

## **Factors that Influence Primary School Participation of Epileptically Affected People in Me'enit Goldia Woreda Bench Maji Zone, Ethiopia**

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**Abstract:** This study has been undertaken to explore the influencing factors that limit the primary school participation of epileptic communities in Me'enit people who live in Me'enit Goldia wereda at Bench Maji zone administration. The target people in the study area are facing extreme form of discrimination and live in a severe poverty and illness. They feel hope less and not seeking for their rights get respected. Majority of them are excluded from all forms of social activities. They all are illiterates and live in a poor and severely affected health condition that resulted mainly from burn injury and fractures. Furthermore, the study employed qualitative research method to collect and analyze primary data from the target people. Accordingly, the sample respondents were selected from people affected by epilepsy, from primary school management bodies (school directors, PTAs, KETB members and Wereda education supervisors), from Government officials, NGOs and Civic society members and from Religious leaders, Elders and prominent members of the community for interview and focus groups discussions. Few of the PWE in the target area were pulled together and settled by Ethiopian Red Cross Society and Mizan Aman town administration to the village called "Bala" though many of them still are living in different towns suffering from severe social marginalization and economic deprivation. According to the results obtained from the study, majority of the people living with epilepsy were found illiterate and didn't go to school. The ones who managed to go to school were not able to resist the stigma and discrimination and had forced to withdraw and remained illiterate. Moreover, the study has sought the factors that had greatly influenced their participation in primary education. In view of that, the social factors, economic factors, cultural factors and psychological factors were the subjects of the study. Finally it has been learned that epileptic people in the study area were highly affected by all of the factors stated above and that led them to severe poverty and instability. It is recommended that attention need to be provided to these people to get educated.

**Key words:** Epilepsy, empowerment, livelihood, participation, schooling

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### **I. INTRODUCTION**

Education is an important weapon to fight poverty and plays pivotal role in accelerating development and improving the life of people so as to help them contribute for the local and national development. As a matter of fact, an educated person and community can understand well their environment, analyze their situation and leads his/her life in a better way, relatively by giving better responses to the natural and manmade disasters in their localities as compared to non-educated ones. In this sense the value of education to promote quality of lives of people is not questionable and the level of inequalities among different groups of people would also be narrowed as a result of having access for quality education at different level.

Epilepsy is defined by different authors in a more similar way, as defined by Folarin Oluseye Abimbola (2010), it is "an umbrella term used for neurological disorders characterized by seizures. Since the seizures might originate in different locations of the brain, the symptoms can differ greatly between patients all diagnosed with epilepsy" the usual symptoms of seizures are classified as uncontrolled, motoric movements or spasms, convulsions, emotional or psychological sensations, loss of consciousness and more. These are usually caused by signal feedback oscillations between neurons. Similarly, as defined by National Center for Project Access (2013). "Epilepsy is a medical condition that produces seizures that can affect mental and physical functions. It is also called a seizure disorder." Many illnesses or severe injuries can affect the brain enough to

produce a single seizure. When seizures continue to occur for unknown reasons or because of a problem that cannot be corrected, the condition is known as epilepsy.

Since Ethiopia is among the countries that committed themselves to create access for primary education and working hard to universalize primary education for their citizens, the Federal Government of Ethiopia has introduced the Education and Training Policy in 1994 and has been working hard to respond to the country's development challenges through expanding Educational facilities across the board. What makes the current policy different from previous ones is that, the policy has been addressing the issues of *Access, Equity, Quality, efficiency and Relevance* which were the critical issues identified in the Education sector to work on the improvement of the education system (MoE, 1994).

Based on the clear direction of the policy, access for primary education is uncompromisingly created for out of school children and adults across the nation. This expansion has been covering all areas rural and urban to provide educational services without any discrimination among citizens of the nation.

Even though, there have been much improvement in the creation of access for primary education across the board in the country, there are quite a lot people who are denied of using these services due to various reasons associated to their cast like discrimination, physical disabilities and ill health condition like epileptic people living in the study area are among the many. These people are not getting equal opportunities to learn even in the available primary education facilities in their respective areas. Among those groups of people who were denied from social and economic services in their localities, this study has made its focus on the epileptic Me'ent tribe people who live in Me'ent Goldia woreda and different towns of the Bench Maji Zone administration.

Me'ent Goldia wereda is found in Bench Maji Zone( in South Nations, Nationalities and Peoples Region, Ethiopia) and is one of the two Weredas where Me'ent tribe people are residing. These people are identified by their own language, culture, and ways of living. In these areas, there has been a wide spread and deep-rooted wrong belief on epileptic patients that people with such problem would be forced to be marginalized and move away from their respective villages and communities because, epilepsy in Me'ent communities is considered as contagious disease and incurable with a modern or traditional medication.

When any person regardless of age and sex found epileptic in Me'ent tribe, the families or relatives of that person affected by the disease would not tolerate to live with them. They will be exposed to social and economic sanctions by their respective communities. For these reasons, they prefer to abandon their children or any other family member who acquired the disease. In case of children majority of the families would prefer to take them to the nearby towns especially to Mizan Teferi town and leave them aside from their sight. In case of youths and adults they usually give them the chance to abscond their village and resources behind and go to anywhere else they like to survive from the hardest punishments they may face in time.

These people, after being expelled from their normal life they will have no other alternatives other than accepting their status to lead the miserable life by making oneself part of the marginalized epileptic communities in Mizan Teferi town where the concentration of the patients is very high as compared to other nearby towns. Churches, mosques, gorges and market areas are the most common places in the towns for the victims to get shelter and lead their life in a vanguard manner.

Furthermore, the marginalization act on these people was not limited to their birth place or respective villages, it moves on with them where ever they go in the administrative area. Nobody cares about them and consider them as a human being that they have feelings, emotions, and needs and deserve respects. Marriage and divorce are common phenomenon in the epileptic families and average children size per family is reported to be five. As a consequences of these practices happening on the target people the people affected by the disease at the study area are denied of their rights as a human being in general and the rights for Education in particular.

Moreover, the living situation of these people did not give them the freedom and capacity to go to school and help them use of the available educational facilities in their surroundings. Whenever they go to a school by chance and the first seizure happen on a student at school, the situation can easily call attention of other students and the school communities and would easily be stigmatized. Then after, the victim will have no courage to continue learning in that school. Due to the high level of stigma and discrimination by the school communities, they would eventually dropped out from school before completing the academic year; that would put them with the people who didn't try to go to school.

Recognizing this fact; the study has attempted to address the following three research questions:

- What is the level of primary school participation of epileptically affected people in Me'ent Goldia wereda?
- What are the factors that inhibit the primary school participation of the study group in Me'ent Goldia wereda?
- What are the possible intervention strategies to minimize the critical challenges of epileptically affected people to effectively participate in primary education?

## **II. PURPOSE OF THE STUDY**

The study is aiming at exploring the factors that affect primary school participation of epileptic Me'ent communities that would further have influenced their lively hood which was in a dreadful situation. It would also seek to find means of including them in the education system to help them improve their living situation. This imply that the focus of the study will remain on identifying the major factors that inhibit the target people from taking part in the education system to be able to contribute for the achievements of "Education for All" goals

Therefore, the study is carried out from the practical observation of the investigators' and found timely and crucial to identify the facts as how being epileptic has affected the target people and their children to participate in primary education which would have bigger impact in the lively hood status of the people and suggested valuable recommendations based on the findings of the study in order to mitigate the predicaments lay on the target people.

## **III. SIGNIFICANCE OF THE STUDY**

The study will help members of Me'ent people, government and other stakeholders to have good understanding on the negative effects of marginalization practiced on epileptically affected people to lead decent life in general and to participate in primary education in particular.

Specifically, the study will have significant contribution:

- To raise the knowledge and understanding of the wider communities, government and non government organizations about the target people under study;
- To enhance the skill and knowledge of the stakeholders to help people with epilepsy get retained in primary schools.
- To devise strategies by government organizations and other stakeholders to improve the primary school participation of the target people and thereby improve their living situation from being destitute to relatively better position.

## **IV. THEORETICAL AND EMPIRICAL PERSPECTIVES**

### **4.1 Theoretical review**

It is believed that development cannot be ensured without education, therefore, a nation need to have clear strategies so as to achieve over all development through provision of quality education to its citizen. As indicated in the new education and training policy of federal democratic republic of Ethiopia "Education enables individuals and society to make all-rounded participation in the development process by acquiring knowledge, ability, skills and attitudes". Similarly, the World Bank development report incorporated a statement "Without education, we cannot expect to gain innovation and skill to tackle poverty and even more importantly, if access to education is not equitable, we will lose perspective and effective influence on eradicating poverty." These added details to the statement in a way that emphasized the importance of education as an important weapon to fight against poverty and get liberation from all kinds of deprivations because education fortify all social progresses. Whenever education level of people improved, unemployment problems can be hugely tackled leading to improvements in poverty and general standards of living. This comment further emphasized that access alone is not enough, and that good-quality education is the key to national development and individual well-being. By and large, the people who have been denied of their rights for education would fall in a vicious circle and will transcend the poverty situation over generation by not having a chance for education because of reasons beyond their control

Sustainable development goals are the continuation of the millennium development goals defined by the United Nations Development Programs that encompassed various development agendas to be implemented in the post 2015 period. Education, among the major development agendas in the guiding document is identified as the most essential area to bring sustainable development by ensuring inclusive and equitable quality education and promoting life-long learning opportunities for all.

The right to education in International Law Article 13 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) states that: Education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. It shall also enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups.

Moreover, the UN Committee on Economic, Social and Cultural Rights (CESCR), stated that:

*Education is both a human right in itself and an indispensable means of realizing other human rights. As an empowerment right, education is the primary vehicle by which economically and socially marginalized adults and children can lift themselves out of poverty and obtain the means.*

In Article 26, of Universal declaration of human rights [UDHR], the right for education is defined in the following manner:

*Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.*

As indicated in the ESDP III document, Access at all levels of the education system especially of the primary education is increased at a rapid rate, the situation of the disadvantaged and deprived groups and of the emerging regions advanced more rapidly than the average and, as a result, disparities became less sharp, though they remain of concern.

People who live with epilepsy usually suffer from psychological problems like fear, anxiety, depression and lack of self esteem to interact with other people in a normal condition. Various literatures have put their statements related to psychological problems of people living with epilepsy in different manner, as Betts et al. presented:

*To be epileptic is to be stressed and stress can influence the incidence of fits. Under stress many people develop anxiety symptoms which may be seen as a fight or flight reaction, some become depressed, and others show obsessive ritualistic behavior (Betts et al., 1976).*

On the other hand, epileptic people in most cases are unemployed and highly dependent on their families in the developed world. The situations in developing countries seem different and highly affected by the traditional beliefs and wrong perceptions about the disease. In support of this statement (Pahl & de Boer, 2005).stated that:

*Unemployment is higher among people with epilepsy, by up to 50% in developed countries if seizures are not fully controlled and up to 100% in developing countries. Across the world and throughout history, epilepsy has been a culturally devalued condition. Such devaluing often leads to people with epilepsy being stigmatized and bearing psychosocial burden .Stigmatization leads to discrimination, and people with epilepsy have been the target of prejudicial behavior in many sphere of life, over many centuries and in many cultures .*

The overall effects of epilepsy in the social relationships of epileptic people with other people are stated in a negative sense that epilepsy has an adverse effect on them to lead decent life and make reasonable earnings for their survival. Employers even have not been interested to recruit epileptic people because of the fear of extra expenses for their medication and other related issues.

Epilepsy is perceived differently in different cultures, the reaction to epilepsy in Africa is shaped by traditional indigenous beliefs which are surprisingly similar, in most of the African continent and result in severe cultural and psychological destitutions. For instance, the African epilepsy sufferers have a hard time to achieve positive feelings about themselves and frequently suffer deprivations without protest (Jilek et al., 1997).

Causes of epilepsy can also be seen differently in different contexts. According to National Center for project center (2010), causes are not known for about seven out of ten people with epilepsy. This is called idiopathic epilepsy. Idiopathic is a Latin word meaning "of unknown cause". For the rest of the people with epilepsy, the cause may be any one of a number of things that can make a difference in the way the brain works. For example, head injuries or lack of oxygen during birth may damage the delicate electrical system in the brain. Other causes include brain tumors, lead poisoning, problems in development of the brain before birth and infection like meningitis or encephalitis.

According to Folarin Oluseye Abimbola (2010), seizures occur due to brief disturbances in the normal electrical functions of the brain. Millions of tiny electrical charges pass between nerve cells in the brain and connect to all parts of the body. When someone has epilepsy, this normal pattern may occasionally be interrupted by short bursts of electrical energy that are much stronger than usual. This can cause muscle spasms or uncontrollable body movements, loss of consciousness or confusion. These physical changes are called epileptic seizures. Normal brain function cannot return until the electrical bursts stop. Seizures can occur in just one area of the brain (partial seizures) or may affect nerve cells throughout the brain (generalized seizures). Most last a few seconds or minutes.

In epilepsy, the normal pattern of neuronal activity becomes disturbed, causing strange sensations, emotions, and behavior or sometimes convulsions, muscle spasms, and loss of consciousness.

## **5.2 Empirical Review**

Epilepsy is a very common neurological disorder that exists in a place where human population is found. It affects people of all ages, nations and races all over the world. According to National Center for Project Access (2010) there are records of it since biblical times. While undertaking this study the investigator has made review of various materials that focus on the epilepsy situation of the people in different countries like United States of America, Europe, Asia, Africa and also Ethiopia.

### **Epilepsy in America**

United States of America is one of the Nations where many people are affected by epilepsy. It is the fourth most common neurological disorder, after migraine, stroke, and Alzheimer's disease in USA. The Institute of Medicine's report (2012) approximately indicated that ,1 in 26 people will develop epilepsy at some point in their lives and an estimated 2.2 million people are Living with epilepsy.

Besides, an estimated 2.2 million Americans which have epilepsy, 150,000 new cases are diagnosed in the United States each year. This shows that approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults. For people with epilepsy, the disorder is often defined in practical terms, such as challenges in school, uncertainties about social situations and employment, limitations on driving, and questions about independent living.

### **Epilepsy in Europe**

According to WHO Global campaign against epilepsy (2007). In Europe, at least 6 million people have epilepsy, and 15 million Europeans will have one seizure at some time in their lives. Nevertheless, in some countries of Europe, epilepsy is not recognized as a brain disorder, and up to 40% of people with this condition may be untreated. This regional report for Europe provides a panoramic view of the present epilepsy situation in the Region outlines the initiatives taken by the Global Campaign partners to address the problems, define the current challenges and offers appropriate recommendations.

The prevalence of epilepsy in Europe is therefore 8.2 per 1000 people, thus around 6.000.000 people in Europe currently have epilepsy whilst 15.000.000 people will have had epilepsy at some time in their lives. Studies of the prevalence of epilepsy show that 1 out of every 20 or 30 persons in parts of the world with poor health conditions has epilepsy; in other parts, such as Europe, the prevalence is about 1 out of every 100 to 150. Thus, a typical family physician in. This shows that, quite a lot people are suffering from epilepsy in Europe as people of different countries are experiencing the same problem elsewhere in the world.

### **Epilepsy in Asia**

According to Kheng-Seang Lim, Chong-Tin Tan (2014), In the Various studies on social stigma or public attitude towards epilepsy, there were as high as (56-57)% of public respondents in epilepsy survey objected their children to play with people who sometimes had seizures, 86% thought that epilepsy patients cannot work as other people, and (71-86)% objected to their children marry a person who sometimes has seizures.

In a systematic review of public attitudes toward epilepsy, Asia and Africa were shown to be the two continents with the worst attitudes against employment in epilepsy where 50.0% and 80.0 of the published papers respectively reported more than 40% of participants with negative attitudes, as compared to none in North and South America, and Australia.

### **Epilepsy in Africa**

The reaction to epilepsy in Africa is shaped by traditional indigenous beliefs which are surprisingly similar, in some way or other, throughout most of the African continent and result in severe psychological hardship. The African epilepsy sufferers have a hard time to achieve positive feelings about themselves and frequently suffer deprivations without protest. In 1970 Osuntokun and Odeku, reviewed 522 Nigerian epilepsy sufferers and observed that the patients suffered psychosocial handicaps including suicidal tendency because they themselves considered epilepsy a social disgrace. Moreover, modern treatment for epilepsy is often unavailable in Africa. The reason might be different in diverse situation but lack of treatment facilities take the major one, because the general belief that epilepsy is of supernatural causation and therefore not treatable by Western medicine (Osuntokun & Odeku, 1970).

Although Africa is a diverse continent, and represents people of different cultural background, a widely held notion is that epilepsy may be caused by evil spirits. Other beliefs include witchcraft and contagious fears from bodily secretions (saliva, stool, or urine) that could potentially transmit seizures to bystanders (Carod-Artal & Vazquez-Cabrera, 2007).

In Uganda epilepsy is thought to be a result of a lizard spinning around in circles in the head disturbing the brain causing dizziness, usually followed by a seizure. In Malawi epilepsy is thought to be due to an insect moving inside the stomach. In Swaziland epilepsy is thought to be caused by sorcery, which sends evil animals or spirits into the body, causing convulsion (Andermann, 2011). A connection between the phases of the moon and convulsive attacks has been made since ancient times. It was, and still, is believed that either the new or the full moon is directly influencing and provoking seizure activity. Sub-Saharan Africa- and the continent of Africa as a whole- attach a huge social stigma to epilepsy. Prejudice against the disease is common, persons with epilepsy are usually stigmatized and even pronunciation of the word 'epilepsy' is a taboo (Jilek et al., 1999).

### **Epilepsy in Ethiopia**

Ethiopia is one of the least developed countries in the world and the incidence of epilepsy in less developed countries tends to be higher than in industrialized countries. Like any other African countries, Epilepsy is the most common cause of neurological disability in Ethiopia. It affects an estimated 5.2 per 1000 of the population, but only 2–13% of people with epilepsy living in rural areas receive medical treatment. Berhanu S, Alemu S, Asmera J, and Prevett M (2008) .

Many of the epileptic persons especially those who live in rural areas do not get treatments. Causes of this 'treatment gap' include inaccessibility of medical services, unavailability of antiepileptic drugs, lack of awareness of medical treatment and cultural factors.

The World Health Organization advocates the use of primary health care in less developed countries to improve access to treatment of chronic diseases, such as epilepsy. In Ethiopia, rural health centres, run by nurses and health officers are the focus of primary health care services to be given to the residing community. In line with health centre policy, patients who are unable to afford the cost of drugs and have the appropriate papers were given treatment without charge even for those patients having to pay for their treatment the cost of Phenobarbital is low. According to the study conducted by Dawit Worku (2013) .It was estimated that 360 to 400 thousand epileptic Ethiopians are living with poor medication. The prevalence of epilepsy was 5.2/1000 inhabitants at risk, 5.8 for males, and 4.6 for females. The highest age-specific prevalence was found for ages 10-19 years.

The annual incidence of epilepsy was 64 in 100,000 inhabitants at risk, 72 for males, and 57 for females. Generalized tonic-clonic seizures were the most common seizure type and occurred in 69 - 81%. During seizures, many patients sustain burn injury and trauma. A history of head trauma was ascertained in 5.7% and was the most common possible etiologic factor identified followed by meningitis. Mental retardation was the most common associated disorder, found in 7.9 - 21% of the persons with epilepsy. Traditional treatment with local herbs, holy water and amulets was the most common. Only 1.6% had been treated with recognized antiepileptic drugs in rural part of the country and as few as 13% were treated with antiepileptic drugs in cities like Addis Ababa.

### **Epilepsy in Me'entit people**

While undertaking this study, the data collection revealed that there are about 233 people from found epileptic and dispersed at different areas around towns in the woreda capital Bachuma, zonal capital Mizan aman town and other nearby places. As per the base line research conducted by Andualem Henok et.al (May, 2016), many of the study participants have acquired the disease for more than 5 years and experienced various forms incidents that lead them to live with permanent injury at different parts of their body.

A person affected with epilepsy often demonstrate behavior of sudden impulsive onset and discharge of bursting seizures make the victim become visible as if in the hold of an eccentric power. This provokes powerful panic in those present and has most likely done much to be responsible for the belief that epilepsy is caused by evil spirits or other supernatural forces.

## **V. METHODOLOGY OF THE STUDY**

The study was aiming at putting on view the factors that affect primary school participation of epileptic persons in Me'entit communities and its effect on their personal and social development. The problems as widely spoken by people around the study area mostly associated with socio cultural factors and deep rooted belief by the people that consider epilepsy as hereditary and contagious disease. However, to ascertain this assumption, the investigators had gone through systematic analysis on the issue under study to be able to identify the factors that affect their participation to be able to forward sound recommendations. For this purpose qualitative approach was employed and descriptive research method was used.

The population of the study was the people affected by epilepsy from Me'entit communities that consists of women, men and children. Though these people were the primary focuses of the study, the people of Me'entit Goldia wereda can also be considered as part of the study and obtaining their opinion has helped the investigators much to have deeper understanding on the factors that affect the primary school participation of the target people and its direct and indirect influences on their lively hood condition.

The sample respondents were selected from people affected by epilepsy, school management bodies (school directors, PTAs, KETB members and Wereda education supervisors). Government officials, NGOs and Civic society members and Religious leaders, Elders and prominent members of the community were selected for interview and focus groups discussions. The sample respondents were selected on purposive and snow bowl sampling techniques. This sampling method was employed because it was an appropriate method to get in-depth information on the problem studied.

This study employed qualitative research method and the data collection was done through interview, focus group discussion and observation in the study area where the target people are living. Interview questions

were prepared for people who had been selected from epileptic communities'. The data analysis was begun in the field at the time of interview, focus group discussion and observation sessions by taking notes at the spot. The actual words of the respondents were properly recorded using paper in a way that can help the investigators comprehend the situation very well.

The responses were categorized to match to the thematic areas decided for interpretation after being summarized, coded and broken down in to relevant patterns of thematic areas. Individual quotations were used to strengthen the responses of the groups. Summary sheets were prepared based on the codes given for the data collected from the observation, interview and focus group discussions .Thus, the investigators with the close support from the translator has captured the responses as immediately as possible and drew out conclusions and recommendations based on the findings of the study.

## VI. ETHICAL CONSIDERATIONS

During the data collection process and all the discussions undertaken in the study area, the investigators had explained the purpose of the research to all the people who were contacted and had obtained their consent orally and in written form in the case of those people who were willing to accept the offer to take their picture and be included in the research paper.

Furthermore, in the case of respondents in the interview sessions , the investigators have obtained oral consents altogether with procedures specified for the study. The rights of the respondents to refuse or answer few or all questions were respected and it did not involve any physical experiment on the respondents.

In doing so, the investigators have got willingness of study participants to give appropriate responses to the questions which were designed to meet the research objectives. Finally, the investigators had made all the necessary precautions to enhance their confidence for the respondents to cooperate in the study.

## VII. 7RESULTS AND DISCUSSION

The data gathered through interview, focus group discussions and observation from primary data sources were analyzed in a systematic manner using qualitative data analysis method to get meanings out of the non-numeric data collected. Moreover, the data interpretation has referred to the task of drawing inferences from the collected facts. In this process the task of data analysis was moved from what is observed and recorded to why that has happened in the target people.

Moreover, the task has been presented by putting forward the epileptic status and the actual literacy level of participants and followed by interpretations of branded thematic areas. These are: social factors, economic factors, cultural factors, psychological factors and suggestions given by the respondents which they think relevant to mitigate the challenges faced by the target communities to increase their participation in primary education and improve their lively hood.

### 7.1. Epilepsy status of the target people

As per the survey made during data collection done to find out the actual number of epileptic people who are suffering from the negative effects of the disease, the investigator has found that there are 201 people identified as epileptic and living in different towns of Bench Maji Zone administration. The following table shows the epileptic status and the difficulty level they are facing for survival due to the disease.

**Table 1: Epileptic status of the target people**

Variables	Frequency	Percentage
Time of epilepsy		
Less than 1 year	4	2.1
2 to 5 years	75	38.7
6 to 8 years	115	59.3
Frequency of seizure (per year)		
< 5	11	5.5
5-9	26	12.9
>9	163	81.1
Ever face physical injury		
Yes	156	78
No	43	22
Ever faced fire injury		
Yes	104	57

No	76	42
Permanent injury		
Yes	125	64.8
No	68	35.1

**Source: Baseline data on epileptic Me'elit people, March 2016; Bench Maji Development Association.**

Among the target people who were addressed in the study,(2.1%) of them were identified as epileptic for less than one year, (38.7%) in between 2 and 5 years and the majority (59.3%) of them were epileptic for more than 5 years. This indicates when a person is once identified as epileptic he/she will have no chance of getting back to his own community. With regard to the frequency of seizure occurred on them, the majority (81.1%) had a frequency of seizure more than nine times a year. Among the respondents 156(78%) faced physical injury and 104(57%) faced fire injury. Among all the participants nearly two-third (64.8%) were affected by permanent injury and (35.1%) were not have permanent injury. These shows, there are high level of vulnerability for being affected by physical and fire injury due to the frequent happening of seizure which would come out of their control.

### 7.2. Basic Information of epileptically affected Me'elit people

The following table shows basic information about the target people that include literacy level of each person who took part in the study.

**Table 2: Basic information of epileptically affected Me'elit people**

Variables	Frequency	Percentage
<b>Sex</b>		
Male	106	52.7
Female	95	47.3
<b>Age (in years)</b>		
≤ 15	28	13.9
16 - 20	46	22.9
21 - 30	61	30.3
31 - 45	53	26.4
> 45	13	6.5
<b>Religion</b>		
Protestant	137	68.2
Traditional	64	31.8
<b>Educational status</b>		
Unable to read and write	151	75.1
Able to read and write	3	1.5
Primary education	47	23.4

**Source: Baseline data on epileptic Me'elit people, March 2016; Bench Maji Development Association.**

The above table shows that there are 201(52.7% Men and 47.3% women) Me'elit people who are identified as epileptically affected people. With regard to their religious back ground (68.2%) of them are protestant Christians and (31.8%) are followers of traditional beliefs. Though majority of them were protestant Christians, not any one of them could attend spiritual ceremonies and funeral ceremonies together with other people who didn't acquire the disease. Regarding the age distribution of (30.3%) were in the age range of 21 to 30 years (26.4%) were in the age range of 31 to 45 years. Children less than 15 years accounted for (13.9%). This implies that majority of the victims were between age 21 to 45 and few of them are children of less than 15 years old.

In relation to their educational status it is indicated that about three-fourth (75.1%) of the study participants were illiterates and have not gone to school in their life time. On the other hand, 23.4% of them have got the chance to go to primary schools but not able to read and write even before they withdrew from education system. Only one percent (1%) of the target people were found literates and able to read and write. This implies that almost all of the target people are illiterates and not able to read and write due to the marginalization act impeded on them because of their health situation. As a result, the sever suffering of the target people in various forms of discrimination have engrossed the attention of government, individuals and nongovernmental organizations operating in the administrative zone to find way outs and helping them to mitigate the challenges they are actually facing .

Among the efforts done to change these situations, one was done by zonal government and Red Cross and pulling some of them to settle in a rural village where no any non epileptic person resides. These people



were provided with land and agricultural materials to help them participate in the production process for their earnings. On the other hand, one primary school was constructed at Bala village by the year 2008 E.C, by the coordination of Bench Maji Development Association and Jimma Bonga Catholic Secretariats with the financial support from British Council Civil Society support Program. By so doing, the school has enrolled 46 students 23 Male and 23 Female students from zero grade to grade two from among the epileptic communities and has provided educational services in 2016 (2008 E.C) academic year.

In support of this effort, the Woreda Education office has deployed 3 teachers to run the teaching learning activities and trying to put efforts to make the school inclusive of non epileptic children from the surrounding areas.

Moreover, the people who reside at Bala village are relatively in a good condition that, they have been provided with land, health care services, education and materials support to plough their land.

**Table 3: Number of students at Bala primary school-year 2016 (2008E.C)**

No	Grade level	Male	Female	Total
1	0 Grade	10	7	17
2	Grade 1	13	16	22
<b>Sum total</b>		<b>23</b>	<b>23</b>	<b>46</b>

The target people have appreciated the effort made so far and the situation was explained and reported by one of the respondents concerning the housing, health care service and education service provision in the following manner:

*I am 31 years old woman and identified as an epileptic person since my child hood, may be at the age of 4-5 years. Currently I am not able to see the bright world as you and others are doing ,It is because I lost my vision in my right eye and has been suffering from seviror injury to my face and neck . I grew up as a beggar at Mizan Aman town and settled at Bala village now with my children and other friends. The support provision from government and other concerned people and organizations has helped us much to think of ourselves and set vision. However, we are still isolated from our relatives and other community members and are feeling excluded.*

This implies, even though they appreciate the effort being done by different parties to support them, they still feel that discussing on issues like education is a less favored business among the epileptic communities. Their basic question and interest in their life is to ensure their survival first.

### **7.3 Factors inhibiting their participation in primary education**

#### **7.3.1 Social Factors**

Social factors are among the major aspects identified as inhibiting factors that affected epileptic people to take part in the primary education facilities bestowed as a result of the rapid expansion of education in the country in general and in the target wereda in particular. All the respondents of the interview sessions were asked questions related to social problems such as access for education, access for health services, poor or no housing condition, participation in social events like, religious ceremonies, wedding ceremonies, funeral ceremonies, stigma and discrimination, social gatherings like Equb, Idir and etc.

As per the responses obtained from the interview sessions, almost all (100%) of the respondents have replied in relation to their experience of social activities since they are found epileptic. For instance, for the question “Did you participate in any social events like, Idir, Equb, Wedding ceremonies, funereal ceremonies, Religious events, cultural events, etc..?” All (100%) of the respondents replied as they didn’t take part in any one of them and even didn’t think that could be possible. This makes certain , the existence of high level of social exclusion which would have the potential of limiting their participation in primary schools and other educational activitie.

One of the respondents has said the following which can support the above conclusion:

*I had been identified as epileptic when I was 56 in the year 2006 E.C. During that time, I had two wives and six children and had reasonable size of farm land, domestic and farm animals on which my lively hood was centered to feed my families and cover all other house hold expenses. Unfortunately, for the reason I have not understood yet, I fall down around my home and labeled as epileptic by the public recognizing that a major symptom of epilepsy. Then all my family members including my wives and children have rejected to live with me and told me to leave the home or vise versa. I tried to tell them as I was not epileptic; however, they decided to leave their home and had stopped any interaction with me. Consequently I moved away from my*

village with bare hands and assimilated myself with the epileptic communities who reside at Bala village. Since then, I had not seen any one of my families, relatives and other people from my village. Moreover, no one has tried to find me or searched for my whereabouts.

This view was shared by many of the respondents. The following phrase illustrates as how the social exclusion practice has affected the overall personality development of an epileptic persons in the target area and there by their education. The other woman said:

*I was found myself epileptic when I was 10 and disregarded by my own families and dropped at Mizan Aman town at that early age. I was totally alone and helpless and has assimilated myself with the people who share similar life style in the town. Now I am 36 years old woman and live with sustained fracture and burn injury on my legs and suffering from disability due to frequent seizure and glow happened to me. Owing to the effects of the exclusion, nobody had rescued me from the serious injury which had happened in different parts of my body at different times. Due to these reasons, I feel worthless, inferior and disliked by all human beings.*

This conception, obviously, made them feel as they are useless and came to this world for no purpose in life except misery and agony. Similarly, lots of respondents had shared similar feelings that helped much the investigator to have deeper understanding on the issue under study.

Furthermore, they were asked questions related to education and the value attached to it in a way "Do you have any experience of schooling so far?" Majority, (80%) of the respondents replied, 'No' and 20% only said 'yes'. Consequently when they were asked to the question "Do you believe education can transform your life to a better position? Or families' life?" Majority (70%) of the respondents replied 'Yes' and about (10%) replied 'No' and about 20% replied 'I don't know'. This shows that majority of the target people didn't have experience of schooling though they believe on the values of education as it can transform their lives.

In a similar fashion, for the question "Do you believe that epilepsy is medically treatable disease?" About (20%) of the respondents replied as they believe it can be treated but not curable disease. However, about (80%) of them replied as they don't believe that it is a medically treatable disease. This is the implication of their bad perception about the disease which is culturally dominated way of thinking.

Secondly they were asked as "Did you get medical treatment so far? About (30%) of the respondents replied as they received medical treatment after they start living at Bala village, though the service provision was not adequate and consistent and has lack of continuity and proper counseling. On the other hand, about (80%) replied as they didn't receive medical services and have suffered from burn and fractures and all other consequences of frequent seizures happened on them.

This entail, the perception of many of the patients towards the disease is very traditional and negative that epilepsy is an incurable disease and they don't believe on searching for medical services and striving to get treatment. As a result of these, they became very weak and less confident to go to school to take part in educational activities and other social activities. This implies the bad perception about the disease by the patients themselves and lack of medical services, the target people have not been able to go to schools.

Similarly, In order to assess perceptions of the target people to wards epilepsy, questions were posed as "How do you perceive epilepsy and how one acquires the disease?" about (90%) of the respondents said that, epilepsy could happen when a person is not liked by GOD and cursed and few of them which were (10%) of the respondents replied as, it could happen due to natural disease. This shows that many of the target people themselves believe as it is a curse and could happen in a person who is not liked by GOD.

In general, from the interview session conducted with the people living with epilepsy, the stated social factors like participation in social activities and events, having access for medical services, having access for educational opportunities and possibility of having marriage with non epileptic person, it is learned that the target people are living in a highly marginalized situation which would further put them in a very serious poverty condition. Furthermore, the social exclusion practice is not limited to deny the rights of participation in social events and activities but also accompanied with bad consequences in their life if they try to disregard the local perception about the disease. For these reasons, it is obvious that they were not able to go to schools and attend classes while living within these states of affairs.

Questions related to social factors were presented to the first group of FGD participants who came from public service offices and NGOs in the following manner "How do you think epilepsy could happen in a person?" and "Do you believe an epileptic person should entertain social life in your surrounding?" More or less similar ideas were entertained in the discussion and majority of the respondents said, "we can't give exact answer for the question which tried to explore how epilepsy could happen in a person, by and large they believe as epilepsy can happen in a person when serious damage happen in his/her brain during delivery. Similarly, for the second question, majority of the discussion participants. Majority, about (70%) have agreed that epileptic people should entertain social life with other people but didn't deny the fact that this is not a reality in the study area. Nevertheless, few of them have insisted to support this idea and have forwarded their comment by negating their participation in social activities and events.

Moreover, the same groups of FGD participants have discussed on the question “Do you tolerate to live with epileptic person if the victim is your child or relative?” Majority, about (70%) of the participants have said they will tolerate to live with them and would look for medical treatment to be given rather than avoiding them from the family. However, about (30%) of the participants have reflected their view as “since we are part of the community and live in the community we should obey to the cultural norms and values of the society and would take them to other town where a relative resides. Finally, for the question posed to the discussants to assess their opinion to the question “Do you think being epileptic affects participation in education?” almost (100%) of the FGD participants confirmed that being epileptic among Me'ent communities seriously affecting participation of the victims in primary education. Because, they couldn't be able to deny the existing practice of social exclusion and the limitations they have to carry out other social responsibilities and gain social services

From the above responses of FGD participants, it is learned that, being epileptic would cause the victims to be excluded from all kinds of social activities even though the people who discussed on the issue tried to hide the fact. Moreover, the participants of the discussion have shown their inner feeling in which they compassionate towards the target people but impossible in the study area to happen in reality. Therefore, the people living with epilepsy are excluded from social activities and it has greatly affected their participation in primary education.

On the other hand, questions related to social factors were propounded for the second group of FGD participants who were composed of religious leaders, elders, cultural leaders and Kebele administrators. These people have shown interest to participate on the focus group discussion after rigorous communication made by the translator. For the questions, “How do you perceive epilepsy? And how do you think epilepsy could happen in a person?” All the participants or (100%) of them have agreed that epilepsy is not a natural disease and would happen in a person due to curse or bad fortune. Correspondingly, participants were also asked a question “Do you tolerate to live with epileptic person if that person is your child or relative?” about three quarters (70%) of the participants have replied as they will not tolerate to live with them as they are part of the community and have nowhere to go. About (20%) of them who were from religious institutions have replied as they should tolerate to live with them and only about (10%) of them have abstained from giving a response. They had also reflected their view as there is a fear of social sanctions conferred on the person who might try to tolerate the case and live with an epileptic person.

This implies, the FGD participants have thought that, epilepsy is not a disease which can be treated medically and it could happen in a person due to curse or bad fortune. According to the belief system in the area, the disease can also be transmitted from the patient to a normal person if there is any physical contact or trial to support during seizure. For these reasons, they believe that an epileptic person should be excluded from all types of social activities that have bigger impact on their participation of primary education.

One of the FGD session participants explained the situation in the following manner.

*As I am one of the members of the Me'ent people; I brought up here and have nowhere to go. Excluding epileptic people from any kind of social activities is a common practice which would happen when ever one is identified as epileptic. Even though the act of social exclusion exercised on those people is in human and rude action, I would be forced to abide myself by the local culture and custom. It is for these reasons that I said, they need to get expelled from any social activities in their localities whether it affects their education or livelihood.*

These perceptions show, majority of the FGD participants have expressed their opinion in a manner that opposes the social inclusion of epileptic people in any social and cultural events.

Furthermore, the second investigator had frequently travelled to the study area and had done keen observation on the living style of an epileptic people in various towns of Bench Maji zone and the place where they reside after being gathered from towns. During these times, it was observed that, the target people didn't have confidence to take part in any of the socio- cultural events carried out in the target wereda. Not only these, it had also been observed that they have admitted their position as an excluded person from the society and lead their lives without having hope to be treated like any other normal person in the area.

In general, the data collected from the responses given from the interview sessions, focus group discussions and personal observation of the investigators have revealed that, the existence of high level of social marginalization on the target people which would have put negative influence on their primary school participation even if they value education as it can change their livelihood and their family too. The question of survival was given much emphasis on their responses. The stigma and discrimination which made them isolated from their own families, relatives and the whole communities have directly affected their interest of going to schools

### **7.3.2. Economic Factors**

From the economic point of view the same groups of respondents were asked questions related to economic factors .In the first session ,interviewees were asked to respond to the questions related to their

income sources and employment opportunities they might have enjoyed as a known income sources to base their lively hood. For these questions, all(100%) of the respondents said they had no any income source when they live in Mizan Aman town but led their lively hood being beggars. However, some of them as they moved to Bala village in 2013G.C, local government had been providing small land and farming tools though it didn't give them yields due to the limited capacity they have to plow the land and access for agricultural tools and modern agricultural inputs. In spite of this, the respondents insisted as they have no any known income source and very hard situation to find employment. Moreover, those who live in the towns are heavily dependent on collecting leftover food from the people in the town and most of the time they live by beggary. In relation to this, one of the respondent replied to the question related to his income source and possibility of employment, he said the following:

*As a grown up person, I had an ambition and courage to have my own income source either by employment or any other means other than being dependent on the public, however, my health situation and social marginalization made me weak and a person liked by nobody including my own families. I have suffered of burn and injury at my head and my face during seizure. Whenever I tried to engage myself in selling my labor for people in the town ,I usually got very small amount of money for a day long work, which couldn't even cover my day meal . The same is true for all other epileptically affected people. We in general are victims of unfair payment for the services rendered as an income generating activities in towns. These made me desperate and hopeless to live in this world with vision and passion. For these reasons, I totally lost my ambition and usually go for alcohol drinks to lose my consciousness. For these reasons, I prefer to stay at begging rather than looking for employment.*

In general, the interview participants have confirmed that they are suffering of economic reasons and lead their lives without having defined income sources. The social environment in their birth place and also in the town where they moved after being expelled by their own families and relatives had not supported them to get employment and generate reasonably sufficient income to cover their daily meal expenses. Therefore, they were not able to go to school themselves or send their children for economic reasons. What we can infer from this situation is that economic factors are among the major deterring factors that inhibit primary school participation of the target people. Almost all of them were beggars and have managed their lively hood on a street, around churches, gorges and places where other people would not be living.

On the other hand, the focus group discussants who were school directors, government office representatives and NGO representatives were asked as they have an experience of working with an epileptic person or have contact with an employed epileptic person. Various ideas were entertained in the discussion and finally all of them have reached in to consensus that they haven't had experience of working with an epileptic person. However, one of the FGD participants who came from education office said that, he knew a teacher who had been identified as epileptic while he was at school. While he was in seizure, no body from the school community members had tried to help him protected from further injury. When the teacher regain his consciousness and came to his normal mental condition, he went alone to home and put himself under isolation. After taking rest at home for a week long time he returned to school and went to class to deliver the lesson he had prepared for the day, however, different scenario happened and all the students left the class and reported the case to the school director. The school director gave him permission to go and discuss the case with the wereda education office to transfer him to another school and he had succeeded on the transfer and went to another wereda. This fact entail, even the educated persons can't engage in employment since they are found epileptic. In conclusion, the FGD participants have finally agreed that the target people can't get employment in the study area even the menial works to cover their daily expenses. Due to these reasons, they live in a very destitute condition and facing the worst of all kinds of poverty situation which is different from any other poor people who reside in the target area.

Alternatively, a focus group discussion was conducted at the target area with participants from community representatives, elders, religious institutions leaders and Kebele administrations. For these people a question posed as "Do you believe an epileptic person should get employment or establish his/her own means of income in the study area? If you don't, why?" most of the discussion participants have reflected their opinion in a way that show the difficulty of generating income to support their family and establish their own means of income in the study area . As explained further, they had emphasized the social marginalization act which put greater influence on their living condition has negatively affected the target people to be able to generate their own income. By this, they agree with the responses given by the interview session respondents.

The economic deprivation of the target people is described in the following manner by one of the FGD participants,

*I am among the Me'ent community members .I know an epileptic people are suffering from seviror poverty for obvious reasons. They are socially marginalized and stigmatized for which they usually move away from their birth place and exposed to live on street and church areas where they can get food and money for their survival. People in the town also have a fear of giving them employment because of the misconception they have about*

*the disease and un willingness to support them whenever they fall down during seizure. Due to these reasons, they are less likely to get employment and seek for permanent employment .They themselves believe that it is their fate which no one can help them to get the situation changed.*

In a nutshell, the responses given by the FGD participants have reflected that the target people are very poor which all the participants agree with, but their opinion was also directed that no one can help them to get them relieved from this fact rather than accepting the reality that it is their fate.

To put it briefly, all the participants of the interview session and FGD sessions have reflected that the target people have suffered a lot on sevir poverty and lead a vanguard life with their dependents mostly their children. Though all of the respondents were convinced that the target people are not able to get employment and generate their own income to support their families, slightly different opinion was reflected by the FGD participants who came from government offices in such a way that the target people should get support to be able to change their living situation through education and other possible means rather than leaving them aside. Therefore, the economic factors such as lack of employment opportunities, lack of land and absence of participation on other forms of income generating activities like petty trade and small businesses have hugely affected their primary school participation

### **7.3.3 Cultural Factors**

Epilepsy in Me'ent communities is considered as contagious disease and everybody in the target area believes in this sense and marginalizes an epileptic person for the reason stated above. As a member of Me'ent people, the target communities have had participated in the interview sessions for questions related to cultural factors as how it has been affecting their primary school participation which was found extremely very small in the study area. For the question which assesses their perception about epilepsy, about ( 70%) of the respondents have replied as they perceive epilepsy as it could happen in a person due to evil spirit and bad cultural practices such as rituals and harmful traditional practices. If that is not the case they would have not gone through such discrimination and mistreatment by the wider community. About (10%) of the respondents didn't react to the question and about (20%) of the respondents replied as it is a natural disease which might be cured through medication.

As a matter of fact, it is a common practice to expel an epileptic person from his/her normal life when found epileptic. Interview session participants were asked the question."How do families, relatives and other community members treat an epileptic person whenever someone is identified as epileptic?"over three quarters of (80%) of the respondents have replied as they all had the experience of marginalization and expulsion by their own families following the first seizure happen in the person. About (20%) of the respondents however said, their families had tried to hide them and suffered by the sanction done by the wider communities and couldn't resist the challenge to lead their lives the same way as they did before. Finally they had taken them to Mizan Aman town and disappeared without telling them their where abouts. This implies, majority of the interview participants have experienced such cultural practices which forced them to encounter eviction by their own families and strived for survival by accepting the action taken as a normal practice.

Through discussions involving participants who were categorized as local communities were asked few questions related to the cultural factors that have affected primary school participation of the target people were raised. The first and second questions were posed to the participants in such a way that "How do you perceive epilepsy and how do you think epilepsy could happen in a person?" Majority of the discussion participants (70%) from the whole FGD members have reached in to consensus that, epilepsy is contagious disease and not considered as medically treatable disease. It was and would happen in a person when one is disliked by God because of evil spirit

To summarize, the opinions of the local communities who had represented religious institutions, Kebele administrations, elders and community representatives with regard to the questions related to cultural factors, majority of them have reached in to consensus that epilepsy is perceived as highly contagious and shameful disease and could happen in a person as a result of insanity, witchcraft or controlled by evil spirits.

On the other hand, a focus group was carried out among people who came from Government offices, primary schools and NGOs that have interest to work on improving the lively hood of the target people. Accordingly, for the questions related to assessing the cultural factors that put negative influence on the primary school participation of the target people, majority (60%) of the discussion participants of the whole group members have reached in to consensus that, epilepsy should be considered as a medically treatable disease and a person affected by the disease should go for treatment to be able to lead a normal life. About (20 %) were found abstainers and didn't give any suggestion however, about (20%) of them have replied and said that: "Though we believe as epilepsy is a natural disease we cannot be sure that it is not a transmittable or contagious disease which wouldn't affect a person who tries to support the one who might fall as a result of seizure.

By and large, when we look at the responses of various groups of respondents, there are some similarities, especially with the opinions of epileptically affected people and the local community representatives of different groups. This can be viewed in a way that, epilepsy is a contagious and shameful disease which can happen in a person due to bad spirit and insanity of a person. It is believed that trying to live with such a person is making oneself vulnerable to be captured by the disease. In a different way, FGD participants of government employees and NGO representatives have shown quite different opinions in relation to the cultural factors related questions as an impediment for primary school participation of the target people. It is therefore, majority of the FGD participants have reached in to consensus that, epilepsy is not contagious and shameful disease that could happen in a person because of evil spirit and insanity. This doesn't mean they deny the fact that the effect of the cultural practice on the target people which put influence on the primary school participation of the people living with epilepsy.

In general, the cultural factors which were described in the study have greater impact on the target people to lead normal life as other people in the area and negatively affecting their participation in primary education.

#### **7.3.4-Psychological factors**

People living with epilepsy commonly have psychological problems like fear, anxiety, lack of self confidence, lack of self esteem, depression and preference to be alone rather than being with others. It is mostly because of the fear of having attacks, being at a disadvantage position from social and economic services and being uncluttered to prejudice and stigma.

Accordingly, participants of the interview sessions, those people who live with epilepsy were asked questions related to their psychological status and they respond to the same in an orderly manner. Consequently, for the question "Are you comfortable being with other non epileptic people? Almost all (100%) of the respondents replied as they don't feel comfortable to be with other people in social gatherings, cultural and religious events. This is because, they have a fear of having depression, seizure at social gatherings that include school and market areas.

On the other hand, they were also asked as "Do you believe as other people like you or ready to help you?" For this question over three quarters (80%) of the respondents replied as they are not liked by other people or didn't believe that they can get supports of different kinds from other people. The reason given for this has multifaceted forms, in one way, the experience they have while they fall during seizure. Many of them have suffered of burn and fractures while many people were moving around them. In another way, all their sufferings were mostly associated with social exclusion and marginalization act practiced on them by other people. However, only(20%) of the respondents have shown different opinion. They want to value the supports they have been provided by other non epileptic people in towns and government and non government organizations who are trying to support them get social and economic services at least for few of them at Bala village.

In general, the responses of the interview participants have indicated that the people living with epilepsy faces serious problem related to psychological harms and they can easily be identified by their isolated social status, feelings of anxiety, depression, lack of self esteem and lack of self confidence in their interaction to live as a normal person in their community. For these reasons, one can conclude that the psychological status of the victims have greater influence to limit their primary school participation and remain illiterate.

#### **4.5 Strategies to enhance primary school participation**

During the study, the investigators have reviewed various policy documents from international and locally prepared literatures. Participants of the study, who took part in responding for interview and focus group discussions, were also requested to suggest strategies to mitigate the challenges and to help them enhance their participation in primary education. Accordingly, the study participants and the literatures reviewed suggested the following strategies and policy statements which can support the efforts being done by local government and other stakeholders to yield results in a positive sense.

These are:

- A strategy need to design(by MoE or REB) to create opportunities for functional adult literacy programs to help them improve their lively hood. They need to make accessible education services to help them send their children to school and the parents themselves get educational opportunities. Since the right for education is among the basic human rights defined in the universal declaration of human rights.
- Special support and protection to be provided by the local government whenever one is identified as epileptic in Me'ent communities;
- Police and the justice sector plays active role in the protection of the rights of these people to live dignified life alike any other person in the area;
- Government has a guide line to provide food support through school feeding program and has introduced school feeding program in the primary school established at Bala village which was established

- Empower Community based institutions and involvement of religious institutions to accommodate the issues of the people living with epilepsy and enhance youth volunteerism to support the epileptic people in their day today life,
- Academic institutions especially universities and colleges have skilled man power to undertake systematic studies and there is a department lead by vice presidents of the universities' to carry out studies on community problems in their localities ;this will contribute much to systematically identify the real problems of the target people and will seek for scientific solutions,
- The availability of rural credit facilities by government and provision of financial and material resources to help them raise their earnings and cover education expenses of their children ;
- Inclusive education is one the areas which has got special attention in the education policy documents to create access for education for all people regardless of age,sex and any form of disability ;
- There is a widely practiced experience of community conversation in all parts of the country to bring the local communities come together and discuss on the matters that affect their lively hood. This will help the local government to air an issue of epileptic people as a common agenda of their localities which seek for urgent solution. Carry out intensive and continuous awareness raising discussions among the wider Me'ent communities and other nearby communities will enhance the knowledge of the local people /main stream communities about the disease and the risks of human right violation they have been undertaking so far;
- The Ethiopian Government has a policy guide line to make Health facilities and education facilities accessible for rural communities throughout the country and especial emphasis need to be given to marginalized and hard to reach people;
- Establishment of rehabilitation centers to bring together the victims in a defined place to follow up their situation and provide appropriate support according to their specific need and difficulty they have to support themselves.

## **VIII. CONCLUSION AND RECOMMENDATIONS**

### **8.1. Conclusion**

Among the problems epileptic people are facing in the study area, access for education is the most critical one. According to Prof. John M. Freeman MD (1990), children with epilepsy fit within the normal range of intelligence, in the natural way of managing his/her education a child who has an average or above average intelligence could perform well in education, however, there are other external factors like social exclusion and fear and lack of confidence that would affect performances of epileptic people to a significant level. Moreover, learning is a life-long process and the learning skills that children develop during childhood will stay with them for the rest of their lives. Children with epilepsy couldn't enjoy learning in school while other fellow students stigmatize them and that eventually lead them to lack of interest for education.

The living situations of the epileptic people in the study area have demonstrated that there is still poor public awareness in accommodating the family member who acquired the disease .The social norm in the society would greatly impact on the accessibility of quality education so that they couldn't be able to improve their livelihood.

In this study it is tried to get perspectives from epileptic persons that live in the study area, about their problems related to their low participation in primary education which is a base for further education and people from local government offices at the target wereda, traditional leaders and elders and religious institutions representatives. Not only these, the study tried to respond to the basic questions of the research which were directed to know the actual primary education participation of the target people, the inhibiting factors that limit their participation and the strategies put in place to mitigate the challenges.

According to the results obtained from the study, almost all of the people living with epilepsy were found illiterate and didn't get the chance to go to school. The few of them who had got the chance of going to school couldn't resist the stigma and discrimination and had forced to withdraw and remained illiterate. On the other hand, the study has sought the factors that had greatly influenced their participation. In view of that, the social factors, economic factors, cultural factors and psychological factors were the subjects of the study. Finally it has been learned that epileptic people in the study area were highly affected by all of the factors and that led them to severe poverty and instability.

Therefore, the investigators have finally understood that, in order to enhance the participation of the people who are victims of epilepsy in primary education in the study area couldn't change their lively hood unless and otherwise they go for education and enhance their knowledge and as how they can manage to live dignified life

In conclusion, the people who live with epilepsy in the study area have problems beyond having access for education but accompanied with multifaceted troubles that have a potential even to risk their life .concerted efforts of government and other stakeholders like nongovernmental organizations ,religious institutions and academic institutions need to participate in searching for lasting solution to help them get relieved from their

current situation so that they will be able to manage to learn in the available education facilities in their surrounding and beyond.

Like any other people living with epilepsy, the target people in the study area were facing extreme form of discrimination by their respective families and the wider communities. As a result they live in a severe poverty and illness. The target people are helpless and not confident to demand their right for education and even for survival. Many of them live outside their birth place excluded from their own families and relatives. They are illiterate and live in a poor and severely affected health condition which came from burn injury and fractures. Majority of them developed disability in different parts of their body and people in the town didn't show interest to give them work and employments due to the fear of convulsion and seizure which frequently happen in the victims.

For these and similar reasons, they feel loneliness and voiceless to speak about their problem and do not seek for solution rather, they hugely depend on begging to get food for themselves and all their dependents usually their children. Although the problems related with these people have multifaceted forms, however, the investigator has focused in this study on the factors that influence their participation in primary education to be able to draw workable recommendations that would help other professional to carry out further studies and evoke ways to improve their participation in primary education.

Though they have good understanding about the value of education, educating oneself and children is not the first priority for these people as many of them have demonstrated the importance of getting food, work, land and other services like housing, clothing and medical treatments while the research was undertaken. However, eventually through the various discussions taken over time, it seems they changed their attitude and have shown interest to send their children and even themselves to the new primary school constructed at Bala village in the year 2008 where they pulled together to live from towns in the administrative zone taking in to consideration that education can at least reduce the suffering of their children. .

## **8.2. Recommendations**

Participants of the study, who took part in giving responses for interview and focus group discussion guides, and from the review of the study results, the investigators have forwarded the following recommendations:

- Provision of free school uniform and scholastic materials for students from epileptic communities by government and other stakeholders to help them stay in school ;
- Provision of school feeding program or creating access for food while they are at school ;
- Provision of adequate farm land and agricultural materials for them to help them increase their earning and support their children in their schooling;
- Provision of lively hood support for families with epileptic children to encourage them send their children to school;
- It would be good if conducive learning environment be created for children with epilepsy to be in school with other non-epileptic children and making classes inclusive of these students ;
- Local government at wereda and Kebele level should own the program to support people living with epilepsy in their surrounding and encourage other stakeholders to participate in planning and managing programs intended to support these people get better lives in their localities;
- Special support and protection to be provided by the local government whenever one is identified as epileptic in Me'ent communities; Police and the justice sector need to play active role in this regard;
- Put in place various empowering mechanisms to help an epileptic people live dignified life like any other person in the study area such as provision of financial and material resources support to help them establish their own lively hood;
- Carry out intensive and continuous awareness raising discussions among the wider Me'ent communities and other nearby communities so as to enhance their knowledge about the disease and the risks of human right violation they have been undertaking so far;
- It would be good if health services are accessible in a consistent manner to the patients so that they can be able to get medical services regularly;
- Make accessible education services to help them send their children to school and the parents themselves get educational opportunities ;
- It would be good enough if local medias do programs related to epilepsy disease and its management to enhance awareness of the wider community;
- Campaign based public Educational Intervention is also important to reduce stigma and discrimination in schools.



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