



**ST. MARY'S UNIVERSITY
SCHOOL OF GRADUATE STUDIES
INSTITUTE OF AGRICULTURE AND DEVELOPMENT
STUDIES**

**IMPLICATION OF CHILDHOOD AUTISM ON THE
WELLBEING OF FAMILIES: THE CASE OF ADDIS
ABABA, ETHIOPIA**

By

Minasie Mekbib

JUNE 2017

ADDIS ABABA, ETHIOPIA

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WELLBEING OF FAMILIES: THE CASE OF ADDIS
ABABA, ETHIOPIA**

**A Thesis Submitted to School of Graduate Studies, Institute of
Agriculture and Development Studies, St. Mary's University for
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Development Economics**

**By:
Minasie Mekbib**

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DECLARATION

I hereby declare that, this thesis titled “**Implication of Childhood Autism on the Wellbeing of Families: the case of Addis Ababa, Ethiopia**” has been written by me and it is record of my own research work. No part of this work has been presented in any previous application for another degree or diploma at any institution. All borrowed ideas have been duly acknowledged in the text and a list of reference provided.

Minasie Mekbib-----

ENDORSEMENT

This Thesis has been submitted to St. Mary's University, School of Graduate Studies for Examination with my approval as a university master's student advisor.

Wondimagegne Chekol (Phd) -----

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LIST OF ACRONYMS

ASD	Autism spectrum Disorder
ATT	Average treatment effect on treated
GDP	Gross Domestic Product
HDI	Human Development Index
HH	Household
IFLL	Inquiry in to the Future for lifelong learning
MOH	Ministry of Health
OECD	Organization for Economic Co-operation and Development
PCI	Per Capita Income
PSM	Propensity score matching
UNDP	United Nation Development Program
WHO	World health organization

ABSTRACT

Autism has an economic, social, psychological implication of the families parenting the autistic children. In the country like Ethiopia, what makes the problem serious is limited institutions which can give education, therapeutic and support service for the children and the awareness level of the community at baby age and families and children with autism are suffering. This will make the families to refrain from jobs, social network and other economic and social activities and eventually they get themselves isolated and almost zero participation in any form of activities. The main objective of this study is to analyses the implication of autism on the wellbeing of families and describe challenges in terms of economic, social and psychological aspects. Quantitative approach by employing Survey questioners is used to gather information from 70 respondents (30 treatment and 40 controlled families). To discuss demographic and socio economic characteristics, Descriptive statistics have been employed. To analyze implication of autism on the wellbeing of families PSM model. For this analysis 5 wellbeing, indicators (total income, total expenditure, health status, education attainment and life satisfaction that are a proxy measure for wellbeing) selected as an outcome variables and impact of ASD on each outcome variables analyzed. The results of the model dictated that autism has a significant impact on the wellbeing of families. Following the findings, the first recommendation is that ensuring easy access to education, therapeutic center and medical treatment centers. Secondly, research works and community awareness raising program are essential to draw attention of different stakeholders. Finally, it is also recommended that inclusion of those households in different income generating activities and livelihood support programs to reduce economic vulnerability of families with autism.

Key Words: childhood, Autism, wellbeing, families, Ethiopia

CHAPTER ONE- INTRODUCTION

1.1. Background of the Study

Autism Spectrum Disorders (ASD), are developmental challenges manifested by impairments in language, communication, social functioning and complemented with limited range of interests and repetitive and stereotypic behaviors. (Amet L, 2013)

It has been reported that psychological difficulties and stress are much more prevalent in parents of children with autism than in parents having non-disabled children. Hare et al. (2004) found that parents felt that their lives is restricted by the needs of their children with ASD, as manifested by reduced social opportunities (as cited on Michigan Autism Spectrum Disorder,2012). These parents generally worried about the future of their children who would care for their children, as they are getting old. Because of these significant stressors, parents of children with ASD may also experience negative psychological outcomes, including depression and anxiety (Hare et al, 2004).

A child with ASD places additional pressures on the family. Difficult and challenging behaviors can prevent families from attending events together; couples often cannot spend time alone due to extreme parenting demands and the lack of qualified staff to supervise the disabled child in their absence. In addition, the responses of fathers and mothers to the disability of a child with autism reveal different levels of perceived stress and impaired health, potentially contributing to conflict. A further significant stress factor relates to the increased cost of living, most particularly for parents who are unable to work due to their duty of care. Additional factors influencing the family relate to the lack of adequate support services, the lack of acceptance of autistic behavior by society and sometimes by family members, and a low level of social support. A National Survey of Children's Health conducted in the United States(2012) has further confirmed a range of problems including diminished family functioning, more school absences, less participation in community activities, and difficulties with child care and employment.

In most cases, Ethiopian parents particularly mothers having an autistic child, become disadvantaged and burdened with full responsibility of care. They are also likely having very little

income due to the constraint on their ability to work and make money for living. In most of the time, there is exceptional demand attributed to the child's disability which creates emotional and financial problems for the parents.

In Ethiopia there is lack of awareness on the existence of such kind of disorder. Children with autism are deprived of their right to education and rehabilitation due to lack of awareness most children are even prohibited to get pleasure from day light. (Nia foundation, 2010). According to Nia foundation in Ethiopia children with autism are even locked behind doors when parents get it difficult to manage their behavior. Currently there are no studies made on the prevalence of autism in Ethiopia however according to estimation made by Nia foundation around 530,000 children are diagnosed with autism and related developmental disorder. So far, there are only two centers for children with autism Joy center and Nehemiah which has established by the mothers of children with autism.

1.2.Statement of the Problem

Parenting a child with a disability can produce great stress and a sense of imbalance in the family system (Burrell, Thompson, & Sexton, 1994). Parents of children with developmental disabilities experience a negative consequence in their wellbeing (Quality of life and material wellbeing) than parents of typically developing children (Hodapp et al., 2003). Even though they have the joy of being able to hold and love their baby, their life is suddenly and drastically changed (Ashley Hartmann , 2012). This in turn produces feelings of grief, stress and confusion. Immediately, with no warning or preparation, the family has to transform and adapt to a new lifestyle. Daily routines become much more complicated, at least the primary care giver has to give up working and families find themselves no longer able to do some of the things they were once able to do. (Meadan et al., 2010)

The initial autism diagnosis leaves parents confused and they may have a hard time accepting that the child they were anticipating is not the child they expected. This new transformation in their family impacts the relationships in the family, as feelings of fear and worry encompass the family system

Parents who raise a child with autism are faced with unique challenges. As a result Parents of autistic children tend to report lower quality of life, more depression, and greater pessimism about the future than parents of typically developing children (Kristin D. Neff & Daniel J. Faso ,2014).

The severity of children’s autism symptoms have been shown to negatively affect parental well-being namely mental or psychological, social wellbeing and support and economic Wellbeing.

ASD is becoming more and more prevalent in today’s society (Rice & Centers for Disease Control and Prevention, 2009). So that social workers with knowledge and experience in this area, proper institutions dedicated to provide exclusive support to the family and children diagnosed autism, government policies that can address real socioeconomic challenges are in high demand as this diagnosis not only affects the individuals themselves, but it affects their families as well

The purpose of this research is to examine implications of childhood autism on the wellbeing of families. The research tried to address the research questions: what is the implication of childhood autism on the wellbeing of families? and what are the socioeconomic challenges that parents are facing? The goal of this research is advocating implications of autism on the wellbeing of families to further initiate additional research by scholars and draw attentions of different stakeholders to intervene in those areas and pose a positive impact on the lives of both the children living with autism and their families.

1.3.Research Objectives

1.3.1. General Objective

The main objective of the study is to find the implication of Childhood Autism on the wellbeing of families expressed by their social, economic and psychological aspects in Addis Ababa.

1.3.2. Specific Objectives of the Study

The research will address the below listed specific objectives. Therefore, the specific objectives of the study are

- To assess implication of autism on families of Autistic child in Addis Ababa

- To describe the economic challenges of the households parenting autistic child in Addis Ababa
- To describe the challenges of family households on accessing social services such as education and health institutions
- To discuss psychosocial problems of families attributed to autism

1.4. Research Hypothesis

- Families having a child challenged with ASD are receiving more socioeconomic challenges than families having a child with normal development

1.5. Significance of the Study

Wellbeing is broad in its meaning and it is indispensable for the families to lead a normal and decent life in their day-to-day activities. Studying the implication of Childhood autism on the wellbeing of the families can provide information to the government, non-governmental organizations, donors and private companies on how family wellbeing is being at stake and initiate the possibilities of providing reliable and sustainable support in the sector. On the other hand, this study can inform policy makers and other interested groups to consider autism as the national agendas, design policies, develop implementation strategies, and ensure better life for the families as well as for the children with autism.

1.6. Scope and Limitation of the Study

Institutions for autism are very limited in Ethiopia and there are only two centers exclusively providing service for autistic child. In addition, there is no organized database about the number of autism children in the city and their location from any of respective government offices. Therefore, the data collected for this study is limited on families who are sending their children to these two centers namely Nia foundation JOY Center and Nehemiya Autism center. The other important point is studies in this area especially to know the connection between autism and family wellbeing are remotely rare in Ethiopia context. As a result, it was difficult to get adequate research works and delaminate through analysis and triangulation with similar researches.

1.7.Organization of the Paper

In the next section of this research paper, Literature review, Research Methodology, result and discussion, conclusion and recommendation and references presented. Chapter 2 dealt with theoretical and empirical literatures in the areas of autism, wellbeing and method of measurements of wellbeing. Moreover, Research methodology comprising research approach and design, sampling design and procedure, Data source and data collection method and method of data analysis discussed in Chapter 3. In the fourth chapter, results and discussion have been discussed. On the fifth chapter, conclusion and recommendation articulated based on the final findings on the result section. Finally, list of references and annexes have been attached

CHAPTER TWO- LITERATURE REVIEW

In this section of the research paper, both theoretical and empirical issues related with Meaning of autism, common characteristics of Autism spectrum Disorder/ASD and causes of autism will be discussed. It will also provide concrete evidence on how wellbeing in general and family wellbeing in particular can be articulated, measured and interrelated with autism.

2.1.Theoretical Literature

2.1.1. Definition and Concept of Autism

Autism is a neurodevelopmental disorder that affects a child's ability to communicate and interact socially (Center for Disease Control, 2009). It is described as a spectrum disorder, which means that it manifests itself across a wide range of behaviors from mild to severe (**Life Journey through Autism**). The symptoms of autism involve three major areas of development: social, communications, and behavior (Weiss & Lunsky, 2011 cited by). Specifically, a person with autism may:

- Have difficulty engaging in reciprocal social interactions with others;
- Not communicate with others in developmentally appropriate ways; and
- Exhibit self-injurious or repetitive behaviors, focus interest on a single topic or activity, or fixate on objects (such as ceiling fans or toys).

According to Volkmar&Wiesner(2009) as cited by Mastewal , autism is one of the five Pervasive Developmental Disorders that vary in the severity of symptoms, age of onset, and association with other disorders like intellectual disability. The others are:

- Asperger Syndrome (or Disorder)
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- Rett Syndrome
- Childhood Disintegrative Disorder

2.1.2. Common Characteristics of Autism Spectrum Disorder

There are various characteristics of autism Spectrum disorder, which the autistic children commonly exhibit. Those challenges have social dimension manifested in to social interaction,

communication dimensions portrayed by communication challenges and behavioral related most of the time depicting differences.

Social Challenges with Social Interaction:

Challenges registering and interpreting nonverbal language, difficulty with pretend play, infrequent eye contact and/or unusual eye gaze patterns, facial expression may appear “flat” or may not match emotional state. difficulty interpreting facial expressions ,inaccurately judges personal space; may stand too close to others ,difficulty identifying and managing emotional states, Challenges managing stress and anxiety ,difficulty understanding of another person’s perspective or how their own behavior affects others (British Columbia Ministry of Education, 2000).

Communication Challenges:

Delayed in expressive and receptive language; there may be an absence of verbal language, very literal understanding of speech; difficulty in noticing figures of speech and nuances. Echolalia— may repeat words or phrases heard without regard for meaning, pragmatic language difficulties, in which an individual has a good or even expansive vocabulary and ability to form sentences but has difficulty using language socially (British Columbia Ministry of Education, 2000).

Behavior Differences:

The characteristics of most autistic children are ritualistic, obsessive, and repetitious and stereotyped which may involve gross and fine motor behaviors or highly complicated verbal rituals (Schreibman, 2005). Whitman (2000) as cited in Sara (2014) describe repetitive, restricted activities and patterns of behavior as the most interesting and major characteristics of autism. Opening and closing doors, flipping light switches on and off and repetitive water play are some of the major repetitive behaviors that an autistic children exhibit (Keenan et al, 2007, as cited in Aynalem, 2014). Those repetitive behaviors elaborates further to finger flicking, hand flapping, body rocking, self-spinning, or running in circles and they are the common motor stereotypes, that is self -stimulating behaviors during preschool years (Keenan et al, 2007, as cited in Aynalem, 2014). According to different studies in the area, unusual sensitivity to sensations: may be more or less than typical individuals , difficulty with transitions, need for sameness , rigid adherence to rules, routines, and expectations , Possible aggressive, disruptive and/or self-injurious behavior, possible lack of awareness of potentially dangerous consequences to behavior whether for self or others

Diagnostic Criteria

The first diagnostic criterion—impaired social interaction, includes reduced eye contact; failure to develop peer relationships; absence of spontaneous joy or interest; and lack of social or emotional reciprocity. The second diagnostic criterion—impaired communication, involves delay in, or failure to develop, spoken language; impaired ability to have a conversation; stereotyped, repetitive, idiosyncratic language; and lack of symbolic play. The final criterion is stereotypic and repetitive behavior, including preoccupation, inflexibility and rigidity, motor mannerisms such as hand flapping and spinning, and preoccupations with parts of objects (American psychiatric association, 1994).

2.1.3. Coping with an Autistic Child

Coping is an important aspect in the grieving process when presented with an autism diagnosis. Coping compliments the family's acceptance process. Parents can cope with their situation having a child diagnosed with autism by employing

- networking with other families who have been affected by the disorder: this will help them to feel comfortable in finding others who are experiencing similar situations as well as receive advice that will be useful in the parenting process (Autism Society, 2011)
- Finding primary places where parents can receive support include support groups, other parents of children with autism, social workers, occupational therapists, special education teachers and other mental health professionals (Meadan et al., 2010)
- Altieri & Kluge (2009) on their study indicated that social support from friends, family and spouses reduced depression and increased the well-being in parents of children with autism
- Spousal support mentioned as the most useful support as they get relief, breaks when they divide household responsibilities, and share the disciplinary role for one another (Meadan et al., 2010).

2.1.4. Review of some studies on Autism

Some Studies in America shows that how the wellbeing of families with autism is affected. But effective early intervention may reduce the impact of ASD on the economy as well as improve

quality of life for people with ASD and their families. According to Dyches, Wilder, Sudweeks, Obiakor, and Algozzine (2004) autism is considered a severe disability secondary to the intense lifelong effects it has on the diagnosed individual and their family (as cited in Plumb, 2011, p. 3). The impairment of autism not only affects the diagnosed individual but also caregivers, family, teachers, and community (Karst & Van Hecke, 2012, p. 247).

Stressors from autism diagnosis can cause a strain on parent's marital relationship, increase financial burdens in the family and result in parents socially isolating themselves from others (Naseef, 1989 as cited in Hartmann, 2012, p. 7).

Sara (2014) indicated that parents lack the knowledge to know about autism and its symptom. In particular, mothers of autistic children who have lost their spouse to HIV/AIDS, other diseases, or who are separated from their spouse due to their autistic child are left with few resources and they carry an incredible financial, social and psychological burden.

Nia foundation pointed out the impact of autism on mothers in particular. Mothers must stay home to manage their children, though financial demands mount. They are unable to work because their children are often not allowed to attend regular schools for children their age. These mothers cannot even leave their children with relatives or neighbors; because their child's uncontrolled behaviors are misunderstood; recognized as the expression of poor parenting, or as punishment for sin. As a result, financial instability and outright poverty are happening to families.

Aynalem Tadess (2014) citing J-CCARDD (2005, p.1) said that most mothers of autistic children are single handedly crying in the dark. They do not feel at ease to talk about their children openly instead, they feel guilty and are ashamed of their autistic children due to the pressure and misunderstanding of the society. Hence, thousands of children with autism are confined to their homes with no access to education or rehabilitation

Autism Spectrum Disorder (ASD) is typically diagnosed in childhood and has a wide range of symptoms, some being more severe than others. Children diagnosed with autism communicate verbally, nonverbally or a combination of both. Due to this aspect of ASD, school curriculum and special education services may need to be modified in accordance to their communication style.

Public debates about autism policy are hardly unique all over the world especially in developed

countries where there is better awareness and knowledge. Sometimes parents challenge the policy maker through the legal process seeking to get funding for early autism interventions (Greschner and Lewis 2003).

There has been an increase in the diagnosis of ASD over a short period of time. Approximately eleven years ago, the cases of autism ranged from five per 10,000 (American Psychiatric Association, 2000) to 60 per 10,000 (Altieri & Kluge, 2009). A recent study concluded that autism is affecting approximately 1 in every 110 children and is growing at a rate of 10% to 17% per year (Meadan, Halle, & Ebata, 2010).

It has been reported that up to 30% of children with ASD regressed in their development skills or completely lost these skills before the age of two and up to 11% of children who are diagnosed with ASD, prior to the age of two, had development skills that did not progress any further (Rice & CDC, 2009)

Regarding financial spending, a number of studies revealed that People with autism are said to spend twice as much as the average American on health care over the course of their lives. The nonprofit organization Talk about Curing Autism estimates the annual cost of treating a child with autism: \$11,250 for speech therapy, \$11,250 for occupational therapy, and \$59,400 for behavior analysts and therapists for a total of \$81,900. According to Gurney as cited in Laura C. Hoffma, relative to children without autism, children with autism, as reported by their parents, experience significantly higher number of preventive visits and emergency and nonemergency hospital visits contributing to the increased spending.

Foundation for People with learning Disability (2015) conducted study on Economic consequence of Autism in UK. In this study, annual costs for children with low-functioning ASD who are living in residential or foster placements were estimated to be £16,185 (for children aged 0-3 years), £40,578 (aged 4-11) and £62,536 (aged 12-17). Costs were considerably lower if children with low-functioning ASD lived with their families: £585 (if aged 0-3), £23,869 (aged 4-11) and £36,474 (aged 12-17). Average annual costs for children with high-functioning ASD ranged from £1,214 to £21,090. These costs exclude informal care by families. The lifetime cost for someone with high-functioning autism was found to be £2.9 million and £4.7 million for someone with low-functioning autism.

2.1.5. Implication of Autism on Families

Parents whose child is diagnosed with ASD experience difficulties and it changes the dynamics of the family in that everyday activities need to be modified and the child with ASD will need extra attention from the parents. Learning that your child is autistic can result in scattered emotions for the parents. Each family handles the vision of their child differently. Upon hearing their child's diagnosis, one study found that in parents, "52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame" (Banach, Iudice, Conway, & Couse, 2010)

Parents often experience stressful situations upon the initial diagnosis that relate to their child's behavior, adapting to this new lifestyle and the complexity of finding access to the appropriate services useful to the family (Banach et al., 2010).

Stressors from an ASD diagnosis can cause a strain on parent's marital relationship, increase financial burdens in the family and result in parents socially isolating themselves from others. Parents experienced stress as a result to modifying goals and activities for their child diagnosed with autism, having to implement different arrangements for the child's education as well as grief due to limited opportunities offered to their child (Naseef, 1989)

Findings indicated that mothers reported having more stress than fathers related to their child diagnosed with autism as mothers are usually the primary care givers of these children and are more active in the child's education (Dabrowska & Pisula, 2010)

It is common that children with autism are nonverbal and unable to express their feeling and their basic needs. This will be a source of frustration for both the parents and the children since the parent experience difficulty in understanding the needs while children experience difficulty expressing their own needs. This can often lead the child to aggressive behavior. In most cases parents have always experience extreme worry as the children diagnosed ASD unable to report abuse or neglect in other settings and their child may be potentially harmed because often, they cannot communicate verbally and are highly vulnerable (Autism Society, 2011).

The other stressor is the feedback from the community while parents are outside home with the child diagnosed with ASD. This also makes parents hesitant to take their kids over to friends or relatives houses because they feel as though they cannot socialize or relate and sometimes feel sense of isolation (Autism Society, 2011).

Parents also concerned about the future wellbeing of their child and they may experience fear as they plan for their children's future and examine ways of proper care. Future care giving presents stress in parents because in certain circumstances, there are no other family members capable of taking over when the parents are no longer able to care for their child (Autism Society, 2011).

The fourth stressor for the parents is financial challenges. A child diagnosed with autism needs several services such as evaluations, home programs, and various therapies which are expensive (Autism Society, 2011).

Last but not the least, feelings of grief on the loss of the child they expected for themselves, the loss of lifestyle change and drastic changes in their family dynamics (Autism Society, 2011). These feelings of grief can occur throughout the parent's life as different triggering which includes birthdays, holidays, continuous care giving, weddings and reproduction

2.1.6. Wellbeing /Quality of Life

Global Agenda Council on Health & Well-being (2012) developed Wellbeing framework, which is consistent with Aristotle distinction between a moral life, which is necessary to maintain happiness, and a material life, which is necessary to meet basic needs.

Some literatures classified wellbeing as mental wellbeing, social wellbeing and economic wellbeing.

Mental wellbeing: measured through stress, fear of uncertainty, anger and weariness (a sense of emotional, physical, and mental exhaustion)

Social wellbeing and Support- Social support and reactions from the social environment depend greatly on the parents and the way they deal with the situation. On the other hand, at some time in life many parents discover that new restrictions imposed on their job, leisure time, and sleep. Moreover, stability in marriage and change in marital life among parents are the main areas of concern, which should be studied in this research work.

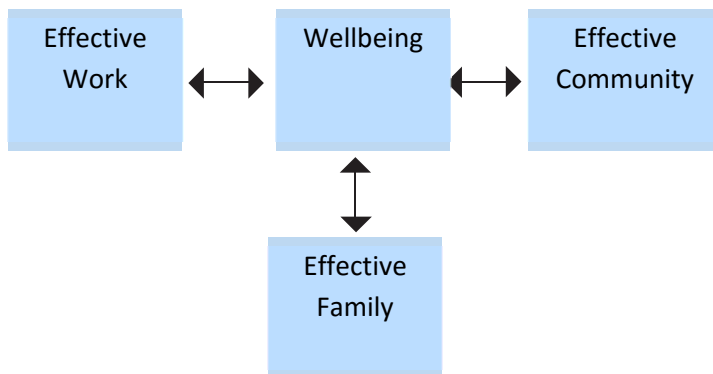
Economic Wellbeing: Often families of low socio- economic status fail to provide appropriate medical treatment, can't send the child to schools where there is proper support, and give up employment and miss regular income and lacks economic independency

As shown in the below Diagram, there are three main aspects of life, which affect the well-being

of each one of us: our work, our family and our community.

Nevertheless, on the other way round, well-being matters about its feedback effect. Our well-being enables us to perform better at work and in our family life and our community:

- Well-being increases the productivity of workers and the profitability of the companies they work for
- Individuals with high well-being produce more resilient families and stronger children
- People with high well-being are better members of the community



Source: World Economic Forum

Figure 2. 1: Causes and Effects of Well-being

Wellbeing has both objective as well as subjective connotation and defined as the state of being happy, healthy and satisfied (Human Organization, 2010). Based on the definition of OECD (2011), Quality of life is referring to the degree of excellence, grade, or distinguishing characteristics. Usually quality of life measures related with the HDI indexes and include per capita income, life expectancy at birth, infant mortality rate, adult literacy rate and political and civil liberties, the latter two are new indicators.

Well-being can be defined as a positive mental state and it is associated with such social qualities as confidence, optimism about the future, a sense of influence over one's own destiny, and the social competences that promote satisfying and supportive relationships with other people and not simply with an absence of diagnosed illness, disability or dissatisfaction. It also, critically, involves the resilience needed to deal with hard times as and when they occur. In policy terms, it can be defined as the conditions which allow individuals and communities to flourish

According to USA Government office for science (2008), Well-being has been defined recently

as:

“A dynamic state, in which the individual is able to develop their potential, work productively and creatively, build strong and positive relationships with others, and contribute to their community. It is enhanced when an individual is able to fulfill their personal and social goals and achieve a sense of purpose in society.”

John Field (2009) conceptualized Wellbeing that “people derive enjoyment and fulfillment from a number of different factors. Leading a satisfying life certainly involves a steady and adequate income, but researchers have shown that money alone is not enough. People also value their health, their social connections (including family), and their ability to contribute to the wider community. People gain pleasure from doing a good job, and having it recognized by others. They enjoy grappling with, mastering and then using new skills and knowledge. All in all, they value freedom – which we can define, following Amartya Sen¹, not as the possibility of ignoring other people and their needs, but as the ability to shape our own destinies”

In the Ethiopian context, wellbeing mainly refers to the availability of resources to satisfy basic needs. For many studies conducted in Ethiopia, wellbeing perceived having some fixed and productive assets such as farmland, cattle, farm implements and a house in rural settings. Where as in urban setting it is all about being permanently employed by government departments, NGOs and private companies or engaged in business activities, which can provide a continuous income (Esubalew, 2013 as cited on Habtamu, 2005). Hence, those without land, ox/cattle, or income are poor and their wellbeing is at stakes. Economic and material condition, , state of health, availability of nutritious food, employment , political situation, freedom, access to education, relationship and family are among the many factors contributing to personal satisfaction and happiness which is finally trigger a complete wellbeing (Habtamu,2005).

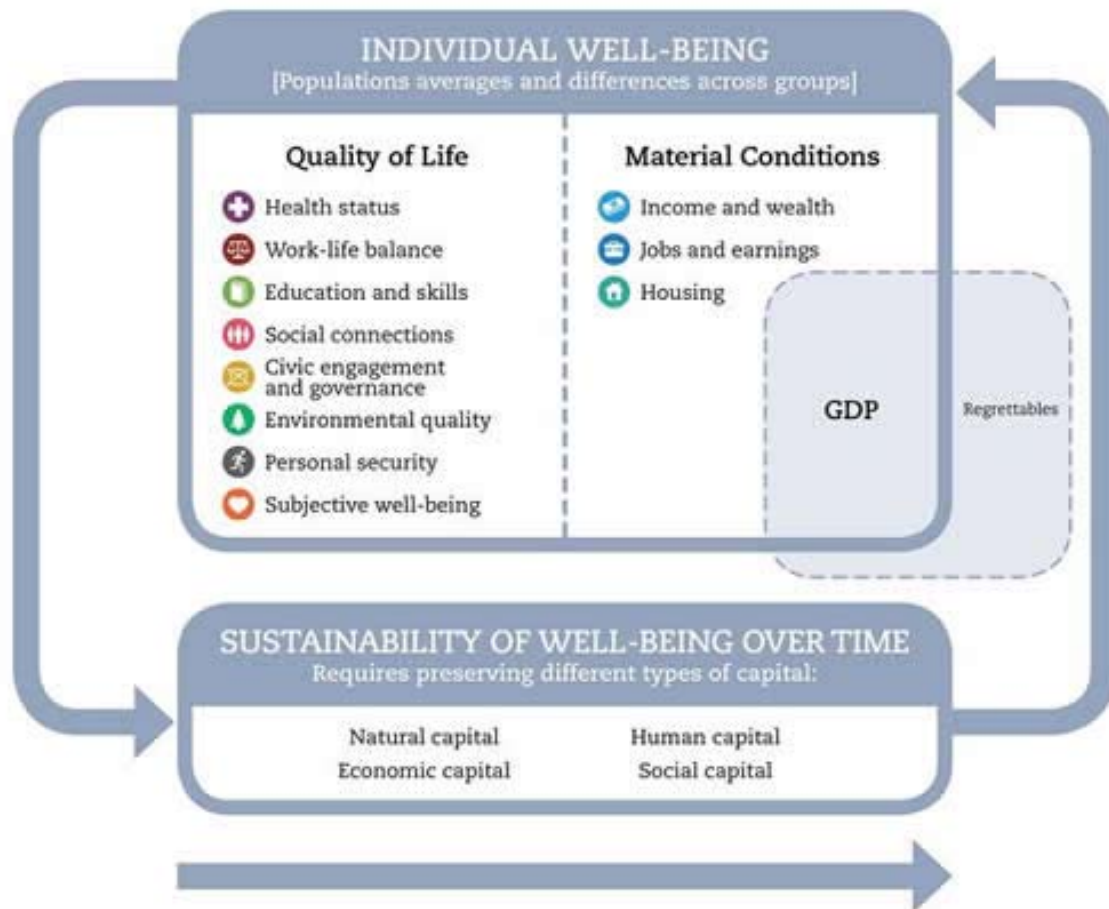
2.1.7. Measurement of Wellbeing

There are many different ways of measuring wellbeing but the measurement mentioned by A. Coudouel found to be appropriate for the purpose of this paper. Poverty is one important aspect of wellbeing mainly expressed by individuals’ income, consumption, education and health, which have their own defined threshold such as poverty line, poverty gap and poverty severity (A. Coudouel, 2001). Mannheim (2007), have been defined household consumption and incomes as

measures of living standards in his analysis on the pattern and structural changes of expenditures, the distributions and inequalities of household incomes and expenditures. Bruce D. Meyer (2003) stated consumption as measure of economic wellbeing is better than using income due to the rationales such as consumption is less vulnerable to under reporting bias and it is better reported than income. In this study, Consumption is less vulnerable to under-reporting bias, and ethnographic research on poor households in the U.S. suggests that consumption is better reported than income this is more appropriate in developing countries. Economic theory also suggests that current consumption measures more directly the material well-being of the family than current income. The other aspect of wellbeing is Inequality, which is based on the premise that the relative position of individuals or households in society. The third one is the vulnerability dimension of wellbeing, which can affect individual's behavior in terms of investment, production pattern and coping strategies (A. Coudouel, 2001).

Under material wellbeing in the below wellbeing framework (OECD, 2013), income and wealth capture people's current and future consumption possibilities. Both the availability of jobs and their quality are relevant for material well-being, not only because they increase command over resources but also because having a job provides the opportunity to fulfill own ambitions and build self-esteem. Finally, housing and its quality are essential not only to meet basic needs but also to have a sense of personal security, privacy and personal space.

There is also important dimension on quality of life comprises Health status, Work and life balance, Education and skills, Civic engagement and governance, Social connections, Environmental quality, Personal security and Subjective well-being.



Source: OECD, 2013

Figure 2. 2 The “How’s Life?” framework for measuring well-being and progress

2.1.8. Using Income and Consumption as a Measure of Wellbeing

Low income has an effect on children development, health; education performance and behavior and family relationship (Mayer, 1997). Therefore income used especially in-developed countries as almost an exclusively measure of economic deprivation and wellbeing. The main reason for using the income as a measure of wellbeing relative to consumption is generally it is easier to report and is available for much larger samples, providing greater power to test hypotheses. However, in developing countries, Consumption is the better tool to measure wellbeing of the poor peoples since it is less vulnerable to under reporting bias. Economic theory suggests that current consumption more directly measures the material well-being of the family than current income. World Bank (2001) report summarized and argued that Consumption viewed as the preferred wellbeing indicator, for practical reasons of reliability and because consumption thought to better

capture long-run welfare levels than current income.

2.2. Empirical Literature

Research is normally scarce in this area particularly in developing countries like Ethiopia, all the academicians, education institutions, policy makers have done little. Despite autism has a great impact on the families' income, consumption pattern, housing, education, health status, security and social interaction, it is still under spoken. However, having a child with autism presents a unique set of challenges that influences the entire family unit and individual family members' health, well-being, and experiences across the life span.

CHAPTER THREE- RESEARCH METHODOLOGY

3.1. Research Approach and Design

In this study, quantitative approach employed to figure out the current living condition, income change, additional or reduced cost incurred due to having a child diagnosed with Autism. As complementary approach, qualitative approach has been used for having a better picture about employment condition, parental relation, and acceptance of the issue, their social interaction, and current living style.

The research composed of descriptive design to scrutinize the social and economic wellbeing of families who have a child diagnosed with autism and who are getting education and treatment service in the two centers namely Joy center and Nehemia autism center of Addis Ababa. The **descriptive design** was used to ascertain some characteristics (family size, education level, occupation, income level, income source, family support). In the processes of describing these all characteristics by descriptive statistics, tests such as t-test and chi-square have been used check whether autism has imposed a negative implication on the wellbeing of households (family income, family consumption, health status, education, employment and social interaction) of families parenting a child with autism or not.

3.2. Profile of the Study Areas

Addis Ababa is the capital city of Ethiopia situated at the center of the country with the total area of 469.44 square kilometer. The city administratively divided in to 10 sub cities, Akaki sub city with 123.46 Sq.Km is the largest, and Addis Ketema with 8.64 square kilometer is the smallest. The total population of Addis Ababa is estimated to be 4,956,635. This research conducted in Addis Ababa where only two autism centers are located. Families of autistic children established those centers with the aim of providing education to children having autism, skill training to children and families and they are spending considerable time to bring about community awareness about autism and the support sought for those segments of the population. The first center is Joy center Nia foundation that is located in Addis Ababa, Nefas Silk Lafto sub city. This center is providing rehabilitation and education service for around 80 autistic children. The second center is

Nehemiya Autism center, located in Bole sub city and giving its service for 60 autistic children.

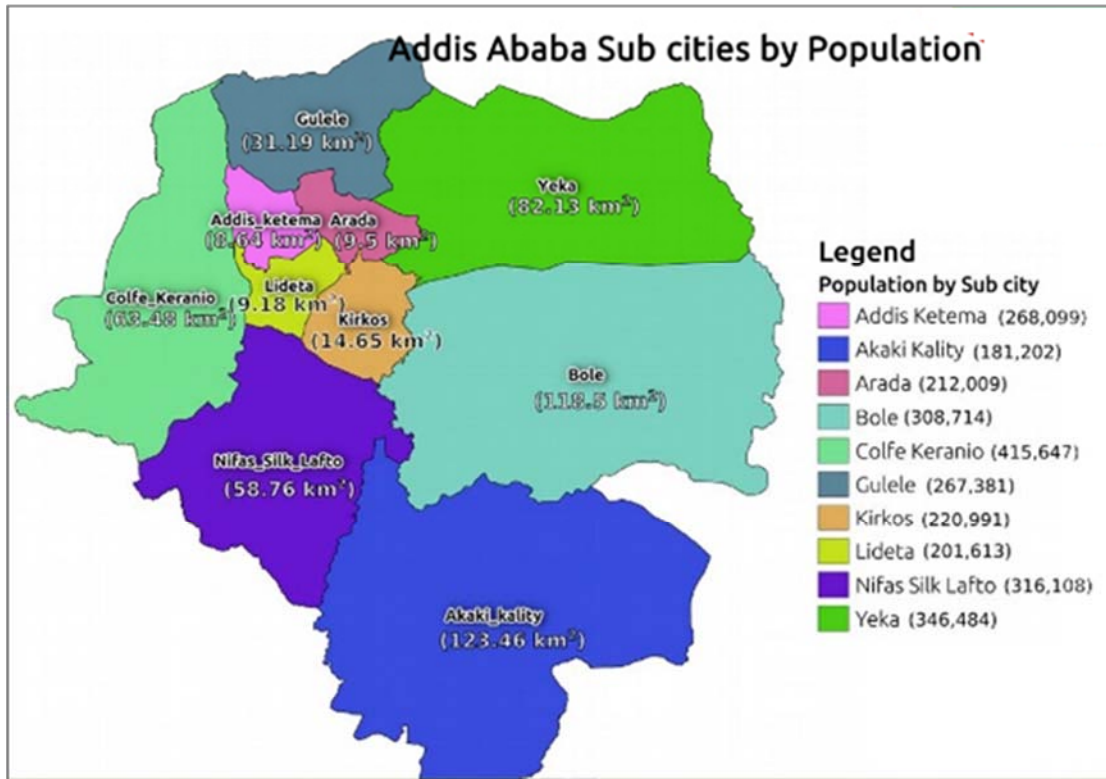


Figure 3 1: Map of Addis Ababa city

The joy center established in 2002 and it is an indigenous, nonprofit and non-governmental humanitarian organization with the objective of alleviating challenges faced by persons with autism and other related developmental disorders.

“Nia foundation is the first of its kind in Ethiopia and offers education to autistic children. Nia Foundation’s overall aspiration and main purpose is to increase the well-being of vulnerable children in Ethiopia. The Foundation runs five core programs: Yagebagnal (“It Concerns Me”), Women for Leadership, Youth Empowerment, Empowering Mothers of Children with Different Abilities, and The Joy Center for Children with Autism and Related Developmental Disorders (the primary and largest program). The Center focuses on full integration of children with autism into society by working closely with the kids, their parents, and extended family networks, as well as the greater Ethiopian community. <http://nia-foundation.org>”

Nehemiah autism center established in 2010 and it is now giving its service for around 60 autistic children. Its program is aimed to provide care, instructions and support for children with autism and related disabilities- promoting cognitive, emotional and relational growth by running individual based programs. Counseling services and support program for parents especially for mothers is also a key component of the programs. It is also working to raise the community awareness about autism

This study has both treated and controlled group in order to compare the impact of autism on the wellbeing of families who are having autistic child with in their family. Therefore, 17 family households in Joy center 13 family households in Nehemiya autism center targeted and requested to complete the survey questioners prepared by the researcher. It is obvious that demographic and socioeconomic characteristics have a strong correlation with households” wellbeing. Accordingly, gender of the household head, household size, and age of household head, dependency ratio, marital status, educational level, health status and main occupation are major demographic issues addressed in the survey. On the other hand, source and level of income, household expenditure type and amount, credit access, saving level, social and psychological challenges given wide coverage and compered between the two groups (treated and controlled).

For this study, 70 family households selected as respondent and the numbers in the treated (families having autistic child) and controlled (families having no autistic child) is 30(42.86%) and 40 respectively.

3.3.Sample Size and Sampling Procedure

Population Size:

Population size refers to the total number of people that the research would like to reach. Therefore, in the case of this research it refers that the total number of autistic children getting services in Nia foundation and Nehemiah autism center. The number of children diagnosed with autism is 140 (80 in Nia foundation and 60 in Nehemiah autism center

Sample size:

Determination of the appropriate sample size is important to get a reliable result out of researches. Therefore, sample size depends on the population size, margin of error (A percentage that describes how closely the answer your sample gave is to the “true value” is in your population in this case it is 0.07), and confidence level (at 99%, 95%, and 90% confidence interval)

The research applied the following formula to decide the number of samples size and the formula dictated to the number of respondent to be 70.

$$n = \frac{\frac{z^2 * p(1 - p)}{e^2}}{1 + \left(\frac{z^2 * p(1 - p)}{e^2 N} \right)}$$

Where:

N is population

e is Margin of error is expressed by percentage but decimal form used in the formula

z=z-score which is the number of standard deviations a given proportion is away from the z-score is

Primarily purposive sampling has been employed to select the specific study areas with in Addis Ababa namely Nia foundation Joy center and Nehemia autism center. In the second stage of the sampling process, 30 households again selected purposively as it is difficult to employ systemic or other sampling techniques in this kind of research as most of the households are not willing for the survey due to their own reason.

To evaluate the effect of autism on the wellbeing of families having autistic child by using propensity score matching, another group of families (40 families that is 133% of the affected households) selected who are living in the nearby areas where the treatment households are living. Both groups of households assumed to have a different characteristics: family size, income level, living condition, and consumption expenditure and wealth status and that is why propensity score matching selected to minimize the effect of cofounders on the results.

3.4.Data Source and Data Collection Method

Secondary sources from the center utilized to get information on the number of total Households who are getting service from the center, the total number of children attending education and treatment, number of professionals by specialty in the center, payment requested by the center per month, other financial obligations expected from families. To get the above secondary information, mainly list of students, employment profile, invoices at the center registrar and administrative office reviewed.

Moreover, primary sources used to collect relevant information on the overall family profile, income and expenditure pattern, family relationship and support, spending pattern, and many other socioeconomic situation. On this regard, survey questioners have been used as data collection tools to gather qualitative and quantitative information from sampler respondents.

3.5.Data Analysis Methods

The research used descriptive statistics (frequency, percentage and mean, median, variances, standard deviation) to examine type of employment, income level, income source, spending pattern, and observed changes from their previous lifestyle.

The research also used Correlation analysis to assess the degree of relation between the dependent variable (ASD) and the covariates which determine the level of family wellbeing.

Definition of Correlation

Correlation is a statistical method that determines the degree of relationship between two different variables. It is also known as a “bivariate” statistics (statistics: a gentle reminder). John & Doris (2009), also defined correlation as the association between two variables so that It is the degree to which two variables share a common relationship

Correlation Coefficient

The correlation coefficient, r , is a summary measure that describes the extent of the statistical relationship between two interval or ratio level variables. A correlation coefficient, or value, is therefore another descriptive / summary statistic, which is concerned with the degree of ‘co-

variation' between two variables and measures the extent of correspondence between the ordering of two random variables (Robin Beaumont, 2012). The coefficient r is the linear correlation coefficient always lies between -1.0 and $+1.0$ inclusive, that is, $-1 \leq r \leq 1$ (John & Doris ,2009). If Y increases when X increases, we say that there is positive or direct correlation between them. However, if Y decreases when X increases (or vice versa), then we say that they are negatively or inversely correlated. In other words when r is close to Zero this means that there is little relationship between the variables and the farther away from 0 r is, in either the positive or negative direction, the greater the relationship between the two variables.

A correlation coefficient can be produced for ordinal, interval or ratio level variables, but has little meaning for variables, which are measured on a scale, which is no more than nominal. Spearman's rho calculated for ordinal scales, Pearson's r calculated for interval or ratio level scales.

Types of Correlation

According to a book "Statistics: A Gentle Introduction 3rd Edition" ,there are four types of correlation coefficient which are commonly used based on the type of data which is going to be estimated.

i. Pearson's Correlation coefficient (Pearson's r)

A measure of the strength of a relationship between two continuous variables. The Pearson product-moment correlation coefficient, better known as the correlation coefficient, or as r , is the most widely used correlation coefficient. Pearson's r summarizes the relationship between two variables that have a straight line or linear relationship with each other. It is generally used when variables are of quantitative nature, that is, ratio or interval scale variables (Robin Beaumont, 2012). The Pearson's r can be estimated by the following formula as indicated in Statistics: A Gentle Introduction 3rd Edition.

$$r = \frac{N\sum xy - (\sum x)(\sum y)}{\sqrt{[N\sum x^2 - \sum(x)^2] [N\sum y^2 - \sum(y)^2]}}$$

Where N is equal to the number of pairs of scores and $\sum xy$ is called the sum of the cross product

ii. Spearman's r:

A measure of the similarity between two ordinal rankings of a single set of data. The Spearman's r sometimes referred to as Spearman's rho or r_s , and used to determine the degree of relationship for ranked data

iii. Point-Biserial r

is a measure of the strength of a relationship between one continuous variable and one dichotomous variable (a two-level-only variable like gender). The point-Biserial correlation (r_{pb}) gives an estimate of the degree of relationship between a dichotomous variable and a continuous variable. Interestingly, Pearson's correlation coefficient yields the same value at the point-biserial correlation formula

iv. Phi (ϕ) Correlation:

A measure of the strength of a relationship between two dichotomous variables. The phi (rhymes with fee) correlation gives an estimate of the degree of relationship between two dichotomous variables. The value of the phi ϕ correlation coefficient is interpreted just like the Pearson r, that is, it can vary from -1.00 to +1.00.

Testing for the Significance of a Correlation Coefficient

A correlation coefficient may be tested to determine whether the coefficient significantly differs from zero. The value r is obtained on a sample and value rho (ρ) is the population's correlation coefficient. It is expected that r closely approximates rho. The null and alternative hypotheses are as follows:

$$H_0: \rho = 0$$

$$H_a: \rho \neq 0$$

The value of r and the number of pairs of scores are converted through a formula into a distribution (similar to the z distribution) called the t distribution. The t formula can only be used to test whether r is equal to zero. The t distribution is most commonly used to test whether two means are significantly different, however, it may also be used to test the significance of the correlation coefficient.

The t test formula in order to test the null hypothesis for a correlation coefficient is:

$$t = \frac{r}{\sqrt{\frac{1-r^2}{N-2}}}$$

where N = the number of pairs of scores and r is the correlation coefficient.

The significance of the point-biserial correlation coefficient is tested the same way as the Pearson's. The phi correlation can be tested for significance by converting the value of phi into a chi-square statistic (χ^2) and comparing it to the chi-square distribution.

The formula for the conversion of phi to chi-square is:

$$\chi^2 = N(\phi)^2$$

Where N = the number of participants in the correlation and the df is always equal to 1.

3.6. Variable Description in view of family wellbeing

There exists considerable debate on the use of either income or consumption as a proxy measure of household wellbeing. However, wellbeing is not all about income and expenditure; it encompasses different aspects of life including access to social services, social relation and networking and psychological issues. Therefore, in this study Income of the household from all sources, family current expenditure, health status of the household, education attainment and life satisfaction are included as an outcome variables. Demographic characteristics of the respondents such as age, sex, marital status, Dependency ratio, main family occupation, outstanding credit, balanced diet and alcohol use are used as a covariate and details presented as follow.

ASD

In this study, there are two types of respondents distinguished with having a child diagnosed with autism or not. Those households who have a child diagnosed with autism are called ASD-Affected and those who have not a child diagnosed with autism are called ASD-Non Affected.

Age

Age is one of the most primary social and cultural categories. According to the lifecycle model, Individuals would choose constant consumption throughout their lives that is called consumption

smoothing. Lifetime utility or well-being would then be independent of age. This form of utility function assumes that the utility of consumption is independent of age. However, some other empirical studies relaxed this assumption and said that the marginal utility of consumption is independent of age. In the contrary Blanchflower and Oswald (2008, p. 1735) pointed out that Consumption and thus well-being would then vary across the lifespan. There is also an alternative explanation by Charles and Carstensen's (2009) in their soci emotional selective theory saying that individuals experience more life satisfaction as age increases due to the spending of time to activities, which contribute to their wellbeing instead of pursuing for future goals.

Household Expenditure

Consumption expenditure means all household expenditures over a period of time, which can affect the present and future standard of living of families (Sue L.T. McGregor Mount, 2000). As elaborated by OECD (2011) economic well-being determines people's consumption possibilities and their command over resources. Income and wealth expand people's consumption possibilities, providing them with the resources to satisfy their needs. Wealth also allows individuals to smooth consumption over time.

Dependency ratio

Dependency ratios are important demographic indicators that set the young and old populations (those generally economically inactive) in relation to the population of working age and shows the economic burden of a certain population (Benedetta, et al., 2011). To this connection, Erich Striessnig and Wolfgang Lutz (2014) in their explanation asserted that Lower dependency burden is associated with higher per capita well-being because the same economic production generated by the working age population must be shared with fewer children and elderly who are not of working age.

Education

Education is considered to be a life long process, where all the experiences, knowledge and wisdom that an individual acquires at different stages of one's life through different channels (i.e., formally, informally and incidentally) are termed as education. Education and skills are vitally important to an individual's well-being. Learning encourages social interaction and increases self-esteem and

feelings of competency. Education is important for the measurement of wellbeing. Hence, higher levels of qualifications and continued formal and informal learning have been found to be associated with greater individual subjective well-being.

Family Size

Average household size is calculated as the mean average number of people (adults and children) per household for households of a given type. There are substantial differences across countries in the average size of households. According to the CSA, 2014 report, the average household size in Ethiopia is 4.7 persons. In urban areas, the average household size is 3.6 persons, compared with 5.0 persons in rural areas

Sex of households

Gender refers to the roles and responsibilities of men and women that are created in our families, our societies and our cultures. Gender roles and expectations are learned. In the other side, Sex describes the biological differences between men and women, which are universal and determined at birth. According to the CSA report, 2014, the size of female population is projected to be 41.6 million (49.7 percent) while that of males is expected to be 42.1 million accounting for 50.3 percent. The 2000 DHS report presented the Ethiopian household characteristics by sex and dwelling. In this report the male and female households in urban area is 64.6% and 35.4% in urban areas and 78.7% and 21.3% in rural areas respectively. CSA, 2014 in the report stated that about one-fourth (23 percent) of Ethiopian households are headed by women.

Marital status

Marital status is recorded for all persons aged 18 years and over. Marital status of men and women is presented as the percent distribution of men and women by current marital status, according to age groups. Marital status is the personal status of each individual in relation to the marriage laws or customs of a country. The categories of marital status are Single, married, widowed, divorced or legally separated. Married people have significantly better health and a lower mortality than their single counterparts (Smith and Zick, 1994)

Health status

Health status tracks the type of illnesses or injuries members of the household incurred during the month preceding the interview. A person is considered to have visited any health facility if he/she received any medical care from any health facility. The WHO defines health as ‘a state of complete physical, mental, and social well-being and not merely the absence of disease, or infirmity’. Health is a cumulative state, to be promoted throughout life in order to ensure that the full benefits are enjoyed in later years. Good health is vital to maintain an acceptable quality of life in older individuals and to ensure the continued contributions of older persons to society. Ethiopia’s population still face a high rate of morbidity and mortality and the health status remains relatively poor, The major health problems of the country are largely preventable communicable diseases and nutritional disorders (Ministry of health, 2010).

Income

Total income refers to the sum of the incomes from all sources of all household members earned during the last twelve months. This is a gross measure (that is, before tax and any other deductions). It is a flow concept and refers to the incoming flow of resources in to the household. The household income can be earned from employment (employees and self-employed), support (Institution, individual and government), others income (Such as income from investment, rent from property). Household, as opposed to personal income, is used in this analysis as typically all members of a household can benefit economically from an increase in income. It is believed that those in households with higher incomes report higher life satisfaction and happiness as income plays an important role in influencing well-being (OECD, 2013). However, there is still an argument that more income allows people to satisfy more preferences, resulting in increased well-being

Household Occupation

Occupation refers to the specific job or work/business that a person was engaged in for most of the time during the last twelve months preceding the interview. This means that it would be the person’s principal means of earning a living during the last twelve months preceding the interview. The socio-economic class of each family was based on the occupational status of the parent(s),

either in their current or most recent employment. AS Employment is defined as, any service performed for payment or compensation.

Table 3. 1: Types and definition of variables

Variables	Variable names	Definition and values assigned
ASD		Dummy variable 1= HH affected by autism, 0=HH not affected
Sex	Sex of the household head	Dummy 1= if the household is female. 0 otherwise.
Age	Age of the household head	Continuous variable refers to the age of the household head
Marital	Marital status of the household head	Categorical variable, 1=married, 2=Divorce, 3 Widow/er, 4=Single
DRatio	Dependency Ratio	Continuous refers to the percentage of dependent divided by percentage of workers with in the household
Occupation	Employment type	Categorical :Refers to the main occupation of the household head and it is categorical: 1=trade 2=permanent employment, 3=temporary employment, 4=jobless
Credit outstanding	Outstanding credit borrowed from different sources	Dummy: it is interested to see the borrowing status of the household and 1= yes, 0 otherwise
Balanced Diet	Balanced diet of the family as a whole	Dummy and 1=yes, 0 otherwise
Alcohol use	Alcohol use of the household head	Dummy: takes 1 if yes, 0 otherwise
Total Income	Total income of the household	A continuous variable refers the total income of the household in birr per month
HH Expend	Household expenditure	A continuous variable refers total monthly household expenditure in birr
Health status	Health status of families	It is a category variable taking a value 1= normal health, 2= occasional illness and 3=sever illness
Educnyr	Education attainment in years	education attainment of the household head measured by number of years-continuous
Lifesatf~n	Life Satisfaction	Life satisfaction is a binary variable: 1= if yes, 0 otherwise

CHAPTER FOUR- RESULTS AND DISCUSSION

4.1. Demographic characteristics

Sex of the households: table 4.1 presented that from 70 households interviewed during the survey, 51.43% and 48.57% are female headed and male-headed households respectively. From 34 male-headed households, 60% are treatment households and 33.33% controlled households. Besides, the number of treatment and controlled households in female-headed households is 40% and 66.67% respectively. Among treatment groups, 60% are male-headed households and 40% of them are female-headed households. On the other hand, the percentage of male headed and female-headed households in the controlled group is 33.33% and 66.67% respectively. The statistical analysis told us that the sex difference the households between the treatment and controlled group is significant and it is statistically significant at 5% confidence interval (Table 4.1)

Table 4. 1: Demographic Characteristics

Types of variables		ASD = Affected		ASD = Non Affected		Total	
		Freq.	%	Freq.	%	Freq.	%
Sex	male	10	33.33	24	60	34	48.57
	female	20	66.67	16	40	36	51.43
	Total	30	100	40	100	70	100
Marital status	single	5	16.67	9	22.5	14	20
	married	21	70	25	62.5	46	65.71
	divorces	3	10	3	7.5	6	8.57
	widowed	1	3.33	3	7.5	4	5.71
	Total	30	100	40	100	70	100
Age category	age<25	1	3.33	2	5	3	4.29
	25<=age<=40	18	60	19	47.5	37	52.86
	40<age<60	11	36.67	16	40	27	38.57
	age>=60	0	0	3	7.5	3	4.29
	Total	30	100	40	100	70	100
Family size category	FS<=2	0	0	8	20	8	11.43
	2<FS<=4	15	50	16	40	31	44.29
	FS>=5	15	50	16	40	31	44.29
	Total	30	100	40	100	70	100

Source: own computation

Marital status of the respondent households: As it is shown in Table 4.1, households categorized based on their marriage status. According to the result, 70% ASD-Affected families and 62.5%

ASD-Non Affected families are married couples this implies that almost majorities of the children who are autistic are living with their two families (father and mother). On the ASD-Affected families single households takes the second rank following the married couples by 16.67% followed by separated households. On the ASD-Non Affected group the percentages of single, divorce and widow/er are 22.5%, 7.5% and 7.5% respectively. One of the challenges that the ASD-Affected families are facing is spouse conflict so that the percentage of divorce is higher in households who have autistic children (10%) than those who do not have a child with autism (7.7%).

Mean age of the household head: the average age of the household head in the study area is 40.357 years with the standard deviation of 10.125 and minimum and maximum age of the household is 21 and 66 years respectively (Table 4.2). However, the average age is different when disaggregated by the household category (ASD-Affected versus ASD-Non Affected groups) which is reduced to 39.933 years for households in the ASD-Affected and a little bit higher for households in the ASD-Non Affected group (40.675 years) with standard deviation of 8.51 and 11.27 respectively. The difference of age is statistically significant at 1% significant level. The average age of female-headed households is 38.61 with the standard deviation of 8.47 while it is 42.52 years for male-headed households with the standard deviation of 11.00. The above figures show that households in the affected group and female-headed households are younger than the non-affected group and the male-headed household (Table 4.2)

Table 4. 2: continuous demographic variables

Variables	ASD = Affected HHs				ASD = non affected HHs				t-Value	P-value
	Mean	Min	Max	Std. Dev.	Mean	Min	Max	Std. Dev.		
Age	39.9	25.0	64.0	8.5	40.7	21.0	66.0	11.3	33.3	0.000
HHsize	4.9	3.0	9.0	1.7	4.3	1.0	10.0	2.0	19.8	0.000
DRatio	2.9	0.5	7.0	1.7	2.1	0.3	6.0	1.3	8.2	0.000
Educnyr	11.8	3.0	16.0	4.1	14.4	2.0	18.0	3.3	28.9	0.000
Numworking~n	1.3	0.0	2.0	0.5	1.7	1.0	4.0	0.8	17.6	0.000

Source: own computation

The other information that the survey result indicated that 60% of the ASD-Affected families and 47.5% of the ASD-Non Affected families are at the age of 25 to 40 inclusive. This implied that almost 52.86% of the respondents are within the active working age/ productive age. The age

between 40 and 60 years accounts 36.67% and 40% in ASD-Affected and ASD-Non Affected families respectively. Only 4.29% of the respondents have 60 years and above and they are under the ASD-Non Affected group comprising 7.5% (Table 4.1). This is also statistically significant at 95% of confidence interval (Table 4.1)

Household size: the average household size of the respondent households is 4.54 with the standard deviation of 1.92 having a minimum and maximum household size 1 and 10 respectively. Average Family size in female household head is 4.72, which is higher than 4.35, the average family size of the male households (Table 4.2). Regarding the family size distribution 11.43% of the households have a family size less than two, 44.29% of them have a family size between two and four. The rest 49.29% have a family size of more than five. Among the households in the treated group, 50% of them have family size more than two but less or equal to 4 and 50% of them have family size greater or equal to 5. More than 20% of The household size for ASD-Non Affected group is less or equal to two, 40% of them have greater than 2 and less than or equal to 4 and 40% of them have 5 or higher family size (Table 4.1).

Dependency ratio: is the ratio of economically inactive household members (age of below 15 years and above 64 years) to economically active household members (between 15-64 years). In this context, dividing the percentage of dependents by the actual number of working individuals with in that particular household gives rise to the dependency ratio of the study areas. According to the survey information as stipulated in Table 4.2, the average dependency ratio is 2.45 with the standard deviation of 1.53. The dependency ratio varies across female-headed households and male-headed households and it is 2.65 and 2.24 respectively. This means that female-headed households have higher dependency burden than the male-headed households. The dependency ratio households in the ASD-Affected and in ASD-Non-Affected group is 2.91 and 2.06. This implied that the affected group have higher dependency Burdon than the non-affected group (Table 4.2). The p-value (0.000) in the t-test (12.67) showed that it is statistically significant at 1% probability level.

Education level of the household head: Table 4.3 presented the survey result about household education performance. According to the survey result, 7.14% and 32.86 % of the household head have 2nd degree and 1st degree respectively. Around 30 of the households are diploma graduates. The rest 30% of the households only complete 12 grade or below at the stage of elementary school.

When we see education disaggregated by gender, 33.33% of female households completed only elementary school and 8.33% of them have been completed their secondary school and the rest 27.78% and 30.56% of them graduated in diploma and 1st degree respectively. On the other hand, the percentage is lower for male households in the lower education level and higher in the higher education level. This implied that male households have a better education performance than the female households.

Table 4. 3: Performance of Treatment and Controlled Families on Services and Employment

Types of variables		ASD = Affected HHs		ASD = non affected HHs		Total		χ^2
		Freq.	%	Freq.	%	Freq.	%	
Education level	Elementary	9	30	6	15	15	21.43	
	Secondary	3	10	3	7.5	6	8.57	
	Diploma	12	40	9	22.5	21	30	
	1st Degree	6	20	17	42.5	23	32.86	
	2 nd Degree	0	0	5	12.5	5	7.14	
	Total	30	100	40	100	70	100	10.006**
Occupation	Trade	3	10	6	15	9	12.86	
	E-permanent	14	46.67	27	67.5	41	58.57	
	E-temporary	11	36.67	4	10	15	21.43	
	no jobs	2	6.67	3	7.5	5	7.14	
	Total	30	100	40	100	70	100	7.309*
Health status	Normal	13	43.33	28	70	41	58.57	
	occasional illness	12	40	9	22.5	21	30	
	Sever illness	5	16.67	3	7.5	8	11.43	
	Total	30	100	40	100	70	100	5.092*
		Male		Female		Total		
		Freq.	%	Freq.	%	Freq.	%	
Education Level	Elementary	3	8.82	12	33.33	15	21.43	
	Secondary	3	8.82	3	8.33	6	8.57	
	Diploma	11	32.35	10	27.78	21	30	
	1st degree	12	35.29	11	30.56	23	32.86	
	2nd degree	5	14.71	0	0	5	7.14	
	Total	34	99.99	36	100	70	100	10.442*
Occupation	Trade	6	17.65	3	8.33	9	12.86	
	E-permanenet	22	64.71	19	52.78	41	58.57	
	E-temporary	5	14.71	10	27.78	15	21.43	
	no jobs	1	2.94	4	11.11	5	7.14	
	Total	34	100	36	100	70	100	4.633

Source: own computation

The education achievement between the ASD-Affected and ASD-Non Affected have a significant difference both at higher-level education and at lower level education. On the higher-level education, the non-affected households have a better achievement than the affected households and almost 77.5% of the households have graduated in diploma and above. All the households who have 2nd degree belongs to the non-affected households. In the contrary 80 % of the affected households have a level of diploma and below. This means that, having an autistic child have a significant impact on the households' educational achievements and it is significant at 1% probability level.

Education performance also analyzed based on the number of years that the individual households stayed in school (Table 4.2). The minimum and maximum years of schooling for ASD-Affected families are 3 years and 16 years respectively with an average of 11.766 years and deviating by 4.07. The average schooling year for ASD-Non Affected families is 14.425 years with the standard deviation of 3.27 and 2 years and 18 years are the minimum and maximum school of years.

Main occupation of the household heads: As stated in Table 4.3, 80% of the sample respondents are making a living by working in governmental, non-governmental and private companies. The other 12.86% are engaged themselves in trade sectors while 7.14% of them are jobless who are leading their living by an earning from rent, remittance and institutional support. Female households have higher number in permanent employment (21 out of 41) and in joblessness (4 out of 6), have shared an equal number (7) on temporary employment and the male households have an advance in trade sector. The majority of the ASD-Affected families are leading their livelihoods by engaging in employment (46.67% permanently and 36.67% temporarily employed in government, NGO and private sectors). Among them 10% engaged in trade and 6.67% are job less. The percentages of ASD-Non Affected families in trade, permanent employment, and temporary employment are 15%, 67.5% and 10% respectively while only 7.5% of them are jobless.

Health status of the households: Based on the survey result, 58.57 percent of the households are having a normal life, 30 percent of them are occasionally ill and 11.43 percent of the households have severe illness. The health status of the households also surveyed and analyzed in accordance with the household categories. As a result, 70% of the households not affected by ASD have normal health but is 43.33% for affected households. On the other hand, 22.55% of non-affected

households and 40% of affected households have an occasional illness. The percentage of affected Households who have a serious illness is 16.67% and it is higher when compared with the Non Affected households.

The other dimension of the health challenges is affordability of the health facilities and Health is affordable only for 26.67% of the affected households but 50% of the households in the controlled group can afford the health service provided by different institutions either private or government. The other most important aspect of health is getting adequate and balanced food to lead a healthy and quality of life. In this regard only 63.33% of the treatment households and 75% of the controlled households able to get balanced diet (Annex II).

Table 4. 4: Impact of ASD on the Outcome Variables

Variable	ASD = Non Affected				ASD = Affected				t-Value	P-value
	Mean	Min	Max	Std. Dev.	Mean	Min	Max	Std. Dev.		
TIncom	11407	2100	28570	6301	8684	600	36500	6495	12.66	0.000***
PCIMonth	2789	100	18250	3221	2606	420	7143	1618	8.59	0.000***
EducExp	1199	0	6400	1492	1217	0	6540	1572	6.62	0.000***
ExpendMedic ^l	286	60	1000	209	252	50	2000	373	6.68	0.000***
HHExpend	6903	600	21900	4168	10043	1890	25142	5500	13.81	0.000***
Saving	1780	0	14600	2610	1365	0	3432	1224	6.30	0.000***
LifeSatisf ⁿ										

Source: Own computation

4.2. Description of Implications on outcome variables

4.2.1. Implication on Household Income

Income is the flow of money to the family and Income level of the households might leads to financial wellbeing. Strumpel (1976) elaborated that financial well-being goes beyond transitory satisfactions to encompass individuals' satisfaction with income and savings, as well as ability to "make ends meet," sense of material security, and sense of fairness of the reward distribution system.

The survey result revealed the monthly income that households who have no jobs are earning the highest income (14,351 birr) and their sources of income are remittance, house rent and to some extent institutional support. Among households who are, employees and self-employed, temporary

employee households are getting 10047.87 birr followed by households in trade sector (9827.78 birr). Permanent employees have the least earning among them (9235.37 birr) (figure 4.1).

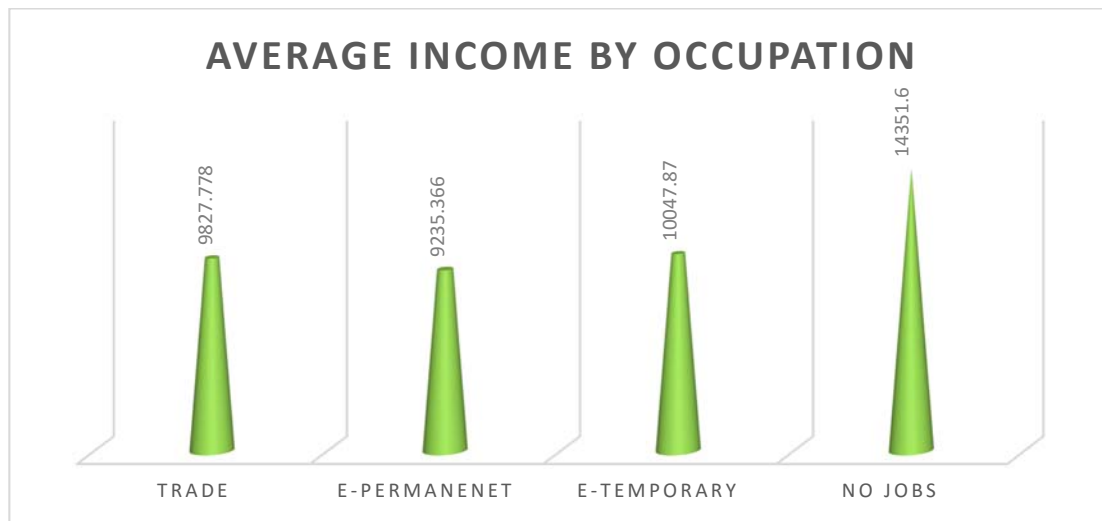


Figure 4. 1: average income by occupation

Income is increasing for 65% of Non-Affected individuals while it is only 46.67% for the affected households. Income decrease reported in 20% and 7.5% of the Affected and non-affected households respectively. Income is constant for 27.5% of the non-affected and 33.33% of the affected households. Therefore, in any case the affected individuals exhibit a performance, which is not favorable for their livelihood (Table 4.4). As per the response of households who have responded that their income is decreasing for the last two years, unemployment and joblessness takes the largest proportion for affected households in the treatment groups and school fee and higher cost of living takes the highest rank for Non-Affected households in the controlled groups (Annex I).

The average total income of the households in the study area is 9851.08 birr with the standard deviation of 6509.214. In addition, the monthly earning of the households is ranging from 600 birr to 36500 birr, this proved that presence of income disparity between high-income groups and low-income groups, and in this case, inequality is much higher. This average income has a significant difference among households who have autistic child and families who has not an autistic child in the family members. The average incomes of households of ASD-Affected and ASD-Non Affected are 8683.95 birr and 11407.27 birr respectively. So that the average income of households in the

treatment is, lower than that of the households in the controlled group. Even though the higher income earner found in the treatment group, many lowest earners found in the same group absolutely offset the hike. The t-value (12.662) and P-value (0.000) proved that the difference of income between ASD-Affected and ASD-Non Affected families is statistically significant and the mean difference of (2723.32) birr between the treatment households and controlled households magnifies the variation (Table 4.4)

Getting lower income therefore, will have an implication on household's ability to meet their basic needs, and it affects children physical and emotional development and quality education. Lower income level has a negative impact on the health status of the individuals with in that family due to lack of balanced diet and access of health services in time of illness. Low income reduces the ability of the households to save money and invest for future improvement of their lives and livelihoods. In sum, low household income means low level of wellbeing and autism has imposed a negative implication on the wellbeing of households

4.2.2. Implication on PCI

Households' per capita income has also a similar function than that of income, it is more accurate to measure the wellbeing of individuals at household level, and it is equated by household income with the household size. Lower household size shows the higher per-capita income. Therefore, it reflects the real income of each individuals with in the family. The average PCI for treatment group is 2605.505, which is less than the average PCI for controlled group (2788.74) with the mean difference of 183.24. When we see the income variation with in the groups, it is wider in controlled (100 to 18250) group than the treatment group (420 to 7142.5) (Table 4.4). This implies that since autism has a significant effect on the income level of the households, it is straightforward to say autism impose a negative implication on the per capita income at household level eventually on the wellbeing of the families. The t-values and p-values on table 4.4 shows a statistically significant variation of PCI between the treatment and controlled households.

4.2.3. Implication on Expenditure

Household expenditure refers mainly expenditures of households for their day-to-day and some ad-hoc needs such as food, medical, house rent, transport, school fee, utilities, cloth, festival, wage

and other similar expenses. The average expenditure has a significant difference between treatment groups and controlled groups (10042.7 birr versus 6903 birr) with the mean difference of 3139.2 (Table 4.4). This means that the treatment households have a higher expenditure due to the associated expenses by having autistic children mainly medical, education and transportation related expenses are expensive. Showing a case of the education expenditure between the ASD-Affected and ASD-Non Affected families gives an adequate evidence to see how the affected households are required to incur more costs than the non-affected households do. The average education expenditure for treatment households (1217 birr) is higher than the average expenditure of education for the controlled groups (1198 birr). Looking at the minimum and maximum expenditure, both are greater in the treatment households (1890 ~25141) than households in the controlled groups (600~21900).

Households offered a question to provide a qualitative answer for their expenditure trend. The response summarized as follow (Annex I).

- Non-Affected Households: 2.5% of them reported decreased expenditure, 85% said expenditure is increasing from time to time and for 12.5% of them there is no change on the expenditure trend. For those reporting increasing expenditure food is the type of expenditure which is growing fast (57.14%), next House rent (25.71%), the third school fee (11.43%) and the fourth is medical (5.21%).
- Affected Households: the expenditure trend for the last two years in this group of households is 6.67% decrease, 73.33% increase and 20% constant for the last two years. The fastest growing expenditure reported here is food (57.14%) followed by house rent (21.43%), thirdly medical (14.29%) and the last is school fee (7.14%)

Hence, households are required to expend more on their current consumption so that they will have less saving in turn their future wellbeing will fall in danger since they are leading a subsistence type of life and they don't have much to buy house and other essentials. As indicated on Table 4.4, autism has a substantial implication on the expenditure of households expressed by mean difference of 3139 and it is statistically significant at t-value of (13.808) and p-value of (0.000).

4.2.4. Implication on HHs' Saving

Saving means part of current-period resources or production are made available for future

consumption and it is alternatively defined as income minus consumption. An individual's perception of income adequacy is based in part on the income and savings level experienced in the past and expected in the future. Dissatisfaction with the amount of income, standard of living, savings/investments, and retirement "nest egg," contribute to lower perceived levels of financial well-being

Having this idea in mind, Households in the treatment group have an average saving of 1364.56 birr which is less than the average saving of households in the controlled groups, 1780.46 birr (Table 4.4). When we see the saving trend of the households across the 2 groups, 54.05% of the Non-Affected households reported that saving is growing, rather the same issue has gotten a positive response only by 16.67% of the affected households. The majority of affected households are experiencing decrease of saving and constant saving (41.67% each). Only 18.92% of the Non-affected respondents reported, as their saving is decrease. Concerning causes for low saving rate, inflation takes the lead (55.56%) and (60%) in the response of treatment and controlled groups respectively but exceptionally low income found to be the main reason for the low saving rate of the treatment households. All the above information leads to a conclusion that ASD-Affected families experiencing lower saving and ASD-Non Affected families are experiencing high saving in the same period. This means that Autism has a negative implication on the saving rate of the households and this variation is statistically significant at t-value of (6.302) and p-value (0.000).

4.3.Partial Analysis of Socioeconomic/Psychological Challenges on Treatment HHs

Families of autistic children have different types of challenges in their day today life. They are facing so many challenges in their personal life, in their income and expenditure level, in their own spouse relationship at home, in the areas of social connection and networking, in the areas where they are working, in their neighborhood and on top in their psychological wellbeing. Most of the challenges faced because of low-level of community awareness about autism and high demanding job to give cares for the autistic children especially for mothers. This will isolate themselves from different activities including from engaging in different economic activities.

Therefore, the study in the below section will summarize the economic, social and psychological challenges of the families with autism. Therefore, the assessment done on the controlled group for impact comparison is excluded and only the treated allowed to be considered in this analysis.

4.3.1. Overall Economic Consequence of Autism

A number of economic consequence encountered by the families who have autistic children and they are receiving challenges in their life by the situation they are living in. The major economic consequence that happened on the life of the families are having difficulty to meet ends(33%), drop of saving rate(33%), dissaving (7%), asset selling (3%) and others which was not specified(7%). 17% of the respondent didn't give their response (Table 4.5).

Table 4. 5: Economic Consequence of Autism

Economic Consequence	Frequency	Percent (%)
Drop of saving	10	33%
Dissaving	2	7%
Asset selling	1	3%
Difficult to meet ends	10	33%
Others	2	7%
Missing	5	17%
Total	30	100

4.3.2. Consequence of Autism on Employment

Having autistic child have also an impact on the employment type and efficiency of the families who have the responsibilities of both accomplishing their task on work place and giving support to their autistic children. Due to this reason 23% of the household families forced to do low quality job, 17% of them have low level of efficiency at work, 10% of them are being unemployed and 7% are forced to be part-timer. On the contrary having autistic children did not impose any negative effect on 30% of the family households. 13 % is missing (Table 4.6).

Table 4. 6: Effect of Autism on Employment

Implications on employment	Freq.	Percent
Involuntary par timer	2	7%
Unemployment	3	10%
Loss of eff.	5	17%
Low quality work	7	23%
No effect	9	30%
Missing	4	13%
Total	30	100

4.3.3. Access to Social Services

According to the survey result 60% of the households responded that they are going to health facilities for medical checkup only during their illness. The rest are visiting clinics or hospitals on monthly basis (16.67%), every 6 month (3.33%), every 3 months (6.67%) and 6.67% of the households are going to health facilities annually. Health facilities are not accessible for all households in this group and 40% of the households are desperately raise their concern on health accessibility. Facilities especially the private institutions are becoming far-reaching institutes in terms of cost and 63.33% of the households cannot afford the health service in Addis Ababa. Especially, when they are required to take their autistic children to the health facilities, even the health practitioners do not welcome them and the entire community neither do. Among the main reasons level of awareness and lack of technical knowledge are the prominent ones.

Fulfilling daily dietary needs of every individuals with in the family is also one of the key aspects of individual wellbeing in order to make them healthy and strong enough. On this regard, only 63.3% of the households are getting balanced diet and the rest 36.67% are not getting adequate and nutritious food so that it has its own impact on their health status and readiness for doing work eventually affecting their personal and household wellbeing.

The other important thing that is essential for leading a normal life is getting access to education. Education have a power to play roles on individual wellbeing especially for those family members who have different dimension of challenges because of having autistic children. Among them 24 households responded that they have a challenge on their education performance. Due to the major reasons articulated in the survey such as having autistic children (58.33%) and high cost of education (16.67%), 70 % of the households could not attend and further their education. Lack of opportunities (31.58%)a and lack of time for continued education (47.37%) are also the main reason which stepped back to advance their knowledge and skill at the end to get better benefit and improve their wellbeing status (Annex II).

4.3.4. Support from Others and Socialization

It is a key requirement for families having autistic child in their household to get social support and

encouragement either from relatives or from the entire communities. According to this survey result, only 26.67% of the households are sure about getting support from their relatives and the other 50% are desperately speaking about the absence of any support from any direction. The remaining 23.33% are not sure whether they have support or not during their difficult times (Annex II).

On the other hand, socialization is a key aspect of personal and family wellbeing. During socialization, it is obvious that, peoples can get advice, share experiences about different aspects of life, get psychological relief, and develop positive thinking. Enjoy the interaction and believe they are included. However, only 40% families of the autistic child are getting this opportunity, the rest 60% of the households lost the opportunity to get all the benefit mentioned above, and this will make their wellbeing status to deteriorate from time to time (Annex II).

Neighborhood and relation with neighbor also have an indispensable role in supporting families and 60% of families have good relationship with their neighbor, 26.67% of them have normal relationship.in the contrary bad relationship accounts 13.33% (Annex I). The understanding and supportiveness of neighbors for both autistic children and their families have different tiers and it is indicated that 55.17% of neighbors understand about what support needed but they are not giving their actual support and 27.59% are providing required support and they have also a clear understanding on what is expected from them. On the other hand, 17.24% of their neighbors do not have the understanding but they are supportive (Annex II).

Safety and security of individuals is also important for their wellbeing. In this aspect only 27.59% of them feel safe when they are walking around the city but the rest 72.41 are not feeling safe due to lack of awareness among the community (57.14%), behavioral challenge of the autistic child (233.33%) and lack of interest by the families themselves (9.52%)

4.3.5. Psychological Challenges

Families with autistic children are happy and their proportion is more than 50% but more than 38% of the families are still worried about the situation about their children as well as the effect on their wellbeing. Nevertheless, what is astonishing here is 33.33% of the households are leading their life with full of hope. The rest 28% of the households are living with disappointment and sorrow, which

are not normally helpful either for families or for the children themselves (Annex I).

The reaction for negative and positive attributes have been assessed and 53.33% of the families have a normal reaction when they experience good things as well as bad happening (Annex I)

4.4. Correlation Analysis

Correlation analysis is used to determine the degree of relationship between the dependent variable that is ASD with the selected outcome variables as presented in the table. ASD is a dichotomous variable and most of the other variables are continuous variables. Therefore, Point-Biserial r is the right correlation coefficient employed to estimate the degree of association of ASD against the other variables.

In this survey analysis, a weak positive correlation found between ASD and dependency ratio, between ASD and household expenditure and a fair correlation between ASD and life satisfaction. As expressed by the t-test, the estimation is statistically significant at 0.05 and 0.01 level. The result conveys meaningful message that the dependency ratio and household expenditure is higher with ASD but the result with life satisfaction is quite different from reality. Further, ASD has a significant negative but a weak correlation with health status, education level, and total income. This implied that families who have a child diagnosed with autism experience ill health, low education attainment, low income level.

Table 4. 7: Correlation analysis of ASD with

	ASD	DRatio	Hlthstatus	Educl	Tincome	HHExpend	Lsatsfcn
ASD	1	.227*	-.258*	-.328**	-.214*	.259**	.471**
DRatio	.227*	1	.023	-.189	-.035	-.013	.070
Hlthstatus	-.258*	.023	1	-.235*	.310**	.301**	.186
Educl	-.328**	-.189	-.235*	1	-.014	.014	-.269**
Tincome	-.214*	-.035	.310**	-.014	1	.887**	.152
HHExpend	.259**	-.013	.301**	.014	.887**	1	.174
Lsatsfcn	.471**	.070	.186	-.269**	.152	.174	1

*. Correlation is significant at the 0.05 level (2-tailed).

** . Correlation is significant at the 0.01 level (2-tailed).

4.5. Summary of Findings

ASD-affected households have higher dependency burden than the ASD Non-Affected households as the households in the treatment group have higher dependency ratio than the ASD non-Affected. ASD-affected families have lower performance in education attainment than the ASD Non-affected households. The survey result demonstrated that ASD has a negative implication on the health status of families and health service is not affordable for the majority of the families with ASD.

According to the result by descriptive statistics on the covariates, ASD has a negative implication on the income level and per capita income of the households, as they are relatively lower than the non-affected households are. Higher expenditure and lower saving level also the peculiar future of the affected households due to the costs associated with education, transportation and house rent. Through partial analysis, ASD-affected households have a number of challenges. In the economic aspect more than 80 % of the households struggling with problems such as unable to meet their ends, drop of saving, dissaving, they are higher percentage of the households are unable to meet ends, their saving is decrease and asset selling. Families with autism found themselves working low quality job and loss of efficiency is their current occupation. Having autism has also a negative implication on their socialization and relationship with relatives and neighbors. Based on this survey result, ASD have not a significant impact on the psychological attributes of the households. Results in the correlation analysis also supported the aforementioned findings.

CHAPTER FIVE -CONCLUSION AND RECOMMENDATION

5.1.Conclusion

Now a days Autism is not only a family issue rather it is a national issue due to the multifaceted impact imposing on the families who are hosting an autistic child. The study analyzed the implication of autism on the wellbeing of families in Nia foundation and Nehemiah autism center located in Addis Ababa. These centers are the only centers providing a service and 70 selected households and the result analysed by using descriptive statistics and correlation analysis. The study followed a comparison approach by conducting its survey in two groups of families(the first one is the treatment group who are having an autistic child with in their families and the second group is a controlled group who have more or less similar life style and living in similar areas. The study t-test and chi-2 test to check the significant of the implication of autism on household income, household expenditure, health status, Education attainment, and life satisfaction and the result is presented according to treatment and controlled groups.

The average age of the autistic children is 10 years with the minimum and maximum age of 3 and 24 respectively. Therefor the impact of autism on families is already long term, which has many backlogs on the wellbeing of families.

As it is presented in chapter four, households who have an autistic child with in their family have registered low income for the last two years. On this regard, especially the caregivers in most cases, mothers forced to abandon their job due to the need to devote the entire time to the child. As a result, they evacuated job or became par timer. Therefore, not all active members in that family are employed and there are peoples mostly mothers will stay at home giving care for autistic child and refrain from working so that the burden will fall on one person as breadwinner. Therefore, autism has impaired the financial wellbeing of the families having an autistic child.

On the contrary having autistic child has significantly increased their expenditure and most of the services such as schooling, transportation, health services and therapies, which are associated with autism, are rare and expensive and this has a direct impact on their expenditure. Moreover, autism has a negative implication on the education attainment of the families hosting an autistic child. The

majority of households in this group are Diploma graduate and below and this in turn has a direct implication on the income level of the households as they are hired in lower quality of jobs getting lower wage as compared with the educated peoples getting a higher wage and salary. The other aspect of wellbeing indicator is health status of the household and in this survey result, the health situation of households having an autistic child is deterioration from time to time. Unable to afford the health service due to low income, social and economic challenges in tending the child and psychological stresses are among the reasons mentioned by the respondent households.

Ultimately, wellbeing is about life satisfaction of individuals and according to the survey result more than 57% of the affected households reported that they are not satisfied in their way of life that they are leading now. They thought that their autistic child is becoming the source of suffering and they just assumed that they have sentenced for life and most of them are feeling helpless and disappointed. They do not think anyone as a source of assistance in case of emergency so that they are feeling helpless and isolated themselves from socialization and networking with other peoples, which is the source of worries and disappointment. Since the awareness level about autism is much lower among the community, they are not feeling comfortable to participate actively on social and economic activities.

Therefore, wellbeing is measured by economic, social and psychological indicators and the result shows that ASD is imposing a negative impact on income, expenditure, health status education attainment and life satisfaction of the affected households.

5.2.Recommendation

Based on the discussion in the result section and the conclusion drawn from the findings, this study come up with the following recommendations as outlined below.

- Ensuring easy access and enrollment to education and affordable therapeutic and support centers. Therefore, the government of Ethiopia and other concerned parties such as private volunteers, institutions and individuals should join hands to establish Autism rehabilitation and support centers and improve the coverage so that families can get a better access for those centers and able to send their children to those centers.

- Specialized Medical treatment centers for autism and family counselling services are among the essential institutions to provide adequate and professional treatment for children diagnosed by autism.
- Universities, research institutions and concerned government institutions should encourage researchers and academicians to do their research in area of autism and produce policy recommendation in the process of improving the lives of autistic children and their families and substantiate the exact implication of autism on economic, social and psychological issues at household, community and country level.
- Effective coordination among autism centers, schools and Medias and families to create and enhance the awareness level of the community on autism .This will help the autistic children and their families to strengthen social connection, being included, and adequate support in school, transportation, neighborhood, recreation and any other places.
- To reduce their economic vulnerability of the households with ASD especially mothers, skill training on income generating activities, livelihood support programs, PSNP programs and other special packages should be provided. For effective implementation of those programs, coordination and synergy between government, NGOs and autism centers is required.

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Annexes

Annex I

Socio economic and psychological challenges by category

		Non Affected		Affected		Total	
Challenges-Economic		Freq.	%	Fre q.	%	Fre q.	%
Income trend	Increasing	26	65	14	46.67	40	57.14
	Deceasing	3	7.5	6	20	9	12.86
	Constant	11	27.5	10	33.33	21	30
	Total	40	100	30	100	70	100
Reason for decreased income	Unemployment	2	33.33	4	50	6	42.86
	Job lost	0	0	1	12.5	1	7.14
	Increased COL	2	33.33	0	0	2	14.29
	Increased tuition	2	33.33	2	25	4	28.57
	Others	0	0	1	12.5	1	7.14
	Total	6	100	8	100	14	100
Expenditure trend	Decrease	1	2.5	2	6.67	3	4.29
	Increase	34	85	22	73.33	56	80
	Constant	5	12.5	6	20	11	15.71
	Total	40	100	30	100	70	100
Fast growing Expenditure	food	20	57.14	16	57.14	36	57.14
	House rent	9	25.71	6	21.43	15	23.81
	school fee	4	11.43	2	7.14	6	9.52
	Medical	2	5.71	4	14.29	6	9.52

	total	35	10 0	28	10 0	63	10 0
Saving trend	growing	20	54. 05	4	16. 67	24	39. 34
	constant	10	27. 03	10	41. 67	20	32. 79
	decreasing	7	18. 92	10	41. 67	17	27. 87
	Total	37	10 0	24	10 0	61	10 0
Reason for decreasing saving rate	low income	3	30	6	33. 33	9	32. 14
	inflation	6	60	10	55. 56	16	57. 14
	not planned	1	10	2	11. 11	3	10. 71
	Total	10	10 0	18	10 0	28	10 0
Challenges- health, education, hrs worked							
Health status of the households	normal	28	70	13	43. 33	41	58. 57
	occassion	9	22. 5	12	40	21	30
	sever ill	3	7.5	5	16. 67	8	11. 43
	Total	40	10 0	30	10 0	70	10 0
Reason for challenges on HHs education	Autism	0	0	14	58. 33	14	38. 89
	Not interested	0	0	4	16. 67	4	11. 11
	Lack of opp.	6	50	2	8.3 3	8	22. 22
	High cost	6	50	4	16. 67	10	27. 78
	Total	12	10 0	24	10 0	36	10 0
relation with neighbour	normal	13	33. 33	8	26. 67	21	30. 43
	good	26	66. 67	18	60	44	63. 77
	bad	0	0	4	13. 33	4	5.8
	Total	39	10 0	30	10 0	69	10 0

Life satisfaction	Satisfied	32	80	16	53. 33	48	68. 57
	Unsatisfied	8	20	14	46. 67	22	31. 43
	Total	40	10 0	30	10 0	70	10 0
interest on social interaction	strongly agree	23	57. 5	12	40	35	50
	agree	11	27. 5	10	33. 33	21	30
	disagree	5	12. 5	5	16. 67	10	14. 29
	strongly disagree	1	2.5	3	10	4	5.7 1
	Total	40	10 0	30	10 0	70	10 0
positive perception about oneself	strongly agree	18	45	10	33. 33	28	40
	agree	18	45	13	43. 33	31	44. 29
	disagree	3	7.5	4	13. 33	7	10
	strongly disagree	1	2.5	3	10	4	5.7 1
	Total	40	10 0	30	10 0	70	10 0
Feeling helpless	strongly agree	4	10. 26	5	16. 67	9	13. 04
	agree	5	12. 82	11	36. 67	16	23. 19
	disagree	14	35. 9	6	20	20	28. 99
	strongly disagree	16	41. 03	8	26. 67	24	34. 78
	Total	39	10 0	30	10 0	69	10 0

Annex II

Economic and social challenges for Binary responses

Economic security	Affected (N=30)%	Non Affected (N=40)%	Total (N=70)%
No	66.67	53.85	59.42
Yes	33.33	46.15	40.58
Total	100	100	100
Credit outstanding	Affected (N=30)%	Non Affected (N=40)%	Total (N=70)%
No	83.33	75	78.57
Yes	16.67	25	21.43
Total	100	100	100
Frequency of Medical check up	Affected (N=30)%	Non Affected (N=40)%	Total (N=70)%
monthly	16.67	7.69	11
three month	6.67	10.26	9
6 month	3.33	7.69	6
annually	6.67	28.21	19
only in illness	66.67	46.15	54
Access to Health Service	Affected (N=30)%	Non Affected (N=40)%	Total (N=70)%
no	26.67	22.5	24
yes	73.33	77.5	76
Total	100	100	100
Health service affordability	Affected (N=30)%	Non Affected (N=40)%	Total (N=70)%
No	73.33	50	60
Yes	26.67	50	40
Total	100	100	100
Balanced diet	Affected (N=30)%	Non Affected (N=40)%	Total (N=70)%
No	36.67	25	30
Yes	63.33	75	70
Total	100	100	100
Access to Education	Affected (N=30)%	Non Affected (N=40)%	Total (N=70)%
No	20	70	48.57

Yes	80	30	51.43
Total	100	100	100
Support from others	Affected (N=30)%	Non Affected (N=40)%	Total (N=70)%
No	50	10.26	27.54
yes	26.67	74.36	53.62
Not sure	23.33	15.38	18.84
Total	100	100	100
Socialization at least once a week	Affected (N=30)%	Non Affected (N=40)%	Total (N=70)%
no	60	17.5	35.71
yes	40	82.5	64.29
Total	100	100	100
Major Challenges on HHs Education	Affected (N=24)%	Non Affected (N=40)%	Total (N=70)%
having autistic child	58.33		39
lack of interest	16.67		11
lack of opportunity	8.33	50	22
high cost	16.67	50	28
Total	100	100	100
neighbors understanding and support to Autistic child	Affected (N=29)%	Non Affected (N=40)%	Total (N=70)%
not understand but supportive	17.24		
understand but not supportive	55.17		
understand and supportive	27.59		
Total	100		
Feel Safe while walking with A child with Autism	Affected (N=29)%	Non Affected (N=40)%	Total (N=70)%
no	72.41		
yes	27.59		
Reason for feeling unsafe when walking with Autism	Affected (N=21)%	Non Affected (N=40)%	Total (N=70)%
lack of awareness	57.14		
lack of interest	9.52		
behavioral challenge	33.33		
Total	100		

Annex III

Survey questioners

Questioners for HHs who are selected as a respondent for the research implication of childhood autism on the wellbeing of families

General Introduction

Dear respondent, my name is Minasie Mekbib attending my Master's degree at St. Marry University in Development Economics. I am interested to conduct my research in relation with the autism with the study title "implication of childhood autism on the wellbeing of Families."

The objective of this study is to find the implication of Childhood Autism on the wellbeing of families which can be expressed by their social, economic and psychological aspects. your answer will be kept confidential and your genuine response is appreciated.

Thank you in advance for your time

I. Wellbeing Indicators

Part One: Background information

1. Name of household head _____
2. Sex: Male Female
3. Age _____
4. Marital Status: Single Married Divorces Widowed
5. Household Size: _____
6. Level of Educational Illiterate 12th complete Diploma 1st degree 2nd degree
7. Health status: Normal occasional illness Sever illness
8. Employment type: Permanent temporary

Part Two: Autism in situation

9. Do you have children with autism? Yes No

If the answer is yes, Number of children with Autism: _____

10. Age of the children with Autism: _____, _____

Part Three: Family income

11. How many peoples in the household do have paid work? _____
12. Source of income

Activities	Number of people engaged	Earnings per month (birr)
Employment-Government		
Employment-NGO		

Employment- Private company		
Employment-Housemaid		
Employment- house guard		
Casual labor		
Trade		
Income from rent (House, Car and others)		
Remittance		
Institutional support		
Others(specify)		

13. What is the trend of your income level for the last two years?
Increasing Decreasing No change
14. If the answer is decreasing, what is the main reason?
Being unemployed due to demanding care for the child with autism
Loss of job due to other reason
Increased cost of schooling and transportation to send the autistic child to school
Overall increase on cost of living
Others (specify) _____
15. How do you explain your economic confidence for the period which is coming ahead
Optimist pessimist Indifferent
16. Do you feel that You are economically secured
Yes No

Part Four: Family expenditure

17. major cost of living per month

Expense type	Cost per month (Birr)	Remarks
Food and drink		
House rent		
Transportation		
School fee for normal children		
School fee for children with autism		
Education Stationery for children		
Medical expense		
Clothing (annual expense divided by 12 months)		
School uniform(annual expense divided by 12 months)		
Festive expense(annual expense divided by 12 months)		
Wage for house servants and guards		
telephone, electricity, water		
Others (specify)		

18. What percentage of your monthly income spent for HH consumption?

100% 80% 60% 40% and less

19. To which direction your consumption expenditure is moving for the last two years

Decreasing Increasing No change

20. If your expenditure is growing, which one is growing fast for the last two years

Food House rent School fee health expenses

Part Five: Saving

21. What proportion of your income goes to saving

10% 20% 30% 40%

22. What is your saving rate looks like for the last two years?

Still growing constant saving decreased

23. If your saving rate is falling, what is the main reason?

Low income growing expenses/inflation lower interest absence of planning

24. How often you are going out for recreation

Once in a month once in 3 months once in 6 month once in a year not at all

25. Are you fully aware about the benefit of saving

Yes No

26. In general, what major economic consequence you are facing as a result of having a child with autism?

Drop of Saving

Dissaving to smoothen consumption

Selling of valuable assets such as house, gold, and other jewelries

Money borrowing from financial institutions as well as individuals

Difficulty to make ends met

Others (specify) _____

Part Six: Credit

27. Currently, do you have outstanding debt from financial institution or individuals?

Yes No

28. If yes, what was the main reason for owing debt?

Medical expense for the child with autism startup capital for business buy house
buy car others (specify) _____

29. Have you borrowed with normal interest rate?

Yes No

Part Seven: Jobs and earnings

30. How many hours you spend working in paid work per week

None Less than 24 hours 24-48 hours more than 50 hours

31. If you are working more than 50 Hours per week, what is your main reason?

Extra financial need nature of the work others

32. What implications does your child condition impose on your employment?

Involuntary part-time job unemployment

Loss of efficiency at work Employed on low quality job Not at all

33. How do you think about your work place relation

Very good Good Fair Bad

Part Eight: Health Status

34. How is your current health status in general?

Very good, good, not very good, poor

35. If you are not satisfied about your current health status, is it due to your child condition?

Yes Yes partly Not at all

36. Is there a person in your family suffering from illness? Yes No

37. How often you are visiting a doctor to check your health status?

Monthly every three months every 6 months annually

38. Do you fully access any health facilities without any form of classification?

Yes No

39. Do you think that health service providers are affordable as compared to your income level

Yes No

40. Do your families are getting the right balanced diet every day?

Yes No

41. Are you using alcohol or drug to the level which can affect your health condition?

Yes No

II. Challenges

Part One: Education and Skills

42. Have you experienced a challenge to improve your education level

Yes No

43. If yes, What is the main reason

Having Autistic child Lack of interest Lack of opportunity increased payment

44. Have you engaged in a continued learning to improve competencies and skills?

Yes No

45. If No, what is the major constraint you have

Lack of time lack of opportunity lack of interest not required

Part Two: Social Network

46. Is conflict happens with your spouse specifically as a result of your child condition

Yes No

47. Whenever you are in trouble and need assistance, do you have relatives or friends to give required support?

Yes No not sure

48. Do you have the chance to socialize with your friends and relatives at least once a week
 Yes No
49. Within the past 12 months, have you been attacked in relation with having autistic child?
 Yes No
50. Do you feel safe walking with your autistic child
 Yes No
51. If you are not comfortable to go out with your child , what is the reason?
Lack of societal awareness I have no interest behavioral challenge from the child
52. How do you perceive your relationship with your neighbors?
Normal good not bad ruined
53. Do you think that your neighbors and relatives understand your autistic child situation and provide their support?
Not understand and supportive understand but not supportive understand and supportive
54. How much you are confident to invite relatives, neighbors and friends to your home?
 Not at all hesitant confident
55. If you are hesitant or don't want to invite peoples, what is the reason?
Poor housing condition lack of time having autistic child

Part Three: Subjective wellbeing

56. To what extent you are satisfied in life?
 Highly satisfied Satisfied unsatisfied highly unsatisfied
57. What is the predominant feeling you experienced when you think about your child condition and its impact on your life?
Courage Hope Worries Disappointment Sorrow
58. I often feel emotional when I think my child's condition
Strongly agree Agree disagree strongly disagree
59. I don't really care about my child situation
Strongly agree Agree disagree strongly disagree
60. Most often, I feel helpless and loneliness when I think my child
Strongly agree Agree disagree strongly disagree
61. My perception for my self is always positive
Strongly agree Agree disagree strongly disagree
62. I always have interest and feel engaged in my social interaction
Strongly agree Agree disagree strongly disagree
63. How do you explain your emotional reaction for things going right
Extremely pleased moderately pleased pleased no change
64. How long you stay with your negative feelings
Very short normal prolonged period