COPING WITH DISABILITY: THE SOCIAL RELATIONS OF DISABLED CHILDREN AND YOUTHS WITH THEIR PARENTS AND THE LARGER COMMUNITY, A CASE STUDY IN SELECTED AREAS OF ADDIS ABABA

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 ARTS IN SOCIAL ANTHROPOLOGY

BY GETENET KEBEDE JUNE, 2001

ADDIS ABABA UNIVERSITY SCHOOL OF GRADUATES
Coping with Disability: The Social Relations of Disabled Children and Youths with their parents and the Larger Community: A Case Study in Selected Areas of Addis Ababa

By
Getenet Kebede Gulelat

College of Social Sciences

Approved by Board of Examiners:

Dr. D. T. Henevou
Advisor

Ibris Salih El Hassn
Examiner

Melissa Getu
Examiner

14/16/2001
ACKNOWLEDGEMENTS

I am deeply grateful to my thesis advisor Dr. Paula Heionen for keeping a kindly and encouraging eye on my work; for encouraging me to start this research; for devoting her valuable time in the methodological discussions and giving me helpful criticism of papers and research reports. For painstakingly working over the text of the research and compiled the theses. Without her collaboration the theses would have been impossible.

I am grateful to the projects and directors, Dr. Tibebu and Woizero Gilnesh of Radda Barnen; Ato Fasil and Ato Amakelew of Forum for street children; Sr.Lina Doyal and Sr. Ann of Franciscan Missionary Sister for Africa, for sponsoring both the writing and the anthropological fieldwork. Without the generous financial backing from them I would certainly not have been able to carry out the extensive fieldwork embodied in my study.

I am also indebted to the co-coordinators of MMM and Cheshire CBR for allowing me to conduct interviews; for possibility of discussions on the research families. I certainly wish to record my thanks to Abeba Tsege and Aynalem, for assisting me in collecting the data; Ato Berhanu and Ato Assefa Adinew who helped in editing and offered valuable suggestions. To Sr. Carol (MD) and Sr. Jeanette for allowing me to pursue my M.A. study while on job. To Mebrat and Bizunesh for typing all the paper.

No person or group is more deserving of thanks than the many people who helped me to contact families and chiefly the thirty-nine families themselves. They invested a great deal of time and emotional energy in the research, put up with my many questions and my mistakes with tolerance and good humour, and did everything they could do to help me understand them. Because of my promise that they should remain anonymous, their identities have been disguised, and all names are fictitious.

Above all I am especially indebted to my parents who gave me support and understanding at all the most difficult times. To Elisabeth Gedle, my dear wife, I owe that final burst of energy and confidence that enabled me to complete these theses. To my children Adam and Ermias who have shown their patience during my study. To my father and my mother and brothers
and sisters for encouraging me a lot from the initial time, both financially and psychologically.
# TABLE OF CONTENTS

ACKNOWLEDGEMENTS ............................................................................................................................................................................. 1  
TABLE OF CONTENTS .................................................................................................................................................................................... 3  
LIST OF TABLES .......................................................................................................................................................................................... 5  
LIST OF MAPS ............................................................................................................................................................................................... 6  
GLOSSARY ............................................................................................................................................................................................................... 7  
ACRONYMS ................................................................................................................................................................................................. 10  
Abstract .............................................................................................................................................................................................................. 11  
CHAPTER I ............................................................................................................................................................................................................. 13  
Introduction ......................................................................................................................................................................................................... 13  
  1. General Description on disability.................................................................................................................................................................................. 13  
  2. Objectives of the Study.................................................................................................................................................................................................... 18  
  3. Methodology ........................................................................................................................................................................................................... 19  
    3.1. Family-units survey...................................................................................................................................................................................................... 22  
    3.2. Informants interviewing.................................................................................................................................................................................... 23  
    3.3. Recording case histories.................................................................................................................................................................................................. 23  
    3.4. Focus group discussions.................................................................................................................................................................................................. 23  
    3.5. Observation and Participation........................................................................................................................................................................... 23  
    3.6. Document review................................................................................................................................................................................................... 24  
BACKGROUND INFORMATION ...........................................................................................................................................................................29  
  1. Administrative History of Addis Ababa ........................................................................................................................................................................ 29  
  2. Demographic Information of the study Area................................................................................................................................................................ 32  
  3. Concentration of people with disabilities in Addis Ababa............................................................................................................................. 33  
CHAPTER III ............................................................................................................................................................................................................... 35  
LITERATURE REVIEW .................................................................................................................................................................................................. 35  
  1. The problems of defining disability.................................................................................................................................................................................. 37  
  2. Coping Mechanism ................................................................................................................................................................................................... 39  
  3. Theoretical Perspectives in Disability and Rehabilitation........................................................................................................................................... 42  
    3.1. Theories of disability.......................................................................................................................................................................................................................................................... 43  
    3.2. Rehabilitation Trends ......................................................................................................................................................................................................................... 46  
CHAPTER IV ............................................................................................................................................................................................................ 50  
THE SOCIAL CONSTRUCTION OF DISABILITY AND ITS IMPACT ON TREATMENT ........................................................................................................................................................................ 50  
  1. MEDICAL MODEL ........................................................................................................................................................................................................ 53  
    1.1 Medical Model and Parents of Children with Disabilities........................................................................................................................................................................... 53  
    1.3. Medical Model and children with Disabilities........................................................................................................................................................................... 59  
  2. THE SOCIAL MODEL .................................................................................................................................................................................... 61  
    2.2 The Social Model and Children with Disabilities.................................................................................................................................................................................................. 63  
  3. COMBINED SOCIO-MEDICAL MODEL ............................................................................................................................................................................. 66  
    3.1 The Socio-Medical Model and Parents of Children with Disabilities........................................................................................................................................................................... 66  
    3.2 The socio-Medical Models and Individual Caretakers........................................................................................................................................................................... 67  
    3.3 The Socio Medical Model and Children with Disabilities........................................................................................................................................................................... 68  
  4. The Social Model in Association with Community, Institution and/or Organization .................................................................................................................................................................................... 69  
    4.1 The Social Model and Community Action........................................................................................................................................................................... 70  
    4.2 Being Disabled After and Before Birth ........................................................................................................................................................................... 71  
  5. Institution’s Role towards "Integration"........................................................................................................................................................................ 72  
  6. Settlement Pattern, Economy and Attitude: ........................................................................................................................................................................ 73  
CHAPTER V ........................................................................................................................................................................................................... 76
LIST OF TABLES

Table 1: Children and Youth with Disabilities by Age and Type of Injury ................. 21
Table 2: Household Profiles of Children and Youth with Disabilities ...................... 22
Table 3: Population of the Municipality of Addis Ababa, 1952 ................................. 30
Table 4: Distribution of the Population of Addis Ababa by Year ............................. 31
Table 5: Total Population of Zones by Sex, 1994 .................................................. 31
Table 6: Population Size of the study areas: Wereda 13, 25 and 8 ......................... 32
Table 7: Population by Disability Status, 1994 ..................................................... 34
# LIST OF MAPS

<table>
<thead>
<tr>
<th>MAP</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>MAP 1</td>
<td>Addis Ababa</td>
</tr>
<tr>
<td>MAP 2</td>
<td>Woreda 13</td>
</tr>
<tr>
<td>MAP 3</td>
<td>Woreda 25</td>
</tr>
<tr>
<td>MAP 4</td>
<td>Woreda 8</td>
</tr>
</tbody>
</table>
GLOSSARY

1. Amharic terms

Annd Amelak: One God
Buda: Evil eye
Debtera: Unordained but highly trained clergyman
Derg: The ex-military government of Ethiopia
Duuaa: Religious Prayer in Muslim religion
Edir: Communal burial association
Egziabbher Kuta: Anger of God.
Egziabbher: God
Ekub: A form of rotating saving scheme
Enatoch Le Enatoch: An association where mothers of children with disabilities gathered.
Ferage: One who has a power of knowing about every problem.
Gabriel: Saint Gabriel
Injera: The staple pancake, like bread, staple food of most Addis Ababa
Kebele: The lowest administrative unit.
Kedus: Holy
Keftegna: Administrative unit higher than kebele [Presently replaced by the term Wereda]
Ketena: Administrative unit higher than Wereda
Komata: Leper. It is a kind of disease considered shameful and hereditary
Kurban: Holy Communion
Lekeft: Spiritual possession caused by a devil
Maheber: Socio-religious association common among Orthodox Christians
Melaekts: Angles
Menfes: Religious Spirit
Rufael: Holy person who is believed for getting sanctity after death by Orthodox Christians. A church is constructed by his name.

Safar: The smallest residential area of a kebele.

Seitan: Devil/Satan

Senbete: Socio-Religions association whose meetings take place in Church Compounds.

Shek: A religious leader in Muslim religion.

Tebele: Holy Water

Tella: Home-made beer

Wereda: Administrative unit higher than kebele

Wogesha: Local name for a person, who does physiotherapy, without a formal training.

Wukabi: Spirit Possession

Yeager Bahil Medhanit: Cultural Medicine

Yebuna Mahiber: Mahiber in which "Buna" (Coffee) is served to the members.

2. English (Medical) terms

Atrophy: A Progressive disease or weakening of the muscles that comes from problems in the nerves.

Calliper (brace): An aid that gives support to a weak or injured leg.

Contracture: Reduced range of motion in a joint, often due to muscles shortening.

Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Dislocation: Damage to the joint, the bone ends have slipped out of their normal position.

Dystrophy: A progressive muscle weakness that comes from problems in the nerves.
**Handicap:** A disadvantage for a given individual, resulting from impairment a disability that limits or prevents the fulfillment of a role that is normal for that individual.

**Hemiplegia:** Paralysis or loss of movement in the muscles of the arm and leg on one side of the body only.

**Impairment:** Any loss or abnormality of physiological or anatomical structure or function.

**Limb:** an arm or leg.

**Muscular dystrophy:** A condition in which muscles, month by month and year by year, get weaker.

**Orthopaedic:** aids, procedures, or surgery to help corrects a physical deformity or disability.

**Orthotist:** A brace maker

**Paraplegia:** Paralysis or loss of movement in the muscles of both legs caused by disease or injury to the spinal cord.

**Physiotherapist:** A person who designs and teaches exercises and activities for physically disabled persons.

**Poliomyelitis:** An infectious disease epidemic and endemic that causes a lower motor neuron type of paralysis with flaccid paralysis and normal sensation.

**Progressive:** A disability that steadily gets worse and worse.

**Prosthesis:** An artificial limb or other parts of the body.

**Spasticity:** uncontrolled tightening or pulling of muscles.

**Spinal Cord:** The main "trunk line" of nerves running down the backbone.

**Spinal:** Having to do with the spine or backbone

**Spinal-Cord injury:** damage or cut both the sensory and action nerves. It is the severe damage of central nerve cord in the neck or back.

**Spine:** Backbone, spinal column, the chain of bones, called vertebra that runs down the back.

**Therapy:** Planned exercises and activities for a person's rehabilitation.
### ACRONYMS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSO</td>
<td>Central Statistics Office</td>
</tr>
<tr>
<td>CSA</td>
<td>Central Statistics Authority</td>
</tr>
<tr>
<td>FDRE</td>
<td>Federal Democratic Republic of Ethiopia</td>
</tr>
<tr>
<td>MOLSA</td>
<td>Ministry of Labour and Social Affairs</td>
</tr>
<tr>
<td>MMM</td>
<td>Medical Missionaries of Mary.</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organization.</td>
</tr>
<tr>
<td>CBR</td>
<td>Community Based Rehabilitation</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>ILO</td>
<td>International Labor Office</td>
</tr>
<tr>
<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organization.</td>
</tr>
<tr>
<td>RAD</td>
<td>Rehabilitation Agency for the Disabled</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Program</td>
</tr>
<tr>
<td>DOC</td>
<td>Daughters of Charity</td>
</tr>
<tr>
<td>VCH</td>
<td>Voluntary Counsel for the Handicapped</td>
</tr>
<tr>
<td>EPRDF</td>
<td>Ethiopian People Revolutionary Democratic Front</td>
</tr>
<tr>
<td>CP</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>MD</td>
<td>Muscular Dystrophy</td>
</tr>
</tbody>
</table>
Abstract

The study is an attempt to make an anthropological analysis of the coping mechanism of children and youths with disabilities and their parents and the social relationship of children with disabilities living in Woreda 13, 25 and 8, with their parents and the larger community. The sample of the study consists of 39 children and youths with disabilities. The study focused only motor impaired children and youths. The type injures constituted in the study were: only one leg; only hand; only back; only hand and leg; and both legs, hand and back. The methods employed for data collection were family unit survey, informants interviewing, recording case histories, focus group discussions, and observation and participation.

The work contains a general introduction on disability and description of the methodology that are used to conduct this research followed by five major chapters. The second of these is devoted to a short summary of the background information of the study areas and historical development of Addis Ababa as well as description of the methodology I used to conduct the research. The third chapter is devoted to a review of literature dealing with the general discussions regarding the various issues involved in conceptualization of the term "disability". It looked into the perception of disability by anthropologists and sociologists and rehabilitation trends. The fourth chapter unveils the social and culture processes that shape the perception of disability and its impact on treatments. In order to make the illustration more clear, respondents beliefs about disability and health care were grouped into three explanatory models: Medical, Social, and the combination of the two. The fifth chapter discusses the type of problems that disability creates for children with disability and their parents. It looked into the types of social support and social network that existed in the study area .The six chapter attempts to show the coping mechanisms used by children with
disabilities and their parents. I have attempted to show the role of family, institutions with lives of disabled as well as children own coping mechanisms.
CHAPTER I

Introduction

1. General Description on disability

Several global estimates of the prevalence of disability have been made in the past. WHO in 1976 showed that 10 per cent of the world population is disabled (Helander, 1993:21). A UNICEF report (1988) indicated that the percentage of persons with disabilities in developing countries is estimated to be as high as 20%. As Pandey and Advany (1995:15) indicated, Helander in his latest edition, prejudice and dignity, 1990, revised his 1974 estimate to 5.21 percent. Helander further indicated that 7 per cent of the world children have disabilities predominantly in developing countries (Helander, 1993:221.)

Tirussew (1998:65) states that there is an enormous knowledge deficit in relation to disabled persons in Ethiopia. Data pertaining to incidence, prevalence and situation of persons with disabilities in Ethiopia are fragmentary and incomplete. Local surveys were undertaken in 1979-80 and 1983, and in 1984 by CSO; but they do not show the whole picture of the country (Tirussew et al, 1995: 2). The most recent report about the disability status and type of disability on Ethiopia is the national population and housing census of the CSO (1994). According to CSO results, out of the total population of 53,095,877, which the census covered, 988,849 or 1.86 percent were disabled.

The history of disability is as old as human history. The early history of societal involvement with persons with disabilities was primarily based on the recognition of the difference of
disabled individuals from that considered normal in appearance or behavior (Tirussew et al, 1995:9). People who were different from the non-disabled were believed to be possessed by demons or evil spirits. Until the 16th Century the general picture was similar. Prior to the emergence of capitalism, Western society had a consistent bias against people with impairments. Physical and intellectual fitness was essential to a person’s life (Barnes, 1996:52). Reactions to the presence of human beings with disabilities in industrialized nations were varied (Helander, 1993:66-71).

As the 19th Century came to a close, new voices and new ideas began to be heard. From 1800 to 1900 the institutional movement swept Europe and the United Sates of America (Tirussew, 1995:9). World War II resulted in a significant increase in the disabled population of most industrialized countries. For many countries, providing those people with a rehabilitation program became a national priority. In the years that followed other groups of disabled people shared the same services (Helander, 1993:4). The International Year of Disabled Persons in 1981, followed by the United Nations Decade for Disabled Persons declared by the United Nations in 1983, put disability into a global context and posed the question of how it may be understood in a multicultural world (Ingstad and Whyte 1995:3).

People with disabilities in developing countries, like their counterparts in Europe, have encountered many problems. The governments of many countries had never committed themselves to providing public services for these large groups of citizens (Helander, 1993:4). Access of the disabled persons to appropriate services in developing countries is generally inadequate. The estimate of those who get such services is generally less than 3 per cent in developing countries (Daniel 1997:4-5). The rehabilitation sector was and still is to a large extent managed and financed by charitable organizations (Helander, 1993:4)
The history of peoples with disabilities in Ethiopia is not different from other developing countries. Disability is one of the social problems prevalent in Ethiopia (MOLSA, 1996). The rehabilitative services that are available today in our country emphasize institutional care, are costly and, therefore greatly limit the number of persons with disabilities who can benefit from them. Worse still, these institutions are very few and concentrated in urban areas and thus exclude the majority of those who need the services (Ibid).

The level of esteem and social standing of disabled people is derived from how disability is perceived in society. In contrast to 'healthy people' the disabled face all sorts of discriminations. They are usually recipients of a range of offensive responses by other people. These include horror, fear, anxiety, hostility, distrust, pity, overprotection and patronizing behaviors. The problem lies in defining disability. One of the dominant influences in shaping both professional and common sense definitions of disability has been the medical model.

As Hahn (cited in Barton, 1996:8) notes:

'This approach imposes a presumption of biological or psychological inferiority upon disabled persons. It emphasizes individual loss or inability thereby contributing to a dependency model of disability. Labels such as 'invalid', 'crippled', 'spastic', 'handicapped', and 'retarded' all imply both
functional lack and lack of worth. Such labels have tended to legitimize
negative views of disability’.

Richardson et al (1961) book on children's attitudes towards disability is one of the early anthropological studies on the issue of disability. Medical anthropologists have long been interested in physical disability as a social issue (Kellmer Pringle et al, 1966; Rutter et al, 1975. More recent anthropological studies have touched upon disabled people’s enabling relationship with their families as well as with members of their communities and explored the effects of disability on their life chances and life styles (Booth, 1978; Shearer, Bibl.1981; Scrambler, 1984; Ablon, 1990; James, 1993; Zinkin and McConachie, 1995; Ingstad and Whyte, 1995; Murphy, 1995; Talle, i995).

Regarding the 1996 social welfare policy of Ethiopia, the ousted military government had paid little or no attention. Where as the constitution of Federal Democratic Republic of Ethiopia has laid the foundation for a new policy. The segments of the society given priority concern, among others, are persons with physical and mental impairment. This policy falls under article No. 5.6 sub article 5.6.1. Issues constituted under this sub article are: encouraging the disabled to use their abilities to associate with others to contribute to development; providing them with education and employment opportunities; helping them to receive appropriate medical/ health services; giving appropriate support services in the context of their family and community environment; establishing special centers for care; raising the level of public awareness concerning disability; make effort towards making public places more physically accessible to persons with disability; and providing support and assistances to community action groups, non- governmental organizations and voluntary
associations involved in providing services to persons with physical and mental disabilities (MOLSA 1996: 13-14).

However, disabled children and youth in Ethiopia are among the most socially, economically and politically disadvantaged social groups. In other words, to be disabled means to be discriminated against as well as suffering social isolation and physical restrictions. Persons with disability do not always have access to rehabilitative services, simply because the availability of such service, due to the low level of attention given to disabled groups by past regimes and the present Government, parents and relatives of disabled were and are still the crucial actors in the provision of care and education for the majority of disabled children and youth (FDRE/MOLSA, 1996:6). Backward societal attitudes perpetuate prejudices towards persons with disabilities. This in turn influences their life style and life chances.

The present study documented the various ways (i.e. in cultural or medical terms) Ethiopian parents defined their children's disability and children and youth with disabilities (physical motor impaired) defined disability and how this affected the enabling relationship such children have with their immediate families and with others. Additionally the study explored economic and social factors that impeded such children's access to health care, education, leisure activities and future life chances. The principal defining criterion for community is what people do for each other. A social network approach was used to study the community supportive networks used by the disabled without necessarily assuming that all communities are local solidarity groups.

The following chapters are grouped into seven chapters, each with a short introduction to give the reader a preview of what is in store and how the chapters relate to one another. The
The first chapter deals with a general description of disability, objectives of the study, and the methodology utilized in conducting the research. In the second chapter, the theme is background information that is to give a short description of the three research settings. The third chapter deals with literature review, which considers the analytical issues involved in dealing with disability and culture by various authors. The fourth chapter, social construction of disability, delves into social and cultural processes that shape the lives of disabled children and youths. The fifth chapter deals with social support and social network systems in the study areas, i.e. the type of social networks and social support systems used by children with disabilities and their parents. The sixth chapter investigates the coping mechanisms at home and within the community. The final chapter, the summary and conclusion part, considers the analytical issues raised in the above mentioned chapters. It suggests directions for further research and shows how the chapters in this thesis point the way.

2. Objectives of the Study

Major Objectives:

- To examine the different ways that disabled children and parents define physical disability i.e. in cultural terms, (That is as a curse, device retribution, fate, etc.) or in medical terms (that is a pathological condition).
- To assess whether family structures (i.e. female headed household, nuclear family, extended family, etc.) and economic circumstances affect the type of social supportive and material care such children receive at home and within their communities.
- To explore the type of social networks and social support systems used by children with disabilities and their parents as coping mechanism at home and within the community.

Specific Objectives:

- To determine whether the manner in which parents define their children's disabilities (cultural versus medical) affect the type of care such children receive in spite of the families’ economic (material) circumstances
- To assess the type of coping mechanism used by parents who define their children's disability in cultural terms and those who explain it in medical terms.
- To assess whether the type of family unit such children stem from affect their social and material well-being
- To investigate whether economic or purely social factors impedes their access to formal education, health care, leisure activities and employment.
- To explore the type of personal ties with relatives, friends, neighbors and Workmates used as social network and social support mechanism by materially deprived versus materially better off parents within the community.

3. Methodology

The decision to choice of three sites of the study areas was mainly because of my acquainttance both with the persons with disabilities living in those areas and the NGOs engaged in rehabilitation activities. I became interested in the study of problems of children and youths with disabilities, in the study areas, due to my direct interaction as a social worker
with these groups. Thus, these relations have helped me a lot in the gathering of data on the various issues I have raised. The population covered in the study are all disabled groups with whom the two NGOs, MMM and Cheshire CBR’ are working. I went to officials in these institutions of the two NGOs and have given me lists of 750 children and youths with different types of disabilities, after exchange of letters and explained what I were doing and that I wanted help in finding families. Regarding the sampling, all the children and youths with physical motor impairments were first screened by check lists. Semi-structured interview was administered on 250 children with physical motor impairments. So random samples were taken from the three sites- 15 children and youths with physically motor impaired were taken each site equally. Of the forty-five families (households) only thirty-nine were willing to be studied. This according to my observation and experience in the field was due to the stigma attached to disability. Had it not been through those NGOs, doing research on those families would not be possible. Therefore the sample printed to disabled groups with whom the NGO are working.

In conducting this research the following research methods were utilized. These included: family units survey, interview, recording case histories, focus group discussions, participant observation and document review. The parents included in this section are parents of children under age seven. The others, children with physical motor impairment, were allowed to respond independently, in the absence of their parents. This was mainly done because children believed to start knowing themselves at the age of seven. According to the study of Radda Barner (1996 on child rearing practices) the notion of LIJ NEFSUN SIAK (when a child is aware of right or wrong) is not a novel classification restricted to Ethiopia. Medical research has established that DHEA a molecule from which the endocrine glands produce sexual hormones appears in the blood at around age of 7 and not before. If increases up to age
of 25 and then gradually diminishes (Addis Tribune: 1995). There is also an extensive literature in psychology and anthropology that asserts age 7 marks the onset of a child's intellectual development (Radda Barnen, 1996:22).

Based on the above facts those children below age 7 were not directly approached during the research interview. Instead parents were asked about their children's disability. But children above age 7 were directly requested about their perception on disability, the causes of their disability, and other issues mentioned on the research objectives. The study consists of parents of children with different kinds of disabilities: injuries of hand; legs; hands and legs; and hand, legs and back.

**Table 1: Children and Youth with Disabilities by Age and Type of Injury**

<table>
<thead>
<tr>
<th>Age</th>
<th>Only leg</th>
<th>Only hand</th>
<th>Only back</th>
<th>Both leg and back</th>
<th>Hand and Leg</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-6</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10</td>
</tr>
<tr>
<td>7-17</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td></td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>18 and above</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>21</td>
<td>39</td>
</tr>
</tbody>
</table>

During the field work parents with disabled children and children and youths with disabilities were asked whether they accept or deny the construction of themselves that are offered by the community, whether they had received support when their children disability began and the type of social support network that exists (whether it is in the form of information, material assistance, or emotional empathy) and their sources of social support (friends, neighbors, families, community etc.)
The study has constituted the following types of families: two parent families (26), single parent headed household families (6); families headed by sisters and brothers (1), families headed by grandparents (4) and children living by themselves no parent (2).

**Table 2. Household Profiles of Children and Youth with Disabilities**

<table>
<thead>
<tr>
<th>Type of Family</th>
<th>Children not living with family</th>
<th>Children living with family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Working Children</td>
<td>Non-working Children</td>
</tr>
<tr>
<td>Two Parents</td>
<td>2</td>
<td>24</td>
</tr>
<tr>
<td>Single parent headed Household</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Sisters &amp; Brothers</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Grandparents</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>No parent</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
<td>6</td>
</tr>
</tbody>
</table>

Details of the methodology utilized during the study are described below:

**3.1. Family-units survey:**
I was given a list of children with disabilities from two NGOs namely Medical Missionaries of Mary (MMM) disabled children unit and Cheshire Community Based Rehabilitation, working in the three woredas. Selected 39 families following a systematic random sampling procedure. An in-depth study was carried out on the above-mentioned target groups. Basic information regarding the demographic characteristics such as age, sex, occupation, ethnic and socio-economic background, and educational level were gathered. Questionnaire interview was administered with the help of two guides from woreda 13 and one each from woreda 8 and 25. This was mainly done to assess whether family structures and economic circumstances in the study areas affected the type of social supportive and material care such children receive at home and within their communities they reside in.
3.2. Informants interviewing:
Semi-structured interviews were carried out with the disabled children and their parents. This was in order to determine whether the manner in which parents define their children's disabilities affect the type of care such children receive in spite of the families' economic (material) circumstances; and to examine the different ways that children and youths with disabilities and their parents define disability in cultural and medical terms. A combination of parents of children with disabilities, caretakers and children with disabilities were approached.

3.3. Recording case histories:
The detailed case histories of thirty-nine children with disabilities, parents of children with disabilities and caretakers living in thirty-nine households were recorded with sixty- and ninety-minute cassette recorder. These people represent various social, economic and cultural backgrounds. I spent many hours with my informants. These were during day and night-time depending on my informant's convenient time. Some of the case studies are presented in full in the text while others are used to support ethnographic descriptions.

3.4. Focus group discussions
A groups of individuals with disabilities, parents of children with disabilities, caretakers (women and men) and community members living in the targeted area were invited and participated in a group session to express their views and feelings regarding disability, coping mechanism and networking. I had to make several lists in order to get relevant information, even after I had selected my key informants.

3.5. Observation and Participation:
Despite the many years of acquaintance with several children with disabilities, youths and their respective families, especially in woreda 13, getting into the research area was not a simple task. Informants were not always available for interview because of the various
personal activities they were involved. I participated in and observed the day to day socioeconomic relations among the target population. I observed experience sharing forums such as communal coffee sharing ceremonies, mother to mother gatherings, funeral association (Edir), saving association (Ekub) and child to child groups. This was to explore the type of social networks and social support systems used by children and youths with disabilities and their parents as coping mechanisms at home and within the community.

3.6. Document review
I gathered relevant written materials from different governmental and non-governmental organizations; university and other institution libraries. The review of documents focused on the works of anthropologists, sociologists and social psychologists. Since the works of anthropologists on disability is limited I could not go into much depth. Therefore this thesis has this limitation. But within its scope the review has tried to demonstrate a familiarity with a body of knowledge in the fields of disability and tried to integrate and summarize what is known in this area.
WEREDA 25

SOURCE: URBAN DEVELOPMENT & WORKS BUREAU, 2001
SOURCE: URBAN DEVELOPMENT & WORKS BUREAU, 2001
CHAPTER II

BACKGROUND INFORMATION

This chapter presents a short summary of the physical and social environment of the present study areas and historical development of Addis Ababa City. It attempts to show an overview of people with disabilities in Addis Ababa and the present status of people with disabilities in the study areas. The first section serves as a short summary of the historical development of Addis Ababa City. The second section deals with short description of the overall demographic characteristics of the study areas. The final section deals with concentration of people with disabilities in the study area.

1. Administrative History of Addis Ababa
Many authors have written about Addis Ababa (Pankhurst R. (1957, 1962,1987); Pankhurst S. (1957); Bahru Zewde (1984, 1987, 1995); Foucher (1987); Garreston (1974); and Eshete Assen (1986). Pankhurst S. (1957: 35) in the journal Ethiopia Observer discussed the pre-Italian, Italian and post-Italian periods of development of Addis Ababa. She pointed out that Addis Ababa at that time was the largest town between Cairo and Johannesburg.

Since its foundation by the Emperor Menelik in the latter part of the 19th century, Addis Ababa has more than a hundred years history from the early Safars (districts) to its growth into a big city. In the history of its administrative divisions the Safars are persisting against changes introduced through time (Zerihun 1999:32). The built-up area that we see today is the result of many decades of steady growth.

Before the Emperor, Haileselassie I, invited a town planner called Sir Patrick Abercormbie in 1946 (Pankhurst S. 1957: 36), the city was divided into ten commissariat which again
changed into ten *weredas* when the municipality administration was established in 1942 (Bahn1 1987). Many safars were constituted under *woreda* (Bahru 1987:51). Different master plans of Addis Ababa were tried. Among others, Professor Polyny's, Architect L De Mariene's, Sir Abercrombi's, Guidi's and Valle's master plans are some (Ibid.).

The population of Addis Ababa in 1956 was estimated to be 397,625, and the three regions of high density at that time were: the valley of *Ginfle* stream; old *Ghibbi*; and the Great Market. The unoccupied areas, were: the areas between the *Bishofteu* Road (now Debrezeit Road in the south of Addis Ababa) and the Kabana river; the *Kolfe* Road and Mesfin Harar Street; and *Akaki* Prison. Addis Ababa at the time was divided into seven zones (Ibid. 3645). According to C.K Wang (1957:56) Addis Ababa City in 1952 comprised 10 districts with a radius of some 12 kilometers round the center of the city.

### Table 3: Population of the Municipality of Addis Ababa, 1952

<table>
<thead>
<tr>
<th>Districts</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arada</td>
<td>51079</td>
</tr>
<tr>
<td>Entoto</td>
<td>31819</td>
</tr>
<tr>
<td>Yeka</td>
<td>15295</td>
</tr>
<tr>
<td>Mekakeligna</td>
<td>59206</td>
</tr>
<tr>
<td>Maychew</td>
<td>33500</td>
</tr>
<tr>
<td>Bole</td>
<td>20396</td>
</tr>
<tr>
<td>Tekle Hymanot</td>
<td>115256</td>
</tr>
<tr>
<td>Geferssa</td>
<td>33622</td>
</tr>
<tr>
<td>Goulele</td>
<td>27826</td>
</tr>
<tr>
<td>Keranio</td>
<td>14016</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>401915</strong></td>
</tr>
</tbody>
</table>


The geographical space of today's *Ketenas* (Zones): *Woredas/Kefitegnas* (Higher/Districts) and *Kebeles* (Safars) of Addis Ababa are recognized in terms of hierarchical (*Kebele* ---- > *Woreda* ------ > *Zone*) administrative regions, after the 1974 Ethiopia socialist Revolution (Feleke, 1999: 26. According to Feleke the city at that time was divided into six *Ketenas* (zones), 28 *Kefitegnas/Woredas* (Higher/ Districts) and 305
Kebeles (23 of them are newly incorporated peasant associations (Ibid.: 27. We can see the growth of Addis Ababa from the data below collected by Feleke (Ibid.: 28).

Table 4: Distribution of the Population of Addis Ababa by Year

<table>
<thead>
<tr>
<th>Year</th>
<th>Population</th>
<th>Average Annual Growth rate %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1909</td>
<td>60,000</td>
<td></td>
</tr>
<tr>
<td>1910</td>
<td>65,000</td>
<td>8.3</td>
</tr>
<tr>
<td>1935</td>
<td>100,000</td>
<td>2.1</td>
</tr>
<tr>
<td>1952</td>
<td>317,000</td>
<td>12.1(8.7)</td>
</tr>
<tr>
<td>1961</td>
<td>443,000</td>
<td>4.0</td>
</tr>
<tr>
<td>1967</td>
<td>644,190</td>
<td>6.5</td>
</tr>
<tr>
<td>1970</td>
<td>795,900</td>
<td>5.9</td>
</tr>
<tr>
<td>1975</td>
<td>1,120,000</td>
<td>6.8</td>
</tr>
<tr>
<td>1980</td>
<td>1,277,159</td>
<td>2.3</td>
</tr>
<tr>
<td>1984</td>
<td>1,412,575</td>
<td>2.1</td>
</tr>
<tr>
<td>1997</td>
<td>2,700,000</td>
<td>6.5</td>
</tr>
</tbody>
</table>


** Refers to the corrected percentage calculated by the author (Feleke)
* Does not include the foreigners who were living at that time, 10,859 (Pankhurst S. 1957;37)

The population data of Addis Ababa shown above indicates an increase fifty-fold time. The population of Addis Ababa in 1909 was 60,000 and in 1997 about 2,700,000. The reason for the growth, according to Feleke (1999:29), was due to the rural insecurity and the attraction of the urban economy. According to the CSA census report (1994) the population of Addis Ababa in its 6 zones or 27 weredas or 305 kebeles had reached 2,112,737.

Table 5: Total Population of Zones by Sex, 1994

<table>
<thead>
<tr>
<th>Zone</th>
<th>Both Sexes</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>314,565</td>
<td>155,478</td>
<td>159,087</td>
</tr>
<tr>
<td>02</td>
<td>427,238</td>
<td>208,204</td>
<td>219,034</td>
</tr>
<tr>
<td>03</td>
<td>380,174</td>
<td>181,222</td>
<td>198,952</td>
</tr>
<tr>
<td>04</td>
<td>416,313</td>
<td>219,807</td>
<td>241,506</td>
</tr>
<tr>
<td>05</td>
<td>434,611</td>
<td>212,290</td>
<td>222,371</td>
</tr>
<tr>
<td>06</td>
<td>94,786</td>
<td>46,451</td>
<td>48,355</td>
</tr>
<tr>
<td>Total</td>
<td>2,112,737</td>
<td>1,023,452</td>
<td>1,089,285</td>
</tr>
</tbody>
</table>

Source: (CSA,1994:11)
The study areas (wereda 13; and wereda 25 and 8) are found in adjacent zones: zone 4 and 5. Wereda 13 is situated in zone 4 and wereda 8 and 25 are situated in zone 5 of Addis Ababa.

2. Demographic Information of the study Area
As a geographic setting, Wereda 13 is situated in the north-east; and wereda 8 and 25 in the west part of Addis Ababa. Wereda 13 is bounded by seven weredas (wereda 1, 2, 14, 1S, 16, 12 and 11); wereda 25 is bounded by three weredas (woreda 24, 7, and 81; and woreda 8 is bounded by four weredas (woreda 25,7,9, and 10) (See map 1). The three weredas; 13,25 and 8; under them have eleven, nine, and fifteen kebeles (safars) respectively. Their population size to-date is as follows.

Table 6: Population Size of the study areas: Wereda 13, 25 and 8.

<table>
<thead>
<tr>
<th>Kebele</th>
<th>Population</th>
<th>Kebele</th>
<th>Population</th>
<th>Kebele</th>
<th>Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>001</td>
<td>4580</td>
<td>001</td>
<td>11,186</td>
<td>001</td>
<td>5127</td>
</tr>
<tr>
<td>002</td>
<td>5535</td>
<td>002</td>
<td>4,222</td>
<td>002</td>
<td>13504</td>
</tr>
<tr>
<td>003</td>
<td>12511</td>
<td>003</td>
<td>12,378</td>
<td>003</td>
<td>4097</td>
</tr>
<tr>
<td>005</td>
<td>6504</td>
<td>004</td>
<td>16,203</td>
<td>005</td>
<td>5841</td>
</tr>
<tr>
<td>006</td>
<td>7001</td>
<td>005</td>
<td>4568</td>
<td>006</td>
<td>6038</td>
</tr>
<tr>
<td>008</td>
<td>7466</td>
<td>006</td>
<td>7800</td>
<td>010</td>
<td>5003</td>
</tr>
<tr>
<td>009</td>
<td>4051</td>
<td>007</td>
<td>8762</td>
<td>011</td>
<td>5624</td>
</tr>
<tr>
<td>010</td>
<td>3798</td>
<td>008</td>
<td>5261</td>
<td>013</td>
<td>5662</td>
</tr>
<tr>
<td>011</td>
<td>4190</td>
<td>016</td>
<td>10,504</td>
<td>014</td>
<td>5208</td>
</tr>
<tr>
<td>015</td>
<td>5219</td>
<td>015</td>
<td>3952</td>
<td>022</td>
<td>4123</td>
</tr>
<tr>
<td>016</td>
<td>3998</td>
<td>025</td>
<td>3139</td>
<td>024</td>
<td>4123</td>
</tr>
<tr>
<td></td>
<td></td>
<td>025</td>
<td>3444</td>
<td>035</td>
<td>14714</td>
</tr>
</tbody>
</table>

Total 64853 80884 87895

Sources: CSA,1994:15-16
Table 6 clearly shows that wereda 8 has higher number of people than wereda 13 and 25. Wereda 13 is the least populated area. But when we compare them by number of kebeles, wereda 8 has fifteen, wereda 13 eleven, and wereda 25 nine kebeles. This implies that the wereda with high number of population has larger area than other woredas.

The total housing unit in the three woredas (13, 25 and 8) is 12370, 13111, and 14146, respectively. On the average the number of persons per housing unit in zone 4 and 5 is 5.3 and 5.8, respectively. Most of the housing units (wereda 13,12090; weredas 25, 12791; and wereda 8, 13947) are constructed with corrugated iron sheets (CSA, 1994). Furthermore, the 1994 CSA report shows that there is a problem in drinking water, availability of toilet facility, kitchen, and lighting.

Reliable data regarding disability and number of people with disability are not available in view of the fact that to date no nation wide study has been undertaken in this area, in Ethiopia. There is therefore an enormous knowledge deficit in relation to disabled persons (Tirussew Teferra, 1998: 65). WHO 1974 estimates that on the average disabled person represent 10 percent of the population of developing countries (Advany, L., and Pandy, R.S., 1996:15). Helander, 1990 in his latest book, Prejudice and Dignity, estimated the prevalence of disability in Developing countries as 5.21 percent.

Even though, data pertaining to the prevalence and situation of person with disabilities in Ethiopia are fragmentary and incomplete, there were four surveys undertaken from 19791990 by four organizations: Ministry of Agriculture, Central Statistics Office, Rehabilitation Agency for the Disabled, National children commission and UNICEF
(TiruSsew et al. 1995:2). The above surveys are major landmarks and highly appreciated moves undertaken in this area of endeavour in the country. According to TiruSsew’s (Ibid. 26) finding, the prevalence of disability amounts 2.95%.

The 1994 CSA census presents disability status and type of disability for the city of Addis Ababa. It is only for each zone. At the country level the 1994 CSO data shows that there were 988,894, disabled persons (i.e. 1.86 per cent of the total population). In Addis Ababa there were 45,936 disabled persons (i.e. 2.2 percent of the total population excluding the homeless) (CSA, 1994: 70).

Table 7: Population by Disability Status, 1994

<table>
<thead>
<tr>
<th>Zone</th>
<th>Total population</th>
<th>No' disabled</th>
<th>Disabled</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>312,145</td>
<td>303,836</td>
<td>8186</td>
<td>2.62</td>
</tr>
<tr>
<td>2</td>
<td>424,467</td>
<td>412,957</td>
<td>11316</td>
<td>2.67</td>
</tr>
<tr>
<td>3</td>
<td>376,656</td>
<td>370,916</td>
<td>5430</td>
<td>1.44</td>
</tr>
<tr>
<td>4</td>
<td>459,424</td>
<td>448,507</td>
<td>10,726</td>
<td>2.33</td>
</tr>
<tr>
<td>5</td>
<td>432,560</td>
<td>424,173</td>
<td>8489</td>
<td>1.96</td>
</tr>
<tr>
<td>6</td>
<td>94,560</td>
<td>92,691</td>
<td>1789</td>
<td>1.89</td>
</tr>
<tr>
<td>Total</td>
<td>2,100,031</td>
<td>2,053,089</td>
<td>45,936</td>
<td>2.19</td>
</tr>
</tbody>
</table>


Table 7 shows that the two zones have the second highest concentration of disabled persons next to zones 1 and 2 of Addis Ababa. The disability status for weredas is not provided by CSA (1994).
CHAPTER III

LITERATURE REVIEW

Many authors indicated that there is lack of literature on disabled people in developing countries. Most of the scholarly work dealt with Europe and North America. Even though there are some literatures on disability in non-Western countries, they have been mostly in the area of mental health; chronic mental illness, epilepsy, and mental retardation (Ingstad and Whyte, 1995:4). In regard to this there is an enormous knowledge deficit in Ethiopia (Tirussew 1998: 651).

Seeing disability as a type of deviancy confuses many issues, leading to a theoretical dead end for social scientists (Murphy 1995:153). The past three decades have witnessed the emergence of the area of the disability studies, whose intellectual heritage is based on the generic academic disciplines of medical science, psychology, political theory and sociology (Lang 2000:1). Though the articles are based on research in North America there are some
earlier anthropological contributions (See Ablon, 1984; Edgerton, 1967; Estroff, 1981; Groce, 1985; Murphy, 1987).

Medical sociology has long been concerned with the process of interpreting, negotiating, and labeling disabilities. Since the 1960's analytical issue have emerged which continue to shape disability studies. One is the notion of stigma and social interaction (Gofman, 1963).

The shift towards studying disability from clinic towards the community dates back to 1983. This was done by encouraging graduate students of anthropology at the university of Oslo to choose "disability and culture" as the topic of their thesis (Ingstad and Whyte, 1995;x). Much research in medical anthropology has "therapeutic" theme. It has concentrated on conception of illness and disease, on models of healing and on the interaction between patient and practitioner (Ibid.).

Today some social anthropologists have done the cultural analysis of disability. Research in social anthropology move away from clinic towards the community, where individuals and families live with deficits. Cultural assumptions about the body and personhood must be seen in the context of ordinary social interaction. Concerned with adjustment than with therapy, concerned with its long-term consequences than with disease. Questions about autonomy and dependence, capacity and identity and the meaning of loss are central.

The works of Patric Devlieger in the Songye of Zaire; Ida Nicolaisen among the Punan Bah of Central Borneo; Aud Talle among the Kenya Maasai; Nayinda Sentumbwe in Uganda; Susan Reynolds Whyte in East Africa; Benedicite Ingstad in Botswana and Helander in Somalia and Kenya are some of the works of social anthropologists, among others (Ingstad and Whyte; 1995: 5-6).
1. The problems of defining disability

Attempts to universalize the category "disabled" ran into conceptual problems of the most fundamental sort (Ingstad and Whyte 1995:5). The World Health Organization's (WHO 1980) definition of disability is based on the model of the International Classification of Diseases (Helander 1993). But because it attempts to categorize the consequences of disease, it includes a consideration of social contexts. The three concepts Impairment, Disability and Handicap are defined by WHO as follows:

An impairment is defined as "any loss or abnormality of psychological, physiological or anatomical structure or function" (WHO 1980: 27).

Disability is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO 1980: 28).

Handicap is defined as "a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual" (WHO 1980: 28).

Ingstad and Whyte (1995: 5-6) criticize the above definitions of three concepts. Regarding the concept impairment, it is defined like a disease primarily by those qualified to judge physical and mental functioning according to "generally accepted standards". While impairment relates to "constituents of the body (the "organ" level) disability has to do with compound or integrated activities expected of a person or of a body as a whole, such as are represented by tasks, skills and behavior." Handicap relates to the social consequences of deficiencies in organs and activity performance. Handicap depends on valuation and expectation that put the disabled person at a disadvantage, the WHO manual states explicitly that valuation depends on cultural norms. In the study areas the concept of disability has a very strong dimension of practical incompetence. A person who is recognized as being disabled is basically one who is unable to help himself or herself practically (lame, crippled,
amputated) or is constrained in his or her activities by one or another disabling condition (blindness, deformity, epilepsy, or other).

Though the position of social scientists and disability differ, most anthropologists prefer a cultural relativist position rather than universalizing the approach proposed by WHO (Ingstad and Whyte: 1995). They support the position that disability should be defined by culture. The tendency to categorize different impairments as "disabled" is a fairly recent phenomenon emanating from Western societies (Lang, 2000:21). With regard to this, my findings support the cultural relativist position. There is no single term in the study areas that embrace all categories of disabling conditions. They employ specific terms for a number of disabling conditions: Komata" (Leper), "Denkoro" (deaf), "Yemitil Beshita" (Epilepsy, "Those who faint") and others.

Recent anthropological researches in non-Western societies have proved that many non-western societies do not have an exact equivalent in their own language for the word "disabled", and they can seldom match the three concepts (Ibid.) The following are some of the illustrations: The Massai term used to for the English word "disabled" a Lizard that walks in an awkward way (Talle 1995:57-69). The emphasis is on the physical movement, so conditions like mental retardation or chronic mental illness are not included.

Twins are not considered human by the Punan Bah of Malaysia nor children born with teeth by Bariba of Benin (Sargent 1982:11)

Among the Tuareg in Mali, freckles, old age, immaturity, illegitimate birth, ugliness and small buttocks are counted as the serious impediments making one physically dependent, socially anomalous and rendering it difficult to marry and could therefore be considered a disabled. Similarly, other anthropologists such as Fortes (1987) stated that trying to define the notion of disability will confront several problem of cultural translation and language use (Halatine and Berg 1990:58-59).

Most of these impairments are not on the WHO list, and several, like illegitimate birth, are social not "organic" problems. Others are organic but never seen as impairment by
biomedical authorities. Some of my findings support this argument. Most impairments are socially defined in the study areas. Persons with severe physical impairments have a difficulty in finding non-disabled friends.

Therefore, cultural conceptualizations of disability must be seen in relation to social contexts. There is recognition that reality is constructed in a double sense: researchers make (second order) constructions of actors (first order) interpretation. Applied to the study of disablement, this entails a careful examination of the process by which people with disability and their families define their conditions and situations as well as critical attention to the way in which data on disability are represented in analysis.

2. **Coping Mechanism**

A person with disability must make an extra effort to establish status as an autonomous, worthy individual, but the reaction of the other party may totally undercut these pretensions through some thoughtless act or omission (Murphy 1995:146). A lot of what can make life better or more difficult for a disabled person comes not from the person's disability itself, but from the way that people in the family and the community look at and treat a person with disability. The treatment of disabled people in the study areas differed from family to family. I found that it is better in economically well families and worse in poor families since chronically ill and weak children were left in closed homes until their parents came back from their business.

According to Nann (1984:287) persons with disabilities face two kinds of problems: how to cope with their disabilities and their limitations and how to cope with the reactions of other people to them. In a way the latter is harder because they can often control their own reactions, but there is a little they can do to control the reaction of others.
In examining coping mechanisms in disability studying the characteristics of social organizations relevant to disability are very important. Regarding this there are three important questions. First, what is the ability of the family to care for the infirm member? Demographic factors such as family size as well as the organization of the economy and social activities are important here. It has been claimed that the "phenomenon of the handicapped" emerges in part as a function of difficulties of the nuclear family in bearing the burden of care. Sociality (work leisure, education) is desegregated in space and time; the technical constraints of special care and training may require removing the person from home, at least part of the time. This, together with the normative demands for conformity and achievement, places an enormous practical and psychological burden on the family, often on the mother (Ingstad and Whyte, 1995:14). During my research, these were some of the facts that I had observed, most of the parents of children with disabilities kept their children home without help because they are unable to provide the necessary care, this was mainly due to their family size and economy. Others, even though they are economically well, do not care their children due to lack of education (information about disability and special institutions with technical equipment's).

Second, how do the occupational structures of the society incorporate people with disability? The organization of production, the degree of specialization, and the nature of the work affect the degree to which people with disabilities are able to participate. The final question concerns the existence of special programs, institutions and organizations for disabled people. This comprises laws and welfare benefits for the disabled as a generic category, as well as institutions and interest groups for people with specific kinds of disability (Ibid.). To this effect, the situation in Ethiopia has changed a bit. The Ethiopian government has started encouraging peoples with disabilities to be organized in associations. Now people with
different kinds of disabilities established associations based on their specific disabilities. Though there are these associations some of my respondents who are youths with disabilities complained about their inability to be organized in most of the government’s occupational structures.

Regarding coping mechanisms, research in Africa has examined the way that households cope with care-giving in contemporary circumstances there. In Tanzania, Whyte (1991) found that their families almost always care for people with mental illness, retardation, and epilepsy and care was regarded as a family, not a community responsibility. Ingstad (1990) describes how Zimbabwean grandmothers care for the disabled children. Ingstad and others (1992) describe similar pattern from Botswana. Coping with care is a matter of the disposition of family resources (Walman 1984) and the willingness to give such care priority over other needs and goals. Increasing pressures on families in developing countries may be instrumental in creating a demand for programs for the disabled, and thus a social category of "the disabled".

Widespread perception of in the popular culture as well as in the professional literature typically disability, associate it with an experience that is associated with sadness and stigma. Singer and Powers (1993:67-68) stated that living with a child with disability produces unusual stresses that can lead to fatigue and low moral in some families. These stresses arise when a family has to alter people's life-style to accommodate the needs of a family member who requires extra assistance and when these adjustments are difficult to maintain over time.

Recently researchers have challenged the above-mentioned notion. Patterson (1991) reviewed the literature on parents of children with disabilities and reports that families can experience period of intensive stress, learn from experience, and emerge stronger. However, the study of successful adaptation to disability is in its infancy.
Further, Patterson stated that families of children with disabilities coped well by doing many of the things that any successful family must accomplish. She described the following characteristics of resilient families of children with disabilities: maintaining family boundaries, developing communicative competence, attributing positive meaning to the situation, maintaining family flexibility, maintaining a commitment to the family unit, engaging in active coping efforts, maintaining social integration and developing collaborative relationship with professionals. But research by Ingstad in Botswana (1995) revealed that in situations of extreme poverty, people with disabilities are particularly vulnerable and show abuse and neglect for their disabled members. Therefore, successful coping is a function of "attitude" towards disabled family members plus household resources.

Another research by Helander (1995:80) in Southern Somalia revealed that a household's ability to meet the various experiences of cash and labor involved in health seeking naturally depends on factors such as its size and economic standing. When many treatments have been tried, the issue of costs involved becomes more distressing.

Finally the patterns of coping with disability differ from society to society. A case in point is a research by Devlieger (1995:97) in Songye of Zaire:

Children and adults who are not able to walk long distances are given specific tasks in the village: are looking after young brothers and sisters and taking care of the house in the absence of their parents. For Songye women however major disability of the upper limbs that inhibit daily activities such as fetching water, cutting wood and washing cloths is a serious situation, since performing these tasks is important for an adult woman.

3. Theoretical Perspectives in Disability and Rehabilitation

A number of commentators have noted that scant attention has been paid to theorizing disability, while some studies, to make their theoretical position explicit. However, we need
to develop theoretical perspectives which express the standpoint of people with disabilities, whose interest are not necessarily served by the standpoints of other social groups, whether dominant or oppressed, of which people with disabilities are also members (Abberley 1987:5-19). The following section will look into the main sociological and anthropological theories of disability to analyze the cultural and political world in which people with disabilities inhabit.

3.1. Theories of disability

A great deal of anthropological and sociological works accomplished so far by the contributors to the study of disability by asking questions, sharpening the focus of concern and providing critiques of existing forms of social conditions and relations.

Although anthropologists have focused primarily on culture there have been relatively few attempts to explain societal responses to people with disability (Oliver 1990). For our purpose I will discuss the following three theoretical explanations by anthropologists.

One of the earliest and, indeed, one of the most influential are the, surplus population theses". An inevitable development of late nineteenth-century thinking-notably liberal utilitarianism and social Darwinism-it argues that in societies where economic survival is precarious any weak or dependent individuals will be disposed of (killed, forced out of the community, and are left to die) (Ibid.).

The argument of this thesis does not always hold true in all kinds of disabilities. According to my findings I saw many children with different degree of disabilities but not disposed of. Infect I faced some individual families due to different reasons (poverty, culture etc.) disposed of their children and gave them to the different institutions (religious or rehabilitation).
The second implicit theoretical explanation stems from the works of Evans-Pritchard (1937). Associated with societies dominated by strong religious beliefs, this suggests that disabilities are viewed as either divine punishment or the outcome of witchcraft. A third approach is rooted in the work of Douglas (1966) and Turner (1967), and rests on the notion of 'liminality.' This concept was used to explain the position of people with disabilities in all societies by a disabled anthropologist Robert Murphy. For Murphy, disabled people lived in a state of social suspension, neither sick' nor well', dead' nor alive'' out of society nor wholly in it... they exist in partial isolation from society as undefined, ambiguous people' (Murphy 1987:112).

Hanks and Hanks (1980:13), in a much overlooked anthropological review, had shown that cultural responses to people with disabilities in non-Western societies were highly variable and determined by a wide range of factors. In sociological terms these responses can be divided into two distinct but interrelated categories; namely, the mode of production and the central value system. The former includes the type of economy, the need for and the type of labor, the amount of surplus it generates, and the way it is distributed. The latter relates to the social structure-whether hierarchical or egalitarian, how achievement is defined, perception of age and sex, its relations with neighboring societies, its aesthetic values 'and many more functionally related factors'.

The problem with the above analysis according to Barnes (1996:50-51) is that regarding the first approach there are many examples of communities where economic survival is extremely hazardous, yet people with impairments remain valued members of the community. Two examples are Dalegura, a group of Australian Aborigines and the Palute, a tribe of native Americans. Concerning the second approach, apart from the fact that such explanations present religious beliefs as autonomous and the only determining factor, they
tend to overshadow other studies which show that people with impairments are viewed as
gifted or touched by God; hence, their status is enhanced rather than diminished. The final
and the third approach is an explanation firmly rooted in metaphysics which ignores social
and material considerations. Most of my research findings support fully the above arguments.

Therefore, it is clear that social responses to disability cannot be explained simply with
reference to single factors such as the economy, belief system, or culture. According to
Oliver (1990:34), they are culturally produced through the complex interaction between the
mode of production and the central value of the society concerned. Debates about which is
the primary determining factor have raged since the rise of principal sociology, anthropology
and political theorists (Devis 1989: 85-93)

Recent researches by anthropologists have shown that the presence of people with disability
is part of the normal pattern of society (Zinken and McCohacie 1995:183). Examples of such
researches within anthropology is the vivid depiction of disability among the Kenya Maasai
by Talle, the Southern Somalis by Helander, in Uganda by Sentumbwe, and the case of East
Africa by Whyte (Ingstad and Whyte 1995), among others.

On the other hand the five current theoretical perspectives in sociology are essentialists,
social constructionists, materialists, post modernists, and the disability movement. The first
two of which have been reflected in official policy documents and the last three of which
represent a challenge to widely accepted understanding (Riddell 1996:85)

Implicit in essentialist perspective is the belief that a characteristic or deficit is inherent
within an individual and is likely to have biological rather than social causes. Social
constructionist’s accounts question the ‘reality’ of impairment and suggest that rather than
residing in the individual, disability should be understood as a negative label applied by some
people to others with the effect of enforcing social marginalization. In other words, disability is a socially constructed category rather than having some material reality. Broadly speaking those working within materialist perspective maintains that the operation of disabled people cannot be reduced to problems within the individual's or within the attitudes of the non-disabled, but is rooted within economic structures. Post modernist writers have questioned the value of the above-mentioned perspective on the grounds that the human experience is too complex and diverse to be accommodated with in a single account and all metanarative is oppressive. The proponents of disability movement ignore their diverse interests and identities (Barton 1996:71-89). In all perspectives, the way in which difference is constructed is crucial. According to my research I do not support a perspective that put disability in a single account. Rather it is better to use the essential element from the different perspectives.

3.2 Rehabilitation Trends

The scope of the term rehabilitation has changed at different times and this change has been noticeable especially in industrialized countries over the last 25 years. The original meaning of the term is to restore a person's dignity and/or legal status' (Advany and Pandy 1995; Helander 1993).

According to Helander (1993:15-16), four phases are suggested to the term's conceptual change: concepts focusing on the disabled individual (the WHO experts definition of rehabilitation in 1969); concepts recognizing the presence of physical barriers in the environment; concepts related to equalization of opportunities; and concepts focusing on human rights.

In phase one, the definition of the term rehabilitation offered by an expert group in 1969 reads as follows:
Rehabilitation is the combined and co-ordinate use of medical, social, educational and vocational measures for training or re-training the individuals to the highest possible level of functional activity.

In the remaining three phases, efforts to include interventions aimed at changing or adopting the environment; efforts to address the questions relating to the general access to society as a whole (equalization of opportunities); and efforts to consider the vital question of human rights for disabled as described in the UN Universal Declaration of Human Rights were raised at different times as central issues (Ibid.).

During the process of the above-mentioned conceptual changes over the centuries, alterative reactions were practiced on people with disabilities. Helander (1993:66-71) has grouped these reactions under five main headings namely, elimination (getting rid of the disabled persons); the poorhouse (removing them from the view of the non disabled); institutional care (providing care for them on a segregated basis); integration (in their families and communities as well as in the general systems of society), and self actualization (supporting them in their efforts to develop their full potential). To this day, all five of these reactions are still in evidence. Traditional societies, however, have not created residential institutions the way developed countries have. Yet, up to our own days, institutions are still the dominant type of facility for rehabilitation in the developing countries. The reasons, among others, are limited professionals and lack of resources. The rehabilitation programs introduced in developing countries are designed generally in terms of the two dominant models: institutional and CBR. Further we can distinguish rehabilitation programs as specialized services, outreach programs, community-based services, and interest organizations (Ingstad and Whyte 1995:21).

Clearly, a new approach, which takes the life of the disabled person in her/his own
Community into account is essential. Moreover, a radical reorganization of services is required.

Community based rehabilitation has been promoted over the past decade as the best way and an increasing number of developing countries follow as a strategy to eliminate constraints of institution-based rehabilitation. Protagonist insists that there is only one Community Based Rehabilitation (CBR), but in practice there are many interpretations of the term and programs vary considerably. Many CBR approaches, programs, and definitions in developing countries are described elsewhere, e.g. Thorburn and Marfo, 1990; Save the Children Fund, 1994; Helander et al, 1989; ILO, UNESCO and WHO. 1994 (Zinkin and McConachie 1995: 152-154).

In fact, specialized institution-based services are often the first type of organized assistance instituted in developing countries. A consequence of such institutional care and training is that "clients" are isolated from normal social life and may find it difficult to adjust to life in their communities when they leave the institutions. And such institution-based rehabilitation has been able to reach only very small percent of people with disabilities (Chaudhury et al, 1995: 152).

It is hard to determine the number of CBR programs in Africa. Some estimate the number of self-proclaimed "CBR" in Sub-Saharan African, exclusive of South Africa, to be around 200-220. Besides the model has been adopted in Kenya, Zimbabwe, Tanzania, Swaziland, Lesotho, Zambia, Ethiopia and many others. Despite the growth in the number of community based rehabilitation (CBR) programs in Africa, services for people with disabilities in most regions of Africa are still limited to what people can do for themselves, or what can be provided by specialized centers such as residential homes, schools, or sheltered workshops. Most of the 'formal' CBR programs implemented till now are products of foreign policy and
interests, with inputs of foreign manpower and money, and not the result of the inventiveness, creativity and hard work of the local people themselves (Vanneste, 2000:127).

The idea of community based rehabilitation in Ethiopia was first introduced by the Rehabilitation Agency for the Disabled (RAD) in collaboration with UNDP and ILO in early 1980's. The initial survey for starting CBR projects in the country was done by a project team composed of UNDP/ILO experts and four national counterparts. Following the survey, the two pilot CBR projects were the Nazareth and Assela projects. Today there are other CBR initiatives. Cheshire CBR, MMM CBR, DOC CBR, "SSEP" CBR and VCH CBR are some of the projects working in the country (Daniel 1997:9)

Finally it is worthwhile to mention that the adoption of rehabilitation program in a developing country has most often taken place in one of the following ways. A non-governmental organization (NGO) from a developed country wants to establish a rehabilitation activity in a developing country and approaches the government for permission. Alliteratively (or sometimes simultaneously), a government from a developing country has identified rehabilitation as a need and approaches other government or NGOs for bilateral and is setting up a program (Ingstad 1995:174).
CHAPTER IV

THE SOCIAL CONSTRUCTION OF DISABILITY AND ITS IMPACT ON TREATMENT

Chapter IV was devoted to general discussions regarding the various issues involved in conceptualization of the term "disability". It looked into the perspectives on disability by anthropologists and sociologists; the coping mechanisms used by persons with disabilities and their parents, and rehabilitation trends. Generally speaking the rational for the above studies on disability is to provide a theoretical explanation of how disability can be understood. It also provides normative principles upon which the operational practices of the community are based, and gives explanations with pertinent insights into how disability is generally conceptualized.

The above scholarly works saw disability in different ways. The issues raised could be generalized as a conceptual one. All approaches cited in the literature review tried to locate the sources of disability. Based on the main elements in them, all efforts in analyzing disability could be categorized into three models namely medical (which is also known as the traditional approach), social, and the combinations of the two. The first two are bi-polar
models and the third one is a model that combines the positive features of the above two models. The medical model locates the sources of disability in the individual’s deficiency and her or his incapacities. In contrast to this, the social model sees disability as resulting from society’s failure to adapt to the needs of impaired people; i.e. human activities are structured by the general social and economic environment, they are constructed by and the interest of non-disabled people.

The objective of this chapter is to delve into social and cultural processes that shape the lives of disabled children and youths. It examines disability in terms of the culturally or socially constructed worlds in which the disabled live in. The aim is to determine how disabled children and their parents separately explain disability. I propose to achieve this by examining the different perceptions of disability projected by children and youth with disabilities; parents of children with disabilities; and caretakers and by exploring the social processes that shape the perception of their disability. Having discussed the theoretical works involved in the literature, I now attempt to link them with particular cases of persons with disabilities in the study areas, in terms of the medical, social and, combined socio medical models. But, before setting down the view of disabled persons and their parents, I would like to elaborate on the social construction of disability.

The concept of disability and handicap emerged in particular historical circumstances in Europe. As a social identity the concept "disabled" is a recent phenomenon in most nonwestern societies: through surveys, research projects and government policies. The significance of impairment depends on the values and assumptions that people have about the nature, functioning, and goals of persons with disability. It involves the ideals and expectations against which people measure them. In other words answers to the question: What is human or inhuman?" are determined by the values of different cultural groups. (Ingstad and Reynolds, 1995: 35).
Generally speaking, as a historical and cultural construct, the notion of disabled is heavily charged with implications of social inferiority or stigma (Talle: 1988. Furthermore, Ingstad (1991) argues that the focus in stigma and severe maltreatment of disabled people may well be a product of our lack of understanding of other fundamental social processes that shape the lives of the disabled. An attitude survey carried out in Ethiopia came up with fairly similar conclusions with most other countries. Namely, that disabled people are stigmatized and have poor chances in marriage and employment (Teklehymanot et. al, 1991).

Several Ethiopian medical professionals have also published striking accounts of the strange beliefs and lamentable conditions with which epileptics live in (Giel, 1965, Teklehymanot et al, 1991, Orley, 1970. Children and youth with disabilities, parents of children with disabilities and caretakers, even if they come from the same social and cultural background, view disability in very different ways. Their perspectives are based on very different premises, employing a different system of proof.

Among the disabled I worked with, adults' descriptions and explanations were the main factors that constitute the children's perception and definition of their own disability. This is because the children themselves loam about the causes of their disabilities from their parents or adults who are taking care of them. Therefore, children's initial perceptions of their disabilities coincide with that of their parents, or caretakers. But, as children with disabilities grow older many form their own view of their personal affections.

However, parents and children differed in their explanation for the causes and present predicament of disabled children. Parents talked in terms of self-blame, guilt and occasionally the failure of modern medicine and medical professionals in helping alleviate the plight of their disabled children. On the other hand, the determinant factors for disabled children was not the root causes of their disabilities since they accept their parents' explanations, but how
to explain or justify their disabled state and assign blame for their present predicament. Conversely, stigma had two different connotations depending on whether the child was born deformed or became handicapped after birth.

The following sections try to establish a link between the views of the targeted population and how it fits into the social, medical or socio-medical models. The perceptions and explanation of the causes of the children’s present predicaments by parents of children with disabilities, institutional individual and caretakers and children and youths with disabilities in the study areas are treated separately under the three models. This is followed by community perception of children's disabilities, the role of institutions towards "integration", and finally a short commentary on settlement pattern, and economy.

1. MEDICAL MODEL

The medical model is an approach that is also known as a traditional approach (Barton, 1996: 61). It incorporates all views that locate the sources of disability in the individual's deficiency and her or his personal incapacity. It gives emphasis to biological factors and does not delve into social factors. In this model, disability is defined as a disease state and perceived as a deviation or abstraction from normality. The medical model of disability is considered to be the predecessor of the social model. Its occurrence as a model can be traced back to the early stages of the past three decades and, with the emergence of studies of disability (Thomas and Thomas, 2000: 2). The following cases illustrate how children with disabilities are regarded in their society/community as disabled.

1.1 Medical Model and Parents of Children with Disabilities

Several studies point out that many parents and grandparents of children with disabilities feel that they have contributed somehow to their child's disability. Parents believe that if they or
other persons who took care of their child had taken better care of it; their child would not have been disabled (Singer, et al, 1993: 176.)

According to Miles and Demi (1986) and Nixon (1989) there are three kinds of self-blame and guilt that apply to parents of children with disabilities: (a) causation guilt, (b) parents role guilt and (c) moral guilt. Causation guilt relates to the parents' belief that they have contributed to the cause of their child's disability in some way. Such parents feel that if they had taken better care of themselves, their children would not have been born with disabilities. Secondly, role guilt is related to the parental belief that they as parents have failed to live up to self-expectations and societal expectations in their overall role as parents. In other words, parents judge themselves as being totally responsible for the fate of their children, or judge themselves as failures and guilty because they "ought to" have been able to prevent harm to their children. Finally, moral guilt is related to the parent's belief that the child disability is punishment or retribution for violating a moral, ethical, or religious standard. Moral guilt is related to self-blame, which involves people interpreting negative event as deserved punishment for past misdeeds. Furthermore, parents of children with disabilities give various reasons for the causes of their children's disabilities. These may be lack of better care by medical professionals; negligence by housemaids who looked after the children in the absence of parents; and/or deserved divinely ordained punishment for past misdeeds.

Among the parents I worked with, their explanations of their children's present predicament differed from the version of children in many ways. The difference lay in the belief that the children were victims of circumstances and their parents were not. The most significant thing was that parents felt that their children's disability was linked to their own failure as procreators. They, therefore, blamed themselves in different ways, whereas children with disabilities did not assume any blame for their predicament.
Although some parents associated the causes for their children's disabilities to professional mistakes and lack of better care, in most cases the reasons are found to be lack of knowledge and poor economic status. The following two examples illustrate lack of better care as a reason for not reaching to medical professionals and getting appropriate medical treatment and help from medical professionals for their children.

**Case No 1: Bezu, Age 48, and Grandmother of Eden with Cerebral Palsy**

Because her daughter went abroad, Bezu took the responsibility of taking care of her granddaughter in 1998. She blames her daughter (Eden's mother) for her granddaughter's disability. She said:

"I did not know that my daughter was pregnant. I found out after she gave birth to the child. She did not take the right medical treatment or medical advice during her pregnancy. If she had taken better care of herself during pregnancy her child would not have been born with a disability"

**Case No. 2; Mulu, Age 35, Mother of Alem with Bum Deformity**

In this case, the mother, Mulu, blames herself for her child's disability. She believes that she contributed to the causes of her daughter's disability in some way. She said:

"My child was a normal child at birth. Because I am poor I was working in several places, moving to different homes in order to earn living. It was a single day’s mistake. I gave the responsibility of looking after my child to my employers. They couldn't protect her from damage. If I had done all the right things, my daughter would have been healthy today."

According to Singer et al. (1993: 179-183) parents who experience a negative outcome during their child's birth relate events to medical professionals' wrong or incomplete diagnosis. But, unlike the above two cases the following two cases blame medical professionals directly. The-parents affirm that they took their children for treatment but the professionals treated them wrongly.
Case No. 3: Shume, Age 29

Shume is the mother of Taye, a victim of cerebral palsy. Shume and her husband are both nurses. Shume relates her son’s disability to medical professionals' wrong diagnosis. Taye had difficulties with suckling, swallowing, and chewing. He choked or gagged often. His head seems as if it will fall off. He is slow to hold up his head or to move around. His mother explained:

My son suffers from cerebral palsy. He is two years old. The hospital doctors are responsible for my son's disability. My son's disability was caused by delayed birth. My son did not receive enough oxygen at the time of birth.

Case No. 4: Yosef, Age 41, Father of Tamiru (CP Victim)

Another informant who is the father of Tamiru blames the doctors of the hospital where his child was born.

I was in the hospital when my child was born. The doctors had thrown him in a basket as if he were dead. It was after several hours that they picked him up when they saw a movement from where he was thrown. They brought him to his mother. But, the child was already damaged. If they had taken the appropriate precaution after his birth, my child would not have been disabled now.

The above four cases have one thing in common; children’s disability could be cured if an appropriate medical treatment been given at the right time. The fact that they depend on medical professionals for their children's cure implies they are convinced that the sources of their children disability are biomedical.

1.2 Medical Model and Individual Care Takers

There are different reasons (such as lack of money for hospital treatment) for children with disabilities being supported and cared for by persons and institutions outside their family and relatives. In this study the term "care taker" applies broadly to anyone who provides services to disabled children and youth, but who is not a blood relative of the disabled. Caretakers thus
include those people and agencies that offer medical treatment, psychological counseling or economic assistance intended to benefit the disabled.

This section focuses on children/youths with disabilities who have no means of support, the extremely poor and orphans without close relatives, and those who are willing to care for them. The most important difference among parents and caretakers is that caretakers do not blame themselves for the cause of the child's disability under their responsibility because they did not give birth to the children with disability. Apart from this, many caretakers hold fatalistic views as well as modern clinical understanding of disability.

In my study areas, caretakers are of two sorts: private individuals and institutions. The institutions were MMM (Medical Missionaries of Mary) and Cheshire CBR (Community based rehabilitation). Individual caretakers were persons without any blood relationships to the children they were caring for. The institutions are organized on religious and philanthropic bases. The conditions and qualities of life offered to the disabled by the institutions differed from that given by individual caretakers. Institutions found in the study area practice modern scientific medicine for children with disabilities. All the individual caretakers were too poor to afford the medical bills for the children they were helping.

The objective of the two NGOs namely M and Cheshire CBR, is almost the same. They are established to meet the aim of CBR in contrast to institutionalized based rehabilitation center. MMM organization began implementing its program in June 1992 and Cheshire CBR January 1994. The objectives of these two organizations are: to change community attitude and behaviors towards diseases and disability; to increase the knowledge of caregivers about rehabilitation techniques for their particular persons with disability; to transfer appropriate care knowledge to the community starting with individuals or small groups, and to intervene
early in rehabilitating the people with disabilities starting with individuals or to achieve better functional results for the people with disabilities to become as self-sufficient as possible and to included in the community where he or she lives. The beneficiaries of these programs are children and youth with disabilities and their families (Tigabu 1997:24)

Ingstad and Whyte (1995: 15-16) looked into special programs, institutions, and organizations for disabled people. They indicated that even though nearly every country has at least some institutions for the disabled, there is a great variation in their accessibility and in the ways they affect people's lives. The authors distinguish specialized services, outreach programs, community based services, and interested organizations. It is through the efforts of these programs, often with government or donor support, that legal, biomedical and social identities for disabled people are being formulated. The following two cases are illustrations for different kinds of institutional and individual care found in my study area.

**Case No. 1: Abebe, age 22, Polio Victim**

Abebe, age 22, is an orphan. He used to live in an institution called Kidane Mehret Boarding School. He said:

I do not know my parents. I heard from older persons in the institution that it was my uncle who brought me to this institution. The religious institution sent me to the hospital for medical treatment. I was operated on both legs and I am now able to walk using underarm crutches. I do not have any interaction with people outside the institution.

Until I received help from an NGO called Medical Missionaries of Mary (MMM). I had no contact with medical institutions. It is after their consultation that I went to the hospital for an operation. Because I could not afford the appliances recommended by the doctor, they bought them for me and now I use a wheel chair and underarm crutches.
According to the research results all institutional and individual caretakers in this section resorted to only medical institutions and located the causes of disability within medical model. Whereas individual care takers used the combined socio medical model.

1.3. Medical Model and children with Disabilities

A. James (1993:85) indicated that children could be seen as people to be studied in their own right and not just as receptacles of adult teaching. Such child-centered approach has offered a way of reflecting on, first on the socially constructed nature of childhood and, second, on the ways in which children's lives are inscribed (Solberg: 1990; Reynolds: 1985, 1989; Bluebond: 1978; and Pront 1989). Therefore, children should be described as independent, active, curious, and verbal instead of being seen as passive subjects. Children with disabilities have their own perception about the causes of their disability and about the world they live in. Blaming other people for one's ill health is common feature of most societies (Helman, 1994). To use Kleinman's (1980) term; an explanatory model is a useful way of looking at the process by which illness is interpreted. People often use their own model and provide explanations for the cause of their condition. In the following two cases children with disabilities in the study areas blame professionals directly or indirectly as the root cause of their disability.

Case No. 1: Tesfu, Age 22

Tesfu age 22 is a high school complete. His mother died when he was 18 years old and his father died when he was a very small child. He lives with his elder sisters. He had been told that his disability occurred after birth. Tesfu puts blames for his disability on professional mistakes by doctors. He is convinced that the injections that was administered to him and the ‘jesso " (gypsum) that was put on him was in-correctly fitted, and that this caused one of his legs to atrophy.

Tesfu believes that the cause for his disability is the mistake made by medical professionals. He is convinced that it is the physiotherapists who brought about his disability.
**Case No. 2: Saba, Age 22**

Another informant, who is a girl, with similar disability accused medical professionals for her disability. She said:

> Due to high fever and illness the doctor prescribed a course of injections which lasted six months. While injecting me, they touched the wrong blood vein (*yedem ser*). As my mother told me, I became paralyzed from that day onwards.

Ingstad and Whyte (1995:14) claim that the "phenomena of the handicapped" emerges in part as a function of the difficulties in bearing the burden of care. The following two cases exemplify different situations regarding the effects of improper care in the study areas. Though the two children did not blame medical professionals directly, their end beliefs fit under the medical model.

**Case No 3: Aster, Age 20.**

Aster has suffered from a leg injury. She is a polio victim. Her parents did not tell her the causes of her disability. Workers of a non-governmental organization told her about the causes of her disability much later in life. Aster describes:

> My disability was explained to me much later in life by an NGO and not by my parents. Since the cause of my disability is a polio virus and it can be protected by vaccine or avoiding unsanitary places, it is my parents who are responsible for the cause of my disability. It is their carelessness that brought about my disability

**Case No. 4: Kuku, Age 14.**

Kuku lives with his parents. His mother earns her living by baking injera. Kuku, helps her mother by polishing shoes. His disability is on his right leg. He has a clubfoot. He blames his father and his neighbors for the cause of his disability. The following is his explanation of his disability.
My father is a daily laborer. He abandoned us and that is why we are poor. My mother told me that she faced a lot of difficulties to take care of me. She told me that my disability happened when I was an infant. But nobody took me to the hospital. Our neighbors discouraged my parents from taking me for medical treatment.

Kuku believes that his condition was caused by carelessness of his neighbors and because his father abandoned him, neglected him and refused to help his mother financially. According to the descriptions above, all the informants' explanatory model for the causes of disability is a single cause that is under human control. But there are some respondents who hold a fatalistic view of their disability and ascribed the cause of their disability to external forces, which are beyond human control, or a combination of two or more causes.

2. THE SOCIAL MODEL

The social model has arisen in response to the critique of medical model. The social model is the total antithesis of the medical model. Its primary focus of analysis has shifted from the deficits of the functional, physiological and cognitive abilities of the impaired individual, to the detrimental and oppressive structure of society, and the negative social attitudes encountered by disabled people by the community throughout their life. Thus, in focusing upon the manner in which disability is socially produced, the social model has shifted the debate on disability from a bio-medically dominated agenda to one which gives central importance to perception and attitude in terms of a socio-cultural rather than a biological construct (Thomas and Thomas, 2000:3). As a consequence, disabled people face separation and social exclusion from the main stream social and economic activity of the communities they live in.

The following section focuses on informants who believed that the causes of their disability was due to socio-cultural reasons and therefore follow traditional /cultural/ religious healing
methods. They are divided into three categories: parents of children with disabilities, institutional and individual care takers, and children with disabilities. On the other hand, other relatives on her husband's side also have a similar fatalistic view of Ababa’s deformity. Kiros explained it as follows:

I wasn't charitable enough in my own heart toward children with disabilities. Besides, my mother-in-law told me that my daughter's disability came due to the sin performed by their ancestors. Her ancestors were feudal with extensive land holding and had many slaves. When a member of a family died, a slave was buried alive with the dead person. So Ababa’s disability is retribution of their past sin and my previous attitude toward disabled children.

Kiros told me that her daughter is still rejected by her father's family because of their prejudicial view of her condition. They feel that God has cursed her.

Case No. 3: Tolosa, Age 43, Father of Abiy (Polio victim):

Tolosa's son is a polio victim. He uses underarm crutches and sometimes a wheelchair. Tolosa believes that children with disabilities are part of the society. It is therefore the moral obligation of their kin to take proper care of them, whether they suffer from bodily impairment or other disabilities. Tolosa gave me a description of his effort to help cure his son as follows:

I asked advice from different persons and went to different places to get cure for my son. Because my neighbors told me about a "Ferage" (faith healer), I went to him. They told me that he has the power to manipulate and alter natural and supernatural events with the proper magical knowledge and performance of ritual. But the "Ferage" told me to take my son to St. Gabriel Church and have him take "Tebel" (holy water). I took my son there and got better result. I went also to my birth place Wollo to seek advice from rural traditional healers.

All the above trials by Abiy's father imply that he has a strong faith in Christian as well as some trust in the power of "Ferage". The reaction of Abiy's father in connection to his child's disability is based on the stock of knowledge that he holds and his neighbor's experience.
According to Abiy's father the will of "Egziabbher" (God) and that of "Melaekts" (Saints) is the ultimate answer or the cause of everything that happens in life.

**Case No. 4: Rehima, Age 29**

During my field work I observed that people following different religions (Christians, Muslims, and Protestants) do not follow only their religious line for the treatment of their children's disability. The case in point is Abdula's mother, who has a child with hand and leg injuries. Rehima's case shows that just like Tolosa people will seek cures for their disabled child outside their professed religion. Abdula's parents are Muslims. In order to get a cure for their child they have tried both Muslim and Christian religious treatment. Abdula's mother took him to Muslim religious healers, to a "Shek" and her child underwent a religious ceremony called "Duaa" (Muslim Religious prayer ceremony). In addition to this she took him to "Tebel" (holy water) in different churches.

As mentioned above, because they believe that the causes of their disabilities are supernatural; all parents of children with disabilities follow religious traditional and cultural healing methods. Therefore the perception and attitude towards disability falls under social model. Furthermore, theses cases support the argument made by Thomas and Thomas (2000) that disability is socially produced rather than a biological construct.

**2.2 The Social Model and Children with Disabilities**

Some writers on disability have noted that the creation of alterative explanatory models and choices of alterative forms of treatment tend to take place only after medical help has failed to produce a cure or when the communication between patient and doctor has broken down (Ingstad and Whyte, 1995: 253). This holds true for the children I worked with in my
fieldwork. When all efforts failed, especially medical help, they tend to embrace a fatalistic view and leave their fate to God. The following three cases illustrate this point:

**Case No. 1: Ably, Age 22.**

Abiy Abebe is a 22 years old polio victim. Both his legs below his waist are injured. He cannot walk on his own. He has severe contracture in the hips, knees and feet. After being treated for several months in a hospital, he is now able to walk with braces and underarm crutches. Although he has learnt from the radio and non-government organization that his disability is caused by polio, he said that he took "Tebel" (holy water) and the result from undergoing the therapy has convinced him that his disability has been caused by direct actions of supernatural entities 'Yeseitan Menfes" (evil spirit). He could not explain or name the evil spirit. Abiy simply said that the devil caused his disability. Abiy told me that he did not even ask his parents about the causes of his disability. He gradually learnt about it from the radio and workers of a non-governmental organization.

I remember that my father took me to "Tebel" (holy water) place called "Kedus Rafael and Gabriel" (Saint Raphael and Gabriel). It was effective. It gave me a relief. Prior to the treatment I used a walker made of four sided iron with four legs. After the holy water treatment I walk holding a cane only.

According to Abiy, the progress shown after using the Tebel (holy water) treatment is an indication of the gradual elimination of "Yeseitan Menfes (evil spirit).

**Case No. 2: Girma, Age 22**

Girma suffers from 'muscular dystrophy.' It is a progressive disability. It is a condition in which body muscles deteriorate from month to month and year to year and the sufferer gets weaker and weaker. Girma cannot use his legs, hands and back. According to Girma his disability started at the age of nine. It was when he passed from grade three to four. He tried
all he could to continue attending school until his disability worsened. He asked his family members and neighbors to take him to school and bring him back home after he finished his daily lesson. They helped him until his disability becomes very severe. In 1995, Girma stopped going to school because he could not move from place to place in the classroom. After he quit his studies Girma received medical treatment and then took “tebel” (holy water).

According to Girma his parents first tried medical treatment and then the "Tebel" (holy water). He said,

After several examinations at the hospital the doctor told my parents that treating my disability was beyond his capacity. He gave me a referral to another hospital. The doctor in the other hospital examined me and decided that I should be operated. My parents and my sister did not agree with his decision and stopped taking me to the hospital. They started taking me to "Tebel" (holy water) places, instead.

Girma has a severely curved spine. He is unable to walk or sit. The disease has affected his feet, thighs, hips, belly, shoulders, elbows, hands and neck. His sister, his father and other family members use pillows to help him sit upright. But Girma has stopped all efforts to help himself. He believes that his disability is "Yeegziabeher Setota" (a gift from God.) He said, all his hope was in "Annd Amelak" (one God)

Case No. 3: Abeba, Age 13:

Abeba, age 13, was born with a deformed left hand. She lives with her mother. Her father was sent to the war front by the Derg and never came back. She explained her disability as follows:

My mother told me little about my disability. She told me to accept that the cause of my disability is the will of "God." I remember that she took me to different hospitals and Tebel (holy water) places, but I was not cured. Although my disease is non-curable, I believe that my disability is a "Gift from God". I will continue going to the church and I hope I will get well one day.
Even though Abeba assured me that her mother took her to different hospitals, due to the failure of treatments within the medical sectors, their final resort to get cure for her disability is non-medical care. She has stopped going to the hospital. They presently believe that her disability is the direct action of "God”.

3. COMBINED SOCIO-MEDICAL MODEL

Given the limitations of both the medical and social models of disability, the alternative explanatory model is a construct that combines the positive features of both models. The assumption here is that an individual's human nature, his/her position in society, and life chances are neither exclusively determined by his/her innate biological characteristics and abilities, nor are they totally prescribed by social, economic and political structure of society. Both medical and social approaches assume that all human beings are essentially passive, in the sense that they are unable to influence the courses that their life will take (Thomas and Thomas, 2000: 4). There is thus an inter-dependent and dynamic relationship between an individual and his society. Conversely, the socio-medical model approach posits the integration of biological and social factors in determining human condition.

The following section provides examples of combined socio medical models in association with parents of children with disabilities, individuals and institutional caretakers, and children with disabilities.

3.1 The Socio - Medical Model and Parents of Children with Disabilities

Parents who associated the causes for the disability of their children to a medical model consult medical professionals. If medical help fails they try traditional healers or "Tebel" (Holy water) in churches or by having special prayers in different churches and Mosques or consulting a "Wukabi" (Soothsayers) or Debteras (faith healers). Both models may be multi-
casual (several causes acting together). Consequently there are therefore a number of non-physiological factors that influence the pathways to the medical or cultural model. This induces parents to resort to a combination of social and medical model. These include the availability of medical care, whether the patient can afford it, the failure or success of treatments within the medical or cultural sectors, how the parents or the disabled perceive the problem, and how others around the child (parents/ caretaker) perceive the problems.

3.2 The socio-Medical Models and Individual Caretakers

Individual caretakers in this study are non-kin adults. They are either neighbors who have a long relationship with the deceased family of the disabled children or persons who took the responsibility of taking care of disabled children. These caretakers have a different perception towards a disabled child in their care than parents who have blood ties. The degree of commitment towards treating or taking the child to different places might be affected by many factors. Since caretakers are part of society, their belief is also shaped by the belief of the society they live in. Several caretakers were unable to identify the aetiology or causes of the disease, if the child under their care had joined them after disability. Some associated the disabled child's illness to the child's ancestors or generation past misdeeds. Such people took the disabled children to traditional healers because they suspected that an "unknown" relative of the disabled child might have committed some kind of sin. Others tried both medical and other cures, i.e. religious and traditional. The following case is an illustration to this point:

Case No 1: Ayou, Age 33

Ayou is Shume's caretaker, who is the victim of cerebral palsy. Ayou brought the child from Gojam. She said:
I brought the child to educate him. His parents are poor farmers. The disability was not severe when I brought him. I thought that the "Egziabher Kuta" (retribution from God) that his parents brought over him would disappear once he was away from them. Even though his fate is determined I will try whatever treatment-medical, religious or cultural_in order to give him a chance to recover. I firmly believe that sick people get well without medical care. This does not mean that I do not like to consult doctors or that doctors have marginal role in curing the child.

She also assured me that her decision to treat the child under her care in medical as well as cultural ways did not imply that her perception towards disability is medical or cultural. Economic and other factors influenced her decision to take him to a doctor or traditional healers or "tebel" (holy water). Since she is very poor, she cannot afford medical treatment or the cost of transporting the child to various clinics. However, she always attends six monthly appointments at Black Lion Hospital to check the Child's orthopedic shoes, as well as taking Shume to different "Tebel" (holy water) places.

3.3 The Socio Medical Model and Children with Disabilities

As mentioned above most children with disabilities cannot cope with their disability on their own. Instead, depending on the severity of their disability, they seek the help of their parents or relatives or care takers. Mixed blame is when children with disabilities or their parents give more than one reason for the causes of their disabilities. Such belief, according to Frantz (1981:127), is associated with faith in God, in the physician and in the help of others. A case in point is Sofia with severe polio case:

Case No. 1: Sofia, Age 22.

Sofia's legs had been paralyzed by polio. She has been walking on her knees for several years. Her father is "autocratic". He was and is the only person who decides about where she should be taken for treatment. She said:

My father took me to "Tebel" (holy water) places, traditional healers, outside and inside Addis Ababa. He once left me at one place, paying rent and people to help me at the treatment places. I have no say in the options considered. Though my disability is a paralysis, I was made to drink medicine prepared by "herbalists" coming to our residence."
Sofia said that in 1998 her neighbors told her story to a non-governmental organization and the fact that she was hidden away for many years without interacting with other people. She started connecting with the people outside her family. After 1998, she received medical treatment. She can now walk using underarm crutches and both her legs has braces. She wears special shoes. She recently started schooling”. Regarding the cause of her disability, Sofia believes that it has a multitude of causes. Her father has done the above things hoping her disability will go away. Over time he shifted his focus partially toward modern medicine. Had he initially taken her to a hospital she might have had a good chance to be integrated with the neighbors earlier. On the other hand, the doctors could not cure her completely. Therefore her blame rests upon both her parents and the supernatural power. She said:

"What the doctors did for my disability was not effective. They simply operated me and made it possible for me to access the external environment. It is not a complete cure. My father still insists that I continue taking "Tebel" (holy water) and visiting traditional healers. This means that he has the belief that my disability is caused by supernatural powers.

4. The Social Model in Association with Community, Institution and/or Organization

Anthropologists generally use the term "community" in a combined social and spatial sense, referring to an aggregate of people who occupy a common and bounded territory within which they establish and participate in common institutions (Singer, and Powers, 1993: 83). I shall employ the term in a purely social sense, however, to describe the set of institutions and organizations used by the parents of children with disabilities and the children and youth with disabilities. The specific institutions that are found in the study area are the church; the school; Kebeles; sefer (neighborhoods) health institutions; and some commercial establishments.
In this section I shall deal exclusively with the variety of perceptions that the sefer (neighborhoods) hold regarding a child or youth with disability as well as labeling/identification of disability in cultural or medical terms. Perceptions of the community about the children and youth with disabilities are revealed from the reactions of peoples outside the family range. These reactions consist of what is said or implied during their expressions about their values, perspectives, and roles. These non-verbal expressions are called meta-communication. The following section tries to explain the identification or perception of disability both interims of verbal or non-verbal expressions.

4.1 The Social Model and Community Action

I have interviewed parents of children with disabilities, and children and youth with disabilities to know about the perception of the community they live in, from the community actions (stigma, rejection) towards them and the aversive interaction of children with disabilities in schools and hospitals. During my fieldwork children and youths with disabilities, and parents of children with disabilities told me that they have faced different challenges during interactions with the community. The following case can serve as one illustration:

Case No. 1: Zeleka, Age 20

Zeleka is a polio victim. She came to live in the "sefer" two years ago. While she was going by taxi to sell the handicraft she produced, people along the road stared at her and expressed their sympathy. She feels that people think that her disability is an act of God or of other supernatural forces.

From Zeleka's point of view, this community reaction is a sign of negative attitude towards her - as if she has a great difference from the non-disabled Zeleka believes that this was the reason why her parents hid her away from society for over ten years. In other words, her
family believed that Zeleka was a threat to their family's ability to be socially integrated into the community.

**4.2 Being Disabled After and Before Birth:**

Although parents and other adults in general do not blame disabled children for their condition, stigma attached to children born with deformities and those who are afflicted after birth differs considerably. This has a major impact in shaping the life of the disabled people. They earn their living by begging. Alem’s mother assured me that she has no contact with people living in the neighborhood. She suffers from severe social isolation. She feels that they are ostracized because she is poor and because of her child's disability. She said:

> I have no contact with my neighbors. I only come home to pass the night. My residence serves two purposes for the owner of the house: as a kitchen and residence. Like other disabled children, my child also faces a problem. Peer groups and adults insulted her by calling her "leper". She has a nickname. The small children on the road call her by an animal name "Kangaro." It is because Alem limps that the children gave her this name, she concluded.

**4.3 The Social Model in Association with "Severe" versus "Moderate" Disability**

Attitudes towards disabled children and youth in the study area vary according to type, cause and severity of the impairments. The following examples illustrate that persons with non-severe or moderate disabilities are not marginalized in the community. Lily dips from side to side with each step due to muscle weakness at sides of her hips. But her disability does not prevent her from main activities and the community does not see her disability as severe enough to prevent from participating in all activities.

**Case No. 1: Lily, Age 24**

Lily lives with her mother. She became lame after a short illness at the age of 4. As she grew older other children humiliated her by mimicking the way she walks and moves. This did not
last longer. Because she was strong and hardworking, she is well respected by adults and kebele residents. The kebele residents now elected her as a leader of women's association.

Case No. 2: Rawda, Age 14

Rawda is a polio victim. She lives with her parents. Rawda told me that she has no problem with her neighbors. She has no problem in playing with children. She noted that:

Though both children and adults teased me when I was an infant, this was a short lived negative experience. My parents loved me, and by the "sefer" (neighbors) standard I am equal to all: I am treated the same way as other children of my own age. I move freely in the village and am accepted in all gatherings.

Case No. 3: Kokeb, Age 16

Kokeb's friends (both disabled and non-disabled) are very kind to him. They often include him in their games or activities:

Kokeb, a polio patient, is popular with all age groups (disabled and non-disabled). He plays all kinds of games with other children. He spends most of the time laughing with his friends. He has a special capability of producing different animals like sounds, which attracts much laughter. The neighbors and friends call him BBC (British Broadcasting Corporation) because he can imitate various broadcasters.

Therefore, the above illustrations show that not all children with disabilities are marginalized or isolated. Instead non-disabled children treat some of those who are not severely disabled consistently with love and respect.

5. Institution's Role towards "Integration"

Present-day rehabilitation programs define disabled people as equal citizens, as individuals enjoying citizen rights and for whom the state and the community have responsibility. Even though they established the principles of integration and normalization as a goal, it has not
always been like this (Ingstad 1995:175). The following case from my fieldwork show that people with disability find themselves in underprivileged position.

**Case No. 1: Yosef, Age 41, Father of Tamiru with Cerebral Palsy.**

According to Yosef, Tamiru's father, the stigma attached to his disabled child by the school officials affects his child's ability to education. He told me that:

> The school officials have a negative attitude towards his son. They eventually accepted to admit him after a charitable organization offered to pay his fees and convinced them that Tamiru will be able to function as a student of the school.

From the above description we can understand that the public lack awareness toward disability and the role institutions play in integrating children with disabilities.

**6. Settlement Pattern, Economy and Attitude:**

Research in many settings over a long period indicates that proximity leads to repeat interpersonal contact and hence repeated exposure to specific individuals. The result is familiarity and the increased likelihood of a friendly interaction. These friendly relationships could be positive or negative and might result in attraction or avoidance based on stereotypes about the observable characteristics of others (Baron and Byone 1997:268). In one way or another most parents of children with disabilities and children and youths with disability in the study area, individually feel that the attitude of their local community is a significant barrier to lead an ordinary life. A case in point is Sofia with severe physical disability in both legs.

**Case No. 1: Sofia, Age 22**

She explained the problem as follows:
The greatest damage from the community after 20 years stay at home was the facial expression and sign language and gesture from the community, when I went out to use transportation and walking along the road. I even heard words disabled friends, both at school and in their neighborhood. They are not isolated or marginalized by their neighbors. Their disability does not interfere with their general mode of living, their social relationships or their occupations. This category of children in my study area perceived their disability as a coincidence like other illnesses and defines them in medical and not cultural terms.

On the other hand children with severe disability had different attitudes towards disability. In my study, children with severe paralysis of the legs told me that they feel their disability intensely. They have no friends both at school and in the village. They are socially isolated. The only reason they go out is to go to school and to church. They spend most of their time sitting at home. Because medical and other treatments failed to cure their disability they are convinced that the only cure they can hope is from God.

During focused group discussions with the members of community- based voluntary organizations in the study areas namely Edir, Ekub, youth association, and women's association the attitudes of the non-disabled towards disability proved to be the same. They believed that disabled people are different and require help from the non-disabled. Chairpersons of different Edirs in the Woreda (Woreda 13) were asked whether they excluded disabled person from becoming members of their respective Edirs. They reported that there were no rules that prohibited the disabled from being members of their Edirs. Similarly all participants assured me that they know of no cases where disabled persons were excluded from other indigenous associations such as Ekub and other local associations: Maheber, Senbete. On the other hand, they told me that they knew of individuals who were prejudiced towards disabled persons. For instance, only non-disabled members decide who may join a school, have a job, and join recreational facilities. Some of these individuals feel that disabled people have low competence; and there is also a widespread belief about persons with disability that their disabilities are due to some wrong doings in their past lives.
Participants to the focus group discussions agreed that enjoyable, voluntary contact with the disabled increased favorable attitudes. A higher frequency of contact with the disabled enhanced the community's attitude. Closer contact with disabled person increased acceptance. Thus, exposure, direct involvement, and meaningful involvement of the community are important in order to create positive public attitudes toward the disabled. On the other hand, there were participants who believe that there are disabilities, which may be treated with modern medicine (like physical injury, some mental illnesses, etc.), and that there are disabilities that could not be treated with modern medicine. Among those diseases, which can't be cured by modern medicine, are severe epilepsy or "Lekeft" (Being possessed by evil spirit); "evil eye" (*Buda*) and others.

During focus group discussions, parents of children with disabilities, and children and youth with disabilities, asserted that the non-disabled people they live among do not exclude them from different associations mentioned above (Eddir Mahabers). Both parents and children confirmed that they are not excluded from becoming members of indigenous associations. They concluded that they faced individual prejudice and barriers from some of their neighbors and the "community". This, according to them, is due to the public's lack of awareness and cultural attitude toward the disabled. But, membership to indigenous associations does not provide emotional and material support for the disabled, it merely creates a sense of social connectedness. Those who are very poor end up by being excluded from such voluntary organizations because they can not afforded the membership fees.
CHAPTER V

SOCIAL SUPPORT AND SOCIAL NETWORK SYSTEM

The empirical parts of chapter five "The social construction of disability" unveiled the social and cultural processes that shape the perception of disability and its impact on treatments. In order to make the illustrations more clear, respondents' beliefs about disability and health care were grouped into three main explanatory models: Medical, Social, and combined medical
and social. Additionally, the chapter attempted to show the role voluntary institutions play towards alleviating the problems of persons with disabilities; and the effects of geographical settlement, economy and the attitude on disability.

In the individual cases of disability, the general beliefs are proved to be more or less relevant as guidelines to explain and interpret a particular case. We have seen that people have their own specific understanding of the causes of disability which partly drawn from the general beliefs and on situational socio-economic factors. We have also seen that the belief of personal moral misconduct and transgression of normative rules may easily lead to disasters like incurable diseases and these in turn require different curative and healing methods. The research results also indicated that the extent to which the physical differences observed in the individual are socially and culturally constructed. Therefore, in some cases a disabled person is looked upon as a sick person whose recovery requires purely medical procedures of disease diagnosis and treatment and in other cases other alterative (social/medical) treatments are required. Generally the research result showed where biomedicine is the medical system, it strongly influences people's explanatory models, and biomedical causation or diagnosis in turn is influenced by the general belief systems. Finally the research result revealed that the labeling and identification of persons with disability and the care taking processes differed. This is based on different factors such as geographical settlement pattern severity of the disability and economic status of the disabled children parents or guardians.

This chapter focuses on types of problems that disability creates for such children and their families. The first part looks into the type of social support they received starting from the onset of the disability. This is divided into familial support and institutional support. The second part looks into the type of social network used by parents of children with disabilities, care takers, and children with disabilities themselves. This part is divided into four parts:
family based networks, neighborhood networks, networks outside place of residence, and institutional based social networks.

1. Social Support

Social support has been defined as "the attachments among individuals or between individuals and groups that serve to improve adaptive competence in dealing with short-term crises and life transitions as well as long-term challenges, stresses, and privations" (Caplan & Killilea, 1976: 41). Social support operates on several different levels, from the very intimate social support that is provided by a spouse or other close family member or friend, to the more casual support that may be received from neighborhood, community, and/or professional connections. The types of support provided through social support networks vary and include information, material assistance, and emotional empathy and understanding.

Families who have a member with a disability not only cope with typical demands of family life, but also with a host of disability-related issues. Several studies documenting the challenges faced by families of disabled persons have reported a diminishing fabric of social support for children within the family and the community (Murphy, 1995:149; Blanc, 1994:28). Where once strong family networks existed that often helped families of children with disability to meet the challenges of family life, parents have now become better health care managers for their children with disability and derive parenting satisfaction and build more positive parent-child interactions (Singer et al 1993: 29-30).

In developing countries, there is strong evidence of a decrease in the support given by extended families (grandparents, uncles, aunts and cousins) in the urban context. In some cases, for example in Africa, where communities are important components of social organizations, there is the failure of support systems extended to the whole community. In the
West, the extended family has already lost much of its importance as a system of daily emotional and physical support, and relations within the nuclear family itself are showing clear signs of erosion. This social deterioration is chronic in urban areas in the developing world, though it is not always clearly recorded (Bradshaw in Blanc, 1994; 38). Based on the above-mentioned facts, the aim of the present chapter is to look into the social support mechanisms of children and youths with disabilities; with their family, neighbors, friends, community, and other members of the extended family.

1.1 Family Support

Families of children with disabilities have a much greater need for a variety of social supports in order to make adaptive adjustments and this need of support may be covered within the family setting. Among my informants the contributions of family members in a range of social support provisions varied in degree, among others, due to different factors:

(a) relatedness (b), economy, and (c) geographical distance. Humans are meaning makers and meanings are established and transmitted by social communities. When difficult life events, such as disability occur, sometimes pre-established ways of understanding the world are challenged primarily by closer family members. The following three cases are illustrations to this point:

Case No. 1: Kerya, Age 42, mother of Shemsu, a polio victim.

Kerya takes care of her child Shemsu, age 17. She said:

My life has been made difficult by my child's disability. Disability-related demands and responsibilities cause added stress on our family income and time. Often, lack of services, such as medical support, financial assistance, and family support, creates conditions of stress. As my husband works in a private house as a guard and has no time to help me in the day to day care of Shemsu. I was obliged to stay with Shemsu in the hospital for six months. My sister was the one who took the overall responsibility
for my home. My child's disability has demanded increased assistance and support from family and friends. Finance was the greatest problem. My neighbors helped me by visiting us at the hospital, bringing food, fruits etc. But I could not afford the cost of medicines and highly nutritious foods ordered for my child by the doctors. It was my relatives who helped me financially.

Similarly, other respondents in the study areas reported that there was a reliable alliance among family members in family support. According to Kerya, successful adaptation to disability requires support from intimate persons. Such people help the disabled child's parents to retain a sense of control over their problems. Therefore, if there are families in which members openly express feelings and support for one another, parents with disabled children are likely to be more successful in caring for children with disabilities. Kerya explains this as follows:

My family and other close neighbors always tried to find positive way of handling challenging situations, when they came to the hospital. Thus, it was the unity among family members and neighbors that promoted cohesion and adaptation to my child's disability

Once parents of disabled children adapt to disability, there are still other problems that need collaborations from both the family and outsiders. The following statements made by parents in the study areas are quite typical:

**Case No. 2: Wondu, age 44, father of Lulu with CP.**

Wondu is the father of Lulu, age 8, who suffers from Polio. He told me his experience as Follows:

Everybody (family relatives, friends etc.) collaborated during my stay at the hospital when I was looking after my child. My families, neighbors and friends came to see me regularly. However, some people stopped assisting me after finding out that my child had polio. Closer family members and friends, however, continued giving my child and me their economic, moral and emotional support.

**Case No. 3: Senedu, age 35, Mother of Cosi who suffers from clubfeet**

Senedu, mother of Cosi, age 10, noted the support given from her relatives and neighbors as follows:
Because my relatives and neighbors know my childbirth was normal, I had not worried about her future prospects. It is normal to have an illness or a disease either permanently or temporarily. Therefore, I do not worry about her future. Every body I know has been supportive. The support from family and relatives continues.

Case No. 4: Abeba, age 23, mother of Mimi with cerebral palsy (CP)

Abeba is a mother of a 5 year-old child, Mimi, with cerebral palsy. She described her experience regarding the social and material support she received from her family as positive; she said:

When Mimi was born and identified as having cerebral palsy after some time, I did not feel isolated. Supportive people surrounded me. My mother and close family were incredibly helpful. My mother immediately took my daughter and allowed me to look for a job. My husband and me continued leading our life. There were people who ostracized and stigmatized my child and me. Others gave me information about where I could find support. My child is getting the right support from professionals working in our residential area.

According to the above-mentioned three cases, the kind of support available for parents with disabled children varied from family to family. These are: (1) moral/emotional support (2) economic support (3) physical assistance in caring for child. We have seen that there is social isolation because of stigma in the case of Kerya (case No 1) and a happy story in the case of Lulu (case No 2) and complaining of outsiders from Abeba (case No 4). The factors affecting the availability of social and material support ranged from lack of economical means to different kinds of support (informational, medical etc.)

According to my research there were additional factors affecting familial support and these factors varied from one family to another. The variation became more severe in the case of relatively "poor" families with disabled children. We will see community support under the different topics of social network.
1.2 Institutional Support

Institutional support in this context comprises institutions and interest groups for peoples with specific kinds of disability and local associations not purposely established for these purpose. The following cases are illustrations of the relationship between persons with disabilities with institutions with regard to social support.

Case No. 1: Elsa, age 35, mother of Gero with cerebral palsy (CP)

Elsa is the mother of Gero, age 4. Her main concern according to her was her child's future. She said:

Bringing Gero home was the beginning of countless hours, days, weeks, and years of physical therapy, speech therapy, special pre-school, doctors, hospitals, clinics, and the list goes on and on. My days were spent searching all over town to obtain service for Gero and my nights were spent planning for the next day. We have a variety of support sources for Gero. But we have not informed our closest relatives that Gero has a disability. Very few persons know about his disability. This is because we think that his disability will improve within a short period of time. He has improved somehow with the help of Cheshire Home.

Case No. 2: Senayit, age 25, mother of Hailu (age 2) with cerebral palsy (CP):

Senayit tells of a different set of circumstances. She was jobless and her child's father did not give her economic support. He was at the war front during the EPRDF versus Derg struggle, and she does not know whether he is alive or dead. After she gave birth, she was able to join her family with the help of elders (local arbitrators). After she moved to her parents home the following were the problems that she faced:

My parents and other family members rejected my child and me since I was jobless. I am an extra burden to my family. Besides, I am with a disabled child who has no bright future in every aspect. My hope became darkened when I think about the daily care of the child that requires a great deal of time and energy. These challenges are beyond the financial resources of my parents. I cannot work as a housemaid because of my child. Employers do not want a woman with a child let alone a disabled one. No one but a charitable organization called Medical Missionaries of Mary (MMM) has given me material
support. The organization helps my child with medical bills and cover part of the nutritional expenses.

In the above two cases both mothers evidenced their satisfaction with social support from institutions. The first mother identified that her problem was not economic but technical and informational, which was impossible for her family or relatives to fulfill. While the second mother's problem was economic. Though her family could not fulfill it due to poverty, she was able to get it from the nearby voluntary organization.

2. Social Networks

Network analysis in anthropology is more than the study of "networking" - expanding and making strategic use of the stock of contacts a person has. Gutkind (1969, 1974) considered the concept of social network to be the most useful and comprehensive tool for the study of urban social relationships. In line with Bott's (1957), Epstein's (1961) Michell's (1966) and Sanjek's (1978) pioneering work in an urban based personal network relations suggested that the various aspects of social network systems, how they are build up and the specific purposes they serve, reveal the degree of social mobility (Boissevain 1979: 392 - 94). The same factors shed light on the where and how ethnic, occupational and class sub-systems overlap and where they do not and why. More specifically he wrote that:

"... the reconstruction of these personal and group networks (or the use of participant observation to observe their construction and use at any moment in time) combine, in rather subtle ways, micro and macro techniques. At the micro level, the network is constricted as it involves primary kin and close friends (the effective network), and at the macro level, the extended level, the network can range (ecologically) over the whole urban area (Gutkind in Paula 2000.74-75).

There is an enormous literature on embedded social networks in various cultural environments. The usual approach of network and support systems is to describe their composition and structure. These may be divided into people one knows and those one count
on in times of need. One form of inquiry into network formation and their mobilization into support systems involves establishing the collection of relationships that connect people. Another way is to study a person's networking strategies in terms of how the individual expands and make strategic use of the stock of contacts she/he has. The way in which different types of social networks provide different kinds of support are often analyzed in terms of a person's set of ties with parents, peers, friends, relatives, neighbors or work mates (Paula, 2000:75).

The terms network systems and support structures are nevertheless frequently used together of interchangeably. This is because social networks can only be fully understood by taking into account the social, cultural and interpersonal context of support interaction. Some authors link network and support by demonstrating the importance of networks in creating social embeddings or a sense of attachment to others as an important element. Others interpret the exchange of emotional and material resources between at least two individuals who are perceived as providers or recipients as one way of forming a social network. Furthermore, social network systems are worked over time by changes and continuities. The variation in time and space in the types of social support and social network people need are essentially related to age, class, gender and ethnicity. This metamorphic aspect of support interaction ultimately enables individuals to construct and confirm their self-identity (Ibid: 86).

Social relationships do not exist in isolation but are embedded in social networks. A network is more than the sum of its ties because the composition and structure of a network can affect the resources to which network members have access and the ways in which social relationships operate (Wellman: 1998). I have therefore considered social network systems among children and youths with disabilities, their parents, the community and governmental
and NGOs to consist of mutual family and non-family social relationships. During my field work, I observed that most of the research families maintained relationships with external people as well as with service institutions, such as school, church, doctor, and clinic; with voluntary associations, such as charitable institutions. They also maintained more informal relationships with colleagues, friend, neighbors and relatives. These relationships could be within their residential area or outside their local area. Apart from the immediate social environment, network relationship included other types of networks away from persons with disabilities and their family residential areas. But the immediate social environment of persons with disabilities can include the network of actual social relationships they maintain, regardless of whether these are confined to the local area or run beyond its boundaries.

I observed a difference between the immediate social environment of families with disabled children and youths living in the three study areas, because of differences in the family's economic and social structure. Some of the families of children with disabilities are characterized by more individuality than others. By 'individuation' I mean that the family is relatively separated off, differentiated out as a distinct, with regard to its social relationship with their neighbors.

2.1 Family Based Networks

Densely knit community networks are more emotionally and instrumentally supportive than sparsely knit ones (Wellman, 1998). Woreda 13 is a densely knit community when compared to Woreda 25 and Woreda 8. From an interview with my informants in the three woredas (Woreda 13, 25, and 8) I found this to be true. This supportive network is more cohesive between people with an equal economic status.

Case No. 1: Meskerem, age 34, mother of Tsegaye, age 10, with Club feet
Meskerem is the mother of Tsegaye,. During my interview with her she told me this:

We do not have close relationship with our neighbors. Every body in this village lives his own life. We have no local associations like "Edir" or "Maheber". Our children do not play with the neighbors children. Our relationship is with our relatives and friends living outside our kebele.

Therefore, Tsegaye's families are encapsulated within their compound. They have a big villa with its compound. The family is a well off financially. But the social relationship with their neighbors is relatively poor, non-existent. The community network in this area exemplifies the sparsely knit community network. Economic ties operate more forcibly between relatives than between friends and neighbors, but there is a wide range of variations in the operations of such cohesive forces even among relatives (Bott, 1964:102). During my fieldwork I asked my informants whether their relatives help them financially or not. Except two parents (5.13 %) of children with disabilities, the remaining 37 respondents (94.87%) responded that they do not receive financial help directly. It is during the initial stage of their children's disability that they may receive financial help. At present the support, especially material support, from NGOs is by far greater than the support from relatives or family members. This was true for those families with low economic status. The reason for relatives not giving much economic help, varied from family to family.

Case No. 2: Shita, age 38, mother of Kokeb, age 12, (a Polio victim).

Shita is the mother of kokeb, a polio victim. Shita noted that the reason for not receiving help from relatives was not because her relatives hate her or her child with disability. She said:

Like all human beings the desire to help to do good for others is common among my relatives. But my relatives are of equal economic status with me. They have no extra economic capacity to help me.

Case No. 3: Mulu, age 35, mother of Alem, age 12, with bum deformity.
Mulu is the mother of Alem. She lives with her daughter. Both of them are engaged in begging to earn their living. Network-connectedness depends on the stability and continuity of the relationships. A family network will become loose-knit if the family move away physically or socially so that contact is decreased and new relationships are established. Mulu's case is an illustration to this point. She said:

We started begging because we had no fixed area of residence. Because of my nature of occupation (injera baking, washing clothes, and toasting barely) I was wandering from house to house. I was not living more than six months in one area. Because of this I had no close acquaintance with my neighbors. My relatives live outside Addis Ababa and many years have passed since I heard news of their well-being.

Case No. 4: Michu, age 33, mother of Selam who suffered from Polio:

The connectedness of a family's network depends not only on external social forces, but also on the family itself. Relatives of the husband and the wife, for instance, may not be equally close to the family with disabled child. Combination of situational factors might affect their relationship. According to Michu the genealogical relationship and network formation in their case is very weak. The problem is the fathers’ side. She said:

The relatives of Selam’s father do not accept our marital relationship because I gave birth to a disabled child. They did not give me the social support required. They even asked me to give my child to them and lead my life alone. She concluded.

Case No. 5: Moges, age 31, a polio victim.

If family members do not live in the same local areas or if they are not accessible to one another, it is very difficult to develop close-knit networks among themselves. A case in point is Moges's family;

I live with my mother. Our relatives all live in Wollo region. My mother came to Addis Ababa 18 years ago. We have no contacts with our relatives. We lead our life alone. Nobody give us any kind of support.
Generally the above five cases show that different factors are responsible for the loose family based networks. They indicated, better off families are more isolated from neighborhood and other disabled families (Case No. 1); families will not be supportive if the resource available is not enough for themselves (case No. 2) relocation of residence or period of time that families stayed in that area will affect the network relationship both with relatives and neighbors (Case No.3); beliefs and attitudes of relatives on the disabled family (case No.4); and residential distance (Case No 5).

2.2 Neighborhood Based Network

The type of neighborhood of the family of the disabled children, and children and youth with disabilities live in is very important. One of the factors affecting the 'localization of networks is the similarity of social statuses among neighbors. Localized networks are most likely to develop in areas where the inhabitants feel that they are socially similar (Bott, 1964:103). As described by Feye, mother of Rawda, a polio victim, because the people who reside around them came from the ex-military camp, with the same social status, they have smooth 'localization' of networks. However another case shows that similar status does not necessarily mean automatic social integration.

Case No. 1: Kiros, age 37, mother of Abeba without left hand below her elbow:

Kiros is the mother of Abeba, age 13. She was given a plot by the order of the kebele Officials. She constructed a small house on an open space. She described about her relationship with her neighbors as follows:

I do not know what happened to them. I do not remember what I did to them. They see me as their enemy. In fact, I do not have equal social status with them. In addition to that I have a child who is disabled and I am very poor, economically. I live an isolated life, even though we belong to the same "Idir."
From the above illustration we can understand that the fact that she is the member of community based voluntary association shows that they are part of a community, but this does not help them in getting community based support or serve them as a coping mechanism.

**Case No. 2: Tolossa, age 43, father of Tegane, a Polio victim.**

Tolossa and his wife take care of their son Tegane, age 18. Tolossa described the social relationship with his neighbors as follows:

> We have no close-knit networks with our neighbors. My son has no relationship with his neighbors non-disabled families and children. In fact the inhabitants are not relatively homogenous with regard to income. My son lives an isolated life. This disturbs me a lot. The problem is beyond my capacity.

During my fieldwork I saw that the three woredas are different in the type of dwellings. Most of houses in woreda 13 do not have separate compounds. It is therefore easy for the residents to have close contact and social interaction. Whereas in Woreda 8 and 25, most houses have their own compounds, people living in these areas lead life relatively isolated with the confines of their compounds. They have relatively less contact with their neighbors. The occupation patters and the livelihoods of the people in the study areas are so complex that they give rise to many different types of urban neighborhoods relationship.

**Case No. 3: Shege, age 41, mother of Seman, a polio victim.**

The type of neighborhood network can also be determined by how long the family has lived in the area. Shege's case is an illustration in this respect. She said:

> Because we have lived in the area for a long time and our neighbors know that Seman became disabled after birth, the people living in this area do not have a negative attitude towards my child. Therefore, because they know that he was not born disabled, the relationship between our neighbors and us is close.

**Case No. 4: Semret, age 33, mother of Tadu with cerebral palsy (CP)**
Unlike case No 3, the perception of the families with disabled children or the children with
disability of their neighbors with regard to economy and social status is also important.
Objective measures of social homogeneity give only a rough indication of how families will
feel about their neighbors. In regard to this, some families with disability are not compelled
to be friendly with them. Semret's case is an illustration of this point:

We live a better-off life compared to other families of children with
disabilities. But, our child's disability is not known by our neighbors. We
do not even want to tell or show him to our immediate (closest) relatives.
This is because we hope that our child will be normal one day.

Case No. 5: Feye, age 40, mother of Rawda, a Polio Victim.

Unlike the above-mentioned family in wordea 8, Feye lives in woreda 13. During an
interview with Feye, she told me that the network relationship with the neighbors is close-
knit. They relate to each other during different occasions such as men's and women's edir,
religious "maheber", "coffee ceremony", and "Ekub". The houses are constructed very close.
There are no separate compounds. The people living in that "sefer" used to live in nearby
military camps. The village was constructed after the fall of the Derg regime as replacement
by the Ethiopian People Revolutionary Democratic Front (EPRDF). Feye described the
network relationship among neighbors as follows:

We have a strong social relationship among neighbors with equal
economic status, ranging from the smaller ceremonial connectedness up
to the larger social network. We hold a "coffee ceremonies". Here, three
to four households drink coffee together. It is routine, everybody
prepares coffee turn by turn. The other one is "Ekub", where we gather
monthly at the chairperson's house. This is in order to cover issues that
need big finance. It goes up to ten months. The maximum amount that
each person contributes is birr 100 per month. But, a person can
contribute one-fourth of the maximum amount and four persons from
one group. The other means of gathering is "Edir": We have two kinds
of "Edir": for men and women. The men's Edir is mainly to cover
expenses when the member of that 'Edir" or his closest relative dies. It
provides a person with a tent and chairs for people who come during the
mourning days. It lasts for three consecutive days. The women's "Edir"
on the other hand performs more detailed things. Besides helping the
person's family with money, they will take the responsibility of providing people with food and drinks for three consecutive days. Each member has a duty programme. She will serve the guests that are present during the three meals times breakfast, lunch and supper.

Therefore, from the illustrations above the local area can be called a community in the sense that they form cohesive social groups. This connectedness helps the disabled in reducing e burden of isolation resulting from the stigma. On the contrary, n the case of woreda 8, its immediate social environment could not be considered as cohesive social groups, because of the loose network of their actual social relationships.

2.3 Networks Outside Place of Residence

Networks outside the local area are more likely to be close-knit if parents or children with disability themselves have many opportunities to form new relationships with persons outside their residential place.

Case No. 1: Shume, age 29, mother of Taye with cerebral palsy.

Taye's family is both professional nurses, their education and professional training has led them to make many relationships with colleagues and friends outside their local area. As Taye's mother, 'Shume', described it, her child's disability is more exposed to their friends than to her relatives and neighbors. She said:

"Many of my husband's friends his father and my friends come to see our child. Because they are professional friends (nurses) they were all at the hospital when I gave birth. But, our child's disability is secret to most of our relatives and neighbors."

Similarly, like educational and professional training, there are other factors like the nature of the occupation and the perception of the family of children with disability of its neighbors that lead to the formation of networking outside its locality. Even if such families keep on living in the same area throughout their lives, their pursuit of the abovementioned factors
leads them to make relationship with people who do not belong to the family's neighborhood network. So the network around their residential area tends to become loose-knit.

2.4. Network and Residential Pattern

During my fieldwork activity in the three woredas (Woreda 13, S, and 25), I have observed that the location or settlement patterns of the houses are different. The two weredas (wereda 8 and 25) differ from woreda 13. The houses of children with disabilities I visited in Woreda 8 are with big compounds. Consequently, parents of children with disabilities in wereda 8 and 25 lead relatively isolated lives. This location therefore creates a situation where there is loose-network among different neighbors. On the other hand, the houses of families of children with disabilities in woreda 13 are constructed close to one another and are not separated by walls. Their entrances are very close and have usually common compounds. Therefore, this situation has created for them closer relationship in many ways children play together, neighbors hold coffee ceremonies every day and perform other local activities together. Even though the wereda 25 families of children with disabilities seem to lead isolated lives because they have separate compounds, I have observed that they have similar class position. Besides they lead an extended type of family life. The family structure is not a nuclear type, like the woreda 8 residents. Rather two or more households live in one compound together.

Case No. 2: Mane, age 52, grandmother of Tezeru with cerebral palsy:

During my interview with Mane, grandmother of Tezeru age 13, she explained her family living situation as follows:

I live with my son's wife and Tezeru and we have a separate compound. My son died when Tezeru was four years old. Tezeru's mother works in a nearby factory called " Gulele Garment Factory." Because she is completely occupied in her work the responsibility of caring her child has fallen on me.
Our family is relatively equal with neighbors. We have close contact with our
neighbors.

2.5 Institutional Based social Networks

During my fieldwork activities in the three woredas (woreda 13, 25, and 8) I saw a small
number of local associations serving as a unique form of mutual support for families of
persons with disabilities and children with disabilities. Both emotional and informational
support provided by parents and children with disabilities themselves. In fact the initial
organizers of these programs were the non-governmental organizations (NGOs) working in
these localities. The present local association forums, known by the name mother-to-mother
program, coffee ceremony program, and child-to-child program only found in woreda 13 that
were established by NGO's. The remaining parent- to- parent monthly meetings (parent to
parents program) and children with disabilities clubs are known by all woredas (Woreda 13,
8 and 25)

The rationale for the above-mentioned programs, according to the managers of the NGOs
working in the study areas, is to create a meeting forum for parents and children with
disabilities in order to: deliver emotional and informational support through voluntary efforts
of parents and their children; create appropriate support opportunities; introduce parents with
similar problems in the area; and share experience and challenges faced by families.

Case No. 1: Shege, age 41, mother of Seman, a polio victim.

According to my informants in Woreda 13, before the introduction of this program in their
residential area by an NGO called MMM, their relationship with their neighbors was loose-
knit. Residences of parents of children with disabilities are scattered in different kebeles of
the Woreda. Shege is the mother of Seman, age 17. She described the newly established local associations among the disabled parents and the community role as follows:

Before we started this "yebuna Mahiber" ("Coffee Ceremony") I did not invite my non-disabled neighbors or parents of non-disabled children. In fact, there was limited relationship. It was after the establishment of the MMM NGO that this "Yebuna Maheber" relationship with non-disabled neighbors gradually increased. The NGO provides us with coffee and sugar in kind and we discuss about our children's disability and disability in general, every month. In my opinion, this coffee ceremony has created a means for improving relationship with non-disabled neighbors and gradually changes their attitude towards our children. It has shown a significant progress. I witnessed that my child relationship with non-disabled peer groups is also increasing.

During my fieldwork, I visited ten different groups at different houses of parents of children with disabilities in different kebeles of Woreda 13. The coffee ceremony was among parents of children with disabilities and their non-disabled neighbors. There were also groups called "Enatoch Le Enatoch" (mother to mother). These groups were constituted of mothers of children with disabilities. As my informants in different kebeles of Woreda 13 told me, each group member comes from the nearby kebele. The group ranged from 5 to 9, which were not known to each other before.

Case No. 2: Eden, age 30, mother of Atse with joined fingers.

Eden is the mother of Atse, age 13. She has for more than 4 years participated in these associations. She told me the benefit she gets from this ceremony as follows:

I found sharing my experiences with different mothers of children with disabilities to be extremely useful. It was useful because I have learnt a lot from these forums. They shared with me many of their own family experiences. Their collective wisdom was just what I needed to make my own decision with confidence.

The above-mentioned group, mother to-mother group, is similarly found in different kebeles of woreda 13. The other common feature of the three woredas is the parent-to-parent monthly meeting. It is an association established by parents of children with disabilities with
the effort of the two NGOs, MMM and Cheshire Community Based Rehabilitation, situated in woreda 13, and Woreda 8 and 25, respectively. The members of these associations are also constituted from different kebeles under the three woredas. But these associations are few in Woreda 25.

Case No. 3: Kalu, age 42, father of Kuku with Club Feet.

Kalu is the father of Kuku, age 14. He is the member of Woreda 13 parents of children with disabilities association. He described the benefits of this association as follows. He said:

The association's role is not only as one helping disabled children and their families gain power, but as part of the larger struggle for social change and liberation of all persons with disabilities who are at the bottom of the society's socioeconomic system.

Conclusion

This chapter has identified the different familial, relatives, and neighborhood and institution based responses to children with disabilities and their families. Similarly identified were the satisfactions felt by the disabled and families with social support received at the time of feeling helpless, afraid, or rejected. It also assessed the parent-to-parent networks and other assistances outside the family network and based on institutional support.

The above-mentioned issues have been dealt with four sections. The first section took a close look at adaptation to disability. Three cases were presented to show the support needed for families with disabilities. The result revealed that the situation differed from family to family. The sources of support, according to my findings, included family members, relatives and neighbors and institutions. The factors that affected the social support were relatedness, economy and geographic distance from members of one's extended family willing to give economic or emotional support.
The focus of the second section was on the type of support (moral, emotional, economic and physical) available to children with disabilities and parents, and factors affecting their availability. The third section has presented familial, community based and institutional based networks of the disabled. It assessed the immediate social environment of person with disability. It dealt with economic ties among relatives, types of neighborhoods, relationships outside the local area network, settlement pattern and connectedness. The results showed that there was a difference between the three areas (Woreda 13, 25 and 8) in terms of immediate social environment and economic help, which varied from family- to family even between relatives of a child's father and mother. Furthermore neighborhood relationship is affected by the difference in social similarity, acceptance of the family with disabled member by neighbors having enough economic resources, integration within the community based on the length of time by how long the family of children with disability have lived in that area. Finally the study shows that parents of children with good economic resources have more relationship outside their residential area than with their neighbors. Last but not least the study revealed that their geographical settlement pattern can contribute positively or negatively to the type of relationship children with disabilities and their families have with society at large.

The final section was devoted to sketching out the contributions of local associations established by the non-governmental organizations for the benefit of children with disabilities and their parents.
CHAPTER VI

COPING MECHANISMS

In chapter five I have pointed out in general terms the types of problems that disability creates for children with disability and their parents. The first part looked into the type of social support received by such children and their families starting from onset of the disability. The second part focused into the type of social network used by the different categories of disabled children, their parents and guardians. The research result show that these networks embrace a variety of participants, family network’ self-help groups institutions, and non-governmental support programs. It depicts the prevalent types of family support, the essential role of reliable alliance in family support where it exists and highlights the contribution of institutional and non-familial networks.

Personal adjustment to disability requires not only the efforts of the child or his/her parent, but also other factors that can add to the success of the disabled individual. Santumbwe (1995:160) study's of the experience of blind women in Uganda indicated that the strategies applied by disabled persons in performing daily routines include management of social relations. Here two concepts come to the fore: coping and life space. Santumbwe defines, coping as primarily referring to an individual's ability to function in everyday life situations and life space can be described as the type and character of social and cultural fields of relations in which people operate, or to which they are confined. Impairment adds to a child's vulnerability in dangerous situations. However, children vary in their responses and their
capacities to cope with their impairment. The way children treat their disability differs from family to family, community from community, and country from country.

Children often show great courage in coping with hardship. In this chapter I shall look into coping and finding meaning in difficult circumstances by parents of children with disabilities and children with disabilities themselves. Additionally, I shall attempt to show that joining with others to promote the well being of children with disability is an important element of effective coping by dividing the coping mechanism under three main sections. The first section deals with institutional help, the second section with parental or family based financial help, and the third section with children with disabilities own coping mechanism.

1. Institutional Help

Institutional help in the study areas constituted providing children with the disabilities with the initial capital in the form of income generating skills, material help such as appliances, education, and employment. The following cases illustrate these points:

Case No. 1: Lakech, age 18, suffers from paralysis of both legs.

She told me that the type of help she has received from an NGO called Medical Missionaries of Mary (MMM) in the form of income generating skills and appliances helped her to a great extent to promote her life. She said:

I was detected by the charitable organization, Medical Missionaries Mary (MMM) in Woreda 13 Addis Ababa, who learned about me through one of my neighbors who is a disabled. I was 16 years old at the time and I was crawling on the ground. After this I was taken to the hospital "Black Lion" hospital, Cheshire clinic unit, for possible treatment and rehabilitation. After some months I was able to stand and could walk with underarm crutches. There was a follow-up by the above mentioned NGO which took me to the hospital every six months. Consequently I was able to gain access to the external environment. I was eager to promote myself in every respect. I became an active participant in different rent a month. My father does not
consider me a burden because the income from the house rent was made possible because of me.

**Case No. 4: Alem, age 13.**

Alem, age 13, suffers from bum deformity in one leg (left). Unlike the above cases in which children and youths with disabilities/parents of children with disabilities lead relatively a descent economic life, there are families who have no choice to care for their disabled children due to their poor economic status. In these families children with disabilities are neglected and expected to take care of themselves. The care taking of such disabled children is often left to the community or an institution. Alem's case illustrates this point:

I live with my mother. My father did not accept me as his child and he did not help us economically. Until some years back my mother used to work in different private business houses doing daily activities: toasting barley for local breweries (Tella houses), washing clothes, and baking "injera." Now she is not able to continue carrying out such activities due to serious health problem. She is forced to earn her living by begging. I also participate in begging activity in order to cope with my disability. We cannot afford to eat three meals a day. Even though I am registered for at school and am provided with appliances by a charitable organization in woreda 13, my living situation is not favorable to compete with my friends at school.

Therefore, the above illustration revealed that stress created by the disability varies according to income groups. In other words relatively upper-income groups have more options available and, hence, are able to deal with disability more effectively. Lower income groups have little or no options at all.

**Case No. 5: Abebe, Age 22.**

On the other hand, one of my respondents, Abebe, age 22, who is an orphan grew up in a Catholic boarding school. He does not know his relatives except his uncle who brought and placed him in the institution. Abebe shared his personal adjustment to his disability as follows:
As my uncle told me, some years back, my disability was due to failing down from the shoulder of my older brother. I grew up in the institution. Until I went out from the institution I was in the care of the boarding school administrators. It was after I started living by myself that the personal adjustment to disability started. The institution administrators gave me a house to live in and introduced me to one charitable organization who helped me financially. My response to disability is a major factor to success or failure. My disability has not caused frustrating limitations. With the financial help I got from the above-mentioned charitable organization, I started a hair-cutting business for the youths living in the Kebele. Life is what I choose to make of it. I am known by non-disabled youths and their families. Gradually I developed confidence in myself. I do not feel uncomfortable when I go to different recreational places with my non-disabled friends. I am now leading a happy life.

Case No. 6: Sehin, age 39, Mother of Meki with cerebral palsy (CP)

Sehin is a mother of Taye, G years old, with cerebral palsy (CP). She is well off economically. The only problem she worries about is her child's future. She expressed her feelings as follows:

For us, the scariest part of being a family for Meki is that there are so many unknowns for him and for us. Will he be able to make himself understood? Will he have friends who accept him as he is? Will a quality educational program be available for him in our community? Who will look after him when we can no longer do so?

Meki's mother continued by saying:

It was after I met a charitable organization called Cheshire CBR (community based rehabilitation) that I got a relief. They shared with me their experience. They showed me other children and helped me to establish contact with other parents of children with disabilities. I saw other children with severe disabilities. Some of the problems gradually went away. It normally takes me about one year to get through the entire process (coping). Now I do not worry about Meki living at home for the rest of his life.

Meki’s mother described her relationship with her husband since their child's illness as follows:

My husband is very supportive. Due to my profession as a nurse I will not be at home during the night. He is the responsible person at that time. He does not complain for inadequate sleep or caring for his child. Thanks to “God”, I do not feel helpless and guilty because I
have a good partner who shares all the problems. In addition to this we approached the above-mentioned NGO for additional help.

Case No. 7: Tutu, age 47, Mother of Chala with mild cerebral palsy (CP)

Tutu is the mother of Chala, age 4, with mild cerebral palsy. In contrast, children with mild disabilities demand or require less time and energy. The caretaker (sister, housemaid, relatives, etc.) or the child’s mother can stay at home without many burdens and parent’s grief is not exacerbated. There will not be other consequences on the family like role redefinition, loss of income (when compared to families with children with severe disabilities). Regarding this, some of the parents interviewed did make statements implying that their child's disability was difficult at the beginning but that all things become easier with time. Tutu remarked about her child's situation as follows:

Chala is 4 years old with mild paralysis on his leg. The disability became known after birth. Initially most of our time was spent taking Chala to doctors and therapy appointments. My husband, who is a teacher, and I educated ourselves about the illness and asked a lot of questions to health officials. Gradually knowledge and understanding of Chala's problems replaced the mystery. Chala has mild cerebral palsy. Some professionals told me that no amount of money or medicine would change the damage to Chala's brain. He will always be disabled. Coming to terms with this was very hard and very depressing and seemed to take too long. I decided to try prayers at the Protestant Church. It was in addition to the range of motion exercises given three times a week by a charitable organization, Cheshire CBR. Chala was able to walk and run by himself within a few weeks. There are few things remaining now, which are insignificant compared to past conditions. Finally, I want to mention that all the credits for the treatment of the child go to me. My husband has made no contribution to nursing him because he is busy teaching day and night.

In both cases, severe or mild disabilities, living with a disability produces unusual stresses that can lead to fatigue and low morale in some families. These stresses appear to arise when a family has to alter its life-style to accommodate the needs of a family member who requires extra assistance and when these adjustments are difficult to maintain over time. Most parents of children with disabilities require much support from their relatives or neighbors as well as institutions in order to cope mentally and physically their children's disability.
2. Parental or Family Based Income

Families who have a member with disability must not only cope with the typical demands of family life, but also deal with a host of disability related issues that accompany their transition from the 'culture of non-disability'' to the "culture of disability" (Singer et al., 1993. They must learn about the disability itself and what this means for the individual as well as for the whole family. They must learn the languages of the medical, legal and special educational worlds. They must find their way in service systems that may or may not provide appropriate support opportunities. They must cope with the possibility of social supports from relatives and friends, and their families. More often than not family members distance themselves out of fear and/or misunderstanding of the disease. Additionally, as new members of a minority group in the society he/she lives, children with disabilities must meet all of these challenges while struggling to understand and adjust to their own new identities and roles.

Case No. 1: Tesfu, age 22.

Another child whom I visited during my field work was Tesfu. He lives with his sister. His father and mother died some years back. He is 22 years old. Their elder sister helped them economically. Tesfu has graduated from a building construction institute around Kotebe. Though his sister has made a lot of contributions to improve his life, he had to contact an NGO for additional help. The NGO supplied him with appliances he needs every six months. He said:

Being disabled, I had to face two kinds of problems every day. How to cope with my disabilities and how to cope with the reactions of other people. In a way, the latter was harder because I could often control my own reactions, but there was little I could do to control the reaction of others. Now I am an adult. My parents/sister equipped me with the weapon. They thought me how to earn money and lead life and an NGO helped me medically. My peers who insulted me during my childhood started to
respect me and work alongside me at different places. The only difference between me and them is like the difference between a person with hair and one without.

Case No 2: Saba, age 22.

One of my female informants Saba who lives with her parents does not find difficult to accept her disability. She said, "I am using my special shoes because of fear of and at the same time love for my parents. I do not use it when I am at home, and I use it sometimes when I go outside. It is very heavy unlike normal shoes". Walking a long distance without the special shoe is difficult for her. Her family is well-to-do. She has no economic problem. She said:

When I first became disabled, I was tempted to say "To hell with life! Life without walking isn't worth living." But I discovered there are other facts equally true: I can still relate to people; I can still do or learn to do many things; human worth is not measured by how many pounds I can lift or how fast I can run. I can control my life by the way I act. I have no economic problem. No discrimination from my parents. Every priority is given to me. There is no need to look outside like my friends with similar problems.

The illustrations above are of children with problems in the legs (especially polio victims). During my fieldwork, I also met children with hand amputations; back injury (muscular dystrophy); and other leg damage (bum deformity). Their responses were not the same as those with minor disabilities. Thus, children's resilience could be flexible. When action is impossible they can resort to useful mental mechanisms to help them cope with their situations such as mentally rehearsing possible responses to the situations. The challenges faced by families of a person or child with disabilities differ according to the type of disability the children have (Sentumbwe, 1995: 160). Intensifying many of their feelings (guilt, anger, depression, loneliness, confusion) are the day-to-day logistics of caring for a young child with special needs. These logistic includes repeated visits to hospital and medical clinics often demanding and time-consuming care giving home responsibilities, little opportunity for respite, managing the concerns and acceptance (or rejection) of family and
friends. Resilient families are active problem solvers and efficient users of coping skills and work at maintaining social links despite these challenges (Singer et al., 1993)

The day-to-day routine for children with motor impairments - polio, back problems, amputations, spinal curve, cerebral palsy - is different from other disabilities such as mental retardation, blindness and deafness (Helander: 1990; Advany and Pandy: 1995). This research embraces is only the motor impaired children. The study documented the challenges and the coping mechanism the parents of children with disabilities utilized. During the research, parents of children with different kinds of disabilities were asked about the day-to-day routines of caring for the young children: the repeated visits to hospitals and medical clinics, other treatment places; and other home responsibilities. Coping with day-to-day demands through different mechanisms can lead to a sense of efficacy and a related sense of hope. The coping mechanisms start from the time of birth of a disabled.

Case No. 3: Enye, age 38, mother of Hawa born with a hip problem

When I gave birth to a child with a hip problem, there were so many questions in my mind. "What did I do wrong" Why did it happen to me' what is wrong with me?" The answers are not less distressing perhaps I can't produce normal children." I wish I had never got married. And then, other questions such as "Oh, why am I thinking these terrible thoughts? What sort of person am I? I asked my "God" to give me a child and he gave me. My child needs a mother to love her, and yet I am going to abandon her. "I was crying for a long time. Finally I tried to adjust myself with the help of "God."

According to the above illustration the mother of the child with disability was thrown into a state of turmoil and disorientation and attempted to find a reason why her child has emerged as a different person than she had dreamed. She tried to associate it with "God". Thus, efforts to cope with the birth of a child with a disability often involve striving both to understand what it means to have a child with a disability and to find a reason why it has happened. Parents who faced the problem of having a disabled child after birth can easily accept the
phenomenon than parents with children with disabilities at birth. Feye, mother of Rawda with polio explained about her feelings as follows.

**Case No. 4: Feye, age 40, mother of Rawda suffers from polio.**

My child's disability began when she was four years old. Neighbours knew about Rawda. They knew that she was a healthy child until she was four years old and the disability started later. An illness or disability can happen even to older persons. Now my child and I have no problems with persons outside the family. I do not forget my relatives and neighbors’ help when my child was in the hospital.

Therefore, difficulty of adjustments varies with whether the disability occurred before or after birth. Being a parent is never an easy job. Luckily children are very resilient, if parents make a good job of their children's upbringing. The coping mechanisms differ with ages of the children as well as with different disabilities. Some of the problems associated with rearing children with disabilities include: movement, toileting, bathing, dressing, feeding, carrying, etc. Yemane is the father of Tezeru, age 4. He is a clergy serving at a nearby church. Satisfaction with what they got (information, support and progress) is an important predicator of adjustment to adversity and bereavement. Here, the kind of disease, whether it is long-lasting or not, is also the most important thing. If it is a disability like severe cerebral palsy, where the child does not move from place to place and requires close attention in his/her day-to-day life, the parents have to sacrifice themselves by dedicating their whole life to unremitting slavery in caring for the child. However, the case is different in some families. Yemane's, father of Tezeru, case is an illustration to this point:

**Case No. 5: Yemane, age 52, Father of Tezeru with cerebral palsy (CP)**

He is 3 years of age. No progress is seen on my child. I have tried religious, cultural and medical treatments. I have no hope in the future. The relationship with the child's mother has broken. Because my child refused to give the child to a charitable institution I blame her for the problems happening now. It is because of my religious obligation that I care for my child, otherwise I would not have cared if she dies.
Whenever I arrived home the child's sanitation was bad, getting worse everyday. So this seems to be an indication of non-existence of enjoyable relationship between the child and the family (especially between father and the child).

From the above illustration we can see that management of loss for some families of children with severe disabilities is a lifelong experience, requiring ongoing recognition that grief-related responses will re-emerge from time to time throughout life. Recycled responses are stimulated by health and developmental changes in the child, additional losses, and secondary stressors. In this case, religion and family income plays the most important role for the alleviation of the child's disability.

Case No. 6: 1DJig, age 25, Mother of Mesfin with Muscular Dystrophy:

Ejig is the mother of Mesfin, age 10, with muscular dystrophy. Ejig and her husband take care of their disabled child and they have no economic difficulty. They live in a big flat with an open space in the compound, which is asphalt. Unlike parents who are under severe stress, both economically and psychologically, better off families like Ejig need little supportive provisions (materially). The only problem they have is getting the right treatment. Ejig's description is an illustration to this point:

We have tried both kinds of treatments: "Yeager Bahil Medhanit" (Traditional Medicine) and modern medicine. We are Muslims but we had tried Orthodox Christian "Tebel" (holy water) places: "Metmiku Yohannes" "Shenkora Tebel" (holy water), "saint Gebriel" Tebel (holy water) by taking him to these places and bringing the "Tebel" (holy water) home. We did not change our religion when we did all these things. We had tried and are trying the appropriate hospitals and clinics. We have tried the Muslim religion special prayer (Duaa). We did not stop the above treatments up to now. We have no economic problems to spend whatever expenses are needed.

3. Children with Disabilities own Coping Mechanism

Case No. 1: Girma, age 22.
Girma suffers from muscular dystrophy. He lives with his father; his mother died when he was an infant. His chronic illness increases his emotional difficulties. The causes are multifactorial and include the effects of unpleasant treatments, upset about limitations to engage in normal activities, anxieties about future well being and life chances, and parental responses. But Girma is using different strategies in order to reduce these difficulties. The following description illustrates this point:

I was healthy up to the time I reached grade 4. It all started when I was in grade 4. I fell down repeatedly and I stopped going to school alone. There was something around my knees that blocked me from walking. The biggest problem after my parents left me at school was urination. When I want to urinate I had to choose between two things: either to hold it back or beg the class monitor to take me to the toilet. Therefore, I have to limit myself from drinking too much liquid in the morning. Gradually my problems became severe: My muscles became weak and I became dependent for every routine activity. Everything was getting worse. I started treatment, with "holy water". First, I went to "Saint Ureal Tebele' (holy water) place. I spent 15 days there. I checked myself whether there is a change or not. There was no change. I established contact with one NGO (MMM) and registered for their income generating activity. I bought some handicraft materials and started producing some items. Besides they helped me by supplying me with appliances.

During my fieldwork, I observed that Girma was showing great courage in facing hardship. He became disabled before 1996. His resilience in the face of adversity included employing a range of coping strategies. According to Girma, he did not expect much from medical intervention. He resorts to religious mechanisms to cope with his impairment. He said:

All my hope is from "God". There is nothing else that I rely on except on "God". I pray to "God" always, though I am not able to go to church due to different problems.

Girma is engaged now in doing different activities at home. His mother passed away eight years previously. His father is busy as a cook and has no time to look after his disabled child. He has established a relationship with an NGO called Medical Missionaries of Mary (MMM). This charitable organization is helping him closely. The organization assigned professional to help him with his exercises to prevent contracture (muscle shortening). Besides, this
organization gave him initial capital for purchasing, materials for the handicraft activities. There is a housemaid who is helping him in his daily routine activities. Finally he said, "all my hope is with my God and I therefore concentrate on what I could do rather than on what is impossible. My belief in God will facilitate the development of self-confidence and sense of personal worth." This is what Girma adopted as a coping strategy to the demands imposed by different stressors.

**Conclusion**

My findings show how disability adds to children's vulnerability and their responses and their capacities to cope with their disability and their courage in facing hardship. The eight cases of children with disabilities presented related to children's resilience in the face of adversity, including having a range of coping strategies that they used flexibly: self employment to earn a living; skill upgrading through private effort and help of relatives and NGOs; resorting to useful mental mechanisms to help them cope with their situation; and mentally rehearsing possible responses to the situation.

On the other hand, whatever the particular causal explanation understood by a family, the families' capacity to accommodate a child with disability depends a great deal on their resources, both personal and material. Six cases of different families were presented to show that children with disabilities and their families must not only cope with typical day-to-day demands of family life, but also deal with a host of disability related issues; sense of efficacy and a related sense of hope; state of turmoil and disorientation; thinking about their child's future coping with day to day caring for the child so many unknown. Most parents sacrifice their whole life to the unremitting labor of caring for the child.
Besides, children and parents pointed out that coping is not the same for all children with disabilities. They indicated that coping differs between those children born with disability and those affected after birth. In the former case, adjustment is not an easy task. Children with disabilities have also mentioned additional factors such as co-operation from family members in coping with their children's disabilities. Mothers of children with disabilities have indicated that the presence or absence of support from husbands together with institutional help, among others, matters to the success in raising or helping a disabled child.

CHAPTER VII

SUMMARY AND CONCLUSION

Preceding chapters have indicated the different ways that children with disabilities parents of children with disabilities and the non-disabled community define disability. Also discussed were values and assumptions that people have about the nature, functioning, goals, of and expectations of people with disabilities. Moreover the study assessed the type of social/supportive and material care children with disabilities receive at home and within their communities. Attempts were made to explore the type of social networks and social support
systems used by children with disability and parents of children with disabilities. The type of coping strategies used by disabled children and their families were also discussed.

With regard to defining the key concepts and issues associated with being a disabled the thesis has examined the different perceptions of disability projected by children and youth with disabilities, parents of children with disabilities and care takers. The research findings showed that the perception of children with disabilities depended mainly on adults' (parents, care-takers, and the community) explanation during the socialization processes. Their understanding of their affliction may change later in life depending on their encounters to modern medicine. Failure of the medical models spurs many of them to revert to using the social model in order to cope with their disability. There is a difference between children with disabilities and parents of children with disabilities in their explanations of the causes and present predicaments of children with disabilities. Parents talk in terms of self-blame, guilt and, occasionally, the failure of modern medicine and medical professionals in helping alleviate the plight of their children. However, according to the study, the determinant factor for children with disabilities, is how to explain or justify their disabled state and assign blame for their present predicaments.

According to the research result the explanations given by parents of children with disabilities and children with disabilities fall under three models: medical, social and the combination of the two. The detailed elements mentioned under these models were lack of better care, professionals' mistake, retribution for the past misdeeds, parents' and caretakers' mistakes, and fatalistic views. The different explanation given by children with disabilities were based on the occurrence of their disabilities; whether the child was born deformed or became handicapped after birth, and whether the disability was "severe" or "moderate". Children parents and guardians associate those who are born disabled and with severe
disability with bad omen. Children with disabilities who become handicapped after birth and with moderate disability as well as their families and guardians attributed their disability to man-made mistakes.

On the other hand, the Community's views toward disability varied according to different factors. Their attitudes, even to similar disabilities, are different. Life long disabilities that cannot be treated are attributed to some kind of curse from God and or retribution from past misdeeds. These and other factors (the type, cause, and severity) are the main reasons for discrimination. The research result indicated that persons with non-severe or moderate disabilities, compared to children with disabilities with severe disabilities, are not marginalized in the community.

Perceptions that held by members of the community regarding child or youth with disabilities embrace not only practical expressions. They also include verbal expressions or non-verbal expressions. These reactions in the study areas were manifested through the community actions i.e. stigma, rejection, and the aversive interaction of children with disabilities in schools, positive or negative interaction with people in hospitals and neighborhood. Because some parents fear that they will be stigmatized and rejected, many hide their children with disabilities from the eyes of the community.

Therefore, children with disabilities enabling environment to lead an ordinary life is largely affected by the factors associated with community attitude to their disability and parent’s reaction to this. Besides, factors, such as being geographically relocated into a new neighborhood, being extremely poor in relation to the community in which they live in; the type and frequency of interaction of the children with disabilities and his/her parents with the community; whether the children with disabilities were exposed to the external environment
or not gave an indication as to how parents and children adjusted and coped with their disability.

Consequently the research looked into how children with disabilities and their parents adjusted or coped with disability and adjusted to its negative effect on their lives. According to the research findings personal adjustment to disability requires not only the efforts of the children with disabilities or his/her parents. The disabled individuals' ability to function in every day life situations (coping), and the type and character of social and cultural fields of relations he/she operates, or to which they are confined (life space). And finally the genuine material and physical support of voluntary institutions matters.

In the study areas, need for support children with disabilities and their parents were covered by the families themselves, close relatives, neighbors, and institutions. The kinds of disability related demands reported by the informants were lack of services such as medical support, financial assistance, emotional and psychological support, other material supports, the day-to-day logistics required for disabled children and home responsibilities. Social support provisions from individuals operated at different levels and varied in degree due to different factors, such as relatedness, economy and geographical distance from support providers. Social support helps to improve the adaptive competence of disabled children and their families in dealing with short-term crises and life transitions as well as long-term challenges, stresses and privations. The research result do not support fully the arguments made by some anthropologists who assert that there is a diminishing fabric of social support for children with disabilities in the urban context.

One of the difficulties of parents of children with disabilities in coping with their children's disabilities is their transition from "culture of non-disability" to the "culture of disability". Though it differs from one disability to another, parents of children with disabilities in the
study areas have reported this feeling specially, at the time of onset of their children's disabilities. Parents who faced the problem of having disabled child after birth can easily accept the phenomenon than parents with children with disabilities at birth. This is because the stigma and societal rejection of children born disabled is greater than for children who are disabled later in life.

Not all parents of children with disabilities and children with disabilities in the study area required immediate assistance's; the kind of disability and parents' economic status In the study areas, need for support children with disabilities and their parents were covered by the families themselves, close relatives, neighbors, and institutions. The kinds of disability related demands reported by the informants were lack of services such as medical support, financial assistance, emotional and psychological support, other material supports, the day-to-day logistics required for disabled children and home responsibilities. Social support provisions from individuals operated at different levels and varied in degree due to different factors, such as relatedness, economy and geographical distance from support providers. Social support helps to improve the adaptive competence of disabled children and their families in dealing with short-term crises and life transitions as well as long-term challenges, stresses and privations. The research result do not support fully the arguments made by some anthropologists who assert that there is a diminishing fabric of social support for children with disabilities in the urban context.

One of the difficulties of parents of children with disabilities in coping with their children's disabilities is their transition from "culture of non-disability" to the "culture of disability". Though it differs from one disability to another, parents of children with disabilities in the study areas have reported this feeling specially, at the time of onset of their children's disabilities. Parents who faced the problem of having disabled child after birth can easily
accept the phenomenon than parents with children with disabilities at birth. This is because the stigma and societal rejection of children born disabled is greater than for children who are disabled later in life.

Not all parents of children with disabilities and children with disabilities in the study area required immediate assistance's; the kind of disability and parents' economic status mattered. For instance, well off parents of children with severe disabilities did not worry about material support from close and/or distant relatives but about their children's future, therapy, education, and getting information about how to cope with their child's disability. The research revealed that having children with disability worsens if the child is born illegitimate. In fact, the economy and educational status of the family matters greatly. In the worst circumstances, even support from closest family members is unthinkable.

The role of charitable organizations/institutions to help and finally integrate such parents with this kind of problems is great. The type of help received by children with disabilities and parents of children with disabilities from such institutions in the study areas ranged from receiving material supports to informational support. Material support, whether financial or medical was a very important factor in putting children with disabilities or parents on equal status with the non-disabled persons. The research findings established that when of children with disabilities started to gain income and earn their living the non disabled individual will respect them and give them a place in the process of social interaction.

The research indicates that children with disabilities after receiving help from institutions are more or less capable of leading a self-sustained life or become competitive with the non disabled. But becoming competitive or not depends on their kind of disability. Those children with disabilities who became successful after such kinds of help in the study area were those
with moderate or mild disabilities. Even though they received help from different institutions, children with severe disabilities, were not able to lead an independent life. They required help from their families and/or caretakers and institutions.

The family structures and economic status of children with disabilities affect the type of social supportive and material care such children receive at home and within their communities. According to my research findings those children born from materially better off families got better material care and those from "poor" families did not. As a consequence children with disabilities from the former families did not seem to feel that they were disabled. This feeling of adjustment was stronger when children had a mild or moderate disability.

In the research areas I found that some children with physical and mild disabilities often resisted using appliances provided by NGOs and charitable institutions. Because appliance served as a tool to symbolize disability and strengthen the existence of disability some children resisted using those appliances feeling that it was the main thing for their rejection and prejudice by the non-disabled. These attitudes and children with disabilities and parents of children with disabilities views or understandings of their environment in a possessive or negative way are the main factors that strengthen or weaken networks among parents of children with disabilities and the community.

Social networks in the study areas went beyond the family and relatives of children with disabilities. Close family members and people who were more intimate with the parents of children with disabilities were the ones who had long-lasting or endurable supportive ties. The collaboration and sustainability of the support was not the same throughout the time. According to the research result, factors affecting familial networks varied from one network
to another. The material supportive networks became loose in the case of relatively "poor" families. But other non-material interactions (relationships) were very high compared to economically well-to-do families.

Other factors that affected social network in the study areas were the settlement pattern, heterogeneous composition of people with different social status, and attitude of the community towards disability. Parents of children with disabilities and children with disabilities who lived in a separate compound and who are materially 'otter off did not even publicize their children's disability even to their closest relatives. They did not have closely-knit interactions even with the non-disabled. Conversely, parents of children with disabilities and children with disabilities with low income and live only in densely populated areas had relatively more interactions with the community. But their interaction with regard to supportive network was materially insignificant. On the other hand, the research has revealed that poor children with disabilities had more exposure to the external environment and as a consequence these situation created for them favorable condition that enabled them to be integrated with the community. Better off children with disabilities had lower access to the external environment and a lesser chance of integration. During the study, richer families proved to have problems in getting information on how to cope with their children disabilities.

The networks in Woreda 13 and some parts of Woreda 8 did not follow the model of networks for urban settings. The cultural elements among members of the community, which are said to exist mostly in rural areas, were not completely eroded. Except some families of children with disabilities others have maintained good relationships with their neighbors and relatives. These supportive networks are more cohesive between people with equal economic status. Economic ties in these areas operated more forcibly among relatives than among
friends and neighbors. Nevertheless, the material and financial support from NGOs was by far greater than support from relatives and/or neighbors.

The non-disabled family members' relationship with children with disabilities was not the same in all families. The research shows that disability affected the marriage relationship and network formation among relatives. The problem varied between the mother’s and father's line of the children with disabilities. Mothers of the child with disability were the one who were mostly blamed for the child's defect especially if this occurred at birth. Therefore, mothers were sometimes treated harshly by relatives of husbands'. Some such mothers ended up abandoning the child to the father's parents and/or relatives.

Besides economy and residential pattern, the study reveals that occupation played significant role in social network formation. Some parent, who led an isolated life in their residential area and had poor relationship with their neighbors, had smooth social networks with their friends and colleagues. The type of neighborhood affected social connectedness was influenced by how long the family with children with disabilities lived in that area. Other things being equal, the longer the family with disabled children lived in that area, the lesser their isolation and stigma they faced from their neighbors.

Objective measure of social homogeneity gave only a rough indication of how families felt about their neighbors. The social status of parents with disabilities with their neighbors did not necessarily indicate their intimate relationship and the research indicated that well off families of children with disabilities who were of equal social status with their neighbors did not even disclose their child's disability to neighbors or even to their distant relatives.
Generally network relationships could be outside the local area and it was likely to be close-knit based on different contacts formed with different people. Even though parents of children with disabilities kept on living in the same area for a long time, their pursuit of the above-mentioned factors led them to establish outside relationship, with people who did not belong to the family's surroundings. The contributions of institutions toward helping children with disabilities living in the study areas were very great. These were provided by both local and foreign institutions, which gave such children medical, psychological, counseling and economic support.

Community based voluntary associations, found in the study area were coffee ceremonies, mother to mother gatherings, parents association, Edir, and Ekub. Some (not all kinds) of these local associations serve as a form of mutual support. These local institutions found in the wider Ethiopian culture, were used by NGO's in order to foster a feeling of community among parents and children with disability and facilitate their integration into the rest of the community. The voluntary associations were also used to raise awareness of disabilities, as experience sharing forums for parents of children with disabilities and to establish a sort of unity among the parents of children with disabilities and children with disabilities. Edir, Ekub which were established by the non-disabled communities did not serve or promote the type of mutual support activities given by associations established and promoted by NGO's.

Foreign institutions established by foreigners in the study areas are known by the name MMM and Cheshire CBR. They are directly involved in the day-to-day social interactions of children with disabilities and parents of children with disabilities. Their role was restricted to indirectly empower such children and parents by establishing local associations and other supports such as appliances and finance. They created conducive environment for children with disabilities and persons with disabilities to help themselves at home. But the two
institutions in the study areas were not free from creating dependency in them. The medical and financial supports in the form of different activities (income generating activities) create some sort of dependency. As a consequence these institutions have disturbed the previous coping mechanisms that existed among neighbors in those local areas. Those children with disabilities who grew up under institutional care or who got direct or indirect supports suffered from isolation from normal social life and had difficulties in adjusting to life in the community.

To sum up, this research has examined the ways in which the socio-cultural construction of disability shapes the significance of disability. It indicated how incurable disability affected possibilities and validity given by society as a person. In the research result there is far greater concern with coping, stigma, adjustment, or social integration than aetiology or causes of disability. Generally it has tried to present the life histories of people with disabilities from their own perspective and in their own words. Accounts of the lives of children with disabilities (children with disabilities) and parents of children with disabilities (PWDs) show that children are capable of having a coherent view of their lives and their predicament. It has also tried to explore the social context, of disability from children's point of view and adults in association to community values.

Finally, the only pointedly gendered aspect of disability is that mother's are usually blamed for their children's birth defect, especially those who give birth to a disabled child. Since the children I worked with were mostly adolescents and younger, their coping mechanisms and their parents networks were similar. A longer time study of their plight and life choice would probably reveal the gendered aspect of entering into the adult social world, marriage, parenting and job opportunities.
Since little research has been done on disability in developing countries, this thesis could serve as a preliminary exploration. Future studies of anthropology of disability could find inspirations in the study of individual experiences, analyses the changing institutional practices and explore the emerging new social categories in association with the concept disability.

**BIBLIOGRAPHY**


California Press.


Approaches. Boston: Allya and Bacon, Inc.


DECLARATION

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

Name
Signature
Place
Date of Submission

Gentent Kebede
Addis Ababa
June, 2001