
5. ተማሪዎቹ ተገቢውን ግልጋሎት እያገኙ ነው ትላላችሁ?

አዎ ካሉ ይብራራ?

አይ ካሉ ለምን?

6. ቤተሠቦች ከተቋሙም ሆነ ከሕብረተሰቡ ምን ምን አይነት ችግር እየገጠማቸው ነው?
7. ቤተሠቦች ምን ምን አይነት ድጋፍ ይሻሉ?
8. ችግሮቹን ለማስወገድና ድጋፉ ጥሩ እንዲሆን ምን መደረግ አለበት ትላላችሁ?

ክፍል አምስት

በቤተሠቦች መካከል እና በመምህራን በሚደረጉ ውይይቶች ላይ የተዘጋጀ ቃለ መጠይቅ

1. ተቋሙ እናንተን ያማከለ እገዛ እያደረገ ነው?
2. የሚሰጡት እገዛዎች በእለት ተእለት ኑሮዋችሁ ላይ ምን አስተዋጽኦ ያደርጋሉ?
3. በሚሰጡት አገልግሎቶች ላይ ምን አስተያየተ አላችሁ?
4. አገልግሎቶቹ በቂ ናቸው ትላላችሁ?
5. አገልግሎቶቹ ወቅታቸውን ጠብቀው ነው እየተሰጡ ያሉት ትላላችሁ?
6. ፍላጎታችሁን ከሚሟላት አንፃር ተቋሙ ምን እያደረገ ነው?
7. ተቋሙ በማቴሪያል ድጋፍ ያደግላችኋል እንዴት ሌላ የምትሉኝ ካለ እድሉን ልስጥ?

Appendix III

ክፍል ስድስት

የዳሰሳ መጠይቅ

1. ቤተሠቦች ወደ ተቋሙ ሲመጡ ምን አይነት አቀባበል ይደረግላቸዋል?
2. ተማሪዎቹ ለነገሮች ምላሽ እንዲሰጡ ምን አይነት ትምህርት ይሰጣቸዋል?
3. በትምህርት ስዓት እንዴት ነው የሚማሩት?
4. ተቋሙ ልጆቹን እና የቤተሠብ አባልን በተመለከተ ከቤተሠቦች ጋር እንዴት ነው? ውይይት የሚያደረገው?
5. እንዴት ነው ተቋሙ ተማሪዎችንና ቤተሠቦችን የሕይወት ክህሎት የሚያሰለጥነው?
6. ከተቋሙ የሚሰጠውን ድጋፍ ቤተሠቦች እንዴት ነው የሚዩት?