

**ADDIS ABABA UNIVERSITY**  
**SCHOOL OF GRADUATE STUDIES**

**PARENTAL KNOWLEDGE, BELIEF SYSTEM AND  
THE EDUCATION OF MENTALLY RETARDED CHILDREN  
IN MEKELLE, TIGIRAY.**

By  
**Yohannes Fissiha Wendu**  
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**A Thesis Presented to the School of Graduate Studies  
Addis Ababa University**

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In Special Needs Education**

**By**

**Yohannes Fissiha Wendu  
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## Acronym

1. AAMR-----	American Association of Mental Retardation
2. MOE-----	Ministry of Education
3. IQ -----	Intelligence Quotient
4. UN-----	United Nations
5. UNICEF-----	United Nations Children's Fund
6. WHO -----	World Health Organization
7. MR -----	Mental Retardation
8. NGO -----	Non-Governmental Organization
9. ENAD -----	The Ethiopian National Association for Deaf
10. ENAB -----	The Ethiopian Association of the Blind
11. ENAELP -----	The Ethiopian National Association for Ex- Leprosy Patient
12. IER -----	Institute of Educational Research
13. EFPD -----	Ethiopian Federation of the Disabled
14. SOOM -----	Support Organization of Mentally Handicapped children
15. RAD -----	Rehabilitation Agency for the Disabled
16. CSA -----	Central Statistics Authority
17. PHCE -----	Population and Housing Census of Ethiopia
18. NCC -----	National Children's Commission

## Abstract

This study focused on parental knowledge, belief and its effect on the educational participation of their mentally retarded children with the objective of finding the belief and knowledge of parents towards the educational participation of their Children's with mental retardation. In Ethiopia, where disability is considered to be a shameful belief people with disabilities are marginalized and excluded from the society. Similarly children with mental retardation are often stigmatized, secluded and neglected in their families in particular and in the community in general.

They are simply kept away from schools. The major reason for their educational participation would be the wrong beliefs of parents and the community towards these mentally retarded children. Similarly, lack of knowledge about the cause of mental retardation and lack of understanding about the potential of children with mental retardation could be other possible reason of the wrong belief of parents. This being the case, the major objective of this study was to investigate the belief and knowledge of parents towards the education of their mentally retarded children in Mekelle town. The method used was a qualitative research approach, using interview and semi- participant observation method. Six parents of children with mental retardation were included from the missionaries of charity in Mekelle.

The finding of the study showed that the parents have several wrong beliefs and misconceptions about the cause, treatment, nature and condition of mental retardation. The parents have given their own explanation about mental retardation based on their religions and cultural beliefs most of them have explained mental retardation as a kind of mental illness or disease. They further mentioned religious, cultural and supernatural attribution to the cause of mental retardation. Specifically, the parents explained that mental retardation is a work of the evil spirits, a curse from the ancestors, a punishment from God or bad luck and a will of god. Further more, what the parents have hoped as a "cure" for their children's retardation seemed to be a reflection of their religious, cultural and traditional beliefs. The parents also reported that they have tried different ways as a means of treatment for their children's retardation.

More specifically they indicated "ፀብል" (holy water) as a best means of treatment. The findings further showed that parents have no hope and expectations to their mentally children regarding their education. In regard to their feelings about having mentally retarded children they expressed feelings of shame and hopelessness.

The study has recommended that focus should be given to awareness raising programmes. So that parents in particular and the society in general will become aware about training or education of the children. The primary and major step in any awareness raising program would be to change the wrong belief of the society in general and those of parents in particular. This awareness raising program is very important for the reason parents need information about the cause of mental retardation which will help them to raise their awareness and help their children to participate in training or education so that they can be self supporting members of the society.

## Background

### Population Size and Demographic back ground of Mekelle City

#### Population

Mekelle is the sixth most populated city compared to the population of the ten top populated cities of Ethiopia. According to CSA statistical abstract, 1999, March 2000, Addis Ababa has been the leading city in the country having a total population size of 2,495,000 followed by Dire Dawa and Nazreth as the second and third respectively.

Mekelle stood as the sixth populated city having a total population size of 128,974 (CSA abstract, 1999). As being the regional capital, Mekelle is the most populated city in the national regional state of Tigray. According to the projection of the CSA for the year 2001, or the total urban population of Tigray region (621,000) Mekelle's share has been 21% which means about one in five urban dwellers is settled in Mekelle. According to Mekelle city finance and Economic development (2002/2003) the total population of Mekelle was 211,351. Out of the total population 98,735/46.7%/ are male and 112,616/53.3%/ are female. There exists also a variation among, the different kebelles of the city. Kebelle Kedamay Weyane, which is located at the center of the city, has the biggest and oldest market called Kedam Weyane. It had a total population of 27,157 and stands as the most populous tabia (kebelle) in the city. Tabia (kebelle) Hadnet and Adi Haki have the population size of 26,106 and 25,650 respectively. Aynalem and Adishimduhun have 3,356 and 6,376 respectively.

#### Population distribution of Mekelle city by Tabia (Kebelle)

S/n	Tabia	Population size			
		Total	Male	Female	Percentage share
1	Aider	24300	10805	13495	11.5%
2	Hawelti	25125	11365	13760	11.9%
3	Adi Haki	25650	12568	13082	12.13%
4	Kedamay Wayane	27157	11799	15358	12.8%
5	Hadenet	26106	12792	13314	12.4%
6	Sewhi Niguse	19000	7823	11177	9%
7	Adise Alem	18000	8820	9180	8.5%
8	Industry	11766	5883	5883	5.6%
9	Quiha	18,000	8820	9180	8.5%
10	Aynalem	3356	1744	1612	1.6%
11	Addi Shumduhun	6376	3124	3252	3%
12	Ellala	6515	3192	3323	3.07%
	Total	211,351	97,703	111,972	100%

Source: Statistics Bulletin 2002/2003, Mekelle city, Finance and Economic Development.

## House hold characteristics

### ▢ Family size

The household size and distribution of persons per household is often used as proxy measure for crowdedness of a population and has great implication to health and house services. Family size in pre-industrial societies tend to be larger than in developed countries not only because of their fertility and subsequent large number of living children, but also because of the extended family system / MOFED, 2004/. According to sample survey conducted in Mekelle city, covering a sample size of 1,598 house hold units /7,883 individuals/ shows that of the total house hold only 6.7% have one person per house hold and 55% of the house holds have persons from 4.7.

The average family size for city of Mekelle is 4.9 persons. The relation ship between household members and head of households is also indicated in the survey. The highest percentage; 54% comprises son and daughter, followed by head and spouse 20.3% and 10.5 % respectively.

### ▢ Headship Rate

In general, male head ship rates are higher than those of female at ages. This reflects the fact that males in most societies assumes the role of chief bread winners in the house hold as well as the ones who mainly bear responsibility for family affairs apart from domestic chores, child bearing and child rearing. According to the survey, about 55.6 % of the households are male headed and 44.4 % are female headed.

## Ethnicity, Language and Religion

### ▢ Ethnicity

Ethnic identity of a person is traced through his/her national origin. According to the 1994 census the over whelming majority (96.4%) of Mekelle's population are Tigrians. Amhara comprised 1.6 % followed by Oromos with 0.15% and Eritrean with 0.99 %. The other Ethnic groups in combination comprise 0.86 %.

### ▢ Religion

Religion is the other important socio-cultural characteristics. It is an affiliation with a group having specific religion spiritual tenets. According to CSA's classification Religion in Mekelle can be categorized in to five categories, *inter alia*:

- 1 Orthodox Christian / including the Kibat and Tsega?
- 2 Protestant Christian /including seven day Adventist, Pentecost, Lutheran, Baptist,
- 3 Anglican and Presbyterian Meserte Kirstos, Mulu Wengel, Kalehiwet etc.
- 4 Catholic Christain
- 5 Muslim

According to the socio-economic survey conducted by Mekelle city Finance and Economic Development office, out of 7,883 individuals surveyed the over whelming population 90.65% of them are Orthodox Christian. Muslim ranks second /8.93% and the remaining 0.36% and 0.06% goes to Catholic Christian and Protestant Christian follower respectively.

## **Organization of the Paper**

Chapter one presents the geographic and demographic background of Mekelle town, back ground of the study, statement of the problem, objective of the study, significance of the study, Delimitation of the study, limitation of the study and operational definition of key terms.

Chapter two will focus on the presentation of theoretical framework, theories used in the study and review of related literature. In chapter three the research design and method used in the gathering of data for the (study, procedures used to collect the data, and steps under taken for the organization and analysis of the data will be presented. Chapter four deals with presentation and analysis of the data. This includes background information, parent's beliefs towards mental retardation, parent's belief about their own role in improving the condition of their children with mental retardation, parent's belief towards their children with mental retardation and short summary.

In chapter five, the presentation findings of the study will be discussed. The last chapter, Chapter six presents short summery, concluding remarks and recommendation. Then, list of references, used in the study will be presented. The appendices will be presented in the final part of the thesis.

## Chapter One

### 1.1. Background of the Study

At present there are not enough local studies on the knowledge and belief towards specific disability like mental retardation in our country Ethiopia. It seems that the importance of the parent's belief, in education and intervention programs, is not given much attention although it is very important for the development of all children in general and children with mental retardation in particular.

It may be difficult to apply the existing western studies to the Ethiopian society since knowledge and belief varies according to the tradition, culture and religion of a given society. In Ethiopia having disability is still considered shameful as a result of this belief persons with disability are stigmatized and excluded from the society. (Tirusew, et al, 1995, Solomon et al, 1991). It is widely accepted that knowledge and belief towards disability have major impact, positive or negative, on the lives of people with impairment (March, 1992; Berine et al. 1994). Our belief will influence how we see the child as a whole person or as sum of function. It will largely influence how we value persons with special needs, how we teach and what we teach. We react to people and situations on the basis of how we evaluate and judge them (kisanji, 1995). When there is wrong belief towards, their disability, they will develop low self-esteem, do not develop independence, and may increase dependency and helplessness. The way children with disabilities are treated is also influenced greatly by the type of perceptions and beliefs towards them. As Wolfensberg (1985), in Berine et al (1994:61) stated, "how a person is perceived affects how that person will be treated", My assumption is that in order to improve the quality of the life situation of children with mental retardation, it is necessary to include their parents in the process of planning and implementing educational and other intervention programs. Through parents' involvement in such processes, intervention and education programs have better possibilities to become successful. If this is the case, how much parents believe that it is possible to improve the life situation of these children with mental retardation through this program? What do they believe about the learning capabilities and potential of these children? How do they perceive the condition of this type of children? What are they doing with their children?

In order to help parents become involved in such programs, first it is necessary to look closely at the parents and to answer the above mentioned belief related questions. It is therefore, in light of this view that this study tries to identify and describe the belief and knowledge of parents towards the education of their mental retarded children in Mekelle town, Tigray.

## **1.2. Statement of the Problem**

In Ethiopia children with disability in general and more specifically, children with mental retardation are often secluded and neglected in the family, and are also kept away from schools. Many of these children are deprived of environmental stimulation which they need in order to succeed in school and to become active members of the society. The same is also true in Mekelle Tigray like in many parts (areas) of Ethiopia. Children with mental retardation do not have the opportunity to meet others and to play with other children since mental retardation is believed as a contagious disease. As a result of this, many parents want to hide these children at home with out any effort to improve their situation through training or education. As to my understanding one major reason for these problems would be the parental belief. As mentioned, before in the back ground study the belief of our society in general and parents of mentally retarded children in particular is the first and the major important issue in the provision of necessary educational and other services for children with mental retardation. With out right perception and understanding of parents, it is difficult to improve the educational participation and the life situation of mentally retarded children. Therefore, the aim of this research study would be to investigate the knowledge and belief of parents towards the educational participation of their children with mental retardation based on the following interrelated leading research questions.

## **1.3. Research Questions**

While this study is conducted, much attention has been given to address the main issues of the research. Hence, the study would answer the following research questions:

- ❑ How do parents perceive mental retardation?
- ❑ What do they believe their own role in improving the condition of their children's with mental retardation through education?
- ❑ What kind of attitude do parents have towards the educational participation of their children with mental retardation?
- ❑ What do parents believed about the cause of mental retardation and possibilities to improve the condition of their children with mental retardation?

## **1.4. Objective of the Study**

Investigating the knowledge and belief of the parents towards mentally retarded children will have a major role to improve the educational participation of these children. This would play a significant

role in improving the life situation of these children's and alleviating the psychological crisis of their families. Therefore, the specific objective of this thesis would be:

- ☐ To identify and investigate relevant information about how parents of mentally retarded children understand (perceived) the educational participation and the overall condition of mental retardation of their children.
- ☐ To explore the parents belief about the possibilities for improvement of the children's condition.
- ☐ To find out what parents feel about having a child with mental retardation and to identify the help that they need from the government and non-government organizations in order to improve or upgrade the educational participation of their children with mental retardation.
- ☐ To explore the interaction between children with mental retardation and their parents look like.

### **1.5. Significance of the Study**

Research studies confirm that little attention has been paid to the study of parent's belief towards the education of children with disabilities in general and children with mental retardation in particular. Therefore, it is necessary to study the belief of parents towards the education of their children with mental retardation. In light of the above-mentioned ideas; this study will have the following significance.

- ☐ It will help to give an insight about the educational situation of children with mental retardation.
- ☐ It will provide possibilities to give information to parents of mentally retarded children, teachers, community workers, who work with children who are mentally retarded (with mental retardation).
- ☐ It will contribute to improve the support given to the education of children with mental retardation.
- ☐ It will provoke others to conduct research study on knowledge and belief of parents towards the educational participation of person with disabilities in general and mentally retarded in particular.

### **1.6. Delimitation of the Study**

The research study is delimited to parents of the mentally retarded children in Mekelle town (Tigray). The main sources of the data for this research study are parents of children with mental retardation and the children themselves. The sources of the data are restricted in Mekelle town. As assured that there is missionary of charity for the mentally retarded children and I believe it is convenient to identify the

children with mental retardation and their parents. Therefore the missionary of charity in the town will be used as a means of identifying these children and their parents.

### **1.7. Definition of Terms**

Before going to the specific Review of the Literature some of the terms used in this research study need to be clarified. They should be defined to make the reader of this paper familiar with their meanings as they are used in this study.

**Parent** - It stands for both father and mother or a person who has parental responsibility for care and up bringing of a child with mental retardation.

**Parent's belief**- It refers to their emotion or feeling

**Example:** - By having a child with mental retardation

-Their behavior or actions with regard to the treatment of their child.

-Thoughts or knowledge about/ towards the child and the condition of mental retardation.

### **Mental Retardation**

It refers to, as defined by American Association on Mental Retardation, a substantial limitations in present functioning. It is characterized by significantly sub average intellectual functioning, existing concurrently with relate limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self direction, health and work. Mental retardation manifests before age 18. (Luckasson et,al, 1992, P. 1, cited in David, 1997:8).

### **Demography**

It is characteristics or variable of subjects. These include: sex, age, educational level and specific occupation of the subject.

### **Special education**

It is specially designed instruction to meet the unique educational needs of a handicapped child, including instruction in: Regular classroom, special classroom or special school (Hallahan and Kauffman 1982).

**Child** - Any person from age six to eighteen or nineteen

**Handicap** - Social disadvantage placed on usually, hearing, and mentally handicapped children and who need special education and related services because of impairment.

**Emotional Experience**

It refers to the feelings parents have in having mentally retarded child and following other people's reaction towards the child and the parents.

**Social experience**

It refers to parent's interaction with and the reaction of neighbors, acquaintances, and significant others towards the mentally retarded child and the parents.

**Qualitative Research**

It is the interpretative study of a specified issue or problem which the research is central to the sense that is made (Pater Banister, 1994).



## Chapter Two

### 2.1 Review of Related Literature

#### 2.1.1 History of Mental Retardation

Historically mental retardation is traced back to the ancient times and then to the civilization of Egypt, Greek, Romans and others. It is also mentioned in the Bible while describing people who were possessed by evil spirits brought to authorities for healing. There is no evidence to indicate that it is a new phenomenon in the history except that the difference is in the interpretation given at various levels of civilization. According to the writer Mary Berne Smith and her associates (1994), the history of mental retardation can be traced as early as human civilization but due to brief documented history, the explainable history revolves around the period of the past 200 years. These writers classified in to nine eras starting from 1700 to the present. These classifications take the major events in each era.

The first era represents the period before the 18th century (Antiquity period). The main idea in this and others literature's (Encyclopedia of MR. 1994), mental retardation before the 18th century was growing from its gravest level to be taken care of the religious organization and the families. However, the conceptuality about the possibilities of training and education was nil. The era of the 18th century brought changes of programs specifically for the people with mental retardation. The two most significant features were the advent of sensationalism and the revolutionary changes that took place both in Europe and America through the effort of the philosophers such as J. Locke and Rousseau all stressed the "importance of the senses in human development. The idea provided new ways of perceiving the nature of the human mind and ultimately influenced educational reform (Mary Berne Smith, page 29). The other event that brought the dramatic influence come after the work of Jean Mark Itard (1774-1838), a French doctor concerned with ear disease that met the wild boy of Aveyron and tried to educate him from the wildness to a civilized behavior. The work of Itard brought a dramatic change to special education of the children with mental retardation.

The era identified with the beginning of the 19th century was significant with the development of a test material for the identification of the mental ability of the regular students in France by Alfred Binet and Theodor Simon (1905) known as intelligent quotient (IQ) test. The test was intended to identify and help students who can benefit from special classes. After sometime this was changed and started to be used for excluding the Low IQ students. Children with severe and profound mental retardation were not even included in the regular schools they were left in the custodial care, although

this has an impact on their special training, these children were isolated, deprived from family love. The other era is the period where initiatives came from individuals who were close to their children or parents who started to question the legislation on the right of their children to be included. The movement started in America that involved the Kennedy and an association was formed. This trend continued in Europe and today the developed countries and some developing countries are working towards "Normalization" and "Inclusive education" This movement provided the opportunity to see the differences of development when care and education are started at earlier than late ages leading the importance of early intervention programs to specifically for children with sever and profound mental retardation. The clear understanding of mental retardation was established until 50 year ago. It has been a misinterpreted concept according to the culture, social, economical and political conditions of a given society. In the different stages of history people described person with mental retardation as evil possessed and the treatment applied was to punish the evil by flogging, starving, burning etc. Hypocrites described it case an imbalanced in the body fluid, later on in the 17th and 18th century philosophers like John Locke and Rousseau emerged with humanistic view and this led to the idea of giving attention to human mind and the importance of the senses. The contributions of these philosophies initiated a French man known as Jean mark Itard in the eighteen thirties and worked towards the education of children with mental retardation.

Later Marian Montessori an Italian Doctor worked with children with mental retardation both the works of Itard and Marian Montessori brought a dramatic change in the education and the development of special education program. The new revival initiated others and the development of intelligence test by Alfred Binet and Theodor Simon (American 19904).

This intelligence test was contributing in identifying all children with mental deficiencies including those who have mild retardation. The impact was positives as well as negative depending on it's application due to that it was also used for discriminating these children from the regular schools since they were placed immediately to special schools (Mary Beirne, etal, 1994). From 19960s on wards the push of organized parents and human right movements in Europe and America impacted on the UN declaration to ratify the right of every child to get equal opportunities. There fore currently children with special needs including with mental retardation are in the inclusive and integrative education programs in the developed countries.

## 2.1.2 Current situation of mentally retarded children

### 2.1.2.1 The progress of early child-hood interventions

The need for early child hood intervention programs had been emphasized in recent decades and are getting increased acceptance in many nations who got the chance of exposures to similar programs. This early childhood program focuses on the age level from birth to 6 years specifically benefiting children with special needs including children at risk and developmentally delayed during birth. Children with Mild, Moderate, Sever and profound mental retardation "... In recent times childhood special education has experienced phenomenal growth. Today the focus is clear on programming for children in the birth to 5 years age range (Mary, Been, 1994).

The significance of studying the post and prenatal factors in the development of behavior for every child is brought in to sharper focus by recent prenatal studies having sensitive assessment of the functioning of the new born infants (Catherine Landreth, 1997). On this line the experiences of the developed countries shows the emphasis to be given to early intervention is so fast expanding. Countries like the united states of America a country that contributed a lot for the development of special care needs education and intervention from early times as of conception, (Drew, Logan and Hardman, 19984) and Canada in North America, countries in Europe Like Scandinavian and the United Kingdom are spending a lot of resource on researches and pilot programs. Maurice chazzan Alick Lating, who wrote a book on early years, mentioned about the growing interest in England at the time of their writing.

In recent years interest has increasingly come to be focused on the educational needs of young children prior to formal school with no exception to children with special needs. The importance of the early years for future development is vital. Any loss of experience which may result from a handicapping condition is compounded as children grow older (1982). Further the book cleared out the importance of early education to prevent some adverse feature of handicap in the early years that very often persists.

In the case of developing countries like our country Ethiopia, although traditional believes and practices are not favoring a child with special needs, there are better traditional methods and ways of caring that can be improvised for a better treatment and care for children is special needs in general. When the case of sever and profound mental retardation come in to focus all available means should be used to change the beliefs of parents who are fortunately very close with children at any time than the parents in developed countries. In general the trend of the developing countries including Asia,

Latin America and some African countries are looking for possible solutions around these issues. Today countries with high population like India and china are also advancing children's programs (profile of the child in India 1998) starting intervention for their children education as early as possible.

### **2.1.2.2 Current situation in African countries**

African countries like South Africa, Uganda, Tanzania and Kenya are showing progressive results in special needs education and in related innovative programs such as Inclusive education and early intervention programs through community based Rehabilitation programs. On the other hand although many of the African countries had ratified the UN declarations of the rights of the child, the educational level of the people and low level of socioeconomic gives way to traditional believes which dominates the modern beliefs on the causes and treatment methods. Due to this factor many of such children get traditional treatments which could have adverse effect on their development. However, there are differences among countries with in the African continent. There are some that had developed educational and social services to their citizens and have scored better results in the special needs education.

Some of these from Eastern Africa are Uganda, Kenya, and Zambia. Uganda and South Africa are putting an exemplary progress for many of the countries in Africa. To emulate, etc. (Inclusive Education, African journal of special Needs Education Vol. 4) Ex. SOUTH AFRICAN CONTEXT. The bill of rights contained in the 1996 South African constitution provides for both political and socioeconomic rights for all South Africans with in a frame work of non-discrimination and equality. The establishment of UNICE in Uganda which is an educational and demonstrative center for people with special needs is a contributing fact or in Africa.

In Ethiopia as in many of the developing countries, addressing the special needs of persons with disabilities in general and mental retardation in particular are used to be the responsibilities of the parents with out support programs. Parents are not aware and have no access to modern treatment methods so are bounded with traditional believes and practices and use their own measure such as witch crafts, traditional medicines and /or spiritually believed holy water.

Having gone through these methods and being exhausted of traditional practices, mostly hoping for cure that never comes true, leave the children alone with regrets, or deny the problems or losing hope totally. Parents of children with mental retardation usually fall into this category. On the other hand

the traditional method of treating the children with special needs such as with sever case is worse as it can be expected from many developing countries where the traditional believes are dominating and is more harming than helping. Parents take their children as punishment of God and feel segregated themselves (Chernet, 1999). The positive element is the parental closeness and the protection to be under the family rather than custodial care programs exercised in Europe some decades ago.

The recent phenomena in the activities of non-governmental organization are the development of community based Rehabilitation (CBR) program that are working at home levels by including early care program. The CBR's are operating in major urban area although the rural community is still not reached. This trend is exemplary and provides optimism that it will lead the NGO's to include such programs long with their other community development activities.

The case of our country Ethiopia is similar to most developing countries where the traditional believes and practices are dominating even those exposed to modern education. While this is the case, the government policy, the services of certain groups such as association of people with disabilities as well as the Non-government organization are trying to make some progress on the issue of disability in the country. The major associations are The EFPD (Federation of person with disabilities on the country level and the individual organizations of disabled persons ENAB for the blind: ENAD for the Deaf: ENAPH for the physically Disabled, RAPL for those with leprosy disability, and SOOM for the association of the parents of children with mental retardation. The EFPD is working with these individual associations at the national level most of these have organized similar associations on regional level. EFPD is now trying to work for the implementation of the rights of persons with disability in order to adopt the standard rules of the Equalization of opportunities for person with disability.

UN standard Rules on The Equalization of opportunities for persons with Disabilities (UN, 1993)

1. Awareness raising of the society
2. Medical care to persons with disabilities
3. Rehabilitation
4. Support services
5. Accessibility
6. Education

7. Employment
8. Income maintenance and social security
9. Family life and personal integrity
10. Culture
11. Recreation and sport
12. Religion (See annex II for the details)

As it was mentioned in the South African international seminar, (DICAG, April 1998) it further elaborates on the rules with the right of children.

The convention on the rights of the children is one of the instruments, which constitute the political and moral foundation for the standard rules. The rules have as its central purpose to ensure that girls, boys, women and men with disabilities, as members of their societies, exercise the same rights and obligations as others, and provide for among others, that: -

1. Governments recognize the principle of equal primary and secondary educational opportunities for children and youth with disabilities in integrated settings (where appropriate), and that parent organizations be involved in the education process.
2. Special attention be given to very young children with disabilities;
3. Provision for social security protection to care givers is made;
4. Children with disabilities are enabled to live with their families, and that families are fully informed about taking precautions against sexual and other forms of abuse;
5. Children with disabilities are provided with the same level of medical care with in the same system as other members of the society.

The case of disabilities in Ethiopia needs understanding, commitment and contribution of the community at the grass root level and knowledge of the believers and traditions of parents (families) which require further study. A number of terms are used to refer to mental retardation. For example, handicaps and developmental disabilities are broader categories that include mental retardation. Developmental delay, which is usually used with pre-school children, is another example which is used to refer to mental retardation (marsh, 1992)..Mentally challenged is also included in terms which are used to refer to a person with mental retardation.

### 2.1.3. Nature and definition of mental retardation

The definition of mental retardation also differs from one professional discipline to another due to the fact that each professional discipline offers the definition of the condition from its own perspective. Hence, we have medical definitions, psychological definitions and behavioral definition (Kirk and Gallagher, 1986). Definitions of mental retardation have changed over the years as behavioral science has grown, become more complex, and included to broader aspects of the environment (Marsh, 1992; Dolce, 1994).

One of the definitions developed during the first half of the 20<sup>th</sup> century and which continues to influence the present definitions of mental retardation is Doll's definition (David, 1997). According to David (1997), Doll's definition included six elements considered essential to the concept of mental retardation. Those elements were "(1) Social incompetence, (2) due to mental sub normality, (3) which has been developmentally arrested, (4) which obtains at maturity, (5) is of constitutional origin, and (6) is essentially incurable" (Doll, 1941, p.251, cited in David, 1997:6).

From Doll's definition one can understand that most of the elements are still considered as important concepts describing mental retardation. "Social incompetence associated with deficits in mental ability is a thread that runs from Doll's definition through subsequent definitions to the most current" (David, 1997:6). Here, the concept social 'incompetence' should be considered in the light of cultural relativism (Whyte & Ingstad, 1995) because the interpretation of 'social incompetence' varies from culture to culture and from society to society. For example, a child who is socially incompetent in Europe, where social integration needs more mental ability, may not be considered equally incompetent in Ethiopia where in many places physical ability is more needed to integrate in the society. As Whyte & Ingstad (1995:6) stated "the disadvantage posed by a disability depends on the capacities most prized or needed in a particular context."

Doll's definition also put emphasis on mental retardation as a disability that originates during the developmental period. According to his definition, mental retardation is of constitutional origin and it is essentially incurable. However, these two elements are not the only operative in any contemporary definitions of mental retardation. As it is indicated in many current studies, retardation is not only caused by "constitutional" but also by many environmental variables. The environmental variables that are important as causes or partial causes of mental retardation are poverty, war, malnutrition, under stimulation, violence and accidents. In addition, mental retardation is no longer considered to be an 'incurable' condition (David, 1997). Through the provision of the necessary education it is, for

example, possible to improve the life situation of children with mental retardation. In current definitions of mental retardation, adaptive behavior becomes a very important element. This is due to the fact that there are people who fall below the average in the IQ test but who can manage their daily life in a very good way depending on the accepted behavior at particular age level and cultural group. They could keep a suitable job and have, for them, functional reading and writing abilities. Therefore, the current definitions involve two main dimensions-measured intelligence and adaptive behavior.

The most common definition, which is used in many studies on mental retardation, is the definition which was devised and regularly adjusted by the American Association on Mental Retardation, AAMR (the previous American Association on Mental Deficiency /AAMD/. In 1992, the AAMR published a revision of the definition of mental retardation. According to this revised definition:

*Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly sub average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self care, home living, social skills, community use, self direction, health and work, Mental retardation manifests before age 18 (Luckasson et al., 1992, p.1, Cited in David, 1997:8)*

In commenting this definition, Luckasson et al. (1992) have pointed out that the definition offers a functional perspective on retardation. According to them, it defines mental retardation according to a person's functioning in daily life, through conceptual, practical, and social intelligence. The definition focuses on relationships among capabilities (cognition, learning, and adaptive skills), environments (the functional match between capabilities and environments). The definition also stressed that mental retardation is the outcome of disabling circumstances. Accordingly retardation is no longer to be viewed as being the characteristic of an individual. It is instead the product of interactions between a person and the nature and demands of that person's environment including attitudes towards the individual with mental retardation. Berine-Smith et al (1994:58) also defined mental retardation as:

*A substantial limitation in present levels of functioning reflected in delayed intellectual growth, and is manifested in inappropriate or immature reactions to one's environment and below average performance in the academic, psychological, physical, linguistic, and social domains.*

According to the definitions given above, mental retardation can be seen as having three dimensions: substantial sub average intellectual functioning; substantial sub average adaptive behavioural functioning; and onset before 18 years of age.

### **Sub-average intellectual functioning**

In explaining the intelligence dimension, Kirk & Gallagher (1986) have mentioned that significantly sub-average general intellectual functioning is determined through standardized intelligence test. Similarly, Eichstaedt & Lavay (1992) have pointed out that general intellectual functioning pertains to the results found by appropriate testing and the use of one or more standardized test batteries developed to measure intellectual quotient (IQ). They also further mentioned that significantly sub-average refers to an IQ of 70 or below.

Based on the above explanations, therefore, it can be concluded that an individual who is mentally retarded would score in the lowest 2 or 3 percent on an intelligence test. This will usually result in problems learning basic academic skills.

### **Adaptive behavior**

Adaptive behavior defined as the effectiveness with which individuals meet the standards of personal independence and social responsibility expected of individuals of their age and cultural group (Sattler, 1992). This definition clearly shows that society and the environment play an important role in defining a handicapping condition. In connection to this, Kirk and Gallagher (1986:118) have stated that in a farming community, where the demands on a child who is developing slowly intellectually are not great, a child who is mildly retarded may not be seen as exceptional. But in a technologically sophisticated society, where language and mathematics mastery is important, the same child would be in substantial trouble educationally and socially.

Based on the 1992 AAMR's revised definition of mental retardation, Eischstaedt and Lavay (1992) also pointed out that deficits in adaptive behavior are seen as outstanding limitations in effectively meeting general standards of maturation, learning, personal dependence, and/or social responsibility for youngsters of similar age and cultural group. According to them, these deficits in adaptive behavior, again must be determined by clinical assessment and, hopefully, standardized scales.

According to Sattler (1992), deficits in adaptive behavior are evaluated according to developmental age of the individual. For example, during infancy and early childhood, adaptive behavior deficits are evaluated in relation to sensor motor skills, communication skills, self-help skills, and socialization skills. Kirk & Gallagher (1986) pointed out that despite the availability of a large number of adaptive behavior scales, the most common method for assessing adaptive behavior is the informal judgment of the teacher or others who have direct experience with the child. According to them, for the young

child, most adaptive behavior scales focus on such self-care skills as eating, dressing and social skills.

During childhood and early adolescence, the focus is on the application of basic academic skills in daily life activities, appropriate reasoning and judgment in interacting with the environment, and social skills.

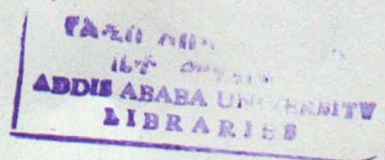
During late adolescence and adult life, adaptive behavior centers on vocational and social responsibilities and performances. As the child grows older and interacts with his/her surroundings, the scales have trouble assessing that interaction because the measurement depends, not only on the characteristics of the child, but on the expectations of the social group the child is encountering.

The criteria to measure the adaptive behavior of a child can vary from place to place. Hence, people in different places may differ in their attitudes towards a child with mental retardation and in their definitions of the level of the child's retardation (Sattler, 1992). This is due to the fact that the expectations to the child can differ from place to place. In Ethiopia for example, where there are a great number of tribes, cultures, beliefs and religions, the expectations to the child can vary in these different places. The expectations of the people in rural areas, for instance, are not necessarily the same as the expectations of people in urban areas. In rural areas, where the tradition is farming, a child with mental retardation may be less socially handicapped than is a child with physical disability. This is due to the fact that in rural areas survival largely depends on different physical activities rather than on mental abilities and the child with mental retardation may fit into the life and production of the community. On the other hand, in cities, where mental ability is highly valued the same child may become socially handicap because the successful integration into society often depends on mental ability rather than on physical fitness (Werner, 1998). Hence, the attitudes towards a child with mental retardation also will differ from place to place depending on the child's ability to fulfill the expectations typical for a specific place.

In connection to this, Zigler and Hodapp (1986) have mentioned that social adaptation is not a well-defined construct. According to them, "Social adaptation varies across sub-cultural groups, changing societal expectations for various age groups and important life changes for each individual (e.g., losing a job)"(P.91).

#### **2.1.4. Classification of Mental Retardation**

Classification, in general, is not a recent phenomenon. It is closely related with the history of mankind, and appears to be a fundamental basis and process of his cognitive activity. It essentially involves



labeling that could be modified or changed as knowledge about the phenomenon under consideration is developed or changed (Clarke and Clarke, 1985). Classification is the bedrock of any scientific field, and its leading purpose is to provide a sense of order and systematic knowledge.

In human science, its primary goals are to enhance the understanding of the area in which it is used and to aid the development of appropriate services (Zigler et al., 1984). More specifically, in the field of mental retardation, it facilitates communication in diagnostic research, treatment and prevention efforts, and therefore, needs to be comprehensive and consistent with the current knowledge of the field (Grossman, 1983).

The efforts to classify the mentally retarded have existed since ancient times. Historical documents provide an insight of such efforts. For instance, during the thirteenth century, there was an attempt to identify the born fools from the lunatics (Clarke and Clarke, 1985); and in the late seventeenth century, also there was an indication of the existence of such more related explanation of differences within mental retardation and those who are unable to learn their letters but can handle mechanical arts, who fail at mechanical arts but can easily comprehend agriculture, who are unfit except to eat and sleep, and those who are doltish or driveling fools (Grossman, 1983).

In his further discussion of the earlier efforts, Grossman (1983) has also shown a number of attempts made during the late eighteenth century and throughout the nineteenth century to classify mental retardation based on some medical conditions, physical symptoms, and causes. Many classification systems with this approach have distinguished between the extrinsic and intrinsic, pathological and sub cultural, exogenous and endogenous, in general, between the pathological and non-pathological or between the organic and non-organic (Cegelka and Prehm, 1982).

More sophisticated classification systems based on etiology have been developed as a result of advances in medical identification of causes of mental retardation. Such classification systems focus on causative factors in order to direct medical treatment and research efforts on the prevention of mental retardation (Cegelka and Prehm, 1982).

IQ scores can be used as a rough indicator of level of retardation. The ranges for mildly, moderately, severely, and profoundly retarded are show in Table 1.

Levels of Mental Retardation Indicated by IQ Ranges Obtained on Measure of General Intellectual Functioning.

Levels	IQ Ranges for the Levels
Mild Mental Retardation	50/55 to approximately 70
Moderate Mental Retardation	35/40 to 50/55
Severe Mental Retardation	20/25 to 35/40
Profound Mental Retardation	Below 20/25

Source: Grossman (1983).

The system widely used for educational placement and the one based on IQ ranges are often used interchangeably, i.e. educable for mild, trainable for moderate, and dependent for the severe and profound levels of retardation, though the terms do not coincide as such (Cegelka and Prehm, 1982; Alberto, 1983; Kirk and Gallagher, 1986). However, the social responsibility theorists criticize this approach on the grounds that it limits the efforts of teachers by determining the ceiling or the maximum level of the individual child's ability, which they consider as a function of the resources that the society is able or willing to allocate for the individual under optimum conditions (Cegelka and Prehm, 1982; Lynch, 1988).

Indeed, the most important factor is the expectation of and the respect for difference. Though prior labels or classification of any sort appears to be important for the administrative purposes, especially for general service planning, there is a need to consider service programs for each individual according to his or her specific needs instead of forcing him or her to fit into a group. This is so because individuals labeled as functioning at one level may behave as if they were capable of more or less the level of the expectation. In this aspect, Kirk and Gallagher (1986) indicating that the term mental retardation covers a broad range of children and adults who differ from one another in the severity of developmental delay, in the cause of the condition, and in the special educational strategies they require, have stressed the importance of these differences.

**Mild (Educable) Mental Retardation:** The mildly retarded refers to the least retarded group who are said to display delays of one to three years in school performance (Alberto, 1983).

As far as their physical condition is concerned, no detectable differences can be observed as there is no obvious pathological condition to account for it in most cases. Thus the mild retardation often goes unnoticed until the child reaches school age, and it is considered to be attributed to a poor home environment (Logan and Rose, 1982; Kirk and Gallagher, 1986). This medical and health service needs tend to be the same as that of the other population. The mildly retarded can benefit from the same kinds of preventive practices and routine health cares recommended for all. The only big issue here is the need to assure them of the availability of prevention, the signs and symptoms of diseases which should be treated and where this treatment can be obtained (Lynch, 1988).

Educationally, because of their delayed mental development, the mildly retarded are unable to profit sufficiently from the regular school programs without modification or assistance. Of course, they are intellectually proficient to the degree that they can profit from an educational program. However, they require a much more organized educational approach (Logan and Rose, 1982). During their school years, this group may require the least restrictive educational placement alternatives where they can get the necessary educational support services to maintain reasonable academic and social progress (Alberto, 1983).

As adults, they may be expected to be self-sufficient and to live independently as productive members of the community (be employed and self-supporting, hold a wide variety of the jobs and thereby contribute in a meaningful way to society), get married and have families as well (Deutsch and Bustow, 1982).

In general, they are considered to have the capacity to develop in:

1. Academic subjects at the primary and advanced elementary grade level (learn fundamental school subjects),
2. Social adjustment to the point that they can get along independently in the community (can learn personal responsibility),
3. Occupational skills to the degree that they can be self-supporting either partially or totally at the adult level (Kirk and Gallagher, 1986).

**Moderate (Trainable) Mental Retardation:** This level of mental retardation refers to those who more frequently have some type of physical symptoms that signal to the casual observer that there is

something different about them, as well as significantly delayed mental and physical development. The moderately retarded individuals are with the greater likelihood of associated medical or health and physical problems (e.g. delayed muscle tone development and physical growth), which often become apparent early and persistent throughout their life span. Thus, this group may need special physical and medical or health care services (Fink and Cegelka, 1982). In fact, the greater the degree of mental retardation is the greater the likelihood of observable physical problems such as facial and cranial deformities. When compared to be mildly retarded, the moderately retarded individuals have been found to be somewhat slower in physical growth tend to be inferior in motor proficiency, which might have deprived them of the necessary activities and thereby affected their learning, further worsening their motor condition (Lynch, 1988).

In addition, the high frequency of sensory and integrative disorders which may hamper their approach to problem-solving, their limited repertoire of personality defenses, and their limitations in language which again could hamper their ability to fully communicate their feelings, may make them more likely to develop atypical or abnormal behaviors such as body-rocking, head-rolling, hand-flapping, inappropriate vocal sounds and the like, in a variety of educational or social settings. The more seriously maladjusted one may also be engaged in more self-injurious acts including head-banging, self-biting, eye-poking, etc. Other yet may be involved in aggressive or destructive acts (Fink and Cegelka, 1982; Lynch, 1988). Indeed, basic social and self-help skills (e.g. skills related to toilet training, dressing, bathing, play, communication, etc.), that have already been learned by their normal age groups, may be lacking for the younger ones. This lag in skill development may increase with age putting the moderately retarded individuals at further disadvantage in regard to adaptive behavior, their age-appropriate independence and movement in social settings (Fink and Cegelke, 1982). These conditions of the moderately retarded individuals may require considerable efforts from the professionals concerned to help them act like people of their age (Lynch, 1988).

From the educational point of view, the moderately retarded are said to be uneducable in the sense of academic achievement but are expected to be able to master self-help skills (dressing, undressing, toilet training, eating, etc.), self-care skills (protecting him or herself from common dangers in home, school, and neighborhood), basic language (survival words and functional vocabulary), basic social skills (sharing, respecting property rights, cooperating etc.), and cognitive concepts to include basic academic skills or functional academics (reading signs, counting etc.) (Alberto, 1983; Kirk and Gallagher, 1986).

Therefore, the school activities for the moderately (trainable) mentally retarded children should include all the kinds of behaviors or activities which are necessary for survival in society (e.g. grooming, communication skills, social adjustment, pre-vocational training and the like). Provided that they have passed through the appropriate school training, the moderately retarded individuals, as adults, may be able to live in community residences, enjoy their leisure time, and may be employed, under varying levels of supervision or independence, of course (Deutsch and Bustow, 1982).

In summary, though they are considered as uneducable in the sense of advanced academic achievement, the moderately retarded can: 1) learn academic skills for functional purpose (functional academics), 2) achieve some degree of social responsibility; 3) attain partial vocational adjustment with assistance (Kirk and Gallagher, 1986).

**Severe and Profound (Dependent) Mental Retardation:** Severe and profound levels of mental retardation constitute a small percentage of those individuals classified as mentally retarded. The severely and profoundly retarded individuals are seriously handicapped, suffer from serious brain damage before or during birth or the early development period, and have the highest death rate when compared to the less retarded groups. A large portion of this group possesses additional serious handicaps; it is non-verbal, engages in severe maladaptive behaviors, and exhibits extreme deviations from the norm in term of the cognitive, motor or locomotion capacity, self-help and care skills, personal and social skills. Furthermore, except for their common characteristics of low IQ, they are an extremely heterogeneous group that defies simple description, and the areas of their self-help and communication skills as well as awareness are directly related to their mobility level (Snell, 1982; Lynch, 1988).

In conclusion, because of their very severe mental retardation, the severely and profoundly retarded can not be trained for total self-help and care, socialization or for economic advantage (total independence). Their education aims to establish some levels of social adaptation in a controlled environment. Thus, their school expectation could be communication, and self-help and care-skill training for partial independence, in the skill, during their post-school living (Kirk and Gallagher, 1986).

#### **2.1.5. Causes of Mental Retardation**

The American Association on Mental Deficiency (AAMD) has identified such causal factors of mental retardation as infection and intoxication, trauma or physical agents, metabolic disorders or nutrition,

gross brain diseases, unknown prenatal influences, chromosomal abnormalities, gestational disorders, psychiatric disorders, environmental influences and others (Grossman, 1983). These identified causal factors can be categorized, in to two broader groups; biological and socio-behavioral causes (Lynch, 1988). As further explained by Lynch (1988), biological causes involve the genetically determined conditions such as inherited chromosomal errors or aberrations and the damage to the central nervous system which include lack of oxygen during labor and delivery, complications of the neo-natal period, head trauma, and a variety of other factors leading to mental retardation.

More specifically, the common biological causes are infectious diseases (congenital rubella, meningitis, encephalitis etc.), gestational and obstetric disorders (prematurely and low birth weight, Rh factor incompatibility between mother and infant, pre-natal injury and anoxia or lack of oxygen, etc.), environmental hazards (radiation of the mother or the child in utero, poisoning from lead, mercury or other environmental toxins, fatal alcohol syndrome or alcohol consumption by the mother during pregnancy, injury due to accidents or child abuse, etc.), genetic and chromosomal disorders (Down's syndrome which results from an extra chromosome), cranial aberrations or abnormalities leading to neurological impairments, inherited disorder in metabolism, and the like), and neurocutaneous syndromes - the progressive growth of tumors within the nervous system and disorders which affect both the skin and nervous system (Robinson and Robinson, 1976; Lynch, 1988).

The socio-behavioral causes, which formerly were called cultural-familial or psycho-social, are acknowledged to account for 70 or 80 percent of the known causes of mental retardation (Garber and McInerney, 1982). Unlike biological retardation, in which a single causative agent can often be identified, socio-behavioral retardation is more often the result of multiple environmental factors acting senergistically (Grossman, 1983). Poverty, poor nutrition, inadequate parenting, substandard housing, and lack of environmental stimulation or enrichment combine to depress the developing child's cognitive and adaptive behavior (Lynch, 1988).

The biological causes are said to occur in families in all strata of a society and attribute mainly to the small population of the case, moderate to severe or profound which are relatively easily identifiable or has readily diagnosed cause. The more severe forms of mental retardation are more evenly distributed across socio-economic levels with only a slightly higher percentage among low-income families. The socio-behavioral causes are most often associated with families in psychologically, socially and economically impoverished environments and concerned with the vast proportion of the case, mild

range, where diagnosis is difficult and unstable (Grossman, 1983; Alberto, 1983; Lynch, 1988). The higher percentage of retardation in general and that of the socio-behavioral retardation in particular among the low-income families may reflect the lack of adequate parental care or stimulation, inadequate nutrition, low education, more frequent and more closely-spaced pregnancies, and the like condition with these families (Lynch, 1988). In fact, because of their poverty, the children from such families are exposed to a greater risk to their biological and psychological development (Garber and McInerney, 1982).

Indeed, though such distinct causes could be identified on a theoretical basis, it would be difficult or misleading to place the primary responsibility on any single factor for the effects or retardation in any individual child, as the interaction of the causal factors is often so great in contributing to the case (Robinson and Robinson, 1976).

Nevertheless, discovering the causes of mental retardation is a key to the prevention that requires efforts in medical research, social support services, and public education. As researchers learn more about etiology, prevention programs can be initiated to reduce or eliminate some type of mental retardation. Though research on etiology and improved diagnostic procedures, many problems which cause mental retardation can be determined and immediate steps can be taken in the form of medical and educational interventions to ameliorate the effects of the handicapping condition. For instance, for the young children with whom occurrences are at risk for socio-behavioral retardation, for whom nutrition is inadequate, interaction with a loving caretaker is not available, stimulation is limited, and abuse and violence are common, efforts could be made in the broader social context to improve the overall quality of life, to eliminate poverty and protect the children whose parents are not able to provide a physically and emotionally safe environment for them. Furthermore, public awareness of the causes and importance of parental care in reducing the incidence of mental retardation will encourage and facilitate such preventive activities as immunizations against rubella and other infectious diseases in the entire population and positive child-rearing practices (Robinson and Robinson, 1976; Lynch, 1988).

It has been generally recognized that the causes and the nature of the impairments differ in the industrialized and in the third world countries. In the former, impairments are primarily linked to the aging process and to occupational diseases. In the latter, they are results of infectious diseases and malnutrition (Noble, 1981). In other words, in developing countries, including Ethiopia, the major factor that cause handicaps in general and mental retardation in particular appears to be such

preventable factors as poor health care, harmful traditional child-rearing practices, malnutrition, accidents, man-made disasters and the like. Thus, improved health status, nutrition, social welfare and public education could play a role of paramount importance in the control and prevention of handicapping conditions, including mental retardation. In Ethiopia, where there are inadequate medical care, poverty, malnutrition, infections and poor conditions during delivery, bounded with different traditional practices, can be taken as the major causes of mental retardation.

## **2.1.6. Ecological Approach**

### **2.1.6.1 Bronfenbrenner's ecological model**

Human development and behavior cannot be understood independently of the social, cultural, environmental and historical context in which it occurs (Bronfenbrenner, 1979; Hornby, 1995). This understanding implies that the social context or social environment influences the family system and its functions. This in turn can have a significant influence on each members of the family, including the development of a child with mental retardation and the belief of family members towards the child. As Hornby (1995:45) explained:

*The effects on parents of caring for a child with any kind of special need [e.g. a child with mental retardation] are strongly influenced by the social environment in which they are living, including extended family, services available and community attitudes.*

The above quotation represents a reciprocal influences: the social environment has a significant influence on the beliefs and values of parents toward a child with mental retardation which, in turn, affects the attention, stimulation and services provided and thereby the overall development of the child. It could be interesting to look at this reciprocal influences and how a family is functioning from the point of view of Bronfenberner's ecological model (Bronfenbrenner, 1997). His model is a general model explaining how different systems in society influence each other and how they all influence the family - the microsystem. The other systems are the mesosystem, the exosystem, and the macrosystem (Bronfenbrener, 1979, in Hornby, 1995).

#### **Microsystem**

The Microsystem is the complex of relations between the developing person and the environment in the person's immediate setting, i.e., the person's home, school, work, etc. (Apter, 1992). The family of a child with mental retardation can be considered a microsystem. In this system there are the parents, a child with mental retardation, siblings and others. These persons are interacting and communicating with each other in their daily life.

In Ethiopian context, for example, members of the family are powerful and very important for the developing child. What happens to the child can affect members of the family and again the child can be influenced by the rest of the family members (Hornby, 1995). In addition, there are different communal self-help organizations or social settings, in Ethiopia, in which parents become active members and interact with others. These include edir<sup>1</sup>, baltina<sup>2</sup>, mahiber<sup>3</sup> etc.

1. Communal self<sup>2</sup>Communal self-help organization.
2. Communal self-help organization. Usually members of this organization are women
3. Association or self-help group (usually at church)

### **Mesosystem**

The mesosystem is a set of interrelations between two or more settings or microsystem in which persons in question are active members. It can include home, extended family, neighborhood, church, Mosque, school, Edir, Baltina, Mahiber, etc. Families of children with mental retardation can have interaction with one or more of these social settings in one way or another. These social settings could play a significant role in shaping the beliefs of family members in general and parents in particular towards children with mental retardation. Therefore, the mesosystem could be a very influential system in Ethiopian with regard to parents' beliefs towards their children with mental retardation.

### **Exosystem**

The exosystem is an extension of the mesosystem embracing other specific social structures, both formal and informal, that do not themselves contain the developing person but impinge upon or encompass the immediate settings in which that person is found, and thereby influence, delimit, or even determine what goes on there (Apter, 1982; Seligman & Darling, 1989; Hornby, 1995). These structures include such social institutions as mass media, welfare services, employment, etc. Even though family members do not directly involve themselves in exosystem, still it can, indirectly, influence the beliefs and values of members of the family. For instance, the beliefs of friends at work place towards disability can affect the belief of the father towards his mentally retarded child which, in turn, could affect the beliefs of other members of the family.

### **Macrosystem**

The macrosystem is the overarching institutional patterns of the culture or subculture, including the economical, social, educational, legal, and political systems, of which micro, meso, and ecosystems are the concrete manifestations. All these institutional systems can play a significant role in

influencing the parents' beliefs. For example, economical problem happen at National level will affect the exosystem (e.g. the welfare services of the community and employment condition) and this will affect the economical situation of the family. The family's economical situation, in turn, plays an important role on the type of beliefs that parents will develop towards their children with mental retardation. In addition to this, inadequate educational services for children with disabilities in the country could affect the expectations of parents to the children which again lead parents to develop wrong beliefs towards these children. Moreover, culture and religion can affect the belief of parents and other people in the community about causes of mental retardation and the selection of ways of improving the child's condition. These beliefs and values play an important role on the child's overall development. The following figure will show the family system (microsystems) as a system embedded within other social systems-mesosystem, exosystem and macrosystem.

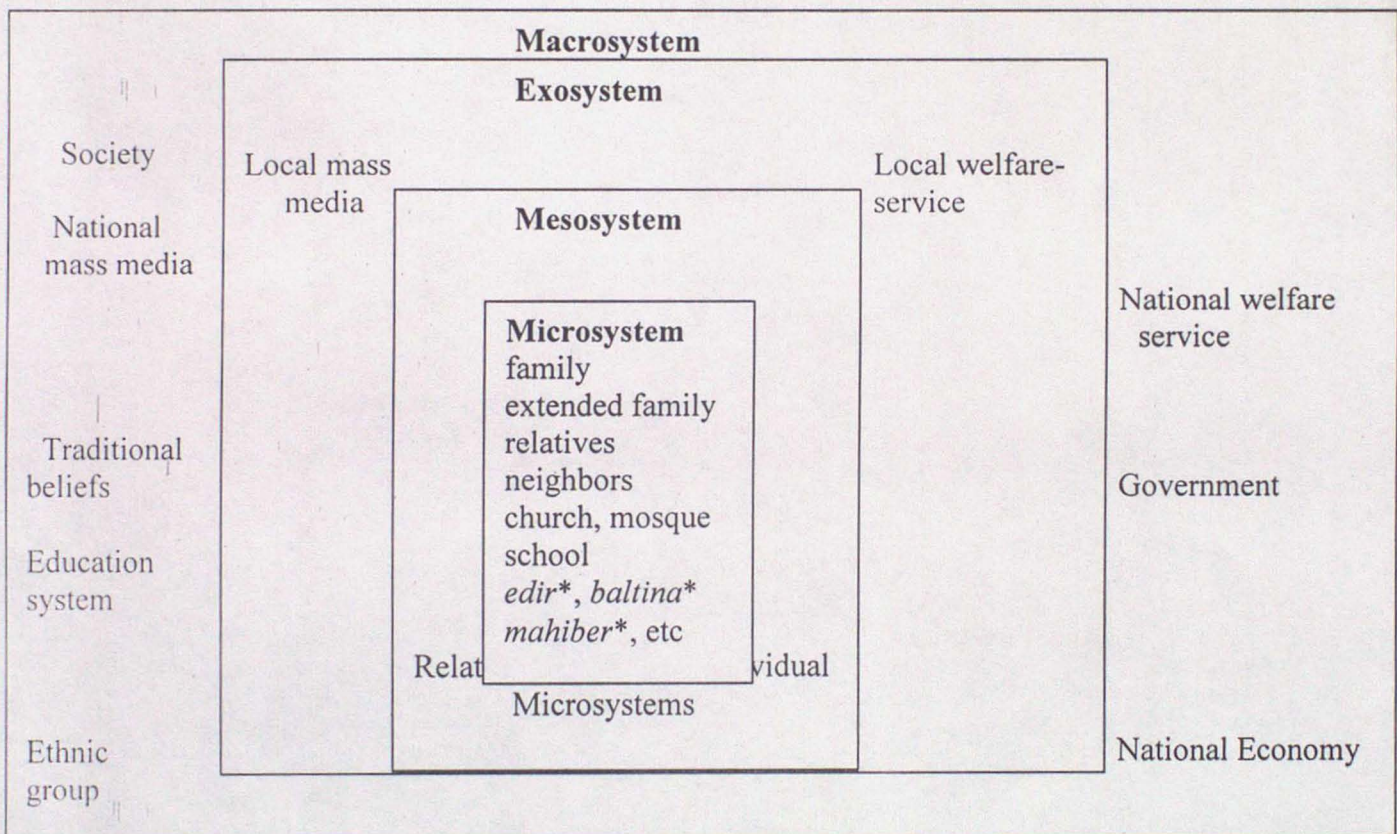


Fig: 2.1 The family system in the ecological model. Adapted from

Bronfenbrenner (1979) in Seligman & Darling (1989:4)

### 2.1.6.2 Relevance of ecological approach to the study

As indicated above, parents and their children cannot be seen out of their social environment. They are influenced, directly or indirectly, by their social environment and vice versa. In discussion children's development in relation to ecological approach, Cole & Cole (1993: 24) stated that:

*The ecological approach sees children in the context of all the various settings they inhabit on a daily bases (microsystems). These settings are related to each another in a variety ways (mesosystems), which are in tern linked to settings and social institutions where the children are not present but which have an important influence on their development (exosystems). All of these systems are organized in terms of the culture's dominant beliefs and ideologies (the macrosystem).*

From the above explanation, it can be inferred that the beliefs of parents towards their children with mental retardation could be influenced by the environment in which they are living. It also shows that the development and behavior of a family with a retarded child is influenced not only by interactions within its own microsystem but also by its interactions with other levels of the entire social system.

In other words, the social system influences the family's belief and values and the family again influence the child since family members interact and influence each other. For instance, the social system defines the nature of mental retardation, it determines the services and supports that are available for children with mental retardation, it formulates social policy and priorities and it fosters values, norms, beliefs and perceptions concerned with disability (Marsh, 1992). This again plays an important role in influencing the beliefs of the family in general and parents in particular.

In Ethiopia, the above mentioned social systems, such as extended family, relatives, Edir, Baltina and Mahiber are the major sources of informal support. As mentioned earlier, a family has many things to share with such social support systems during good or bad times. In an extended family, for instance, parents have an opportunity to share the responsibility of taking care of a child with other members of the family. The type of this support can play a significant role in shaping the type of beliefs parents will have towards the child. The interrelationship between all the social support systems, mentioned above, can be compared to what Bronfenbrenner refers to as the mesosystem. This is due to the fact that parents of a child with mental retardation interact and communicate with other people in such systems or settings. They interact and communicate, for instance, with neighbors, relatives, people in church, Edir, Baltina, Mahiber, etc. These interactions and communications play a significant role in shaping parents' knowledge and believe about the condition of mental retardation and their belief towards a child with mental retardation.

Improving the life situation of a child with mental retardation will include changing the beliefs of the family members in general and parents in particular towards the child and changing the patterns of interaction between the child and his environment the family, friends, neighbors, community and society at large (Cole and Cole, 1993; Harris, 1995,). One should see the child in a holistic way within a holistic environment. To reach this goal it is important to examine the beliefs of family members towards the child as well as the child's interaction with his immediate environment - the family.

A child with mental retardation does not function in isolation but lives within a familial context. Hence our effort for improving the child's life situation should take this context into account especially with regard to parental beliefs towards the child. In connection to this, Hornby (1995:44), referring Chilman et al (1988), explained as follows:

*The whole family system needs to be taken into account when considering the effects of an intervention on an individual family members since the treatment of individual children, without taking their families in to account, may result in an increase in problems experienced by the family as a whole.*

The major objective of this study is to assess parental knowledge and beliefs towards their children with mental retardation. These parental knowledge and beliefs is a product of the interactions within and between the above social systems (Brenfenbrenner, 1997; Hornby, 1995). Therefore, the ecological model in general and the microsystem in particular have a great relevance for this study.

Given the very purpose and objectives of this study, attempt will be made, in the subsequent parts of this chapter, to discuss the nature of the family system (microsystem) with particular emphasis on parental belief towards their children with mental retardation in the light of the micro and meso systems within the ecological model.

### **2.1.7. The Family System**

The family is an important and the most basic of all social institutions. It is one system within a larger social system and a child with mental retardation and his/her parents are members of the family system. This unit is comprised of a certain number of individuals and they function in a dynamic interrelationship (Seligman and Darling, 1989). According to Broderick (1993:52) family is defined as "two or more persons, sharing a common residence, and related by blood, adoption, or marriage."

Family, as understood by Ethiopian context, is "a group of two or more persons characterized by common residence, economic co-operation and reproduction. It includes adults of both sex, at least two of whom maintaining a socially approved sexual relationship, and one or more children, own

and/or adopted by the sexually cohabited adults" (Seyoum and Desta, 1997:1). However, there are different types of families in Ethiopia. These include extended family, nuclear family and single-parent family. In each type of these families there could be different beliefs and ways of treating a child with mental retardation.

### **2.1.7.1 Family structure**

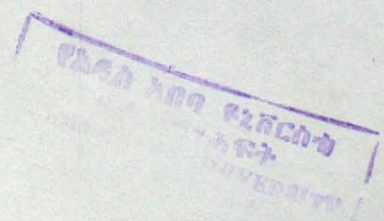
Structural elements of a family, most often comprises the married couple, their children, parents of a married couple, cousins and other relatives. The nuclear family includes two adults of the opposite sex living together with their children (born to the family and/or adopted). The single-parent family consists of either of the parents and his/her children, born to the family and/or adopted (Seyoum and Desta, 1997). As mentioned above, these different family structures can have different influences on the beliefs of family members towards a child with mental retardation and the type of interaction between parents and the child. In an extended family, for instance, parents may have opportunity to share responsibilities and will be less loaded.

Furthermore, the presence of a child with mental retardation in the family can influence how the family views itself - the family identity. Patterson & Garwick (1994) mentioned that how a family defines itself is reflected in who are the members of the family. The family's views of itself in turn determine the type of beliefs towards the child.

### **2.1.7.2 Family interactions**

With regard to interaction, members of a given family interact and communicate with each other since they are living in one residence. In a given family there are subsystems. According to Mitchel and Brown (1991), referring Turnbull et al (1986), these subsystems are the spousal sub-system, which shows the husband and wife interactions; the parent sub-system, which signify the interaction between parents and their children; the sibling sub-system, which shows child-child interactions; and the extra-marital subsystem, which signify the interaction such as the ones between children and grandparents or those between the father and maids, etc.

The above explanation clearly reveals that in each sub-system the child interacts with different members of the family in general and with his/her parents in particular. In the case of extended family, which is common in Ethiopia, the child has the opportunity to interact with different members of the family.



At this junctures, Seligman & Darling (1989) pointed out that the makeup of the subsystems and the dynamic interaction among them is affected by the structural elements in the family system. The size of extra-familial network, single-parent, and number of children in the family and the presence of a child with mental retardation could obviously bear an influence on the dynamics of interaction. For instance, in many parts of Ethiopia having a child with disability is considered as a punishment from God (Tirusew et al, 1995). As a result, family members may keep the child away and they minimize interacting with the child or they may not interact at all.

### **2.1.7.3 Family Function**

Turnbull and Turnbull (1990) conceptualize family functions as products, or outputs, of family interactions. They also explained that the tasks families perform, to meet the individual and collective needs of their members, are referred to as family functions. According to Turnbull, et. al. (1984), cited in Turnbull & Turnbull (1990), such family functions include economics, daily care, recreation, socialization, self-definition, affection and educational/vocational functions.

Some of the major functions of the family in Ethiopian are childbearing, serving as an agent of socialization, as agency to determine permissible sexual relations and as an economic production and consumption unit (Seyoum and Desta, 1997). There are interactions and different activities in the family to fulfill such functions as economic, domestic/health care, recreation, affection, educational/vocational, socialization and negotiating life-cycle events (Dale, 1996). From this explanation one can among others conclude that family functions depend up on the results of interaction in terms of the ability to meet the needs of the members of the family. However, in order to carry out such functions successfully there must also be interdependence and interaction between the family and its extra-familial network.

In the light of this understanding, and remembering the fact a family with a child with mental retardation is negatively labeled, the presence of such a child can affect the family's functions in many ways. In Ethiopia, most often, parents want to have many children in order to get physical and other types of assistance in daily life situations. In most places, children are expected to contribute in the family's functioning process. Therefore, when there is a child with mental retardation in the family, he/she is considered as a substantial burden to the family and affecting the family's ability to meet the needs of its members. This in turn could shape the family's belief towards the child.

In addition, the presence of the child with mental retardation can restrict the family's social activities (Dale, 1996) especially in a country like Ethiopia, where disability is still taken as a shame (Abraham, 1998). Furthermore, the presence of the child can bring a role change in the family. The mother of the child may stay home and spend much time giving the necessary care for the child instead of going to work. This can affect the family's income, thus, militating ability of the family to meet the demands of the child and other members. This, in turn may affect parents' belief towards the child.

#### **2.1.7.4 Family life-cycle**

Family life-cycle includes developmental stages related to the family such as childbearing, school-age, adolescence-launching post parental, and ageing; adaptation to the child with mental retardation and crisis/transition period (Dale, 1996). Each of these sequences of developmental changes can play an important role in the family life. Family functions vary depending on these stages. For example, parental ways of treating the child with mental retardation during infancy is not the same as that of adolescence (Turnbull et al, 1986).

In addition, whenever, parents come to a new life cycle, they often experience parts of the crises or feelings of having a child with disabilities. In other words, in each new part of the life cycle, they get a new reminder that they have a child which gives them a hard time.

#### **2.1.8 Prevalence and Incidence of Mental Retardation**

Prevalence is a term associated with the explanation of the number of handicapped people or children. The number of handicapped individuals including the retarded can be expressed as either a prevalence or incidence estimate. While prevalence expresses the number of persons within a defined population who are considered handicapped or retarded at any one time, incidence refers to the number of new cases identified within some specified time period. Consequently, since they reflect only those newly identified, incidence figures are always lower than prevalence figures (Lynch and Lewis, 1988).

Incidence is mostly related to the frequency with which disorders arise in a new or different way in a population during a period of time. In doing so it relies heavily on clinical identification. Prevalence, however, is directed to the total number of existing cases in the population at a given point in time. As a demographic statistic, prevalence refers to the percentage of a population that is expected to fall within a given category, classification or sub-group (Alberto, 1983).

This shows that the search for causes is best pursued by studies of incidence, whereas prevalence is often used to determine community needs in chronic disorders (Hallahan and Kauffman, 1986; Kirk

and Gallagher, 1986). Therefore, prevalence studies or estimates give more general ideas concerning the needs for services than the incidence estimates.

However, exact counts of the number of handicapped people are difficult to obtain. Establishing accurate prevalence figures for any handicapping condition depends on accurate counts of the number of the handicapped and normal persons, and normal persons and on other associated factors (Lynch and Lewis, 1988). For instance, in the case of mental retardation, determining the prevalence depends upon the definition used to include or exclude individuals and on the accuracy of current census data on both the total population and those who are classified as mentally retarded. In addition to the problems related to definition and accuracy of current census, one may also find the impediments involving diagnosis and the diverse methodologies employed to collect incidence and prevalence data, including the sampling process, affecting the prevalence estimates (Robinson and Robinson, 1976; Hallahan and Kauffman, 1986). Furthermore, the uneven distribution of mental retardation across gender, age, socioeconomic status, geographical residences, and culture, according to which the parental beliefs and the practices of the community differ, requires a careful sampling process in determining the prevalence figures (Cegelka and Prehm, 1982; Lynch and Lewis, 1988).

Particularly, the prevalence of mental retardation is highly correlated with poverty and social disadvantage (Noble, 1981). In other words, the prevalence of mental retardation is closely tied to the social, economic, and health conditions in the society and the resources it provides for the education, development, and rehabilitation of the children and adults (Grossman, 1983).

Different studies, as cited in Lynch (1988), in the United States of America and other developed countries, for instance, have shown higher rates of retardation among the socially and economically disadvantaged sub-populations of the society than among the more affluent sub-population. This may shed some light on the condition in developing countries, like Ethiopia, where the very large segment of the population live in absolute poverty without minimally accepted health care. In this respect, a report (Rehabilitation International, 1981) has included that approximately 80% of the handicapped children under the age of 15 years live in the developing world without access to rehabilitation services of any kind. Thus, it seems realistic to expect more than double the mental retardation prevalence figures in developed countries, like the United States of America, that range from 1 to 3% (Alberto, 1983; Lynch, 1988), for the developing world.

In Ethiopia, however, no direct survey of the magnitude of any handicapping condition is made, and thus, no reliable data are available. But, based on the WHO's (World Health Organization) conservative estimate, which stated that at least 10% of any population are born with or acquired physical, mental or sensory impairments, the prevalent assumption that the share of mental retardation is 3%; and the current population projection of the country, it is possible to calculate the approximate figure for mental retardation.

The first national population census of the country, Ethiopia, in 1984, has reported a total population of 42.2 million for the year (Central Statistical Authority, 1985, 1988a). The projection of this figure by the annual population growth rates provided by the Central Statistical Office for the years 1985 to 1995 (Central Statistical Authority, 1985) raised the figure to 50.1 million, indicating about 5 million of total handicapped population in 1990. In a similar manner, the projection of age group population showed 19 million children of age between 5 and 19 years (Central Statistical Authority, 1988a), and thereby 1.9 millions of the handicapped population falling between the age of 5 and 19 years, again in 1990. Similarly, the virtual 3% mental retardation prevalence estimate would make the total number of the retarded persons about 1.5 million with 0.57 million falling between 5 and 19 years of age, for the same year.

Nevertheless, this should be considered as a minimum estimate; because, the various crippling diseases, malnutrition, and other adverse environmental conditions with the lack of appropriate health care, social welfare, and educational services could make the number of handicapped children in general and that of the mentally retarded in particular higher.

### **2.1.9 Education for Children with Mental Retardation**

The development of education for the mentally retarded throughout the world has for many years been hampered by wrong belief and superstitions (UNESCO, 1988a). Many people in developing countries including Ethiopia still would probably doubt the advisability of suggesting that resources should be spent on the mentally retarded, because of the scarce public funds with so many pressing problems facing the governments in their attempts to provide educational services for the normally developing children. They may consider that developments in educational provision for the retarded must be delayed until future dates (Hughes, 1984).

Indeed, what is particularly relevant to the situation in developing countries is that the major benefits derived from improved education and training of the mentally retarded, that increased independence

and ability to perform daily tasks and live a more normal life which will have practical benefits in terms of reduced costs and loss of earnings for the family and community (Hughes, 1984).

Furthermore, from the literature we have learned that the high level of dropouts and repetitions of grades being experienced by the educational systems of many developing countries, like Ethiopia, is a really serious obstacle to the attainment of national development goals such as universal primary education, eradication of illiteracy and equality of educational opportunity. Unless realistic attempts are made to identify and attack the problems of these dropouts and repeating children, the attainment of the national development goals will continue to be under question (UNESCO, 1979b).

In fact, the use of elaborated screening systems being used in the richer developed countries takes a lot of time. However, it is possible to develop basic and simple screening procedures in the efforts to move the population out of the poverty band, and to provide advice on nutrition and primary health care. In other words, usable screening techniques can be developed with the development of the primary health schemes and the organization of paramedical teams who could contribute to the provision of educational service by accumulating data on the incidence and distribution of various forms of handicap (UNESCO, 1979c).

Nevertheless, there is a very important factor, if one intends to consider educational services for the children with special needs including the mentally retarded. While identifying these children, one must be realistic and fully appreciate the prevailing social and economic conditions of the country. One must be sure that the appropriate educational and others services are available to the children (Hughes, 1984).

With respect to Ethiopia, at present, the educational program for the mentally retarded is in its infancy stage. The program seems to lack ways and means of applying almost anything that is right. Particularly it lacks the means of identification, diagnostic assessment, and most importantly the possibilities for various alternative educational environments (e.g. resource rooms, special classes, special schools, materials, trained special teachers, etc.).

By the year 1987, there were only two special units for the retarded, one under the Ministry of Education, attached to a primary school, namely, Kokebe Tsibah (Ministry of Education, 1988) and the other, the one which first started as a project for mentally retarded and later continues as a day school or care center, under the guidance of the Ethiopian Evangelical Church, Mekane Yesus (EECMY), at Cazanches in Addis Ababa in 1986/87 (Ministry of Education, 1988; Lehnert, 1988/89).

The starting year for the first unit, at this time, is unclear, because of the two contradictory official reports, the one by the teacher Education Department in the Ministry of Education in July 1987, which explained as there was no educational program for the group; and the other by the Ministry of education, may be by the Special Education unit, in January 1988, that indicated three years of age for the program at the time of the reports, respectively.

Nevertheless, one conclusion can be drawn from the two reports. Either the first report has ignored the development at the negligible level, or it might be the case that the second was talking about months but not years, and thus the service at the unit might have been started at the beginning of the Ethiopian academic year, after July in September 1987.

Here, the total pupil enrollment for the year 1987 was reported to be 40 with 5 teachers in both units (Ministry of Education, 1988). But with the third additional special unit at Yekatit 23 primary school, by the Ministry of Education, this figure was raised to 46 with 6 teachers by the year 1989/90 (Ministry of Education, 1989/90). However, the use of the WHO estimate and the Central Statistical Office's Population growth rates provided for the years 1984 to 1995 (Central Statistical Authority, 1985) will make the number of the mentally retarded children between 5 and 19 years of age 0.51 million for the years 1987 and 1989/90, respectively. This shows that the rate of enrollment is steady at the negligible level (at below 0.01%) as in special education in general.

The figures 0.51 million and 0.57 million are calculated, based on the 3% mental retardation prevalence, from the projected population of 17 million and 19 million children of age between 5 and 19 years, for the years 1987 and 1989/90, respectively.

In fact, in addition to the above-mentioned special units and day care center, at present, there are also others, like the Special program for the Disabled at Higher 3 Kebele 41, financed by the Swedish Save-the-Children program (Radda Barnen). Providing or attempting to provide services almost similar to that of the above mentioned day-care center, Mekane Yesus, for substantial numbers of children with one teacher, and another similar program at Higher 4 Kebele 37 run by a foreign organization, Concern, which is also providing some form of special educational service to some children with one teacher. But neither, so far, is registered or recognized by the Ministry of Education.

Indeed, all the afore-mentioned units and day-care centers have similar functions. In their special education provision, they all are limited, at least in their full-time program, to the moderately retarded children, have given priority to the ages between 5 and 14 years though, in practice, others above 14

are also included in their programs, and focus, mainly, on the development of basic social and self-help skills, motor skills, environmental awareness, and language.

However, other than the daily formal educational service programs, the Mekane Yesus day-care center, in its annual report (1988/89), has also indicated such special programs as Saturday Programs providing some skills training on every fifteenth Saturday for some children including their parents or relatives, early care services for considerable number of families with arranged home visits, and the like, as parts of its planned activities starting from the beginning.

### **2.1.10 Parental Involvement**

By its very nature, education concerns all citizens and its development and implementation are the concerns of the entire society. Therefore, it is necessary to have the full support of the organized elements and individuals including parents in the community and mobilize it for the actual processes of education.

Parent involvement in all educational matters of their children works for greater parental satisfaction with schools and better working relationship with the school staff. Nevertheless, as mentioned elsewhere in this study, parents may require information about the educational aims and objectives, their wishes regarding their children's education to be discovered and met, parent-teacher association and meetings or adequate opportunity to discuss curriculum matters and their children's work and progress, informative school reports, and forms of evaluation to discover whether they are satisfied with their children's education, to actively be concerned with all school matters.

In fact, parents comprise a powerful resource, possessing highly sustained motivation. Throughout the world, particularly parents of handicapped children are in a strong position as concerns the educational needs of their children. The involvement of parents and other family members at all levels of intervention is a vitally important aspect of special education development (UNESCO, 1984, 1988a).

However, as to the experience of the researcher as a teacher, the involvement of parents of children in Ethiopian regular schools is limited to the economic and disciplinary measures or governance. Through the organized school administrative committee, present at every school, that includes the adults or parents as chairperson and members, the parents/adults, according to their potential financial ability to support, mainly involve in building schools and additional classes, repairing them, providing equipment and in raising funds as necessary. Occasionally, they may also be called by the school to discuss some cases of discipline as related to their children. But the parents' involvement in pure

academic matters has not been considered feasible except to confirm, on request, their children's term and annual overall academic results and the teachers' opinion about their children and their results by signing the report cards they receive, through their children often without their stating their own opinion and understanding just with is there.

Concerning the parents of the handicapped children, neither experience nor reliable information is available for the time discussed here, except for the report cited in UNESCO (1988b) that has indicated the future trend as promising to involve parents in the education of their children. Even this future trend has not been made clearly defined. Information on the parents' opinions in this aspect is not available either.

Despite of the worldwide recognition of the parents as irreplaceable low-cost resources, no attempt was made to assess and know what the parents need and expect as related to their handicapped children's education, to support them and facilitate their active involvement. For that matter, the present study directed its efforts to examining some aspects of this pressing problem, specified through leading questions in the next part of the study.

### **2.1.11 Factors Affecting parental belief towards Disability**

Studies on belief have shown that there are many factors that determine the formation of belief. Among the many factors knowledge, culture and religion, are the most influential once. (Rogan, 1987; Oppenheim, 1992; Eagly & Chaiken, 1993 posi, 1996; Selway & Ashman, 1998).

According to Rogan (1987), almost all researchers, regardless of their bias, agree that beliefs are learned from a very young age. He further mentioned that when a category of people or behavior toward people has been frequently associated with positive or negative events, the person learns belief toward the category of behavior reflecting these events. In other words, one can develop or learns belief towards an event or object depending on his/her learning or knowledge about the event or object. One can get this knowledge through culture, folk tale and from religious orientations in a society.

#### **2.1.11.1 Culture**

In any society, culture also has a strong influence on beliefs of one group of persons to another one. As indicated in many studies, cultural values attached to physical and mental conditions are one of the important factors affecting the formation of beliefs toward disability. This is due to the fact that the birth of a child with disability has different meaning in various societies. These meanings can even be

shaped by subcultural values within a single society (Seligman and Darling, 1989; Selway and Ashman, 1998).

Selway and Ashman (1998) indicated that the Juken tribe of Sudan believed disability as something caused by evil spirits. They also indicated that during the Middle Ages, persons with a disability were believed to be possessed by the Devil and burned as witches. There are also evidences which show the inconsistent treatment of persons with disability in the middle ages. For example, Ashman (1990), cited in Selway and Ashman (1998) found out that people with disability were either viewed as possessed by the devil and persecuted, or cared for and sheltered in monasteries.

In developing countries, including Ethiopia, the non-disabled peoples' perception and understanding toward persons with disabilities are greatly influenced by supernatural beliefs, witchcraft and other adverse practices which are a reflection of culture (Nambira, 1994; UNISE, 1994; Tibebu, 1995; Tariku, 1996; Possi, 1996). In his study, TIBEBU (1995:106) STATED: "although human beings have common values, the content of their beliefs is influenced by the culture of a society..."

Possi (1996) indicated that among the Wapare in Northern Tanzania, mothers are forbidden to eat fruits that are joined together like banana because there is a belief that if the mother eats the two bananas she may get twins. In that tradition it is believed that if the mother gets twins, one of them should be killed. This was because if both of them were left to alive, a misfortune might be fall on the family of the children.

In a similar way, BBC's report (1998) indicated that tribal and other traditional beliefs strongly influence the way people with disabilities are viewed. A child with disability in the family is sometimes thought of as a punishment from the Gods for the sins of the ancestors. People with disabilities can be thought of as bad omens and rejected or abandoned. In parts of Zambia and Tanzania for example, pregnant women try to avoid seeing people with albinism for fear of giving birth to a child with albinism.

All the above explanations indicated that culture and other beliefs have an important role in shaping belief.

### **2.1.11.2 Religion**

Studies have shown that religious orientation plays a significant role in influencing the belief of parents and other people toward disability (Yuker, 1988; Possi, 1996; Selway & Ashman, 1998).

In his study, Yuker (1988) has mentioned that, in Israel the belief of Arab Christians are influenced by the biblical notion that disease and physical disability are punishments sent by God for sins or immoral behavior. According to him, the Muslim religion also consider disability as punishment from God fore sins. As a result of this, persons with disability were seen as physically and spiritually weak individuals who do not contribute to the society.

Similarly, Selwey and Ashman (1998) have emphasized the influential power of religion orientation on acceptance or rejection of disability as well as parental coping strategies. After conducting interviews with 12 parents of children with disabilities, Bennet et al (1995), cited in Sewey and Ashman (1998) found out that prayer, Church attendance and specific religious beliefs were sources of support which give hope and strength to some parents.

The influence of religion on belief also reflected in the report of earlier researchers in Ethiopia (Tadesse, 1991; Tirusew et al, 1995; Tariku, 1998). The reports of these studies indicated that disability was attributed mainly to God. In his study Tadesse (1991:26) stated that "in rural communities, the causes of disability are usually attributed to supernatural power or a curse from God for a misdeed". Similarly, after studying 5220 households' beliefs towards different kinds of disabilities, Tirusew et al (1995) found out that 51.8% of the respondents ascribed the cause of disability to be a curse or punishment from God.

Oral tradition in many place of Ethiopia also reveals that when a mother gives birth to a child with disability, it will be said "gud waladech". This expression implies that the mother gives birth to something strange as a result of a curse/punishment from God for a sin of the mother or the family.

Alt the above findings of the studied and views implies that religion has an effect on the development of beliefs toward persons with disabilities.

### **2.1.11.3 Labeling /Language of Disability**

Languages (words) which we use to classify persons with disabilities can have negative influences. Hence, labeling could be one factor for the development of beliefs towards persons with disability. It has a negative effect on the life of these people because most often labeling explains and focuses on their inability rather than their quality of ability and on how they differ from other people.

There are often marked differences in beliefs towards disability and the roles of people with disability from one country to the other. There are even variations within the same culture. So words to describe aspects of disability vary greatly from place to place. In many languages, isolating and often insulting labels are attached to persons with disabilities. Some labels define these people as medical cases rather than as individuals. In Ethiopia, naming a child after his/her impairment, for example, Ewir (blind), duda (deaf), komata (leper) and dedeb, kilakil, fezaza and mognamogne (retarded) in Amharic are very negative loaded terms and have negative influence on an individual's development and self-esteem.

In his study on meanings attached to disability, Tibebe (1995) has found that the label mentally retarded was the most unfavourably evaluated. The result of his study indicated that the most negative meanings were attached to people with mental retardation. They were described or evaluated as passive, inattentive, slow, dumb, solitary, insecure, careless. He also found out that the evaluations of teachers, students, and parents were similar. According to him, "this indicates that, there is a stereotyped belief towards the mentally retarded and the stereotype has a negative meaning" (p.103).

It is evident that these unfavorable stereotyping and categorization lead to the formation of unfavorable prejudice towards children with disabilities (Berns, 1997). As I mentioned above, the expression 'gud waladach' has a very negative connotation in Ethiopia society. It emphasized that the mother gives birth to something strange but not a child.

Studies on classification of mental retardation have shown that several early classifications used terms like moron, imbecile and idiot. Accordingly to Drew et al (1988), the use of such terms has been discontinued in the United States and other places because of the negative connotation. However, these terms are still found in some literature. Using such isolating and insulting labels have negative influences on the self-esteem and overall development of persons with mental retardation.

#### **2.1.11.4 Societal beliefs towards Persons with Mental Retardation**

Studies reveal that what we call 'mental retardation' has existed in all cultures and societies in one form or another. The definition, diagnosis, and ways of improving the condition, however, have changed through time-parallelizing the philosophical, political and economical trends of the period (Manion and Bersani, 1987; Marsh, 1992; Hallahan & Kaufman, 1997).

Drew et al Hardman (1988) have mentioned that in early period's people with mental retardation were not considered to be an overriding social problem in any society. This was because the more severely retarded either were killed or died of natural causes at an early age. Similarly, Eichstaedt and Lavay

(1992), have pointed out that in early history misunderstanding and inhuman treatment of persons with disabilities were usually the rule in many societies.

Many people with mental retardation still face many disadvantages in their lives because of the way in which society operates. They are, for example, far less likely than their non-retarded counterparts to get a decent education, find employment or have a family. As a result of these wrong beliefs, most of these groups of persons are excluded from the community and the society at large.

As mentioned earlier, the key factors which can contribute to the exclusion of persons with disabilities from society include wrong perception towards disabled people in a community or culture, a lack of enforced laws and active policies which relate to disability and equal opportunity, barriers caused by the natural and built environment, inadequate services and lack of information appropriate for disabled people.

In many literatures a number of widely accepted but inadequately validated assumptions toward people with mental retardation have been presented (Rogan, 1987). According to Jones and Guskin, 1984 (cited on Rogan, 1987) these assumptions include: a beliefs toward people with disabilities have been overwhelmingly negative; wrong beliefs are based on experience and/or misinformation. Others include that beliefs and perceptions become increasingly more positive as people become more knowledgeable and familiar with this population (McCord, 1982, cited on Rogan, 1987).

In some societies people with mental retardation are in general less respected, less valued, and in some cases feared. They are also considered as a shame, a sign of God's punishment, and evil spirits (Barof, 1986; Fcheten, 1988). Similar studies from African countries have revealed that these people are socially stigmatized (Namibira, 1994; Kisanji, 1995; Tariku, 1996).

## **2.1.12 Parental Reactions, Knowledge and beliefs**

### **2.1.12.1 Parental reactions /feelings about having a child with mental retardation**

Unless parents have the experience of having a child with some kind of impairment they are not psychologically prepared for anything but a 'normal' child. When they discover that their child is mentally retarded, they will experience a wide range of emotions such as shock, grief, sadness, etc. (Barof, 1986; Masoud, 1988, Dolce, 1994).

The sequence of parental emotions includes the parents' reactions beginning at the time of the initial discovery of the disability through which parents pass in order to come to recognize the disability. Some studies found out that the sequences of these emotional reactions are almost similar for many

parents of children with mental retardation (Berne-Smith et al, 1994; Dolce, 1994; Hornby, 1995). According to these studies, the stages of reactions begin with shock and pass through denial, anger, sadness, detachment and reorganization until the person achieves a mature emotional adjustment to the situation. Each of these reactions may influence and change the kinds of beliefs parents develop towards these children. However, as also mentioned by Seligman & Darling (1989), reactions may vary depending on cultural background (see page 32).

### **Shock**

As mentioned above, since parents' expectation and anticipation is to get a normal child, their first reaction to the diagnosis of the child's disability is a shock. In discussing this point Hornby 1995) stated that "Parents report feeling of confusion, numbness, disorganization, and helplessness and are typically unable to take in much of what they are told at this time" (p.37). He also further indicated that especially for the first few hours, they may have strong feeling of shock.

### **Denial**

Shock is typically followed by a phase characterized by denial or disbelief of the reality of the child's situation. For many parents it is difficult to accept that their child is mentally retarded. They will try to escape from the reality. They want to refuse to accept the information that their new lovely child is mentally retarded (Dolce, 1994). As Beirne-Smith et. al (1994) mentioned the refusal to accept the new information may be particularly acute when it pertains to a child who looks normal, is somewhat shy or reserved in temperament, and is an only or eldest child. They also continued saying that the greater the severity, the earlier the diagnosis, the more arduous the denial.

### **Sadness, anger, Anxiety**

Sadness, anger and anxiety are the most common reactions following to denial. Hornby (1995) pointed out that following denial, when they are beginning to accept the reality of the situation many parents experience anger about the situation. They may start searching for the cause of the disability or for someone to blame. In the case of mental retardation, they may start to study each others' family background assuming that there is something inherited from the family.

In addition to anger, parents will have feeling of sadness and depression. This sadness can be due to parents' grief for the loss of the healthy child which they thought they had, or it can be due to sadness about the loss of opportunities and ambitions which their children may not be able to fulfill. Since a child with mental retardation is considered as a person who can not fulfill the society's expectations in

many places, they will have feeling of sadness by having this child (Hornby, 1995). After the discovery of the child's disability some parents, especially mothers, may spend a lot of time crying. They may have feeling of anxiety and a feeling of neglecting or cut themselves from meeting any person because of their child's retardation and they may become depressed for a long time. These reactions can lead parents to develop wrong beliefs towards their children with mental retardation.

### **Adaptation and Acceptance**

At this stage of reaction, parents may begin to accept the reality of the loss or the child's retardation. They may start to begin doctor-shopping, to search endlessly for someone or something that can diminish or even cure the disability of the child (Berine-Smith et. al., 1994). In this stage parents still need help and advice.

Although the reactions mentioned above may be present in parents of disabled children, studies show that these reactions are not necessarily experienced sequentially. The reaction may vary according to the family culture, family system, etc. The reactions may also vary according to the time of the diagnosis. For example, mental retardation is sometimes recognized later. In this case, it may be difficult for parents to redefine the child as a disabled which one defined as 'normal'. In addition to this, the reactions of parents who suspect and who were waiting the news may differ from the reactions of parents who hear the news just after the birth of the child.

According to the 'kinds of families /kinds of children' theorists (cited in Seligman and Darling, 1989), whether a family will pass through certain stages or have specific reactions will vary according to a number of factors such as socio-economic status, support services or lack of them. Physician belief, presence of other children and spouse in the home, prior information, availability of support persons in the community, single-versus two-parent homes, religion, previous births of non-disabled children and actual physical appearance of the child.

Other factors noted by Seligman and Darling (1989) include general emotional maturity of the parent, cultural beliefs, education, parent's age, birth order, child's sex, child's ability to respond to the parent, etiology of the disability and prognosis.

Since families differ from one another, it is difficult to get one single sequence of reactions of parents of a child with disability in general and mental retardation in particular. The coping resources of the families, familial perception of the event and ecological environment that the family interacts with also affects the family's reaction to the child with mental retardation.

As studies indicate parents can show a feeling of shame to be with others after having a child with mental retardation (Mosoud, 1988; Abraham, 1998) in identifying parental problems, as a result of having a child with mental retardation in Jordan, Mosud (1988) presented 11 social, psychological and economical problems associated with mental retardation for 193 parents. He found that more than half of the parents felt ashamed about their child's mental retardation. According to his findings, this feeling prevented them from continuing their social life in a normal way.

A similar experience has been reported in a research conducted in Ethiopia in the same area by Abraham (1998). The research of Abraham revealed that quite many parents felt inferior and ashamed so much that they would not want to be seen in public with their children with mental retardation.

#### **2.1.12.2 Parental knowledge and beliefs about potentials and learning capabilities of children with mental retardation**

In addition to developing the above-mentioned feelings, parents could also have less expectation to their new child when they find the child is not as their dreams and hopes they have built before the birth of the child. Studies have revealed that many parents have little expectations to their children with disabilities (Nambira, 1994; Miron, 1994; Tariku, 1996).

A study was conducted on belief of the Society towards Learning Capabilities and Characteristics of Mentally Retarded Children in Ethiopia by Tariku (1996). In this study Tariku indicated that parents do not believe that children with mental retardation can be taught like any other children, the reason for this was that there is a belief that the minds of children with mental retardation are preoccupied by Satanic spirits. It is evident that this belief also can have negative influence on parents' beliefs toward the potentials of children with mental retardation to participate in some activities.

#### **2.1.12.3 Importance of Parental beliefs to the Development of a Child with Mental Retardation**

It is more than a fact that most children with mental retardation, in Ethiopia, spend most of their time with their parents in the family. Therefore, parents are the key persons for the development of a child and it is only with their support that it is possible to improve the life situation of a child with mental retardation. It may be easy to build special schools or even to develop adapted educational programs but without parental support it will be difficult to reach to the successful goal (Turnbull, 1990).

Parents know their own children best, as well as the environment in which the child is growing up (Mittler et al, 1986). Parents will usually have a special bond with their children which will give them an understanding of their children that different from other people. In general, parents are experts and the voice of their own children. Professionals may have certain specific strategies and methods to help children with mental retardation. However, without co-operating with parents and without a mutual sharing experience with them, the educational and development goals may not be achieved.

Parents and professionals can share experience, knowledge and activities in the provision of special needs education and in the improvement of the situation of children with mental retardation. They can co-operate in helping the child to learn to communicate and to understand others, to master self-help skills and finally to adapt to the expectations of the local community (Mittler et al, 1986). Therefore, both parents and professionals should bring their knowledge together to achieve these common goals. It is from this point of view that the importance of the congruence between the belief of parents and professionals need to be underscored. In order to reach to the successful goal, there should be strong correspondence between the beliefs of both groups (parents and professionals).

Parents can help teachers and other professionals in supplying and giving valuable information about the child during assessment, reinforcing the child to do at home what is learned at school, telling to teachers and professionals about the strong side of the child and about what the child is good at, telling what the child's needs are and what the child can't manage at home. Parents can help the child with any activity. It is through parent's involvement that it is possible to change the life situation of children with mental retardation.

To be involved emotionally, socially and practically all the above mentioned activities and to give valuable information and support to professionals, parents need to have right perception and understanding about their children with mental retardation. Behavior is guided by belief (Berns, 1997). Knowledge and believe that the life situation of these children can be changed in the future, if they are given the opportunity to learn and to actively participate in the family, will influence the beliefs.

## Chapter Three

### 3.1 Method, Instrument and Procedure of Data Collection

#### 3.1.1 Method

The method of data collection and the analysis of the research were planned to be based on qualitative research methods during the design period. This was due to the following major reasons.

- ☐ The researcher was gathering information from previous researches in similar cases. As a result it was convincing to use only qualitative method for in depth information on beliefs of parents who are not used to interviews of a questionnaire.
- ☐ The validity of using standardized tests developed in other cultures trying to adopt it in this context was still questionable in quantitative method although the Questionnaires could be useful to large number of sample.

The researcher know from his experience that a one time observation and filling out of questionnaire do not give satisfactory information since the beliefs of the parents are the reflection of their deep rooted emotion and experiences. Besides parents with such experiences are uncomfortable to express their feelings in the classical type of interview methods and observation. It was easier to be friendly for some times and gather whatever is observable concerning the child and make comments or questions that are fit and natural to the situation rather than preparing structured interview schedule which has its drawbacks.

It was advisable to limit the number and make in depth study to find out a better or closer data on the real beliefs of the parents have with their children with mental retardation. The research is about a particular real world problem rather than to be used for generalization as in many sample surveys cognizant of this fact the method allows to recommend and even to design interventions for that particular family after the research is accomplished.

#### 3.1.2. Instrument

In this research study interview were used as the main research instrument of gathering relevant data and information. (Additionally observation and informal talks were used as supplementary instrument.) The researcher used observation in two ways one by being a non-participant just by trying to divert their attention from the research and try to observe the natural situation. The other method of observation is by participation like in group discussion, plays with the children and chatting (some times the researcher created these settings). The researcher mostly used the method of the participant

and the non-participant observation alternatively. Since the parents were curious to see their children to play or interact with the team in the research, their verbal and physical reactions to the child were observable.

Dynamically necessary efforts were done to make the questions easy and understandable for the interviews in order to promote positive interaction between the interviewer and interviewees.

### **3.1.3. Sampling techniques**

The sampling techniques have been administered by purposive sampling. The researcher has purposefully selected six files of children's out of the 38 children's with mental retardation from the missionary of charity in Mekele Tigray and took the full address of their parents from the files found in the missionary. After identifying the parents of the mentally retarded children the researcher has contacted the parents in their homes and has identified whether they are biological parents or main care giving of the children. The sources of the data for the research study were parents of the children with mental retardation and the children themselves. The parents were major informants of the research study. The researcher decided to conduct the research study in Mekele Tigray because he knows that there is a missionary charity project in the area.

### **3.1.4. Procedure**

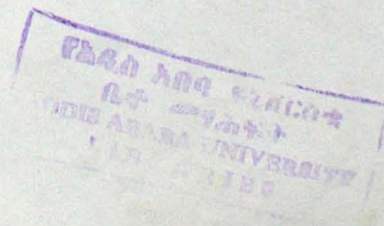
The following specific procedures have been followed in the process of undertaking the research from onset to the completion.

The instrument which is intended to be employed for collecting the data has been initially prepared in Tigrigna. Then, it was translated into English, first by the researcher, and then by language experts. The differences at both the forward and backward translation were compromised by a joint discussion of the two groups of translators. Finally, the instrument was tested in pilot studies, which were carried out at the selected area. The purpose of the pilot study was to find out the clarity and validity of each item of the instrument. Lastly, the data obtained were organized and interpreted.

### **3.1.5. Data Analysis**

To carryout this research study, qualitative research method of data analysis was applied. To examine the belief of the parents towards the education of their mentally retarded children the data collected using interview was analyzed in relation to some major categories.

☐ Background information



- Parental belief towards their children's with mental retardation
- Parents belief towards mental retardation
- Parents belief about their own role in improving the condition of their mentally retarded children through education

Depending on the finding of the research study discussions are made and finally some recommendations are forwarded.

## Chapter Four

### 4.1 Findings of the Study

#### 4.1.1 Overview

The purpose of this study was to identify and describe the belief and knowledge of parents and its effect on the educational participation of their mentally retarded children in Mekelle town Tigray. Consequently the finding of this study includes

1. The demographic and socio-economic profiles
2. The back ground information of the parents
3. Responses to the particular research question and
4. The result of the observation with the interaction of the parents and their mentally retarded children.

The profiles in the table1 and 2 provide the general information about the parent's age, education, occupation and the target children's level of retardation.

The background of parents is presented so as to give the reader the profile scenarios before the birth of the child with mental retardation. Then after the birth of the child, on the onset of the child's retardation, the child's social interactions, education and the future of each child is presented. As to the relation to the research question, the parent's knowledge, belief on the cause, treatment of the retardation and their role in improving the condition of their children through educational participation are presented. The researcher had got opportunity to observe the child's interaction in a natural setting in the family and the parent's responses as well as some of the family members. The comments of the family members were also taken as an important view to know more about the actual life style of the family in relation to the child in focus.

## Demographic and Socio-economic Profile of the Parents

Table 1:- Parent's profile

Parents	Age	Sex	Wereda, Kebele	Education	Occupation
1	40	F	Adiltaki	Mother Grade 6	House wife
	58	M	"	Father Grade 4	Driver
2	39	F	Elalla	Mother Literacy	Petty trade
	52	M	"	Father Grade 3	Guard
3	34	F	Lachi	Mother Literacy	House wife
	60	M	"	Father Literacy	Daily laborer
4	45	F	Adiltawissi	Mother Grade 2	Janitor
	68	M	"	Father Grade 5	Guard
5	38	F	Lachi	Mother Grade 3	House wife
	61	M	"	Father Grade 6	Driver
6	33	F	Tabia Hayelom	Mother Grade 8	Cashier
	57	M	"	Father	Engineer

As indicated in the table above, the six parents in the study consisted 6 mothers and 6 fathers, Those who were directly in the study are 6 mothers and 2 fathers and one grand mother who is also taking the responsibility of her daughters engaged in petty trade. It was impossible to get much information from the fathers because for most of the time, they were not available. The age of the parents ranged from 33 – 68. Regarding ethnicity four parents were Tigrans except one Agaw and one Kunama. All parents were Orthodox – Christians while one parent was Muslim. With regard to education two parents have completed primary school, two parents attended up to grade three while the two parents have literacy. According to the socio-economic classification of the town Mekelle, all parents can be categorized as low in come classes.

## Profile of the children

Table 2:- Children's Profile

Parents	The child with Mental retardation <i>Age sex</i>		No of siblings living together	Birth order	Type & level of Retardation
1	10	M	4	3 <sup>rd</sup>	Mild
2	15	M	6	1 <sup>st</sup>	Sever
3	12	F	3	2 <sup>nd</sup>	Moderate
4	17	F	4	3 <sup>rd</sup>	Mild
5	13	F	5	4 <sup>th</sup>	Moderate
6	19	M	4	2 <sup>nd</sup>	Sever

The classification was made based on the parent's report on the characteristics of the children and my own observation. The children in each of the six families have different stages of mental retardation and behavior.

Among the children with mental retardation three were females and three were males. Their sexes are equally distributed. With regard to their birth order two are 3rd born, one is the 1st birth order, two are in the 2nd birth order and there is one who is in the 4th order of birth. The children's degree or level of retardation ranges from mild to severe retardation. Among the six cases analyzed in the study only one was attending special class in Eritrea with the help of missionary of charity before the war between Ethiopia and Eritrea. His parents came from Eritrea after the end of the war. Formerly they were living in Eritrea. In regard to the onset of their condition, three children were born with mental retardation, two developed their mental retardation sooner or later after birth while the onset of the retardation for the sixth child was unknown.

The children's retardation can be identified easily since their physical and facial structures are distinctly observable. Therefore, their level of retardation were determined based on my observation and based on what the parents told about the characteristic of their children with mental retardation. The observation of the researcher mainly focused on the children's adaptive ability to their home environment (adaptive behavior) in aspects such as physical functions, intellectual functions, and communication and self-help skills. Additionally an attempt was made to relate the information gathered to accepted categories and explanations about the characteristic of different levels of mental retardation. The two other children from Adihaki and AdiHawissi kebele are under mild retardation stage when their physical ability and communication skill is observed they walk properly, can wash themselves, can put on their clothes, can communicate and can differentiate coins and paper money but they are behind their age mates educationally.

The two children from Tabia Hayelom and Elalla kebeles are classified under severe mental retardation have a problem or difficulties of walking, keeping their balance, they need help and follow up during toileting, washing, they shake their heads, they let their tongues out and they are unable to control their saliva, they can't speak or communicate using their mother tongue or by the use of spoken language.

The children classified under moderate mental retardation were from Lachi and Kuha kebeles and they show a behavior, which is in between the categories of mild, and severe mental retardation. They are mild in their physical ability and moderate in their social and mental stages.

#### 4.1.4 Parental perception and understanding about Mental Retardation

In the interview conducted parents were asked to explain the nature of their children's retardation. The question was asked with the purpose of finding out the parent's perception and understanding about their children's mental retardation. Table 3 shows perception and understanding of mental retardation as given by parents.

Table 3:-Parental perception and understanding about Mental Retardation

Mental retardation is perceived and understood by parents in the following way.

❖ **As an Avoidable condition**

Example Parent 1 (mother)

My child's "አማም" (Disease) is unavoidable. I have nothing to do. I believe it is only God who has power to change the condition of my child.

❖ **As a condition related to evil eye**

Example parent 2 (mother)

The condition of my child is a result of "ዐይኒ ሰብ" or "ጠቢብ" (evil eye). I remember one day I was invited to a group celebration and I took the child with me to the celebration carrying him at my back. It was on the celebration that my child has become victim of evil eye.

❖ **Being possessed by devil's power**

Example parent 3 (mother)

I think my child's "አማም" (Disease) is in her "አእምሮ" (Brain). You know there is "ፀላኢ ሰናይ" on her brain. It is the demon or satan who has made her to be like this.

❖ **As Mental illness**

Example parent 4 (mother)

The way my child behaves is like "ዕሰል" (mad or mentally ill). I don't let her to go out of our compound for she doesn't know her environment. She simply follows some one and go to any direction. She doesn't know where she will be going.

❖ **As weak mind**

Example parent 5

My daughter has "ዘሐቱል አእምሮ" (weak mind). I think my daughter's mind is possessed and controlled by "ርኩስ መንፋስ" evil spirit. I feel and believe it is the evil spirit who made her to be like this.

❖ **As Biological problem and as foolishness**

Example parent 6 (mother and father)

I think my child's condition is "ፍዘት" (slow, feeble) and the father responded as a condition occurred in the time of pregnancy as a result of biological problem.

As it is clearly seen in the table above parent one explained mental retardation as an avoidable disease which can only be change by the power of God. The second parent understood mental retardation as a condition related to evil eye and the third respondent perceived devil power associated with demon or Satan. The perception and understanding of the 4th and 5th respondent is a bite different, the 4th parent understood mental retardation as mental illness and the 5th parent understood mental retardation as a condition of having weak mind only one parent who is the 6th parent in the study explained his understanding of mental retardation as a condition occurred in the time of prenatal development as a result of biological problem. From the explanation he has one can easily understood how the educational exposure of parents affects the understanding of parents to the condition of mental retardation.

#### **4.1.5 Belief of parents about the possible cause of mental Retardation**

In the interview and discussion conducted parents were asked different questions so as to identity their understanding about the possible causes of their children's retardation. When answering the questions all parents were not certain. Their beliefs about the cause of mental retardation are highly connected with super natural power like evil eye, possession of evil spirit, God's will and God's punishment. The ideas they for warded are possibly been transferred to them from their respected religion and from culture

Table 4;-Parent's belief about Mental Retardation Associated with their Religion

<p>❖ <b>Cause of Mental Retardation Associated with the falling to respect the rule of Bible</b></p> <p>Example Parent One</p> <p>I believe we all are sinful, we don't respect Bible's rule and I believe it is because of our disobedience that God punished us and gave us a child with such condition.</p> <p>❖ <b>Cause of mental Retardation Associated with God's wrath</b></p> <p>Example Parent four</p> <p>I feel that the condition of my child has become like this for the reason I missed to celebrate "ሚካኤል ሕዳር" (the day of Michael ) which I used to celebrate before and I believe it is a result of "ናይ እግዚአብሔር ቁጠዐ" God's wrath that my child has become like this.</p> <p>❖ <b>Cause Associated with the Inherited sin</b></p> <p>Example parent five</p> <p>It is because of our inherited sin from our ancestors. I Guess I have inherited sin from my families.</p> <p>❖ <b>Cause Associated with the will of God</b></p> <p>Example Parent two</p> <p>My child's situation is because of " ትዕዛዝ ፈጣሪ" (the well of God) that my child become a child with a situation like this. God can create people in different ways.</p> <p>❖ <b>Cause Associated with god's punishment</b></p> <p>Example Parent one</p> <p>We people are always doing out of God's way. I think my child's situation is also a result of God's punishment. Though I don't remember. May be I did some thing wrong which is out of his way. I believe that is why God punished me by giving a child with such condition.</p>
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As it is clearly indicated in the above table 4, five of the parents associated the cause of their children's retardation with their respected religion i.e. God. They reported that their children's retardation is the will of God, punishment for personal wrongdoing like missing to celebrate ritual ceremonies which they used to celebrate, inherited sins and disobedience the rule of bible.

Table 5:-Parental Belief Associated with evil spirits

❖ Cause Associated "ጠቢብ" (evil eye)

Example Parent Four

My child's situation was caused by "ብናይስብ ዐይኒ" ( ጠቢብ ) evil eye. I remember it is on the social gathering that my child was caught by the tebebe and become like this (calling her child's name)

❖ Cause Associated with "ፀላኢ ሰናይ" (satan)

Example Parent three

My child condition was started after my grand mothers made him to sleep alone in a house were meat and other lefts over food are stored. I feel it might be satan who has mate and made him to have such a disease. It is since that time that my child's situation started.

❖ Cause Associated with Demon or power of evil spirit

Example Parent Five

I Gave birth in a new house with out killing chicken before I move in. Additionally I was alone. Therefore I believe "ደባስ" (Demon) made my child condition to be like this.

❖ Cause Associated with "ልክፍቲ" being contaminated by evil spirit

Example Parent two

I Gave birth at "ፍርቁ ለይቲ" (mid night) and I believe my child's situation could be a result of "ልክፍቲ" by some thing which I don't know.

❖ Cause Associated with "ሐሳድ" envious person

Example Parent one

I some times feel that my child's situation could be a result of "ሐሳድ ሰብ" envious person. Some one who is "ሐሳድ" (envious or spiteful) may put some thing to interrupt my life.

As it is indicated in table 5, parents provided cultural and super natural attribution to the cause of their children's retardation. One parent attributed the cause to evil eye. (ጠቢብ)

The 2nd parent reported that her child retardation is attributed to evil spirit i.e "ፀላይ ሰናይ" (satan) . According to her, condition of her child was started after her grand mother made her child to sleep in a house where the family used as a store for meat and other left over foods. The third respondent reported that her child's situation was caused by being contaminated by evil spirit (ልክፍቲ). As to her explanation, she gave birth after she moved in to a new house with out sacrificing chicken for the evil spirit. As a result of this, her baby was contaminated by the evil spirit and become mentally retarded. The fourth parent also reported that her child's condition was caused by being contaminated to evil spirit (ልክፍቲ) as the third responded reported. According to her, she gave birth at " ፍርቁ ለይቲ (mid

night) and she believes her child was contaminated by evil spirit (ልክፍቲ) .The fifth parent reported that her child's condition is a result of "ሐሳድ" (power of evil spirit by envious person.)

Table 6:-Parental belief about the cause of mental Retardation associated with Bad luck, disagreement within a family, bewitchment and biological problem

❖ Cause Associated with Bad Luck

Example Parent Four (father)

My daughter's situation (pointing to the child) is a result of her mother's (his wife) "ሐማቅ ዕድል" (bad Luck).

❖ Cause association with Biological problem.

Example Parent Six (father)

The cause for my child's retardation is a result of biological problem during the prenatal development in the time of pregnancy.

❖ Cause Associated with bewitchment / curse by ancestors.

Example Parent three

I believe my child's condition is a result of curse from my parents. You know I was not obedient for my parents when I was young.

❖ Cause Associated with disagreement in the family.

Example Parent four (mother)

When I was pregnant I was quarrelling with my husband. I believe that could be the cause for my child's condition.

❖ Cause Associated with moving in a new house where animal is not scarified.

Example Parent Five (mother)

We just moved in to a new house with out sacrificing a chicken and I gave birth in the new house. I believe that must be the cause for my child's situation.

❖ Cause Associated with Looking (seeing) mentally retarded child.

Example Parent four (mother)

I remember one day I was traveling from Asmara to Massaw by bus. On my way to Massawa I saw a child with the same situation. I believe that could be the cause for my child's situation.

As it is clearly indicated in table 6 parents have also explained attributions for the cause of mental retardation associated with bad luck, biological problem bewitchment / cure by parents (older people) disagreement / quarrel with in a family. According to the report of parent four (father) his child's condition is a result of the bad luck. As to the father's explanation, the child was seen by "ጠቢብ" (evil eye) as a result of the bad luck of the mother (his wife) and become a child with such condition. On the other hand his wife reported that it is because of the disagreement / quarrelling with her husband

during the time of her pregnancy that she gave birth a child with such condition.. She also believes that she saw a child with the same condition, when she was traveling by bus to visit her relatives in the time of her pregnancy as a result she believes she gave birth a child with such condition. One mother (third) respondent reported her child's retardation was caused by bewitchment / curse for she was disobedient for her families when she was young. Parent five reported that her child condition was caused for they move to a new house with out sacrificing chicken. According to the mother she gave birth just after they moved to the new house which they didn't kill (sacrificed) chicken and she believes it is because of their failure to kill or sacrifice chicken that her child has become a mentally retarded. The sixth respondent (father), who is found in a better academic status, reported that his child's retardation was caused by biological problem during the prenatal development of his wife's pregnancy. What we can understand from his explanation is how education affects the understanding of parents to the condition of mental retardation.

#### 4.1.6. Belief of parents in improving their children's Retardation

Table 7:- Parent's Belief in improving the retardation of their children

❖ **Sprinkle of holy water by priest as means of improving Mental Retardation.**

Example Parent One I believe the "ፀላኢ ሰናይ" (evil spirit) will be eradicated (washed out) if a priest sprinkles holy water to my child.

My child is getting better after I took him to different " ማይጮሳት " (holy water)

❖ **Prayer to God as means of improving Mental Retardation**

Example Parent two I am always praying and crying to God to give me his mercy. I believe the only one who can improve my child's condition is God. So I always use "ንእግዚአብሔ ይፅልይ" " to pray to God.

❖ **Holy water as means of improving Mental Retardation**

Example Parent three

I have taken my child to different "ማይጮሳት" holy water places for it is the only way of improving my child's condition.

❖ **Witch doctor or traditional healer**

Example Parent five

I have been in different "ፈላጢ/ፈላጥቲ" witch doctors or wizards for the treatment of my child.

❖ **Medical treatment as means of improving mental Retardation**

Example Parent Six (father)

I have taken my child to different medical doctors here in Mekell. I even took him to Addis Ababa but I didn't see any change.

As it is indicated in the above table 7 in regard to improving the condition of mental retardation parent's belief is focused on "curing" of mental retardation. The parent's belief as means of curing their children's retardation is witch doctor or traditional healer, priest, holy water and prayer. Three parents (parent 1, 2 and 4) mentioned that holy water is means of treatment for their children's retardation. They also explained that, in addition to holy water, prayer to god as an important means of improving their children's retardation. One mother who is the five respondents reported that she had tried witch doctors or traditional healers as means of treatment for her child. It is only one parent who is a father of the sixth child in the study reported differently. He reported that he has tried medical treatment for his child's retardation as a means of treatment.

#### 4.1.7 Parent's feeling by having a child with Mental Retardation.

Table 8:- Parent's feeling by having a child with Mental retardation

❖ **Feeling of sadness by having a child with mental retardation.**

Example Parent One

I always feel sad and I ask to my self why God gave me a child with such situation (pointing to the child.) It is shock for me I was not expecting a child with such situation.

❖ **Feeling of Hopelessness**

Example Parent Two

After I realized that my child is with such condition, I started to feel hopelessness I also feel as if I lost something from my inside.

❖ **Feeling of Shame**

Example Parent Three and Four

**Parent Three-** After I got a child with such situation I stopped going to social gatherings like marriage, Edir etc. I feel shame to be with other.

**Parent Four -** I always have feeling of shame of and I don't want to be Seen with my child in social gathering. I have a feeling of shame, which I can't express, and which I cannot stop it at all.

❖ **Feeling of Acceptance.**

Example. Parent Five and Six

**Parent Five -** I have a feeling that having a child with such situation is "ኖይ ፋጠሪ ውሕብቶ" God's gift and it is must to accept God's gift. You must know also it is not only me who is having a child with such condition. For your surprise I know some five parents who have children like my child. And I share ideas with them and I also feel better when I meet them.

**Parent Six (father) -** I feel that it is one of the happenings in once life that People face in their life. So I accept the situation as one Phenomenon in my life.

As clearly indicated in table 8 parents was experiencing different feelings like feeling of sadness, shame, Hopelessness and feeling of acceptance. I clearly noticed from the interview and discussion that I conducted with the parents that it was so difficult for the parents to participate in their surrounding. Some of them even they were not interested to go out and to be seen with their children. Two parents (3 and 4) reported that they feel shame for having a child with mental retardation. One parent (2) reported that she feels hopelessness when ever she looks her child with such situation. She further expressed her feeling and said she feels as if she lost some thing from inside. One mother also reported that she feels sadness by having a child with mental retardation. She further expressed her feeling and said some times I as to my self why God gave me a child with such condition. Two parents provided a feeling of accepting for the condition of their children. They said they don't feel any thing by having children with such situation for they are gift from God and for the situation is one phenomena a in once life that can possibly be happen in any human being.

#### **4.1.8 Parental knowledge and belief about their own role to improve their children's retardation**

When parents were asked about their own role to improve and bring a change in their child's situation all the parents except one father for my sixth case think that they have no role to play except praying to God, and using "tseble" (holy water) as means of improving their children situation. Mother of case 3 further explained her belief in the following way. She said every body in this wide world, whether disabled or normal, is God's creature, therefore, God is the only one who can change his creatures with his Almighty and my child is also one of God's creatures. I have no power to change my child's situation. That is God's power and God's job. It seems that all parents have the same belief as the mother for case 3 explained even though the father for my six cases who has better academic status explained his belief and understanding about his role in improving his child's condition of mental retardation is creating opportunity of education and training.

#### **4.1.9 Parent's knowledge and beliefs about the potential of their children with Mental Retardation**

It is obvious that parent's knowledge and belief play the greatest role in the advancement or delay of the potential of children with mental retardation. Considering this reality in to account the researcher asked the parents of the mentally retarded children if they are trying to stimulus their children to participate in some activities which are relevant activities in the homo environment. Five parents who are mothers of the children said they never asked their mentally retarded children to perform or

participate in homo activities. Only one parent who is a father of one mentally retarded child said he encourages his mentally retarded child to participate in some home activities like watering flowers, operating TV, and radio and tape recorder.

Parents were also asked the reason that hindered them to do not encourage their children with mental retardation. Five of my respondents who are mothers of the children reported that their children can't do any thing properly and it is worthless to ask them to participate already the "Hangal" (Brain) of the child is governed by "ፀላኢ ሰናይ (ጋንዶን)" (Satan) as a result they can't do any thing properly. One mother also added, as a reason God has created my child just to be like this and the only thing I can do is to take care of my child with out asking him to do any thing until "God" takes him again.

#### **4.1.10 Beliefs of parents about learning capacity of their children with mental retardation**

When considering education for children with mental retardation, the belief and knowledge of parents should be assessed for their belief & knowledge about the education of their mentally retarded children plays greatest role in helping the children to advance and use their potential to the maximum level. In regard to the learning capacity of the children with mental retardation parents were asked if they think that their children with mental retardation can learn like any other normal or healthy child. Only one parent from the six cases responded that, since he has seen some improvement in his child after he encouraged and assisted him to participate in some activities in his home, he thinks that his child can learn like any other children using his potential to the maximum level. The other five cases in this research who are mothers of the mentally retarded children responded that they do not believe and think their children with mental retardation can learn like any other children. They put as a rational the children with mental retardation have no normal or pure Hangoal (Brain) to learn and acquire academic knowledge and it is waste of time to try teaching these children. One mother from the five cases also added as a rational since there is "ፀላኢ ሰናይ" (Satan) or devil in my child's Hangoal (Brain), the devil can not allow my child to learn any thing.

According to the mother if at all she is going to send her child to school she will send him to use the school as a means to protect her child in her absence, she believes that her child is just created to be like this and he can not understand what the teacher thought to him as a result the situation of my child can not be changed. What we can understood from the explanation given by the mother is parents belief about the learning capacity of their mentally children are making them to be disinterested in creating conducive atmosphere for the education of their children, but in action they are telling to their

children that they are not capable of doing things or understand. Therefore, the children are not free to learn about their environment on the level they can. Generally speaking except one parent in this study all parents of children with mental retarded have several misconceptions about the nature, cause and potential of the mentally retarded children to learn and participate in education.

#### **4.1.11 Parent's communication and Interaction with their mentally retarded children**

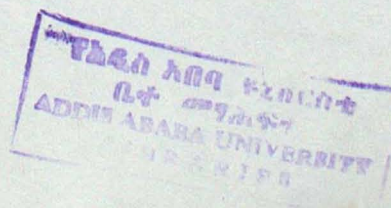
One aspect of the need of children in their development is communication and interaction. The child with mental retardation has also the same need as any child. He/she has to be included in the social group by being allowed to interact with his/her peer groups. Cognizant of the above-mentioned fact the data concerning the communication and interaction of parents with their mentally retarded children was collected mainly through observation. In addition to the formal observation, which was conducted during interviewing the parents formal observation was made to assess the kind of interaction and communication between parents and their own children with mental retardation focusing on events such as meal time, during coffee ceremony and other times. In these observations an attempt was made to answer important and major questions to assess and evaluate the interaction and communication under the following appropriate sample event.

##### **Meal time**

- Is the child given the same attention the other siblings family members?
- Do parents treat the child in the same way as they use to treat the other children of their own?
- Do parents give the child what he or she needs?
- With whom the child with mental retardation eats?
- Is the child with mental retardation eats the same food as the other children use to eat?
- How do parents react with their child with mental retardation?

##### **During Coffee ceremony**

- Is the child with mental retardation allowed to participate in the ceremony?
- Do parents give access or opportunity to the child to participate in some activities like presenting coffee, bread and inviting family members for the coffee ceremony etc.
- How do parents react to their child with mental retardation?



### Other times

- ☐ Do parents allowed the child to participate in the family discussion?
- ☐ Do parents listen or give attention to the child and to his/her initiatives?
- ☐ Do parents allow the child to play with other neighbor children?
- ☐ Do other neighbor children include the child in their play?
- ☐ What are the reactions of neighbor parents when their children play with the mentally retarded Children?

As a result of my observation the communication and interaction of parents and their children with mental retardation the five children out of the six cases were not given much attention by their mothers and by the entire family. They were usually found seating in the compound of their house with out any stimulating materials around them. Informal talks with some neighbor individuals indicate the same. According o the neighbor's the parents were not communicating and interacting with their children. Instead, they were hiding the children.

The result of my observation in the family also indicates that parents were giving much more attention to their other children's feeling than to the feeling of their child with mental retardation. Additionally, in most cases, it was observed that parents were interacting and talking much more with the non-retarded children. In all cases parents preferred to ask their other children to do some thing for them than a child with mental retardation. It seems that the children were not encouraged to do things by them selves except in one family where the child with mental retardation was participating in some activities in the house. I have observed that this child was watering flowers with one member of the family. I also observed while he was operating TV, by expressing his interest to watch the children's program presented by Ethiopian Television Tigrinya Program. He was also operating tape recorder. Except this child who is from family who are having better academic status all children with mental retardation were not interacting and participating in social events such as coffee ceremony, especially when there was a guest while the younger siblings were allowed to be there. Finally the finding of my observation further indicated that, in two of the cases, children with mental retardation were eating alone while the rest of the family members eat together.

## Chapter Five

### 5.1 Discussion and analysis of the Findings

#### 5.1.1 Method of the research and nature of the parents

The method of data collection enabled the researcher to find out the whole picture of the respected families, about their belief and knowledge towards their mentally retarded children, about possible causes of mental retardation, about their underlining belief and knowledge on the learning capacity of their mentally retarded children, about their feeling in having a mentally retarded children and their communication and interaction in their daily life. As mentioned in the methodology these beliefs and feelings of the family couldn't be quantified or expressed. In this research study the researcher has left various information but limited to certain research questions though tempted by the diversified data gathered.

#### Timing

In regard the time limit, the researcher was attracted more and more to the family's life and also reinforced by the favorable conditions created the behavioural change in each family towards the betterment of each child with mental retardation. Therefore the researcher limited the extent of involvement for the sake of the major objective of the study, but with designing simple strategy for the near future meetings and discussion for interventions. Here the dilemma mentioned in the methodology was abiding the researcher.

Timing was also challenging during the data collection. This was due to the differences among the parents. Such differences like for instance one parent was not patient enough to spend as much time as required discussing matters of her son. More time was required to wait and use the very limited spare time. It was difficult and time taking to discuss with mother's, especially those who have children with additional problems like hyperactivity for there life is hectic and busy. Time allotted for parent 6 who use to live in the industrial zone of Mekelle i.e. Lachi kebele was a bite longer due to the hamble and intelligent responsive behavior he had in explaining and analyzing the whole of the child's behavior as well as the family. This parent who is a father of one mentally retarded child out of the six cases on my study attracted the researcher to spend a lot of time since his ideas were rich, impressive and educated. The parents who were my 1 and 3 case who wanted frequent visits before they start to talk their inner hearts' feeling was another constraints of time in my stay in Mekelle. The research had the challenge in Mekelle town Tigray of observing the time limits and the need to acquire more. It

was really challenging problem to get fast and gather as much information as possible with in 48 – 62 hours in each family.

### **Challenges of the information needs**

The researcher faced very challenging situation in the effort needed to get the actual responses from the original belief and knowledge of the parents that have existed with in the parents and being careful not to influence their behavior by introducing new idea or valuable information about their children with mental retardation. That is the parents of children with mental retardation usually lack knowledge and are not aware of the possible causes of mental retardation therefore, their knowledge and belief are built based on their misinformed idea which they developed from their culture and religion that they follow. However, their knowledge and belief can be easily be penetrated if the right information are provided for the reason that they are looking or searching for possible solution. The parents of the mentally retarded children are fast to understand the right way than any outsider who got the knowledge through formal education, training or other means. They have the best understanding of their children's behavior than any one else. Therefore, intervention can easily be applied to bring change in the wrong belief that they developed from several misperceptions about mental retardation although this was avoided during the data collection in order to get the original beliefs and knowledge that they developed about mental retardation. Therefore, for the purpose of the study concerning parent's belief and knowledge about their mentally retarded children in the family, neighborhood and other family members enough data have been gathered.

### **Background of the parents**

The parents' backgrounds have covered each family's picture and the trend of beliefs and knowledge. The differences in education, economic status, living area, the type of mental retardation their children have, gives the reader of this study to have holistic picture about other parents in similar situation. There was equal sex distribution on the children side but female parents were more dominating on the study focus. This is due to the availability and interaction they have with the children as well as the fact that some of the house holds were headed by mothers.

### **Education**

The parents' educational status has impact on the early intervention but has not brought distinct differences in their belief and knowledge instead the case of one parent who is a father of one mentally retarded child from the six cases in the study is outstanding although his wife believes in the

traditional method. He strongly thrives to find out solutions as fast as possible rather than leaving the problem as it is. His academic status and his attempt have helped his son to improve in addition to his loving care.

### **Economy**

All parents with the different economic status have common wish i.e. to find a means to cure their children's retardation as compared to their income. Two parents have devoted their lives to their children and could not work since their children needed some one who looks after them. So they believed they are economically affected. The economic status of one parent who is a father to one of my cases in the study is higher so he and his wife were not mentioning about economic related problems. The only common problem they share is what to do for the future of the child. The fear of what will happen to the child if they passed away?

### **Parents' knowledge about mental retardation**

There are differences among the parents about their knowledge on mental retardation. All of the parents did not have any idea before the retardation happened to their own children. Two of the parents in the study who are living <sup>in</sup> on the kebele where the missionary of charity in Mekelle is found got advice from the missionary of charity to take their children to physiotherapy. The parents got knowledge about other children with similar children after they approached to the missionary of charity in Mekelle. The sixth parent who is a father of one mentally retarded got knowledge about mental retardation after he has visited a medical doctor. This father has brought the child to Addis Ababa for cure before five years. He is also planning to come and live in Addis Ababa in order to get access of educating his child in one of the special schools in Addis Ababa for the reason there is no school for mentally retarded children in Mekelle Tigray. These three parents have therefore, an idea about their children's retardation and decided to accept or not to accept the retardation of their children as compared to the others. The remaining three parents have no idea about other children with mental retardation in general. This could be due to lack of exposure and awareness to the problem or may be taking it as if the problem had only happened to their children so they didn't take action. Therefore those parents who knew others with similar problems have better explanations concerning mental retardation.

### Beliefs on the causes and treatments of mental retardation about their children

In this study, an attempt was made to assess the beliefs of parents about the possible causes of their children's retardation. As the finding indicates except one parent all the parents were not certain about the possible causes of the problem of mental retardation. The parents understanding of the possible causes of mental retardation seems very much related with culture, religious and superstitious beliefs.

As it is indicated in the previous chapter, at most all parents have mentioned views which imply their attribution of the cause to their respected religions, such as curse or punishment from God, the will of God, etc. One mother of a child with mental retardation supported this line of thought by explaining the cause of her child's retardation as I got this child with this situation pointing to her child because God punished me. But I don't know my mistake. May be I did some thing which is out of God's way that is why God punished me and gave me a child with such condition. As clearly stated in her description above, the mother believes that the condition of her child is caused by God's punishment. Similarly, one mother out of the six respondents' believes for having a child with mental retardation as a result of some kind of sin in the family. There is a belief in her family that if failed to celebrate ritual ceremonies, there will be god's wrath "ናይ እግዚአብሔር ቁጠዐ" (God's anger) on them and they will get a child with some kind of impairment. In connection to this, one mother of a child with mental retardation reported that her child became mentally retarded because she missed to celebrating ritual ceremony which she used to celebrate each year and God becomes angry and gave her a child with mental retardation.

According to this mother and other parents, when there is a sin in the family or in one of the members of that family, God can punish the family in different ways and one of punishing the family may be giving a child with mental retardation. These findings were in agreement with the report of earlier research in Ethiopia by Tirusew et al (1995) that the cause of disability was attributed to a cure or punishment from God.

The perception of these parents may come as a result of failing to understand the real cause of their children's retardation. When parents fail to answer the question of "Why" their children are born with mental retardation, they will start attributing the causes of the condition to God (Devlieger, 1995). According to Devlieger (1995:98), "God is a residual category that is used when no other cause can be found. The finding of the study also indicated that parents have explanations about the causes of their children's condition which reflects their cultural and other traditional beliefs. For example, there

seems to be a strong belief among them in the power of a curse from the ancestors. Some parents believe that they might be cursed by the ancestors and that is why they got a child with mental retardation while others ascribed the causes of their children's condition will be evil spirits.

According to these parents, children with mental retardation are possessed with evil spirit. For instance, a grand mother of one of the children explained her view as follows.

The child's retardation started because of evil-eyes (ጠቢብ). I remember one day we all were at home and the child was on the bed. He was smiling and moving his hands and legs. The mother and I didn't put any clothes on him to cover his interesting smiling face. At "ቀትሪ መዓልቲን" (Mid day sun), one woman, who live near our home and who lost her child recently, came to visit us and she just entered home and said if my child was still alive, he would play like your child. After commenting this, she went out immediately with out seating and talking more with us which she used to do. Just when she left, the child started crying loudly. Some thing was coming out from his mouth like saliva. Then he started vomiting we all were scared assuming that the child was already going to die. Since that time, the child's situation became like this. The cause for his condition is that Tebab (ጠባብ ሰበይቲ) evil eye women. It is she who ate our child.

According to the grand mother, her grand child becomes mentally retarded because the woman who is considered as "ጠባብ" evil eye women focused on the child with her "envious eyes" because the child was very attractive and lovely. This grand parent seems to believe that since the women lost her own child, she was envious with the new child of ours. Therefore, she came to visit at mid-day and "ate" the child with her strong eyes. The grand mother also reported that people who have strong eyes (ጠባብቲ) prefer to do such activities at mid- day because the spirit of "ጠቢብ" evil eye person has strong power at (ቀትሪ መዓልቲ) mid day.

Some of the other parents also support this view by indicating that there are special people who are "buda" (person who have strong eyes) and have a power to bring a child into some kind of difficulties. The understanding of the parents seems to be a reflection of cultural beliefs. In most cultures in Tigray, it is believed that when any one comes to visit the new born baby, he/she should spit on the child. There is a belief that, if the person is, in case, "ጠቢብ" evil eye when he/she spits on the child, the power of the evil spirit will disappear.

The assumption behind is, doing the spitting shows to the parents of the child that the visitor is not

“*malin*” evil eye. This is also due to the assumption that to escape from being responsible if some thing happens to the child after he/she has visited the child. One important point which should be mentioned here is that the spitting could have other consequences here is that the spitting could have other consequences on the child’s health since there will be a risk of getting some diseases through the saliva.

As to some parent’s belief, “*malin*” evil eye has also strong power to make a child sick or mentally retarded through admiring the child’s face, way of smiling, physical appearance or the child’s unique activity. They indicated that this admiration is not positive admiration; it is something bounded with a feeling of envy. After the “*malin*” evil eye admires the child’s unique appearance or behaviour, focusing on the child, the child will have some kind of sickness or impairment including mental retardation. Parents also reported that they usually cover their children with clothes to protect them from the focus of those persons who have evil eyes.

More over, among parents, getting a child with mental retardation was considered as a sign of not abiding to social values and norms such as being respectful to elders, seeing a child with mental retardation during pregnancy, and making fun of a child with a disability. They believe that one should respect the elders to avoid a curse which may have the consequence of getting a child with some kind of disability including mental retardation during her pregnancy and / or if parents, especially the mother, laugh at a child with mental retardation, there is a possibility of getting a child with the same condition of retardation.

All the above beliefs clearly show how culture, religion and other elements in the social and cultural environment affect the belief and knowledge of parents about causes of disabilities in general and mental retardation in particular. Mittle et al (1986) explain that parent’s knowledge and belief are reflection of society that they came from. The parents beliefs also show that they are not aware that there are a number of genetic and environmental causes of mental retardation such as down syndrome, fragile x, alcohol misuse, malnutrition, under stimulation, poor social and cultural environment, and other child hood diseases like measles and very high fever during infancy (Patton et, al, 1990; Beirnesmith et, al, 1994; Dolce, 1994). Surprisingly enough genetic and other environmental factors were not mentioned by the parents in the study. Only one father mentioned his child’s situation is the result of biological problem during prenatal development in the time of pregnancy.

This father has better exposure and educational background out of the six respondents in the study. It

This father has better exposure and educational background out of the six respondents in the study. It seems that this father, although he doesn't know much about possible consequences of mental retardation in particular, he has developed a rational way of combining cause and effect.

The assumption behind most of these beliefs also is that getting a child with mental retardation is a negative reinforcement for the wrong doing against such culturally designed social rules mentioned above. As explained by Whiting (1994), beliefs in supernatural powers (sanctions) may be used as a mechanism of social control in a given society. This means, the fear of wrong doing and its consequences may control the behavior of members of the society. However, it is important to note that such beliefs also are significant factors for the concealment of these children. For instance, parents' believe that a child with mental retardation is a result of wrong doing to others.

### **Knowledge and Belief of parents to improve the condition of their children's with mental retardation**

In the discussion and interview conducted with parents of the mentally retarded children participants of the study were asked what they think is essential for the improvement of the condition of their children with mental retardation. Except one father all have the idea and explanation that the parents gave concerning these questions were focused on "curing" of mental retardation. This misunderstanding might come as a result of mixing the condition of mental retardation with illness. What we can understand from the parents explanation is that the alternative which they have chosen for the improvement of the condition of their children retardation seem to be a reflection of their traditional and religious beliefs about causes of mental retardation. For instance two mothers of the mentally retarded children mentioned that they have tried different witch doctors or traditional healers seeking treatment for their children. These parents spent their time and money taking their children from one herbalist to another hoping that their mentally retarded children will be cured and become normal.

Another two mothers on this study also used as an alternative for the improvement of the condition of their children "Holy water" treatment. According to them they used the holy water treatment because they believe that children with mental retardation are possessed by evil spirit and it is possible to eradicate the evil spirit by washing the child with the holy water. My fifth respondent also used other alternative as means of improving her child retardation. She believes prayer to God is the only and best means of curing her child from the condition of retardation. It is only the sixth parent among the

families who has reported that he tried to visit medical doctors seeking treatment for his child with mental retardation.

From all the explanation given by the parents as possible alternative of treatment for their children I found that the treatment chosen by the parents seem to be dependent on their knowledge of understanding and belief about causes of mental retardation which are discussed above. In connection to this, Ingstand (1995:253) has stated "In all societies the belief about the cause of impairments may have consequences for action". From Ingstad's explanation it is easy to understand that the choice of treatment for a given impairment depends on the casual explanation of the impairment. The finding of this study show that the same tendency. Since the parents' beliefs and knowledge about the cause of mental retardation are very much related with supernatural power (superstition) and religion, the treatments considered were greatly influenced by such beliefs and understandings.

Finally what have been observed in the study about the cause effect relationship with regard to the choice of parental means of treatment is parents unsuccessful experience seem to result in losing hope concerning the possibilities to improve the condition of their children. This in turn, led them to develop another belief that it is impossible to improve their children's situation and affect their choice of treatment to shift to another causal attribution i.e. God. This implies that parents who are in the same situation could develop a belief that the condition of mental retardation is beyond human knowledge and ability to change. Consequently this lead them to the belief that they have no role to play in improving the life situation of their children but although it is believed that mental retardation is not an illness and can't be cured, a lot can be done to improve the life situation of children with mental retardation and promote their learning and development through education and training.

#### **Parental feeling and reaction about having a child with mental retardation**

Any person thinking of his/her future life process in thinking of the kind and potential of the child he or she will have, the ideal child. Whenever one plans to have a baby, he/she generally has expectation, thinking and prophecies about the child's future carrier, goal and competence to lead independent life. In this aspect, all prospective parents are widely known dreamers. Mostly they wish for the best, that their child will be free of any unwanted behavior and expect that their child will be at least better than they were and are. If these wishes and expectations are attained, there is no problem with the parents feeling. But in the case of the opposite, if the first diagnosis comes with the information that the child is mentally retarded the parents will be forced to experience the sense of disappointment and react

accordingly. The finding of this study also showed that most parents experience a feeling of shame and hopelessness in having a child with mental retardation. They reported that they feel shame to be seen with their children who are mentally retarded. This feeling clearly shows why they usually keep their mentally retarded children at home not to be seen by others. One mother explained her experience and the problem that she has faced in the social interaction with in the society where she lives in the following way. It was difficult for her to participate in social gatherings like marriage and Edir. The rational she gave was her feeling of shame to go out and to be seen by the members of these social settings after having a child with mental retardation. In the same way my fifth respondent explained her feeling as follows.

After I realized my child's situation, I had a feeling of hopelessness and shame. Still now I feel the same. I am always asking my self why my child becomes like this. My dream was not to get a child with this kind of situation. Especially when the child was very young, I was afraid to touch couch him and I had little interaction with him.

It is clear that the mothers feeling of hopelessness comes from her awareness that the child will not be able to fulfill her hopes, dreams and expectations which she has been built up prior to her child's birth. She might have also perceived her child as different from any other children and that could be the very reason for her to limit her interaction with the child. Consequently as a result of her feeling of fear to touch her child, this mother failed to show intimacy, which is the essential and primary need to any child especially for a child who is mentally retarded. In regard to this Rye (1997: 84) stated "The way parents perceive their children seems to have great significance for the belief and feeling which they develop in their relationship with their children. According to Rye, when parents perceive their children as "abnormal" and with few possibilities for development, they will also feel hopelessness, disappointment, guilt and little inspiration to try to achieve meaningful interaction. The mothers' explanation also shows the same. The child may not be able to give any response to the mother actively. The failure of the child to stimulate the mother could lead the mother to develop depression. The mother's depression again leads to the failure of her to react to and interact with the child. When parents have such feelings, they will develop a feeling of hopelessness (Jareg and Jareg, 1994). All these parents emotional reaction may lead the parents to develop misconception or wrong belief towards the condition of their children.

The feeling of hopelessness could also be rooted in the parents viewing of their mentally retarded children as an unfavorable reflection of themselves (Barof, 1986; Ingstad, 1988, Dole, 1994). As Ingstad (1988: 6) stated.

In their own judgment family members will most often compare their life situation to what they feel it would have been with out a disabled family member. They also compare their new situation with the life of other people living around them with whom they identify them selves.

This feeling, in turn, can lead the family members in general and the parents in particular to develop low self-esteem and to minimize their interaction with the child and with the members of the society where they live.

In the study it is also seen that three parents who are mothers of the mentally retarded children show a feeling of acceptance. The mothers expressed their feeling in the following manner. Since children with mental retardation are gifts from God, they should accept these children and they should treat them in a positive way. It seems that their beliefs are affected by their religious orientation that encourage charity and care of person who are sick and who are with some kind of disability. As mentioned by Selwey and Ashman (1998), this type of religious orientation has a significant role in acceptance of disability. However, the parents' acceptance and treatment seem to be irreconcilable with a realization of the child's individual needs and potential ability.

As the finding of this study show, it seems that the parent's evaluation of their children and their reaction to the children is a result that comes from:

1. From the parents lack of knowledge how to handle their mentally retarded children.
2. From the beliefs of the society they belong or they live in which about having a child with mental retardation that is attributing to punishment.

It is evident that all these parental feeling and emotional reactions could be taken as a basis of their beliefs towards their children with mental retardation. All these feeling are natural reactions to disability, but to avoid a prolonging of these reactions, it seems that these parents need social support and appropriate information from professionals so that they can get help to develop feeling of acceptance to their children's situation and have clear cut information about the cause of mental retardation.

It is also clear that the above parents experience and feeling are significant factors for the concealment of children with mental retardation as well as for the development of misconception of parents towards the situation of their children. Lack of social support also is one of the major factors for all these feelings of parents. In Ethiopia, there are few organizations that provide educational, intervention and other important services for children with mental retardation and their parents. However, these services are negligible compared to the number and individual needs of parents of the children with mental retardation in the country. It could be this lack of social support that made the parents of the mentally retarded children develop such feelings as sadness, hopelessness, anxiety, neglecting themselves from the social setting in their society. This in turn could lead them to develop wrong beliefs and misperceive to the situation of their children with mental retardation. To develop positive feeling and accept their children's situation the parents need other members of the society to take an interest instead of just to stare at them when they are out with their mentally retarded children. It is with the social and professional support given that the parents of the mentally retarded children that they can cope with the situation of retardation of their children and start treating them positively and think about their children's participation in education and other important trainings.

#### **Interaction of parents with their mentally retarded children**

According to the finding of this study the interaction of parents with their mentally retarded children were limited. In fact the parent's concealment of their children could be a result of the stigmatization of their children with mental retardation by the society and the local community was they live (Seligman & Darling, 1989). Results of the observation at home and the interview conducted with the parents further showed parents were hiding their children with mental retardation from others. This in turn affects children their communication with other members of the community and hampers the children's ability to adapt to their local community, and even promote deep social deprivation. For example, they lose the opportunity to play with their age mates which can in turn, lead to further social deprivation.

In addition to this, as mentioned by Iwaniec (1995), these children, when deprived from communication, they will develop social emotional problem. As indicated in the literature part of this study, the ecological approach sees children in the context of social settings developed in to a microsystem, a mesosystem, an exosystem and a macrosystem. This is because the children's overall development can not be understood independent from these social settings.

a mesosystem level his/her interaction are extended to neighbour and other social settings. These interactions, in turn, have a significant influence on the child's social, emotional and physical development (cole & cole, 1993: Hornby, 1995) on the other hand, hiding mental retardation could affect other people's perception negatively. For instance, hiding a child with mental retardation can give other children in the surrounding the idea that something is very wrong with the child and provoke them to misperceive the child with mental retardation wrongly. This can clearly show how the social settings intervene to make the situation of parents more difficult, challenging and hopeless.

Parental believes about the learning capacity of their children with mental retardation Children with mental retardation often can learn by doing if given the opportunity to participate in any activity adapted to the children's potentials and needs. Being able to participate in activities will help the children to become independent in their future life. This way they can also contribute to the community and the society at large. Unfortunately, this group of children is viewed through spectacles that only focus on their inabilities, not seeing their abilities. The finding of the study revealed that except one parent who is a father to one of the mentally retarded children's included in the study other parents have no expectations for their mentally retarded children with regard to education. It seems that parents have the belief that their children have no at all ability to learn. According to the parents, since their children are possessed by evil-spirit, they have no "normal" or "pure" mind for learning academic and other skills. For some of the parents, sending their children to school is waste of time since they are created by God to be retarded. One mother out of the six respondents explained her idea about the educational participation of her child with mental retardation in the following manner.

I don't think my child can learn like the other normal children. It is wasting time to send him to school. He already has "ድኩም ርእሲ" (weak mind) as a result of "ፀላሊ ሰናይ" (devil). Unless the devil is washed out (driven out) from his mind by holy water or other means of treatment, I don't think he can learn like the other normal children.

This shows that parents with such an opinion lack awareness about the learning potential of children with mental retardation. Parents do not realize that it is possible to improve the present situation of their children retardation through the provision of adopted education. Here one can easily understand the effect of parental knowledge and belief to wards the education of their mentally retarded children.

As Hallahan (1997) mentioned with intensive educational programming, children with mental

retardation, particularly children who are mildly retarded, can improve to the level that they are no longer retarded.

As marsh (1992) stated when parents believe that no change will occur, it is evident that they will not show any effort to change the situation of their children's retardation. Additionally, they may not have positive perception for any intervention programs since they have already developed a feeling of hopelessness.

In fact the views of the parents are rooted in their superstitions beliefs about the **ናይ ፀላእ ሰናይን** or "devil causing the condition of their children and leading them to believe that the spirits can have a strong power to control the learning capabilities of the children.

Generally, the wrong-beliefs of parents blocked the children's with mental retardation their opportunity to go to school and made them to remain at home.

## Chapter six

### 6.1. Summary, Conclusion and Recommendation Overview

This portion (part) of the study includes three parts i.e. the summary, the conclusion and the recommendation.

The conclusion is specific to the particular situations of the parents in the study so that it is not for generalizing from minuscule sample of 6 subjects. However, there are some universal facts found in the previous studies and theories equally seen in the finding of this study that has enabled the research to make inferences on the belief of parents and the typical situation of their children with mental retardation. But the result can not be generalized to the majority of parents. Therefore, the conclusion is particular but with general truths similarly the recommendation focuses on issues of the parents in the study however, the particular parents of the study are the reflection of the general situation of the society in terms of knowledge believes social services and economics situations. Therefore, the recommendations are useful to the majority of the people with disabilities, parents of children with disabilities of various types of as well as parents of children with mental retardation.

#### Summary

Historically mental retardation is a type of disability that has been misconceived for centuries. People with mental retardation were cruelly treated and put in custody until the past two centuries when the human Italian movements enlightened the caregivers for education and better treatment. Recently with the human rights and the concerned associations' movements, exclusive programs are changing to be more of inclusive nature in most of the developed and some of the developing countries. Ethiopia with ratification of the right of the child had included a special needs education program in its educational policy. These measures have their own impacts for the better development of the child. However, the vast numbers of children with mental retardation in the urban and rural communities need to be addressed and the parents who are the primary agents are more influenced by the traditional believes. Due to these believes, the children are not included in the society as a right.

This study focused on the effect of parental knowledge and belief towards the educational participation of their mentally retarded children. The primary objectives of the study are finding out the effect of parental belief and knowledge to the educational participation of the mentally retarded children on the ongoing educational process.

### Specific objectives

1. To identify the specific knowledge and belief of parents towards the educational participation of their mentally retarded children.
2. To explore the parents knowledge and belief about the possibilities for the improvement the condition of the mentally retarded children.

To propose possible and implemental recommendations in the areas of knowledge and belief of parents towards the educational participation of their mentally retarded children.

The research questions were formulated with the basis of the objectives of the study.

1. What do parents believe about their own role in improving the condition of their children's with mental retardation?
2. What do parents believes about the potential of their children in participating in some activities?
3. What do parents believe about the learning capabilities of their children with mental retardation?

The method of the study includes assessment facilitators and selection of parents as entry points. The method used is qualitative in depth study on their backgrounds, knowledge and beliefs about the cause of mental retardation, about the potential of the children in participating in some activities, belief about their (parents) own role in improving the condition of the children. The method used to collect data was interview and observation. A video camera, tape recorder together with facilitator for each family was used to advance and get in depth data. The selection of the parents of the children was randomly selected from the missionary of charity in the study area i.e Mekelle town. Surprisingly the sex distribution of the children's was equally distributed. The finding of the study showed 5 parents have the same economic status. Both of them are from low economic status only one parent is from higher economic and educational status. The parent's background history of each parent has direct relation ship to their belief and is different one from each other.

## Conclusion

Based on the general and specific objective of the study and the research question the finding of the study has come to the following conclusion.

1. The parents believe as the cause of mental retardation to be evil eye, Evil spirit, God's punishment, and God's well. It is only the educated parent (father) believes cause for his child's retardation to be biological problem in the time of pregnancy (prenatal development). The parent belief is a reflection of their cultural and religious orientation. It seems that parents lack awareness about the cause of mental retardation.
2. Among the five parents there is myth and misconception about their children's performances five of the children are under estimated, since they have lost their hope earlier when the children was not performing as their age mates. As a result of these, the parents do not have expectation to their children with mental retardation with regard to their education and active participation in the family and community.
3. Five of the parents involved in the study have psychological strees having a child with mental retardation. Having the child with mental retardation has different meanings according to their level of acceptance of the children. As this was expressed by five of them, the general feeling is to be inferior from the general community. These feeling of inferiority made the parent to hide at home, to neglect and keep their children with mental retardation away from education (school).
4. According to the five parents the treatment for their children's condition is God's mercy, traditional healers, while one parent (father) believes medical treatment as a means for cure.
5. All the children with mental retardation involved in the study have capabilities of their own, but these capabilities are hidden. It seems that the parents lack awareness about the potential and learning capacity of these children through stimulating them to learn and participate in some relevant activities. If the child does not get the necessary stimulation with in the family and is not participating in activities at home, it will be very difficult to help the child. Therefore, the priority needs of these parents seem to be education, support and advice while the primary focus of professionals should be raising awareness of parents and the entire community. Parents need to understand the nature of their children's condition more fully. They also need to know what to expect in terms of children's development and what they can do to help these children. In addition



to this, they need support in coping with the fact that their child has mental retardation. Furthermore, they need information and support in raising their children with MR so that they will be prepared and it will be easy for them to cope with the situation and become involved in intervention and other programs. One major problem of bring these children to the available school is and other services is the wrong beliefs of the parent's towards the potential and learning capability of the mentally retarded children.

6. Three of the parents out of the six cases do not see other children with mental retardation (similar problem) either did not have information about the condition of mental retardation. Therefore, parents need support for teaching their children to become active members of the community. For instance, organizing (forming) parent association and conducting regular parents to meeting will help parents to get opportunity meet other parents with the same situation which in turn would help parents to feel that they are not the only parents with such situation and to become psychologically ready to help their mentally retarded children to participate in education?
7. Through out the study, parents of children with mental retardation are isolated. It seems that being a parent of a child with mental retardation makes them to be considered as different from others. This resulted, in some cases, that parents have stopped their relationship with their neighbors and other people. However, it should be noted here that the reason for their isolation may not necessarily because of their child with mental retardation. It could be because their neighbors, friends and other are unsure how to behave and how to react towards these parents.
8. All parents involved in the study have psychological stress in relation to the futurity of their children with mental retardation. For instance, one parent expressed her fear about her child's futurity in the following manner. "I would like to do every think for my child until my death. After that God knows.

The mother's expression implies that parents are under the stress of fear about what will happen to their children with mental retardation after they passed away (die).

## Recommendation

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

The main barrier for the educational participation of the children's with mental retardation is the wrong belief of parents in particular and the community in general. And these beliefs are again the reflection of the society. So it is highly recommendable to organize.

- ☐ Awareness raising and education to the grass root level and the community members (neighbors, local associations) about the nature and cause of Mental retardation and about the potential of the children with mental retardation.
- ☐ Community based rehabilitation program for awareness raising and the focus on the follow up and the training of the parent and family members to take early measure for the development of the child with mental retardation.
- ☐ Creating a supportive Environment for parents of children with mental retardation by organizing parent's association.
- ☐ Conducting regular meetings through the parent association so that parents will get the opportunity to meet other parents with the same condition, which in turn would help them to impress the situation and become psychologically ready to help their children with mental retardation.
- ☐ Almost all the parent was not willing to let their children with mental retardation to interact with the members of the community Ex-neighbors. This trend is common with most of the parents. The reason behind as the finding show, the people are not aware of the right of a child with disability, no to be discriminated or abused. They are also in similar believers that such children are the punishments of God. Therefore, the remedy is educating the parents and neighbors in particular and the other members through participatory methods to gain true change rather than pushing them to change the beliefs that may not stay long.
- ☐ In order to help the parents and the community members to develop right perception and change their wrong beliefs about their children with mental retardation focus should be give
- ☐ In creating regular contact and strong relation ship with parents since they need some body to talk with concerning the issue of mental retardation.
- ☐ Teaching the parents about the possibilities of-changing the situation of their children so that they can understand the role they can play their children.

- ☐ Teaching them about the potentials and learning capabilities of the children as well as the individual needs of these children with special needs.
- ☐ Teaching them about the importance of early intervention.
- ☐ Expansion of community based rehabilitation (CBR) programs like the missionary of charity found in the town Mekelle to expand the programs for awareness raising and the focus on the follow up and training of the parents and the community members to take early measures for the development of the child with mental retardation. The existing NGO's working in limited areas of Mekelle even can focus with heir programs to include peripheral and remote areas of the city.
- ☐ All professionals from different disciplines who are involved in any organization helping the disabled children in general and mentally retarded children in particular should see the child in a holistic way and take the entire family system in to consideration. Hence, they should involve themselves in the family of a child with mental retardation and help the family to cope with the situation so that all members of the family can accept the child above ass as a child and then as child with mental retardation (with special need). This will facilitate the parent's coping and adaptation process.

In order to provide better and effective services for disable children in general and mentally retarded children in particular there must be correspondence between the beliefs, values and thinking of professionals and those of parents. Other wise, what the professionals recommend (say) is meaningless to the parents and the community. Therefore, cognizant of the above mentioned fact, the first and major condition which should be taken in to consideration, in planning intervention and education programmes for children with mental retardation, is making parents, family members and other community members to have right and positive perception towards these children so that they will be involved in the programmes and play their own role in helping the children with special needs.

## Appendices

### Appendix – A:- Description of the levels of the children's retardation involved in the study

#### child one (Case - 1)

##### ☐ Parent's report

- ☐ He can walk properly
- ☐ He can feed himself properly
- ☐ He can put on his clothes
- ☐ He can tie his shoe
- ☐ He can wash his face
- ☐ He can bath himself
- ☐ He uses non verbal way of communication
- ☐ He can't differentiate money specially coins and he can't use it.

##### ☐ Researcher's Observation

- ☐ He can walk properly
- ☐ He can perform many self-help skills
- ☐ He was participating in some home activities
- ☐ He can communicate using signs with his family members

=> Based on the information collected from parents, the researcher's observation and with the accepted behavioral characteristics of the mentally retarded child, the child may fall to the category of mildly mentally retarded

## Child two (Case - 2)

### Parent's Report

- ☐ He can walk/sometimes ~~she~~ <sup>his</sup> has difficulty to keep ~~her~~ body balance
- ☐ He needs help in toileting
- ☐ He usually shake his head (frequently)
- ☐ He can't talk many words /he speak only few words
- ☐ It is difficult to understand him.
- ☐ He is always smiling
- ☐ He likes following anyone on the way
- ☐ He has no friends /~~she~~ usually stays at home
- ☐ He can't put on his clothes properly
- ☐ He can't tie shoe
- ☐ He can feed herself /he needs help
- ☐ He can wash his face with supervision
- ☐ He can remember some events.

### Researcher's Observation

- ☐ He can not use words to express his felling.
- ☐ He has difficulty to walk properly.
- ☐ He can't communicate using his vernacular language properly.
- ☐ He needs help in most self-help skills.
- ☐ He always lets his tongue out.
- ☐ He can't control his saliva.

=> Based on the information collected from parents, the researcher's observation and with the accepted behavioral characteristics of the mentally retarded child, the child may fall to the category of severely mentally retarded.

### Child three (Case - 3)

#### ☞ Parent's report

- ☞ She can speak a few words
- ☞ She can walk.
- ☞ She has difficulty to remember events.
- ☞ She can wash her face.
- ☞ She can bath herself /with supervision/
- ☞ She can ask when she needs toilet
- ☞ Sometimes she can't control her urine
- ☞ She can feed herself
- ☞ She can put on her clothes
- ☞ She can tie shoes /with the help the family members. /

#### ☞ Researcher's observation

- ☞ She was trying to communicate using few words.
- ☞ She is interested to communicate with others.
- ☞ It seems she has problem in motor control.
- ☞ She was bathing herself and putting things properly.
- ☞ Sometimes she has difficulty to remember things.

=> Based on the information collected from parents, the researcher's observation and with the accepted behavioral characteristics of the mentally retarded child, the child may fall to the category of moderately mentally retarded

### Child four (Case - 4)

#### ☞ Parent's Report

- ☞ She can talk /sometimes She repeats words

- ☐ She usually plays with her brothers and sisters.
- ☐ She can feed her self /without help.
- ☐ She can put on her clothes.
- ☐ She can bath
- ☐ She can jump and run.

#### ☐ Researcher's Observation

- ☐ She can walk properly <sup>and</sup> she is physically active
- ☐ She can perform many activities at home.
- ☐ She can communicate using her vernacular language
- ☐ She was playing in her compound (with ~~his~~ brothers and sisters)

=> Based on the information collected from parents, the researcher's observation and with the accepted behavioral characteristics of the mentally retarded child, the child may fall to the category of mildly mentally retarded

#### Child five (Case - 5)

##### ☐ Parent's report

- ☐ She can communicate using few words.
- ☐ She can walk but she sometimes falls down.
- ☐ She has difficulty to remember some events
- ☐ She can wash her face with the help of her brothers and sisters
- ☐ She can bath herself /with supervision/
- ☐ She can ask when she needs toilet
- ☐ Sometimes she can't control her urine
- ☐ She can feed herself
- ☐ She can put on her clothes
- ☐ She can tie her shoes /with help/

- ☐ She can't help me by preparing some food items

#### ☐ **Researcher's observation**

- ☐ She was trying to communicate using few words
- ☐ She is interested to communicate with others.
- ☐ It seems she has problem in motor control.
- ☐ She was bathing herself and putting things properly.
- ☐ Sometimes she has difficulty to remember events,

=> Based on the information collected from parents, the researcher's observation and with the accepted behavioral characteristics of the mentally retarded child, the child may fall to the category of moderately mentally retarded

#### **Child six (Case - 6)**

##### ☐ **Parent's report**

- ☐ He can talk /sometimes he repeats words
- ☐ He usually play with children outside
- ☐ He can feed himself /without help
- ☐ He can put on his clothe
- ☐ He can button /unbutton
- ☐ He can bath
- ☐ He can jump, run, climb
- ☐ He uses to dance whenever he watches Varsity show in Television.
- ☐ He can play foot ball and others games with his brothers.

##### ☐ **Researcher's observation**

- ☐ He can walk properly he is physically active
- ☐ He can perform many activities at home .e.g. he was watering flowers, he was operating TV, Radio and Tape recorder.

↳ He can communicate using the vernacular language

↳ He can use money because he can differentiate the paper money and coin.

||↳ He was playing in his compound with his brothers and sisters.

=> Based on the information collected from parents, the researcher's observation and with the accepted behavioral characteristics of the mentally retarded child, the child may fall to the category of mildly mentally retarded

## **Appendix B:- Interview Guide**

First, we have discuss about some general practical things in the area of mental retardation. Then I have explain to the parents about the objective of my study in general and the interview in particular.

I have also ask the willingness of the parents to be recorded during the interview by explaining the objective of the recording. After I assured the willingness of the parents I have start the interview by giving positive comment about the child.

### **The initial interview**

- ☐ Greeting
- ☐ Giving my name and title
- ☐ Anonymity
- ☐ Telling about the aim of the study
- ☐ Asking permission to record the interview
- ☐ Opening the interview with an introductory statement

E.g. by telling them positive comments about the child

### **Background information**

- ☐ Parents
  - ☐ Education (to be asked at proper time)
  - ☐ Occupation
  - ☐ Sex
  - ☐ Age
  - ☐ Religion
- ☐ Family History
  - ☐ Number of family members
  - ☐ Medical history
  - ☐ Number of children

☐ Experience of having other children with disability

☐ **The Child**

☐ Age

☐ Medical history

☐ Social history

☐ The child's strength and weaknesses

☐ The child's interests and play activities

☐ Other information

**Questions related to parental beliefs and knowledge of their mentally retarded children.**

☐ Can you tell me about the child's day?

☐ Can you tell me about your child's situation?

☐ What do you believe about it? (How do you explain the condition of your child? What do you think it is?)

☐ How did you know about it?

☐ What do you believe the cause of the child's disability is (child's name)?

☐ Why do you think child's name is like this?

☐ What do you think is the reason?

☐ How do you know this?

☐ Does (child's name) go to school?

☐ If not, why?

☐ What do you expect in relation to the child's education?

☐ Do you think that the child can learn like any other children?

☐ Is the child participating in home activities?

- # Do you ask your child to do something for you?
- # If not, why?
- # Do you think that the situation of (child's name) can be improved?
- # If yes, how?
- # If no, why?
- # What do you think is important for the improvement of your child's situation (child's name)?
- # Do you think/believe you can do anything to improve the situation (child's name) through education?
- # Can you tell me what you felt when you heard about (child's name) problem for the first time?
- # What did you do after you realized the situation of your child?
- # What do you feel when you have a child of this type (child's name)?
- # Why you feel like that?
- # Did you talk with others (like your neighbors) about the situation?
- # Where does (child's name) play?
- # Does (child's name) have friends?
- # What age? Are they his peer group?
- # Have you been out with the child? (Like shopping, church, recreation center, etc.)
- # If not why?
- # If yes, can you tell me your experience?
- # Can you tell me about experiences in having (child's name)?
- # What expectation do you have for (child's name)?
- # How do family members react to (child's name)?
- # With whom does (child's name) usually spend his/her time?
- # Which things bother you regarding the child?
- # How much contact have you had with others (other family, neighbors, relatives, etc?)

- # To what extent has the presence of (The child) affected your relationship with others?
- # What you do with the child?
- # Who looks after the child when you are not there?
- # How do you interact with the child?
- # Do you let the child to play with other children?
- # How often you stay with you<sup>o</sup> other children?
- # Do siblings include in their games and activities?
- # Who talks most in the family with the child? The last?
- # What are you doing now to improve the situation of (child's name)

## Appendix C :- Observation guide

In addition to the informal observation, which was done during interviewing parents, formal observation was made to assess the type of interaction and communication between children with mental retardation and their parents. The focus events for the observation include: meal time, coffee ceremony and other time. In these observations an attempt was made to answer the following basic question.

### Meal time:

- ☐ With whom the child is eating?
- ☐ Do parents treat the child in the same way as they are treating other children of their own?
- ☐ Is the child given attention by his parents and other members of the family?
- ☐ Is the child eating the same food as the other children of the family?
- ☐ How do parents react to the child?

### During coffee ceremony:

- ☐ Do parents allow the child to be there?
- ☐ Does the child have the opportunity to participate in activities such as presenting coffee materials, inviting neighbors for the coffee, etc.?
- ☐ What role has the child in the ceremony?
- ☐ How do parents react to the child?

### Other times

- ☐ Is the child allowed to participate in discussions with in the family?
- ☐ Do parents give attention to the child's feelings, the child's initiatives, etc.?
- ☐ Do parents allow the child to play with other children?
- ☐ What are the reactions of other parents when the child is playing with their children?
- ☐ What are parents doing with the child so as to improve the participation of their child in education?
- ☐ How are they doing it?
- ☐ What are their reactions?

- Ⓜ Are they giving the child a chance to participate in some activities, which can have importance to broaden the child's social interaction?
- Ⓜ Do they listen to the child?
- Ⓜ What initiative is the child taking?

**Appendix D**

**Introductory letter from Tigray labour and Social Affairs Office to the Missionaries of Charity Mekelle, Tigray.**



ገጽ 01/02/97  
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Date 17-5/001/174  
Ref.n 5-9-97.

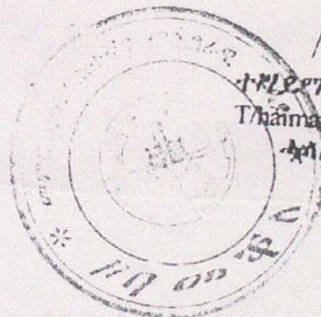
To Missionaries of charity

Mekelle

Ato Yohannes Fissiha Wendu is masters' student in Addis Ababa university Department of psychology. He is currently planning to conduct a research on parental knowledge, Belief and its effect on the educational participation of their mentally Retarded children with particular Reference to Mekelle town.

His Research findings will help as to explore more about this disadvantage group and be an initial gate for Further research and project planning. Cognizant of this fact we request your organization to collaborate and support him by providing relevant data for his research study.

Sincerely



ተዘጋጅ ገ/ሃንበ ተክሉ  
T/haïmanot G/yohannes Teklu  
ገዢ ቢ. ስራ  
Office Head

Appendix E

Introductory letter from Tigray labour and Social Affairs Office to Women Association Office Mekelle, Tigray.




Date 17-5/094/44  
Ref.n 5-9-97

To Tigray women Association  
Mekelle

Ato Yohannes Fissiha Wendu is masters' student in Addis Ababa university Department of psychology. He is currently planning to conduct a research on parental knowledge, Belief and its effect on the educational participation of their mentally Retarded children with particular Reference to Mekelle town.

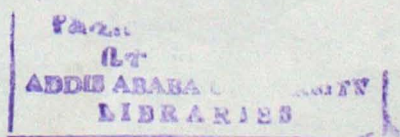
His Research findings will help us to explore more about this disadvantage group and be an initial gate for Further research and project planning. Cognizant of this fact we request your organization to collaborate and support him by providing relevant data for his research study.

Sincerely

  
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Thaimanot Gyohannes Ter'ia  
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Office Head

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## Declaration

"I hereby declare that this thesis is my original work. It has not been presented for a degree in any other university and that all sources of material used for the thesis have been duly acknowledged."

Name: Yohannes Fissiha Wendu

Signature: .....

Place: Addis Ababa University

School of Graduate Studies

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

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

A STUDY OF LOCAL COMMUNITY PARTICIPATION

IN THE IMPLEMENTATION  
OF  
PRIMARY SCHOOL IMPROVEMENT PROJECTS  
IN  
TIGRAI

BY  
GEBRE KIDAN WELDEGEBRIEL TEDLA

A THESIS  
SUBMITTED TO  
THE SCHOOL OF GRADUATE STUDIES  
OF  
ADDIS ABABA UNIVERSITY

IN PARTIAL FULFILMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF MASTER OF EDUCATION  
IN EDUCATIONAL PLANNING AND MANAGEMENT

MAY 2001  
ADDIS ABABA



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A Thesis Submitted to the School of Graduate Studies of Addis Ababa University in Partial  
Fulfillment of the Requirements for the Degree of Master of Education in Educational  
Planning and Management



By

**GEBREKIDAN W/ GEBRIEL TEDLA**

Approved by Board of Examiners

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Chairman, Department Graduate Committee

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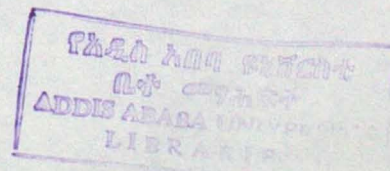
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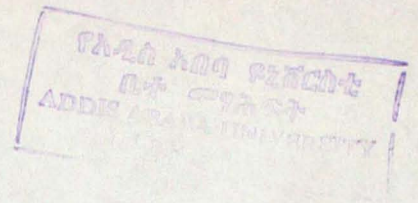
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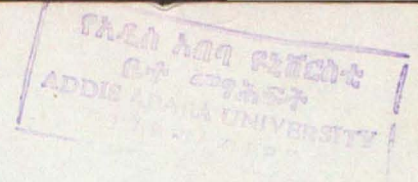


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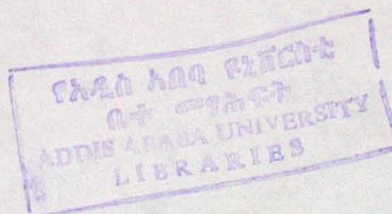
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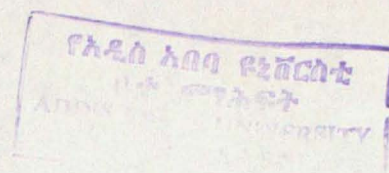
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## ACRONYMS

<b>ABEL</b>	Advancing Basic Education and Literacy
<b>ADF</b>	African Development Foundation
<b>BESO</b>	Basic Education System Overhaul
<b>BRAC</b>	Bangladesh Rural Advancement Committee
<b>CSGP</b>	Community School Grants Programme
<b>DM</b>	Deutsch mark (German Currency)
<b>EFA</b>	Education For All
<b>EPRDF</b>	Ethiopian Peoples' Revolutionary Democratic Front
<b>ESDP</b>	Education Sector Development programme
<b>GROs</b>	Grassroots Organizations
<b>GTZ</b>	Gesellschaft für Technische Zusammenarbeit
<b>HSDP</b>	Health Sector Development Programme
<b>IDCIs</b>	International Development Cooperation Institutions
<b>KFW</b>	Kreditanstalt für Wiederaufbau
<b>MoE</b>	Ministry of Education
<b>MoH</b>	Ministry of Health
<b>NFE</b>	Non Formal Education
<b>NFPE</b>	Non Formal Primary Education
<b>NGOs</b>	Non Government Organizations
<b>OECD</b>	Organization for Economic Cooperation and Development
<b>PEAP</b>	Primary Education Assistance Project
<b>PHRD</b>	Policy and Human Resources Development Project
<b>REB</b>	Regional Education Bureau
<b>SBM</b>	School Board Members
<b>CSSP</b>	Competitive Selection of School Principals
<b>SNNP</b>	Southern Nations and Nationalities Peoples
<b>SNNPR</b>	Southern Nations, Nationalities Peoples' Regional Government
<b>TDA</b>	Tigray Development Association
<b>UNDP</b>	United Nations Development Programme
<b>UNESCO</b>	United Nations Educational, Scientific and Cultural Organization
<b>UNICEF</b>	United Nations Children's Fund
<b>USAID</b>	United Nations Agency for International Development
<b>WEO</b>	Warada Education Office
<b>ZED</b>	Zonal Education Department

## ABSTRACT



This study investigates the participation of local communities in the management and resource support to current primary improvement projects in Tigray Administrative Region. Financial, material and human resources constraints are persistent problems in the education system.

To meet the demand for primary education and improve its quality, it requires the involvement of local communities and the NGO interventions through programs and/or projects. The additional support gained from the community for schools do not seem carefully scrutinized by the education administrators in the region under consideration. To observe the level of local community participation achieved and how it is managed, the study was conducted in 36 primary schools, 12 Woreda education offices, 4 zonal education departments, and the Regional Education Bureau. Contributions of TDA-BESO and PEAP projects were also studied.

Questionnaires and interviews were used for primary sources, and internal documents for secondary sources of data collection and percentages were computed to analyze the data.

Focusing on issues related to additional inputs and management of primary school projects, the study moderately explored where the major gaps remain and what encouraging lessons have been learned. The findings suggest that the support gained from the local people for primary school projects is promising. However, the study evidenced that the following participation problems prevailed in the implementation of primary school improvement projects in the Region. There is lack of regular and open communication and cooperative planning among major partners resulting overlap of project activities in the communities. The accumulation of power from region to local administration but not to the school level reduces its ownership of the projects. The low local community management capacity building has created some problems on proper handling of the day to day activities of the projects such as