

ADDIS ABABA UNIVERSITY

COLLEGE OF EDUCATION AND BEHAVIORAL STUDIES

DEPARTMENT OF SPECIAL NEEDS EDUCATION

PARENTS' INVOLVEMENT IN IMPROVING SELF- HELP SKILLS

OF CHILDREN WITH AUTISM: JOY CENTER OF NIA

FOUNDATION FOR CHILDREN WITH AUTISM IN FOCUS

BY: ELIYAM WERETU TAYE

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Declaration

I declared that this study is my original work towards the degree of masters of art in special needs education and has not been submitted for any degree or diploma in any university. To the best of my knowledge, all sources of materials used for the study have been appropriately acknowledged. I have undertaken the study independently with the guidance and support of the research advisor.

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Table of Contents

	Page
Acknowledgments	i
Table of Contents	ii
Appendixes	v
List of Acronyms	vi
CHAPTER ONE.....	1
INTRODUCTION.....	1
1.1. Background of the Study	1
1.2. Statement of the Problem.....	4
1.3. Objective of the Study	7
1.3.1. General objective.....	7
1.3.2. Specific objectives	7
1.4. Significance of the Study	8
1.5. Scope of the Study	8
1.6. Limitations of the Study	8
1.7. Definition of key terms.....	9
CHAPTR TWO.....	10
REVIEW OF RELATED LITERATURE.....	10
2.1 Parental Involvement.....	10
2.2. Intervention Implemented By Parent	11
2.3. Self-Care Activities	15
2.3.1. Dressing	16
2.3.2. Toileting.....	16

2.3.3. Grooming and Hygiene	17
2.3.4. Self-Feeding.....	17
2.3.5. Safety skill	18
2.4. Importance of Parent Training	18
2.5. Parents as Therapists	19
2.6. Highly Trained Teachers.....	20
2.7. Collaborative Practices	21
2.8. Factors Contributing to Lack of Parental Involvement	22
2.8.1. Stress	23
2.8.2. Financial Impact	24
2.8.3. Divorced.....	24
2.8.4. Time and Socioeconomic Status	25
CHAPTER THREE	27
RESEARCH METHOD	27
3.1. Design of the Study	27
3.2. Research Setting	27
3.3. Study Population.....	28
3.4. Sampling Technique.....	28
3.5. Data Collection Methods	29
3.5.1. The Semi-Structured interview	29
3.5.2. Focus Group Discussion	29
3.5.3. Anecdotal observation.....	30
3.5.4. Document review.....	30
3.6. Procedure	30

3.6.1. Interview	31
3.6.2. Focus Group Discussion	31
3.6.3. Anecdotal Observation	31
3.7. Method of Data Analysis	32
3.8. Ethical Considerations	32
CHAPTER FOUR	33
RESULTS OF THE STUDY	33
4.1. Socio-Demographic characteristics of the Respondents	33
4.2. Supports/Services and Trainings	36
4.2.1. Trainings	36
4.2.1.1. Trainings for teachers and care givers	36
4.2.1.2. Training for parents.....	36
4.2.1.3. Provision of self-help skills training for CWA	38
4.2.2. Services and Supports	40
4.2.2.1. Autism diagnosis.....	40
4.2.2.2. Economical support.....	40
4.2.2.3. Provision of safe and conducive environment	41
4.2.3. Changes and Improvements on CWA	43
4.3. Communication between Parents and Teachers/Care givers	44
4.4. Parents' and Teachers' Involvement in Improving Self-help Skills of CWA	47
4.5. Factors Hindering Self-Help Skill Development of CWA.....	48
4.5.1. Challenges of CWA	48
4.5.2. Factors that hinder parental involvement.....	49
4.5.2.1. Socioeconomic status.....	50

4.5.2.2. Mother who lives separate with husband	50
4.5.2.3. Transportations.....	51
4.5.2.4. Housemaid	52
4.5.2.5. Siblings’ responsibility and Mothers child attachment	52
4.5.2.6. Accommodation Materials	54
4.5.3. Challenges that teachers and care givers face	54
4.5.3.1. Feeling sympathy from people.....	54
4.5.3.2. Parents’ negligence	55
4.6. Ways forwarded by teachers and care givers to improve the self-help skills of CWA	56
CHAPTER FIVE	58
5.1. Supports/Services and Trainings given	58
5.2. Communication between Parents and Teachers/Care givers	62
5.3. Parents’ and Teachers’ Involvement in Improving Self-help Skills of CWA	65
5.4. Factors Hindering Self-Help Skill Development of CWA.....	66
CHAPTER SIX	70
CONCLUSIONS AND RECOMMENDATIONS	70
6.1 Conclusions	71
6.2 Recommendations.....	73
Appendixes	

List of Acronyms

CWA Children with Autism

SWD Student with Disability

SWASD Student with Autism Spectrum Disorder

SES Socioeconomic Status

FGD Focus Group Discussion

ABSTRACT

In Ethiopia there are only three centers for children with autism, all are found in Addis Ababa. In this study the researcher focused on parents of Joy center of Nia foundation for children with autism. The purpose of this study was to investigate the existing and real practice of Parents' and teachers' involvement on improving Self-help skills of children with autism, at Joy center-Nia foundation. In order to achieve the objective, the researcher had employed a qualitative research approach namely, case study method. The participants of the study was nine parents of children with autism, two teachers and one care giver were selected from the targeted center for interview and focus group discussion questions. The methods of data collection were semi-structured interview, focused group discussion, anecdotal observation and document review. Data were analyzed using thematic analysis. The findings revealed that lack of parental involvement is detriment to the child's development and progress within an early intervention program. The findings also revealed that Joy Autism center for children with autism is supporting parents of children with autism to maximizing the implementation of self- help skills of children with autism by involving them in different awareness creation programs, helping their children to develop self -help skills, giving periodic and updated information regarding autism, providing economical support, creating job opportunity for those economically weak, providing free lunch service, providing school bus and giving them monthly training on the area of autism and self-help skills. The finding also disclosed that some parents did not involve themselves in their child's program and this affected their skills to support children with autism, their children also manifest low self-help skills on their environment, and showed only minimal developmental progress. The study recommended that parents and school management needs to work together to meet the same goal, that is to improve the specific problem of the child both at home and school. It would be better if integrated activities between the parent and the school implemented to alleviate the problems of CWA.

CHAPTER ONE

INTRODUCTION

1.1. Background of the Study

Autism is a mental health problem that affects children from communicating easily with their parents and the community that they are living in. Regarding to this (American Psychiatric Association, 2013) states autism, as a neurodevelopment disorder that are noticeable during the early stages of child development. It is usually recognized before the child goes to school and such kind of disorders are characterized by developmental shortfalls that weaken the normal personal, social, academic and occupational functioning.

There are major signs of autism that parents easily distinguish while caring their children. As (American Psychiatric Association, 2013) the main signs of autism are demonstrated by impairment in social communication and interaction. Restricted and cyclical patterns of behavior, interests or activities are as well the signs that children with autism (CWA) reflect. These symptoms are normally seen before 3 years of age and may limit the day to day activity of the child.

Even though there is no finding on the root causes of autism, researches show that the number of CWA in the world is increasing. A decade ago, autism seemed to affect around 1 in every 2,000 children. However this ratio increases in recent years. Fombonne (2003) says that the number of children diagnosed with autism is increasing. The ratio also reaches to 1 in every 600 children and possibly 1 in every 200 children. Around 80 percent of autism also occurs in boys. When it comes to Ethiopia, Nia foundation (2010) estimated that there are 530,000 CWA.

All CWA do not need the same care and functional diagnoses are different. Some cases can be independent and need minimal support and vice versa for others. Thus the intervention needs interdisciplinary approach. Parent participation in therapy, as well as direct behavior intervention services, can have a significant effect on the outcomes of those interventions (Moroz, 2015)

Regarding effective interventions, an interdisciplinary approach encourages speech therapy, behavioral therapy, family support, occupational therapy, special education programs and self-help skills.

Since CWA are suffering from helping themselves because of their mental disorder, engaging in self -help activities are imperative. As Ozonoff and Cathcart (1998) self- help activities includes tooth brushing, toilet training, independent feeding, dressing, shopping, street crossing, using public transportation and other related activities. Although caring for a child with ASD can be stressful for many parents, professionals can help parents to overcome those challenges and minimize as much as possible the potential barriers that may come with raising a child with autism using the strengths perspective (Moroz, 2015).

There are some common approaches to equip CWA different self- help skills. As Ozonoff and Cathcart (1998) using structured behavioral and educational methods, providing parents with training to implement strategies at home and enrolling CWA prior to the age of five are the major methods that any organization uses to improve the livelihood of CWA.

Though a number of Ethiopian children are experiencing autism, there seems a lack of awareness on the existence of such kind of disorder. Thus CWA are deprived of their right to

education, rehabilitation and even prohibited to get pleasure from the day light (Nia foundation, 2010).

Even though it is difficult to manage CWA behavior, lack of awareness and centers, CWA parents are blamed form locking their CWA behind doors. Nationwide there are only three centers for CWA so far which teaches CWA. Even if there are parents who want to send their CWA to school, the opportunity is minimal and the capacity of the centers are limited (Nia foundation, 2010).

Many individuals with autism spectrum disorder exhibit impairments in daily living skills that can hinder their functional independence in terms of their personal care skills, domestic skills and community skills. Thus parental involvement is significant on assisting their CWA in order to equip them with self-help skills. Parent's participation on education for all students especially for student with disability (SWD) as well is imperative and it results better effects for students with autism spectrum disorder (SWASD) (Burrell & Borrego, 2011).

Since every child falls somewhere different on the spectrum there is no single best treatment for CWA but each approaches to improve the living of CWA has one thing in common, which is the need for parental involvement (National Institute of Mental Health, 2004). Parental involvement is one of the invariable factors and an integral part of the success of intervention programs for CWA. The collaboration between parents and professionals in the program is critical to the effectiveness of intervention programs (Ozonoff & Cathcart, 1998). Strong connection between parents and their children, as well as parents and their children's intervention programs provides a greater potential for positive effect on their children's development (Moroz, 2015).

Teachers' are an integral part of the assessment, diagnosis and treatment plan of a CWA. They also promote parental involvement and provide training and support to parents of CWA. In order for self -help skill programs to be effective and improve the living of CWA parents and teachers' need to be involved and work together.

Parental involvement with high-risk and children with special needs (CWSN) (e.g., children of poverty, handicapped children, immigrant children, children with emotional problems) has also shown that parents are instrumental in the teaching of academic, language, social, motor, and vocational skills and managing their child's behavior (Gray DE,1993). Parents involvement is the one constant factor and an essential part of the success of self- help skill programs for CWA. Thus, this paper also aims to investigate the parents' and teachers' involvement on improving self -help skills for CWA at Joy Center of Nia Foundation.

1.2. Statement of the Problem

Parental involvement is the one invariable factor and an integral part of the success of early intervention programs for children with autism. The collaboration between the parent and the professional working with the child in the program is critical to the effectiveness of programs (Ozonoff & Cathcart, 1998).

Due to the parents being the child's earliest teacher, many specialized early intervention programs offer training for parents to continue therapy within the home (National Institute of Mental Health, 2004). Some children attend a structured day treatment program and return home to their involved parents who have training in how to continue the learned behaviors from school to the home environment. Others come home to lack of parental involvement. Lack of parental involvement could be a result of many different variables. Parents of children with ASD

experience varying levels of motivation, stress, depression, and different socioeconomic levels, which could impact their availability to resources and education (Ozonoff & Cathcart, 1998; Mancil, Conroy, & Nakao, 2006).

Taking care of children associated with greater positive affect and meaning compared with the other activities parents performed on the same day it ranked toward the bottom of the list of daily activities in terms of positive affect (Nelson, Kushlev, Dunn, and Lyubomirsky, 2013).

Training for parents increases the amount of support for children who require intensive, individualized intervention and support. Parents can serve as a therapist for their CWA if they get appropriate and sufficient training from organizations. If they get training they can implement their knowledge at any time by using different mechanisms.

Regarding this, Corsello (2005) says that parent training, education and involvement are important factors of successful behavioral intervention and meeting the needs of children with autism. Parents' training is a critical component to improve the lives of CWA successfully.

Since parents are primary caregivers at home they need intensive trainings to assist their CWA to obtain self-help skills. In addition teachers and other care givers are expected to know how to help CWA to be self-reliant. As Kroeger & Sorensen (2010) say children with autism characteristically demonstrate difficulty in generalization of skills across environments and individuals. Thus parents, teachers and care givers training are even more critical.

The collaboration and communication between parents and teachers in the training program is critical to the effectiveness of programs (Ozonoff & Cathcart, 1998). If communication between teachers and parents is strong parents spare responsibility of teachers to give educational and life skill support at home. Since expecting teachers to teach all life skills at

school for CWA is impossible, the need of effective communication and collaboration between teachers and parents are imperative to make CWA less dependent. The relationships between parents and teachers develop in schools become critical to positive development. Because of the amount of time children spend in school, children may for the first time be developing relationships with adults outside their immediate family. These connections help a child develop cognitively and emotionally (Louise, 2002).

Teachers are also expected to give all supports rather than expecting everything from parents which is also less practical. To this end, the need for communication between parents and teachers either by communication book or face to face is significant.

According to Burrell and Borrego (2011),parents' and teachers' involvement results in better outcomes for CWA and family support improves family functioning and the well-being of CWA. Training, communication, involvement and collaboration have several impacts on the CWA to learn and adopt different self-help skills that minimizes the challenge that CWA faces on their daily life.

Children with autism lack understanding on how to help themselves on their day to day activity and mostly dependent on their parents and care givers it is imperative for parents, teachers and caregivers to get trainings and to communicate on how to support CWA to be independent on their daily lives.

In order to better explore the parents' and teachers' involvement on self-help skills for CWA, the following basic research question were raised in the study:

1. What types of support/services and training parents, CWA and teachers get from Joy Center on self-help skill of CWA?

2. In what way do teachers' and parents' communicate daily regarding self-help skills for sustainable solutions of CWA at joy center?
3. How do parents and teachers are involved in improving CWA self-help skills?
4. What are the major factors that hinder parent's involvement in self-help skills for CWA at joy center?

1.3. Objective of the Study

1.3.1. General objective

The general objectives of this study were to investigate the existing and real practice of Parents' involvement in improving Self-help skill for CWA.

1.3.2. Specific objectives

The specific objectives of this study are:

- To identify the supports/services and trainings that given for the parents', CWA and teachers' from the Joy center.
- To see the way of communication between parents' and teachers' daily on the self-help skill development for sustainable solutions of CWA at Joy center.
- To evaluate the engagement of parents' and teachers' in the implementation of the program/training on the implementation of self-help skill development for CWA at Joy center.
- To find out factors that hinder parents involvement in the implementation of self-help skill development for CWA at Joy center.

1.4. Significance of the Study

The collaboration, communication and involvement of parents' and teachers' can improve the lives of CWA. Thus the findings of this study might offer some awareness to CWA's parents and teachers on how to improve the livelihood of CWA. It will also show how effective communication and involvement are imperative to assist CWA. The result of this study might as well assist the center to know their service regarding to self- help skills and others who are interested to work on CWA on how self- help skills are imperative for CWA Furthermore, the study will also serve as a launching pad for those who might be considering conducting further studies on the issue.

1.5. Scope of the Study

This study was delimited on self-help skills of children with autism and their parents' involvements on the program. Regarding the study area, it was done in Addis Ababa: Joy center of Nia foundation for children with autism. Parents of children with autism, teachers and care giver were involved in the study.

1.6. Limitations of the Study

Hopefully there were several strengths; there are also limitations to this study. There was a significant gap in research literature regarding lack of information on the success of early intervention programs for CWA in Ethiopia. As a result of this gap the researcher had to be self-aware throughout the interview to not have an "investigator effect" or probe in a way that would steer the interviewee in a certain direction. The researcher needed to ensure there were no biases within the interview and remain neutral throughout the interview. The sample consisted of parents and teachers/care giver from one agency, which resulted in the sample not being

diversified regarding perceptions, age group and interventions used; this could be considered as a limitation to the study.

1.7. Definition of key terms

- **Parents' involvement:** parents participation on self-help skill, treating and giving care for their child at home and participation during the school year in attending a general school meeting, a scheduled meeting with their child's teacher; a school event and training to help their children at home in different ways by communicating with the center .
- **Self-help skill:** ability to perform self-care tasks independently. It includes basic activities like keeping hygiene, eating, dressing, safety skills and other related activities.
- **Parents':** who is participating in the child development and have close relationship and stay with the child a long period of time.

CHAPTR TWO

REVIEW OF RELATED LITERATURE

This section reviews existing literature in relation to the main concept and the research questions of the present study. First, a brief review of literature regarding the history, definition and symptom of autism is presented in order to provide an overall understanding of the condition. Afterwards, literature in relation to the experiences of parents and teachers communication, the importance trainings and the concept of self-help skills of CWA is presented.

2.1 Parental Involvement

Parents were taking care of their children and one for all episodes when they were not taking care of their children. This approach allowed us to compare each parent's score during child care with the same parent's score during other activities the parent engaged in during the day. Thus, we were able to examine whether individual parents experienced higher or lower well-being when taking care of their children than during all other activities they engaged in during the day (Nelson, Kushlev, Dunn, and Lyubomirsky , 2013).

Parental involvement in the interventions of their children can be observed in many forms. Parents can be involved by communicating directly with intervention staff or through communication notebooks, participation in their children's intervention staff team meetings, attending workshops and trainings on strategies to use with their children, observation of their children's therapy, and/or by conducting one-on-one instruction and therapy with their children at home. However, research shows that more intensive parental involvement in treatment results in more positive treatment outcomes will be (Burrell & Borrego, 2011).

Parents' active involvement in the intervention efforts is especially important because they are the ones who spend the most time with their children and have the most influence on them. Children whose parents are involved in the intervention methods can receive an even greater amount of learning opportunities in addition to the intervention they already receive from intervention staff (Burrell & Borrego, 2011). According to parent involvement, numerous studies have shown that parents can learn the techniques of interventions and effectively implement it with their children (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008).

2.2. Intervention Implemented By Parent

One of the ways that parents can participate in their children's intervention program is by directly conducting formal sessions with their children. Parent directed interventions have shown to be successful in studies ranging from children of different ages and disabilities. Researchers have found that parents are indeed capable of implementing effective interventions themselves and have identified many benefits of this (Levy, Ae-Hwa, & Olive, 2006). Studies find that when parents act as intervention agents, their children benefit from increased number of hours of therapy focusing on language and behavior, without increasing the costs of service providers with the ability to continue interventions as necessary throughout the child's lifespan (Levy, Ae-Hwa, & Olive, 2006) and continue reduction of problem behaviors of their children with ASD as necessary throughout the child's life (Levy, Ae-Hwa, & Olive, 2006).

Some research has suggested that parents acting only as 'teachers' of their children can negatively affect the parent child relationship (Turnbull, Blu-Banning, Turbiville, & Park, 1999). The message that parents must always act as teachers to their children may miscommunicate the idea of the parenting role to parents with CWA and other developmental disabilities. Children

with disabilities need to have a feeling of acceptance, appreciation, and love, especially from their parents, no matter the disability (Turnbull, Blu-Banning, Turbiville, & Park, 1999) .

Because parents spend the most time with their child and know their child best, parents can offer much support to the intervention staff and because intervention staff is more knowledgeable in the interventions of the child, they can provide guidance to the parents (Turnbull, Blue-Banning, Turbiville, & Park, 1999). When parents follow through with the intervention plans of the child with ASD in the home and the community, in addition to the intervention already provided to the child outside of the home, the child has more opportunities to learn new skills in a consistent fashion (Volkmar & Pauls, 2003). Consistency in intervention is important because it aims to generalize learned skills across environments to ensure mastery and maintenance of those skills. Generalizability of skills for children with ASD is essential because they have difficulty in displaying learned skills across settings and situations (Burrell & Borrego, 2011). Children receiving therapy must be able to apply learned skills in various appropriate environments outside of the therapy room without the help of the therapist. Engaging in experiences and social interactions in varying situations with individuals who have the skills to help teach appropriate responses in all setting and environments is one of the most important aspects of successful outcomes (Burrell & Borrego, 2011). Therefore, therapy staff must work with parents and encourage parent implemented treatment in activities that parents and children engage in daily, such as playing, self-care, chores, shopping, etc.

In order for children with autism to gain the most out of their intervention, it is important parents and professionals to collaborate and support each other. Parents must not only be aware of the therapy goals of their children, but must also work with therapy staff to help their child achieve that goal. For example, if parents are unaware of the intervention plan the staff utilizes

to modify a child's particular behavior problem and are not addressing this problem at home in the same manner as the staff does in the classroom, attempted behavioral modification will not be effective. Miscommunication between parent and therapy staff, or rather lack thereof may impede progress and make it more difficult for the child to achieve the goal. Furthermore, parents need specific instructions and useful techniques on how to deal with and how to modify their children's problematic and destructive behaviors (Rapin, 1997).

Best outcomes are observed when clinicians and parents have supportive and understanding relationships that allow them to work together, share goals, expertise, responsibility, and problem solving (Burrell & Borrego, 2011). This can be done through that aforementioned strategies such as participating in intervention staff team meetings, continued communication in person as well as communication journals, and attending trainings on appropriate strategies they can use with their children (Burrell & Borrego, 2011).

Various types of methods exist to provide parents with the necessary training in the intervention and techniques of their children. Some programs stress importance on positive parent-child interaction to teach age appropriate communication and promote language development of the child (Burrell & Borrego, 2011). Other programs such as Parent Child Interaction Therapy (PCIT) which involves providing in-vivo coaching to parents by observing parent and child through a one way mirror and providing immediate feedback to the parent through a hearing device, have also been used (Burrell & Borrego, 2011). Other parenting programs, under the supervision of the clinician, integrate parents into directly implementing the intervention skills they learned after observing the intervention provide by the therapist. This training technique is effective because it includes clinicians providing parents direct in-vivo training and guidance as well as feedback (Burrell & Borrego, 2011).

Another effective training technique used to provide ABA training to parents is the Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) home based model (Burrell & Borrego, 2011). The TEACCH model involves parents working with two therapists such that while the parent is observing one therapist implement therapy behind a one way mirror, the other therapist explains what is being done to the parents. The parent is then encouraged to implement those strategies at home (Burrell & Borrego, 2011).

Another in-home program approach includes parents in therapy from the start of the intervention program. In this approach the therapist and parent work together to identify areas that are most important for the child to learn and then teach the parent strategies to use to improve overall condition, prevent problem behaviors, redirect inappropriate behaviors, and effective implementation of consequences to problem behaviors. Following this, parents are left to implement them alone with their children with the therapist remaining available to the parent for ongoing support, education, and strategy modification as needed (Burrell & Borrego, 2011).

Studies have shown that when parents are trained in the systematic therapy techniques of the therapy that their children receive, both parent and the child harvest the benefits of this interaction (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008; Gilbert & LeBLanc, 2007). Parents gain confidence in providing effective intervention and children benefit from the increased interaction with their parents, as well as modified behavioral problems, learning awareness of emotion, increased self-esteem, and stimulated speech and language development and play skills (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008; Gilbert & LeBLanc, 2007). Furthermore, when parents implement therapy themselves, they receive a sense of confidence and empowerment therefore reducing their feeling of depression and stress related to raising a

child with developmental disabilities (Estes, Vismara, Mercado, Fitzpatrick, Elder, Greenson, & Rogers, 2014) as well as increased optimism and confidence in parenting ability, as well as (Solomon, Ono, Trimmer, & Goodlin-Jones, 2008) Parent involvement strategies can be as intensive as providing parents opportunities to practice therapy guided by clinician coaching, or by providing parents with treatment manuals, videos, and other information. Although just a few of the many existing parent training approaches are described here, and more research needs to be done about the effectiveness of each method, options are possible and should all be considered when including parents in the interventions. Furthermore, regardless of the methods used to involve parents in the interventions of their children, it is essential to the successful outcome of the intervention (Burrell & Borrego, 2011).

2.3. Self-Care Activities

Their ability to perform self-care tasks independently gives children some control over their environment. Lack of ability in self-care skills compared with others can be isolating and lead to frustration (Louise, 2002). Children's achievement of self-care skills reflect cultural, class and family expectations as well as their intrinsic abilities and closely reflect their acquisition of hand skills (Henderson, 1995). With increased exposure at younger ages in play groups and child care to children of the same age, observation of others performing independence tasks appears to motivate young children to learn the same skill.

Self-care skills have varying degrees of manipulative, perceptual and cognitive components (Henderson, 1995). Encouraging development in self-care needs to focus on functional outcomes that will make a difference for the children and their families. Training is best achieved by direct practice of the desired skill, rather than concentrating on Components of the tasks. Self-care skills include the following points

2.3.1. Dressing

When teaching dressing for the children always begin with undressing, as this precedes dressing become a developmental skill. Children learn one-handed skills before two-handed and so teach such tasks as doing up buttons at a later age. Another suggestion is to use the children's favorites clothes, those with an obvious front and back (e.g. those with designs or pictures on the front), and clothing and foot wear large enough for easy donning. Point to clothes to the children in such ways that they are already oriented to them, and allow children with poor balance to sit down when pulling on pants (Louise, 2002).

2.3.2. Toileting

This is another important independence skill. Children with sensory processing difficulties are unable to perceive correctly information from their touch and pressure receptors, and so have reduced awareness of their need to empty their bladder or bowel. For children with autism and developmental difficulties, the general guidelines suggested by and available from your local community health organization for introducing toileting are likely to be useful. These will comprise advice such as ensuring that the children have ready access to a toilet and can remove their own clothing quickly and easily; that their feet are able to reach the floor while sitting on the toilet to maximize the use of muscles that assist with elimination; ensuring that they can reach and use taps; and helping position their hand for wiping their bottom. If children have suspected constipation, they will need to be assessed by a pediatrician or a general practitioner interested in family health (Kroeger & Sorensen, 2010).

2.3.3. Grooming and Hygiene

Most preschoolers require assistance with the third area of self-care tasks namely, grooming and hygiene tasks such as bathing and cleaning their teeth, hair and nails. When children have additional developmental needs, it often seems easier for carers to perform these tasks for them, but the children's ability to perform even aspects of these tasks can build feelings of mastery and promote later independence. Therefore it is useful to encourage the children's active involvement as soon as they show some interest. We can help by ensuring that they can reach the sink, taps and mirror; that they can sit if balance, postural control or stamina is problems for them; and that brushes have large handles that are easy to hold (Louise, 2002, p.136).

2.3.4. Self-Feeding

Self-feeding is a crucial self-care or independence skill. It requires the motor skills of trunk stability, head and mouth control as well as eye-hand-mouth co-ordination. Sensory information needs to be interpreted accurately to facilitate an efficient eating process. Children with significant eating difficulties are likely to be managed by a pediatrician aided by a, feeding team, that is a multi-disciplinary team with expertise in feeding issues. Fussy eating is a common problem. In some cases the child may be fixated on a detail that identifies a certain food. Try putting different but similar foods in the cereal box or another package of a favorite food (Louis, 2002, pp.136-137).

The children might drool excessively, and this is not better explained by teething or a blocked nose. This can indicate poor sensory awareness around the mouth so that the children are unaware that they do not have adequate lip seal. Another explanation would be that the children

have low muscle tone in the facial muscles and so have trouble lifting their jaw against gravity (Louis, 2002, pp.136-137).

2.3.5. Safety skill

Safety skill include knowing basic information (name, address, phone calling), household safety (fire, gas smells, locks, emergency number) medical safety (doctors number, when to seek medical attention), and physical safety (traffic rule, seatbelts, avoiding stranger).statistics indicate that people with cognitive disability are at high-risk being the victims of sexual and physical abuse it is critical to keep this in mind when assessing safety skill hhh://www.autism consortium .org.

2.4. Importance of Parent Training

Importance of Parental training has significantly influenced .When parents complete the training with the intervention plans of the CWASD in the home and the community, the child has more opportunities to learn new skills in a consistent fashion (Volkmar & Pauls, 2003).The Strong action of parents that lead the movement of acceptance of individuals with autism through advocacy for their children's rights throughout history, and initiated a more collaborative, rather than confrontational relationship with professionals (Langan,2011).Parent and supporters have greatly contributed to significant impact in the legal system in effort to initiate the delivery of intervention services at home and at schools for CWA (Axelrod, McElrath, & Wine, 2012).

Families of children with disabilities have found that when important stakeholders (such as parents) are included in intervention of their children, both parents and children return the benefits of improved family functioning (Burrell & Borrego, 2011). Raising a child with a developmental disability has its own challenges and problem behaviors play a role in the normal

development of children. Some of these problems consist of inattention, aggression, and impulsion (Kaminski et al., 2008). Some of the examples of skills learned in the programs include teaching parents to encourage their children's social interactions, cognitive abilities, self-help skills and academics (Kaminski et al., 2008). It is important for parents to be well educated to understand if they are able to provide the support and services needed for their child to develop and establish a healthy relationship with their children (Schultz et al 2011). McConachie and Diggle (2006) examined the effectiveness of parent implemented intervention programs for CWA and found evidence that parent training is effective as a result of improved self -help skills in CWA. Knowledge, skills and performance increased in the parents after partaking in a parent-training program McConachie and Diggle (2006). McConachie and Diggle (2006) also found parent training to have a positive effect on the parent and child relationship.

2.5. Parents as Therapists

One of the ways that parents can participate in their children's intervention program is by directly conducting formal sessions with their children. Parent directed interventions have shown to be successful in studies ranging from children of different ages and disabilities. Parents are indeed able to learn the intervention techniques and implement them correctly and help their children learn the skills they lack. Researchers have found that parents are indeed capable of implementing effective interventions themselves and have identified many benefits of this (Levy et al., 2006). Studies find that when parents act as intervention agents, their children benefit from increased number of hours of therapy focusing on the child limitation, without increasing the costs of service providers with the ability to continue interventions as necessary throughout the child's lifespan and continue reduction of problem behaviors of their CWA as necessary throughout the Childs' life (Levy et al., 2006).

Some research has suggested that parents acting only as teachers' of their children can negatively affect the parent child relationship (Turnbull et al., 1999).The message that parents must always act as teachers to their children may miscommunicate the idea of the parenting role to parents with CWA and other developmental disabilities. Children with disabilities need to have a feeling of acceptance, appreciation, and love, especially from their parents, no matter the disability (Turnbull et al., 1999).The research attempted to hypothesize that this type of relationship between parents and children may cause children to feel unworthy of unconditional acceptance due to the subtle and not so subtle messages from parents that they must be changed before they can be accepted (Turnbull et al., 1999).The majority of literature that exist regarding parental involvement states that parents of CWA are critical components of the rehabilitation process, without whom gains [in skills] are unlikely to be attained (Kern, 2000) and professionals among the behavioral science field agree regarding the importance of parents' involvement.

2.6. Highly Trained Teachers

The first element of a comprehensive program for this population is the presence of highly trained teachers at the professional level. Without a trained staff that has explicit knowledge and understanding of autism, districts will be poorly prepared even to identify the current state of their program, let alone understand how to create systemic change. Lack of training that currently exists in predicts that the need for trained staff will only grow. The Autism LODAM measures the training of professional staff by noting both the license of the case manager and any specific autism training they have undergone. In addition to highly trained teachers, programs must also consider the background and educational level of professionals who often work most closely with students. professionals working with students who have significant disabilities such as autism must be closely supervised and supported, well-trained in

instructional procedures and have an understanding of the philosophies and values of intensive needs and autism education (Giangreco & Doyle, 2002; Lacey, 2001). The Autism LODAM asks schools to rate the autism-specific training that its professionals have completed and the supervision system that exists.

2.7. Collaborative Practices

Schools have been expected to develop working partnerships with parents. Characteristic relationships between parents and teachers have varied across different eras, systems, and cultures teacher-parent partnerships are increasingly realized as vital to student and can benefit all parties, they are seldom fully realized, as both parties face different barriers therapy staff must work with parents and encourage parent implemented treatment in activities that parents and children engage in daily, such as playing, self-care, chores, shopping, etc. Few educators would dispute the value of collaboration in creating effective educational outcomes for all students. The need for collaborative, disciplinary teaming is even more essential in the education of students with significant disabilities such as autism. The nature of these students' disabilities typically requires that teams consult with a variety of educational, medical, psychological and other outside professionals in order to effectively provide services (Jackson et al., 2000).

Teachers need to be able to deal with a great variety of family systems in understanding their students. In today's society the family is less frequently the archetypical combination of stay-at-home mother, working father, and sibling children. Single parent families, generation skipping families, and other non-traditional groupings are more common today than the traditional family (Louise, 2002).

The importance of collaboration among classroom teachers, special educators, outside service providers and families in the entire education process (Jackson et al., 2000). Miscommunication between parent and therapy staff, or rather lack thereof may delay progress and make it more difficult for the child to achieve the goal. Furthermore, parents need specific instructions and useful techniques on how to deal with and how to modify their children's problematic and destructive behaviors and activities (Rapin, 1997).

Best outcomes are observed when schools and parents have supportive and understanding relationships that allow them to work together, share goals, expertise, responsibility, and problem solving (Burrell & Borrego, 2011). The use of collaborative practices is particularly important in the education of CWA. An effective program for CWA may include services from speech pathologists, occupational and physical therapists, medical professionals, educators and more. In order to integrate such therapies into a comprehensive educational program, collaborative practices must be in place. "Effective programming for CWASD and their families requires that the direct service provider be a part of a support system team (National Research Council, 2001). Practices that are particularly important to collaborative teams and are measured in the ASD include accessing consultants from a variety of disciplines on the team as needed, having an established method of communication, and holding frequent meetings in which collaborative practices (forming agendas, taking and distributing meeting minutes) are used. All of these practices aid in the creation of shared goals and in having a system in place for resolving conflicts.

2.8. Factors Contributing to Lack of Parental Involvement

Parental involvement is considered to be a key element in the success of self-help skill programs, the impact of parental involvement can have on the success of self-help skill program,

there are many factors due to various causes like Single parents, low- income families, and parents experiencing depression, or with poor social support, may be less likely than others, to benefit from such programs without additional support (Sander,1997) Lack of support, time, and socioeconomic status are also contributing factors to the lack of parental involvement (Benson et al., 2008).

2.8.1. Stress

Research has shown levels of stress to be higher in parents of CWA than most other children with developmental disabilities (Ozonoff & Cathcart, 1998). Stress is the main reason for lack of parental involvement alongside a child who is enrolled in self-help skills program. The high amount of stress experienced by parents of CWA, particularly those who express behavior and self- help problems at home (Benson et al., 2008). Osborne & Reed (2010) found the amounts of stress in mothers were correlated to level of expression in emotions and feelings from a child to their mother. Teachers and parents who care for CWA showed parents had more stress in relation to child problem behaviors than teachers (Lecavalier et al., 2006). Lecavalier et al., (2006) believed this to be a result of teachers being better prepared with education and training resources to handle problem. Osborne and Reed (2010) parents of CWA in the stress is a direct result of problem within the child.

Mothers have reported poor to fair in their mental health rating when compared to mothers of children without developmental disabilities (Schultz et al., 2011). Moes and Frea (2010) found the daily routine at home to be stressful on parents with a CWA. Schultz et al. (2011) found mothers who received parent training felt more knowledgeable about their parenting skills. McConachie and Diggle (2006) found stress and maternal depression to be

reduced amongst parents when they are involved in a parent-training program (Moes and Frea, 2010).

2.8.2. Financial Impact

Glendinning (1986) added the financial impact of families for CWA is vast. Caring CWA requires more finance in provision of care, special education, day service provisions, and family expenses as compared to a typically developing child. The total cost of raising a child with disability is greater than as compared to cost incurred in raising a normally developing child.

Having a CWA 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 full file their demand, loss of full-time employment can have a dramatic and negative impact on the family's finances (McConachie et al., 2005).

2.8.3. Divorced

Hastings and Johnson (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 CWA 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 CWA, which also makes it hard for parents to go out as a couplet, all the burdens filled on the single parent in addition to these financial stresses can cause additional problem for other family members.

Divorce had force that can changed the family landscape in our society is divorce. Children of divorced parents often have a split family life, at fathers for the weekend, at mothers during the week, or any number of other situations. The divorce arrangement can have a profound effect on the family and the development of the child, but it is often a product of society, decided by a judge, enforced by social services. In turn, the divorced family affects the community and society because by the proliferation of divorce social attitudes change and the social perception of family is modified. The school is also affected by the changes in a divorced family (Louise, 2002).

2.8.4. Time and Socioeconomic Status

According to Sharpe and Baker (2007,) many of intervention strategies require long hour's one to one interaction with a trained therapist, and use of costly foods or drug supplements. Parents of a child with autism often face greater outlays of time and money than they would for typically developing child to access specialized care needed for longer period of time. Participation in extracurricular activity for children with autism also puts additional costs to the family.

The participation of families in the labor market is another factors affected in relation to economic aspect. Gray (2003) found that brining up a CWA also had a significant effect on career. For those who did manage to work, they were often forced to miss work, perform below their normal level or drop back to part time .Gould (2004) added that one or both parents often must reduce work hours or step out of the labor market altogether (as cited in Sharpe & Baker, 2007, p. 248).

Research has shown working parents, particularly mothers, have a hard time caring for their child with ASD when they need to balance out work and child care commitments (Benson et al., 2008). Mothers tend to take on more domestic concerns where fathers are more anxious about the financial aspect of how raising a child with autism will affect the family (Tehee et al., 2009). Socioeconomic status plays a significant role in parental involvement. Benson et al. (2008) found a significant positive effect on mothers' home-based involvement and higher SES status. Mothers felt they knew more about educating their child than a school-based program would. Support, time and SES are factors that contribute to the stress parents feel when taking care of a child with autism. McConachie and Diggle (2006) Measurement of the efficacy and effectiveness of the involvement of parents in programs to help their children's development should include a range of outcomes: child developmental progress, parent-child interaction patterns, parents' knowledge, attitudes and stress levels, family functioning, and cost-benefit analysis.

CHAPTER THREE

RESEARCH METHOD

This chapter set out a plan to which the research is carried out and contains operational definition of key elements such as research design, population and sample, data collection methods, sampling technique, sample size, the way in which collected data was analyzed and interpreted. Ethical considerations were also included in this chapter.

3.1. Design of the Study

The main purpose of this study was to investigate parent's involvement in improving self-help skills of CWA at Joy Center of Nia Foundation for CWA in Addis Ababa. In order to achieve this objective, qualitative research approach specifically case study design was found to be appropriate. Since primary sources provide first-hand information and straight indication regarding to the topic under study the research fundamentally relies on interview, focus group discussion and anecdotal observation to inform its analysis. Regarding to qualitative approach nine parents, two teachers and one care giver were interviewed and besides parents were participated in FGD. To complement the interview and FGD the researcher used anecdotal observation and document analysis.

3.2. Research Setting

Joy center-Nia foundation for children with autism is found at Kirkos sub city in Addis Ababa. It is located opposite to Vatican Embassy. For this particular study, Joy center-Nia foundation for children with autism was taken as research sites purposely for the following reasons. Firstly, the center provides integrated services for both CWA and their families. Next, the school (center) is known for its recurring participation in different societal affairs and also

other organization was not willing to be incorporated in the research. Therefore, this study used to comprehend parents involvement in improving self-help skills of CWA at this center.

3.3. Study Population

In the center there are 80 children, among whom 16 are female and 64 are male. They are between 8 and 23 of ages. There are 39 teachers and supporting staffs. The informants of the study were parents of CWA from different socio economic background, teachers and care givers of CWA of the center. Nine parents of CWA, two experienced teachers and one care giver were actively participated in the study.

3.4. Sampling Technique

Samples are selected on their ability to clarify and deepen understanding of cases, events or actions and rich knowledge of the research issue to provide a good insight. In addition to this qualitative research usually work with small samples. Accordingly, this research utilized non-probability sampling method, specifically purposive and Convenience sampling techniques. The criteria's were used for selecting teachers' and care givers' are; service providers, currently working in the self-help skill class rooms and those who are involving in direct child care, those who have at least two years working experience, teachers who are teaching in the self-help skill class room and having enough time and ability to express ideas clearly. Thus two teachers and one care giver were selected based on the criteria. Parents were selected by convenience method.

The selection process of the informants was carried out based on the willingness of informants and nine families were selected to participate in the study.

3.5. Data Collection Methods

As it is intended to comprehend parent's involvement in improving self-help skills of CWA, the researcher used to collect data through interview, anecdotal observation, focus group discussion and document review. Those methods helped the researcher to uncover the reality of the research problem posed. The interview and FGD were conducted with informants through tape recording. The researcher also took field notes.

3.5.1. The Semi-Structured interview

The preparation of the semi-structured interview guide for families CWA was concerned, questions that could produce relevant information were prepared by the researcher. Since Amharic is 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.

The interview guide comprised open-ended and with Semi-structured questions those were driven from the research questions. It allowed the researcher to have a framework in which necessary open-ended questions were posed to encourage the informants to talk freely about their experiences in their own words. It was administered for five parents, two teachers and one care giver. For the purpose of this research data gathered from informants were translated into English.

3.5.2. Focus Group Discussion

Focus group discussion guide for families of CWA was concerned; questions that could produce relevant information.

FGD was employed by the researcher to get more insight about parents' involvement, challenges and communication with teachers. It was an intensive discussion made with four parents of CWA in order to get in depth information. The intention of FDG was to triangulate and enrich the data obtained from families of CWA through interview.

3.5.3. Anecdotal observation

In this study CWA cannot be able to give verbal expression about the service they got from parents and teachers. Thus the researcher observed CWA's daily activities in the class room and school compound for ten days and used anecdotal observation to gather relevant data with an intention to cross check the similarity of the data obtained from parents and teachers and to compare their activity and skill with the service given.

3.5.4. Document review

The preparation of key points for document review, points that could elicit relevant information were prepared by the researcher. Document review was conducted by taking information regarding the educational background of service providers and communication between parents and teachers on the communication book. This was found in the center so as to increase reliability of the data. That is why, the researcher included in her present study.

3.6. Procedure

The researcher plan in this regard was to avail her first in the center to employ a participant-observer method using interview, focus group discussion, document review and anecdotal observation.

3.6.1. Interview

This was a form of in-depth conversation made with five parents of CWA, two teachers and one care giver. At the time of the interview, the researcher asked the informants to be tape recorded and except the care giver the rest were agreed. So the researcher had recorded while conducting the interview. Each parent was interviewed for an average of an hour. Therefore, a total of 5 hours were used. In the case of interview each teacher and care giver was interviewed for about an hour. Regarding the way the interview was held, after getting the consent of the informants, the researcher interviewed the teachers at their free time and parents when they came to take their children to home.

3.6.2. Focus Group Discussion

Focus group discussion holds on the day of coffee ceremony which is held once a month for half a day. 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 her recorder and FGD guide, with four parents and asked questions that would produce discussion.

3.6.3. Anecdotal Observation

The observation carried out was anecdotal. That is, the researcher was constantly available in the center both in the morning and afternoon to observe the kind of services that were given for parents. Moreover, the researcher was frequently present in classes during class time to see the type of lesson given for CWA which could help parents when the children are at home.

3.7. Method of Data Analysis

The data collected from participants was thematically grouped, translated, organized and analyzed in qualitative form. The researcher had paid special attention to the actual words that participants expressed frequently.

The obtained data was translated directly from Amharic (mother tongue) to English by the researcher with consultation to peer MA friends. Finally, discussion of major findings was made by categorizing findings in to major themes. Finally, conclusions and recommendations of the research were made based on the discussion.

3.8. Ethical Considerations

In doing 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.

CHAPTER FOUR

RESULTS OF THE STUDY

In this chapter, data obtained qualitatively from interview, focus group discussion, anecdotal observation and document review were presented.

As primary source of data nine parents of CWA, two teachers and one care giver were purposefully selected and interviewed. Parents were also participated in FGD. Anecdotal observation was as well conducted by the researcher. The researcher also reviewed documents as a source of secondary data. Informants are also given numbers and their views are incorporated in the discussion.

4.1. Socio-Demographic characteristics of the Respondents

Background Parents

In this study nine participants who are parent of children with autism were involved, all were mothers and five of them participated in interview, and the four were involved in FGD.

The age background of these parents who were involved in the interview aged between 27 and 53. Regarding to their level of education, one of the participants have completed grade10, one completed grade 12, two of them are diploma holders and the other participant is not educated. Three of them are married and the rest two are divorced and widowed. Their economic status ranges from high to low. All of them have children averagely two to four. They received service from 2 to 12 years in Joy center. The rest four parents were participated in focus group discussion their socio-demographic characteristics were not presented in the study because the

focus of the researcher were on the common understanding and reactions of the FGD participants, not on their individual and specific situations.

Table 1: Frequency of Socio-Characteristics of Parents

No	Age of the Child	Highest level of educational Qualification	Years of Service within Joy Center	Marital Status	Perceived Economic Status		
					Higher than others	Same as many	Lower than most people
Parent one	18	Grade 12	10	Married		✓	
Parent two	16	Basic education(reading and writing)	9	Widow			✓
Parent three	7	Grade 10	2	Married		✓	
Parent four	16	Diploma	8	Divorced		✓	
Parent five	20	Diploma	12	Married	✓		

Teachers and care givers

In this study two teachers and a care giver of CWA were involved. Their age ranked from 26 to 39. Out of two teachers one is degree holder in Management and one has diploma in clinical nursing. The care giver completed grade 12. Regarding the work experience, one teacher has 2 years of work experience and the rest has 10 years. The care giver has 5 years of work experience as a care giver of CWA.

Table 2: Frequency of Socio-Characteristics of Teachers and Care givers

Sample	Sex	Age	Level education	Field of specialization	Total work experience	Work experience with CWA
Teacher one	F	26	Diploma	Clinical nurse	4	2
teacher two	F	29	Degree	Management	10	10
Care giver	F	39	12 completed		5	5

From the above data, we can conclude that all respondents of CWA are mother who have an economic level ranked from high to low level and more over they received a service from the center CWA form 2-12 years. There for, they can give enough and pertinent information about the parental involvement and the program life-skill of CWA. On the other hand, with regard to teachers and care givers, their field of study is not parallel to the profession they are working on whereas the job experience of teachers in CWA is ample enough to give information regarding to the implementation of the program in self- help skill of CWA.

Under the Individuals with Disabilities Education Act (IDEA), elementary and secondary special education teachers are required to be “highly qualified.” The definition of “highly qualified,” within IDEA, closely aligns with the Elementary and Secondary Education Act, and requires highly qualified teachers to: 1) have a bachelor’s degree, 2) have full state certification or licensure, and 3) demonstrate subject-matter knowledge for the subjects they teach. While reports indicate that almost 90% of special education teachers are “highly qualified,” there is a considerable shortage of teachers qualified to serve students with ASD (Institute of Education Sciences, U.S. Department of Education, 2011).

4.2. Supports/Services and Trainings

In order to understand the supports/services and training provided from the center for CWA and their respective parents, the study brought these findings with supports/services and trainings accordingly.

4.2.1. Trainings

4.2.1.1. Trainings for teachers and care givers

Teachers and care givers are getting on the job training for continuous professional development. As mentioned by the teachers and care giver, counseling and trainings are provided by the staff in the organization and invited guests also provided various trainings. As the teachers and care giver thought they do not have certificate or diploma in the area they are working, and they did gate the opportunity on the job training on autism but the opportunity they got was on self-help skills.

4.2.1.2. Training for parents

Trainings are given periodically once in a month session for parents, the contents of the training they received are varied but compounded by Autism. Parents who participated in the study pointed out how their life changed after their child joined the center. According to the information parents provided, the Joy center plays a vital role in developing their competency unto helping their child by showing the way how to help their children. According to them, the contents of the training they received are varied. The topical issue of the training and the project is changing and upgrading their views and understandings on autism. This in turn made available their help and support for the CWA.

The core significance of the training, as for them is, proves to be the awakening and disillusionment of them that they wrongfully held a thought that they would take another risk of giving birth of CWA. But all respondents of parents thank the center for its encouragement and re-directing their motivation towards the adherence of the autism society in a continuously re-energizing way. Many parents reported that they learned the most hopeful thing from allowing their child to the center. On the other hand, some parent reported that the trainings are not formality based; there are redundancies on the content of the training.

They met once a month to discuss the issue. They exchange ideas about the changes, improvements and challenges they faced in dealing with autism. As such they reach at possibly viable solutions. These training and the meeting fully concentrated on the possible early development of autism disorder, about the occurrence of autism and the care and support for CWA.

Parent one suggested that they have been getting trainings from the center. The training made her life start new and successful journey; because her life was miserable before that. Nowadays, after the training she received and learned a lot about autism; the provisions and how to care for autism subjects and the training and instruction of autism topic. By practicing this method she witnessed the mind blowing great change of my child. She pointed out that trainings are given to them in a month interval. The duration is not fixed but it would last as the time of cases took. Supporting the above reactions, Parent three expressed her experience as:

The training and education activities of the center gave me a great sense of relief since I had a repulsion and frustration about autism before that. As a part to the success of the training, I re-train the house maid help and relatives to practice the

optimal way of handling autism related obstacles. Some instrumental tricks to initiate the child to speak and express emotions are shared among the center for CWA. Community and describing things that the autism rates and fears is part and parcel of our task. Even, food types are identified and artistically suitable ones are discussed in public.

4.2.1.3. Provision of self-help skills training for CWA

CWA are provided trainings on development of self- help skills like brushing ones teeth clean and placing objects properly, washing even with the help of others, putting on/off cloths, Washing underwear and socks. The data revealed that both CWA and parents receive various trainings. Training about skills is too pivotal to life, social conformability and self -help skills and resulting independent way of life. Trainees performing these wonderfully and with ease are also allowed and empowered to take mainstream academic courses.

In supporting the above idea, teacher one expressed that appropriate and necessary training courses were given in her class and this relieved them/CWA/ and their parents from massive trouble. In her class as well as in the center, Children were led through self-reliance process. Brushing ones teeth and placing objects properly, Bathing with the help of others, Putting on/off cloths, Washing under wear and socks, Strolling with trainers to cafes, parks and super markets, Recognizing and respecting rules at different areas, for instance avoiding the impulse to take other person's food and the like. Throughout their travel they are trained or instructed especially adapting to things through long time and doing things self-help skills.

As teachers and parents indicated, extensive training is given on self-help skills. Trainings are determined by CWA skills and talents. Yet undeveloped potentials existed and

trainings are varied and individualistic in content which depend on the potential manifested by the children. Therefore: Using toilet and cleaning after using it are given as a training practically and demonstratively, washing socks, taking a bath, changing dirty cloths, sorting and placing cloths in kind, cooking easy foods, socializing with other people, attending events and observing ground rules are some. Noticing traffic rules, conforming with rules at market places and recreational facilities are all clarified and this has evidently enhanced trainers' capacities and perceptions as well as for their parents.

Similarly, the care giver revealed that the levels of training were different based on skills and grades. Trainers at her class were a step higher to beginners as such they had capacities of performing any task. Due to this the center amended the courses and provided them with the best knowledge, at the end, the trainers and their parents lead a very simplified and convenient way of life. Primarily, the trainings focused on nervous system and bone strength. Next, concentration and visual recognition of colors were developed. For instance, make shifting spoons for tooth brushes were practiced. Differentiating objects in color and size or choosing between foods is also included. Using the hands/fingers in taking off or putting on cloths, using tissue papers and changing sanitary are among the activities to be encouraged. Eliminating by themselves or sibling others to help them, applying tooth paste appropriately, and washing up after going to the toilet and putting on cloths independently and smartly are among the lessons given within the center. These all were encouraged and demonstrated because lacks of these skills were identified by the center during the identification of the children.

Moreover, during anecdotal observation, the researcher was frequently attended in classes to see the type of lesson given for CWA which could help parents to support their children's day to day life at home. Generally, the school frequently taught them basic self-help skills such as

toileting, put on and off clothes and shoes, zipping, eating, washing their hands and faces, and waking.

4.2.2. Services and Supports

4.2.2.1. Autism diagnosis

Medical evidences and certification of children with autism is vital and became the first criteria for diagnosis and membership in the center. Based on the medical evidences attached to these children, the center prioritized and categorized the children for the purpose of support. The center also performs continuous medical diagnosis and categorization to appraise the current statuses of autism subjects. The center continuously did identification and specification of autism related abnormal characteristics under the chair person W/ro Zemi and others staffs. Then identifying their specific behaviors became the responsibility of center. If trainee with autism is found to be outstandingly/exceptionally smart in the middle of a certain grade, he/she would be promoted after discussing it with trainers. In supporting, the center, the care giver expressed her idea that the center served a broad spectrum of interests. This especially took place while the CWA arrived and were recommended for various treatments like reinforcing self-reliance, improving articulation or vocalization and building a bridge towards mainstream courses. The trainers and other workers of the center do their roles to realize these.

4.2.2.2. Economical support

The kind of support/service provided by the center for parents depends on the nature and severity of the problems; but they also receive some sort of support in common, others get dual support from the center. Parent two could be an example for this; she presented that she gained much support from the center. For instance, her first born autistic daughter became able to go to

school like her age mates and she also completely disillusioned about autism which made her interested in religion with her daughter's disability. Furthermore, because of her meager income she was running her life so tightly. Currently she became employed by Joy Autism center on income generating job and brought home a good payment. This improvement is being shown in her family's life and especially her daughter with autism.

4.2.2.3. Provision of safe and conducive environment

The center is favorable for CWA. To strengthen the interview and focus group discussion result, the researcher carried out anecdotal observation in Joy center for CWA. In parallel to respondents reply, the center is conducive for children; the toilet, sink for hand wash, shower room, etc. are comfortable for CWA. All the center employees have good personal relationship to each other. Beginning from the manager up to the guard attentively follows the child's movement. The guards supported the children beyond their responsibilities. The center equipped all necessary materials which are used for the training as well as teaching purpose beginning from equipment's what children can touch up to musical instruments, in addition to this, in the school compound there are pets such as dogs and cats which can be used for developing students relation with animals. In addition to this the children sing a song, dance and did physical exercises freely in the school compound. Generally they pass all the day through refreshing exercises. Even if the school compound is very narrow, they use it properly and effectively for bicycle riding, basketball playing and for a variety of outdoor games. Moreover, the administration office and the corridors are decorated by pictures and photographs and by looking the photographs, every person can understand and evaluate the level of progress of the child. To conclude all participants in the study revealed that the different type of primary support in the

center they gain were created a social, cozy and lively atmosphere for CWA and they are encouraged to bring them to the center. The children are also happy to be at the joy center.

Parent five explained about the Provision of safe and conducive environment she and her CWA gain from the center as follows;

We get a number of advantages from the center for a long time. My child spends much of his time with the center's workers and other trainee with autism here. He is happy better than us, his own family. Therefore, comparable condition is facilitated and his interests are fulfilled in the center because he can receive some professional and social supports that were missed at his home. This protection unimaginably made grateful benefits.

4.2.2.4. Transportation and lunch

Transportation in cities like Addis Ababa is too much challenging; but Joy center for CWA provide the service for CWA. As sample respondents revealed, children used the center transportation services and free lunch, parent two and three also added on the service they gained from the center, like door to door transportation services for CWA in affordable cost and free lunch provision for all. Respondents presented their views that especially in cities like Addis Ababa getting transportation on time is unexpected circumstance and on account of this, if they could not get this opportunity, their child would not get appropriate service and support from the center.

4.2.3. Changes and Improvements on CWA

CWA showed development in self-help skills in how to use toilets, put on/off clothes, wash their hand and face etc. Parents who participated in this study emphasized the significant improvements they observed in their CWA is the most important resource for them to strengthen themselves and work towards further progress. Similar to the rest, parent three expressed that great improvements were observed on CWA after they joining the center. Some of the improved characters were; changing up dirty cloth with neat ones and brushing her teeth all by herself, being able to choose shoes/cloths on her own and conforming to parent's advice, helping her mother and other family members by cooking simpler foods and boiling tea during breakfast.

As of Parent four the progresses are vital source of strength for parents, mainly the child's development of self-help skills such as toilet training, eating independently and show visible improvement in phoneme training were the main themes, improved sleeping time, behaving politely and cautiously while at cafe by wanting for his order and not picking up things which did not belongs to him, keeping his hands clean and sanitized at meals are the major one.

As parent one replied a lot of changes were observed on her child after joining the center, she expressed her idea as follows;

The first change I noticed on my daughter is that she grew to hear and understand my instructions and behave pleasantly. Being conscious about pain, trouble and death keeping TV volume pleasantly normal and watching interesting show or program attentively.

Parents have almost similar idea on the benefits they received from the center. As they replied on the focus group discussion, the support/service they gain from the center helped them

to change their bad attitude and they developed awareness about Autism. Also the periodic informational training about the cause, characteristics and related issues were of a vital advantage for them. As a result, their understanding improved their awareness on the area of autism and the way they understand and help their children. Parent one expressed her idea as:

Now, I become aware of thinking the wrong way about autism and helped me to change my view. First, I was not able to identify and understand the behavioral challenges of my child who is Autistic. This in turn facilitated previously troubled mother child relations. The improvements and changes I experienced are due to the training I received from the center.

Similarly, all teachers and care giver revealed that when CWA came to this school, they did not know about how to use toilets, put on/off clothes, wash their hand and face etc. but now they improved their self –help skills and can perform independently.

4.3. Communication between Parents and Teachers/Care givers

Communication of parents of Joy center is different in type, some parents communicate actively and have effective and continuous relationship with the center personnel and some parents had less and passive communication. They had different communication Methods such as communication book, phone, and face to face contact. The parents' involvement to convey information effectively to teachers is important to develop the quality service and care of their children and they made day to day or monthly meetings depending on the cases they had.

The data gathered from parents revealed that, the center workers keep record of CWA and inform the day to day progress of the children to their families. The record formats included the child's daily living challenges, their perceived solutions, the type of instructions given to

them which aimed to improve their self- help skill in the school as well as at home, and other similar issues are covered with in the formats. They commonly use the communication book to keep track of the child's progress and difficulties. Parents exchange information with the teachers and center personnel through the communication book and they describe home related daily living challenges on the communication book to inform the center for the provision of better intervention. Parents also wrote detailed to the center what they won and lost. Teachers/care giver refuels those shortcomings by giving them technical and need based interventions, as parent two and five described, they discuss on monthly sessions, they communicate with parents, teachers and the head of the center W\ro Zemi about the school-home success in relation to improvement. After learning and examining the good experiences of other parents, the center adopted it and followed their footsteps for another families with similar cases. Parent four expressed her experience as follows, she said:

We have close contacts with the teacher and center. The boy's siblings also help us maintain our efforts. We use phone and communications book to work on the case jointly. Uncommon traits/acts of the boy would be marked and analyzed based on the track record of the child. They inform us of new training sessions and we are also told to practice based on the updates at home. Sometimes we work together with the teachers when new findings and internet based tips are gathered and tested by his sister. Hence, we are able to achieve tremendously through short period of time and we are also motivated to work efficiently in the future.

Similarly teachers and care givers revealed that, there is good communication with parents and with all employers of the center to support CWA. All employers in the center took their time in developing CWA self-help skills. For all families they exchange daily information

about their child orally as well as by writing on communication book. The communication occurred generally between parents, teachers and care giver on a regular basis and this helped them to see the progress of CWA development continuously.

To strengthen the information collected by interview and focus group discussion, the researcher reviewed easily accessible documents available in the center such as children's communication book. The document review indicated that, there is an exchange of information, the exchange of information differs from parent to parent.

All the teachers take informing all activities for parents as a major job description of them, so that they always inform all the observed information for parents by using communication book. For any parent's comments and questions teachers/care giver respond very soon as the date of response on the note book imply. As the note book revealed, some parents respond for the comments and information given from the teachers and they request a solution for a challenge they face at home. The researcher observed on the communication book that some parents ask teachers support for what new things their child's did out of the school and to would continue and exercise in the school also, and even if they do not have a question to ask or information to give, some parents express their availability by putting their signature on the note book.

On the other side, the document review indicated that some parents did not understand their participation and contribution to their child development and fail to give information and requests that intended to support their children and resolve the challenges they face. The researcher understood that poor participation of parents is due to shortage of time or lack of adequate knowledge.

Similarly the researchers observed in the center when parents came in the morning with their child, the teachers communicate and share information's about their child. When the time of the day's lesson ends the student's families wait their child by discussing with the teachers carefully, like in the morning some parents ask the teachers about the day occasion and this is most of the time seen by mother parents. Those who came and return by drivers and home servants did not have a good relationship with the center workers and they do not communicate with teachers/caregivers about the child's stay in school.

4.4. Parents' and Teachers' Involvement in Improving Self-help Skills of CWA

Within the experiences of parental involvement, positive experiences and experiences with lack of parental involvement were shared by the teachers/care giver and parents. The teachers/care giver and parents expressed parental involvement as it is different with each family and their experiences have extremely varied from one to the next, except for parent one, who expressed that their experience has been really good and all the parents in their treatment room are involved and invested in seeing their children succeed. Teacher one expressed the variation of parental involvement in working with children as they are some parents that are fantastic, when they mention something or a different way to follow through and they try it and they would inform the teachers on how it went and then the teachers have worked with families where there is limited involvement according to their request.

Similar to teacher one experience, care giver had described that, some parents who are not involved at all and basically would attend the meetings they have to and then will drop off and pick up and that's about it. However, conversely, teacher one has also seen, Parents had

better involvement always ask questions, made phone calls, and letting us come to home to work on their child skills in the home.

Parent one expressed the involvement of parents with teachers that, all the center workers did positively and collaboratively for her child development, she presented in line with what they direct her, at any time they communicate to each other by communication book, by phone and face to face contact. She request support when she face a challenge in helping her child and they give her a solution immediately, more over they have monthly meetings for experience sharing and capacity building trainings, the teachers motivates her always on her participation and this all minimized teachers and care givers burden and they grasp results in a short period of time.

4.5. Factors Hindering Self-Help Skill Development of CWA

4.5.1. Challenges of CWA

Improper use of lavatory such as not washing and cleaning after defection and failure to keep oneself clean during menstruation, manifesting small appetite etc. are some of challenges that CWA faced. Most of Participants described similar types of difficulties with regard to self-help skills of CWA. Participants explained that their children lack the ability to feed themselves, control their hygiene skills, so most of the time they became dependent on their parents and need their support.

Parent one expressed that there are several predicaments in capacitating CWA; in terms of self-help skills, like failure to keep cloths neat and clean and to take caution not to soil it. Stunning, Hydrophobia like condition or fear of water, inability or lack of hygiene in using lavatory such as not washing and cleaning after defection and failure to keep oneself clean during menstruation, having abnormally small appetite, in ability to adjust and keep TV/Radio

volume in a unitarily normal sound. For instance, keeping the volume deafeningly loud that is normally uncomfortable to others and disturbing, misbehaving, crying and irritatingly testing others and wearing shawls of other people that could awkward or even dangerous because of body weight and using cosmetics unwisely and inappropriately.

On the other hand Parent two expressed some of the challenges of CWA she observed are like Wearing clothes inappropriately and one top of other in an awkward style, lack of communication and social interaction being unable to differentiate actions and things.

Similarly, Parent four exercises challenges not self-reliance related challenges observed except for avoiding eating independently while she is around, trying to be involved in the house activities and disturbing while she is working, not taking a bath without the help of others and behaving frequently and hyperactive while having his hair dresser.

Parent five response on Challenges she faced on her CWA are; going to bed late and waking up frequently and intermittently, confusing day and night, forgetting to keep his cloths neat and he haven't interest, failure of identifying his want, need and demanding other things while he is given the thing he asked for while things are not done and given according to his interest he Shout, slosh the wool, crying harm on himself always eating a unique type of food permanently are the most.

4.5.2. Factors that hinder parental involvement

Factors like socio-economic status, time, divorce and mother who lives separately with her husband because of his work etc. are some of the challenges that hinder parental involvement. The following section present, the different dimension of challenges or difficulties

experienced by participants in, to list some: socioeconomic status, time, divorce and mother who lives separately with her husband because of his work and others.

4.5.2.1. Socioeconomic status

Socioeconomic status played a role in parental involvement while some expressed socioeconomic status not being a factor in the level of involvement but parent two presented her experiences interrelated to these.

The organization provided certain amount of initial capital for women who are living in extreme poverty and it allowed them to small business as per the preference of parents. Only Parent two explained her experience on these and she is working in joy center preparing ‘Baltna’ products with families who identified as low socioeconomic status and who are leading abject poverty. In contrast, she put her experience as follow;

Since I am the one who took all caring responsibilities for her and coupled with my studies and low income, I could not rise above the challenges of accommodating for her special needs. My daughter always wants to have special and delicious meal. If the meal served is not well prepared and delicious, she refuses to consume by closing her mouth. In food preference, meat is her favorite. Providing balanced diet and Meeting the need of my daughter as per her interest is difficult to me even to fee house rent.

4.5.2.2. Mother who lives separate with husband

Participants of the study have been in marriage. Parent number one and three presented the presence of problem in engagement with their husbands. Because of their work, they move from place to place. The burden of taking care for the child became mother’s responsibility; it is

difficult for them to be involved for their children especially for their child with autism. Parent one presented challenges that hinder her involvement for her child as:

I am doing my level best to treat my daughter but I have encountered obstacles that curtail my success rate. If I treat my daughter the outcome would be encouraging and I supposed to do it and I am hoping for. To top it all, my husband is not here with us; he works away from home. Therefore, I am forced to deal with house chores and look after children; as a result the burden weakened me to perform efficiently and effectively. It is difficult to me to take care all my children's, especial for my child with autism.

4.5.2.3. Transportations

Most participants mentioned that transporting their child had been a major challenge to them. Most of them do not own a private car and they are forced to use public transport and they faced challenges when they took their child to school.

The family's cash strapped backgrounds contend them from going away to a new place. Most of the time, we walk a long way. Both positive and negative views from the community can be felt around. Fortunately, they had a ticket privilege not to wait a bus queue.

Even though the school provide transport service and accessible for households that are nearby, parents who reside far away still struggle with issues related to transport for their child.

Parent three also explained that the fees for the school bus are similar whether the distance is long or short. As a result, they preferred to use other options such as public minibuses for their children. Another alternative for them were contracting a taxi. Such taxi related complications bounded us from leading a free life.

They are able to access support from family members in transporting their child to school and this restricted them to work and earn a living, as Parent five responses;

The school bus does not going to far areas like 'garji' because of these we take the responsibility to takeout our child from the school it is difficult for his father to move another place it may be work or another appointments know a day his work is only giving transport service for our child accidentally when he got crisis our child absent from the school because our dwelling compound is far from the center it is heavy going to try by taxi.

4.5.2.4. Housemaid

It was difficult to leave home for work while having children with autism. This was a major challenge to most parents; unless they work, they cannot provide the needs of their child. Parent three put her constraint is absence of housemaid. Housemaids usually abuse the child with autism simply because her child is not able to speak and explain. Beating, feeding foods not advisable for such medical conditions, intimidation and strongly discouraging remarks are mentionable. In times she is not at home, the house maid feeds him food not necessary for his condition to persuade him avoid wetting his bed, or not act up now and then. The housemaid irrationally and repeating complains about payment and asks for more and more. Most housemaids behave as such. She put up with a harsh condition like one. Having a good housemaid would facilitate household especially off spring related occupation. She strongly speaks to would not to leave her child alone at home.

4.5.2.5. Siblings' responsibility and Mothers child attachment

Parent four and five have presented the importance of sibling by relating with their children experience. The siblings carried similar burden with their parents and it is helpful for

both parents and children. Participant four has three daughters and one son. She explained her experience that her family shares her burden and they (his sister and brother) try all their best for their brother. She explained that they have no hindering conditions from supporting and nurturing the child. They have tried their own best to treat the child optimally. His mother and siblings are beside him for custody and special parental company. In near future like one year ahead, his younger sister will join university and his other sibling will start other life as a result of marriage. As her explanation these conditions would affect her son social and personal life and by extension leaves a heavy burden on her to take on all home related responsibilities.

Parent five explained as her and his father devoted their time and minds to help their CWA. Consequently, time seems not to be a concern for them. She gives him training and support domestically. Since his siblings are away and us being adults, he found it rather boring not to have a partner to play with. As her justification it became boring to him to play with them because they are too old to him it is better to him to play and pass his time with his Siblings but they all live abroad.

Parent one have a problem which is related over protection and attachments she put like these;

Because of our closeness she frequently rejects what I tell her to do and I consequently feel sorrowful. Most of the challenges could not be tackled yet. Her negligence and refusal at home could be solved through trainers at school in a practical way but still there reaming to other constraints.

4.5.2.6. Accommodation Materials

There is shortage of accommodation materials for their children in and outside the school even it is difficult to gate in the country. It is not only materials but also the physical environment is not considered children with disability such as road, school physical environment, game zones, hospitals and others. According to this, parent five expressed her experience like these;

For instance, the accommodations of spaces for CWA makes the child attained only one school even it is difficult to get the chance. In schools, playgrounds and recreational centers, lack of modified supplies of cloth at shops especially for a person with disability, clubs for people of various talents and lastly hospitals. These can indicate the double standard in the society. The child, being advanced in age made it hard for him to defect in a potty by himself. Finally we restarted to asking our relatives abroad for a modified disability friendly apparent us to help him eliminate with no one else getting involved.

4.5.3. Challenges that teachers and care givers face

Parents participation is different with respective of their economy, marital status and family size. In the interview schedule of teachers and care givers they replied; the following as a challenge they face in the implementation of the self-help skills programs for CWA.

4.5.3.1. Feeling sympathy from people

The first challenge they face started when they move outside the school with CWA. The center have field trip program/schedule like visiting different places by traveling to parks, to

market, etc., and while in the moment, teachers or CWA faced different problems like some people shows unused deep feelings of sympathy, in different shops CWA touch different things frequently and took it to their mouth, in different places some peoples when CWA had disturbed them they became angry too, etc., and to overcome this all the teachers negotiate with café managers, walk through non trafficking roads and they create awareness to the community.

4.5.3.2. Parents' negligence

Another recipient of teachers and care giver had faced challenges that rise from CWA parents: passive involvement on their CWAs' development of self-help skills. Parents participation is different with respective of their economy, marital status and family size. Some parents participate actively on their child development, they teach their child's at home different things and exercise them different self-help skills and perhaps some parents do not teach their children how they would be self- reliant, even if they do not exercise them at home what they learned at school, they do not give and take information's about their child's development from child's communication book. They do not respond for teachers and care givers request at a time. Even if, some CWA may kick and injure the service providers of the center by different things, some parents do not cover medical costs and as a result teachers and care giver are feeling dissatisfaction to the profession on this aspect.

The other challenge teachers and care givers have been facing is on the aspect of CWA nutrition, that is autism by nature do not want carbohydrate foods, it makes them aggressive in behavior. But some parents give this kind of foods for CWA at home, on account of this CWA boot to each other, damage different materials of the school etc., while this moment the rest students disturbed and may got some physical injury, and this made their families angry and they feel as we did not follow/wait the children's seriously at the center.

4.6. Ways forwarded by teachers and care givers to improve the self-help skills of CWA

Respondents replied for further improvement of the program self-help skills of children with autism as follows;

For further improvement of the program the center care giver forward that building should be added because there are shortage of rooms and classes visible in the center. additional buildings in Joy center is needed to increase enrolment of CWA to live in the center and to pass their full time with experts; opening autism centers in all regions to enroll CWA near to their home and can give a door to door help/support for CWA in the early stage and this can avoid the problem of poor achievement of the training on self-help skills for CWA when increases their age.

As teacher one suggestion; creating awareness by different strategies and programs will increase the large community and families of CWA understanding of autism, autism characteristics, treatment and how to help the CWA in self-help skills development.

Teacher two also proposes; “The government and the community collaboratively shall built a center for CWA to give self-help skills and technical and vocational and handicraft trainings for CWA to will make them self -reliant in all aspects. To make CWA economically self- reliant like in our/Joy center, in our center there are CWA employed by monthly salary, as waitress, as a copier, etc., moreover if all stakeholders do on behalf of them, we can improve the life of CWA.

Similarly, parents replied for further improvement by saying; the government with all stakeholders collaboratively have to work together to give due attention for the acceptance of programs like self-help skills. In addition to this, the government as an initiative has to mobilize the citizen to raise a fund and to build centers like Joy near to all CWA. Different social Medias also, as they have been giving attentions for different issues, they should have to give similar attention.

CHAPTER FIVE

DISCUSSION OF MAJOR FINDINGS

The previous chapter dealt with the results of the study and this chapter deals with discussion of the findings in relation to literature reviewed and results of the study. A limited amount of research has been conducted on the effect of lack of parental involvement and could have on CWA enrolled in an early intervention program. The interviews, observation, document analysis and focus group discussion were used for this study. This section of the study interprets the findings and compares and contrasts the findings with previous findings reviewed.

5.1. Supports/Services and Trainings given

According to the reaction of participant teachers and caregiver, kinds of children who get support from Joy center are like these mainly children with autism are supported. In general Children with autism and related disabilities are treated in the center. From this we can conclude that in the Joy center are those children with Autism.

As respondents not satisfied the support given for parents of CWA differs from parent to parent but of all participants get something in common others get dual support from the center. Commonly, by provision of trainings their bad attitude was changed and they developed awareness about autism improved and changed, due to the training given to their child enabled and developed potential and self-help skills, periodic informational training about the cause, characteristics and related issues they gain helped them in being helpful to their child on developing self- help skill.

Their child spends much time with the center's workers and other trainee with autism, some parents recruited by Joy Autism center for an income-generating job and bring home a

good payment and the mothers as well as their child's receive some professional and social support.

From the above data one can conclude that Joy Autism center for CWA is giving services and supports by Autism diagnosis, economically, by Provision of safe and conducive environment and providing Transportation and lunch for CWA. The support/service for parents of CWA aimed to maximizing the implementation of self- help skills of CWA by participating them in different awareness creation programs, by helping their child's in developing self -help skills, by giving periodic information regarding to autism and their child development and more over by creating job opportunity for those economically week and the services/supports given has been helping in their CWA self-help skill development.

In the same way the data from the researcher observation revealed that, the school is giving necessary services .More over the infrastructures equipped in the center are satisfactory and this attracts and makes CWA happier than ever. The compound is conducive for CWA, the center equipped with necessary materials needed for the training of self-help skills, the school provides transportation and free lunch for CWA specially for those who are economically week, the children's sing a song, dance and do physical exercises together, they pass all the day through happiness, effectively for bicycle riding, basketball playing and for a variety of outdoor games, the administration office and the corridors are decorated by pictures and photographs. In general the center is doing/servicing the CWA to make them self-reliant by participating them in self-help skill programs collaboratively with their families.

In line with this, Mancil et al. (2006) conducted a case study that examined a child's problem behaviors in the home and the decreased behaviors as a result of parent trainings.

Similarly, findings suggested providing different supports and trainings in self- help skill development for parents of CWA in the home greatly increased the child's ability. Benson et al. 2008 reported mothers implementing as many activities as possible outside of programming to generalize program based activities into daily routines. Similar to the study conducted by Benson et al. (2008), one participant expressed satisfaction when she has parents who are seeking information and practicing games, words, and gestures used in programming with their child.

As parents, teachers and care givers revealed, the center is delivering trainings for parents, CWA and for teachers/care givers. Training for parents of CWA is given periodically once a month at a periodic session. The duration is not fixed but it would last as the case might be the contents of the training they receive are varied. As parents revealed, they fully concentrated on the possible early development of autism disorder, about the occurrence of autism, the care and support for CWA. The contents of the training were mainly; how to teach their CWA basic self-help skills such as toileting, eating, shopping, dressing and playing which were great problems previously in them and their child's life.

Generally, from the above data we can conclude that, Joy center of CWA is delivering trainings. the content of the training were autism disorder, about the occurrence of autism, the care and support for autistic children, and more over the training concentrates on basic self-help skills are such as toileting, eating, shopping, dressing and playing for parents of CWA. More over the training given for parents is periodically in a month and the duration of training depends on the content of the training prepared for that month and the trainings provided for parents positively influencing CWA development.

By supporting this International studies indicate that parental education influences expectations, in that having higher parental education is significantly related to having higher expectations of CWA achievement. Parent education is defined as an educational effort that attempts to enhance or facilitate parent behaviors that will influence positive developmental outcomes in their children (Dillenburger, Keenan, Gallagher, & McElhinney, 2004).

The primary focus of parent education programs in general is that of teaching discrete skills that are designed to aid parents in managing problem behavior, teaching skills to their child, and improving the quality of the parent-child relationship (Kaminski et al. 2008). Parent education differs from psycho education, which is typically designed to teach parents particular knowledge-based content (e.g., what is autism?) as opposed to skill-based (e.g., how to implement a treatment for autism). Broadly overviewed, research to date in the field of parent education suggests that parent education programs have a positive effect in the amelioration of symptoms in children and families. Influenced by the seminal work of, Forehand and McMahon (1981), behaviorally-based parent education programs are well-established, empirically supported treatments for a variety of childhood problems.

Educating teachers and care giver on this topic may help parents be more involved in their child's treatment and assist community in finding the most beneficial ways to support the parents and their involvement.

Changes/improvements of CWA after joining Joy center

The participants reported that after their child was joined Joy center the child showed a progress mainly in the development of self-supporting skills such as toilet training, eating independently and making sounds, Improved sleeping times, doing procedurally things like going to the toilet, washing face and brushing teeth, Putting on and off shoes and socks, Responding to impulses questions, Behaving politely and cautiously while at café, Not picking up things which are not their own and Keeping hands clean and sanitized at meals.

From all progresses listed above we can conclude that CWA after joining joy center and participating on the program of self-help skill development showed a great progress and development. The progresses are vital source of strength for parents, teachers and care givers.

In supporting the above, Ozonoff & Cathcart, (1998) reported significant progress in increased cognitive and developmental skills by children dually enrolled in an early intervention program and parent taught program at home. Ozonoff & Cathcart, (1998) study contributes to the participants' experiences with parent involvement within the home; resulting in increased skills for the child and progress within the program.

Similarly, previous studies reported on numerous early intervention programs and the success of the children when their parents were involved in their treatment as well as involved at home (Ryan et al., 2011).

5.2. Communication between Parents and Teachers/Care givers

As mother participants reviled, They exchange information between the center and parents is day to day, systematically by teachers keeping a record of their stay at the center and

inform parents, they elucidate their challenges and their solutions; also they give for parents instructions on helping their child at home, they recommend parents to train their child's domestically by giving tips and how to, by giving them techniques and methods, also they use phone and communications book and face to on the time of getting in and out from the school to work on the case jointly. Uncommon traits of the boy/girl would be marked and analyzed based on the track record of the child. They inform the parents about new training sessions. In response, the parents describe the problems they faced tackling the matter domestically. Additionally, they have regular monthly sessions of meetings, they discuss communicate with parents teachers and exchange about the good experiences of the other parents the rest adopt and follow their footsteps. Moreover respondents showed the communication varies from family to family, from one parent to another parent. Some parents communicate better and vice versa.

As the researcher revealed from document analyses, there is an exchange of information with teachers/caregivers and parents. Teachers always observe carefully the CWA, weather they did well or not, challenges and solutions they used, they wrote down on the communication book, to inform parents to make them aware and to get parents support. The exchange of information differs from parent to parent. Teachers/care givers respond very soon for parents request as the day of response implies on the note book, and for this reason, parents also giving them a positive feedback on the note book. As the document revealed, some parents even if they do not have a question to ask or information to give, they express their availability by putting their signature on the note book. On the other side, few parents did not reply for teachers request, did not give information and request a support as the researcher reviewed the communication book.

From the above information generally we can conclude that, the joy center teachers and respective families communicate on the daily basis, systematically by keeping notes to parents about the challenges they face, the solutions, instructions, training and meeting schedules, and the parents also reply what they face at home. Moreover they communicate by using phone, face to face on the time of getting in and out of the school and interestingly they have regular monthly meetings to discuss and share experiences. The communication varies from parent to parent, some parents communicate actively and some parents communicate poorly. Some parents are more open to communicating than others and others may be more hesitant to being involved or requesting support.

By supporting the above conclusion, The National Educational Longitudinal Study performed by Feuerstein showed that parent contact with the school was most highly influenced by the amount of contact began by the school; especially contact regarding student behavior and student grades. Similar study carried out by Howlin and Yates (1990) showed that direct teacher–parent communications may not only improve the quality of interpersonal bonds between teachers and parents but also permit for the disclosure of child specific information, which allows teachers to better understand their students’ strengths and challenges and to use this understanding to promote student success in the classroom.

Other study illustrated parent’s reports of their interaction with the specialists who worked with their children with special needs. In this view, it was revealed that parent–teacher communication in special education could be described as a shared and productive focus on child-directed services. For strengthening the degree of communication between parent and teachers of special school, LeoKanner, (1943) have suggested that psychologists have an essential role and can assist teachers to enhance their communication skills with parents, as well

as methods for organizing effective parent-teacher conferences. Psychologists can also encourage the involvement of parents in home and school based parental involvement. In this view, Burrell and Borrego, (2012) indicated that both parents and school staff asserted that it was essential for parents to have an actual connection with the school because it permitted them to better comprehend their child and their child's high school experience.

5.3. Parents' and Teachers' Involvement in Improving Self-help Skills of CWA

As respondents revealed parental involvement is different with each family and their experiences have varied from one extreme to the next, except for parent one, who expressed that their experience has been really good and all the parents in their treatment room are involved and invested in seeing their children succeed.

Some parents who are not involved really at all and basically will attend the meetings they have to and then will drop off and pick up and that's about it. However, conversely, there are Parents who are very involved and always asking questions, making phone calls, and letting us come do in-home to work on their child skills in the home and carrying things over. Generally, within the experiences of parental involvement, positive experiences and experiences with lack of parental involvement were seen by the teachers/care giver and parents.

Similar to Wieder & Greenspan's (2003) study that showed statistically significant trend between uninvolved parents and children who did not make as much progress, the participants expressed the importance of parental involvement. The participants reported the difference in children whose parents are involved when compared to children whose parents are not involved. Wieder & Greenspan's (2003) study that showed the effect lack of parental involvement could have on a child with autism. Several studies indicated the importance of parental involvement within an

early intervention program; however, several studies did not provide information on the success of a child and their success in the program when there is lack of parental involvement (Dillenburger and Keenan, 2009; Ozonoff & Cathcart, 1998).

The findings indicated in-home services as a requirement for parents who have children enrolled in an early intervention program; however, not everyone is utilizing the service. This information suggests that in-home services may need to be modified and given by appropriate way to fit the child's needs. Another suggestion was to offer childcare during the support group so parents are able to attend. In regards to supporting the whole family, suggestions were made on how to best support the siblings of children with autism. A sibling support group or sibling gathering was expressed as a way to have the whole family involved.

5.4. Factors Hindering Self-Help Skill Development of CWA

As respondents of parents, Failure to keep cloths neat, Hydrophobia, Having abnormally small appetite, Inability or lack of hygiene is using lavatory such as not washing and cleaning after defection and Failure to keep oneself clean during menstruation, Being unable to differentiate actions, Lack of communication, social interaction, Wearing clothes inappropriately, Consuming foods not advisable for the medical conditions , Going to bed late and waking up unusually intermittently, Forgetting, Failure of identifying want, Shouting, slosh the wool crying harm always and eating a unique type of food permanently are the challenges they face with their CWA.

The participants also expressed their lower level of involvement in their child's self-help skill development factors contributing to this lower level of involvement are socioeconomic

status, mother who are dependent on husband income, transportations, housemaid, accommodation materials and siblings' responsibility.

From the above information we can conclude that, all mother parents were facing a great challenge on account of their child being with autism. Basically the challenges were occurred because of their child lacks a knowledge of self-help skills.

These findings support Benson et al. (2008) study of working parents, particularly mothers, having a hard time caring for their child with autism when they need to balance out work and child care commitments. The findings and previous studies indicate the level of socio economic status having an effect on parental involvement (Benson et al., 2008). However, a higher socio economic status does not result in more involvement and a lower socio economic status does not result in less involvement. The participants expressed the parent's level of education playing a role in parental involvement. Parents with a higher education, for example a 4 year college degree or graduate degrees resulted in the ability to access resources and understand the diagnosis. Parents with not as much education, high school diploma or less might not be able to access certain resources.

like some people shows a unused deep feelings of sympathy, in different shops CWA touch and taking into their mouth different things, in different places different peoples when child's disturb them they become angry too, parents passive involvement in giving and taking information about their children development, some parents do not teach and exercise their child's at home, do not respond for teachers/care givers request, boot to each other, CWA damage different materials, boot each other, families angry in case of physical injury etc. are challenges that teachers and care givers face.

From the data above we can conclude that Joy center of CWA teachers and care givers are facing challenges in the implementation of self-help skills of CWA on account of passive participation and involvement of parents. For better development and self-help skills of CWA, Parents should attend trainings, meetings, work actively with the teachers and care givers, give and take information's to teachers and care givers on the daily bases are needed. Where as in the Joy center some parents are involving passively and this is seriously affecting the development of CWA in self-help skills.

In supporting the above Previous studies reported parents' involvement through case studies; however, the case studies did not report the specific roles parents' play in order for their child to be successful (Tehee et al., 2009) Contrary to previous studies, all of the participants reported on the following areas as important to the success of a child in an early intervention program when asked to describe parental involvement: 1) what is going on in the treatment room, 2) connecting with mental health professionals and practitioners on a regular basis, 3) attending meetings, 4) participating in in-home therapy; 5) working actively with the mental health family practitioner, 6) professionals and practitioners being available for questions, 7) parents wanting to learn the techniques that are used in the treatment room so they can do them at home, 8) getting to know other parents in the program, and 9) getting to know the people working with their children by building a relationship with them (McConachie & Diggle,2006).

5.5. Way Forwarded to Improve the Self-Help Skills of CWA

As respondents of teachers and care givers response for further improvement the of self-help skills program of CWA suggestions; it is better to create awareness in the community shall be improved by creating different awareness creation strategies and programs, government and

the community collaboratively shall built a center for CWA to give self-help skills and technical and vocational and handicraft trainings for CWA to will make them self- reliant in all aspects also economically, if Joy center build additional buildings and if CWA by joining the center live and pass their full time with experts, it is better to open autism centers in all regions, to enroll CWA near to their home and can help in the early stage.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

The previous chapter deals with the discussion of the findings and this chapter deals with in relation to literature reviewed conclusions, recommendations and implications in a bid to influence Government policies and aid in the operations of Non-governmental organizations that operate in the area of Autism.

The major objective of this study was to investigate the existing and real practice of Parents' and teachers' involvement on improving Self-help skills of CWA, at Joy center-Nia foundation for CWA. To this end the following specific objectives were raised; to identify the support and training that given for the parents' and teachers' from the center ,to see the way of communication between parents' and teachers' daily on the self-help skill development for sustainable solutions of CWA ,to evaluate the engagement of parents' and teachers' in the implementation of the program/training on the implementation of self-help skill development for CWA at Joy center and to find out factors that hinder parents involvement in the implementation of self-help skill development for CWA at Joy center.

In order to achieve the above objectives, the researcher had employed a qualitative research approach namely, case study method. For this, nine parents of children with autism, two teachers and one care giver were selected from the targeted center for interview and focus group discussion questions. Qualitative data was obtained via semi-structured interview; FGD, anecdotal observation and document review were conducted. To this effect, the following conclusions and recommendations were obtained:

6.1 Conclusions

The study brought to light some revelations from which conclusions were drawn based on the findings and basic research question of the study:

This study revealed that, Joy Autism center for CWA is supporting parents of CWA to maximizing the implementation of self- help skills of CWA by participating them in different awareness creation programs, by helping their child's in developing self- help skills, by giving periodic information regarding to autism, by supporting economically by creating job opportunity for those economically weak, by providing free lunch, school bus and by delivering trainings. As a result progresses achieved. The progress includes self-supporting skills such as toilet training, eating independently and making sounds, Improved sleeping time, doing procedurally things like going to the toilet, washing face and brushing teeth, Putting on and off shoes and socks, Responding to impulses questions, Behaving politely and cautiously while at café, Not picking up things which are not their own and Keeping hands clean and sanitized at meals are the basic.

The Findings show that, the joy center teachers/care givers and respective families communicate on the daily basis, systematically by keeping notes to parents about the challenges they face, the solutions, instructions, training and meeting schedules, and the parents also reply what they face at home and request support. Moreover they communicate by using phone, face to face on the time when they take in and off their child after class end and interestingly they have regular monthly meetings to discuss and share experiences. The communication varies from parent to parent, some parents communicate actively and some parents communicate poorly. The exchange of information differs from parent to parent, and the way is also differs, some parents

exchange in face to face orally, and the others by communication book and the rest communicate by phone also.

Most of parents of Joy center are participating actively in the improvement of self-help skills by taking trainings, attending meetings, by helping and exercising their child at home, by doing what teachers and care givers supposed, by giving and taking all necessary information's. Few of Joy centers some parents of CWA are involving passively and this is seriously affecting the development of CWA in self-help skills. For better development and self -reliance of CWA, Parents should attend trainings/meetings, work actively with the teachers and care givers, give and take information's to teachers and care givers on the daily bases are needed.

There are factors that hinders parents involvement, the findings of this study display that, the lower level of participation and involvement in their child's self-help skill development is due to less education, socioeconomic status, parent's work place, transportations, Siblings' responsibility and mothers to child attachment parents and teachers didn't give the service for the children because the above points hinder their involvement.

6.2 Recommendations

In light of the findings and conclusions drawn; the following recommendations are forwarded;

1. Parent and school management needs to work together to meet the same goal, that is to improve the specific problem of the child both at home and school. It would be better if integrated activities between the parent and the school implemented to alleviate the problems of CWA.
2. Parents are at front for their children at home level. Thus it would be better if they follow their children activity at home and regularly inform teachers about their children's special needs. Teachers need to consider the information of the parent about the child and take their own major to facilitate the education of the child in the classroom.
3. Ministry of Education need to give more attention to the implementation of special needs education programs and the availability of trained teachers.
4. It would be better if the government and other concerned bodies work on awareness creation in order to minimize wrong belief against CWA.
5. It is also recommended that it would be better if there are additional schools for them, if parents' especially single parents would be assisted; if poor parents would be given free transportation services
6. It is better if the school management creates conducive environment for research works and professional relationships in order to strengthen parental involvement based on understanding.

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Appendix I

Addis Ababa University

School of Graduate

College of educational 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 topic: parents' and teachers' involvement on improving self-help of children with autism. Therefore, I would like to thank you in advance for your kind cooperation.

Part I Interview with family of children with autism

1. Background information

A. Age _____

B. Sex _____

C. Sex of your child _____

D. No of children without autism female _____ male _____

E. Education Level _____

F. Years of service received _____

G. Marital status _____

H. Economic status High _____

Moderate _____

Low _____

Interview with parents of children with autism

1. Do you think you are getting adequate support and training from the center?
2. What are the contents of the training? For how long?
3. Describe the challenges your child encounters in terms of self-help skills?
4. What are the problems of your child?
5. In what way do you implement the training that you got from the institution in your home for your child practically?
6. What are the changes or improvement in self-help skills of your child?
7. As a parent, how do you communicate and work with the teachers and school community to improve the child's self-help skills at home and school at the same time?
8. What are factors that hinder your involvement in improving your child's self-help skills?
How do you solve it?
9. What do you do or your role to develop your child's self-help skills?

Part II: Interview with Care Givers and teachers

A. Background information

1. Sex _____

2. Age _____

3. Level of education: _____

4. Field of specialization _____

5. Work experience _____

1. Did you get training on improving self-help skills of children with autism?

2. What are the contents? For how long?

3. What roles do you and your colleague's have in the improving of self-help skills of children with autism?

4. Do you think your support is helpful?

5. What changes have you noticed as a result of your support?

6. As a teacher, how do you communicate with the parents and care givers to develop the child's self-help skills together in the way of teaching day to day activity and its transformation?

7. What challenges do you face when providing the services? How do you overcome the challenges?

8. What should be done further to improve the self-help skills of children with autism?

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

Dear participants, the following focus group discussion items are designed to collect data for MA thesis study on: teachers' and parents' involvement to improve self- help skills of children with autism. Therefore, I would like to thank you in advance for your kind cooperation.

General for focus–group discussion guide

1. Benefits of the training for parents in self –help skills?
2. How closely do parents work with the teachers daily?
3. What changes have you observed in improving the self –help skills of children?
4. How you participate in monthly discuss and rise ides for the solutions?
5. What should be done for the further to improve these skills?
6. Do you think you are quite satisfied with the provision of support from the center?

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Key point for Document review

1. Self-help skills training manual which is prepared by the institutions.
2. Comments and communications between parents and teachers on the communication book.
3. Educational background and field of specialization of teachers and care givers.
4. Personal profile of children on their daily progress.